Palliative care for life-limited children and young adults: the role of medical care in the development of children's and young adults' hospice services

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Abstract

Paediatric Palliative Medicine [PPM] within children's and young adults' [CYA] hospices has developed in an ad hoc manner. To date, clear description and classification of PPM service provision within CYA hospices has been absent (Help the Hospices Commission 2013; TfSL 2013). National guidelines state that specialist children's palliative care services will include a Consultant in PPM (NHS England 2013; NICE 2016c). However there is limited research into the benefits of this (Mitchell et al. 2017). The aims of this study were to: (1) Describe and classify existing approaches to PPM service provision in CYA hospices across the UK, (2) Explore how CYA hospices respond when a child with a life-limiting or life-threatening condition [LLLTC] has unstable symptoms, is deteriorating or is dying, and (3) Determine if and how varying approaches to PPM service provision in CYA hospices impact on abilities to respond when a child with a LLLTC has unstable symptoms, is deteriorating or is dying.

A mixed methods survey was conducted by telephone interview with leaders of CYA hospices. The convergent mixed methods design included quantitative, qualitative and case scenario data collection. A comparative case study approach guided analysis of case scenario data and data integration. 31 interviews were conducted, relating to 28 CYA hospice services, representing 34 inpatient units and 25 community services. Thematic analysis identified two overarching themes: *Increasing complexity of care needs* and *Diversity in PPM approaches.* Quantitative analysis demonstrated participating hospices supporting children with significant complex medical needs. All participating inpatient units provided some medical cover but with a diverse range of approaches and limited specialist PPM involvement. Participating hospices employed 0-13 doctors each, providing 0-120 hours medical presence weekly plus on call. 159 doctors were identified as working in CYA hospices; 63.5% were GPs. Only 27.5% of doctors working in participating CYA hospices had specialist training in PPM. The majority of CYAs' hospices (67.9%) did not have involvement from a PPM consultant. A geographic-specialist classification of approaches to PPM service provision by CYA hospices was developed. Case scenario analysis identified a diverse range of responses by CYA hospices when a child with a LLLTC has unstable symptoms, is deteriorating or is dying.

The impact of specialist PPM indicates a unique function of regional specialist CYA hospices as distinct from regional non-specialist, local specialist and local non-specialist CYA hospices.

Findings demonstrate the diversity in amount and specialism of medical service provision in CYA hospices. Alongside this the complexity in medical needs of CYAs with LLLTC is increasing. The geographical-specialist classification of PPM service provision within CYA hospices could be used as a foundation for future recommendations for a networked approach to PPM within CYA hospices in order to promote equity and maximum positive impact for children with LLLTC.

1 Introduction

1.1 Origins of the research

Eddie and Jill Farwell founded Children's Hospice South West (CHSW) in 1991. They had experienced the need for hospice care for their two eldest children, Katie and Tom, who had life-limiting conditions (CHSW 2019). From 1995 onwards CHSW established three children's hospices across the South West of England: Little Bridge House, Charlton Farm and Little Harbour (CHSW 2019).

I was privileged to work as part of a multi-disciplinary children's hospice team at CHSW in the role of hospice doctor and subsequently medical director from 2007 to 2013. During this time I developed an interest in children's palliative care and in research to guide the development of children's hospice services. Having previously worked as a paediatrician in community, local hospital and tertiary hospital settings, I often reflected that it seemed possible within the hospice, to provide a quality of holistic care difficult to achieve elsewhere. One of my strongest memories is of a mother who said of the day her child died at the hospice, "*for the worst day of my life, it was the best it could have been".* This personal reflection resonates with families' experiences of the world's first children's hospice, Helen House (Hearn 1990; Worswick 2000a).

Having completed an MSc in Paediatric Palliative Medicine I formed a collaboration between CHSW and Bournemouth University to develop a research study to investigate an issue being raised at a local and national level, namely the role of medical care in the development of children's hospice services. CHSW provided a research grant and I was also awarded a PhD scholarship at Bournemouth University. I come to this research not just as a paediatrician and researcher, but as a sister of a brother with a life-limiting condition, who against all expectations has lived well into adulthood. On a personal and professional level I remain passionate about the value of research to guide the development of children's palliative care (CPC).

1.2 Background to the study

CPC is an evolving field and is delivered by multidisciplinary teams of professionals in a range of settings including children's and young adults' hospices (Chambers 2018). Since Helen House opened in Oxford, in 1984, the role of medicine within children's hospice care has similarly been evolutionary. Paediatric Palliative Medicine (PPM) was recognised as a sub-speciality of Paediatrics in 2009 (Hain et al. 2012). However, children's hospices have developed in an ad hoc manner and approaches to PPM service provision range widely (Hunter 2017).

There have been estimated 49,000 children (0 – 18 years) in the UK with a life-limiting or life-threatening condition (Fraser 2012; Chambers 2018). In 2012, it was reported that 7,638 children were supported by children's hospices in the UK (Devanney and Bradley 2012). These children and their families have wide ranging needs that vary throughout their lives (Hunt and Coad 2013; Coad et al. 2015). The phases of instability, deterioration and dying have been identified as times when there may be increased need for palliative care provision (Hughes-Hallet et al. 2011) including access to specialist CPC services (Harrop and Edwards 2013). European and UK standards define specialist CPC services as those supported by a consultant in PPM (European Association for Palliative Care 2007; NHS England 2013) but there is limited research to support this recommendation (Mitchell et al. 2017).

The Commission into the Future of Hospice care (Help the Hospices Commission 2013) and the response by the CPC sector (TfSL 2013) highlight the need for evidence based service development. Thirty-five years on from the inception of children's hospice care there is limited evidence regarding the form and impact of PPM service provision within children's hospices. There is therefore a clear imperative for research to address the following questions:

1) What are the current approaches to PPM service provision in children's and young adults' hospices across the UK?

2) How do children's and young adults' hospices respond in situations when a child with a life-limiting or life-threatening condition has unstable symptoms, is deteriorating or is dying?

3) Do varying approaches to PPM service provision in children's and young adults' hospices impact on abilities to respond to the needs of children with life-limiting or life-threatening conditions and their families when a child has unstable symptoms, is deteriorating or is dying?

1.3 Study aims

Specifically this research aimed to:

1) Describe and classify the existing approaches to PPM service provision in children's and young adults' hospices across the UK.

2) Explore how children's and young adults' hospices respond when a child with a life-limiting or life-threatening condition has unstable symptoms, is deteriorating or is dying.

3) Determine if and how varying approaches to PPM service provision in children's and young adults' hospices impact on abilities to respond when a child with a life-limiting or life-threatening condition has unstable symptoms, is deteriorating or is dying.

1.4 Key definitions

Child or children: The Children Act (1989) refers to any person under the age of eighteen as a child. Children over the age of 13 may be referred to as a young person (Chambers 2013). The terms child or children are used throughout to refer to babies, children and young adults unless otherwise stated. This includes the use of children's hospice to refer to children's and young adults' hospices unless otherwise stated.

Complex care needs: This term is used interchangeably with the term "complex health care needs" to refer to children who are either dependent on technology or require a significant amount of additional care (Hewitt-Taylor 2012).

Life-limiting condition: A condition for which there is no reasonable hope of cure and from which children will die either in childhood or adulthood (Chambers 2018). This term is used throughout to refer to both life-limiting conditions and life-threatening conditions unless otherwise stated.

Life-threatening condition: A condition for which curative treatment may be feasible but may fail (Chambers 2018).

Young adult: Refers to any person from their 19th birthday onwards (Chambers 2013).

1.5 Glossary of terms

APPM: Association of Paediatric Palliative Medicine

CCG: Clinical Commissioning Group

CCN: Community Children’s Nurse

CPC: Children’s palliative care

DH: Department of Health

DGH: District General Hospital

GP: General Practitioner

IV: Intravenous

MDT: Multi-disciplinary team

NICE: National Institute of Clinical Excellence

NICU: Neonatal Intensive Care Unit

Paediatric Palliative Medicine: PPM

PICU: Paediatric Intensive Care Unit

POONs: Paediatric Oncology Nurse Specialists

RCPCH: Royal College of Paediatrics and Child Health

SLA: Service Level Agreement

TfSL: Together for Short Lives

TPN: Total Parenteral Nutrition

WHO: World Health Organisation

1.6 An Outline of the thesis

The thesis is structured in fourteen chapters.

1.6.1: Chapter Two charts the development of children's hospices beginning with the origins of adult hospice care and the pioneering work of Dame Cicely Saunders. The foundations of the hospice movement as an alternative to a traditional medical model are explored. The later emergence of children's hospice care, with the first children's hospice, Helen House and the parallel development of CPC are then described. The pivotal role of nursing in the development of CPC is presented followed by the development of PPM, beginning with the history of its adult counterpart and initial tensions around the role of medicine in palliative and hospice care. The roots and subsequent growth of medical service provision within children's hospices are presented in order to set the scene for this study. The lack of current research relating to PPM service provision within children's hospices is highlighted providing a mandate for the research presented in this thesis.

1.6.2: The third chapter focuses on the children who require access to hospice care and their needs. The scope of the need for children's hospice care is examined, firstly by discussing the definition and classification of life-limiting and life-threatening conditions, with a description of the consequent wide range of conditions encompassed within this classification. Secondly evidence of a rising national prevalence of life-limited children is outlined alongside the limited data on numbers of life-limited children supported by hospices. The needs of these children and their families are then reviewed in broad terms followed by a focus on the medical aspects of care in particular when a child with a life-limiting condition deteriorates and during care at the end of their life. Finally the rationale for research to guide the development of children's hospices is stated in order to position this research within the national priorities for building an evidence base within the field.

1.6.3: The fourth chapter focuses on the chosen methodology of mixed methods research. The history of mixed methods research, its origins and use within the field of adult and children's palliative care are explored as a basis for the rationale of the choice of mixed methods in answering the research questions posed in this study. Following on from this, the philosophical foundation of mixed methods research is explored, with particular reference to pragmatism. With this pragmatic foundation in mind, a theoretical framework is set out in the absence of an existing theory applicable to the research questions, using the intersection of a number of important concepts within children's hospice and palliative care. The development of a range of mixed methods research designs are set out and contrasted to the original design and eventual convergent design for this study. The principles of a mixed methods comparative case study approach are introduced as relevant to the use of case scenarios and data integration. The chapter ends with a summary of the advantages and disadvantages of mixed methods research.

1.6.4: Chapter Five outlines the data collection method, a mixed methods survey conducted by telephone interview. The chapter begins with an outline of the overall research plan, explaining its development. The background to survey research as a method of data collection is explored with reference to the use of surveys in adult and children's palliative care. The use of a mixed method survey in practice is discussed for each stage of the process: recruitment and sample characteristics, survey design and a telephone interview for data collection. The benefits and challenges of mixed methods surveys are considered throughout, alongside the experience of recruitment and data collection in this study before the chapter concludes with a summary of the approach to data storage.

1.6.5: The sixth chapter describes the methods of analysis employed for the quantitative, qualitative and case scenario data gathered by the mixed methods survey conducted by telephone interview. In this chapter the method for quantitative analysis is outlined, followed by a detailed discussion of the use of thematic analysis of qualitative data. This includes both a brief history of thematic analysis and review of its wide spread use in palliative care research.

Braun and Clarkes' (2006, 2013) six-stage process for thematic analysis is presented as a guide to the detail of the process of analysis undertaken. The application of principles drawn from mixed methods case study research to analysis of case scenario data is explored. Following this, the centrality of ethics in conducting research is discussed with reference to the ethical considerations inherent to this study. The unique issues of being an insider researcher are explored and applied to personal experience before the chapter concludes with confirmation of the ethical approval process followed for this research study.

1.6.6: Chapter Seven presents the quantitative findings. Firstly demographics of the children's hospices represented in the study are presented to give a picture of the study population and the characteristics of the interviewee leaders of care representing these hospice services. Secondly referral patterns and caseload data provide a numerical framework for understanding the increasing complexity of the population of children receiving hospice care. The medical workforce of children's hospices, at the time data were collected, gives a picture of the doctors working in children's hospices, their education and level of specialist PPM training. Arrangements for 24 hour a day seven day a week PPM service provision and relationships between hospices and hospitals are analysed. The roles undertaken by doctors and the parallel roles of nurse consultants and prescribers are presented. Finally a summary of key data collated by region demonstrates an inequity across the UK in PPM and children's hospice resources.

1.6.7: Chapter Eight describes the qualitative findings from the analytic process outlined in chapter six. The qualitative findings give depth and breadth to the picture of approaches to PPM service provision within children's hospices provided by the quantitative findings. Thematic analysis led to the development of the 'overall story' of the qualitative data comprising two overarching themes and four main themes that are presented through the use of supportive extracts. The over arching themes: (1) *Increasing complexity of care needs* and (2) *Diversity in approaches to PPM service provision* are described first as these are the major themes overlying all four main themes. The four main themes: (i)

The current and developing workforce of children's hospices, (ii) Relationships between services and professionals, (iii) Developing the delivery of children's hospice care and (iv) *Challenges facing medical service provision*, are outlined subsequently as these represent the detail of what influences the approaches to PPM and contributes to their diversity.

1.6.8: Chapter Nine describes the way in which the quantitative and qualitative findings presented in the previous two chapters have been integrated to develop a classification of approaches to PPM service provision within children's hospices. The definitions of the identified approaches and the data by which they have been classified are discussed. The main geographic-specialist classification is outlined and contrasted to an alternative classification based on 'outlier' approaches. The complexity of this process within a diverse population of hospices is explored, including the challenge in defining what it is to be a specialist hospice.

1.6.9: Chapter Ten presents the case scenario findings. In this chapter the findings of analysis of four case scenarios are presented. The chapter focuses on the overall integrated findings of the case scenarios giving an overview of the range of responses by hospices in situations when a child with a life-limiting condition has unstable symptoms, is deteriorating or is dying. The chapter begins by presenting a summary of the main themes from the cross case thematic analysis. Following this, for each case scenario the findings of the combined analytic techniques of cross case thematic analysis and explanation building are presented to give a view of the decision making process taken by the participating hospice services in response to the hypothetical scenarios alongside factors influencing the way in which the hospices' respond.

1.6.10: Chapter Eleven goes on to investigate whether the participating hospices' activity and case scenario responses differed depending on the classification of PPM service provision as defined in Chapter Nine. Data from across the study were integrated and cross-referenced to the geographic-specialist classification and alternative classifications of PPM service provision in children's hospices. In addition correlation calculations of aspects of the quantitative data set are presented in an attempt to give a statistical analysis as to whether aspects of the PPM service provision impact on the hospices' activity and case scenario responses. Trends in the data are explored through the integrated analysis in order to search for patterns as to whether the classification of PPM service provision influences the response by the hospice in situations where a child with a life-limited condition is becoming unstable, is deteriorating or is dying. Three potential areas of impact of the classification of PPM service provision within children's hospices are then reviewed: (1) Impact on activity data, (2) Impact on complexity of care needs and (3) Impact on case scenario responses.

1.6.11: Chapter Twelve presents a discussion of the contribution of findings from across this research study to a foundation of knowledge in CPC. Consideration is given to the implications for theoretical development in the field. The outcome of the research based geographic-specialist and alternative classification of PPM service provision within children's hospices are discussed in light of historical concerns in relation to the 'medical model' and children's hospice care. The history of the progression of the medical model to a biopsychosocial model is explored, with its application within the field of palliative care. Emerging approaches to hospice and palliative care within current literature are presented and the place of the classification developed within this study is reviewed. The contribution of this study to knowledge on the role of children's hospices as specialised CPC services is discussed and on-going questions around the definition of a specialist CPC service are addressed. Finally an exploration of what this study adds to the evidence base on the impact of specialist CPC services is undertaken.

1.6.12: Chapter Thirteen discusses the key findings from across the qualitative, quantitative and case scenario analysis exploring their relevance to the current climate in CPC. Firstly the diversity of the medical provision within children's hospices is discussed with the implications for equity. The relevance of findings in relation to the workforce of children's hospices with the predominance of GPs and the role of nurses in medical service provision are presented. This chapter goes on to discuss the findings from this study supporting widespread anecdotal and limited research evidence of the increasing numbers and complexity of care needs of children with life-limiting conditions. The medical service provision that children's hospices offer in practice is explored with particular relevance to phases where a child with a life-limiting condition becomes unstable, is deteriorating or dying. The unique challenges of caring for a child at the end of life at home and the limitations of children's hospices' involvement are a striking finding from the study and are contrasted to national guidance and policy. The implications of these research findings in practice are discussed throughout and finally a rationale for the need to preserve the holistic, multidisciplinary philosophy of children's hospices whilst positioning excellent medical care at the heart is laid out. The importance of integration of CPC services is discussed with the possibility of the application of the geographical-specialist classification of PPM in children's hospices to a networked approach to CPC.

1.6.13: The final chapter draws together all aspects of the study findings and their implications by making recommendations relevant to, policy, practice, guidelines, education, training and future research in the field of children's hospice care. Findings overall indicate a diversity in approaches to PPM service provision within children's hospices across the UK alongside an increasingly complex population of children with life-limiting conditions in need of hospice care. Inequity was demonstrated, both in terms of resources across the country and a limited and diverse response from hospices to situations where a child with a life-limiting condition has unstable symptoms, is deteriorating or is dying. In view of these findings, this concluding chapter builds upon the previous chapter's discussion of implications of findings and makes recommendations before finally summarising how the initial research aims were addressed.

2 Children’s hospices and children’s palliative care: setting the scene

2.1 Chapter introduction

In view of the relatively recent development of the field of CPC, the evidence base in relation to service provision and in particular to children’s hospices and PPM is in its infancy. Therefore in place of a more traditional literature review, the current chapter sets out the relevant historical literature in order to describe the context for the development of children’s hospices and PPM.

The research outlined in this thesis aimed to explore the role of medical care within children’s hospices. Specifically the research aimed to describe and classify current approaches to PPM within children’s hospices across the UK. The impact of these differing approaches was then explored in terms of the care delivered, in particular at times when a child’s symptoms deteriorate and when a child is cared for at the end of their life. The research therefore encompassed four key elements that require consideration: (1) children’s hospices, (2) PPM, (3) children with life-limiting or life-threatening conditions and (4) their needs, in particular their needs at times of deterioration and during end of life care. This chapter focuses on the first two of these elements and in particular charts the development of children’s hospices. As the foundations of children’s hospice care have arisen in part from the adult hospice movement, it begins with the origins of adult hospice care and the hospice movement as an alternative to a traditional medical model. The emergence of children’s hospice care, with the opening of the first children’s hospice, Helen House and the parallel development of CPC are then described. The role of nurses as foundational to the development of children’s hospices and CPC is outlined.

The development of PPM is then presented, beginning with the history of its adult counterpart and initial tensions concerning the role of medicine in palliative and hospice care. The beginning of medical service provision in children’s hospices is reported and the ad hoc way this has evolved is explored. The lack of current research relating to medical care in children’s hospices is highlighted and contrasted with recent national guidance and standards.

2.2 The foundations: adult hospice care and adult palliative care

The backdrop to the development of the modern hospice movement took place in the UK and USA in the 1950s with growing concerns around the care of dying people (Clark 2002). Clark (1999) described preconditions for the hospice movement citing two published surveys as particularly influential (Marie Curie 1952; Hughes 1960). These highlighted a shifting focus from what had been described as a medical ‘neglect’ of the dying (Clark 2002) to literature based on research and systematic observation, an active approach to care of the dying with dignity as paramount and a recognition of the interdependency of physical and mental suffering (Marie Curie 1952; Hughes 1960; Clark 1999; Clark 2002).

Dame Cicely Saunders is widely regarded as the founder of the hospice movement and subsequently palliative care (Saunders 1965, 1966; Clark 1998; Saunders 2000; Clark 2001, 2007; Clark 2018). She was a nurse, medical social worker and later a doctor (Clark 2018). She was inspired whilst caring for a dying patient named David Tasma from Warsaw in 1947. Through their dialogue she developed the ideas which eventually became the basis for the world’s first purpose built adult hospice, St Christopher’s, in South East London established under her guidance, in 1967 (Saunders 1978).

The ancient word ‘hospice’ dates from the fourth century of the Christian era (Saunders 1996; Simms 2007). These ‘hospices’ were houses of hospitality where a welcome was given to pilgrims, travellers and the sick (Saunders 1996). The name was later used by Mme Jeanne Garnier who set up institutions for dying people, known as ‘Maisons Medicales’ (Saunders 1996). Saunders chose the name ‘hospice’, to signal joining *“a long tradition of hospitality and care”* (Saunders 1996).

In her writing she described a *“realisation that patients facing the end of life… would, need all the skills that could be developed, researched and taught, together with the friendship and care of the heart”* (Saunders 1996). Her vision was not bounded within the discipline of medicine but sought to address suffering through the combined skills of a multidisciplinary team of caregivers (Clark 2001).

St Christopher's was established outside the NHS as an independent charitable institution (Clark 2018). This set the blue print for provision of hospice care predominantly separate to NHS funding. St Christopher's became a source of inspiration to others and the vision was emulated and elaborated in the UK and throughout the world (Clark 2002). Within a decade it was accepted that the principles of hospice care could be practiced in many settings: hospices, home care, day services and even hospitals. This wider orientation of the hospice movement, became the foundation for palliative care, a term first proposed in 1974 by a Canadian Surgeon Blafour Mount (Mount 1997).

An early definition of palliative care was:

> "*The total (physical, emotional, social and spiritual) care of patients with life-threatening diseases and their families. The focus of care is both the quality of remaining life of the patient and the support of family and friends" (Higginson 1993)*

2.3 The development of children's and young adults' hospices

In contrast to the development of the adult hospice movement and adult palliative care, recognition of the need for palliative care for children has occurred relatively recently with services evolving only over the past 35 years (Hain et al. 2012; Hill and Coyne 2012; Mellor et al. 2012). The need for palliative care for children was first identified in an article relating to specific case studies published in the late 1970s (Chapman and Goodall 1979). Since that time, the UK has led international CPC development, beginning with the children's hospice movement. Helen House opened in Oxford in 1982 (Dominica 1982; Worswick 1995). Worswick (2000) described the starting point for Helen House as: *"not a medical one"* but as arising out of a friendship between Sister Frances Domenica and a child, Helen and her family (Worswick 2000a). Helen House initially had eight beds, six for short-break care, previously termed 'respite care', and two for flexible use for urgent need. The priority was given to children in need of care at the end of their lives, and to their families. This was previously referred to as terminal care and is now described as end of life care. It was modelled on a home environment with children referred to not as patients but as visitors or friends (Worswick 2000a).

An analysis of the first year in operation demonstrated that Helen House considered referrals according to two priorities, children requiring end of life care and children with severe long-term illness usually cared for at home, whose parents were in need of respite (Burne et al. 1984). The bed occupancy was found to be higher than expected in the first year and it was noted to be important to keep this under review in order to retain the capacity to respond to the need for end of life care and crises at short notice in addition to safeguarding time for members of the multi-disciplinary team to focus on the children and their families (Burne et al. 1984).

Initial concerns were raised by one prominent paediatrician that widespread development of children's hospices should be resisted and a recommendation made that no more than four would be needed in the UK as a priority should be given to supporting care in the home or in units attached to hospitals (Chambers 1987). However by 1991, five further children's hospices had been established in the UK and during the 1990s numbers began to increase rapidly (Worswick 2000c). By the time of the millennium there were 22 children's hospices in operation in the UK and 13 in the project stage (Worswick 2000c). In 1995 guidelines for good practice in children's hospices were set out by a group of representatives from six children's hospices (Worswick 2000c). This guidance described the aim of children's hospice care: *"to offer holistic care for a child with a life-limiting condition and his or her family"* (Worswick 2000c). Statements described aspects of children's hospice services including the need for symptom control to aim to provide comfort and improve quality of life and care to be continued during the end of life phase of a child's life and following death (Worswick 2000c). The aim of these guidelines was to influence the development of services caring for life-limited children. In 1998, based on this initial group, the Association of Children's Hospices was formed and the first guide to CPC was published (ACT 1997).

The need for palliative care provision for young adults has been growing in line with the increasing life expectancy of children with life-limiting conditions (Fraser et al. 2015) and is discussed in the following chapter. Early on in the life of the first children’s hospice it became apparent that as some children ‘out-grew’ the hospice there was no comparable provision within adult services to enable transition to adult palliative care (Worswick 2000c). The children’s hospice movement responded to this need, at first with units for young adults within hospices intended primarily for children and in time, with separate units designed specifically for young adults (Worswick 2000c). The first of these was at Martin House hospice in Yorkshire in 2002, followed by the opening of Douglas House in Oxford in 2004 (Worswick 2000b; Dominica 2003).

There are currently 54 children’s and young adults’ hospice services in the UK (Chambers 2018). This has risen from a figure of 38 at the time of recruitment to this study (TfSL 2014) illustrating the dynamic and continuing evolution of children’s hospice services. The majority have been established through voluntary sector funding and in response to individuals’ experiences and their desire to support children and families in need of hospice services in the future (Hain et al. 2012). Today’s children’s hospices provide care to children with life-limiting conditions throughout their life, from the point of diagnosis or recognition, to end of life care and subsequent bereavement support. Care is provided for whole families and can be wide ranging, including psycho-social support, symptom management, specialist short-breaks, care at the end of life and after death in a cooled room, bereavement and sibling support (Kirk and Pritchard 2012; Harrop and Edwards 2013; Hunter 2017; Chambers 2018). There is no single model of children’s hospice care and services can comprise of inpatient bed units or a range of configurations of outreach services, sometimes termed ‘hospice to home’ (Chambers 2018).

Admissions to children’s hospices occur for planned short-breaks or symptom management at any time from diagnosis to death. This has been described as a dual approach, cutting across a conventional divide between active and palliative care (Spathis et al. 2012). The term ‘parallel planning’ has also been used to describe this concept, where hospice care or palliative care are offered alongside treatment aimed at either cure or prolonging life (Chambers 2018). Foundational to the approach of children’s hospices is a multi-disciplinary team of nurses, therapists, teachers, doctors, social workers, psychologists, chaplains and volunteers working together to deliver care that is family focused

(Stein and Woolley 1990; Chambers 2018). From its outset this approach has enabled parents of children with life-limiting conditions to find peace at the most difficult and distressing of times (Hearn 1990) .

2.4 Children's palliative care

As with adult hospice and palliative care services, the field of CPC emerged alongside its hospice counterpart with a shared philosophy and purpose. The World Health Organisation (WHO) principles of CPC (WHO 1998a) are encompassed in the following definition first proposed by the Association of Children's Palliative Care (ACT) and the Royal College of Paediatrics and Child Health (RCPCH) in their landmark guide (ACT 1997).

> *"Palliative care for children and young people with life-limiting or life-threatening conditions is an active and total approach to care, from the point of diagnosis or recognition throughout the child's life and death. It embraces physical, emotional, social and spiritual elements and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement "* (Chambers 2018).

Paramount in the philosophy of CPC is the promotion of best quality of life for every child and their family. To achieve this, giving children and families choice at every stage of their care is a key consideration (Chambers 2018). In planning services for children with palliative care needs it is imperative to consider their needs and choices in the context of whole families and overall quality of life (Fraser et al. 2012). "Better Care, Better Lives" was the Department of Health's (DH) first national strategy for CPC (DH 2008), it set out a vision for equitable access to high quality, family-centred, sustainable care, with services provided in a setting of a child and family's choice. This vision was subsequently translated into practical guidance (ACT 2009). Since then various service models have developed (Devanney and Bradley 2012).Unique services have evolved across the UK in response to local need, local resources, existing service configuration and the commitment of motivated professionals (Mellor et al. 2012). Despite the DH (2008) vision for equity, a lack of sustainable funding and issues with coordination of services has meant that care was and remains patchy (Craft and Killen 2007; Marston 2013; Pentaris et al. 2018). Research into met and unmet needs of children with life-limiting conditions confirms this, with evidence of inequities in service provision evidenced in one region of the UK (Coad et al. 2015).

2.5 Differences between adult and children's palliative care

Although adults' and children's palliative care share similar roots and philosophies there are important distinctions. In comparison to adults the numbers of children dying are small (Chambers 2018). Palliative care for adults traditionally focused on people with cancer (Saunders 1996; Clark 2007), only latterly caring for patients dying with neurodegenerative diseases, the consequences of cerebral ischemia and chronic cardiac conditions (Brian et al. 2008; Hussain et al. 2018; Datla et al. 2019; Miranda et al. 2019). From the outset CPC services have provided for children with a range of diverse life-limiting conditions and their families. Individual life-limiting conditions can be extremely rare and many are familial (Chambers 2018). The disease trajectories of life-limiting conditions can be long and unpredictable (Spathis et al. 2012) with care encompassing episodes of active intervention for medical emergencies, often respiratory crises (Spathis et al. 2012). Whilst for children with cancer there may be a shorter dying phase, for non-malignant conditions there can be a stepwise deterioration which occurs over many years where a child may seem to be on the point of death on a number of occasions only to recover temporarily (Hain et al. 2012; Mellor et al. 2012).

A further differentiation between CPC and adult palliative care is the way in which children grow and change over time. Children continue to develop physically, emotionally and cognitively throughout their lives (Spathis et al. 2012; Chambers 2018). The educational, developmental and play needs of children with life-limiting conditions must be met right up to the end of life (Mellor and Hain 2010; Chambers 2018), this requires flexible care across home, hospital and school settings (Spathis et al. 2012). A child's approach to decision making and their capacity for autonomy emerges over time and careful consideration of competence is needed (Mellor and Hain 2010).

Also important in distinguishing CPC and adult palliative care is the focus of working with and supporting families. Parents are impacted by a heavy burden of care needs (Mooney-Doyle and Deatrick; Bailey-Pearce et al.; Courtney et al.) and siblings are vulnerable and need specific support (Olivier-D'Avignon et al.). The dynamic of caring for whole families and decision-making in partnership with parents is unique to CPC and has presented escalating ethical challenges in recent years (Hain 2018).

2.6 The role of nurses in the development of CPC

In exploring the role of medicine in the development of children’s hospices it is important to acknowledge the foundational role of nursing. At Helen House, Oxford, the world’s first children’s hospice, the original service provision model was nurse-led. The service model comprised a registered nurse to be on duty at all times with sufficient nurses on the team to provide 24 hours care seven days a week. Nurses now make up the most significant proportion of the children’s hospice workforce. In a 2011/2012 service mapping project, nurses made up 51% of the workforce in children’s hospices in the UK, with 830 whole-time equivalent posts in the 43 children’s hospice services represented (Devanney and Bradley 2012). At that time three children’s hospice services reported employing a nurse consultant. Although nurses provide the majority of clinical care within children’s hospices, the way in which the roles have developed and the contribution that specialist nursing care now makes to the medical aspects of children’s hospice services is undefined. Whilst in adult palliative care there is a body of literature relating to nursing models and theories for hospice and palliative care nurses (Dobrina et al. 2014), nursing roles and models in CPC are still in a process of evolution (Hill and Coyne 2012; Bennett and McKinnon 2016).

Children’s nurses with particular skills and expertise have played key roles in the development of CPC services (Chambers 2018). Community children’s nurses (CCNs) are well placed to provide palliative care to children and young people (Maunder 2006; Chambers 2018) and in particular to take on key worker roles to coordinate care. CCNs have been required to develop a range of specialist skills in order to work effectively in collaboration with parents of children with complex health care needs (McIntosh and Runciman 2008) who are often also children with life-limiting conditions (Pinney 2017), as discussed in the following chapter. In the recent past when supporting children at the end of their lives, the workload of CCNs in a CPC team has been shown to be wide-ranging and often hidden (Tuffrey et al. 2007). Currently this work has come to the fore with CCNs considered a key part of core CPC services (Chambers 2018). Recent models of collaborative working between CCNs and hospice nurses have been shown to be beneficial in supporting children and families (Bennett and McKinnon 2016). This collaborative working is a key area for future service development (Bennett and McKinnon 2016).

In allied specialities such as oncology, the role of the specialist nurse was developed in part in response to the need for home-based care throughout treatment but also for children where treatment was not curative and palliative care needed (Hunt 1995). Originally termed Paediatric Oncology Community Nurse Specialists later became Paediatric Oncology Outreach Nurse specialists (POONSs), these nursing roles developed in parallel to the growth of children's hospice and palliative care. The first service was established at Great Ormond Street Hospital in 1986 (Hunt 1998). The role of these specialist nurses has been explored (Hunt 1995) focusing on their interaction with other health care professionals and the influence that location and funding arrangements have on practice (Hunt 1998, 1999).

The specialist role of nurses in CPC has been defined and competencies outlined (Hill and Coyne 2012). As for all health professionals providing palliative care, obtaining and maintaining appropriate education, knowledge and skills is vital (Hill and Coyne 2012). Nurse consultants were introduced in 1999 in response to a lack of a clinical career pathway for senior nurses (Manley and Tichen 2012) their role was implemented much later with a significant gap between policy and implementation. The role of nurse consultant and other nursing roles denoting 'specialist' knowledge and training such as the clinical nurse specialist and advanced nurse practitioner, have only relatively recently been developed in CPC and there has been limited research on their impact in practice (Maynard and Lynn 2016a).

2.7 Palliative medicine

The specialty of palliative medicine emerged as a continuation of the development of the adult hospice movement (Field 1994). Palliative medicine was recognised as a specialty by the Royal College of Physicians in 1987 and defined as "*the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life" (Doyle 1993).* It is of note that from the naissance of the adult hospice movement in the 1960s there was a delay of two decades before the emergence of the specialty of palliative medicine, a pattern subsequently followed by the children's hospice movement and PPM.

At its inception there were concerns voiced about the role of palliative medicine in palliative care. For some, paradoxically, palliative medicine caused a resurgence of the fear of medicalisation of death (Field 1994). Historically, one of the most extreme critics of the medicalisation of death was Illich, who proposed that people's ability to cope with their own pain and suffering was diminished by medical care (Illich 1990). While hospice care emphasised the needs of the whole patient there was a concern that this holistic care could gradually be subverted (Field 1994). In a more measured critique, concerns related to the clarity of the remit of palliative medicine, as a specialty related to the stage of a condition rather than its pathology (Doyle 1993). In view of this the palliative medicine model was described as overarching the course of an illness, unified by quality of life goals (Clark 2002).

Others mourned the loss of the early ideals of hospice care with an emphasis on physical symptoms at the expense of psychosocial and spiritual concerns (Clark 2002). Kearney (1992) voiced the risk of "selling out" to a medical model where palliative medicine specialists were symptomatologists and suffering was a problem to be solved (Kearney 1992). Clarke (2002) explained this medicalisation as an expected rather than the intended consequence in the development of palliative care, describing palliative medicine as a specialty that *“opens up a space between the hope of cure and the acceptance of death”* (Clark 2002). This tension is important to acknowledge as it sets the scene for the relationship between hospice care and palliative medicine for adults and may give insights into the current position within children’s hospice medical service provision.

2.8 Medical service provision within children’s hospices

In Helen House, medical care was provided by one GP, the medical director, who took on full medical responsibility for some children whilst it was planned that the majority would remain under the care of their own GP (Burne et al. 1984; Worswick 2000a). The medical role quickly evolved, as the children’s own GPs devolved care to the medical director. Over time the medical team at Helen House was expanded to three GPs with regular working hours at the hospice and on call duties. The aim was for the doctors to be involved, not in crises, but in what was described as “*ongoing palliative treatment”* (Worswick 2000d). Although the GPs worked outside the NHS, close liaison with hospital and community services was deemed essential (Burne et al. 1984).

Since this original hospice medical team, doctors’ roles in CPC, much like those of nurses, have emerged in an ad hoc manner. Historically, doctors from a range of professional backgrounds including community paediatrics, general paediatrics, paediatric oncology, general practice and adult palliative medicine have worked in CPC across hospital, community and hospice settings (Mellor et al. 2012; APPM Education Subgroup and RCPCH 2015). The rapid and varied development of children’s hospices has led to a multiplicity of approaches to medical service provision within these hospices (Hunter 2017). Various approaches range from minimal input by GPs in primarily nurse-led services to hospice-employed teams of specialist paediatricians providing 24 hour on call and clinical review and management as part of in-reach into tertiary children’s hospitals (Frost 2013). To date there has been no research to define these approaches to hospice medical service provision or to determine the impact on the care delivered. To this end service development and delivery in CPC has been recognised as a priority for research (Steele et al. 2008; Liben et al. 2014; Baker et al. 2015).

A landmark study (Amery and Lapwood 2004) identified 55 doctors working in children's hospices in England, the majority of who were GPs with a special interest in CPC. At this time there was no organisational structure or core syllabus for the speciality of PPM and doctors' training needs within the specialty were explored in order to develop and implement a curriculum (Amery and Lapwood 2004). This 'combined curriculum', was developed jointly by the RCPCH and the Association of Paediatric Palliative Medicine (APPM) and designed for use by doctors from a range of professional backgrounds. It defines competencies in relation to knowledge, skills and attitudes in PPM and enables doctors from a range of backgrounds to define their experience at various levels (APPM Education Subgroup and RCPCH 2015). There has been minimal further research into the population of doctors working in children's hospices. Information on medical staff from the data mapping project for UK children's hospices was limited and doctors were reported to make up only 1% of the direct care team workforce (Devanney and Bradley 2012) .

2.9 The development of PPM

PPM has been described as the contribution that doctors bring to the provision of CPC (Hain et al. 2012). Integral to the philosophy of children's hospice care is the concept of a multi-disciplinary team (Jassal 2006). The provision of medical care has an important role within this context and is interwoven with psychological, social, educational and spiritual care (Hain 2004).

Since 2009, PPM has been recognised as a subspecialty of the RCPCH (RCPCH 2010). Prior to this individual doctors with a pioneering interest in CPC worked across hospital, community and hospice settings providing medical aspects of CPC (Goldman et al. 1990; Goldman 1995; Goldman 1998; Craig 2003; Hain 2004). These pioneering doctors advocated for the development and formal recognition of PPM (Hain and Goldman 2003; Hain 2004) Since 2009, significant steps have been taken to standardise education and training through the development of a recognised set of competencies and publication of a curriculum (RCPCH 2018, 2010). This curriculum sets out requirements for developing a special interest in PPM and for educating and training consultants in the sub-specialty. However, subsequent development of new consultant PPM posts has been slow (Mellor et al. 2012). By 2016 there were 15.7 whole time equivalent consultants in PPM, seven of whom were all or part funded voluntary-sector funded by hospices the other posts being entirely NHS funded (Hunter 2017). The challenges in developing these posts relate, in part, to the relatively small numbers of children needing palliative care over large geographical areas (Mellor et al. 2012; Chambers 2018). A need for a small number of tertiary specialists, providing regional leadership through managed clinical networks, working with a larger number of locally based paediatricians and GPs with a special interest in PPM and a range of local CPC core services has been identified (RCPCH 2012; NICE 2016c). The number of consultants in PPM currently working in children's hospices in the UK and their impact on medical care within children's hospices is unknown.

2.10 National standards

In 2016, the National Institute of Clinical Excellence (NICE) published a clinical guideline and associated quality standards in relation to end of life care for infants, children and young people (NICE 2016c; Villanueva et al. 2016). The guideline and quality standards cover the planning and management of end of life care for 0 – 17 year olds with life-limiting conditions (NICE 2016c). Of particular relevance to this research, one of the quality standards recommends that children at the end of their lives being cared for at home have 24 hours access to both children's nursing care and advice from a consultant in PPM (Villanueva et al. 2016). Alongside this, European and UK standards on specialist CPC services define specialist services as those supported by a consultant in PPM (European Association for Palliative Care 2007; NHS England 2013). This has raised a tension within the field for the many services that specialise in CPC but do not have the support of a specialist in PPM (Mitchell et al. 2017). This is particularly notable in children's hospices. In addition, there is little published evidence on the benefits to children and their families of this type of specialist CPC service (Mitchell et al. 2017), in particular at times of deterioration or at the end of life.

2.11 Chapter conclusion

The purpose of this chapter has been to present the backstory of children's hospice care and PPM. In order to do this the roots of the hospice movement and the pioneering work of Dame Cicely Saunders were reviewed. The inception of children's hospice care and the parallel development of CPC were charted. The crucial role of the development of nursing roles in CPC was outlined. Initial responses to the specialty of palliative medicine gave an insight into the 'fault lines' which may be present in the interplay of the hospice movement and palliative medicine, raising concerns over the potential dominance of a medical model within a philosophy intended to be holistic, multi-disciplinary and family-centred. The initial and current knowledge of medical service provision within children's hospices was explored alongside the development of PPM as a new sub-specialty. Recent national and European policy standards regarding specialist CPC services were explained as important external forces impacting on the inter-relationship of children's hospices and PPM.

3 The numbers and needs of children requiring hospice care

3.1 Chapter introduction

The previous chapter considered two of four elements important in this research study, children's hospices and PPM. This chapter focuses on the third and fourth elements of the research presented in this thesis, the children who could benefit from access to hospice care and their needs. The way in which children with palliative care needs are defined and identified is explained, including the wide range of health conditions classified as life-limiting and life-threatening. Research findings confirming a rising national prevalence of life-limited children and young people are outlined and the limited data on numbers of life-limited children supported by hospices given. The needs of these children and their families are then discussed in broad terms followed by a focus on the medical aspects of care in particular when a child with a life-limiting condition has unstable symptoms, deteriorates or is dying. Finally the rationale for research to guide the development of children's hospices is stated in order to position this research within the national priorities for building an evidence base within the field.

3.2 Which children would benefit from palliative and hospice care?

Early in the evolution of CPC, four categories of life-limiting and life- threatening conditions in children were proposed (ACT 1997, 2009) Life-limiting conditions are defined as *"those for which there is no reasonable hope of cure and from which children will die"* (Chambers 2018). These conditions can involve continuous deterioration and increasing dependency and disability with complex health needs. Life-threatening conditions are those *"for which curative treatment may be feasible but may fail"* (Chambers 2018). For these conditions there can be significant changes in goals of care depending on the outcome of active treatment.

The original classification has remained the blueprint for defining the population of children who would benefit from palliative and hospice care (Chambers 2018). A wide range of health conditions is encompassed in this practical classification. Figure 3.1 details the four categories of life- limiting and life-threatening conditions and has been included to give a picture of the breadth and depth of needs for such a diverse population. It is important to note that a significant number of life-limited children do not have a defined diagnosis (Hain et al. 2012).

Figure 3.1: Categories of life-limiting and life-threatening conditions. Adapted from the Guide to Children's Palliative care (Chambers 2018).

Category	*Examples*
Category one Life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be necessary when treatment fails, irrespective of the duration of that threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.	Cancer, organ failures of heart, liver, kidney, transplant and children on long-term ventilation
Category two Conditions for which premature death is inevitable, these may involve long periods of intensive disease-directed treatment aimed at prolonging life and allowing participation in normal activities. Children and young people in this category may be significantly disabled but have long periods of relatively good health.	Cystic fibrosis, Duchenne muscular dystrophy and SMA Type 1
Category three Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.	Batten disease, mucopolysaccharidoses and other severe metabolic conditions.
Category four Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care.	Severe cerebral palsy, complex disabilities such as following brain or spinal cord injury.

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Over the past decades this classification has provided a template for CPC and children's hospice service development (Fraser et al. 2012; Hain et al. 2012) supported by research conducted to describe patterns of disease trajectories within each of the categories of life-limiting and life-threatening conditions (Wood et al. 2010). This is of relevance to understanding when a child and family may need medical review within the context of children's hospice care.

In addition, the identification of different phases in the life of children with life-limited conditions potentially enables planning for appropriate levels and types of support including when specialist PPM input could be needed. These phases have been identified as: stable, unstable, deteriorating and dying (Hughes-Hallet et al. 2011; Jarvis et al. 2016). Originally defined and applied in practice in adult palliative care (Masso et al. 2015; Mather et al. 2018) the phases of illness were intended for use as subjective terms, applied by the lead clinician as part of the palliative care funding review in England (Hughes-Hallet et al. 2011). However recent research in Scotland has provided objective definitions in order to assess the scope of need (Jarvis et al. 2016). These are discussed further in Chapters Ten and Fourteen.

3.3 Epidemiology: children with life-limiting and life-threatening conditions

There have been estimated 49,000 children (0 – 18 years) in the UK with a life-limiting condition (Fraser 2012; Chambers 2018). In England the prevalence of children with life-limiting conditions was shown to have increased over ten years from 25 per 10,000 to 32 per 10,000 population of 0 – 19 year olds (Fraser et al. 2012). In Scotland, prevalence of children and young adults from 0 – 25 years has been investigated, with a complete prevalence of 95.7 per 10,000 population of 0 – 25 year olds, in 2013/2014 (Fraser et al. 2015). Rising prevalence was again demonstrated in comparison to the previous figure of 75 per 10,000 population of 0 – 25 year olds in 2009/2010. However a later report (Pinney 2017) alluded to a lack of accurate, current data on numbers of children with life-limiting conditions, how this is changing over time and the potential need for CPC and children's hospice services. A recently published report (Fraser et al. 2020) confirms a further increase in prevalence of children with life-limiting conditions in England to 66.4 per 10,000 population of 0 – 19 year olds. This represents a trebling in prevalence of children with life-limiting conditions in England over the past 17 years (Fraser et al. 2020).

There is an overlap between the population of children with complex neuro-disability with complex health care needs and those requiring palliative care (DH 2004; Pinney 2017). Previously termed complex and continuing health care needs (Hewitt-Taylor 2005), the original definition encompassed children dependent on technology including; tracheostomies, long-term ventilation, enteral or parenteral feeding, intra-venous medications and could also include children with limited mobility or movement disorders (Hewitt-Taylor 2005). There is no current consensus on the definition of complex care needs. The broad term complex needs and/or life-limiting conditions was used in a review for the council for disabled children (Pinney 2017) whereas the RCPCH uses the term complex medial needs to describe a wide range of conditions and technology dependence (RCPCH 2014). Spratling's (2015) review of literature to identify terms and definitions to describe children and young people who require technology, found a range of definitions. The terms 'technology' and 'complex needs' were found to be linked and a rationale given for combining these terms to differentiate children dependent on technology who therefore require complex care from children with other complex medical needs (Spratling 2015).

For the purpose of this study a broad definition of complex care needs was chosen to include both technology dependent children and children who require significant additional care in relation to other factors (Hewitt-Taylor 2012). The rationale for this decision was that in addition to asking specific questions in relation to the technology dependence of children accessing hospice care, the study questions were also intended to gather the views of respondents as to what contributes to the complexity of care needs in children with life-limiting conditions.

The DH has highlighted the increased prevalence of children with complex health care needs in the past, estimating there to be 6000 children at home, dependent on technology for survival in 2004 (DH 2004). This increase in complexity and the changing profile of children with life-limiting conditions are consistently linked to two key trends; namely an increased survival of low birth weight babies and advances in technology and treatment leading to increasing life-expectancy in conditions which would previously have led to death in the neonatal period or early childhood (Craft and Killen 2007; DH 2008; Pinney 2017).

Devanney and Bradley (2012) reported that 7,638 children and young adults with life-limiting conditions were supported by the 43 children's hospice services in the UK at that time. Although likely to be an underestimate of the care provided, this is a fraction of the overall population of children with life-limiting conditions based on the prevalence figures reported above, indicating a higher demand for children’s hospice services than is currently being met. Research and expert opinion concur that the number and complexity of children who could benefit from palliative and hospice care is increasing rapidly.

3.4 The needs of children with life-limiting and life-threatening conditions

Research has established a wide range of needs for children with life-limited conditions and their families (Hunt and Coad 2013; Coad et al. 2015). Qualitative research exploring the perceived met and unmet needs of children with life-limiting conditions in one region of the UK demonstrated that overall children and their families have felt that medical and nursing needs are well met (Coad et al. 2015). However many instances of “*services under pressure”* were cited indicating a limited and stretched service provision for the needs of these children and their families. These needs include: pain and symptom management, information, communication concerning choice and decisions, advanced care planning and short breaks.

Pain and symptom management including complex symptoms throughout life and at the end of life are an important part of a child’s palliative care needs (Harrop et al. 2017). As the complexity of care needs and technology dependence for life-limited children have increased (Pinney 2017) the associated symptom management for these children has become increasingly complex (Harrop and Edwards 2013). The approach to managing these symptoms must be a ‘whole child and family’ approach with pharmacological treatments alongside psychological, emotional, social and spiritual care as well as non-pharmacological management (Harrop et al. 2017). With close links to managing the palliative care needs of adults, this type of approach is epitomised in Cicely Saunders concept of ‘total pain’ and its treatment (Ali et al. 2010).

Information for children with palliative care needs and their families has been identified as a priority throughout their care (Coad et al. 2015), starting with information at the point of diagnosis and initial signposting to local resources (Chambers 2018). Children need age appropriate information about their health condition and care and families need guidance to navigate the maze of information available via social media and online (Chambers 2018).

Communication with children and families around choices is a core element of the practice of CPC (Bluebond-Langner et al. 2017). Partnership with parents and children in decision-making is built primarily on an ongoing relationship of trust between the clinician and parents (Bluebond-Langner et al. 2017). Goldman et al’s (1990) seminal study described the work of a symptom care team, in particular in relation to choice in location of care. Choice in place of care has been a key policy driver in national CPC strategy (DH 2008). However a systematic literature review has raised concern as to the wisdom of using location of care, and in particular place of death as a primary aim and outcome measure (Bluebond-Langner et al. 2013) and further research is needed to evaluate the factors influencing choice in place of care and in particular place of death (NICE 2016a).

Advance care planning is the process whereby parents and when possible children and young adults, discuss in depth their hopes and plans for current and future treatment, including care at the end of life (Beringer and Heckford 2014; Harrop et al. 2018). This is a process over time, resulting in a shared documentation and is of particular importance in supporting choice in place of end of life care (Harrop et al. 2018). Children with life-limiting conditions have been shown to be 75% more likely to die on a Paediatric Intensive Care Unit than children without life-limiting conditions (Fraser and Parslow 2018) and therefore advance care planning is vital if a family wish their child to be cared for at home or in a hospice at the end of life (Wolff et al. 2011).

The need for and benefits of short breaks for parents providing care for life-limited children are reasonably well documented (Eaton 2008; Mitchell 2017), From the outset short-breaks have been a pivotal part of the core service offered by children’s hospices as demonstrated in the earlier section on the development of children’s hospice care (Chapter Two). Support for siblings

(Olivier-D'Avignon et al. 2017) is also a recognised part of the whole family care that the philosophy of CPC advocates.

Hospices, with their ethos of holistic, family-centred care, are well placed to meet each of these needs (Hain et al. 2012; Hunter 2017). When doctors work within multidisciplinary teams with a range of expertise, the medical care offered can take its place as part of the encompassing child focused philosophy of CPC (Hain 2004). In addition, when short-break support is given to a child and family over a number of years, this gives an opportunity for building trusting relationships (Mitchell 2017), so vital in making decisions and giving choices regarding treatment through life to end of life care (Bluebond-Langner et al. 2017).

3.5 Care at times of unstable symptoms, deterioration and at the end of a child's life

There is an extensive literature base concerned with understanding bereaved parents' experiences of caring for a child at the end of their life (Vickers and Carlisle 2000; Wheeler 2001; Cherlin et al. 2004; Seecharan et al. 2004; Steele and Davis 2006; Theuissen 2007; Edwards et al. 2008; Widger and Picot 2008; Rodriguez and King 2009; Price et al. 2011). Studies seeking the views of children with life-limited conditions and their families have shown that it is not the service alone which matters but the way in which it is delivered, including reports that parents perceive services as not seemingly designed to meet their needs (Coad et al. 2015; Mitchell 2017). Challenges in communication between professionals and with parents and children have been found to be a major factor determining the quality of service provision (Brooks et al. 2013). Lack of coordination between community services and hospitals (Monterosso et al. 2007) and a poor understanding of the underlying concepts of CPC have also been identified as impacting service development (Monterosso et al. 2007).

Price (2013) drew on priorities identified by bereaved parents' to investigate professionals' perspectives on developing end of life care services for life-limited children. The six issues identified as challenging within this context were: symptom management; communication with and relationships between families and professionals; emotional impact; the withdrawal of feeding or treatment and sibling support (Price et al. 2013). The conclusions affirmed end of life care as a ‘multi-dimensional experience’ for both parents and professionals and identified a need for joined up, accessible, family-centred services through end of life care and in particular to bereavement support (Price et al. 2013).

Research specific to the experiences of those providing care at the end of life in children’s hospices has found that although a rewarding experience, there are significant challenges in finding the right approach to relieving distressing symptoms and in communication with families (McConnell and Porter 2017). As evidenced (Price et al. 2013; McConnell et al. 2016), challenging symptoms can occur at the end of life and children’s hospices have from the outset been intentionally focused on providing holistic, family centred care at this most crucial time (Worswick 1995). There is little published research on the form that services to support parents and children at this time should take (Widger and Picot 2008) particularly with regard to medical service provision within children’s hospices. In spite of recommendations for specialist PPM presence as part of specialist CPC services (European Association for Palliative Care 2007; NHS England 2013) there is little and low quality evidence to identify the impact of this specification (Mitchell et al. 2017).

The pathway to end of life care can involve ethical decision making around the withdrawal of treatments. In line with advances in technology and medical treatments, the need for decision making in partnership with parents has become a priority area in CPC (Hain 2018). This is one of the recognised skills of those with education and training in PPM (APPM Education Subgroup and RCPCH 2015; RCPCH 2010). Specific points during a child’s life may prompt the need for these discussions and the involvement of a specialist in PPM. Compassionate extubation describes the process whereby a decision is made that ventilation is no longer in a child’s best interests and will be withdrawn (ACT 2011). The choice for and facilitation of compassionate withdrawal of treatment including ventilation, has become one of the services offered by specialist CPC services including hospices (Harrop and Edwards 2013). Collaborative work between the CPC sector and fields of neonatal and paediatric intensive care has led to a pathway to extubation within a CPC framework (ACT 2011). This can be applied within a children’s hospice setting

(Harrop and Edwards 2013) but there is little known as to the equity of this provision across the UK.

There is limited published research around the needs of children with life-limiting conditions at times when their symptoms become unstable or their condition is deteriorating. It is recognised that the need for different levels of specialist PPM review will vary for each individual child over the course of their life and during end of life care (Hain et al. 2012). It is also acknowledged that some children with life-limiting conditions will never need access to specialist PPM, whilst others will depend on this throughout life and death. However the most common pattern is anticipated to be one of intermittent episodes of need for specialist review (Hain et al. 2012). One of key triggers for review is deterioration in symptoms, this may be pain or a range of other complex symptoms experienced by children with life-limiting conditions (Harrop and Edwards 2013). Children may be admitted to an inpatient setting (either hospice or hospital) for assessment of these symptoms and review or initiation of medication as part of a multi-disciplinary approach or reviewed in the community (Harrop and Edwards 2013).

Overall there is knowledge that children with life-limiting conditions have increased need for medical care both at a general and specialist level at times of unstable symptoms, deterioration and at the end of life (Harrop and Edwards 2013; Chambers 2018). However there is limited evidence as to the contribution children's hospices make to the care of children with life-limiting conditions and their families across the UK at these times and the impact of differing PPM service provision within these hospices.

3.6 The call for research to guide the development of children's hospices

Barriers, challenges and recommended responses for research within the adult hospice sector have been clearly defined (Payne 2013). Together for Short Lives (TfSL) is a national charity for children living with life-limiting conditions, their families and the professionals involved in their care and in research in CPC. TfSL provide resources, raise awareness and advocate for funding and policy change. The TfSL research strategy (TfSL 2017) has adopted Payne's (2013) recommendations as of equal importance to the children's hospice sector, calling for evidence to demonstrate the impact and effectiveness of CPC and highlighting the need to respond to changing demographics. In addition NICE have made five recommendations for priority areas for research in association with the end of life care guidance for children (NICE 2016a). These include a need to develop an understanding of factors influencing the preferred place of care and place of death for children with life-limiting conditions and their families. One factor suggested to be significant in this choice but as yet un-evidenced, is the treatment of distressing symptoms (NICE 2016a). Therefore access to PPM within children's hospices may be an important consideration.

To date evidence based service development in CPC has been lacking (Help the Hospices Commission 2013) The children's hospice movement is currently seeking to redress this shortfall. Hain (2012 p383-384) called for "*a co-ordinated national approach to regulation of the number, location and professional accountability of children's hospices* [that] *would ensure that the highest standards are consistently achieved and that each hospice is 'fit for purpose' ".* To date there has been limited evidence to recommend what this would entail, both in general terms and specifically in relation to medical service provision within children's hospices including the interface with PPM.

There is therefore need for research to determine:

- The approaches to medical service provision within current children's hospice provision in the UK.
- The current medical workforce in children's hospices in the UK and their contribution to CPC.
- The specialism and education of doctors working in children's hospices.
- The contribution of the evolving specialism of PPM to children's hospices.
- The impact of different approaches to PPM service provision on the response by children's hospices at times when a child with a life-limiting condition has unstable symptoms, is deteriorating or is reaching the end of their life.

- The inequities in PPM service provision within children's hospices across the UK.

The original hospice movement and the subsequent children's hospice movement have a rich history of family centred, multi-disciplinary care aimed at supporting adults and children as a whole whilst providing timely and compassionate medical care within this context (Worswick 1995; Saunders 1996). At this crucial point in time it is vital to understand how medical care has shaped the development of children's hospices and to determine how best to maintain this foundation of holistic care whilst ensuring an equity of access to PPM.

3.7 Chapter conclusion

The purpose of this chapter has been to give a picture of the children and their families who would benefit from access to hospice care and their needs. The origins and on-going use of the classification of life-limiting conditions into four categories was given in order to enhance the picture of the significant and diverse needs of this population. Research determined numbers of children with life-limiting conditions confirmed an escalation in this population and subsequent resource implications on children's palliative and hospice care. The potential needs of these life-limited children were outlined in order to demonstrate the importance of locating medical care and specialist PPM within a multi-disciplinary framework, as is foundational to children's hospices. The specific needs when a child's symptoms deteriorate and at the end of life were discussed although there was limited evidence to illustrate these. Finally the manifesto for research to support CPC development and service delivery was presented with the need for this research study justified.

4 Mixed Methods Research

4.1 Chapter introduction

Following on from the rationale given for this research at the close of the previous chapter, this chapter focuses on the methodology of mixed methods research adopted within this study. The definition and history of mixed methods research are outlined. The use of mixed methods research within the field of CPC is presented with a rationale for the application of mixed methods within this study. Following this, the philosophical foundation of mixed methods research is explored with particular reference to the origins and relevance of pragmatism to this study. With this pragmatic foundation in mind, a theoretical framework is set out in the absence of an existing theory applicable to the research questions, using the intersection of a number of important concepts within children's hospice and palliative care. The development of the current range of mixed methods research designs is set out and contrasted to the original design and eventual convergent design for this study. The use of mixed methods comparative case study approach is introduced and its relevance to the use of case scenarios and the integration of findings outlined. Finally a summary of the advantages and disadvantages of mixed methods research is given

4.2 Definition of mixed methods research

Mixed methods research has been described as the *"third methodological movement"* (Tashakkori and Teddlie 2003) proceeding from the development of quantitative and qualitative research. On a simplistic level, mixed methods research has been defined as combining quantitative and qualitative components within a single study (Creswell 2015b). However, as mixed methods research has evolved over time, a number of approaches to defining its meaning have emerged. These focus on various aspects of the methods, methodology, purpose and philosophy of the research as summarised in Figure 4.1.

Figure 4.1: Authors and the focus of their definition of mixed methods (Creswell and Plano Clark 2018b)

Author(s) and Year	Focus of Definition
Greene, Caracelli, and Graham (1989)	Methods
Tashakkori and Teddlie (1998) (2003)	Methodology (the process of research)
Johnson, Onwuegbuzie, and Turner (2007)	Viewpoints (philosophy), methods and research purpose
Tashakkori and Creswell (2007)	Methodology and Methods
Greene (2007)	Multiple ways of seeing, hearing and making sense of the social world
Creswell and Plano-Clark (2007)	Methods, methodology and philosophy
Creswell (2014)	Methods and core characteristics
Hesse-Biber (2015)	Methods and contested terrain

Most recently Creswell and Plano-Clark (Creswell and Plano Clark 2018b) have provided a definition of the core characteristics of mixed methods research emphasising the key components of designing and conducting a mixed methods study. Foundational to such a study is the collection and analysis of qualitative and quantitative data in response to research questions or hypotheses. Following on from this, integration of the two forms of data and their results should take place. The authors emphasise the importance of a specific research design providing logic and procedures for conducting the study and the need to frame these procedures within theory and philosophy (Creswell and Plano Clark 2018b).

4.3 The history of mixed methods research

The origins of mixed methods research date back to the 1950s in 'multi – method' research with Campbell and Fisk (1959) combining multiple quantitative methods within one study. The early stages of development, termed the *formative period* (Creswell and Plano Clark 2018a) continued into the early 1980s. Researchers in a number of fields tested out early approaches to combining qualitative and quantitative methods and data (Sieber 1973; Denzin 1978; Cook and Reichardt 1979).

Subsequently an on-going debate regarding the challenges in combining research methods with different epistemological and methodological assumptions arose, termed the *paradigm wars* (Bryman 2006a) or the *paradigm debate* (Creswell and Plano Clark 2018a). For a significant period of time from the 1970s to the mid 1990s researchers argued from a variety of philosophical standpoints (Bryman 1988). Rossman and Wilson (1985) discussed stances within the debate and suggested that multiple paradigms can be used to address research problems. By 1998 there were calls to embrace pragmatism as the philosophical foundation of mixed methods research (Tashakkori and Teddlie 1998, 2003). Pragmatism in this context, discussed further below, focuses on what works in practice to address a research question (Tashakkori and Teddlie 2003). It is a philosophical stance that accepts combining the epistemological foundations of both quantitative and qualitative research in order to achieve a shared aim (Yardley and Bishop 2015).

As the paradigm debate subsided two further phases: the *early* and the *expanded procedural development,* followed (Creswell and Plano Clark 2018a). These developments focused on the way in which mixed methods research is designed and implemented. A seminal article published in 1989 (Greene et al.) laid the foundations for mixed methods research design, relating five types of design: triangulation, complementarity, development, initiation and expansion (Greene et al. 1989) discussed further in section 4.5.

Since these early developments the acceptance and use of mixed methods research has become mainstream, with the publication of several key texts

(Tashakkori and Teddlie 2003; Hesse-Biber and Johnson 2015; Creswell and Plano-Clark 2018c). Guidelines for best practice in combining qualitative and quantitative research have been agreed within the health sciences (National Institute of Health 1999; Creswell 2011a) and publications of mixed methods research articles across disciplines have increased as examined in the work of Plano-Clark (2005).

From 2003 onwards a period of *reflection and refinement* was declared (Creswell and Plano-Clark 2018c). During this time critiques of mixed methods research continued to be aired and examined, culminating in a discussion by Creswell of eleven controversies and questions raised in mixed methods research (Creswell 2011b). These ranged from questions relating to definitions, through to paradigm, design, procedures and discussion of the value of mixed methods research (Creswell 2011b). The conversation continues, but mixed methods is now firmly established and utilised in multiple research fields including health care and specifically palliative care (Farquar 2011).

4.4 Mixed methods research in the field of CPC

Mixed methods studies are increasingly used in health care, reflecting the complex nature of the research questions to be answered. Various ways to combine qualitative and quantitative research have been developed in health research (Bishop 2015). The use of mixed methods research within the field of palliative care has become prominent in view of the complexity of questions relating to interventions and the challenges in identification of outcomes (Farquar 2011). Within CPC, mixed methods research has been used to address a range of questions including; the educational needs of children's hospice doctors (Amery and Lapwood 2004), the impact of children's hospice short breaks (Mitchell 2017), the epidemiology and evaluation of the needs of life-limited children and their families (Donnelly et al. 2005; Fraser et al. 2015), the investigation of health-care staffs' experience of providing end of life care to children (McConnell et al. 2016), the understanding of perspectives of parents and professionals to inform the development of CPC services (Contro et al. 2004) and the exploration of parents' and young people's perspectives of hospice support (Kirk and Pritchard 2012).

4.5 Rationale for use of mixed methods in this study

It is important for researchers to have a clear rationale for using mixed methods (Greene et al. 1989). Greene presented a scheme of five possible types of design with accompanying rationales for combining quantitative and qualitative research. These are summarised in Figure 4.2:

Figure 4.2: Rationales for the use of mixed methods research, adapted from Bryman (2006)

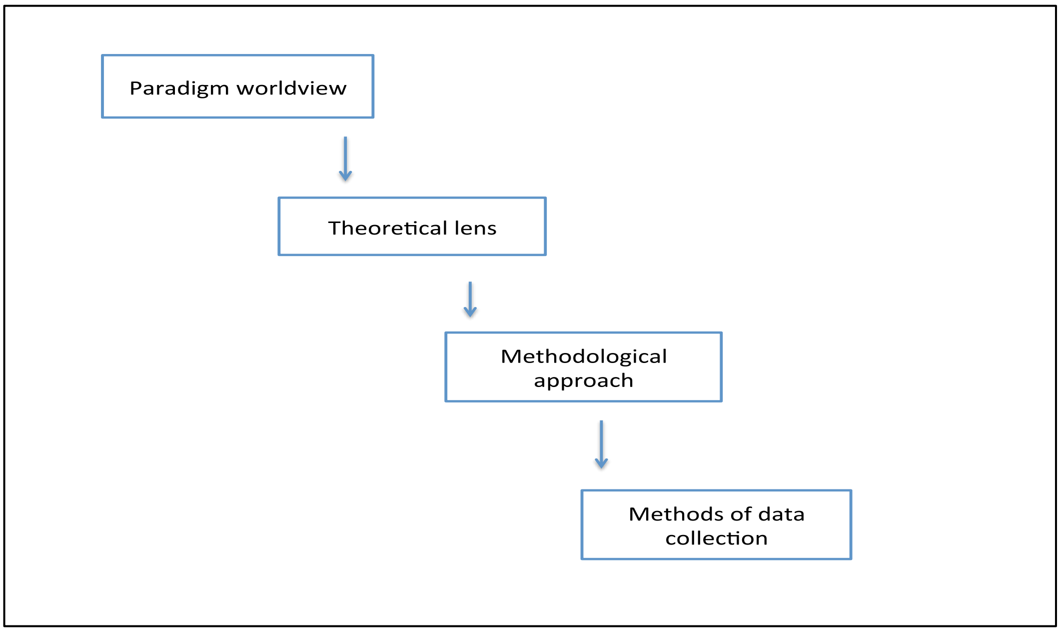
Rationale	*Description*
Triangulation	Seeking corroboration between quantitative and qualitative data.
Complimentarity	Seeking elaboration, enhancement, illustration or clarification of results of one method with another.
Development	The results from one method are used to develop or inform another.
Initiation	Seeks discovery of a paradox and contradiction, the recasting of questions or results from one method with questions or results from another.
Expansion	Seeks to extend breadth and range of enquiry.

In his formative paper, Bryman (2006) expanded upon Greene's (1989) scheme and developed a more detailed scheme of possible rationales for the use of mixed methods, using content analysis to examine the ways in which quantitative and qualitative methods are combined in practice. The rationale for the use of mixed methods within this study is to provide a rich picture of the approaches to PPM service provision within children's hospices. This approach is consistent with Bryman's (2006) rationale of 'completeness' (Bryman 2006)where using mixed methods provides a comprehensive account of the field of enquiry. Creswell termed this as the "*collective strength"* of combining qualitative and quantitative methodology (Creswell 2015b). Within this study the combination of quantitative and qualitative approaches to research design, data collection and analysis provided a more complete understanding of the research problem than would be possible with either approach by itself.

4.6 Philosophical foundations of mixed methods research

It is important for a researcher to acknowledge the world-view of the phenomenon under investigation, providing a foundation for their research. This, in turn, will influence the theoretical stance, research design and methods of data collection, as represented in Crotty's (1998) four-stage conceptualisation (Figure 4.3).

Figure 4.3: Crotty's conceptualisation (Crotty 1998)



The term 'paradigm' was originally used by Kuhn (1970) who described it as a set of generalisations, beliefs and values of a community of specialists. A broader definition, that has received more attention, is the use of a paradigm as a world-view or way of thinking (Morgan 2007). Within research the term has been used as a way of describing the epistemological stance, which impacts on the way in which research questions are approached (Morgan 2007). For example a post positivist worldview is one often associated with quantitative research where researchers consider there to be an objective 'truth' but acknowledge this to be influenced by context and theory (Clarke 1998). This contrasts to a constructivist worldview which has historically been linked with qualitative research (Creswell 2013), and questions the idea of objective knowledge, arguing that what we know of the world is constructed through various discourses and systems of meaning we reside within (Braun and Clarke 2013b).

The worldview typically linked to mixed methods research and foundational to this research study is pragmatism. Pragmatism as originally conceived was a set of ideas expounded through the years by Dewey, James and Pierce (Pierce et al. 1970). Pragmatism draws on the concept of ‘what works’ and values both objective and subjective knowledge (Creswell and Plano-Clark 2018c). It was formally linked to mixed methods research by Tashakkori and Teddlie (2003) who argued that the forced choice dichotomy between post positivism and constructivism should be abandoned, with quantitative and qualitative methods used within a single study. They advocated a practical and applied research philosophy to guide methodological choices (Tashakkori and Teddlie 2003).

Overall pragmatist approaches to mixed methods research generally acknowledge the epistemological differences between qualitative and quantitative approaches but do not see these forms of enquiry as incommensurate and advocate a shared aim for all research: *“to produce positive change in the world”* (Yardley and Bishop 2015). Yardley and Bishop have argued that it is not how the knowledge produced by research accurately represents reality but whether it has valuable external consequences in the context of the researchers own time and place, further stating the best research design to be the one that achieves desired external consequences (Yardley and Bishop 2015).

For this research study, the world-view or paradigm of pragmatism aligns with the aims of the study. The mixed methods design involved data collection that relied on both objective facts and subjective views and both these have a place in defining the approaches to PPM service provision within children’s hospice care. Having a dual role as a paediatrician working in clinical practice alongside a role as a postgraduate student carrying out research strengthens my resolve to conduct research that will be of practical use in producing positive change in the field of CPC. This position of insider researcher is recognised to present both advantages and challenges (Blythe et al. 2013) and is discussed in detail in Chapter Six.

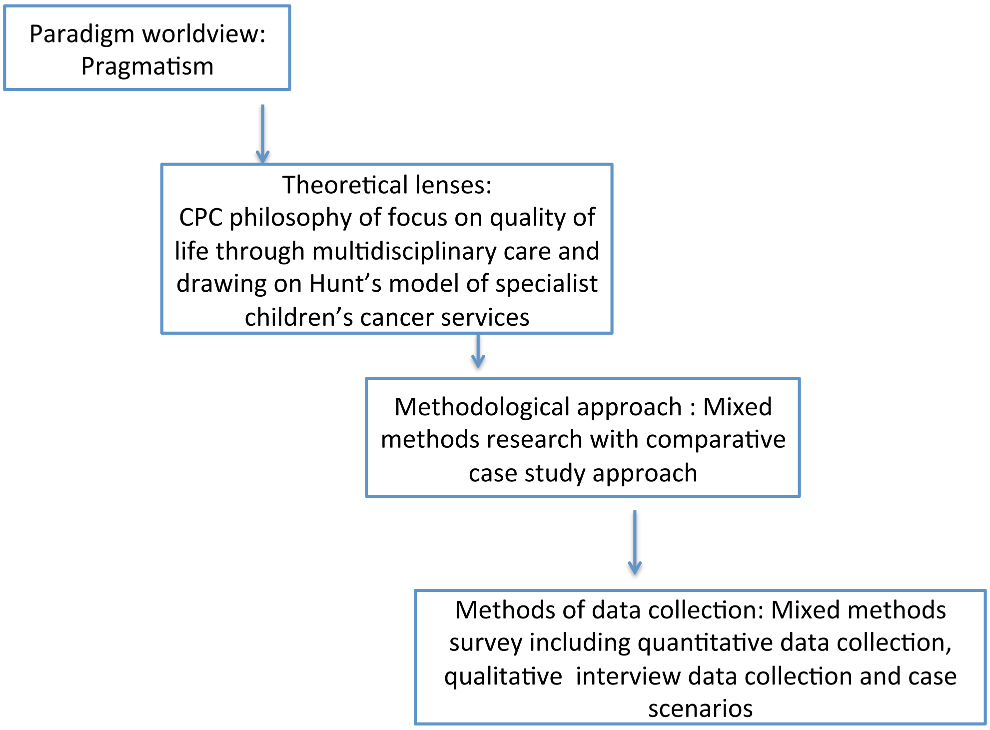
4.7 Theoretical framework

A theoretical framework sets the parameters for a study within the bounds of existing theory (Creswell and Plano-Clark 2018c). Within quantitative research the theory involves testing hypotheses with respect to key variables, known as a hypothetico-deductive approach (Kelle 2015). In qualitative research the theory is often generated through the research process in an inductive-interpretive approach (Creswell 2015a).

In mixed methods research one approach suggested by Creswell (2018) to the use of theory is the application of an existing social science theory. In the absence of an existing theoretical perspective relevant to the research questions posed by this study, the research is positioned at the intersection of a number of important theoretical strands. Firstly, the philosophy foundational to children's hospice care of a multidisciplinary approach that focuses on enhancing quality of life, however short (ACT 2009). Secondly the concept that in CPC, PPM service provision sits within this philosophy and at its best has been described as "*patient focused, holistic and visionary"* (Hain et al. 2012). Thirdly, theory around the definition of 'specialist' services developed in relation to paediatric oncology outreach nurses (Hunt 1999), both in terms of the meaning of 'specialist' (Hunt 1999) and the influence of geographical location on models of practice (Hunt 1995). Finally the concept of breadth and depth in relation to specialist CPC services (Hain 2013) is drawn upon to complete the framework for evaluating children's hospice services and the role of PPM. With this framework in mind, this research sets out to explore the impact that PPM service provision has in the evolving field of children's hospice care.

Figure 4.4 demonstrates the sequence provided by Crotty's conceptualisation (Crotty 1998) to summarise the worldview, theoretical framework, methodological approach and methods of data collection as applied to this research study.

Figure 4.4: Application of Crotty's (1998) conceptualisation to study design



4.8 Mixed methods core designs

A research study requires a clear declaration of the procedures planned for data collection, analysis and interpretation. This plan is the research design. In mixed methods research a number of key concepts to research design have been suggested (Creswell and Plano-Clark 2018c). Firstly whether the design is fixed or emergent: whereas a fixed deign will have planned to use mixed methods at the start of the research, an emergent design will adopt the use of mixed methods at a later stage during the project (Creswell and Plano-Clark 2018b). These two approaches are end points of a continuum within which a research design can sit at any given point. This study was planned as a mixed methods study and therefore had a fixed design. However the design subsequently became emergent as the way in which the research progressed changed and the final design emerged over time.

The debate on the typology of research designs has been at the forefront of the development of mixed methods research. A broad range of typologies has been suggested over the years within different fields of research. In health care and nursing research early, published typologies were based on the principles of triangulation and complementary designs (Morse 1991), where triangulation refers to combining quantitative and qualitative research in order to corroborate findings from each approach (Bryman 2006). These principles were further developed into simultaneous, sequential and complex designs (Morse and Niehaus 2009). In contrast to this typology-based approach Maxwell et al (2015) suggested an interactive approach to mixed methods design. This involves the interaction between five components: study goals, conceptual framework, research questions, methods and validity (Maxwell and Rogers 2015). This interactive approach acknowledges that these will be shaped by external factors including a researcher's skills and experience, research funding and ethics. The interaction of all these components will impact upon final research design (Maxwell and Rogers 2015).

Most recently Creswell and Plano-Clark have simplified their approach to typology suggesting three core designs: explanatory sequential, exploratory sequential and convergent (Creswell and Plano-Clark 2018b). These designs provide a description of the timing and the intent of planned research. Using these as models for core designs in combination with a notation developed by Morse (1991) gives clarity to the approach taken as summarised in Figure 4.5.

Figure 4.5: Summary of core designs, description and notation (based on (Morse 1991) and (Creswell and Plano-Clark 2018b))

Core design and notation	Description
Convergent design *QUAN +QUAL =converge results*	Quantitative and qualitative data collection take place at the same time and have equal emphasis. The researcher intends to converge and compare the results.
Explanatory sequential *Quan > qual = explain quantitative results*	A sequential design where there are two distinct phases. Quantitative data collection occurs first and has greater emphasis and the qualitative methods follow to explain the quantitative results.
Exploratory sequential *QUAL > quan = explore and generalise findings*	A sequential design that begins with and prioritises qualitative data collection. Following analysis of qualitative data, a quantitative data collection phase seeks to explore how the results generalise to the population.

This design of this study originally intended to adopt an explanatory, sequential design. The first phase planned was a quantitative survey to define the approaches to PPM service provision within children's hospices followed by in-depth qualitative interviews to explain and contrast the approaches. However during development of the research it became clear that a convergent design with joint quantitative, qualitative and case scenario data collection was better suited to the research aims.

Convergent designs have also been termed parallel studies, convergence models or concurrent triangulation (Creswell and Plano-Clark 2018b). Morse (1991 p122) defined the intent of a convergent design *“ to obtain different but complimentary data on the same topic”*, in order to develop understanding of the research question. This description fits well with the intent of this research study to use qualitative, quantitative and case scenario data for the purpose of understanding the current role of PPM service provision within children’s hospices in the UK.

The features of a convergent design have been described in relation to data collection being both qualitative and quantitative and having equal importance. Analysis of each takes place separately but a point of ‘interface’ is reached when a researcher works to merge the results. Finally, these results are interpreted to give a better understanding in terms of the overall research aim (Creswell 2018 p69). For this study, the intent of this integration was to merge the results of all sets of data so that a comparison could be made and a more complete understanding reached than by either quantitative or qualitative alone. The use of a mixed methods comparative case study approach guided analysis of case scenario data and integration of findings.

4.9 Mixed methods comparative case study approach

A mixed methods comparative case study approach enables an in-depth understanding of a case or series of cases, to be developed and contrasted in light of relevant contextual conditions (Creswell and Plano-Clark 2018a; Yin 2018b). In the use of case scenarios as part of the mixed methods survey conducted by telephone interview and in the subsequent integration of all findings, principles were drawn from a mixed methods comparative case study approach (Creswell and Plano-Clark 2018a). Each of the children’s hospices in the study was regarded as a case in a multiple case series.

One of the key principles of case study research is the use of multiple sources of evidence with convergence of data in a triangulating fashion (Yin 2018b). In this study for each case (a children's hospice) the following data were collected:

- Numerical data relating to PPM service provision and activity of the hospice
- Interview data relating to the approach to PPM service provision and activity of the hospice
- Case scenario data both qualitative and quantitative relating to how the hospice service works in a 'real life' situation

4.10 Advantages and challenges of mixed methods research

Mixed methods research has many advantages, most relevant to this study is the ability to answer complex questions (Tashakkori and Teddlie 2003; Bryman 2006). In line with the concept of 'completeness' (Bryman 2006) the use of mixed methods enables a fuller understanding of the area studied. It is seen to be comprehensive and to give a greater knowledge yield (O'Cathain et al. 2010) giving *"a whole greater than the sum of the parts"* (Barbour 1999*)*.

There is perceived to be an off-set of the strengths and weaknesses of purely qualitative or quantitative research with the ability to gather and make use of more evidence, using a variety of research tools (Bryman 2006). This can in turn lead to a novice researcher developing more skills and to the eventual possibility of multiple publications (Creswell and Plano Clark 2018b). The use of a mixed methods case study approach enables in depth practical understanding and conclusions, which can be transferable (Creswell and Plano Clark 2018b).

Mixed methods research can be challenging in terms of the need to be skilled in both research disciplines (Farquar 2011). As a mixed methods case study approach requires additional expertise, this could compound this challenge (Creswell and Plano-Clark 2018a). It can be time consuming and financially costly (Tashakkori and Teddlie 2003; Farquar 2011). One of the greatest challenges for the mixed methods researcher is integration of findings (Bryman

2012). Without integration it has been argued that a study cannot be considered as mixed methods research (O'Cathain et al. 2010). This integration is a challenging process and the researcher must avoid the temptation to present qualitative and quantitative elements separately (Farquar 2011). Once the elements are integrated and a complex description and comparison of cases has taken place, this can be challenging to present as a written report (Creswell and Plano Clark 2018b).

With a convergent design there are particular challenges in terms of sample size within the strands of the study. Morse (1991 p121) cautioned researchers stating, "*the greatest threat to validity is to use inadequate or inappropriate samples".* Within this study the total number of children's hospices within the UK at the time of recruitment dictated the sample size. The use of the same sample for both quantitative and qualitative elements of a mixed methods study has been questioned (Morse 1991). However in the case of this study as the total population of children's hospices was relatively small and the intention was to recruit participants representing all of these hospices, the same sample was used for all elements of data collection.

4.11 Chapter Conclusion

This chapter provided a review of the history of mixed methods research and included a justification of the choice of mixed methods to address the research questions posed by this study. The paradigm of pragmatism was outlined with reference to mixed methods research in general and specifically to research intended "*to produce positive change in the world*" (Yardley and Bishop 2015). This underpinning of pragmatism was applied to develop a theoretical framework in the absence of one existing theory of relevance to the research questions. The development of core mixed methods designs was discussed and the use of a convergent design with parallel collection of quantitative, qualitative and case scenario data within this study was presented. The principles of a mixed methods comparative case study approach were introduced as a methodology to guide case scenario analysis and integration of all data, before a final review of the advantages and disadvantages of mixed methods research as relevant to the study design. The following chapter goes on to discuss the chosen method of data collection, a mixed methods survey conducted by telephone interview.

5 Mixed methods survey conducted by telephone interview

5.1 Chapter introduction

Building on the review of mixed methods research provided in the previous chapter, the focus of this chapter is on the method of data collection: a mixed methods survey conducted by telephone interview. In order to set this in context, the evolution of the overall plan for the study is outlined with the final plan of a convergent design presented. The background to survey research as a method of data collection is explored with particular relevance to the use of surveys in adult and children's palliative care. The use of a mixed method survey in practice is discussed for each stage of the process: recruitment and sample characteristics, survey design and a telephone interview for data collection. The benefits and challenges of mixed methods surveys are considered throughout, alongside the experience of recruitment, data collection and plan for data storage in this study.

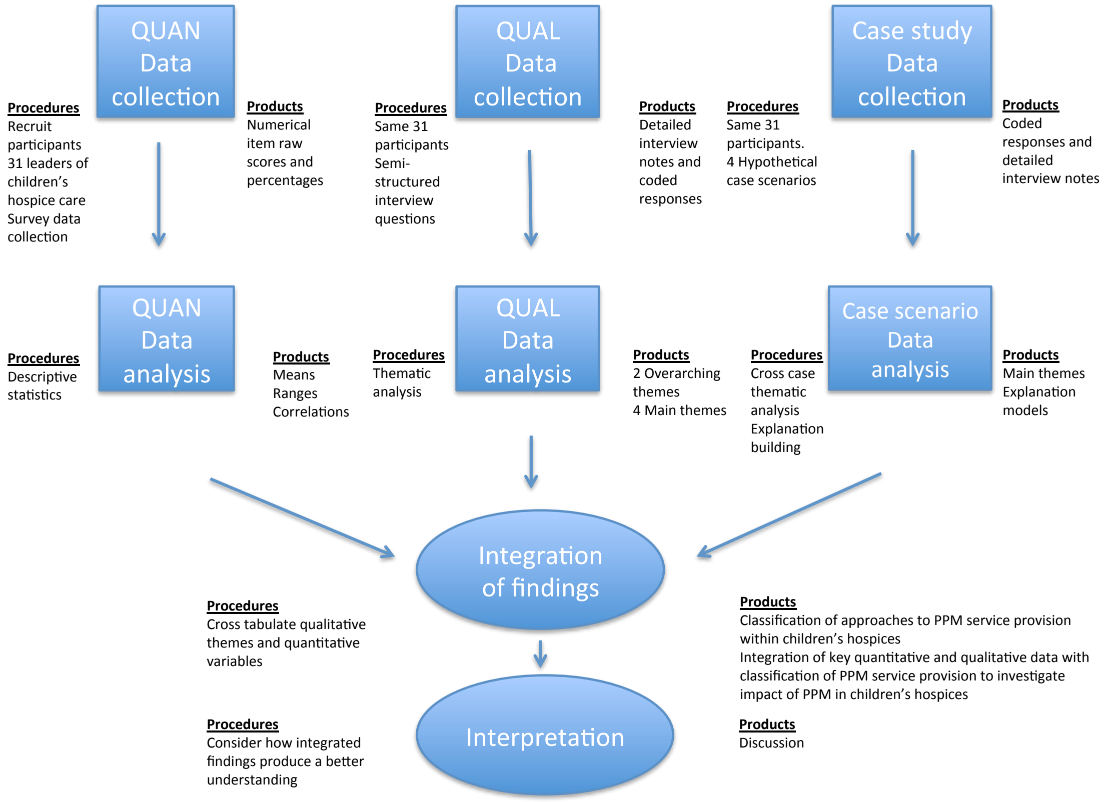
5.2 Overall research plan

To address the aims of the study, data collection and analysis comprised a mixed methods approach. The original intent was for the research to have an explanatory, sequential design (Creswell and Plano-Clark 2018b) with a first phase planned as a quantitative survey to define the approaches to PPM service provision within children's hospices. This was to be followed by in depth qualitative interviews to explore and contrast the models. Explanatory, sequential designs have two distinct phases: the first phase of quantitative data collection has greater emphasis than the second, qualitative phase which is designed to explore and expand upon the quantitative findings (Creswell and Plano-Clark 2018b). This approach fulfilled the aim to describe and classify the range of current approaches to PPM provision within children's hospices across the UK. By conducting a first phase of quantitative data collection and analysis via a national survey it was anticipated that clear approaches to PPM within children's hospices would emerge. The intent of the design for the second stage was to evolve from the definitions and classification of these approaches with a plan to recruit a small number of hospices to represent each approach. In depth qualitative data collection via semi-structured interviews was intended in order to explore and contrast the approaches and their impact on the provision of palliative care from parents' and health care professionals' perspectives.

As the research progressed, it became clear that in view of the complexity of the area of study and the high response rate from leaders of children's hospice care, an alternative approach to the research design was needed. In order to fully examine the current approaches to PPM provision within children's hospices the final design was of a mixed methods survey including quantitative data collection through closed question, qualitative data collection through open ended questions and case scenario data collection. This convergent design (Creswell and Plano-Clark 2018b) with quantitative, qualitative and case scenario data collection taking place in parallel was better suited to the research aims. Convergent mixed methods designs give quantitative and qualitative data collection equal importance and the first parallel stages of data collection and analysis are followed by an integration and interpretation of results in order to give a more complete understanding than could be reached by either method alone (Bryman 2006).

A mixed method comparative case study approach was chosen in order to guide analysis of the case scenario data and the integration of the data from qualitative and quantitative analysis. The participating children's hospices were considered to be cases as part of a multiple case series. This enabled investigation of approaches to PPM provision in the cases (children's hospices) and in depth and exploration of the relationship between these approaches and the response of the hospices in clinical case scenarios. This mixed methods comparative case study approach to analysis of case scenario data is discussed in Chapter SIx. The final study design is represented in Figure 5.1.

Figure 5.1: Overall convergent study design



5.3 Mixed methods survey conducted by telephone interview: method overview

5.3.1 Background to survey research

Surveys are an important research tool with which to *"draw reliable, unbiased conclusions"* about a population (Addlington-Hall 2007) and are widely used in health care research (Rattray and Jones 2007). The term survey is synonymous and intertwined with questionnaire. Rattary and Jones (2007, p2) describe questionnaires as being:

> "*used to collect information in a standardised manner, which when gathered from a representative sample of a defined population, allows inference of results to the wider population".*

For the purpose of this thesis the term survey will be adopted throughout.

Surveys of health professionals are a valuable tool in health services research as a cost effective method to assess knowledge, attitudes and practices in the delivery of health care (VanGeest et al. 2007; Klabunde et al. 2012; McLeod et al. 2013). Surveys have contributed to the knowledge-base in adult palliative and hospice care. Systematic review of the literature (Lendon et al. 2015) identified 51 studies reporting on surveys relating to patient and family experiences of end of life care. Surveys have been used to address diverse research questions in adult palliative care including: the quality and location of end of life care (Beccaro et al. 2010; Miyashita et al. 2015), educational needs of professionals working in palliative care (Kraus et al. 2016), the experiences of health professionals working in hospices (Addlington-Hall and Karlsen 2005), symptom control (Palos et al. 2004; Hudson et al. 2008), delivery of specialised inpatient palliative care (Sanjo et al. 2008) and bereavement support (Field et al. 2004). Although the research base in CPC is in its infancy, surveys have contributed to the study of aspects of children's hospice care, including the use of cool rooms (Forrester 2008), training needs of hospice doctors (Amery and Lapwood 2004) and short-break care (Mitchell 2017).

Surveys have a number of advantages. They are time and cost efficient in comparison to other methodologies (Gillham 2007; Rattray and Jones 2007). When developed in a logical and structured approach, surveys can contribute reliable and valid findings (Rattray and Jones 2007). In sensitive areas of research participants may feel they have assurance of anonymity in written or on-line surveys (Gillham 2007). Comparative studies have demonstrated that sensitive information is more frequently and accurately reported in self-administered survey methods (Aquilino 1994; Tourangeau and Smith 1998). Another school of thought argues that telephone or personal interviews allow the rapport needed to collect sensitive data (Floyd and Fowler 2014b). As the mixed methods survey in this study was conducted by telephone, to named participants, anonymity at the point of data collection was not possible. Participants were assured of anonymity in the storage of data and presentation of findings as discussed in the later section on ethics in Chapter Six.

Response rates to surveys are typically low (Sinclair et al. 2012) in particular amongst health care professionals (VanGeest et al. 2007). Sudman's (1985) seminal work related to improving response rates to mail surveys by professional groups. The low responses from doctors were suggested to be in relation to lack of time, perceived lack of importance and confidentiality and bias concerns (Sudman 1985). There is evidence of further decline of response rates in this group (McLeod et al. 2013) and strategies to address this have been reported. These include successive invitation emails to recruit participants (Funkhouser et al. 2017) and the importance of an experienced interviewer to recruit and to complete the survey (Klabunde et al. 2012). Both these strategies were employed in this study.

5.3.2 Mixed methods surveys

Surveys have traditionally been designed to collect quantitative data in the form of specific measures or closed questions with a choice of responses (Floyd and Fowler 2014d). However in line with the progression of mixed methods research the use of surveys with a combination of quantitative scales and qualitative data collection has developed. For example Mazzola et al (2011) used a concurrent mixed model design (Creswell and Plano-Clark 2010) to assess stressors and strains in graduate assistants. The use of both quantitative scales and qualitative incident reporting within the survey enabled combination and comparison between these methods to strengthen findings (Mazzola et al. 2011). Similarly in the field of palliative care, surveys have traditionally been predominantly quantitative (Lendon et al. 2015) until more recently the collection of qualitative data in combination with quantitative data has been introduced (Bainbridge et al. 2017).

5.4 Mixed methods survey in practice: development and implementation

Three key components in survey research are (1) sampling, (2) designing questions and (3) data collection method (Floyd and Fowler 2014d). These are described in relation to this research study as follows:

Sampling

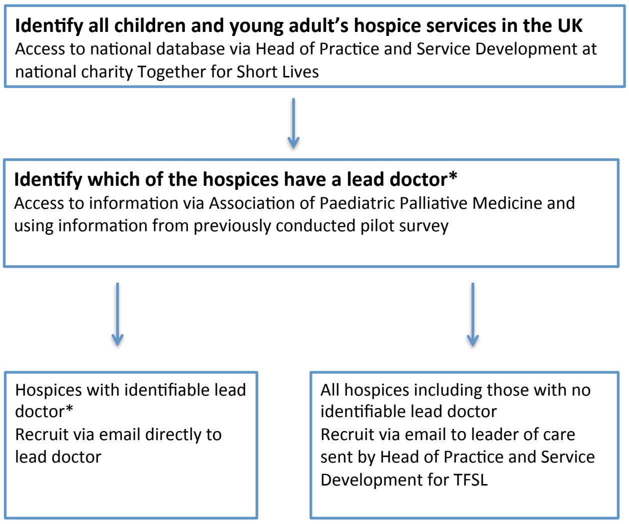
In general, a survey will gather data from a representative sample of a total population (Rattray and Jones 2007). However in view of the relatively small total number of children’s hospice organisations in the UK, the aim was to recruit the leaders of care representing the whole population of UK-based children’s hospices. This approach to sampling in related clinical areas has previously been employed (Hunt 1995). For the definition and identification of this population a database held by the national charity TfSL was used as part of the sampling strategy.

5.4.1 Recruitment of participants

At the time of data collection, 38 children's hospice organisations were identified in the UK as fulfilling the inclusion criteria for the survey. These hospice organisations relate either to an individual hospice service, which could be an in-patient or community service, or to a group of hospice services under one overarching organisation. For example, a number of in-patient hospices across a region as part of one hospice organisation. Hospice services with a lead doctor were identified in discussion with the APPM.

For all children's hospice organisations in the UK an invitation email (Appendix A) and participant information sheet (Appendix B) explaining the purpose and details of the project were sent to the leader of care via the Head of Practice and Service Development at TfSL. This approach was taken in line with the ethical principle of informed consent (Holloway and Wheeler 1995), arising from the Nuremberg medical trials and subsequent Nuremberg code (Weindling 2001). For the hospices with an identifiable lead doctor, where possible (when contact details were available) an invitation email and participant information sheet was sent directly to them. If there was no response, a second email was sent to the same individual after a period of one month. This style of personalised recruitment has been shown to enhance response rates (Sinclair et al. 2012) with the use of reminders further boosting the response (Funkhouser et al. 2017). The recruitment strategy is illustrated in Figure 5.2.

Figure 5.2 Recruitment strategy



*Definition of lead doctor: A Doctor working for a children's hospice service who has lead responsibility for clinical medical care and leadership of a team of doctors if one exists.

5.4.2 Sample characteristics

This study was unusual but not unique, in aiming to recruit a whole population rather than a representative sample. Thirty-one leaders of children's hospice care responded to the invitation email and agreed to take part in the study. For three of the hospice services both the medical and nursing leads responded and agreed to participate. The 31 surveys conducted by telephone interview relate to 28 children's hospice services representing 25 children's hospice organisations, a response rate of 66%. This relates to a total of 34 inpatient children's units, 74% of the total of 46 inpatient units in the UK at the time of data collection (TfSL 2014). For the majority of surveys conducted by telephone interview, the hospice service represented relates to a whole hospice organisation but for two organisations with multiple hospice services the leads of each hospice service were interviewed separately. This decision was based on how the medical cover is organised and the distance between hospice services.

The response rate is the most common statistic used to illustrate the success of a survey (Addington-Hall 2007). It is used to give a measure of how representative the sample is of the whole population studied (Addington-Hall

2007). Response rates are usually presented as percentages. There is no single agreed standard for an acceptable response rate for a survey. One classification of response rates categorises a response of 74% within the very good and 66% within the acceptable range (Mangione 1995). Surveys conducted on behalf of the US government are required to reach a response rate of 80% and above this threshold a non-response analysis is conducted (Floyd and Fowler 2014d). Response bias, whereby those who respond differ from those who do not on an outcome of interest has been described as a measure of quality of a survey (Floyd and Fowler 2014c). Of relevance to this study, where the intention was to recruit doctors, the response bias in surveys of doctors has been shown to be low (Kellerman and Herold 2001; Field et al. 2002).

5.5 Designing questions

Klabunde (2012) emphasises the importance of a considered survey design to enhance the quality of data gathered. Participants are thought to answer truthfully when the area studied is of personal interest and the burden of the data collection imposed by the survey is considered reasonable (Klabunde et al. 2012). At the outset, consideration was therefore taken to ensure the relevance of the topic of study and to limit the burden of taking part in the research. A clear definition of the aim of the survey was provided in accordance with recommendations for survey design, (Floyd and Fowler 2002; Floyd and Fowler 2014d) - principally, to describe and classify the range of current approaches to PPM provision in children's hospices across the UK. This information was made available to each potential participant within a detailed participant information sheet explaining the purpose of the study, the type of data to be collected, how the data would be used and the potential benefits of the research.

The development of a survey should follow a structured approach. For the design of the survey three stages, as recommended by Rattery and Jones (2007) were employed: stage one, defining what the survey will measure, stage two, deciding what type of scale(s) to use and stage three, generating items for the questionnaire. These are detailed below.

5.5.1 Stage one: Defining what the survey will measure

Drawing on insights from a previously conducted and analysed survey (Frost 2013) an initial list of topics to be included was made (Figure 5.3) and discussed with the supervisory team and experts in the field of CPC. These topics were considered in light of the original research aims and questions.

Figure 5.3: Initial domains identified for survey inclusion

Domains relating to medical service provision within children's hospices

1. Participant demographics
2. Hospice demographics, referrals and caseload
3. Model of medical service provision
4. Doctors working in hospices
5. Nurse Consultant posts
6. 24/7 on call arrangements
7. Consultants in PPM
8. Outreach into community and in reach into hospitals
9. Risk areas
10. Clinical case scenarios

Following discussion of the initial list of identified domains for inclusion within the survey, a further key domain arose. A new domain: 'care needs', was suggested, to include questions relating to the care needs of the population of children and young people served by children's hospices. In the final survey the question domain relating to risk areas was eventually omitted due to its leading nature and that any risk areas existing for hospice services would be evident in other question domains. Although leading questions within qualitative interviews are not always considered negative, it is well documented that the wording of a question can influence an answer (Kvale and Brinkman 2009a). Therefore a decision was made that to suggest 'risk areas' could lead to bias in responses.

Clinical case scenarios were included as a strategy to explore the hospices' responses in 'real life' situations relating to the medical care of children. The scenarios were intended as a research tool to investigate, 'by proxy' what happens in children's hospices when medical care is needed at times when a child's symptoms deteriorate or a child reaches the end of their life. In this sensitive area of research, to study such situations, in reality, would be intrusive, practically challenging, difficult to justify ethically or to recruit to as part of a research design. Therefore the decision was made to ask the leaders of children's hospice care a series of hypothetical clinical case scenarios based on personal experience and the experience of the supervisory team and experts in the field of CPC.

Four case scenarios were formulated based on possible 'real life' situations developed from personal experiences. These hypothetical scenarios were reviewed and refined in consultation with experts in the field of CPC. The first scenario related to increasing symptoms while a young person is receiving short-break care. The second and third scenarios related to a request for emergency transfer of a child for end of life care either to an inpatient hospice or to home. The fourth scenario concerned a hospice being contacted for advice regarding symptom management for a young person during an admission to hospital. The situations chosen mirror the phases of instability, deterioration and dying as referenced in the palliative care funding review (Hughes-Hallet et al. 2011; Jarvis et al. 2016).

The four phases are: stable, unstable, deteriorating and dying. The aim of the national palliative care funding review was to develop a classification that categorised patients with palliative care needs and at the end of life into meaningful groups (Hughes-Hallet et al. 2011). This was designed to consider level of need and similarity of resource use. Used in this context these phases were to be self-defined by the lead clinician (Hughes-Hallet et al. 2011). Phases of illness had previously been developed through clinical consensus as a key component of case mix classification in adult palliative care in Australia (Masso et al. 2015; Mather et al. 2018) and are currently being evaluated in CPC. Recent and on-going research taking place in the duration of this study has sought to use objective measures of health care to define the clinical stage (Jarvis et al. 2016). However it is known to be problematic to define the potential pathway for a child with a life-limiting condition, where there are known to be numerous possible conditions with different disease trajectories and when prognosis is unpredictable (Wood et al. 2010). Therefore using objective measures of health care to define the clinical stage for any given child may not be a realistic or inclusive approach.

The four case scenarios used in this study did not use the same objective measures as Jarvis (2016) and it could be argued that the scenarios chosen for this study are more relevant to the work of children's hospices. Jarvis's (2016) definitions of unstable and deteriorating rely on a child needing unplanned admission to hospital or an emergency admission to a PICU. Given that, as part of the advance care planning process a decision can be made not to transfer a child to PICU, it could be the case that a child may be deteriorating significantly without reaching this objective measure. Table 5.1 gives the stage of illness represented by this study's case scenarios in comparison to the definitions used by Jarvis et al. (2016) and Masso et al. (2015).

Table 5.1: Comparison of the case scenarios to phases of illness as defined by Jarvis et al. (2016) and Masso et al. (2015)

Phase of illness	*Summary of definitions for use in adult palliative care (Masso et al. 2015)*	*Jarvis definition (Jarvis et al. 2016)*	*Case scenarios developed for this study*
Unstable	An urgent change in plan of care, a patient experiences a new problem or increase in severity of current problem or change in family circumstance	Entering unstable stage: an unplanned admission to hospital lasting >48 hours.	Deterioration of symptoms during short-break stay
Deteriorating	A patient's overall functional status declines with gradual worsening of existing problems or a new problem or increase in family distress	Entering deteriorating stage: an emergency admission to an intensive care unit or PICU	Admission to hospital with multiple complex symptoms requiring symptom management and review of goals of care
Dying	Death is likely within days	Entering dying stage: the last 28 days before death	Request for urgent transfer to hospice or home for a dying child

Although case study research in primarily focused on real world phenomena rather than hypothetical scenarios, it is acknowledged that in some fields, an 'abstraction' or hypothetical scenario can be a starting point for research (Yin 2018b). In this study, hypothetical case scenarios were developed as an exploratory device given the complexity, time, ethical and practical considerations involved in observing these situations in reality. The intention was to create an opportunity to provide a preliminary investigation of how the individual hospices responded in situations when a child under the care of the hospice needs medical review and the impact of varying approaches to PPM service provision on this response. The four case scenarios are detailed in the full survey interview schedule (Appendix C) and in Chapter Ten.

5.5.2 Stage two: Deciding what type of scales to use

In view of an absence of previous research addressing the question of medical care within children's hospices, there were no predefined scales on which to base the survey design. In keeping with the convergent mixed methods design of the study the survey design included both closed questions with choices of response, numerical answers for quantitative analysis and open-ended questions for collection of data for qualitative analysis.

The closed questions with multiple-choice based responses were developed based on knowledge from a previously conducted pilot survey (Frost 2013) and were worded according to recommendations relating to survey design (Gillham 2007). The measures developed included nominal and ordinal data collection. Numerical data questions included continuous variables collected as raw scores, percentage values and ranges.

The use of open-ended questions in surveys relating to palliative care services has historically been limited (Lendon et al. 2015). However qualitative survey data in the context of provision of palliative care services has been shown to be more informative than quantitative survey data collection alone, leading to recommendations for service developments (Bainbridge et al. 2017). In line with the paradigm of pragmatism underpinning this study, the intention was to generate recommendations to promote positive change in the field of children's hospice care. Therefore, using both qualitative and quantitative data collection as part of the design fitted within this approach and the hoped for outcomes.

5.5.3 Stage three: Generating items for the questionnaire

Areas to be investigated were developed into survey questions, designed to be both reliable and valid (Fowler 1995). Validity refers to whether a questionnaire is measuring what it purports to (Polgar and Thomas 1995; Bowling 1997) reliability, to a questionnaires repeatability and internal consistency (Rattray and Jones 2007). To increase reliability, Floyd and Fowler (2014) define a good survey question as having a scripted question written out in full that means the same to each respondent. In addition, the choices of answers must be communicated consistently. To ensure adherence to this guidance the questions were written out in detail and to enable consistent understanding for respondents, definitions of aspects of the questions were given. For example the definition of levels of PPM education and training were provided (see Appendix D).

In considering a survey question's validity, landmark studies have evaluated reports of factual information against records (Edwards 1994, 1996). These demonstrated good factual recall in many cases but problems arising in relation to: understanding the question, recall of events, lack of knowledge and unwillingness to answer a question in the context of an interview (Floyd and Fowler 2014a). In order to mitigate for these issues, within the context of the study reported in this thesis, developing clear, comprehensible wording for the questions was paramount. Areas of enquiry were chosen to be relevant and accessible to a person leading hospice care and therefore should be known and recalled by the participant. Information relating to the type of data to be collected was sent to potential participants prior to the interview.

The drafted survey was sent for comments to experts in the field of CPC as a measure of content validity. Content validity relates to expert opinion on whether scale items represent the concepts the survey is intended to measure (Rattray and Jones 2007). An assessment of convergent or discriminant validity is also recommended (Rattray and Jones 2007). However as this requires correlation of measures with existing related measure this was not possible for this survey.

In relation to the collection of qualitative interview data, the concept of validity as "*quality of craftsmanship*" has been described (Kvale and Brinkman 2009a). This refers to the need for validity to permeate all stages of the research process from the design, interview process, to the analysis and reporting of findings. Applying this concept, the open-ended questions were designed to be clear and unambiguous (Floyd and Fowler 2014a). During the survey interview and analysis a continual approach to checking, questioning and theorising the data findings was taken (Kvale and Brinkman 2009a). Recommendations for ensuring quality in qualitative research (Braun and Clarke 2013b) are discussed further in the later section detailing the process of analysis in Chapter Six.

The final survey design was ‘pre-tested’ in accordance with recommendations (Fowler 1995; Floyd and Fowler 2014d) with a colleague in the field of CPC who had recently retired from leadership in a children’s hospice. Feedback from this pre-test interview was used to refine the schedule and to provide an opportunity to test the method of telephone interview and practical usage of the survey interview schedule. In particular, this pilot interview tested the burden of the survey upon potential participants with the duration of the tested telephone interview being approximately one hour. Feedback was given that this length of interview was acceptable in view of the relevance of the topic and questions but that participants needed to be alerted to the time commitment before the interview commenced. This length of interview is also acceptable in terms of an adequate depth of qualitative data collection.

The full survey interview schedule can be viewed in Appendix C.

5.6 Data collection method: telephone interview

The choice of survey data collection method has been described as “*one of the most far reaching decisions a researcher must make”* (Floyd and Fowler 2014b). Consideration of possible methods of data collection was made, including use of postal survey or on-line survey, personal or telephone interview and group administration (Floyd and Fowler 2014b). For this research, the use of a telephone interview was chosen, with the participants being guided through each question, in view of the detailed data to be collected and complex areas for discussion (see Appendix C). The small sample size also made this a realistic approach. Telephone interviews have the advantage of allowing researchers to build a rapport with their participants and enable completion of a complex survey tool (Floyd and Fowler 2014b).

High response rates have been demonstrated using postal and telephone strategies to conduct surveys with doctors (VanGeest et al. 2007). In addition personal interviews are known to have a good response rate, particularly where the interviewer is experienced (Addlington-Hall 2007). Telephone interviews also best suited the wide geographical spread of participants, making travel to each participant an unrealistic and costly option (Addlington-Hall 2007).

Answers to the survey questions were annotated during data collection and following each interview were typed up, a method recognised by Kvale (Kvale and Brinkman 2009b). This choice was made at the outset of the study when it was anticipated that the survey would relate predominantly to quantitative data. With hindsight, with the volume of qualitative data obtained, recording and transcription of qualitative data would have been a valid option. However note taking has recognised advantages in relying on the interviewer's active listening and remembrance working as a selective filter. Although this could be seen as a bias it has been reported to*" retain those very meanings that are essential for the topic and purpose of the interview"* (Kvale and Brinkman 2009b).

For questions where a participant did not have required information during the interview, the option of sending a follow up email with the desired information was given. This was taken up by a number of participants in relation to some of the quantitative data requested regarding case load and care needs of the children cared for by their hospice.

5.7 Data collection and storage

Each participant was assigned a unique participant number and each hospice service was assigned a unique participant letter to maintain anonymity and reduce researcher bias. In line with the four foundational ethical principles discussed in Chapter Six (Beauchamp and Childress 2013), maintaining the anonymity of participants is a fundamental right of the individuals taking part in research (Holloway and Wheeler 1995). Data were anonymised and stored on a password-protected computer. A codebook was written relating to all questions in the survey and can be viewed in Appendix E. All data from this stage of the research, quantitative, qualitative and case scenario data were entered into SPSS^{TM} (Statistics Package for the Social Sciences) version 22 for Mac (Pallant 2013) to create a database. Quantitative data and data from closed questions were coded in accordance with the codebook. Data from open-ended questions in the survey interview were entered in brief as 'string data' (Pallant 2013) to the

SPSS^{TM} database. Anonymised qualitative and case scenario data in its entirety were stored in table form as word documents.

5.8 Chapter conclusion

The chapter provided both a review of the use of mixed methods surveys and the detail of the process of recruitment, survey design and data collection by telephone interview followed within this research study. To this end, a background to the development and use of surveys and in particular mixed methods surveys, was provided with examples within the field of palliative care. The recruitment strategy and resultant sample characteristics for this study were outlined followed by a discussion of the design of questions for the survey, with a review of the different question types needed to collect quantitative, qualitative and case scenario data. The use of telephone interviews was explored and contrasted to use of postal or on-line surveys as means of data collection. To complete the chapter, a summary was given of the way in which data were coded, anonymised and stored, thereby setting the scene for discussion of the method of quantitative, qualitative and case scenario data analysis provided in the following chapter.

6 Data analysis and ethical considerations

6.1 Chapter introduction

The preceding chapter provided a review of mixed methods surveys and the application of this knowledge to the strategy developed for recruitment, survey design and data collection within this research study. The current chapter's focus concerns the methodology of analysis employed for the quantitative, qualitative and case scenario data gathered by the mixed methods survey conducted by telephone interview. In this chapter the method of quantitative analysis is outlined, followed by a detailed discussion of the use of thematic analysis of qualitative data. This includes both a brief history of thematic analysis and review of its wide spread use in palliative care research. Braun and Clarke's (2006, 2013) six-stage process for thematic analysis is presented as a guide to the detail of the process of analysis undertaken. The approach to analysis of case scenario data using principles drawn from mixed methods comparative case study research is presented. Next, the centrality of ethics in conducting research is discussed, with reference to the ethical considerations inherent to this study. The unique issues of being an insider researcher are explored and applied to personal experience before the chapter concludes with confirmation of the ethical approval process followed for this research study.

6.2 Quantitative data analysis

Analysis of the quantitative data took place after completion of the telephone interviews to enable analysis of the data set in its entirety. For the hospice services where two separate interviews took place, relating to the same service, a pragmatic decision was made that, for the purposes of analysis, responses of the participant who had been in post for the longest would be used. This decision was made on the assumption that the longer the person had worked at the hospice the more detailed their knowledge of the medical care would be. Therefore analysis of quantitative data relates to 28 participants, representing 28 children's hospice services.

Raw scores and percentages were calculated to define aspects of medical provision in children's hospices. For normally distributed data the mean was calculated and for non-normally distributed data the median (Foster et al. 2001). Data were transformed and analysed by region using cross tabulation to compare aspects of medical service provision across the UK. Analysis for correlations between specific variables was attempted in order to test hypotheses in relation to the approach to PPM service provision within the hospice and the activity of the hospice and complexity of care delivered. The statistical test chosen depended firstly on whether data related to a continuous or dichotomous variable and secondly on whether the data were normally or non-normally distributed. For continuous variables with non-normal distribution the non-parametric test, Spearman rank correlation was undertaken (Pallant 2013; Foster et al. 2015). For dichotomous variables with non-normal distribution the Mann-Whitney was used (Pallant 2013; Foster et al. 2015).

With relation to the complexity of children cared for by children's hospices, a measure of the complexity of care was created. This involved recoding of the original data using a defined scoring system of complexity of care. This enabled extrapolation of a classification of complexity of care from the data.

6.3 Qualitative data analysis: Thematic analysis overview

Qualitative data from the survey interviews were analysed using thematic analysis (Braun and Clarke 2006; Braun and Clarke 2013b). Qualitative data from all 31 interviews were included in the analytic process in contrast to the 28 data sets for quantitative analysis as described above. Braun and Clarke (2006 p79) defined thematic analysis as: *"a method for identifying, analysing and reporting patterns within the data".* Thematic analysis originated from Holton in the 1970s (Merton 1975). Whilst Ryan and Bernard (Ryan and Bernard 2000) defined thematic coding as a process within major analytic traditions, Braun and Clarke (2006) argued for recognition as a method in its own right. Although thematic analysis has been widely used in the process of qualitative data analysis, it has only been accepted as a specific method in the last ten years (Howitt and Cramer 2008; Stainton-Rogers 2011; Joffee 2012) with a clear outline of procedures (Braun and Clarke 2006). Braun and Clarke developed the method of thematic analysis within the field of psychology (Braun and Clarke 2006; Braun and Clarke 2012) and it is now used frequently in health care research.

In the field of adult palliative care, thematic analysis has been widely employed as a methodology. For example, to investigate end of life care in the elderly (Hirano et al. 2011), to understand the emotional impact of palliative care on professionals (Funk et al. 2017), to develop a triage tool for urgency of need in palliative care (Russell et al. 2018) and to explore perspectives on the use of advance care planning (Smith et al. 2017). Qualitative systematic review has been used in palliative care with a process of thematic synthesis (Thomas and Harden 2008) to answer complex questions, such as “what facilitates patient empowerment in cancer patients?” (Jørgensen et al. 2018).

Research in CPC has again relied heavily on thematic analysis to explore a variety of issues. These include: the barriers to research in CPC (Beecham et al. 2016), professionals’ experiences of providing a palliative care service (Clarke and Quin 2007), the experiences of parents in caring for a life-limited child (Collins et al. 2016) and of a CPC team (Verberne et al. 2017), the use of advance care planning (Mitchell and Dale 2015) and in order to define the disease trajectories for different ACT categories in CPC (Wood et al. 2010). Integration of studies using thematic analysis has been used to develop psychosocial palliative care standards for children with cancer (Weaver et al. 2016) and to explore health care staffs’ experiences of providing end of life care to children (McConnell et al. 2016).

Thematic analysis offers a theoretically flexible approach to analysing qualitative data (Braun and Clarke 2006). Whilst thematic analysis does not relate to one epistemological framework or theoretical position, it can be adapted to suit a range of approaches. In the palliative care literature this is demonstrated with both the use of inductive thematic analysis, based on an interpretive framework (Collins et al. 2016) and deductive thematic analysis using codes derived from the literature (Russell et al. 2018). Researchers must make their epistemological assumptions known (Holloway and Todres 2003) and a good thematic analysis will make the underlying theoretical framework clear (Braun and Clarke 2006). Within this study the paradigm of pragmatism underpinned the approach to analysis, as outlined in Chapter Four.

A data-driven approach can be taken to thematic analysis, identifying themes in a ‘bottom up’ way where themes are strongly linked to the data without use of a pre-determined coding framework. Alternatively a ‘top down’ approach to explore theories driven by the researchers theoretical or analytic interest can be employed (Braun and Clarke 2006; Braun and Clarke 2013b). These approaches can be combined within one analysis. This combined approach was taken for analysing data from the survey interviews. Themes were generated both from the detailed analysis of the data and through application of previous knowledge tested against the data.

Thematic analysis can be predominantly illustrative, where the analysis develops as a description that tells a story in relation to the research questions. Alternatively it can be analytical using a conceptual or theoretical framework to uncover latent meanings within the data (Braun and Clarke 2013b). The analysis undertaken for this research study was predominantly of the illustrative approach, seeking to tell the story of the role of medical care within children’s hospices at the time of interviews.

The key strength of thematic analysis lies in its flexibility, enabling the method to be applied to a variety of research questions with different theoretical positions (Braun and Clarke 2006). Well documented as an advantage is the ease with which thematic analysis can be learnt and applied even by a novice researcher (Braun and Clarke 2013b). Thematic analysis has been critiqued for a lack of depth, accused of being an approach where “anything goes” (Antaki et al. 2002). There is less guidance than with interpretative forms of analysis and less concern with an individual’s account of an experience (Braun and Clarke 2013b). Disadvantages associated with thematic analysis are often related to poorly conducted research rather than inherent to the method itself and there is limited interpretive power unless an existing theoretical framework is used (Braun and Clarke 2006). In order to address these concerns attempts have been made to improve the validity of the method. Reicher and Taylor (2005) advocate a systematic approach with assumptions in keeping with the conceptual framework. Braun and Clarke provide a checklist of 15 criteria for good thematic analysis (Braun and Clarke 2006) relating to the processes of transcription, coding, analysis, overall approach and the written report.

There are no absolute criteria for assessing quality in qualitative data analysis. In 1999, guidelines were proposed for the publication of qualitative research in psychology and related fields (Elliott et al. 1999). These were criticised for not taking into account the theoretical assumptions of the research methods (Reicher and Taylor 2005). Yardley (2008) developed four theoretically neutral validity principles: (1) Sensitivity to context (2) Commitment and rigour, (3) Transparency and Coherence and (4) Impact and Importance (Yardley 2008). Mays and Pope (2000) provided a list of questions to apply to qualitative research in the field of medicine (Mays and Pope 2000).

The concept of reliability relies on a realist view of a single external reality knowable through language (Seale 1999). This view of reliability is therefore not applicable to qualitative data but the concept of reliability has been used more broadly to show the trustworthiness of the research (Mcleod 2001). In terms of validity, that the research shows what it claims to show (Goodman 2008), the concept of ecological validity has been described as most relevant to qualitative research (Braun and Clarke 2013b). This concerns the relationship between the ‘real world’ and the research.

Two long-term practices that have been used to improve quality in qualitative research are triangulation and member checking. Triangulation, first proposed in 1970 (Denzin 1970) uses two or more methods of data collection or sources of data to investigate a research question. It has been described as a way of strengthening analytic claims (Smith 1996). Member checking is the practice of checking an analysis with participants and was initially presented as a type of credibility check (Lincoln and Guba 1985). It is rooted in a phenomenological approach where the goal is an in-depth understanding of participants’ experiences (Smith 1996). It has inherent practical and methodological problems (Braun and Clarke 2013b). The idea of member reflections as an alternative involves sharing dialogue with participants with opportunities for feedback (Tracy 2010).

Methodological strategies exist to improve the quality of qualitative data analysis. The concept of ‘analytic effort’ outlines five factors that demonstrate the amount of effort a researcher puts into analysing the data to generate themes (Howitt and Cramer 2008). A coding framework was proposed by Joffee (2012) to classify datasets as a guide for thematic analysis. The coding framework can be derived inductively from the data and theoretically from prior research in the field. A coding framework consists of the code name, code description and an example of the code (Joffee 2012).

6.4 Thematic analysis: the process

Braun and Clarke (2006, 2013) defined a six stage approach to thematic analysis: 1) Reading and familiarisation, 2) Coding across dataset, 3) Searching for themes, 4) Reviewing themes and producing a thematic map, 5) Defining and naming themes and 6) Writing and finalising the analysis. This approach was used to conduct thematic analysis of qualitative data gathered from the surveys and is described as follows.

6.4.1 Stage one: reading and familiarisation

Note taking during the data collection and the process of typing up notes following the interviews gave an initial opportunity to become familiar with the data. Data were then read and re read in their entirety both as part of the original interviews and in collated form by question topic. This process has been described as emersion in the data (Braun and Clarke 2013b) in order to become familiar with the data content. During this familiarisation, comments were made in a research journal to describe observations regarding the data.

6.4.2 Stage two: coding across data set

Coding can be selective, identifying data relating to certain aspects of the area of study, or complete whereby the whole data set is coded (Braun and Clarke 2013b). The analysis conducted was complete and the entire data set was coded to produce a comprehensive set of codes. Every feature of relevance to answering the research question was coded.

A code is a word or brief phrase (Braun and Clarke 2013a) encapsulating the relevance of the data to the research question. Codes have been described as the simplest or most basic part of the data that can be evaluated in a way that is meaningful to the phenomenon being investigated (Boyatzis 1998). Two types of codes have been described; semantic or data-derived and latent or researcher-derived (Braun and Clarke 2013a). Semantic codes directly reflect the language and meaning of a participant's response. Latent codes rely on a researcher's ability to apply a theoretical or conceptual framework to discover a latent meaning in the data. Coding should ideally show a progression, where first, data are organised to show patterns in semantic content and, then, progressed to interpretation where the significance of these patterns is theorised (Patton 1990). The method employed in code development in this study followed this ideal of progression.

The codes derived were both semantic and latent and each data item could be coded multiply when relevant. Initially the coding process took place sequentially in relation to each open-ended question within the survey. Coded data were then collated by code with each coded item identifiable by unique participant number and hospice letter. The codes were organised into a coding framework (Joffee 2012) (see Appendix G). In the example given below (Figure 6.1), the code: *the whole picture* is a semantic code based on the participants' own words as demonstrated in the example given. This code informed the theme: *Increasing complexity of conditions*, which in the final analysis fits within the overarching theme: *Increasing complexity of care needs.*

Figure 6.1: Example of a semantic code within the theme: *Increasing complexity of conditions*

Code name	*Description*	*Example*
The whole picture	The whole picture will refer to any reference to a combination of multiple needs within one child	"*It is not one individual care need but the combination that leads to complex*ity…*not the individual pieces but the whole picture".*

In the example in Figure 6.2, the code *changing goals of care* is a latent code and relied on the application of knowledge of the concept of goals of care within palliative care, applying this to give meaning to the participants' description of a complex situation in a child cared for by the hospice. This code informed the theme *changing parameters of care,* which in the final analysis sits under the overarching theme *Increasing complexity of care needs.*

Figure 6.2: Example of a latent code within the theme: *Changing parameters of care*

Code name	*Description*	*Example*
Changing goals of care	Changing goals of care will refer to any reference to a change in the expected or hoped for outcome of care or treatment. This refers to a theoretical concept in palliative care.	"*Children awaiting transplant, for example bowel transplant are severely ill and the hospice is providing care but they may improve and be discharged post transplant".*

6.4.3 *Stage three: searching for themes*

Coded data were then reviewed in order to identify patterns across each data set. A theme:

> *" captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set"* (Braun and Clarke 2006).

An approach of searching for themes that describe a distinctive concept or topic in relation to the research questions was taken in this study. These were termed *candidate themes* as they were subject to later revision and refinement as part of the analytic process.

6.4.4 *Stage 4: reviewing themes and producing a thematic map*

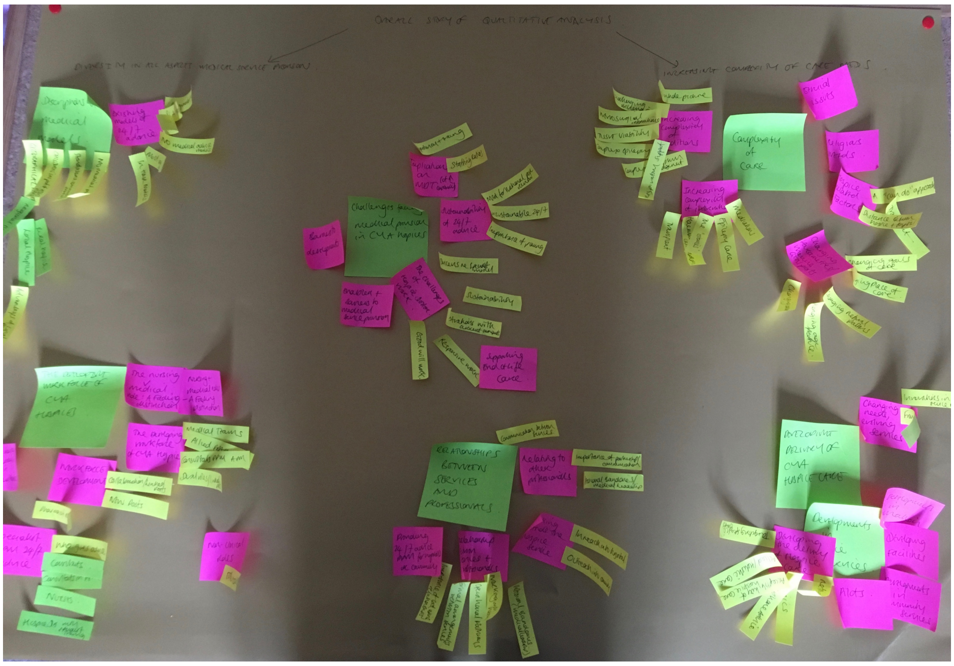
Initially a review of candidate themes took place within each question area gathered during this research, combining codes into centrally organising concepts in relation to the research questions. Relationships between themes were identified to create an overall pattern. The preference was to complete this stage of the analysis ‘by hand’, using written codes and themes documented on post-it^{TM} notes that could be moved manually to test out different structures and patterns before arriving at the final thematic maps, this process was documented by photograph in Figure 6.3.

Figure 6.3: Photograph of initial codes and thematic maps for each open-ended question

Qualitative survey data has been recognised to present particular challenges for thematic analysis, in particular when the responses are coded and analysed by question (Braun and Clarke 2013a). This can be resolved by looking across a whole data set to determine themes rather than by a question-based approach.

Therefore a second part was added to this stage of the analytic process in re-analysing the codes, candidate themes and thematic maps for all the questions as a whole. The themes were revised and original coded data reviewed to develop one thematic map with a hierarchy of overarching themes, main themes and sub themes, documented by photograph (Figure 6.4) and presented in detail in Chapter Eight. This was in keeping with the sentiments of Braun and Clarke who recommend that the analytic process result in an overall story from the data (Braun and Clarke 2013a).

Figure 6.4: Photograph of revision of codes and themes into one thematic map



6.4.5 *Stage five: defining and naming themes*

The theme definitions were developed over time as has been recommended (Ely 1997). Input from the supervisory team following a presentation of this 'overall story of the analysis' led to further thought and progression of the analytic process. The comments and questions of a senior paediatrician in the field of CPC on the supervisory team gave an important check on the validity of the research process. The researcher was questioned both on the absence of themes which the supervisory team anticipated would be present in the data and on the meaning and definition of themes, giving examples from the coded data to justify these. An example of this was the supervisory teams' questions on the sub theme: *Medical cover not fit for purpose* within the main theme: *Challenges facing medical service provision within hospices*. The researcher was able to give a number of examples to justify this theme name and definition from the initial coding framework, as demonstrated in Figure 6.5.

Figure 6.5: Example of code developed into a sub theme within the main theme *Challenges facing medical service provision within hospices*

Code name	*Description*	*Examples*
Medical cover not fit for purpose	Medical cover not fit for purpose will refer to any reference to the current arrangement for medical cover not fulfilling the participants' expectation.	*"What is contracted is not what is delivered. GPs are contracted for a full four-hour session but in practice they are edgy if they are needed at the hospice for over an hour and a half. We have an SLA with seven GPs and one GP employed. The employed GP is part of a historical arrangement that does not work well and therefore is being phased out".* "*The out of hours GP service for other hours is rarely used. If a child needed a medical review at 4pm we would need to send them into hospital for medical review".* "*The GPs do not feel specialist, they do not understand the need to share the uncertainty and accountability".*

6.4.6 *Stage six: writing and finalising the analysis*

The definitions and names of themes were further developed during the final stage of writing up the analysis. The writing up of a qualitative analysis and the analytic process are intrinsically linked. The presentation of a qualitative analysis has been described as: " *a deliberate and self-consciously artful creation by the researcher… constructed to persuade the reader of the plausibility of an argument"* (Foster 1995).

Extracts of data were selected to provide illustrations of the themes, to provide a detailed description and interpretation of each theme. The aim of this process of writing was to *'tell the story'* of the data as described by Barun and Clarke (2006, p93) "*in a way that convinces the reader of the merit and validity of the analysis"*.

Analysis has been described as a *"recursive process"* (Braun and Clarke 2006) and although these stages were followed sequentially, there was also a 'back and forth' dynamic to the analysis whereby earlier stages were revisited to refine aspects of the analysis.

6.5 Case scenario data analysis: a mixed methods comparative case study approach

6.5.1 Analytic strategy

In analysing case study data, Yin (2018, p165) describes that much depends on the researcher's *"style of empirical thinking, along with sufficient presentation of evidence and careful consideration of alternative interpretations".* An analytic strategy within case study research, links data with concepts of interest and gives a sense of direction to the analysis (Yin 2018b). The overall cycle of an analytic strategy starts with the original research questions, moving to analysis and a defensible interpretation of the data resulting in conclusions. Yin presents four main analytic strategies summarised in Figure 10.1.

Figure 6.6 Analytic strategies in case study research, summarised from Yin 2018 (p168 – 173)

Analytic strategy	*Description*
Relying on theoretical propositions	Following the original objectives and design of the study, basing the analysis on the research questions and underlying hypotheses
Working data from the ground up	In line with the inductive strategy used in grounded theory (Glaser and Strauss 1967) (Corbin and Strauss 2015)
Developing a case description	Providing a descriptive framework for the data relating to initial motives for the case study or literature review.
Examining plausible rival explanations (Yin 2000)	Working in combination with other strategies to examine for rival interpretations of findings

The analytic strategy applied to the case scenario data was to base the analysis on the original research questions and the hypotheses or propositions underlying these.

- How do children's and young adults' hospices respond in situations when a child with a life-limiting or life-threatening condition has unstable symptoms, is deteriorating or is dying?

- Do varying approaches to PPM service provision in children's and young adults' hospices impact on abilities to respond to the needs of children with life-limiting or life-threatening conditions and their families when a child has unstable symptoms, is deteriorating or is dying?

Underlying these questions is an assumed hypothesis that different approaches to PPM service provision influence the response by the hospice and that the level of specialist PPM service provision available impacts on the response when a child with a life-limiting condition has unstable symptoms, is deteriorating or is reaching the end of their life.

Within a case study analytic strategy different analytic techniques can be employed. There are five analytic techniques described for use in case study analysis: (i) pattern matching, (ii) explanation-building, (iii) time series analysis, (iv) logic models and (v) cross case synthesis (Yin 2018a). In this study elements of the techniques of cross case synthesis and explanation building were used.

Applying the analytic strategy of relying on the original research questions and hypotheses, the analytic techniques of cross case synthesis and an explanation building approach were undertaken with respect to the case scenario data. In addition a quantitative analysis of numerical data gathered in relation to the case scenarios was conducted to produce raw scores and percentage values relevant to understanding the hospices' responses and in particular, data relating to the involvement of doctors in these situations and their level of PPM specialism.

6.5.2 *Cross case thematic analysis*

Cross case synthesis can be used in multiple case series. It resembles a case-based rather than a variable-based approach (Byrne 2009). The aim is to retain the integrity of a case whilst comparing or synthesising any patterns across the cases (Yin 2018b). Qualitative data from the case scenario responses were collated and a cross case thematic analysis conducted in order to identify common themes from across the cases. The cross case thematic analysis was conducted using the same thematic analytical methodological approach as for the qualitative analysis outlined in this chapter. This process involved mapping out individual case scenario themes, reviewing the data and translating them into an overall scheme.

6.5.3 *Explanation-building approach*

Explanation-building seeks to analyse data by building an explanation of a case (Yin 2018b). A similar approach in the political sciences is termed *process tracing* (Beach and Pederson 2013*).* To explain a phenomenon, in this case the response to a request for review of unstable symptoms for a child or for a rapid transfer to hospice or home for end of life care, a set of presumed causal sequences is developed relating to how or why an outcome has occurred. Yin (2018 p 181) described the building of an explanation as *“similar to the process of refining a set of ideas”.*

In multiple case studies, a further goal is to build a general explanation that fits each individual case although the details of each individual case will vary (Yin 2018a). The process of explanation building is both deductive and inductive (Yin 2018b). At the outset, a proposition or hypothesis is set out and data from case studies is compared against this (Yin 2018b). The propositions and inherent hypotheses were outlined above in the analytic strategy. In order to develop a causal sequence for the responses to the case scenarios, quantitative and qualitative data were combined and a systematic process followed of developing an explanation for the outcomes.

The analyses described above were conducted separately and the findings have been integrated to give a combined picture of the case scenario findings presented in Chapter 10.

6.6 Ethics

The foundations of existing ethical principles in research were formed at the declaration of Helsinki (1946) following the Nuremberg medical trials (Shuster 1997; Weindling 2001; Thieren and Mauron 2007). Prior to the trials Andrew Conway a physiologist and the commission on medical war crimes worked on the concept of a medical war crime in response to experiments conducted by Nazis in the Second World War (Weindling 2001). This was developed by John West Thompson and became the background to Ivy’s 1946 “*Code on human experiments”* (Weindling 2001). It was the interaction between Ivy and the judges at Nuremberg that demonstrated the need to formulate ethical guidelines for clinical research (Shuster 1997; Weindling 2001; Thieren and Mauron 2007).

The basic ethical framework used in current research which grew from the early code developed from the Nuremburg trials concerns four main ethical principles

(Beauchamp and Childress 2013) relating to the duty of researchers to participants and to the usefulness or utility of the research. These principles are; (1) Autonomy: *participants are free to make an independent choice*, (2) Non-maleficence: *good derived outweighs the harm*, (3) Beneficence: *the benefits outweigh the risks for the individual and society*, (4) Justice: *research strategies and procedures are fair and just*.

Within this framework the rights of individuals are paramount and include a duty to obtain informed consent and ensure voluntary participation, to give assurance of confidentiality and anonymity and to treat participants with dignity and respect (Couchman and Dawson 1990).

6.7 Informed consent

Informed consent has been defined as an agreement by research participants, given without threat or inducement and is based on information that any reasonable person would want to receive before consenting to participate (Sieber 1992). Consent of participants for the survey conducted by telephone interview, was assumed by response to the invitation email indicating agreement to take part and subsequent participation. The provision of a participant information sheet (Appendix B) was key to the process of informed consent and in line with recommendations was sent to participants prior to the interview (NHS Health Research Authority 2019). The information explained the background and purpose of the study and the involvement of participants agreeing to take part. Specific reassurances regarding confidentiality and anonymity were made.

Informed consent is an on going process throughout a research study rather than permission being given at one point in time (Ford 1990). Therefore the process of informed consent continued as the research took place with opportunity given for participants to ask questions both prior to and following the interview. Direct questions on research methods, design or participation by email or telephone discussion were responded to as they arose.

6.8 Ethics and the insider researcher

An insider researcher is described as sharing the role, characteristics or experiences of participants in a research study (Holloway and Wheeler 1995). This is recognised to be a frequent occurrence in qualitative research (Blythe et al. 2013). Having a dual role of health professional and researcher can lead to role conflict (Holloway and Wheeler 1995). However there are recognised benefits, with advantages in recruitment and rapport with participants (Blythe et al. 2013). An insider researcher is assumed to have a greater understanding of the issues inherent to the research in question and therefore to be able to obtain richer data (Blythe et al. 2013). In contrast there may be issues of presumption of understanding leading to insufficient detail in data collection and a lack of objectivity in analysis (Blythe et al. 2013).

The concept of reflexivity refers to a researchers awareness of their subjectivity in relation to the research they are conducting (Sheldon and Sargeant 2007). This is important in order to avoid bias in any research but in particular for an insider researcher (Blythe et al. 2013). Intrinsically, reflexivity implies an understanding of the researcher as part of the world they are studying and how their values and interests may impinge on research work (Sheldon and Sargeant 2007).

I have worked as a paediatrician for the past 22 years, for twelve of these years in the field of PPM. As a medical director of a children's hospice I cared for many children as they reached a period end of life care and finally death. I continue to support children with life-limiting conditions and their families as part of my current clinical role. Having regularly attended national PPM meetings and networked with colleagues regarding clinical care, service development and research, I am acquainted with many of the leaders of children's hospice care across the UK.

Of my family background, I am the daughter of a health economist and nurse, one of four siblings. My brother had complex neuro-disability from birth and was not expected to live beyond the age of two years. I spent much of my childhood in hospitals with him and was inspired to become a doctor. My family founded and run a residential and respite unit for young adults with profound disabilities where my brother now lives. Professionally as a paediatrician, and personally as a sibling of a brother with a life-limiting condition, I approached this research with my own unique set of experiences and views. These may have influenced my role as a researcher, with the possibility of bias during both data collection and analysis.

Reflexivity has been named as one of a number of strategies to mitigate for the challenges of being an insider researcher (Blythe et al. 2013). Others include the role of review of data, with analysis by an outsider researcher and regular debriefing (Blythe et al. 2013). Throughout the research process my supervisory team provided regular access to review of progress and debrief. This included review of the analytic process and at times involved issues raised by my dual role as a clinician and PhD student.

6.9 Ethical approval

Completing the BU online ethics modules and attending a workshop on NHS ethics enabled consideration of ethical issues inherent to this research. The key ethical principles of informed consent and confidentiality were upheld throughout the project. With the original plan for an explanatory sequential mixed methods study design, it was initially anticipated that there would be different ethical requirements for each stage of the project and discussion took place regarding the best approach. The first stage was given ethical approval via BU ethics (see Appendix F) and an outline of the subsequent stages of the study was given at this time. The final emergent research design of a convergent mixed methods study did not require a further stage of ethical approval. All three elements of data collection; qualitative, quantitative and case scenario were addressed in the original application for ethical approval which was granted at the outset of the project.

6.10 Chapter conclusion

This chapter provided an insight into the method of analysis followed for quantitative, qualitative and case scenario data collected by mixed methods survey conducted by telephone interview. Following a discussion of the approach to quantitative analysis the method of thematic analysis was reviewed with particular relevance to its use in the palliative care literature. A description of the process for thematic analysis gave step-by-step detail of the way in which qualitative data were reviewed to develop codes and then themes. The process of searching for patterns across these themes and the development of an overall story of the analysis was described. The use of a mixed methods comparative case study approach in the analysis of the case scenario data was explained and the chosen analytic strategy and techniques of cross case synthesis and explanation building were presented. The chapter concluded with consideration of the origins of research ethics and highlighted the ethical principles that guide current research. The application of these principles to this research study in practical terms was set out with particular reference to informed consent. The challenges, benefits and ethical issues relating to being an insider researcher were raised with a declaration of how personal experience may have influenced the research and strategies employed to mitigate for this. Finally the ethical approval process for this study was stated. The following chapters present the findings from the quantitative and subsequently the qualitative analysis.

7 Quantitative findings

7.1 Chapter introduction

To address the first research aim, to describe and classify existing approaches to PPM service provision in children's hospices across the UK, quantitative data were analysed using SPSS^{TM} version 22 (Pallant 2013). In line with the mixed methods convergent design, these quantitative data were collected in parallel to qualitative data. Quantitative and qualitative analyses were conducted separately and integrated subsequently in order to develop a classification of the approaches to PPM service provision. In view of the small total population size, in some instances data is presented as both a percentage value and a numerical value to give clarity. Where the data is normally distributed the mean has been presented and where the distribution is non-normal the median (Foster et al. 2001). Ranges are presented as raw data.

Demographics of participating children's hospices represented in the study are firstly presented to give a picture of the study population and characteristics of the interviewee leaders of care representing these hospice services. Secondly, referral patterns and caseload data provide a numerical framework for understanding the increasing complexity of the population of children receiving hospice care. Thirdly, the medical workforce of children's hospices, at the time data were collected, gives a picture of the doctors working in children's hospices, and their level of specialist PPM education and training. Fourthly, arrangements for 24/7 PPM service provision and relationships between hospices and hospitals are analysed before finally the roles undertaken by doctors and the parallel roles of nurse consultants and prescribers are presented. The chapter concludes with a summary of key data points collated by region in order to give a comparison of the PPM and children's hospice resources available across the UK at time of data collection.

7.2 Demographics

7.2.1 Children's hospice services

Interviews were conducted with 31 leaders children's hospice services. For three of the hospice services both the medical and nursing leads were interviewed. Therefore the interviews related to 28 children's hospice services. For the purpose of the quantitative analysis where there were two sets of data for one hospice service, a decision was made to use the responses of the respondent who had been longest in the post. A range of service configurations were represented in the data (Table 7.1), with hospices from all regions of the UK participating (Table 7.2). Regions were defined in line with NHS England and by country for Scotland, Northern Ireland and Wales.

Table 7.1: Configuration of hospice service

Configuration of hospice service	*Number of hospice services (N = 28)*
Stand-alone community hospice service	4
Hospice with inpatient unit for children	3
Hospice inpatient unit for children and young adults	2
Joint inpatient and community outreach children	6
Joint inpatient and community outreach for children and young adults	9
Children's hospice as part of an adult hospice organisation	4

Table 7.2: Hospice services in study grouped by region

Region	*Number of hospice services represented (N =28)*
Scotland	1
North East and Yorkshire	4
North West	1
Midlands	4
East of England	4
London	3
South West	5
South East	3
Wales	2
Northern Ireland	1

7.2.2 *Characteristics of interviewees*

Interviewees came from a range of professional backgrounds with nursing representing the majority (Table 7.3). Fifty percent of the leaders of hospice services interviewed had no CPC qualification although importantly, for this study, a quarter of interviewees either possessed a PPM qualification or were in training for one (Table 7.4). In terms of experience, the number of months in role for the leaders of care ranged from four to 228 months with a median of 57.5 months (Table 7.5).

Table 7.3: Primary professional qualification of interviewee

Primary professional qualification	*Number (%)* *N = 28 (100%)*
Medical	11 (39.2)
Nursing	15 (53.6)
Other	2 (7.2)

Table 7.4: Specialist CPC qualifications of interviewees

Specialist CPC qualification	*Number (%)* *N = 28 (100%)*
PPM qualification	3 (10.7)
CPC qualification	5 (17.8)
Specialist PPM training	4 (14.3)
Other type of palliative care qualification	2 (7.2)
No palliative care qualification	14 (50.0)

Table 7.5: Number of months in role for interviewees

	Number of months in role for interviewees
Range in months	4 – 228
Median in months	57.5

7.3 Referral patterns

7.3.1 *Referral area*

There was no consensus amongst participants about how referral areas were defined. Thirteen interviewees reported their hospice service received referrals from one region. One hospice service reported receiving referrals from two regions. Fourteen hospice services did not receive regional referrals but accepted referrals from a smaller specified geographical area.

The majority of hospice services (85.7%) received referrals from clinical commissioning groups, (CCGs). Participants reported taking referrals from as many as 20 different CCGs within one region, with a median of seven CCGs.

7.3.2 *Referral age range*

Almost three quarters (71.4%) of the participating hospice services accepted referrals for children under the age of 19 years whilst just over a quarter (28.6%) accepted those over 19 years of age (Table 7.6); some, in reality, provide care to young adults up to the age of 38 years. The caseload age range was from 12 – 38 years with a mean of 22 years.

Table 7.6: Age range for referrals

Age range for referrals	*Number of hospice services (%) (N =28) (100%)*
0 – <19 years	18 (64.3)
0-25 years	6 (21.4)
Other*	4 (14.3)

*Other: 0- 16 years, 0 – 21 years and 0 – 22 years

7.4 Caseload

7.4.1 *Hospice activity*

A wide range in all caseload data was identified between the participating hospice services, indicating different activity levels. In terms of parameters chosen for data collection, these were constrained by the data routinely collated and available from participating children's hospices (Table 7.7). Two figures were collected for each participating hospice service regarding episodes of end of life care over the previous year. One was the total number of episodes of end of life care supported by the hospice service. The second was the number of episodes of end of life care for a child who had died at that time. These two differing data were collected recognising the reality of difficulties predicting when a child will die and therefore not all episodes of end of life care will result in a child dying. In addition to these numbers, in view of the increasing role of children's hospices in supporting compassionate extubation as outlined in Chapter Three, data was collected on the number of compassionate extubations supported by the hospice service over the past year.

Table 7.7: Hospice service caseload and activity data

Type of caseload data	*Range in number on hospice caseload*	*Median number on hospice caseload*
Total caseload	38 - 700	174
Bereavement case load	6 - 251	79
End of life care in past year total	0 - 88	10
End of life care for children who died in past year	0 - 86	9.5
Compassionate extubations in past year	0 - 20	1

7.4.2 *Supporting complex care needs*

Participating hospice services reported their abilities to support children with a range of complex care needs, the majority facilitating non-invasive ventilation, invasive ventilation, total parenteral nutrition (TPN) and peritoneal dialysis (Table 7.8). The most frequent was non-invasive ventilation (96.4%) closely followed by invasive ventilation (89.3%). Transfusion was facilitated by just under a half (46.4%) of participating hospices.

Table 7.8: Complex care needs supported by the hospice services

Care need	*Number of hospices supporting care need (%)*	*Number of hospices not supporting care need (%)*	*Don't know*	*Total number hospice services*
Non-invasive ventilation	27 (96.4)	1 (3.6)	0	28
Invasive ventilation	25 (89.3)	2 (7.1)	1 (3.6)	28
TPN	24 (85.7)	3 (10.7)	1 (3.6)	28
Peritoneal dialysis	22 (78.6)	4 (14.3)	2 (7.1)	28
IV medications	20 (71.4)	8 (28.6)	0	28
Transfusion	13 (46.4)	15(53.6)	0	28

The participants were asked to estimate the percentage of children within their hospice caseload with particular complex health care needs (Table 7.9). Overall the most frequent care need supported by participating hospices was non-invasive ventilation, with a figure of up to 40% of children on the caseload depending on this intervention. The range of hospices offering blood or platelet transfusions is skewed by one hospice service with a large caseload of children with malignant conditions, whereby 30% of these children needed transfusion. Otherwise the range would be 0 – 10% of children's hospices' caseloads with the majority of responses at 0%. The data also demonstrates that although a significant proportion of the participating children's hospices have the capacity to support children who require TPN, IV medications and peritoneal dialysis, these complex health care needs are present in a far smaller proportion of the total number of children on the caseload.

Table 7.9: Range of estimated percentage of hospice service caseloads for each complex health care need

Care need	*Range of estimated percentage of hospice service case loads*
Non-invasive ventilation	<5% - 40%
Transfusion (Platelets or blood)	<1% - 30%
Invasive ventilation	<1% - 10%
TPN	<1% to 7.1%
IV medication	<1% to 5 %
Peritoneal dialysis	<1% - 1.9%

7.4.3 *Complexity score*

Data on the complex care needs of children outlined above was combined and transformed into a simple scoring system for complexity of hospice caseloads, developed specifically for this study. Firstly, coded values for the estimated percentage of each complex care need of children on each hospice caseload were totalled and transformed into a score. This overall complexity score was then coded according to the resultant spread of results;
low complexity 3 – 7, moderate complexity 7 – 14, high complexity 15 – 21.
Using this scoring system confirmed the diversity in the participating hospices' caseloads in relation to complex care needs as presented in Table 7.10.

Table 7.10: Complexity coding for hospice caseloads

Complexity code	*% of hospice services (number)*
Low complexity	10.7%(3)
Moderate Complexity	32.1% (9)
High Complexity	35.7%(10)
Missing data not included	21.5%(6)

7.5 Configuration of medical service provision

Of the 28 participating children's hospice services, four had no inpatient units, 16 had one inpatient unit, six had two inpatient units and two had three inpatient units. Defining community hospice services as those with an element of nursing or medical outreach rather than purely bereavement support, play support or short-breaks that are non-nursing; eight of the hospice services had no community outreach service, 17 had one outreach service, one had two outreach services and two had three outreach services.

7.5.1 *Medical service provision for inpatient units*

Based on a previously collated and analysed survey (Frost 2013), possible configurations of PPM service provision were predefined. All the participating hospice services with inpatient units had a system for medical cover. This was provided in a range of ways, over a quarter of which did not fit into the predefined configurations (Table 7.11).

Table 7.11: Configurations of medical service provision for inpatient hospice services

Configuration of PPM service provision	*Number of hospice services with inpatient units (%) N=24 (100%)*
Nurse led MDT: formal arrangement with GP surgery	4 (16.7)
Nurse led MDT: formal arrangement with one or more GPs with special interest in PPM	4 (16.7)
Consultant in PPM employed by hospice working with team of doctors	4 (16.7)
Consultant in PPM employed by hospital providing in reach into hospice	2 (8.2)
Team of doctors from differing backgrounds providing daily sessions: no integral level 4 doctor	3 (12.5)
Other configurations	7 (29.2)

7.5.2 *Configurations of medical service provision for stand-alone community hospice services*

Half of the participants interviewed representing stand-alone community hospice services had no formal arrangement for medical service provision; indeed each was led by a nursing service rather than a medical one (Table 7.12).

Table 7.12: Configurations of medical service provision for stand-alone community hospice services

Configuration of medical service provision	*Number of stand alone community hospice services (%)* *N=4 (100%)*
Nurse-led community hospice service with no formal arrangement for medical service provision	2 (50)
Nurse-led community hospice service with formal arrangement with GP surgery	1 (25)
Nurse-led community hospice service with an agreement with another hospice	1 (25)

7.6 The medical workforce of children's hospices

7.6.1 *Background specialty of doctors*

A total of 159 doctors were identified as working at children's hospices during the time of data collection. The core background specialism of 155 was identified with the majority working as GPs. Only 6.3% worked as consultants in PPM (Table 7.13).

Table 7.13: Core background specialty of doctors

Core Specialty	*Number off doctors working in hospices (%)*
General Practice	82 (51.6)
GP Special interest in PPM	18 (11.3)
Consultant PPM	10 (6.3)
Consultant Adult PM	10 (6.3)
Paediatric Oncology	5 (3.1)
PICU	5 (3.1)
Community Paediatrics	8 (5)
Paediatrics (any specialty with Special interest in PPM)	7 (4.4)
Specialist Registrar	4 (2.5)
General Paediatrics	4 (2.5)
Other	2 (1.2)
Background specialty not given	4 (2.5)
Total	159 (100)

7.6.2 *Number of doctors working at each hospice service*

There was a variation in the number of doctors working at each hospice service ranging from none in three of the hospice services to a maximum of 13 on one hospice team (Table 7.14). The majority of hospice services had between one and nine doctors working as part of their medical team with only 21.5% of the hospice services with 10 or more doctors.

Table 7.14: Number of doctors working at each hospice service

Doctors working at each hospice service	*Number of hospice services (%)* *N= 28 (100%)*
0	3* (10.7%)
1 – 4	10 (35.7%)
5 - 9	9 (32.1%)
10 and over (max 13)	6 (21.5%)

*Two of these are the hospice service with no medical cover. One is a hospice service with an Service Level Agreement (SLA) for medical cover for telephone advice but not direct medical work.

7.6.3 *Organisation employing hospice doctors*

Just under two thirds of hospice services did not directly employ doctors (60.7%). Of those that did, over half employed only one doctor. A total of 40 doctors were directly employed by the participating 28 hospice services. A total of 119 doctors working at the hospice services interviewed were employed by other organisations. General practice was by far the largest employer of children's hospice doctors (Table 7.15).

Table 7.15: Employing organisations for doctors

Employing organisation	*Number of doctors working in hospice services*
Children's hospice service	40
General Practice	85
District General Hospital	12
Tertiary Hospital	13
Community Trust	8
Other (Post graduate deanery)	1
Total	159

The data demonstrated a striking predominance of GPs working in children's hospices and general practice as the biggest employer of children's hospice doctors.

7.6.4 *Doctors' hours for direct patient care*

Participating hospice services provided the total number of the hours worked each week, by doctors in direct patient care, excluding on-call hours. Where there was more than one doctor working at one time the hours were calculated as a multiple of the number of doctors to give a total of hours for doctors providing direct patient care each week. Four (14.3%) of the hospice services did not have any regular doctor hours. The number of doctors' hours provided in direct patient care per week was diverse, ranging from none to 120 hours, with a median of 16 hours The majority of participating hospices (60.7%) had less than 30 hours a week for doctors to provide direct patient care (Table 7.16).

Table 7.16: Doctors' hours in direct patient care per week

Doctor hours in direct patient care per week as a range	*Number of hospice services N =27**
0	4
1 - 30	13
30 - 60	6
60 - 90	2
90 - 120	2

*1 hospice service answered "Don't Know" in relation to the total number of doctor hours

7.6.5 *Pattern of work*

Participants were asked whether the way in which doctors' working at participating hospices fitted within predefined categories. Half of the participants interviewed suggested a pattern of work existed for doctors that did not fit within these categories (Table 7.17). The need for responsive doctor hours was apparent in the answers given. In addition the varying workload and increase in need for doctor hours for end of life care was frequently mentioned.

Table 7.17: Pattern of work for doctors

Pattern of work	*Number of hospice services N=28*
A session per day	2
9-5 weekdays and as required at weekends	3
No regular hours (responsive to need)	6
Other pattern	14
Answered as not applicable*	3

*Two of these had no doctors and one answered that it was not applicable as they had an SLA for "when needed".

The participants were asked how many hours per week doctors working for the hospice are available for telephone advice if needed. This ranged from 0 – 168 hours, median 168 hours. 64.3% of interviewees report doctors being available 24/7 if needed for telephone advice.

Participants were asked to give the number of hours per week doctors working for the hospice are available to see patients face to face on request. This ranged from no hours to 168 hours, median 168 hours. Again 64.3% of interviewees reported the doctors working regularly for the hospice being available 24/7 to see patients face to face on request. This is of note, as this expectation appears to be in spite of the doctors having a far lower number of contracted hours.

7.7 Level of specialism in PPM

The APPM and the RCPCH have defined levels of specialist training from one to four in PPM as part of the combined curriculum (APPM Education Subgroup and RCPCH 2015).Consultants trained in PPM according to the RCPCH curriculum (RCPCH 2010) are considered to be at level four. Participants were given the definitions of these levels to enable them to accurately report on the level of specialism of doctors working at the participating hospice services (Appendix D).

Twenty percent (32) of the doctors working at children's hospices in the study were reported to be at level three in PPM and 7.5% (12) at level four in PPM. Therefore only 27.5% of doctors working in children's hospices in the study had a specialist level of competency in PPM.

7.7.1 *Consultants in PPM working at children's hospices*

Overall, ten consultants in PPM were reported to be working at nine hospice services in the study. Half of these were employed by the hospice and half were employed by a hospital. Therefore the majority of children's hospices in the study did not have a working relationship with a consultant in PPM. All the consultants in PPM working at the hospice services were reported to be available for telephone advice and visits if requested. In eight of the nine hospices, the consultants in PPM worked specified half-day sessions in the hospice including face-to-face medical review.

7.8 Arrangements for 24/7 medical advice for the hospices

7.8.1 *Overall arrangement for 24/7 medical advice*

Just under ninety percent (89.3%) of the participants reported having access to 24/7 medical advice. This was delivered in a variety of ways over a quarter of which did not fit within the predefined configurations (Table 7.18). For those hospice services with access to 24/7 medical advice, the most frequent arrangement was with a general practice (25%), closely followed by the team of hospice doctors running a continuous rota (21.4%).

Table 7.18: Arrangement for 24/7 medical advice

Arrangement for 24/7 medical advice	*Number of hospice services (%) N=28 (100%)*
24/7 rota run by hospice doctors	6 (21.4)
SLA with general practice or co operative	7 (25.0)
SLA with another children's hospice organisation	1 (3.6)
One individual person 24/7	3 (10.7)
None of above (other arrangement)	8 (28.6)
No access to 24/7 medical advice	3 (10.7)

Importantly, one tenth (10.7%) of the hospice services had no formal arrangement for continuous medical advice of any type. Of these, two, had no formal arrangement for medical advice overall and one had a team of nurse specialists in CPC with prescriber qualifications. This alternative approach to PPM service provision is discussed further in Chapter Nine.

Of the 25 hospice services reporting access to continuous medical advice, 24 (96%) reported this being for general medical issues, 21 (84%) for general PPM advice and 18 (72%) for specialist PPM advice. (One answer was coded as system missing on SPSS therefore the total number of responses for this question was 24). This is of interest, as if the re-coding (below) is an accurate reflection of the access to specialist PPM advice 24/7, for some hospice services the interviewee believed they had access to continuous specialist PPM advice but on closer analysis they did not.

7.8.2 *Recoding of access to 24/7 medical advice to reflect access to specialist PPM advice*

On conducting the analysis of the data it became apparent that there was the opportunity to give further clarity to the type of 24/7 medical advice available, in particular whether the hospice services had access to continuous specialist PPM advice. Data were recoded by combining qualitative data on 24/7 medical advice and answers regarding the level of advice previously coded in combination with a question relating to whether the advice was specialist PPM advice. This gave a complete picture of the type of 24/7 advice. In half of the hospice services there was access to 24/7 specialist PPM advice (defined for this purpose as a doctor trained to level three or level four in PPM) but for the other services a variety of ways of covering the need for specialist PPM advice had been developed (Table 7.19).

Table 7.19: Type of 24/7 medical advice

Type of 24/7 medical advice	*Number of hospice services N=25*
Specialist PPM advice	14
Generic 24/7 medical advice used to cover PPM in an emergency	5
Generic 24/7 medical advice with augmentation for end of life care to give specialist PPM advice	6

These categories were further divided to capture the differences in the ways this advice was accessed. This analysis demonstrates that of the 14 hospices with access to continuous specialist PPM advice; two of the methods were not comprehensive 24/7 cover, either relating to one person or to a subsection of patients (Table 7.20).

Table 7.20: Description of 24/7 specialist PPM advice

Description of 24/7 specialist PPM advice	*Number of hospice services N=14*
Hospice run rota of doctors	8
One person specialist in PPM 24/7	2
SLA with another hospice organisation's 24/7 specialist PPM rota	1
SLA with tertiary hospital for all patients	2
SLA with tertiary hospital for subsection of patients	1

For the six hospice services with ways of augmenting generic 24/7 medical cover in order to provide specialist PPM advice for end of life care, these approaches were described (Table 7.21). Of these, two related to one person with specialist PPM training covering continuously for end of life care and was therefore again not comprehensive cover. For two other hospice services this augmentation related to rotas of GPs, for one with access to a consultant in PPM but for the other with no specialist PPM.

Table 7.21: Ways of augmenting generic cover for end of life care

Way of augmenting generic cover for end of life care	*Number of hospice services N=6*
One person with specialist PPM training covering end of life care	2
Rota of regular hospice doctors levels 2 – 4 covering end of life care	2
Rota of GPs with access to advice from a consultant in PPM	1
Rota of regular hospice GPs but no specific specialist augmentation	1

7.8.3 *Mode of 24/7 advice*

All the 25 hospice organisations with access to medical advice offered telephone advice. Twenty three of the 25 could request a doctor to directly review a child in the hospice as part of the 24/7 advice, for one this was not applicable as there was no hospice building, the other offered telephone advice only. Ten of the 25 provided an opportunity for doctors to review a child whilst an inpatient in hospital. Thirteen of the 25 could provide review for a child in the community.

7.8.4 *Access to 24/7 advice*

Continuous medical advice was predominantly offered to children previously referred to a hospice and already known to staff, whilst they were in the hospice inpatient unit (96%). For a significant percentage of the hospice services, the system for continuous medical advice could be used by children already on the hospice service caseload, when they were either at home (64%) or in hospital (60%). The system for 24/7 medical advice was available less frequently for children not known to the hospice service, either at home (20%) or in hospital (24%) (Table 7.22).

Table 7.22: Location of children offered continuous medical cover

Location of children offered continuous medical cover	*Number of hospices (%) N=25 (100%)*
At Home:	
Children known to hospice	16 (64)
Children not known to hospice	5 (20)
Inpatient:	
Hospice	24(96)
Hospital (known to hospice)	15 (60)
Hospital (not known to hospice)	6 (24)

The systems for 24/7 medical advice were mainly accessed by nurses working for the hospices (100%) and in some cases by the wider multi-disciplinary team at the hospices (36%). In 44% of cases, the system for 24/7 medical advice could be accessed by professionals outside the hospice service. It is notable that parents of children under the hospices' care had access to this 24/7 medical advice system least frequently of all (20%).

7.9 The relationship between children’s hospices and hospitals

7.9.1 *In-reach into hospitals*

The way in which children’s hospices related to NHS hospital services in terms of medical service provision was explored. Findings demonstrated that 15 of the 28 participating hospice services reported doctors providing in-reach into hospitals. Overall this in-reach was to 49 district general hospitals (DGH), 14 tertiary children’s hospitals and 57 neonatal units. Individual hospice services provided in-reach for between one and 12 district general hospitals. The majority of hospice services providing in-reach related to one tertiary children’s hospital and to at least one neonatal unit. However, one hospice service reported relating to 13 neonatal units.

Only two of the 15 hospices providing in-reach into NHS hospitals did this as part of a formal funded arrangement. For the other hospices, five had a formal arrangement with an honorary contract but no funding. Four had no formal contract or funding. For four, the doctors were employed by a hospital in an NHS post in addition to working at a hospice and therefore providing in reach was a bi-product of their dual role.

7.9.2 *Outreach into the community*

Relationships between hospice services and NHS community services were also investigated. Thirteen of the 28 hospice services reported doctors employed to work for them providing outreach into the community. Of the 13 hospices providing outreach, six had a formal arrangement with funding and an honorary contract, one a formal arrangement with an honorary contract but unfunded. Four had an informal arrangement with no contract or funding and two had other arrangements.

Findings in relation to both in-reach into NHS hospitals and outreach into the community in lieu of NHS community services indicate the hospice services took a significant, unfunded in role in contributing to PPM service provision in these settings.

7.10 Roles undertaken by doctors working in children's hospices

The majority of doctors working in children's hospices across the UK were reported to be undertaking similar roles, as demonstrated in Table 7.23. It is of note that in many of the hospice services, doctors were undertaking roles considered specialist PPM roles (APPM Education Subgroup and RCPCH 2015; RCPCH 2010), including providing specialist PPM review, symptom management advice and discussing advance care plans. However, data indicate that the majority of these doctors did not have specialist training in PPM.

Table 7.23: Doctors' roles in hospice services with medical input

Role	*Number of hospice services (%) N=25(100%)*
Writing medications charts	25 (100)
Prescribing new medications	25 (100)
General medical review	24 (96)
General PPM review	23 (92)
Specialist PPM review	21 (84)
Advice on symptom management	22 (88)
Writing and circulating symptom management plans	20 (80)
Writing discharge summaries	16 (64)
Discussing advance care plans	22 (88)
Arranging admission to hospice	18 (72)
Arranging stepped discharge	17 (68)
Arranging emergency admission	15 (60)
Medical review family members	12 (48)
On-going team review of child/family	23 (92)
Certification of death	24 (96)
Clinical governance and policy	23 (92)
Teaching and training	22 (88)
Strategy and development	21 (84)

7.11 Nurse consultants and non-medical prescribers working in children's hospices

7.11.1 *Nurse Consultants*

Six of the 28 hospices employed at least one nurse consultant. In these hospices, participants reported on the roles undertaken by these nurses. All of these nurse consultants were reported to give advice on symptom management and prescribe new medications (Table 7.24). The majority of nurse consultants (83.3%) wrote and circulated symptom management plans, discussed advance care plans and arranged admissions to the hospices. Half (50%) were considered to give a specialist CPC review and two-thirds (66.6%) a general CPC review (Table 7.24).

Table 7.24: Nurse consultant roles

Role	*Number of hospice services (%) N=6 (100%)*
Signing medications charts	5 (83.3)
Prescribing new medications	6 (100)
General health review	3 (50)
General CPC review	4 (66.6)
Specialist CPC review	3 (50)
Advice on symptom management	6 (100)
Writing and circulating symptom management plans	5 (83.3)
Discussing advanced care plans	5 (83.3)
Arranging admission to hospice	5 (83.3)
Medical review family members	1 (16.6)
Verification of death	4 (66.6)

7.11.2 *Non-medical prescribers*

Ten of the 28 hospices had at least one non-medical prescriber. Overall these ten hospices employed a total of 39 non-medical prescribers, one with a team of seven non-medical prescribers. 38 of these were nurses and one was a pharmacist.

7.12 Regional service inequities

Data in relation to the number of hospice services, the total caseload of children and young adults, the level of specialist PPM training of doctors working in the hospices and numbers of consultants in PPM were collated by region. These figures demonstrate an inequity in numbers of children's hospices and PPM resources across the UK with more resources by area in the south in comparison to the north. Table 7.25 presents a summary of this data showing a higher number of children's hospice services and doctors working in hospices, both level three and level four trained in PPM in the south of the UK in comparison to the north of the country. Numbers of consultants in PPM were also higher in the south of the UK.

Table 7.25: Case load and level of specialism of doctors in children's hospices by region

Region	**No. of hospice services**	**Caseload total**	**No. of consultants in PPM**	**Level 3 doctors in hospices**	**Level 4 doctors in hospices**
Scotland	1	310	1	2	1
North East and Yorkshire	4	475	2	4	2
North West	1	68	0	1	0
Midlands	4	1462	0	6	2
East of England	4	688	0	5	0
London	3	972	2	0	2
South West	5	541	1	5	1
South East	3	614	3	6	4
Wales	2	426	1	2	0
Northern Ireland	1	250	0	1	0
Totals	28	5806	10	32	12

7.13 Chapter conclusion

Quantitative analysis of data presented in this chapter provides a numerical framework for describing and classifying current approaches to PPM service provision. The referral and caseload data demonstrated the increasing complexity of the population of children receiving hospice care. The data on the current medical workforce of children's hospices highlighted the predominance of GPs and general practices in the delivery of children's hospice care. Alongside this the analysis of levels of specialist training in doctors working in children's hospices alludes to a striking lack of specialist training in this group of doctors and a limited involvement of consultants in PPM in children's hospice services. In relation to the provision of 24hour a day, 7day week access to medical advice for children's hospices, the data presented demonstrated a lack of true and equitable access to specialist PPM advice. The chapter ended by presenting evidence of a disparity in children's hospice and PPM resources from the north to the south of the UK. The following chapter on the detailed qualitative analysis adds strength and depth to these quantitative findings.

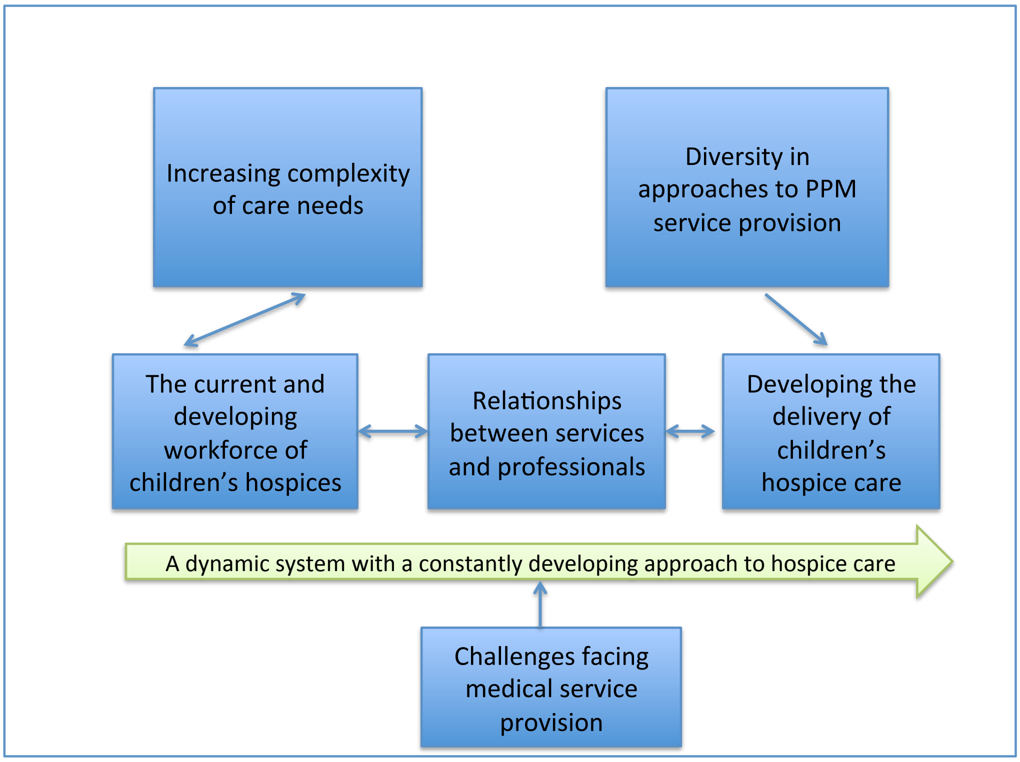
8 Qualitative findings

8.1 Chapter introduction

Braun and Clarke (Braun and Clarke 2013b) suggest developing a clear idea of the overall story of a thematic analysis. For the qualitative data gathered in this study, the overall story was developed through the process of analysis outlined in Chapter Six. Using thematic analysis two overarching themes became evident: (1) *Increasing complexity of care needs* and (2) *Diversity in approaches to PPM service provision. The first of the overarching themes: Increasing complexity of care needs* describes the ways in which the population of children and young adults receiving hospice care are changing and becoming more complex, and the second: *Diversity in approaches to PPM service provision* encompasses all aspects of the way in which medical services are provided in the children's hospices. Underlying these two overarching themes there is a strong sense of a dynamic system, where the way in which hospice services are approaching CPC is constantly developing and changing. This dynamic system underpins three of the main themes to have evolved from this research: (i) *The current and developing workforce of children's hospices, (ii) Relationships between services and professionals and (iii) Developing the delivery of children's hospice care.* The progression in the delivery of CPC overall and in particular PPM service provision is opposed by a number of factors represented in a fourth main theme: (iv) *Challenges facing medical service provision*.

The two overarching themes will be presented first, as (1) *Increasing complexity of care needs* and (2) *Diversity in approaches to PPM service provision* are the major themes overlying all four main themes. The main themes will be outlined subsequently as these represent the detail of what influences the approaches to PPM and contributes to their diversity. The way in which these overarching themes and main themes inter-relate is represented in Figure 8.1. Both the overarching and main themes contain subthemes defining specific aspects of each area discussed. For clarity, diagrams depicting each of the overarching and main themes with subthemes and the accompanying coding frameworks can be found in Appendix G and can be used as a guide for the written analysis.

Figure 8.1: The overall story of the qualitative analysis. Braun and Clarke (2013)



8.2 Increasing complexity of care needs

The findings indicate an increasing complexity of care needs in children with life-limiting conditions. This complexity is multi-faceted and spans the conditions lived with by children themselves, the variability and unpredictability of each, the interventions now possible and a 'moving of the goal posts' leading to changing parameters of care; such that the referrals to children's hospices, expectation of choice in place of care and goals of care in themself are constantly altering and expanding. Alongside this the ethos of the children's hospice movement of responding to challenges and finding solutions, in a 'can do approach', tends to result in every increase in complexity of care causing a consequent development in service delivery. The following five subthemes to emerge from analysis of this overarching theme are; (a) *Increasing complexity of conditions, (b) Increasing complexity of interventions*, (c) *Changing parameters of care, (d) Ethical issues and facilitated decision making and (e) Hospice related factors.*

8.2.1 (a) *Increasing complexity of conditions*

In the early days of children's palliative care four groups of life-limiting conditions were defined (ACT 1997). These have continued to be used as the basis for children's hospice referral criteria (Chambers 2018). Although the conditions themselves have not changed, the complexity of the conditions and associated symptom management appears to have increased over time as demonstrated in the research findings.

This increasing complexity of conditions accordingly impacting on the increasing complexity of care needs was described by participant 3/C as: "*not one individual care need but the combination that leads to complexity. Not the individual pieces but the whole picture".* This description of taking into account "*the whole picture*" for any individual child or young person is a helpful metaphor for the increasing complexity of complex health needs leading to combinations of interventions. A number of interviewees referred to this combination of needs when asked what adds to the complexity of the care provided by children's hospices, as reported in the following responses:

> 15/M "*Increasing multiple needs and comorbidities".*
>
> 20/Q *"The combination of management in one child. For example a child with a stoma, tracheostomy and central line".*
>
> 25/V "*The combination of multiple needs in one child".*

Widening out this description, this "*whole picture"* includes not just the health conditions of individual children but the consequent complex symptoms and the ethical issues in decision making with respect to possible interventions. Participant 15/M referred to this as "*complex combinations of symptoms, interventions and ethics".* These ethical issues are discussed further in subtheme (d). Similarly 8/G reported complexity in relation to "u*nstable symptoms, managing symptoms and juggling medications".* Respondent 15/M further stated, "*symptoms are more complex in view of longer life expectancy*".

Further dimensions adding to the increasing complexity of conditions are the concurrence of behavioural issues that increase over time in a number of children with degenerative conditions and the presence of additional developmental needs in children requiring palliative care. The following participant commented on these complexities:

> *12/J "Neurodevelopmental conditions with behavioural needs such as autism spectrum disorder and challenging behaviour".*

These behavioural and developmental needs lead to unique challenges in care that were reported by respondent 17/N to be compounded by professional regulations, as described in the following excerpt: "*children with behavioural problems including aggression towards staff add to the complexity of care provided… this is impacted by adult social care inspections, like bringing in Deprivation of Liberty".*

In terms of distinct conditions impacting on the increasing complexity of conditions "*complex epilepsy management*" (2/B, 28/Y) and *"seizure management and status",* (23/T) were frequently mentioned as adding to the complexity of care. The following leader of hospice care gave additional insight into this stating the possibility of a child with complex epilepsy being transferred from a children's hospice to an intensive care unit in order to control seizures, as a factor increasing complexity of care needs:

> 19/P "*Seizure management is challenging, for example seizures leading to ITU admission".*

As reported by participant 12/J: *"Epilepsy with Vagal Nerve stimulation adds to the complexity of care needs".* The implications of this on care support were expanded on by participant 24/U who described, "*vagal nerve stimulation with intractable epilepsy needs 2 to 1 support".*

8.2.2 (b) *Increasing complexity of interventions*

> 11/I "*New things come up all the time".*

This simple quotation sums up the increasing complexity in relation to new interventions. Interviewees commented frequently on the technological interventions now possible. These have developed in every area of specialist care pushing the boundaries of what is possible and impacting on the increasing complexity of care needs for children receiving hospice care.

Respiratory interventions were the most frequently cited contributor to increased complexity of care. This includes the use of ventilation both "*invasive and non invasive ventilation",* (12/J) also described by participant 6/F as: "*complex ventilation".* Tracheostomies have a number of implications on care needs including on the level of care as described by participant 14/L who stated: *"one to one care at night is required for tracheostomy dependent children and is provided from the outside carers"*. Cough assist machines were described by a number of respondents and for the following leader of hospice care were reported to affect a significant percentage of the children cared for by the hospice increasing the complexity of care needs:

> 5/*E "Cough assist with a physio regimen adds to the complexity of care. Children are prescribed a cough assist program twice daily. This applies to 12% of the case load".*

Hospice leaders reported that they are now being asked to support children and young people undergoing dialysis as participant 13/K described: "*Haemodialysis adds to the complexity of care, and may be needed three to four times week".* This was echoed by participant 9/H who reported:

> *"Hameodialysis has been supported for one child who was under [Tertiary hospital] for the home dialysis program but the home was not suitable. We have been supporting this [child] for two years".*

Types of catheterisation were also cited as a contributory factor to increased complexity of care by participant 11/I who mentioned: "*Suprapubic* *catheterisation” and* 2/B who commented on: “*complex bladder abnormalities and complex catheters”.*

A phenomenon termed: “*multiple ostomies”,* by participant 15M, sums up the increasing frequency of children with feeding tubes and other types of stoma. These can include: “*gastrostomy”, “jejunostomy”* (10/H, 3/C) and *“nephrostomy”* (13/K). It is the combinations of these “*ostomies”* within one child that add to the increasing complexity of care needs as illustrated in the following excerpt:

> 13/K “*Stoma care [adds to the complexity of care], often multiple stoma care, for example; urostomy, ileal conduit, nephrostomy. Increasingly children have complex combinations of these”.*

The following participant’s comment alludes to the normalisation of these complex interventions:

> 16/M “*Jejunal tubes are starting to become the norm”.*

Neurosurgical interventions were mentioned by one interviewee, 13/K as contributory in increasing complexity of care needs, reporting “*neurosurgical interventions; shunts and reservoirs”* as a key factor and later commenting on the use of “*epidural for pain management”*, as a complex intervention in palliative care for children.

In addition to interventions in technology, the management of medications in children’s palliative care is continually progressing. This was frequently cited as a factor in the increasing complexity of care needs, as stated simply by participant 8/G: “*Drug combinations add to complexity”.* This was both in relation to numbers of medications, new medications, combinations of medications and the mode of delivery of medications. As illustrated by respondent 15/M who said: “*Each child has a significant number of medications, the hospice has a role in managing and rationalising these medications”.* The outworking of this was described in practical terms by participant 3/C who described “*multiple and frequent medications add to complexity of care, for example a child with a medication needed every hour”*.

For one hospice, inpatient stays for initiation of medications or changes to medication were becoming part of their provision for symptom control. Participant 7/G described: "*admission for opiate rotation including on to methadone and the use of ketamine. We arrange admission [*to the hospice*] to initiate… we also arrange admissions to establish medications".* This participant also referred to "*syringe drivers with multiple drugs"* as adding to the complexity of care needs.

8.2.3 (c) *Changing parameters of care*

In addition to the increasing complexity of the conditions and interventions there is a sense of a '*moving of the goal posts'* in the expectations and demands on children's hospices. These changing parameters of care are part of the increasingly complex profile of children receiving hospice care and relate to where the care is provided, the number and age profile of children referred and to the changing goals of the care that is provided.

In terms of place of care, the stark nature of the following quotation highlights the gravity of this change in expectations:

> 28/Y "*In the past these children would never have come out of hospital".*

For children dependent on medical technology, children's hospices were reported to provide a middle ground in the 'stepping down' of place of care in order to provide an out of hospital choice for families. Participant 21/R described an example of this in practice, highlighting consequent challenges:
"*One step down admission became a two year admission for a child with non-invasive ventilation waiting for a package for home".*

Respondents reported: "*babies with multiple complex needs"* (25/V) and "*younger children less than five years" (28/Y)* being part of their caseload and adding to the complexity of care needs. Findings from this study confirm that babies now make up an increasing proportion of a hospice's caseload as described in the following quotation:

> 21/R *“ There is a changing dynamic, previously we provided respite and play therapy. [The hospice] started with 120 children and now 80 -90% are less than 3yrs old therefore there is a different profile, including antenatal referrals”.*

This has impacted on the parameters of care offered by children’s hospices and was reported by the leaders of hospice care interviewed as being a contributory factor in the overall complexity of care needs, as participant 1/A explained: “*for neonates who have highly complex needs, we need to work in collaboration with the hospital”.* This changing dynamic can also affect the short break care offered, as participant 25/V described: *“respite has changed, previously this was five to seven days, now babies have 24 – 48 hours care on a regular basis, twice a month”.*

Some participants commented on an overall increase in the numbers of children and young people on their caseload, reflecting the known increase in prevalence of life limiting and life threatening conditions (Fraser et al. 2012; Fraser et al. 2015). For example 26/W explained: “*our case load has increased by 50 % in the past year”.*

Others had deliberately changed their referral policy to accept children with conditions that are life-threatening but potentially curable, thereby changing the parameters of care provided as discussed in the following excerpt:

> 5/E *“We have been working with oncology services around referrals. Previously we only accepted when a child was terminally ill. We have changed our criteria to emphasise the life threatened group of children with cancer”.*

In contrast to this, some groups of children’s access to hospice care has been deliberately reduced through the introduction of specific criteria for children in ACT category four as participant 26/W described: “*we are a relatively new hospice service so we can be picky about which referrals we accept in category four”*.

The phrase *"goals of care"* summarises a key concept in CPC, denoting the expected or hoped for outcome of a particular course of action or treatment (Chambers 2013).This needs to be constantly reviewed and agreed in discussion between parents and professionals. The goals of care for a child on a palliative care journey can and will change over time. However the advent of potentially curative treatment, such as transplant may change the outcome, even after a child is accepted for hospice care, such that the initial goals need to be revisited. The following participants discussed their experience of this:

> 1/A "*Children awaiting transplant, for example bowel transplant are severely ill and the hospice is providing care but they may improve and be discharged post transplant".*
>
> 9/H "*Initially this child [at hospice requiring haemodialysis] was for palliation but is now on the transplant list".*

In children with cancer the hope and potential for cure adds a different emphasis to the parameters of hospice care, leading at times to an abrupt turn around in the provision of care as alluded to by participant 5/E who stated: *"if they are cured, then they are discharged".*

8.2.4 (d) *Ethical issues and facilitated decision-making*

Several participants reported requests for their hospice service to be involved in the ethical decision making process and at times in the practical action of a decision to withdraw a treatment. As stated by respondent 7/G: *"Other admissions occur for withdrawal of other types of treatment for high dependency unit, oncology patients".* Participant 15/M described this as a necessary expansion of the hospice's role saying: **"***We need to be involved in withholding and withdrawing, for example the withdrawal of Parenteral Nutrition with agreement".*

8.2.5 (e) *Hospice related factors*

In responding to the need to develop to meet the complex care needs of children with life-limiting conditions, the attitude of the CPC sector has been one of a “can do approach”. This is encapsulated by the following responses:

> 21/R “*We would rise to any challenge”.*
>
> *14/L “If patients manage it at home we can manage it at the hospice”.*

This approach has resulted in a considerable shift in the work of a number of children’s hospices from a predominantly short-break based service, to a service able to respond to acute needs in palliative care. This links with the diversity in approaches to PPM service provision that may relate to the range of responses to the increasing challenges of supporting children with complex care needs. Whereas some services have expanded their remit others have retained their traditional boundaries.

Findings indicate that the location of the hospice and in particular the proximity of the nearest children’s hospital impact on the care given. One participant commented on this in relation to the management of prolonged seizures as discussed in the following response:

> 22/Q ““*For children with epilepsy and major seizures or status. The care provided is complicated by the distance to hospital. There has been consideration of giving one patient a port for IV access for this reason”.*

For some patients it is the transport itself that adds to the complexity as described by interviewee 10/H: “*transport for a child with a menigomyelocoele was an issue as the child could not fit into standard seat”.*

In summary, this first overarching theme arising from thematic analysis of the data highlights the ways in which there is an *Increasing complexity of care needs* in the population of children receiving hospice care. The complexity of the conditions that children live with and the range of interventions now possible are shown to be a key factor in this complex picture. The consequent decision-making around ethical issues arising from these new interventions adds a further layer of complexity. In addition the demands on hospice services by changing parameters of care within the dimensions of age profile, referral patterns, goals of care and place of care have been discussed. Lastly the way in which hospices respond with a ‘can do approach’ has been seen to be a factor in the increasingly complex care needs provided for by hospices.

8.3 Diversity in approaches to PPM service provision

One of the key aims of this research study was to describe and classify the range of approaches to PPM service provision in children’s and young adults’ hospices across the UK. The overarching theme evident from the data is of a vast diversity in all aspects of the medical service provision; the amount, configuration and level of specialism of medical services. There is therefore a complex picture when seeking to classify these approaches to PPM service provision and it is important not to oversimplify this diversity but to represent its parameters as accurately as possible, through identifying patterns from the data. The following four subthemes: (a) *Defining the overall hospice classification, (b) Diversity in approaches to 24/7 PPM advice, (c) The specialist question and (d) Diversity in approaches to outreach* demonstrate the different perspectives arising from the data which make up the overall picture of diversity in approaches to PPM service provision.

8.3.1 (a) *Defining the overall hospice classification*

Defining the approaches to PPM service provision is a challenging process in light of the diversity uncovered by this research study. However detailed qualitative analysis has identified patterns from the data in terms of ways of defining the overall hospice classification that are helpful in creating a typology. The context of the overall hospice classification impacts on the medical service provision. This was evident in the data in relation to geographical issues, relations with adult hospices and approaches to hospice leadership. These classifications are not mutually exclusive and can coexist within the same hospice, adding an additional diversity.

Several participants self-defined their approach to service provision as being one based on geography. For some hospice services it was evident from responses given that the medical cover operates over a whole region. This was reported by participant 12/J who explained: *“Three separate hospices are supported by one medical director”* and interviewee 9/H who stated: *“A symptom management team work across all three hospices and community teams”.*

For others there was an aspiration for medical cover to work across a geographical region. For example participant 11/I described that their hospice service: *“needs to be on a cooperative regional basis” and participant* 27/X explained that their hospice was: *“looking at regional partnership with [hospice service]”.*

In contrast other hospice services self-identified as a local hospice, both in terms of overall design and medical cover as described by participant 25/V, who explained: *“the children’s hospice is described as a local children’s hospice as opposed to regional hospice”.* Some interviewees commented on the desire for, and the benefits of local medical professionals stating, *“local expertise also needs to be utilised”* (1/A), and: “*we value the local service, that is only five minutes away*” (2/B).

The impact of geography was particularly notable in rural areas where there was no hospital service in the proximity. This type of service faced unique challenges as one participant commented:

> 22/S *“ The hospice is set in a rural and large area, in comparison to a hospice near a tertiary children’s hospital. The workload is variable, and the skills needed are variable”*.

Four of the participating hospice services were children's hospices linked to an adult hospice. Within these four hospices there were differences in the way in which the medical service provision was organised. The following two comments demonstrate contrasting approaches; the first where the care was delivered separately for children and adults and the second with a joint care provision for all ages:

> 3/C *" We are* part *of an organisation that has an adult hospice but the children's hospice runs entirely separately ".*

> 27/X *"A five bedded inpatient hospice is attached to an adult hospice. From the care point of view the adult and children's hospices support each other as one hospice that takes all ages. The hospices were built independently in* the *same grounds and ten years ago came together."*

The origin of the hospices is also of interest, respondent 25/V explained how a children's hospice "*grew*" out of an adult hospice: ***"****the organisation was originally an adult hospice which always took children. When the numbers of children increased we opened a children's hospice in 1996. The children's hospice is a separate building on the same site".*

For this participant the linked arrangement was seen as having multiple advantages:

> 25/V *"The joint services with the adult hospice enable a larger service to be offered. For example the pre and post bereavement service …. There is a great advantage in being attached to the adult hospice, they are forward thinking and keep things up to date".*

A further delineating factor identified through data analysis was the hospices approach to leadership. The phrase *"nurse led hospices"* (11/I) was a frequently used explanation for the approach to medical service provision. As participant 2/B explained: "*The hospice is described as a nurse led unit".*

For some of hospices the nurse-led service was provided in combination with a system for formal medical service provision. For example participant 3/C described their hospice as:*“nurse led with a link to local GPs”*. However in others nurse- led service was provided as an alternative to a medical service as described here:

> 18/O *“ There is no formal medical cover. We have paediatricians and other doctors as trustees involved on informal basis. We work with hospice doctors, GPs and paediatricians”.*

For hospice medical services led by a doctor these can be classified as either “*one-person pioneer”* or “*medical teams*”. As the name dictates, in a one-person pioneer approach the medical service is strongly led by one person, often an early pioneer in the field as is demonstrated in the following excerpt:

> 6/F *“In the hospice the regular medical* director *sessions are: Three PA hospice (one and a half days) and 24/7 cover. This is worked as a Monday a “clinic” at the hospice and on Tuesday in the community with home visits”.*

In this system the service was given boundaries and supported by an experienced nursing team to make this role possible:

> 6/F *“Not all the hospice patients come under medical director care, only if referred to this part of the service specifically at which point they are under dual consultantship. Therefore of the total case load of the hospice the medical director only sees approximately 30 children who are at end of life or unstable. The system works because of a 24/7 band 6/7 nurse rota being in place and also because of proactive planning and prescribing”.*

Where a team of doctors led the medical service provision there are multiple ways in which the service was configured. The following two examples give descriptions of two types of medical teams:

> 5/E *"There is a medical* director *of GP background who is a lead for the development of PPM nationally. He works with three local GPs who have a special interest. These doctors have set up a company and have an SLA with the hospice to provide the medical care*".
>
> 4/*D "There is a team of doctors; a GP with special interest, another GP, a paediatrician working with a multi-professional team with a daily doctor's session".*

8.3.2 (b) *Diversity in approaches to 24/7 medical advice*

The overall diversity of medical service provision was reflected in the ways in which the hospice services accessed 24hour a day, seven days a week medical advice, both at a specialist and generalist level. Many of the hospices accessed 24/7 medical advice via an SLA with another service, either a GP cooperative, NHS service, another hospice service or a combination of these. For example participant 19/P stated: *" an SLA with another children's hospice service"* as the arrangement. In contrast the following interviewees described an SLA with a GP co operative:

> 20/Q "We have an *SLA with a GP Coop for medical advice on general issues level one and two".*
>
> 29/Z **"**We have an *SLA with a general practice or cooperative".*

Participant (11/I) explained: *"the hospice has an SLA with [Tertiary Children's Hospice] for out of hours telephone support for the children under [Tertiary Children's Hospice]".* Some hospice leaders reported combinations of service level agreements as stated by participant 23/T, *"We have an SLA with general practice and an SLA with the tertiary children's hospital".*

For the hospices with teams of doctors there was the possibility of running an '*in house'* rota to provide both general and specialist PPM advice 24 hours a day, seven days a week. Interviewees 13/K, 14,L and 25/V all described a *"24/7* *rota of hospice doctors".* One way in which regular hospice doctors worked to cover on call was as part of a team of at least four doctors as described by participant 13/K:

> *"We have a team of doctors doing daily sessions and covering on call. Two to four hour sessions on weekdays covered by GPs and paediatricians with regular sessions at the weekends".*

The following description illustrates the way in which a small team of regular hospice doctors, reported a pattern of work with a wider group of doctors on a bank system to cover the hospice on call:

> 14/L "*Therefore there are four regular doctors in total: a consultant in PPM, GP with Special interest in PPM (level three), adult oncologist (Level two/three) and a GP in the second year of the diploma. These doctors cover regular sessions, one weekday evening and one in five weekends (Friday evening to Monday morning). A handful of other doctors cover two weekends a year. We have a bank of eight other doctors".*

Participant 7/G gave more detail on how their system was structured in practice with time in the hospice over a weekend in addition to availability for telephone advice explaining:

> *"For weekend cover the doctors are on call from Saturday morning to Monday. On Saturday the estimated time in the hospice is six hours. On Sunday the estimated time in is two to four hours. This varies according to need and can be more".*

The analysis gave evidence of the need for increased medical care when caring for a child or young person at the end of their life. Hospices responded to this in varying ways, in order to '*augment'* the regular system for access to medical advice. Participant 17/N referred to this increased provision, stating: *"A 24/7 on call rota of doctors is run by regular hospice doctors for end of life care episodes". Similarly respondent 20/Q reported: "For end of life care, GPs who* *work at the hospice run their own rota".* The word 'responsive' was used by participants with reference to this practice as shown in the following extract:

> 24/U *"A 24/7 on call rota is run by the hospice, this is set up responsively for end of life care with doctors from the hospice".*

For many of the participating hospices there were a combination of arrangements for accessing medical advice in order to fulfil the need for general medical advice, general palliative care advice and specialist PPM advice. This led to complex systems that were diverse in the ways in which they were configured. Some participants described two-tiered systems, for example participant 12/J explained:

> *"We have two tier on call with the consultant/medical director acting as specialist on call for end of life care and an SLA with general practice for two of the three hospices for general medical advice".*

Other respondents reported differing approaches to this two-tired on-call, as shown by the following two excerpts:

> 27/X *"A 24/7 on call rota of doctors is run by the hospice and we have an SLA with a tertiary children's hospital. This is a two-tier system, a rota by regular doctors and back up by [Tertiary children's hospital] 24/7".*

> 10/H *"There is a managed clinical network for specialist advice and each hospice has a relationship to a single general practice by an SLA for 24/7".*

For a few participants the systems for continuous medical call were three-tiered as described by respondent 22/S:

> *"There are three ways of accessing advice 24/7; specialist level three or four advice via the consultant in PPM in [Region], general OOH GP which is not that brilliant and our own GPs set up a rota for end of life care for out of hours and weekends".*

For some hospices, these systems led to inequity between patients, with specific patient groups having access to a level of specialist PPM advice that other groups were not able to access as described in the following quotation:

> 11/I *"The hospice has a SLA with a general practice or cooperative for the majority and an SLA with tertiary children's hospital. Therefore a subsection of children have [Tertiary Children's Hospital] 24/7 if under [Tertiary children's hospital's] OOH for acute symptom management".*

For a number of the hospices the multi-layered levels of advice related to a *'first on call'* system where a team of nurses provided the first layer of medical advice as explained by participant 19/P, who explained: *"we have two tiers of on call, nurses are tier one with a single point of contact. Six nurses on a rota are on call all the time. 5 – 9pm on weekdays and Friday 5pm – Monday 9am".*

A small number of the hospices reported providing a 24/7 medical advice service as detailed in the comments of the following interviewees:

> 28/Y *"There is an advice line for the region. If anyone calls, this is triaged to the most senior doctor on the team. There is one line for the children's palliative care side and one line for adult advice side. There is an honorary contract with the hospital. If asked we will give community advice but generally this is run by the community. A paediatrician or community nurse can phone about any patient".*

> 9/H *"The managed clinical network run a 24/7 rota. There is a 24/7 nurse on call rota of nurse specialists and a doctor on call rota of level three PPM doctors".*

Of the hospices with no access to formal medical advice, for one this was a deliberate decision within a nurse led service. Participant 26/W described: *"we have no access to 24/7 medical advice. There is a nurse led 24/7 on call rota of senior nurses all prescribers".* For another hospice service, participant 18/O described informal relationships with doctors, describing: *"If the child is at* *the end of life, we build up an arrangement with their GP or paediatrician and we have their mobile number".*

8.3.3 (c) *The specialist question*

A number of the participants voiced concerns in relation to the drive to a specialist model of PPM in children's hospices, demonstrated in the following excerpt:

> 1/A *" [I am] not convinced that having a PPM consultant is the only way to deliver the expertise needed. Local expertise also needs to be utilised. I'm concerned about the palliative care funding pilot and whether only level four services will have access to specialist funding".*

For some there was not seen to be a need for access to level four, specialist PPM advice, as participant 20/Q commented:

> *"[Region] has no level four advice and this has not made a huge difference. We have access to level three advice and the child's own paediatrician. It is only very rare to need level four advice. Other paediatrician's ask the level three GP for specialist advice".*

The analysis of qualitative data highlighted an area of confusion in terms of what is specialist PPM advice and who is a specialist in PPM. For some respondents, their knowledge of the levels of competency as defined by the RCPCH and APPM combined curriculum (APPM Education Subgroup and RCPCH 2015) guided their answers. For example participant 9/H reported: "*This is a person with level three in PPM who has the Cardiff diploma in PPM"* and respondent 5/E explained*: "All the GPs have a special interest in PPM. Three are level three and one works in neuro-disability and is also the medical director of a neuro-rehab unit".*

For others there was confusion around what constitutes the levels of PPM competency. For example participant 9/H appeared unsure as to the meaning of these levels saying of one of their medical team: *"this is a consultant with a background in oncology employed by the hospital trust for sessions in PPM who therefore is at level four? ".*

In line with other findings around PPM service provision, for a number of respondents nurses were considered to be part of the provision for specialist PPM. Participant 11/I stated: ***"**The on call system for specialist advice is nurses and consultant".*

Consultants in PPM were mentioned as a source of specialist advice, less frequently than other sources of advice. One examples was participant 20/Q, who stated: *"for specialist advice: If [Region] we contact [Name] consultant in PPM".*

The place of consultants in PPM in the overall scheme of the current hospice workforce is discussed further in the related main theme: *The current and developing workforce of children's hospices.*

8.3.4 (d) *Diversity in approaches to outreach*

The diversity in approaches to PPM service provision extended to the ways in which hospices provided CPC in a community setting, which for the purpose of this study has been termed 'outreach'. This diversity encompassed both the type of outreach offered and the way in which the service is configured. For some hospices this included medical outreach but for many was a combination of other types of professional support. A range of different outreach support was offered, at times within one hospice service. Some leaders of hospice care described the clinical aspects of an outreach service as typified in the following response by participant 7/G:

> *“The outreach service is led by a nurse consultant who oversees two clinical nurse specialists, one paediatric, one adult based. They have medical support and the doctors can do domicillary visits.”*

For other outreach services the psycho-social aspects of care were a focus, alongside nursing care including short-break care as demonstrated in this description of an outreach service:

> 12/J “ *There is psychosocial support from community team workers. Nursing outreach includes a hospice at home service for palliative short-breaks and can do end of life care, making up for deficiencies in children’s community nursing teams. Generalised outreach out into the real world supports preschool, short breaks and nursing needs”*

Play therapist and sibling support could also constitute the outreach service offered as described by participant 26/W, who described a service tailored to the individual child stating: *“the complexity of the child depends on who is sent home. Visits can be play support, nursing outreach or sibling support. We can also use family volunteer support workers”.*

One key approach to outreach was demonstrated by hospices that had developed an integrated service whereby staff worked flexibly across an inpatient hospice and in the community. Participant 2/B described this as an: *“integrated care service with care in the home, community respite and day care at the centre”.*

Other similar examples were given of this way of working flexibly to facilitate care in the community. Participant 26/W reported: “*A Nurse and therapist lead a team that is integrated and works across inpatient and community settings. 70 % of our work is in the community”.* This way of working was reiterated by respondent 14/L who stated:

> *“The community service is two and a half whole time equivalent nurses from the hospice in the community and any nurse in the hospice can support end of life care in the community. This gives flexibility”.*

A further key approach was of dedicated outreach services, often self-described as "*hospice at home*" as discussed by the following participants:

> 15/M *"The hospice at home service has four sites across the region with eight whole time equivalent nurses. In order to support at home we need two people at times".*

> 26/W *"All children on the case load have an allocation of hours of hospice at home a week and nights at the inpatient hospice unit. This model has been set up in response to family needs".*

One of the findings to be highlighted in the case scenario section of the results was the universal difficulty of supporting children within their own homes for care at the end of life. This is discussed in detail in Chapter Ten. This was reflected in the discussions relating to hospice outreach into the community where difficulties were recounted in medical outreach as described by participant 20/Q: *"We struggle with community patients and find out if the GP or Paediatrician will be involved".* A comment echoed by interviewee 12/J: *"It is difficult to be effective [in outreach] and we do this rarely, occasionally when requested".*

However some leaders of hospice care considered this work to be part of their overall role, as for participant 6/F who described: *"the community outreach work is considered part of the hospice work".*

There appeared to be conflicting views over the need for contracts for doctors working within the community as shown by the differing views of participant 7/G and 10/H:

> 7/G "*The medical team has no community contract".*

> 10/H *"As an NHS employer I am entitled to see patients wherever I want to therefore I don't need an honorary contract as long as I have signed an agreement to provide this type of care".*

In summary this second overarching theme of *Diversity in approaches to PPM* service provision covers the different dimensions of diversity as evidenced by data analysis. The classification of overall hospice care, outreach services and access to 24hour a day seven day a week medical advice for the hospices have been demonstrated as important aspects of these diverse models. The questions around specialist PPM; what this is and who can deliver specialist PPM as arising from the qualitative data have been discussed, highlighting the need for clarity in this area.

8.4 The current and developing workforce of children's hospices

Data from this research study gives a 'snap shot' of the workforce of children's hospices at the time of data collection and the way in which this workforce is developing. The qualitative data described in this main theme is complimentary to the presentation of quantitative data in the previous chapter. There are four subthemes within this main theme. The first three: *(a) The foundation of General Practice, (b) The nursing versus medical role: a fading distinction? and* (c) *The current workforce of children's hospices,* are closely connected and all relate to professionals working within children's hospices at the time of data collection. The final subtheme*: (d) Workforce innovations,* describes the ways in which new posts and collaborative posts were reported by leaders of hospice care to be developing across the UK.

8.4.1 (a) *The foundation of General Practice*

One of the key elements in the diversity of approaches to medical service provision was the variation in numbers of doctors working in the hospices, the hours they worked and their level of specialism. One of the most striking findings in both quantitative and qualitative data analysis is the predominance of GPs in the hospice workforce.

When asked to describe the medical service provision for their hospice, leaders of care almost without exception described an aspect of the hospice medical cover being provided by a general practice or GPs. For many, this was a formal link with a general practice as stated by participant 2/B: ***"****The hospice has a link with a local general practice, it is a three man GP surgery and one of the GPs works for the hospice and is very dedicated".* Or as respondent 11/I explained: *"Two General Practices provide dedicated daily sessions".*

For others this involved the employment of one or a team of GPs. Many had undertaken a specialist level of training in PPM to develop a special interest as described by participant 5/E:

> *"There is a medical director of GP background who is a lead for the development of PPM nationally. He works with three local GPs who have a special interest. These doctors have set up a company and have an SLA with the hospice to provide the medical care".*

The following participant outlined a similar approach:

> 20/Q *"[Hospice] have a lead medical officer, a GP who has been working with them for 17yrs. He has diploma in PPM. There is a deputy GP. They provide their own rota for end of life care. All other OOH care is from a GP cooperative".*

In other situations GPs worked within a team of doctors of varying professional backgrounds as reported by participant 4/D: "*There is a team of doctors, a GP with Special interest, other GPs, a Paediatrician working with a multi-professional team with a daily doctor's sessions".*

And in some instances the arrangement was for the children at an inpatient hospice to become temporary residents at a local General Practice as respondent 6/F explained:

> *"For the group of children who do not come under the remit of the medical director they are temporary residents at a local General Practice but if their situation changes they can be referred to the medical director."*

8.4.2 (b) *The nursing versus medical role: A fading distinction?*

In terms of the hospice workforce there was a notable finding in that the nursing and medical roles appeared to be becoming less distinct. Questions regarding medical care were answered in relation to nursing roles and the medical service provision was shown to be dependent in many cases on nurses. In some instances the nursing roles had replaced doctors' roles and there was a deliberate decision not to have traditional medical cover.

Nurses with specialist training provided an important component of care within many of the hospices in the study, as described by participant 27/X: "*There is a children's nursing specialist team and supportive care team".* One participant (5/E) described these nurses as "*integral" outlining their work:*

> "*Integral to the team are two clinical nurse specialists; one in palliative care who is piloting nursing outreach working with a community nurse specialist, the other is a respiratory nurse specialist".*

These nurse specialists were further reported to provide advice to doctors thereby enabling an enhanced service to be offered in the way described in the following excerpt:

> 5/E *"The respiratory nurse specialist advises doctors on this need. It has taken five years to be at a stage where a long term ventilation child could be accepted to stay at the hospice within 24 hours".*

Whereas the nature of the specialist training was not obvious from the majority of responses, participant 11/I described the way in which the nurses had developed their specialist skills:

> "*The PPM consultant works closely with two experienced PPM specialist nurses. Specialist symptom care nurses have developed a set of skills through in house training from the consultant in PPM".*

Nurse consultant posts were being developed at many hospices or were seen as an approach to developing the medical cover. For example as participant 18/O suggested: *“a nurse consultant might be a way forward”.* Several interviewees described the role of their nurse consultants as represented in the following comments:

> 7/G “*The outreach service is led by a nurse consultant, who oversees two clinical nurse specialists, one paediatric, one adult based”.*

> 26/W “*Clinical [care is] led by the nurse consultant. The nurse consultant will liaise with the consultant paediatrician but it is rare to call them”.*

Nurses were reported to be taking on roles that have traditionally been viewed as medical. This included prescribing as detailed by participant 26/W: “*There is a senior nurse on call rota 24/7 on which all the nurses are prescribers”* and by participant 11/I, stating*:* “*One [nurse] has an oncology background, assessment of child training and independent prescriber qualifications*”.

A PPM review of children was also reported by some leaders of care as being a nurse led role. For example respondent 7/G sited this as a nurse consultants remit, explaining: “*The nurse consultant has an honorary contract with hospitals. The specialist PPM review is done with support of the [hospice] medical team”.* The following respondent considered the general PPM as predominantly the role of nurses, describing:

> “*But this system [GP cover] is rarely used by nurses. Estimated use of on call is once a month. Although general issues would wait for the sessional doctor, the general PPM is nurse led”.*

A further extended role of writing advance care plans was discussed by 8/G: “ *[We are] encouraging senior nurses to be involved in writing advance care plans but it is still a requirement that doctors sign them*”.

8.4.3 (c) *The current workforce of children's hospices*

One complicating factor leading to such diversity in medical service provision was the ad hoc way in which the medical teams within hospices had developed. This resulted in multiple configurations of medical professionals where no two services were alike. The medical teams encompassed varying numbers of doctors, from a variety of professional backgrounds, with varying levels of specialist training, working a range of regular and on call hours. The following participant commented on their medical team that represents the configuration with the highest level of medical cover in terms of both specialist input and doctor hours:

> 7/G *"The team is a mixture of GPs and paediatricians. Regular clinical sessions are; consultant PPM: (six and a half sessions), consultant PM (six sessions), level four doctor with research interest (six hours), consultant PPM (six hours), oncology staff grade (six hours), adult PM consultant (eighteen hours), GP with special interest (twenty four hours) and a registrar from PICU [Paediatric intensive care]".*

At the other end of the scale the smallest medical teams comprised of just two doctors as described by interviewee 26/W: "*Two doctors work one and a half days at the hospice.* One *a GP and one a consultant paediatrician."* In contrast, participant 11/I demonstrated that having a number of doctors working at a hospice does not always constitute a *medical team: "there is a contract with a consultant in PPM, who links in with the GPs but they could not be described as a team".*

The interview data demonstrated variability in the access hospices had to consultants in PPM, both for PPM advice and as part of the established medical service provision. In some areas there was no such post within the region as described by participant 1/A: **"***in terms of a level four consultant in PPM there is not one in the region but there is access to [hospice] consultants if needed".*

Other hospices had employed a consultant in PPM who could act as a resource for local hospitals as described by respondent 15/M: "*There is a consultant in*

PPM full time across two hospices. Currently we have funding for two part time consultant PPM posts to work across hospital and hospice."

In other hospices this situation worked in reverse with the hospital employing the consultant in PPM who then had an arrangement to work within the hospice. Participant 13/K described this arrangement:

> "A consultant in PPM is employed by [hospital] with an SLA to [hospice]. The consultant is only on call through the hospice and works half time in each setting".

A similar approach was reported in the following excerpts:

> 6/F **"***The hospital employs the PPM* consultant *and has an SLA with the hospice. The consultant post had college approval as a PPM post".*

> 14/L "*The consultant in PPM paid for by [Hospital Trust] but has a contract with hospice".*

In line with the increasing upper age of children supported by children's hospices as confirmed in the quantitative analysis in the previous chapter, participants reported seeking the expertise of doctors with training in adult palliative medicine. This was planned by respondent 13/K**:** " *We are looking to appoint a consultant in adult palliative medicine to work across [children's and young adults' hospice]".* An approach already reported to be in place by participant 7/G who explained: "*An adult palliative medicine consultant leads [hospice] and a PPM consultant leads [hospice]".*

In discussions relating to the medical teams it was evident that other allied professions were considered key to effective hospice care and were an increasing part of the hospice workforce at the time of data collection. This includes therapists as participant 13/K reported: *"we have an in house physiotherapist now two days a week".*

Psychological support was also part of care offered. Respondent 14/L explained: *“we have a part time psychologist who gives holistic support and is a vital part of the team”.* This need for psychological support was described by respondent 25/V who reported: “*a counselling service has a link with every school. Both for group work and formal one to one”.*

8.4.4 (d) *Workforce innovations*

A number of the hospices reported reviewing and developing their medical cover (4/D, 6/F). This subtheme relates to the main theme: *Developing the delivery of children’s hospice care* described subsequently. These developments relate to recruitment to new posts and reconfiguration of existing posts as reported in the following extracts:

> 2/B **“***At present we have recruited two planned sessions from a paediatric oncology consultant and a community paediatrician may also work two sessions”.*
>
> 17/N ***“****The post of medical director is being developed. The organisation are planning to have one medical lead across the whole organisation to cover three inpatient hospices”*

A new approach being explored by hospices was the utilisation of trainee doctors in paediatrics and in general practice as described by participant 3/C: “*We plan to offer a training opportunity for a paediatric SpR [Specialist Registrar] to develop a special interest in PPM. The plan is to pilot this for a year*”. These types of posts were seen as benefitting the hospices and the trainees who gained exposure to and experience in PPM as outlined in the following excerpt:

> 27/X **“***A new model being developed is a six month placement for trainee paediatricians full time (off placement), they are supported by a paediatrician. This doctor has a range of experiences and has induction by the lead GP. This helps to give safety on the unit. We needed*

> *someone who can recognise an acute episode, one has been a trainee GP, the other two have been paediatric trainees".*

Leaders of hospice care reported numerous examples of the creation of new nursing posts, for example: *"Diana children's nurses" (15/M)* and the appointment of nurses with specific skills as described by participant 3/C*:* "*we recently appointed a nurse with an A and E background."*

The areas of transition and neonates were a specific focus for new posts as reported by interviewee 15/M: **"** *we are developing neonatal palliative care fellows"* and participant 20/Q who explained:

> " *We have a lead nurse in transition who is working with adult services. 18 months ago we appointed a lead nurse for neonates who is building relationships with NICU as neonatal services have developed".*

This targeting of specific groups of children with key posts is further discussed in the later main theme: *Developing the delivery of children's hospice care.* In the development of new posts, collaboration between organisations enabled a double-benefit in both workplaces in terms of improved joint working and sharing of palliative care expertise. This was demonstrated between hospices and NHS trusts as described in the following interview extracts:

> 1/A "*One of the key components of the service is the development of two NHS posts in the children's community nursing team funded by the hospice service but contracted with the NHS and titled with the hospice service name. This enables a collaboration with NHS intrinsic to the service design".*

> 2/B **"** *We are trying to create a joint post [medical lead] with hospital and hospice in order to replace the one GP who has been doing 24/7 cover for many years and will be coming up to retirement".*

> 16/M " *We are about to recruit two consultants in PPM full time equivalent part funded by [Hospice],* part *funded by the NHS. Nurse*

> *consultants are employed by the hospice organisation and are part based in the NHS".*

Where the posts were not formally linked, there was reported to be effective collaboration by professionals working across two settings as discussed by participant 24/U:

"*Doctors have a dual role but not a formal hospice role for in reach into hospital. We don't have formal in reach or outreach but this is achieved in practice by having a role in hospital or community in [the doctor's] main post".*

Participant 5/E explained how a nurse working in two settings enabled specific skills to be brought to the hospice team:

> "*This nurse was previously an ITU sister from a local hospital able to stay on the bank for shifts in ITU. We now have a "vent team", it took time to train up half the nurses to be fully competent".*

In summary the main theme: *The current and developing workforce of children's hospice care,* demonstrates important findings regarding the hospice workforce at the time of data collection. In particular *The Foundation of General Practice* compliments the quantitative data previously presented and shows how links to general practices and the work of GPs are predominant in children's hospice care. *The nursing versus medical role: a fading distinction?* demonstrates the ways in which nursing and medical roles appear to be becoming less distinct. *The current workforce of children's hospices* described the workforce at the point of data collection and *Workforce innovations* explored the proliferation of new posts and collaborative posts.

8.5 Relationships between services and professionals

Part of the dynamic in the development of hospice services and the difficulty in obtaining an accurate picture of the overall pattern of services at the point of data collection, was that the way in which the hospices worked was becoming increasingly interconnected. These relationships were formed on all levels from organisational structures to individual professionals and fall within three subthemes: (a) *Formal arrangements between services*, (b) *Relationships between professionals* and (c) *In reach from hospice to hospital.*

8.5.1 (a) *Formal arrangements between services*

This subtheme demonstrates the way in which the participating hospice services had developed agreements, predominantly SLAs, to deliver care. This theme also delineates the use of operational pathways and formal systems for communication regarding patient care. These formal arrangements between services cover a variety of aspects of hospice service delivery and as can be seen in this respondent’s comments can benefit both partners, improving confidence in joint working:

> 19/P “*The SLA with [hospice] covers all children on the case load. This has been in place since 2010 and makes a massive difference. Previously there was informal support. The SLA [Between hospice at home nursing service and hospice] has given confidence to nurses having specialist doctors to contact. This has worked both ways as the doctors have also increased in confidence in the nurses’ ability”.*

In some cases an SLA was reported to be in relation to one specific post as in this example:

> 9/H *“There is a formal arrangement for the medical director support delivered by one consultant community Paediatrician with local community services with an SLA to the hospice organisation”.*

Alternatively it could be a solution to the provision of access to specialist advice out of usual working hours as participant 11/I explained: “there is an *SLA with [Tertiary children’s hospital] for OOH telephone support for the children under [Tertiary children’s hospital]”* As demonstrated in the following comment by participant 23/T, an SLA would usually involve a financial component: “*we have* *a contract with [Tertiary Children's Hospital]. The SLA is £11,000 for 24/7 advice on symptom control".*

On a practical level the agreement of formal pathways for aspects of palliative care where multiple services, both NHS and hospice services were involved enabled a more coordinated service overall. In one example this related to transfer between hospital acute services and a hospice as interviewee 10/H described: "*there is* a *pathway for rapid transfer from PICU and NICU [Neonatal intensive care unit]".* These pathways could be part of a commissioned arrangement as reported in the following quotation:

> 28/Y " *We have a pathway and coordinator for referrals from day one and* pathway *for end of life care which is a commissioned pathway".*

Strategies to formalise the liaison between services and communication on an individual level were commented on by a few participants. For example respondent 17/N stated: "*We are planning to attend community nursing meetings*" and participant 26/W described: *"We are developing a children's multi disciplinary team meeting to discuss all palliative children".*

8.5.2 (b) *Relationships between professionals*

In addition to the links between services, the way in which boundaries were delineated was reported to be of importance. This was true both at a service and an individual professional level. As stated by participant 12/J: "*there is a need for professional boundaries".* In view of the number of doctors a child with palliative care needs may be seen by, the issue of medical leadership was stated to be of paramount importance. The practical outworking of this leadership was discussed in the following excerpt:

> 9/H "*There is a principle within the team that each child has a lead consultant and it is their patient, we provide palliative care input for them under the lead consultant. This is part of the organisational boundaries*

> *and governance. For end of life plans the clinical accountability is with the lead consultant".*

This clarity is achieved by some hospices with clear professional boundaries from the point of referral of a child or young person:

> 6/F "*There are clear boundaries around referral to the medical caseload. Letters are written to the consultant when the patient is seen. The referrals to the hospice are from consultant paediatricians, they can also be from GPs but are generally from consultants".*

This formal approach to professional boundaries was seen by participant 6/F to be an enabler of trust: "*consultants are very protective of their patients and therefore we need to build trust".* Other approaches to clarity in medical leadership included involving the lead NHS Consultant in the hospice care as participant 9/H explained: "*we work closely with the child's own consultant and if there are complexities most consultants will come out to the hospice"*.
Formal shared care arrangements were also reported as a way to provide clear boundaries, as described by respondent 23/T: "*the specialist clinic has a shared care list with [Tertiary Children's Hospital]".*

In addition, the building of good working relationships where there was a shared understanding of the roles of each professional and service was seen to be important, demonstrated in the following responses:

> 6/F **"***It has needed hard work to get all previous services working together. Relationships are important: the key to the success of this post was that this [respondent] was known well in the area ".*

> 10/H *"We do not have formal agreements with hospitals but good relationships based on positive outcomes. We've done good stuff together".*

Several leaders of hospice care commented on the importance of communication as reported by respondent 5/E: "*good lines of communication* *have been set up between nurses and doctors". Participant 10/H* described the way this communication was achieved between the medical team: "*the doctors use nhs.net as a way of documenting and communicating about patients. This enables updates on decision making to be documented. There is a need for joint decision making and documenting*".

8.5.3 (c) *In-reach from hospice to hospital*

The leaders of hospice care described a range of ways in which the hospice services worked with NHS services. For some, this was in terms of building relationships and for others in the form of honorary contracts for agreed aspects of clinical work. For the purposes of this study the '*in-reach*' described, relates to hospice professionals working within hospital settings and with NHS professionals. The outreach role of hospices working in the community was described in the earlier subtheme: *Diversity in approaches to outreach.* Participant 1/A described this in-reach role as based on relationships: **"***The hospice service aims to work directly with NHS Paediatricians. The model described works well in [Area] with a good relationship with the local hospital".* Whilst interviewee 7/G stated: "*The nurse consultant has an honorary contract with hospitals"* as the basis for the in-reach work. It is of note that these formal agreements to provide a service did not always, or indeed often, come with funding. As participant 15/M reported, **"***There is in reach into [hospital] and we have three honorary contracts but they are not NHS funded".*

There were key aspects of a child's journey described where the in reach work of a hospice medical team became more important. For example as described by participant 12/J: "*the hospice is becoming more involved in decision making in hospital discharges for end of life care".* In other instances the hospice service was reported to take a role in practical aspects of care or to give advice as participant 14/L described: *"We could be rung about a syringe driver during end of life care by the hospital".* Other participants spoke of an increased role for hospice services in giving telephone advice to professionals:

> 16/M "*We take an increasing number of calls about children not known to the hospice, more for children who don't want referral to hospice but where professionals want to ask advice".*

Some participants described in-reach into hospitals as led by other members of the hospice team, in particular nurses. For example respondent 20/Q said: "*This is not medical in reach. The lead nurses for neonates and transition do nursing in-reach and outreach". A response reiterated by participant 26/W: "The neonatal nurse coordinator attends the neonatal ward rounds. The nurses are leading the in reach".*

Although less frequent the reverse approach was also mentioned where the design was intentionally for hospital doctors to support hospices with in-reach arrangements as described by participant 22/S:

> "*There are three general hospitals in [Region], with one consultant with a special interest in PPM in each area. The set up is for consultant paediatricians with a special interest in general hospitals to provide outreach from hospital to the hospice".*

In summary the main theme *Relationships between services and professionals* covers the ways in which hospice services inter-relate as part of *Formal Arrangements between services,* demonstrating this at an organisational level and as part of operational pathways for delivery of care. *Relationships between professionals* have been described with the boundaries in leadership of care as an important finding from the data contrasting to partnership working. Finally the relationship between hospices and the NHS have been discussed in terms of *in-reach from hospice to hospital*.

8.6 Developing the delivery of children's hospice care

In response to the changing demographic of babies, children and young adults receiving hospice care and the increased complexity of care needs, hospices across the UK were found to be developing the effectiveness of the care provided. These developments related to the workforce as earlier described in the main theme: *The current and developing workforce of children's hospices* and to the way in which services were provided, to the facilities used and the provision of education and training.

This main theme: *Developing the delivery of children's hospice care* is described under five sub headings representing a wealth of data in relation to survey schedule questions regarding hospice developments at the time of data collection. The sub theme (a) *Innovations in hospice services* describes a number of new approaches to medical aspects of hospice care evident from the data. Subtheme (b) *Developing facilities* describes the responses relating mainly to building developments. Many of the interviewees discussed their plans for (c) *Developments in outreach* discussed in the eponymous subtheme. Subtheme (d) *Developments in research and education* were mentioned by a minority of respondents but have been included in view of the importance of research as a priority in children's hospice care. The final subtheme: (e) *From strategy to change* describe how developments were approached and accomplished.

8.6.1 (a) *Innovations in hospice services*

Findings from the study, identified innovations aimed at improving accessibility for families, without them having come to the point of acceptance normally required for a referral to the hospice. Participant 1/A described this in relation to a community nursing post, stating: "*it also makes the service more accessible to families not ready for a hospice via the introduction of a community nurse".*

Another hospice leader described referral through allied support services as improving the timing of referrals in children with cancer:

> 20/Q "From *oncology we previously had last minute end of life referrals. We have developed links with the oncology team. Now most children are referred through the counselling service and sibling support".*

The provision of clinics was a key area of development in many of the hospices. These were run predominantly in inpatient hospice buildings but could also be home-based reviews. The pattern of diversity was evident in their design, ranging from consultant PPM reviews within MDT clinics, as discussed by participant 23/T:

> “[Tertiary Hospital] *consultant in PPM runs a clinic with a social worker, a physiotherapist and a specialist nurse, who is a nurse prescriber.* [Tertiary Hospital] *consultants in PPM cover different sides of* [region] *At clinic we see four children in a day”.*

To nurse led clinics as reported by respondent 13/K: “*Two nurses are based at [hospice], to see the complex children, this is not for respite, they see the children a week prior to admission” and participant 26/W who said:* “*We are developing day support and nurse led clinics”.*

Several regional hospice services taking part in this study spoke of their aspiration to run 24/7 specialist telephone advice services to meet this requirement. As participant 21/K reported: *“it is our aspiration to run 24/7 advice with access for the whole of [Region] for medical advice”.* The following quotation links provision of proactive telephone advice with sustainability:

> 2/B *“We are planning for a sustainable model of medical cover for the future with 50% GP and 50% sessions with proactive telephone advice”.*

In line with the total approach of CPC many of the developments in delivery of care were in relation to the holistic care of children and families. This included social care, as described by participant 19/P: “*Our developments include consideration of social support for young adults”.* The use of alternative therapies, as cited by respondent *23/T: “We are developing a holistic centre for yoga and music”* and support for siblings as participant 22/S stated: *“We are increasing our sibling work”.*

A focus on children with specific conditions was evident. This relates to the findings in the earlier section on *workforce innovations.* This approach was commented on in particular in relation to neonates with palliative care needs and children with cancer as demonstrated in the 7/G's comment: "*Populations of children in NICU and oncology are being targeted".* Participant 15/M outlined a similar strategy:

> "*We are working on a neonatal pilot learning from early cases and to enhance care within terminal care for children with cancer. We have a pilot with paediatric oncology".*

Participant 14/L commented on a development for a specific group of young adults as they undergo transition, describing: "*we aim to support DMD [Duchenne Muscular Dystrophy] young adults, to involve adult rehab and to get them into employment. We are setting up day care for young adults 17 – 25 years jointly with the local adult hospice".*

For several hospices the key aim as for respondent 29/Z was *"expanding referral criteria"* to enable a wider provision of palliative care. An aspiration was shared by the following participants:

> 18/O "*We are increasing the referral area to cover new CCG's".*
>
> 19/P "*We are expanding the catchment area in line with adult service".*

8.6.2 (b) *Developing facilities*

The building of new facilities was reported as a focus for several leaders of hospice care. For example participant 1/A explained: "*A build for an inpatient unit is in progress and registered with CQC for an inpatient unit and community hospice care".* For some participants these building projects were expansions of existing services as described by participant 3/C: "*We are developing a second hospice base, with four beds. We are currently offering only day care but overnight stays are planned*". For others these developments were to refurbish existing provision as mentioned by respondent 13/K: "*The children's hospice unit is currently being refurbished".*

In some of these developments a response to the need for bespoke facilities for young adults was evident. For example participant 19/P referred to a "*Refurbishment of the adult day hospice",* whilst participant 28/Y described*:*
"*we are looking to develop a young adult stand alone unit. Currently young adults are in the same space [as children]".*

8.6.3 (c) *Developments in outreach services*

Leaders of hospice care frequently commented on the provision of hospice services within the community as a priority for development as described by participant 7/G: "*The outreach service in its current form has only been running for two years. It is actively being developed".* Participant 25/V similarly explained: *"We are looking at the hospice at home service. At the current time it is for end of life palliative care only. We are looking at developing day and night visits".*

However it appeared that these developments were made hesitantly, with initial pilots and taking time for a service to progress. Participant 5/E discussed one such a project:" *We are just about to pilot an outreach service for nursing and planning for medical outreach".* Whilst interviewee 13/K described the beginnings of their outreach service saying: "*The community service is fledgling. Nurses and carers are based at [Hospice service] to cover [County]".*

8.6.4 (d) *Developments in research and education*

The need for research to guide development in CPC is well recognised but was mentioned by only a small number of participants. One hospice leader (15/M) spoke of a strong commitment to research: "*We are increasingly involved in research by [University] under [lead researcher] aiming to find out the number of children and young people with palliative care needs in [Region] and where are they. The [University] work identified 4000 under 25 yr olds"*

The requirement for revalidation was seen to be impacting upon the choice doctors make in employment in a few of the participants responses. A route for revalidation via an NHS trust was mentioned respondent 13/K as key to the success of a Consultant PPM post: “*Revalidation is much easier with the employment through an NHS trust and includes whole practice appraisal”.*

8.6.5 (e) *From strategy to change*

In planning for change the importance of a strategic approach was discussed by respondents. One interviewee had overseen a significant change of direction in the ethos of hospice care provided. This quotation stood out as an insight into a process of intentional transition:

> 27/X “ *Three years ago I would argue that we weren’t even delivering palliative care let alone specialist palliative care. Previously we were a respite unit. Now [respondent is] in post we made a decision not to be a respite unit for complex neuro-disability and we transitioned from respite to palliative care. This came out of strategy. We had to turn down commissioned work and transitioned children. We had to skill up staff. This was a painful process but the right process. We had to work on all departments”.*

The use of a palliative care strategy for a region as a driver for change was reported by participant 3/C:

> “ *We are actively trying to change the current situation where there is no specialist PPM input. This is by the publication of a [region] children’s palliative care strategy and appointment of a consultant in PPM”.*

It is of note that the word “*pilot”* was frequently used in relation to developing the delivery of care. This may relate to caution in terms of sustainability, or to a lack of knowledge and a limited research base to give evidence as to which approaches are best. The difficulties in measuring outcomes in CPC and a lack of agreed outcome measures compound these limitations. The following responses relate to developments where a pilot was being used as a first stage:

> 3/C *“We plan to offer a training opportunity for a paediatric SpR to develop a special interest in PPM. The plan is to pilot this for a year”.*

26/W "*We are looking for funding to pilot a children's register".*

In summary the main theme: *Developing the delivery of children's hospice care,* encompasses five subthemes: *Innovations in hospice services*, demonstrated a wide range of ways in which leaders of hospice care reported developing the delivery of their hospice services. Subthemes *Developing facilities and Developing outreach services* were straightforward discussions of development plans for these areas. Whilst *From strategy to change* described aspects of the way in which changes to service delivery were planned and executed.

8.7 Challenges facing medical service provision

This study highlighted a number of challenges facing the medical provision and future development of hospice services at the time of data collection. These are in addition to the challenge presented by increasing need for such services due to rising prevalence of life-limited children and the increasing complexity of care. This main theme is composed of five subthemes that give evidence of the variety of challenges faced as arising from the survey data.

The first subtheme: (a) *Sustainability* is a major factor and relates to unsustainable arrangements for 24hour a day, seven day a week medical cover and the linked issue of a history of good will work patterns. Secondly the subtheme: (b) *Variable workload* outlines the challenge of a need for responsive doctor hours in hospices that was particularly evident during the care of a child at the end of life. In the third sub theme: (c) *Workforce challenges,* the wide range of issues evident from the thematic analysis is discussed. Final subthemes relate to: (d) *Medical cover that is not fit for purpose;* describing the ways in which respondents voiced frustrations over medical service provision within their hospices and (e) *Financial challenges,* referring to the unique funding of hospice services.

8.7.1 (a) *Sustainability*

Responses from leaders of hospice care demonstrated multiple examples where the 24/7 medical provision for hospices was provided by one or two doctors and was therefore unsustainable and unable to respond to increased or unexpected medical needs. A number of example responses have been included as follows to demonstrate the strength of this finding:

> 15/M "*For 24/7 cover two of the doctors provide cover 95% of the time".*
>
> 16/M "*Only two doctors are providing the cover".*
>
> 21/R *"We have 24/7 cover but this is one person therefore not sustainable 24/7".*
>
> 2/B "*There is 168 telephone availability but this is one person and not available when s/he is on holiday or off sick".*
>
> 6/F *" The medical director is 24/7 for hospice "palliative care" patients"*.
>
> 12/J "*The medical director works four full days and provides 24/7 cover when in the country".*
>
> 21/R *"The lead GP is always available 24/7".*

The phrase "goodwill" was used by several of the participants to express the working patterns of doctors who provided far more in terms of a medical service than was formally contracted or funded. As participant 11/I stated:
"*The system relies on the good will of one person".* A response repeated by respondent 1/A:

> "For *24/7 there is a dilemma in answering as the one doctor employed for a two hour contract can be contacted 24/7 but this is not a formal part of the role and is good will".*

For one of the respondents, 6/F at the time of interview, the researcher made the observation "*what is delivered is far more than the SLA for the hospice medical cover".* This goodwill working was also demonstrated in the unfunded in reach work discussed in the earlier subtheme: *In-reach from hospice to hospital.*

8.7.2 (b) *Variable workload*

Findings indicate that many doctors working in hospices at the time of data collection worked responsively. This was demonstrated in the quantitative findings in the previous chapter and confirmed in the qualitative analysis. As participant 5/E described: "*the GP is responsive to need and will be in house many more hours if needed".* This responsive work was echoed in participant 10/H's comment: "*The consultant in PPM gives responsive input"* and discussed by respondent 21/R, who said: "*the doctors regular hours are eight and a half hours but they are responsive to need".*

For some hospices, responses seemed to allude to a lack of need for medical service provision. Participant 23/T stated: "*There are no average hours, the doctors provide a responsive service but we have months of not seeing them".* This limited need was confirmed by respondent 26/W who reported: "*There are no fixed hours, the doctors are available but have full time jobs in other places and are only occasionally needed".*

One of the main reasons cited for responsive hours was the increased medical service provision during care for a child at the end of their life. This was discussed as part of the subtheme: *Diversity in approaches to 24/7 medical advice*, and relates to the challenge posed by a variable workload. As participant 2/B outlined: "the *doctors hours are variable depending on if there is end of life care at the hospice. For end of life care one hour a day is needed and therefore seven hours a week. If there is no end of life care they do pop in visits".*

Comments made in relation to the medical care given for a dying child gave an indication of the aspects of this care in which doctors take a key role. For example, communication with families around advance care plans was referenced by 20/Q as a reason for longer hours:

> "*The doctors hours are erratic; some days half an hour, for end of life care, two to three hours a day, for example to speak about an ACP [advance care plan]. The doctors hours are responsive for end of life care and symptom control".*

8.7.3 (c) *Workforce challenges*

Leaders of hospice care reported on a number of challenges in recruiting, training and equipping the hospice teams, both medical and nursing. In particular this was in relation to knowledge and skills concerning new types of equipment and new interventions. For example participant 15/M commented: "*Keeping up with new equipment is a challenge, for example: gastrostomies and masks".* For respondent 9/H this challenge was linked to a specific intervention, as described: "*It is very difficult to do haemodialysis with respect to governance, competencies are difficult to maintain".* Participant 5/E discussed a further factor in maintaining skills, as follows:

> "*We have difficulty with maintaining competency and keeping up to date… Barriers to up-skilling the team have been the catch 22 of no ventilated patients therefore we are not able to develop skills therefore we have no ventilated patients".*

These difficulties were reported to be compounded in rural settings where access to the training opportunities in a local hospital were not available, as participant 22/S explained: "*we have the challenge of keeping staff up skilled in a rural and large area in comparison to a hospice near a tertiary children's hospital. The workload is variable and the skills needed are variable".*

Increased complexity of care needs was reported by several leaders of care to result in a need for increased staffing ratios. Participant 4/D described: "*in children with challenging behaviour there is an increased staffing need for 2:1* *care. This is compounded in children who also have complex health care needs".* This links to the subtheme described earlier: *increased complexity of conditions* described within the main theme: *Increasing complexity of care needs.* The phrase "*challenging behaviours"* was mentioned by a number of other respondents as a factor in the need for increased staff ratios, as in the comments by participant 24/U: "*Challenging behaviours lead to significant training needed for restraint. And a need for two to one staff".*

Responses demonstrated that many of the doctors working in hospices were at risk of professional isolation. This resulted in doctors calling colleagues from across the UK in order to access specialist PPM advice and peer review as reported by participant 15/M: "*Sometimes I need to call on national colleagues for advice*" and respondent 13/K: " *the consultant in PPM can call other specialists nationally, for example: [Tertiary Children's Hospital]".*

A number of leaders of hospice care voiced frustration that having developed and funded a post within the hospice, either medical or nursing, it was not possible to recruit to the post or to encourage existing team members to develop their skills. This was epitomised in the following response:

> 2/B "*We have been trying to recruit a medical lead for the past three years, trying to create a joint post with hospital and hospice in order to replace the one GP who has been doing 24/7 cover for many years and will be coming up to retirement. We considered having a nurse consultant in the medical development plan but none of the nurses have the aspiration to develop in this way. This has been one of the problems in development, a lack of staff desire to develop skills*".

A shortage in the nursing workforce was demonstrated as impacting on the potential to deliver palliative care. Participant 9/H described the impact of these staffing shortages in practical terms: "*We have three hospices with 17 beds overall, not all funded as the nursing establishment is not big enough overall therefore we only have eleven to twelve beds in use".* This challenge in terms of the hospice's capacity was also stated by respondent 2/B who said: **"***It has an* *eight bed inpatient unit but is only running five beds currently in view of staff shortages".*

The additional issue of a limited number of training posts as a workforce challenge was reflected in the following comments of participant 3/C: "*We have no consultant in PPM in [Region] and no specialist registrar training posts so it is difficult for interested registrars to develop a special interest*".

8.7.4 (d) *Medical cover that is "Not fit for purpose"*

A significant challenge identified through the analysis related to difficulties with arrangements within hospices for medical service provision at the time of data collection. For participant 3/C the following excerpts relay the frustrations in relation to these concerns:

> *"What is contracted is not what is delivered. GPs are contracted for a full four-hour session but in practice they are edgy if they are needed at the hospice for over an hour and a half. We have an SLA with seven GPs and one GP employed. The employed GP is part of a historical arrangement that does not work well and therefore is being phased out".*

> "*The current medical model does not serve us well… We need someone bringing something to the table, we have to lead the GPs 99% of the time and they are not proactive. We find in terms of the medical model that we can't actively offer as much symptom management as we want to*".

Other participants shared these views, using the interview process as an opportunity to voice frustrations. For example participant 9/H stated bluntly: "*GPs are responsive except for a one hour session in one hospice, this is a waste of time".* A view shared by respondent 10/H: "*The GPs do not feel specialist, they do not understand the need to share the uncertainty and accountability".* The consequences of this inadequate provision were evident in participant 24/U's comment:

> “*The out of hours GP service for other hours is rarely used. If a child needed a medical review at 4pm we would need to send them into hospital for medical review”.*

For one hospice leader (20/Q), where services had been developed to deliver specialist PPM there were frustrations that there was no “capacity” built into this design:

> *“There are different issues in [Region], the local provision is different. There are three lead paediatricians [for children’s palliative] care in [Region] but they have no capacity”.*

8.7.5 (e) *Financial challenges*

Investigating the financial arrangements for the funding of children’s hospice care was not a specific focus in the aims of the study. However a number of participants alluded to the challenges of the charitable aspect of hospice provision. As respondent 12/J stated: “*they need to decide that that NHS will properly invest in children’s hospice care or not”.*

Participant 28/Y outlined the funding arrangements for the hospice as follows:

> “The *adult service is completely charitable. The funding arrangements for all 0 – 18yr olds are 50/50 health and social care funded for 30% costs and 70% costs charity funded”.*

Responses highlighted the impact of funding as both an enabler and barrier to medical service provision. One leader of hospice care (13/K) commented on the joint funding of a new post stating: “*Financially the consultant PPM post is a joint arrangement but NHS has ownership of the post”.* Another participant (29/Z) used the limitation of funding as a rationale of the lack of medical service provision, stating: “*currently the best use of our financial resource is to put money into care rather than medical cover”.*

In summary the final main theme *Challenges facing medical service provision within hospices* demonstrated the factors arising from thematic analysis of the data that oppose the development of PPM service provision within hospices. *Sustainability* was a major challenge apparent from the data. The *Variable workload* for children's hospices and reasons for this arising from the survey responses were discussed. Finally the examples of where *Medical cover is not fit for purpose* and *Financial challenges* were presented.

8.8 Chapter summary

The detailed qualitative analysis findings presented in this chapter give a picture of the changing population of children receiving hospice care within the overarching theme: *Increasing complexity of care needs.* Alongside this the diverse ways in which hospices represented in the study provide medical care to these children have been discussed in the second overarching theme; *Diversity in approaches to PPM service provision.* Underlying these two overarching themes, three main themes have given further substance to aspects of the medical provision within children's hospices: *The current and developing workforce,* explored in more depth the configuration of professionals working in hospices, *Relationships between services and professionals,* described the way in which the hospices themselves and NHS services interrelate and *Developing the delivery of children's hospice care* presented a proliferation of new approaches and innovations in children's hospice care. The final main theme *Challenges facing medical service provision* outlined findings in relation to factors that challenge and at times oppose the effective delivery of medical care within children's hospices. The following chapter integrates this qualitative analysis with the quantitative analysis in order to define and classify the approaches to PPM service provision within children's hospices across the UK.

9 Approaches to PPM service provision in children's and young adults' hospices: development of a classification

9.1 Chapter introduction

The first aim of the research presented in this thesis was to describe and classify existing approaches to PPM service provision in children's and young adults' hospices across the UK. This chapter describes the way in which data have been integrated to develop a classification of approaches to PPM service provision within children's and young adults' hospices. The definitions of the identified approaches and the data by which they have been classified are discussed. A geographic-specialist classification as the main classification is outlined and contrasted to alternative classifications based on 'outlier approaches'. The complexity of this process of classification within a diverse population of hospices is explored, including challenges in defining what it is to be a specialist hospice.

9.2 Defining the approaches to PPM service provision

9.2.1 Geographic-specialist classification

Following analysis and in line with the mixed methods convergent study design, quantitative and qualitative findings were integrated to describe differing approaches to PPM service provision. The main approaches have been defined at the intersection of geographic considerations and considerations based on the level of specialist PPM service provision. A further process of integration then classified these approaches to PPM service provision using quantitative and qualitative data. In terms of the geographic classification, qualitative data relating to the sub theme of: *Defining the overall hospice classification* (Chapter Eight) was used as this was the predominant way in which respondents described the hospices they represented. Quantitative data on referral area, size of case load, number of in-patient hospice units, number of outreach services and relationships to NHS services were combined to give a picture of regional versus local children's hospice services. A process was followed by which these data were collated for all participating hospices and then reviewed in order to define parameters consistent within those defined as 'regional hospices' compared to those defined as 'local hospices'.

In terms of the level of specialist PPM service provision, qualitative data relating to the sub-themes: *The specialist question* and *Diversity in approaches to 24/7 medical advice* (Chapter Eight) were considered. Quantitative data with respect to the number of hours doctors provided each week, the level of specialist training and education of these doctors and the access to 24 hours a day 7 days a week PPM advice were collated in an attempt to distinguish specialist from non-specialist children's hospices. Again a process was followed whereby these data were gathered and compared for all the hospices in the study in order to define parameters for those defined as 'specialist' hospices and those defined as 'non-specialist' hospices.

The definition of 'specialist' in both general terms and in CPC is contentious (Hunt 1999). Specialist CPC services have been defined as those with a consultant in PPM (NHS England 2013; NICE 2016c) but with minimal evidence to support this recommendation (Mitchell et al. 2017). For the purpose of this study, the definition used for specialist children's hospice services has taken into account not only the presence of a consultant in PPM but the overall hours of medical presence, the level of specialism in PPM as defined by the APPM and RCPCH (APPM Education Subgroup and RCPCH 2015) for all doctors, the ability to access PPM advice 24/7 and in terms of regional services the ability to act as a resource for PPM advice and review and the way in which the hospice interacts with NHS services. This broad approach to the definition of specialist PPM within children's hospices encompasses the narrow definition of a specialist CPC service given previously. In intersecting with a geographical classification the definition of specialist PPM includes the way in which regional and local services are intended to interact in a networked approach (RCPCH 2012). Therefore what it means to be a specialist hospice on a local level has been defined differently to what it means to be a specialist hospice on a regional level. This is due to the need for an interrelatedness of the services that is vital for sustainability (Quill and Abernethy 2013).

The geographical-specialist classification for children's hospices comprises four groups: (1) *Regional specialist, (2) Regional non-specialist, (3) Local specialist and (4) Local non-specialist*. Given that one of the key qualitative findings is the *Diversity in approaches to PPM service provision* (Chapter Eight), this classification has been based on a 'best fit' for an extremely diverse collection of services. Detailed data on how each hospice service in the study was classified are available on request, including the questions raised by this classification and the challenges in giving definition to such a diverse population. The classification of individual hospices has not been included as the individual hospices would be identifiable to professionals working within this small field but are available for the purpose of scrutiny of methodology.

9.2.2 *Alternative classification*

In addition to the main definition and classification, an alternate view on approaches to PPM service provision has been given in three 'outlier' approaches. Two of these are derived from the qualitative subtheme: *Defining the overall hospice classification* (Chapter Eight), whereby participants gave an overall description of their hospice in terms of which professional led the service. These have been described as the: *One-person pioneer approach* and *Nurse led 24/7 PPM approach.* The third outlier model is a separate geographical model described as a *rural hospice,* which faces unique challenges. Although four of the hospices participating in the study were children's hospices aligned to adult hospices, these have not been used in the final classification as these sat within the geographical-specialist classification and therefore are not defined as a separate entity. Tables 9.1 and 9.2 give a summary of the numbers of participating hospices within each classification.

Table 9.1: Numbers of hospices in the study within geographic-specialist classification

Classification	*Number of hospices*
Local non-specialist	8
Local specialist	7
Regional Specialist	6
Regional Non-specialist	3

Table 9.2: Numbers of hospices in the study within alternative classification

Classification	Number of hospices
One person pioneer	1
Nurse led 24/7 PPM	1
Rural	2

9.3 Description of geographic-specialist classification

The following descriptions give a summary of the combined geographical and specialist PPM classification. It is important to restate that this classification is based on research findings in the real and diverse world of children's hospice care. The words 'usually', 'often' and 'may' are used frequently, indicating a need for flexibility in the definitions of the status of the hospices participating at the time of data collection. This is a 'what is' classification as opposed to a 'what could or should be'. The use of this classification as the basis for a discussion on aspirational models as part of recommendations for the future is explored in Chapters Twelve and Fourteen. The descriptions are summarised in Table 9.3 enabling a comparison of the hospice classification characteristics to be made.

9.3.1 *Regional specialist children's hospice*

A regional specialist children's hospice is usually one with multiple in-patient units in one place or across a region often with associated outreach services. Referrals to hospices in this classification are accepted from across a region and caseloads usually exceed 250 children. Many doctors work in hospices in this category and hours worked by these doctors usually exceed 40 hours per week and include an on-call service. In terms of the level of specialist training and education of the doctors, this will include one or more consultants in PPM or level four trained doctors or more than three level three trained doctors usually with a link to a level four trained doctor. A robust system for 24/7 PPM advice will be in place, which may also offer specialist advice across the region or as part of SLAs with other hospice services. A close working relationship with tertiary children's hospitals and multiple DGHs and neonatal units across each region will have been developed, often on a formal basis, including medical in-reach into these hospitals.

9.3.2 *Regional non-specialist children's hospice*

A regional non-specialist children's hospice will have multiple in-patient units in one place or across a region with or without associated outreach services. Referrals are accepted from across a region and the caseloads would be expected to exceed 250 children. Fewer hours are worked by doctors than in the regional specialist classification, usually fewer than 40 hours per week, in addition to the any provision for an on-call service. In terms of the level of specialist training of the doctors working in this classification of children's hospice service, there are no level four doctors and fewer than three level three doctors. There is no robust system for 24/7 access to PPM advice, although often there will be augmented cover at times when a child is being cared for at the end of their life. Regular 24/7 medical advice is usually provided in this type of hospice service by multiple SLAs with general practices or GP cooperatives. There is usually an intermittent or limited relationship with relevant tertiary children's hospitals, DGHs and neonatal units in the region. In particular there is no medical in-reach into these hospitals within this category of children's hospice.

9.3.3 *Local specialist children's hospice*

A local specialist children's hospice usually has one in-patient hospice unit that may have an associated outreach service taking referrals from a geographical section of a region, defined either in terms of specific counties or distance in miles. The caseload of this category of hospice usually comprises less than 250 children but may be more. The number of hours worked by doctors here is usually high and may be greater than 40 per week in addition to providing an on call service. In terms of the level of specialist training of the doctors, there is at least one or more level three doctor and the hospice may have a link to a level four doctor. There is a system for access to 24/7 PPM advice at level three and there may be an informal or formal link to level four advice when needed. Hospices in this category have developed close working relationships with their local DGHs and neonatal units including medical in-reach into the hospital.

9.3.4 *Local non-specialist children’s hospice*

A local non-specialist children’s hospice has one or no inpatient units and one or no outreach services. Referrals are accepted from a defined geographical section of a region. The caseload is usually less than 250 children. The number of doctors working in this hospice class is low, with significantly less than 40 hours per week of doctor provision, plus any on-call service provided. In terms of the level of specialism of the doctors working at this type of hospice, there are no level three trained doctors and there is no link to a level four doctor. There is no system for 24/7 access to PPM advice and 24/7 medical cover is usually provided by a service level agreement with a general practice or GP cooperative. The hospices in this category have not developed a close link to their local DGHs or neonatal units. In particular there is no medical in-reach into the local hospital.

Table 9.3: Summary of characteristics of geographic-specialist classification

	Regional specialist	*Regional non-specialist*	*Local specialist*	*Local non-specialist*
Referral area	One region (or majority of region for larger regions)	One region (or majority of region for larger regions)	Geographical section of a region	Geographical section of a region
Inpatient units	Usually > 1	Usually > 1	Usually 1	1 or none
Outreach services	At least one	Variable	1 or none	1 or none
Caseload	> 250	>250	Usually <250 or may be higher	Usually <250
Number of doctor hours	High, usually > 40 per week plus on call	Fewer doctor hours, may be less than 40 hours a week plus on call	High, may be > 40 per week plus on call	Significantly fewer doctor hours < 40 hours per week plus on call
Level of specialist training of doctors	One or more level 4 or Consultants in PPM Or > 3 level 3, usually with a formal or informal link to a level 4	No level 4 < 3 level 3	At least one level 3 or more May be linked to a level 4	No level 3 or level 4 link
24/7 PPM advice	System for 24/7 access to PPM advice including level 4 advice or robust system for level 3 advice	No robust system for 24/7 access to PPM advice. May have augmented cover for end of life care	System for access to 24/7 PPM advice at level 3 May have link to level 4 when needed	No system for 24/7 access to PPM advice
Relationship to NHS hospitals	Close relationship with tertiary children's hospital offers medical in-reach to a number of DGHs and neonatal units.	Intermittent or limited relationship with tertiary hospital, DGH or neonatal units. In particular no medical in-reach.	Close relationship to local DGH and neonatal unit including medical in-reach.	Limited relationship with local DGH or neonatal unit. In particular no medical in-reach.

9.4 Description of alternative classification

The alternative classification represents important alternative approaches to providing PPM service provision within children's hospices demonstrated through analysis of the data. These have been included as evidence of different perspectives on a classification. Following the descriptions, Table 9.4 gives a comparative summary of the characteristics of the alternative classifications.

9.4.1 *One-person pioneer*

As the name suggests, the one-person pioneer approach relies on the work of one key individual, often one of the early pioneers in the specialty. There will usually be one inpatient hospice unit often with an associated outreach service. The hospice may take referrals from across a region or a defined geographical section of a region. The caseload is usually high, often exceeding 250 children. However the number of hours worked by doctors is typically low as a hospice in this class relies on the work of one doctor. The hours worked by the doctor may be fewer than 40 hours a week plus any additional on-call provision. The level of specialist training of the one doctor is often level four. The system for access to specialist PPM advice depends on this one person and may be supported by a robust rota of on-call nurses. There is usually a close relationship to tertiary children's hospitals, DGHs and neonatal units.

This category may be best considered as a necessary developmental stage in the evolution of the role of PPM service provision within children's hospices. Although only one of the hospices in the study was classified within this framework others had elements of this approach or over time had moved from this type of approach to become a local specialist or regional specialist children's hospice.

9.4.2 *Nurse led 24/7 PPM*

This alternative approach concerns an intentionally nurse-led service. This type of children's hospice service resonates with the qualitative findings in the sub theme: *The nursing versus medical role, a fading distinction?* (Chapter Eight). Although there were hospices with elements of this approach, the majority of hospices initially described as 'nurse-led' did have a formal or informal arrangement for medical cover at a general level if not a specialist PPM level and therefore were considered as either regional or local non-specialist hospices. The defining factor of this alternative classification was the intentional use of nurse consultants and nurse prescribers to provide the 24/7 cover considered specialist and an alternative to PPM 24/7 cover. For this category there are one or no inpatient units with one or no outreach services. Referrals are made from a defined geographical section of a region. Caseloads are usually fewer than 250 children. There are a low number of doctor hours, with doctors used as a resource rather than for regular reviews. The level of specialist training of these doctors could vary and may include a level three trained doctor. The 24/7 PPM advice is provided by a team of nurse consultants who are also nurse prescribers. The in-reach into local hospitals is led by nurses and includes medical aspects of in-reach into these hospitals.

9.4.3 Rural

The rural children's hospice as an alternative classification derived from: *Defining the overall hospice classification* (Chapter Eight). This stands out as an important outlier in view of the unique challenges faced by these hospices concerning geographic location. In this class there is usually one inpatient hospice unit with or without an associated outreach service in a rural setting. The defining factor is the lack of proximity to either a tertiary or a DGH. The caseload is usually fewer than 250 children. The number hours worked by doctors is usually significantly fewer than 40 hours per week in addition to any on call provision. The level of specialist training of doctors is variable and there may be a level three trained doctor. There is usually no robust system for 24/7 PPM advice.

Table 9.4: Summary of characteristics of alternative classifications

	One person pioneer	*Nurse led 24/7 PPM*	*Rural*
Referral area	Variable may be a region or part of a region	Usually a geographical part of a region	A geographical section of a region
Inpatient units	Usually one	One or none	Usually one
Outreach services	One or none	One or none	One or none
Case load	Usually high May be > 250	Usually lower <250	<250
Number of doctor hours	Usually fewer hours as only one doctor <40 hours per week plus on call	Low number of doctor hours	Fewer doctor hours, usually significantly less than 40 hours a week
Level of specialist training of doctors	Usually level 4 based	Level 3 or no level 3 or 4. Doctors as a resource rather than lead	Variable, may have one level 3 doctor
24/7 PPM advice	One person PPM 24/7 may be supported by 24/7 nursing rota	24/7 nurse consultants and nurse prescribers	Usually no robust system for 24/7 access to PPM advice. May have augmented system for end of life care or informal Level 4 link
Relationship to hospitals	Close relationship to tertiary hospitals and DGH's	Inreach in local hospitals led by nurses	No nearby hospital either DGH or tertiary

9.5 Chapter Conclusion

The purpose of this chapter was to present the way in which the approaches to PPM in children's hospice across the UK have been described and classified by integration of qualitative and quantitative data. The classification has been defined at the intersection of geographical factors and factors based on the level of specialist PPM. The resulting classifications of *Regional specialist, Regional non-specialist, Local specialist* and *Local non-specialist* children's hospices have been presented. In contrast an alternative classification of *One-person pioneer, Nurse led 24/7 PPM* and a *Rural children's hospices* have been presented and discussed. Overall the challenges in giving definition to such a diverse population of hospices alongside the debatable issue of what constitutes a specialist hospice have framed the discussion of the proposed classification.

10 Case scenario findings

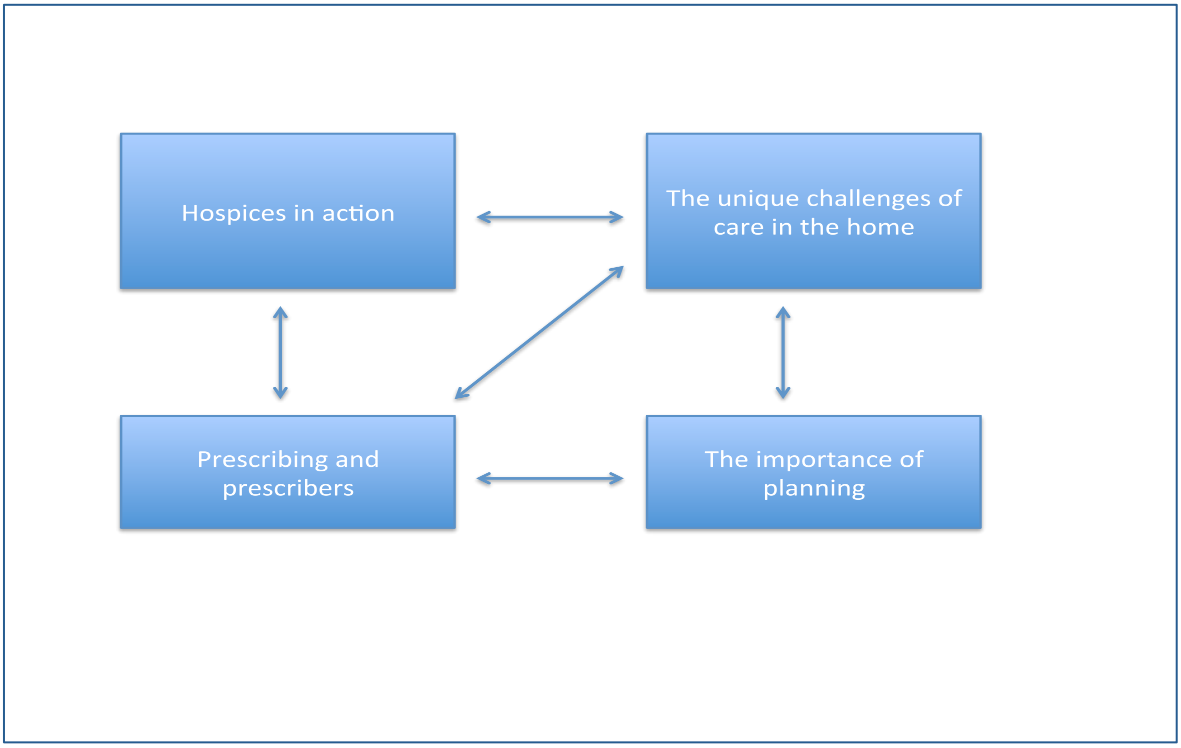
10.1 Chapter introduction

This chapter presents integrated findings of analysis of the four case scenarios. It focuses on the overall integrated findings of the case scenarios giving an overview of the range of responses by hospices to situations when a child may need medical review. The intention of this integration is to address the second research aim: to explore how children's hospices respond when a child with a life-limiting condition has unstable symptoms, is deteriorating or is dying. Firstly the main themes from the cross case thematic analysis are presented. Following this for each of the four case scenarios, a summary of the consequent sequence of events, the decision making process and factors influencing the hospices' responses, which were identified using an explanation building approach, are presented in diagrammatic form. This sequence is used as a framework for exploring the hospices responses to the specific hypothetical clinical scenarios in detail using the findings of the cross case thematic analysis and analysis of quantitative data from the case scenario responses. The subsequent chapter focuses on the impact of the different approaches to PPM in children's hospices using the geographic-specialist classification and alternative classification developed in Chapter Nine.

10.2 Main themes from cross case thematic analysis

The four interrelated main themes from the cross case thematic analysis related to: (1) *Hospices in action, (2) The unique challenges of care in the home, (3) Prescribing and prescribers* and *(4) The importance of planning***.** These are represented in Figure 10.1.

Figure 10.1: Cross case thematic analysis: map of main themes



This cross case thematic analysis and evidence to support these themes has been amalgamated with other elements of the case scenario analysis in order to give an integrated picture of the participant responses that is presented in this chapter. The following brief overview of these themes is provided in order for the integrated analysis to be read in context of this overall picture.

(1) Hospices in action demonstrated how hospices offered care in practice, the extent and limits of this care and the diversity of specialist PPM skills available across differing hospices. A further key finding was how hospice leaders reported experiencing a constant pressure in balancing the priorities in services delivered, between short break care and emergency care for end of life or symptom management.

(2) The unique challenges of care in the home demonstrated that despite recommendations to offer choice to families in place of care, in particular for end of life care for a child, it was problematic for this care to be safely and equitably provided in a child's home across the country. The role of CCN teams

employed by the NHS was shown to be pivotal for children to be cared for at home when reaching the end of life but inequities were identified in this provision across the UK. A number of recurring challenges were demonstrated through data analysis. These related to variable resources, a need for collaboration between NHS and voluntary sector organisations, confusion over medical leadership, clinical risk and limitations of children's hospice involvement in caring for children at the end of their life at home.

(3) Prescribing and prescribers identified that throughout the case scenario responses, issues in relation to prescribing and prescribers were highlighted. These included the wide range of prescribers, both medical and non-medical, involved and at times uncertainty relating to who prescribes medication for a child whilst under the care of a children's hospice. The practices around prescribing in CPC were also evident, including proactive prescribing, prescribing and provision of medication at home and safety in prescribing.

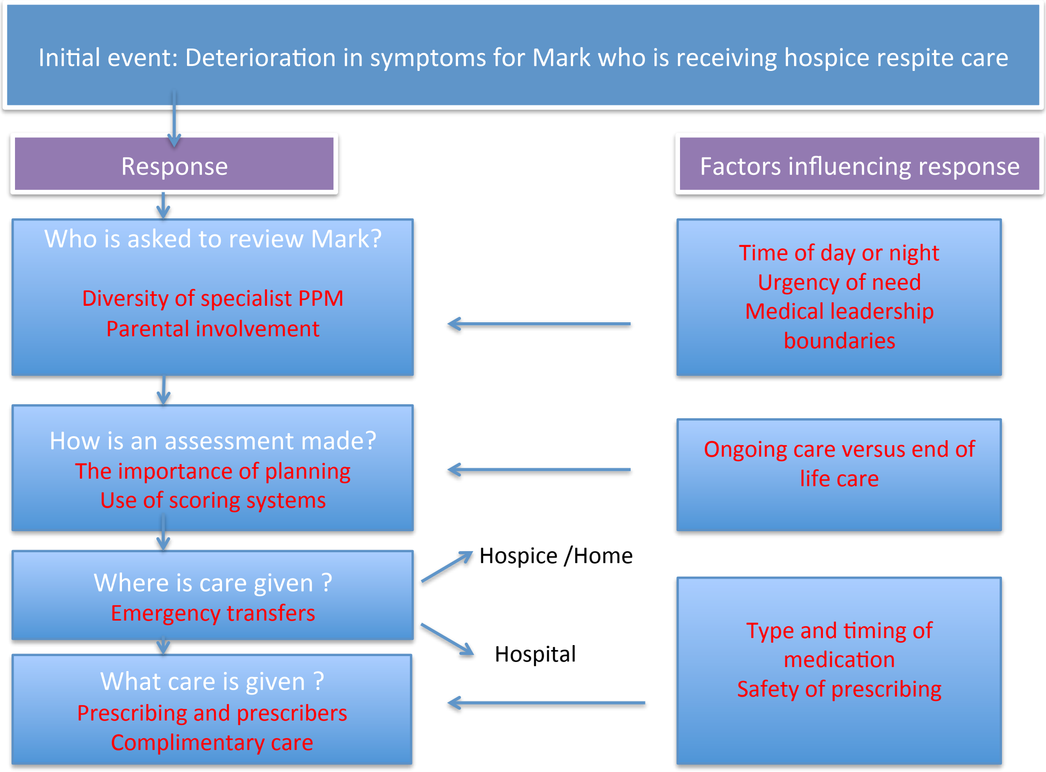
(4) The importance of planning related to the many references to the need for planning as essential to the effective delivery of PPM. This includes the strategies that hospices have adopted to enable them to respond to the situations outlined in the case scenarios. The use in practice of symptom management plans, advance care plans and parallel planning in these scenarios was also apparent.

10.3 Case scenario one: the findings

14 year-old Mark is under the care of your hospice service with a neurodegenerative condition. He experiences deterioration in symptom control during a period of respite care (either at home or in your hospice). Mark is in distress but it is unclear whether this is due to muscle spasm, seizures or pain of another cause.

Figure 10.2 is a summary of the sequence of events that follow on from this initial event of deterioration in a young person's symptoms. In line with an explanation building approach this outlines the response in terms of *who, how, where and what* happens, alongside the factors influencing the response. This figure can be used as a guide for the analysis that follows, which integrates data from across the responses given to case scenario one.

Figure 10.2: Case scenario one summary of sequence of events



10.3.1 *Who is asked to review?*

Diversity of specialist skills

When a patient having short-break care has deteriorating symptom control the first point of call was most frequently a nurse working for a hospice service. A doctor was then contacted by the nurse in the majority of cases (71.4%) but which doctor this was and their level of PPM training varied across hospice services and within the services depending on situation and timing. The following excerpts were typical of many of the responses demonstrating the diversity in level of specialism of doctors called:

> 14/L "*A hospice doctor is always on call. Level 2 – 4 depending on the day. We would call the level 4 doctor about a transfer".*
>
> 18/O "*Varies from level 1 or 2 to 3 or 4 depending on who is contacted".*
>
> 13/K "*The doctor on call is called in to review, level 2 – 4".*
>
> 17/N **"***Hospice doctor is contacted and asked to come in and review, level 2 – 4 depending on day".*

Parental involvement

Several participants mentioned the role of parents or family as part of the process of assessment as demonstrated by participant 16/M who commented: "*We would discuss with the family to find out the history". And by participant 18/O who said:*

> **"***We speak to the parents as they usually know what's causing the distress. We would call the parent to ask whether this has happened before, as respite is only a short period in the day. And have a discussion with Mark himself. The* next *point of contact would be the doctor".*

Time of day or night

Who was asked to review Mark was found to be dependent on the timing of the request with varying responses given out of usual working hours. For example one participant stated: "*In day time the hospice doctor for the day covering the session would be able to review" (4/D). A second suggested that:*

> **"***A doctor is in house from 10 – 7pm every weekday and out of hours a doctor is on call for telephone advice and can come in if needed" (7/G) whilst a third reflected that:*
>
> "*Out of hours it would be the managed network of doctors" (9/H).*

Urgency of need

An additional key factor influencing the response was the perceived urgency of need. The following participant mentioned:

> "*It would depend on whether it was urgent. Urgent issues would need a call to the on call GP to come to hospice. Non urgent would be added to the list for the* GP *session later in the day" (3/C).*

This was reiterated in the responses of participant 12/J, who stated: "*Depending on urgency through the phone call, if needed we would arrange an urgent review*" and by respondent 16/M's explanation that the response: **"***Depends on urgency. We would discuss on the telephone and decide when review was needed".*

Medical leadership boundaries

Participants identified boundaries in medical leadership, with need to defer to the young person's lead consultant for a clinical review or change of management. For example, participant 1/A described how: "*the hospice doctor would go and review at home and also liaise with the child's paediatrician"*. This was echoed by participant 6/F who explained, **"***we would contact child's consultant or the medical director depending on situation".*

Boundaries in leadership were important in relation to prescribing by hospice staff. One of the respondents used the word *"meddling"* in association with changing medications:

> 15/M "*Prescribing [is done by the] hospice doctor in discussion with hospital specialist. If [we are] meddling we need to discuss this with the tertiary specialist*".

Participant 10/H was opposed to a hospice doctor initiating or changing medications commenting: ***"****our view is that if a child is in for respite we should not be fiddling with their medications".*

10.3.2 *How is an assessment made?*

The importance of planning

In terms of how an assessment was made the theme: *The importance of planning* was demonstrated, with many participants commenting that a symptom management plan or its equivalent should guide a response. As respondent 9/H explained: "*we would want a 'what if… plan' in place for this eventuality".* Or stated simply by participant 18/O: "*we would hope to have planned for this".*

Use of scoring systems

Scoring systems for assessment of the young person in this case scenario were raised as a means of giving a structure to outcomes of an assessment. Two scoring systems were given. The first example concerns an early warning scoring system. This was depicted by participant 9/H who said:

> "*There is an early warning system covering this, depending on the scores we might inform the nurse in charge or call the nurse specialist. This is the "Paediatric Early Warning System". Which is analogous to the one used by the hospital team".*

A second type of scoring system for assessing the young person's health status was illustrated by participant 18/O who stated: **"***Nurses use SBAR formal assessment: Situation / Background /* Assessment *ABC, Recommendation/ Documentation*".

On-going care versus end of life care

One of the factors influencing the response to this case scenario seemed to be in relation to the stage of a child's illness. Participant 12/J perceived a distinct difference when a child was referred near the end of their life:

> "*Fundamentally this is difficult as there is no NHS referral for consultant input and the child is under their own NHS team. Whereas for end of life care the child is transferred to the hospice and is under the medical director's care."*

10.3.3 *Where is care given?*

The location of care provision was found to be a key point in decision-making processes, with some hospices arranging an emergency transfer to hospital for a young person whose symptoms have deteriorated. For example participant 1/A explained: "*Or in an acute situation we arrange emergency transfer to hospital".*

This decision for transfer to hospital was further described by participant 26/W, who said: "*If symptom management is not working we would send [Mark] into hospital. Usually the named nurse gives advice or arranges 999 transfer to* hospital*".*

Participant 27/X also spoke of the potential need to arrange transfer but appeared to consider this not to be the ideal choice, citing an improvement in the frequency of emergency transfers: *"At the weekend we phone the doctor and make a judgment about whether a doctor comes in or whether emergency transfer to hospital is arranged if a resus request is in place…We are much better than we used to be". [Researcher comment: Speaking of frequency of emergency transfers].*

10.3.4 *What care is given?*

Prescribing and prescribers

In terms of medical care given, the most frequent response concerned increasing medication or prescription of a new medication. This highlighted multiple issues around the prescription of medications and prescribers aligning with the theme from the cross case thematic analysis, *Prescribing and prescribers*.

Type and timing of medication

Distinctions in who prescribes medications were made in relation to whether an existing medication is increased or a new medication commenced, the urgency of the prescribing, the type of medication and whether the medication is being prescribed during on-going care or end of life care. For example one participant explained: "*it would be the GP [who prescribes] for an increase in medication, for a different medication in the day it would be the consultant for the child" (9/H).* Participant 12/J also stated this need for the child's consultant to change a medication, describing:

> "*For prescribing if it's not urgent this would be part of a routine visit. In the short term, by a GP at the hospice. In the longer term if a general change is needed this would be arranged via the consultant paediatrician".*

One respondent linked this need for consultant prescribing to specific medications stating:

> 22/S "Who *prescribes depends on what the medication is. We would need to liaise with the paediatrician for example about epilepsy medications. We would prescribe short term analgesia."*

Several responses described the stage of a child's illness being the important factor, citing a change of prescribing responsibility when a child is dying, as stated by participant 20/Q:

> *"If prescribing is part of a child's maintenance regimen this would be discussed with the child's paediatrician. If the child is approaching end of life care then the prescribing is done by the medical officer"*

Safety in prescribing

For one participant, prescribing practices presented issues of safety. For example, participant 12/J described: *"the hospice is not in a position to change medications as this is not safe".*

Complimentary care

Medication was only one aspect of the response given by hospices to case scenario one. In contrast, one participant described complimentary care as being offered at the hospice represented. Participant 23/T explained: "*we consider complimentary care first, for example yoga for the special child and relaxation".*

10.3.5 Case scenario one: summary

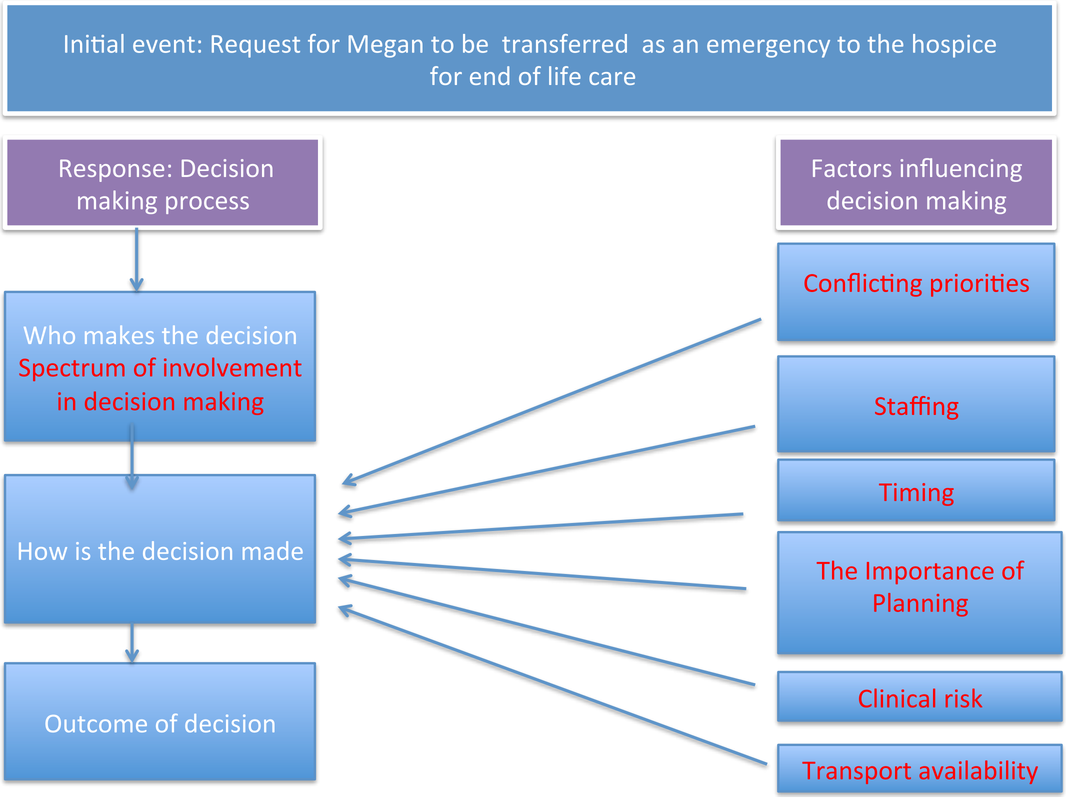
Findings from a combined analysis of case scenario one demonstrated diverse responses from the participating hospices. The diversity in PPM service provision was seen in action with a range of specialist PPM review and varying abilities to respond to a deterioration of symptoms for a young person receiving short-break care. Factors influencing the response included the timing and urgency of the episode and concerns around leadership of care. A key point in the decision-making was whether to transfer the young person to hospital, for some hospice services an emergency transfer was almost inevitable in this situation. The response most frequently given was of an increase or change in medication although issues were raised with respect to prescribing in the hospice setting.

10.4 Case scenario two: the findings

Your hospice service receives a call from the local hospital's oncology team at 3pm on a Friday afternoon. The call is regarding Megan, an 8 year old girl, with a diffuse pontine glioma. She has completed one year of treatment and is known to your hospice service. She has a VP shunt in situ, is in hospital and has headaches, can no longer swallow and has a chest infection. The opinion of her lead oncologist is that she is in the last weeks of her life. Her family would like to be transferred to the hospice for end of life care, supported by your hospice service. It is a bank holiday weekend and they do not want to remain in hospital any longer.

Twenty-four of the 28 hospice services represented had inpatient units and therefore were able to respond to this scenario. Figure 10.3 is a diagrammatic representation of the sequence of events in response to this request for an emergency transfer to the hospice for care of a child at the end of their life. An explanation building approach was used to examine the decision making process in terms of *who makes the decision*, *how the decision is made* and the *outcome of the decision* alongside factors identified as influencing the decision making process. Figure 10.3 can be used as a guide for the integrated analysis of data from case scenario two that follows.

Figure 10.3: Case scenario two summary of sequence of events



10.4.1 *Who makes the decision?*

Spectrum of involvement in decision-making

Findings indicated a pattern of decision-making whereby there were differing levels of medical involvement in decisions to accept an emergency referral and different professional groups involved in such decisions. This ranged from a nursing decision with no medical involvement to a multi-professional team decision. Between these two spectrums the phrase “*informed but not involved”* was used by a number of participants to indicate a decision made by the nursing leadership of which doctors were later made aware. Table 10.1 summarises examples of this spectrum of decision-making.

Table 10.1: Examples of spectrum of decision-making

Nursing decision	*Informed versus involved*	*Team decision*
8/G “*this is a nursing led decision with the Director of Clinical Services and senior members of the nursing team”.*	3/ C “*not unless there was likely to be an unresolved issue with medication. They would be informed after transfer”.* 11/I **“***We let the doctor know but it’s a nursing decision. We inform the* GP *and if relevant inform the PPM Consultant”.* 16/M *“ The doctor would be informed but not involved in the decision. We would let the doctor know the plan”.*	7/G **“***A discussion would take place between the doctor on call, the house manager and a team decision made”.* 24/U **“***Discussion between team leader and medical director”.* 27/X **“***Nurse and doctor sit down and discuss what is needed, who is on unit and staffing”.*

10.4.2 *How is the decision made?*

Conflicting priorities

A number of factors influencing the decision-making processes were highlighted. The case scenarios revealed some of the unique pressures on hospices that led to conflicting priorities. These related to the tensions about providing short-breaks for children and families and also to conflicts between clinical care and fundraising. From the data, the greatest of these tensions was the balance between short break care, which for many hospices is seen as their ‘core business’, and the unpredictable need for emergency beds for end of life care. In reality, decisions were reported to frequently result in a child and their family receiving short-break care being sent home, or having their hospice stay cancelled. The following are two of the multiple excerpts describing this situation:

> 5/E "*We might need to negotiate with the family how urgent this admission is but if a rapid response is needed then we would send a respite patient home".*

> 8/G "*The decision depends on who is in the hospice, beds available and staffing. There are emergency beds and staffing needs planning. If needed we would cancel a respite patient*".

For some of the respondents, as for participant 5/E: "*end of life admissions are prioritised"*. Or as respondent 13/K considered: *"on the basis of need, end of life care referrals are always accepted".*

Because of the ways in which hospices are uniquely financed, (Help the Hospices Commission 2013) a need to fundraise is always prominent. For one respondent this fundraising was perceived to conflict with a request to accept an emergency transfer of a child from hospital to the hospice for end of life care:

> 28/Y "*We don't like saying no. Last weekend we had to say no as there were a lot of bank staff and a big fundraising event".*

Staffing

The availability of clinical staff, both medical and nursing, was shown to be a limiting factor in the ability of hospices to accept an emergency transfer from hospital. Of the 24 hospices with the ability to accept an emergency transfer to an inpatient unit, seven participants (29.2%) responded that they may be able to accept this request depending on staffing of the unit and two (8.3%) depending on medical cover in particular.

Reliance on one person for medical service provision was also identified as common to a significant proportion of hospices in influencing the decision making process. For example participant 2/B described: "*It depends on whether the local GP [name] is here. If he was away the whole situation would need more planning".* This situation was reiterated by participant 12/J who responded that: **“***we may be able to accept but it depends on medical cover, depending on the medical director’s availability” and by respondent 20/Q who explained:* “*We would do everything possible to accept but it would depend if the doctor was away”.*

Timing

The timing of a request for an emergency transfer for end of life care was shown to be important. Some of the hospice leaders reported that the timing given in the hypothetical scenario of a Friday afternoon request would prohibit a transfer. For example participant 21/R stated: “*Our policy is not to transfer on Friday*”. A point reiterated by respondent 22/S who said: “*We would ask [the hospital] not to call at this time”.* Participant 30/a expanded on this, explaining: “*We would not take an admission later than 4pm therefore we would transfer the child at a later stage with planning. This is in child’s best interests. You want to get it right…. We would plan for transfer on Saturday”.*

For some hospices this type of scenario indicated a lack of planning that they would hope to avoid. As participant 26/W described:

> “*We would have been in contact with the oncology team and planning for this situation before a Friday afternoon therefore would expect to have a plan in place and have attended a discharge meeting”.*

Strategic planning

This case scenario added further weight to the cross case analysis theme: *The importance of planning* with numerous responses highlighting a need for planning in order to be ready to accept an urgent referral of this type. This point is summed up by interviewees 26/W: “*What we have to be is very well planned*” and 9/H: “*It’s all to do with planning*”.

Where a hospice service leader reported confidence in the ability of a hospice to respond to an urgent referral for end of life care at all times, this was related to strategic planning as for the following responses:

> 6/F “*There are two emergency beds and at least one is free. There are no issues with staffing as the Band 6 nursing on call can be brought in house if needed, therefore staffing is not a problem”.*

> 12/J “*There is a regional rapid discharge protocol through the [Region] tool kit. The standing protocol says ‘will always accept’”.*

For some hospices, a checklist was reported for use as part of a strategic planning process to decide on whether to accept an urgent referral. For example participant described: 20/Q “*Is there a bed? Who can we cancel? Nurses on duty?... call them in. There is a checklist that is followed”* and participant 30/a explained: *“We are working on a question sheet for this process*”.

The use of clinical pathways provided further clarity in some areas and were described by a number of participants as enabling a planned process of emergency transfer to take place from hospital to hospice. For example participant 20/Q stated: “*We use documentation provided by the tertiary hospital and the transfer for end of life care pathway”.* The following participant described a process of planning and handover framed in a *“regional rapid discharge plan”*:

> 18/O **“***There is a regional rapid discharge plan which has formalised this process. The symptom management plan would be done in the hospital and the lead doctor would hand over to the doctor covering in the community. The lead nurse would hand over to the nurse”.*

The need for symptom management and advance care plans were frequently stated as a pre requisite to transfer of a child for end of life care. For example participant 13/K reported: “*We would want a symptom management plan, drugs available and an advanced care plan discussion”.* Similarly participant 26/W stated: “*We would need a symptom management box of medications and a care plan. We would have said to the hospital team: ‘This is what we need’ ”.*

Participant 10/H linked this planning to a safe transfer as illustrated in the following excerpt:

> “*It has to be safe, and planning in place, is there a symptom management plan and an end of life plan in place? If “no” there is an issue about the patient transferring”.*

The concept of parallel planning was evident in practice from the responses to this scenario. One participant cited this parallel planning in terms of the possibility of a child returning from hospice to hospital, as in the following extract:

> *“Key factors are medical cover, access to medication, advanced care plan in place. Parallel planning, with an arrangement to transfer back to hospital if needed in place” (21/R).*

Another respondent (30/a) perceived a lack of parallel planning to be an omission by the hospital team, stating: **“***The tertiary centre needs to do parallel planning at an earlier stage with parallel symptom management”.*

Clinical risk

The importance of the safety of children and limiting of clinical risk was paramount in influencing clinical decision-making. For example participant 9/H reported: “*The clinical nurse specialist would be looking at clinical risk and safety and what is needed”* and similarly respondent 10/H said: “*It needs to be safe, hospice services are to keen to be helpful, don’t do an unplanned transfer”.*

Transport availability

Finally the availability of transport to move children from hospital to hospice was a factor for a number of participants, as it was perceived to limit abilities to respond to this type of emergency transfer request. This concern was depicted by one participant (3/C) who suggested: "*Consideration of availability of an ambulance to do a transfer would also be an issue" and by participant 27/X who commented:*

> *"I would like to say always but in reality [we would transfer on] Saturday morning in view of logistics…they often ring at 3pm but a vehicle is not ready until midnight".*

10.4.3 Outcome of decision

Fewer than half of the hospices (41.7%) with inpatient units represented in the study reported always being able to accept an urgent referral as determined by this scenario, and arrange a transfer to a hospice. For the remaining hospices, factors affecting the abilities to accept the referral and an indication of acceptance at a later stage, related to staffing or to a need for planning as discussed above. The outcome of this decision making process is summarised in Table 10.2

Table 10.2: Outcome of response to request for emergency transfer to inpatient hospice for end of life care

Outcome of decision	*Number of hospices with inpatient unit (percentage)* *N=24 (100%)*
Always accept and transfer	10 (41.7%)
Accept at a later stage with planning	5 (20.8%)
May be able to accept depending on staffing	7 (29.2%)
May be able to accept depending on medical cover	2 (8.3%)
Never able to accept	0 (0%)

10.4.4 *What happens next?*

Who in practice carries out the medical elements of Megan's admission?

The case scenario questions relating to events following Megan's transfer from a local hospital oncology team to a hospice for end of life care, gave a picture of how, in practice, aspects of her care that would be considered as medical roles were carried out. Responses demonstrated the outworking of the theme from the main qualitative analysis (Chapter Eight): *The nursing versus medical role, a fading distinction?* Examples of this are summarised in Table 10.3, which demonstrates the range of ways in which medical roles were carried out by nurses, through joint working to distinct nursing and medical roles.

Table 10.3: Examples of responses to questions relating to aspects of medical review on admission

Nurses in medical roles: the fading distinction in practice	*Joint working with doctors and nurses*	*Distinct medical and nursing roles*
2/B *"A nurse on the care team [assesses Megan on arrival] and when the GP arrives he would get feedback from the nurse*". 3/C "*A senior nurse on team (Band 7 or 8, Care service manager is Band 8, Care team manager is band7) leads on the symptom control plan".* 27/X "*A nurse [assesses Megan on arrival] the senior nurses all do a 6 months course: the top to toe assessment course and then specific training on symptom management with a pre course test. They have sessions, then jointly write a plan with the doctor and then write one alone for their competency to be assessed. The course was designed in house for training in symptom management".*	11/I **"***Depends on the child, the GP or symptom care nurse [writes the symptom control plan] If complex symptom management it would go to the consultant".* 24/U "*There is a* collaborative *discussion between parent, nurse and doctor [to write a symptom control plan]".* 25/U **"***Mainly the outreach team do ACP's. The inpatient nursing team have also been trained to do this. It's done in conjunction with the paediatric consultant… Whoever the family feel comfortable with".*	7/G "*The doctor on call [assesses the child on arrival] a decision would be made as to who this needed to be, either the level 3 or level 4 doctor. The consultant in PPM if the plan was being written from scratch. The other doctors would update an existing plan".* 9/H **"***Before transfer a doctor to doctor and nurse specialist to nurse handover would take place. At one of the hospices the GP team in the hospice and the hospital team would have a discussion and the GP may be present and would attend the hospice for her arrival".* 30/a ' *A symptom management plan is] already in place from hospital consultant at [tertiary hospital]".*

Who in practice prescribes medication?

The range of prescribers and the use of proactive prescribing were seen in action in the responses to this case scenario. The following professionals were named as prescribers of medication to manage symptoms at the end of a child's life:

GPs (2/B, 3/C, 10/H, 11/I, 22/S), hospice doctors (5/E, 4/D, 14/L, 15/M, 17/N, 20/Q, 24/U, 25/V, 27/X, 28/Y), hospital consultants (6/F, 9H, 29/Z, 30/a, 21/R, 26W) and consultants in PPM (11/I, 23/T).

The role of nurse prescribers in practice was also demonstrated. For example participant 16/M explained: "*The nurse prescriber on shift would do an assessment and make a recommendation and discuss with the doctor on".* Further comments highlighted the remit and boundaries of this prescribing, for example participant 25/V described:

> *"The non-medical prescribing nurse, prescribes the medication. On the prescription sheet we have a range of drugs and if these were not working we would call a doctor".*

Linked to the theme the *importance of planning,* the practice of proactive prescribing was frequently referenced by respondents. This practice, sometimes termed 'just in case' prescribing enables prompt responses to changes in symptoms as a child's condition changes. The following excerpts illustrate this practice:

> 6/F "*All the drugs would be proactively prescribed and would come with the child. Pre-emptively prescribed in hospital by the hospital consultant. The child would be transferred with a palliative care box, this would be sorted out by the paediatric oncology outreach nurse".*

> 9/H "*Medications are prescribed in hospital prior to transfer, we would take the documentation into the hospital to be completed if the symptoms*

> *are already well controlled. It would be individual according to the situation".*

Who in practice is available at 3am to give PPM advice?

The second part of case scenario two asked about the capacity of the hospice to respond to the need for medical advice for a child with worsening symptoms at the end of their life out of usual working hours.

At 3am on Sunday morning Megan's symptoms deteriorate with increased headaches and development of muscle spasms.

The majority of the participating leaders of hospice care indicated access to medical advice at this time, 23 (95.8%) of the hospices had a doctor available to give telephone advice and 22 (91.6%) had a doctor available to visit the hospice to assess Megan. However there was diversity in the level of PPM expertise of the doctors available to give advice as demonstrated in Table 10.4.

Table 10.4: Response to case scenario two: level of PPM 24/7 medical advice

Level of PPM specialism	*Number of hospices with inpatient units (%) N=24 (100%)*
Level 3 or 4 advice	10 (41.7%)
Level 4 advice	2 (8.3%)

The frequently recurring theme of *the importance of planning,* from the cross case thematic analysis was particularly evident in the responses regarding how a deterioration in Megan's symptoms would be responded to at 3 am. As participant 14/L stated: "*Hopefully there would be a plan in place for this". Other* respondents referred to the need to 'anticipate symptoms' as seen in the following examples:

> 7/G "*We would hope that these symptoms would be anticipated with a symptom management plan".*

> 12/J *"If anticipated then the nurses would manage [the symptoms] according to the plan".*

10.4.5 Case scenario two: summary

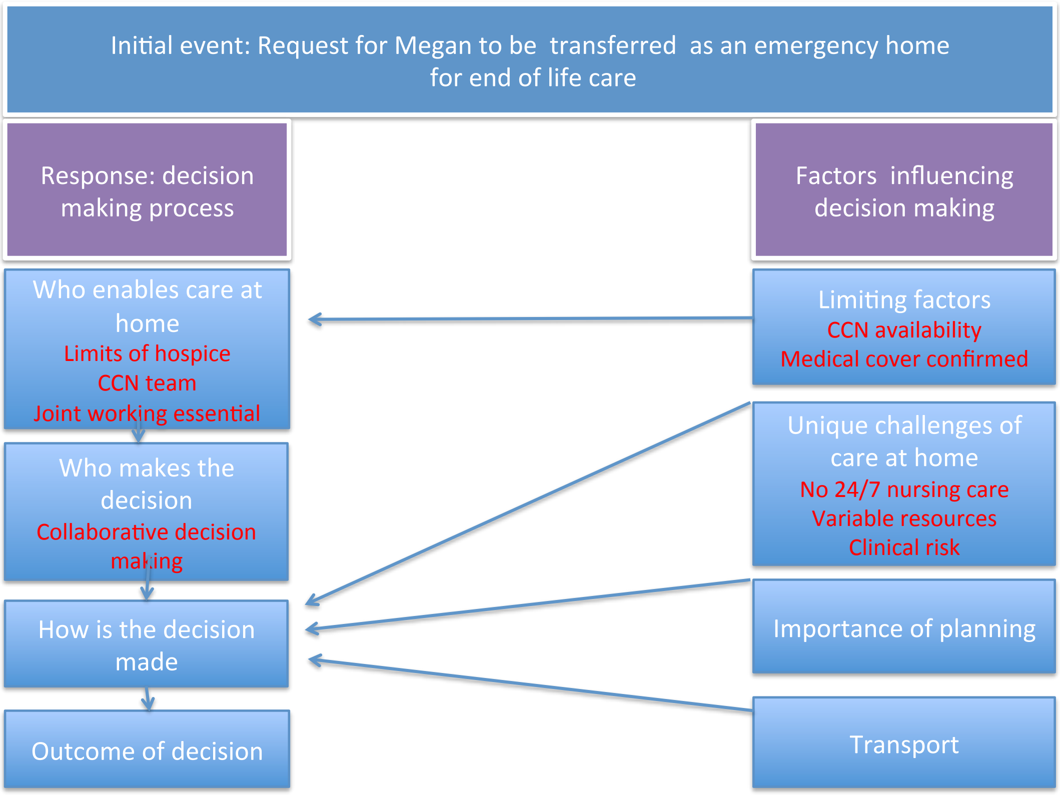
The integrated findings from case scenario two highlighted the decision -making process when a hospice service is asked to receive an urgent transfer of a child for care at the end of their life to an inpatient hospice. Although all the inpatient hospices represented were able to accept such a request, less than half could arrange an immediate transfer. The other hospices were able to accept at a later stage depending on a range of factors including planning, staffing of the unit or medical cover. The conflict in providing responsive care for a dying child alongside planned short-breaks was evident. Qualitative themes from Chapter Eight were confirmed with a demonstration of the blurring of medical and nursing roles in practice, described in both decision-making and clinical care. The diversity in access to PPM was also evident in practice. Although the majority of hospices could contact a doctor at 3am, their level of PPM training varied, with specialist PPM level 3 or 4 advice available in less than half of the cases and Consultant PPM advice available in less than 10% of cases.

10.5 Case scenario three: the findings

Your hospice service receives a call from the local hospital's oncology team at 3pm on a Friday afternoon regarding Megan, an 8-year old girl, with a diffuse pontine glioma. She has completed one year of treatment and is known to your hospice service. She has a VP shunt in situ, is in hospital, has headaches, can no longer swallow and has a chest infection. The opinion of her lead oncologist is that she is in the last weeks of her life. Her family would like to be discharged home for end of life care supported by your hospice service. It is a Bank Holiday weekend and they do not want to remain in hospital any longer.

Seventeen of the participating leaders of hospice care gave responses to this case scenario. For the other eleven leaders of hospice care their hospice service either could not respond to this type of request or would take part in supporting end of life care at home but not to the extent to be able to answer the questions posed in the case scenario. Figure 10.4 is a diagrammatic representation of the sequence of events when a hospice service is asked to support the urgent transfer of a child who is nearing the end of their life from hospital to home, identified through an explanation building approach. This summarises the decision making process in terms of *who makes the decision*, *how the decision is made* and the *outcome of the decision* alongside factors identified as influencing the decision making process. In contrast to case scenario two, additional limiting factors were identified in terms of whether a child can be transferred home at this time and who enables this care at home. Figure 10.4 can be used as a guide for the integrated analysis of data from case scenario three that follows.

Figure 10.4: Case scenario three summary of sequence of events



The outstanding finding from this scenario was in relation to the challenges faced in supporting a child and family to be cared for at home at the end of the child's life. At the time of reviewing the notes from this part of the interviews this observation was made:

> *"Researcher comment: on reading data when a child and family are at home for end of life care there appears to be a wider range of people involved in the care and more confusion over who takes the lead. Overall the respondents seemed to find the questions relating to home discharge far more difficult to answer and there was less clarity in all aspects of the care provided".*

10.5.1 *Who enables care at home?*

Limits of hospice involvement

In responding to questions regarding supporting a child at home for end of life care, the hospice leaders showed uncertainty as to whether this would be possible. For a number of the hospices, caring for a child at home at the end of their life was never part of the care offered. Participant 24/U reported this as a deliberate decision, stating: "*We do not support end of life care at home as this is led by NHS community teams".* For others supporting end of life care at home was a possibility but had never taken place as summed up by participant 4/D: "*In theory we can support this but it has not been done in practice*" and respondent 18/O: "*We have never actually been involved at the point of death*".

For other respondents this non-involvement was seen as a consequence of a decision on the part NHS professionals and services rather than a direct choice, as described in the following excerpts:

> 13/K "*The hospital would not involve the hospice, the consultant in PPM is involved as part of the NHS role but the hospice would only be involved as back up".*

> 17/N "*Not at the moment, we are not even called by oncology team about this, although the clic nurse might let the medical director know".*

For other hospice services, interviewees reported that there would be a limitation in their involvement, with members of the team involved but not the whole hospice service, as participant 16/M outlined:

> "*The more notice the better for home discharge, as this is a different type of care and support. We would not necessarily be involved in the actual transfer hospital to home. We try to be involved but are not always involved in this type of situation".*

For some leaders of hospice care, the hospice service was reported to be able to support specific aspects of care such as on call rotas or telephone support as the following participants suggested:

> 3/C "*The children's hospice nurse specialist would support symptom management, be part of an on call rota and hospice to home carers may be able to be sent into the home".*
>
> 4/D "*The community team with the hospice is available for advice for telephone on call, either the hospice care team number or a 24/7 community team number".*

The decision making process for a transfer home was shown to be markedly different to a transfer to an inpatient hospice setting. Prior to making a response, the interview data demonstrated a need for joint working and collaboration between NHS and hospice services. In particular the NHS CCN teams were frequently cited as being key to enabling care of a child at the end of their life at home.

Children's community nursing teams

CCN teams were mentioned more frequently than PPM service provision as a vital part of arranging for a child to be cared for at home. Therefore a hospice's involvement in this care at the end of a child's life was often reported to be dependent on these teams. As participant 3/C stated:

> "*It depends on factors outside the control of the hospice service, mainly the community children's nursing team availability…The decision would be made by the CCN team. The hospice could give input but would not be able to make the decision".*

Inequity in CCN team provision was stated by the following leader of care as a frustration when planning to care for a child at home at the end of life:

> 2/B *"There is a huge variation in community nursing teams, and the hospice works with CCN teams to facilitate discharge home in this situation. There is a big difference in CCN teams, leading to inequity, in some areas in reality this would not be an option. The CCN team in [area] work 24/7 and have a palliative care resource. The other team are not 24/7".*

In some areas the CCN team were reported to respond to this lack of resource by working on a good will basis to support a child at home at the end of life as described by participant 3/C: "*one limiting factor would be that the CCN team work 9 – 5 Mon – Fri and all other work is on a good will basis".*

Joint working essential

A need for increased joint working and collaboration between teams, both NHS and hospice based, in order to care for a child at home at the end of their life was clearly demonstrated. As summed up by participant 20/Q: *"we will collaborate with anyone around".* The following extracts reiterate this need for joint working:

> 13/K *"This would differ in process as the consultant in PPM would arrange [to transfer the child home] by liaising with the local nursing*

> *team, working with the local consultant and POON's and CCN to plan for visits".*

> 22/S "*The hospice provide some of the nursing service working with community children's nursing team….As the child is already on someone's case load we would do this with community services, not leading alone".*

> 31/b "*We can continue to support within the home but would need to work with another full team providing end of life care either the community team or the hospital team*".

One participant (16/M) reported this joint working with CCN teams as an area for development: "*Projects are on-going with community nursing teams looking collectively at how to support children at home for end of life care* ".

10.5.2 Limiting factors

In terms of factors influencing the decision making process, an additional step termed *limiting factors* was added to the explanation building approach. It was clear from the responses that it was not possible to safely support a child at home for end of life care without the availability of a CCN team as discussed above. Confirmation of medical cover was the other limiting factor identified. Particular areas of concern were the availability a doctor and confusion over medical leadership in the community.

Medical cover confirmed

Evidence from this study suggests that there is a variability and at times confusion in who provides medical leadership and PPM advice for a child cared for at home the end of their life. Respondent 15/M linked this medical provision to geographical inequity describing this as "*hugely variable depending on* *resources and who can provide medical input and has medical autonomy. This depends on where the child lives".*

For the following interviewees the involvement of a lead doctor was seen as a pre requisite to their involvement in supporting a child to be cared for at home at the end of their life:

> 18/O *" It would support the decision to be involved if we know there is medical support from the GP or the hospice".*

> 2/B " We *would let the GP know but the decision [regarding transfer of a child home for end of life care] would involve the need to work out what medical support the child has, i.e who is the most relevant and appropriate medic".*

10.5.3 *Who makes the decision?*

Collaborative decision-making

With respect to who makes the decision to support a child to be transferred home for end of life care, this was shown to be a process of collaboration in contrast to the decision-making process in case scenario two. At the time of reviewing the data the following observational note was made:

> Researcher note: *"Interestingly this is much more about collaborative decision making and multidisciplinary team decision making than a hospital to hospice transfer".*

This approach was consistent throughout the responses and is articulated in the following excerpts:

> 4/D "*The decision would lie with the community nursing team in liaison with the [county] palliative care team. The decision would be with the community team and the hospice could provide back up".*

> 8/G “*The outreach team would discuss with the local community team as to whether it is an option”.*
>
> 18/O “*The care team leader and care manager make a decision:* Based *on the number of staff available, working in partnership with hospice, medical, and other community nursing teams”.*

Some participants cited the use of MDT meetings as a forum for decision making, as raised by participant 11/I: “*The decision is made by multidisciplinary team meeting. The child’s own GP, the CCN team in the local area and the community team. It is a joint MDT decision*”.

10.5.4 *How is the decision made?*

In terms of how the decision is made this relates to two of the main themes from the cross case thematic analysis: the *unique challenges of care in he home* and *the importance of planning* and in addition the availability of transport. The challenges identified in caring for a child at the end of life at home included a lack of 24/7 nursing care, variability and inequity in resources and the clinical risk.

The unique challenges of care in the home

One of the main differences for a family receiving care for a child at home at the end of their life was reported to be the nursing provision. As opposed to children in the inpatient hospice, where nurses were on site 24/7, in a child’s home, for the majority of the time there was not this provision for a nurse to be present at all times as described in the following responses:

> 9/H “*The difference is that there would not be 24/7 nursing in the home, there would not be whole nursing shifts but visits for specific tasks, care would be by the family. Therefore the family need to competent carers. Only occasionally has the nursing need been too great to care for a family at home”.*

> 14/L "*The nursing on call would be the hospice and CCN team in conjunction: set up as a rota of nurses. Parents would have times without a nurse or doctor with them if they plan to be at home, there is not full time nursing cover".*

The issue of inequity was raised by participants in relation to many aspects of caring for a child at home. These included medical leadership, CCN teams as discussed in the section above and also in care for children with differing underlying conditions as raised by participant 2/B:

> "*For oncology children, as in this case, the consultant oncologist would be on call with the hospice giving back up, therefore a big inequity compared to other conditions".*

Providing care for a child at home at the end of life was demonstrated by the responses to be seen as a challenging and at times high-risk area of clinical care. Interviewee 18/O described the following situation relating to the care of a child at home at the end of life:

> "*We have done it, communication was a challenge, we felt it wasn't a good quality service. One difficult situation occurred over a bank holiday weekend with parents wanting more detailed advice about drug administration".*

The need to establish access to medical advice was stated as of paramount importance in the safe delivery of care by participant 29/Z: "*we would have established consultant or registrar medical on call, otherwise its not safe".*

The following respondent (20/Q) spoke of circumstances where access to medical advice and leadership was not established:

> *"Situations occur where children go home without medical advice, except the GP cooperative. In the worse case scenario, nurses provide the advice by supporting the GP to give advice. This is really awful."*

In providing care in the home, in spite of the clinical risks, it appeared more likely from the data that this care was provided on a good will basis as stated by participants 1/A: "*The hospice doctor is available on good will basis on call*" and 18/O: "*Visits out of hours are based on good will of the GP or paediatrician".*

The importance of planning

The importance of planning was again evident in the responses regarding transferring a child home for end of life care. As for case scenario two, this related to both symptom management planning and advance care planning. However the data demonstrated unique challenges in relation to the prescribing and provision of medication in the home. The following participant (2/B) described these difficulties:

> " *Prescribing of medications is tricky. The child's own GP [prescribes] with access to liaison from the hospice GP. In a more complex situation, the hospital consultant would prescribe".*

There appeared to be an increased uncertainty in who prescribes the medication, with a variety of possible prescribers in any given situation for a child at home for end of life care as described by respondent 4/D: *"The hospital team or consultant or child's own GP prescribe medications".* This variability in prescribers was reiterated by participant 27/X:

> ***"****This varies between GP and hospice doctor. The hospice doctor does prescriptions for patients at home or the child might come home with a plan".*

There was also reported to be variation and uncertainty in how medication is supplied to a child at home. Interviewee 27/X described this variability:

> "*Medications are provided in a variety of ways; Prescriptions to pharmacy or nurses take the medications from hospice or from the GP to the pharmacy".*

Some participants reported the hospital as supplying medications as described by participant 26/W: "*The medications should come with the child from hospital, prescribed by the consultant paediatrician. If not the nurse consultant prescribes".* Participant 18/O reported problems with this process, explaining: **"***Initially a locked box of medication comes from the hospital but it doesn't always happen".*

Transport

As for the transfer from hospital to hospice in case scenario two, for a transfer home the issue of transport can also have a profound impact on the outcome for the child and family, as in participant 5/E's recollection of the following incident:

> *"One big issue is getting an ambulance out of hours to transfer a patient to home for end of life care. There was an incident last year where a compassionate extubation planned for home ended up being in hospital due to transport".*

10.5.5 *Outcome of decision*

Only five, (17.8%) of the 28 hospice services represented in the study were able to accept an urgent request to support a child to be transferred home for end of life care. For the hospices unable to accept this type of urgent transfer, a variety of factors were reported as influencing their abilities to respond at a later stage, including staffing, medical cover and the need for planning. Collaboration between NHS and hospice services was again highlighted as essential in providing this care at home. A third of the hospice leaders responded that the outcome of the decision was dependent on other services and that they would not be in a position to lead the care of a child at home. Of these eight respondents, only one went on to answer questions relating to this scenario, indicting a significant likelihood of involvement in such a situation. For this scenario it is notable that four (14.2%) of the hospice services represented were never able to respond to this type of request. The outcome of the decision in response to a request to transfer a child home for care at the end of their life is summarised in Table 10.5.

Table 10.5: Outcome of response to request for emergency transfer to home for end of life care

Outcome	*Number of hospices (%)* *N=28 (100%)*
Always accept	5 (17.8%)
At a later stage with planning	4 (14.2%)
Maybe but depends on staffing	5 (17.8%)
Maybe but depends on medical cover	2 (7.1%)
Never able to accept	4 (14.2%)
Other response *	8 (33.3%)

*Other includes answers relating to being able to support and contribute to end of life care in the community but not to lead.

10.5.6 *What happens next?*

Who in practice carries out the medical elements of Megan's care at home?

For a number of respondents, the person leading on aspects of Megan's care at home such as advance care planning or a symptom management plan was a matter of significant variability. As participant 8/G described: "*This is a difficult one. Usually the [hospice] doctor team leads on a symptom control plan but there are lots of variables".*

The following respondents reported a range of professionals' involvement in these aspects of Megan's care:

> 15/M ***"****Community children's nurses or POON or primary care or paediatric oncologist would lead on the advanced planning".*
>
> 27/X "*Whoever has closest relationship with family leads on the ACP either the community hospice nurse, community children's nurse or the GP".*

Who in practice is available at 3am to give PPM advice?

The second part of case scenario three related to the capacity of the hospice to respond to the need for medical advice for a child with worsening symptoms at the end of life at home out of usual working hours.

At 3am on Sunday morning Megan's symptoms deteriorate with increased headaches and development of muscle spasms.

The case scenario questions relating to events following the transfer of Megan home for end of life care further confirmed the challenges experienced in practice. In particular a lack of certainty in access to 24/7 medical advice was evident. The following quotations confirm the widespread nature of this difficulty in arranging a point of contact for both medical and nursing advice for parents caring for a child who is dying at home:

> 1/A *"The hospice doctor is available on a good will basis on call. Or in some circumstance the [other hospice] 24/7 medical advice service".*

> 15/M "*There are any number of combinations. Community nurses work 8 – 8pm. Or call to the hospice".*

The use of the words *ideally* and *probably* in the following responses demonstrated a degree of uncertainty in this planning for access to 24/7 advice:

> 20/Q "*If outreach nurses from hospice are leading we give a number to call. [The family are]* ***probably*** *left a number to call. We try to partner with CCN team locally. Then number given is for a rota for nurses or GP cooperative".*

> 18/O ***"Ideally** parents would know who to call with forward planning, it would depend who was available".*

The use of the word *might* in the following three excerpts emphasised this uncertainty:

> 16/M *" It **might** be the hospice if parents requested this, or **might** be the consultant on call for oncology at the hospital, or **might** be the on call hospice doctor".*

> 27/X "*It **might** be community [hospice] nurses with 24/7 on call hospice nursing team for community. We do have an issue here with this as CCN is here 9 – 5 routine therefore the hospice have to do out of hours".*

> 18/O "*If previously arranged the GP or paediatrician **might** have given their number".*

One reported solution to this challenge was the use of collaborative on call rotas as described by participant 3/C: "*An on call rota of nurses is given. The rota would be arranged for the child and could include CCN, children's hospice nurse specialist and Macmillan nurses".* Participant 11/I described such a rota as the first point of call for a family:

> "*The child's own GP [is called at 3am for advice] However [the parents] would usually call the on call rota set up for that child made up of CCN team and hospice at home nurses, organised by director of care and the CCN team*".

Responses to this scenario indicated that a child cared for at home at the end of life had less likelihood of access to telephone advice and review by a doctor than if cared for in an inpatient hospice. Thirteen (76.5%) of the 17 hospices able to respond to this scenario reported that a doctor would be available to give telephone advice at this time and nine (52.9%) reported that a doctor would be able to visit and review Megan at home.

The level of training in PPM of the doctors giving advice was again variable with just over half of the hospice leaders reporting telephone access to a doctor with level three or four training in PPM out of usual working hours and a low percentage of access to 24/7 level four advice. These results are summarised in Table 10.6.

Table 10.6: Response to case scenario three: level of PPM 24/7 medical advice

Level of PPM specialism	*Number of hospices (%)* *17 (100%)*
Level 3 or 4 advice	9 (52.9%)
Level 4 advice	3 (17.6%)

Alongside this quantitative data, participants' responses revealed a 'fall back' position of relying on GPs in providing care for a child at home at the end of life as discussed by the following respondents:

> 7/G "*This would be harder to do OOH, [referring to arranging to assess Meghan at 3am] but we could offer to visit the next morning.*
> *If needed sooner we would look at whether the GP could visit. We are not always able to visit at 3am".*

> 11/I "*The child's own GP [could visit at 3am]. A consultant in PPM visit could happen but we try to avoid this".*

One respondent (15/M) referred to the involvement of NHS direct as the first point of contact for a family caring for a dying child at home, stating: "*more often it would be NHS direct than not. In some situations the GP will give a mobile number. Back up from hospice is provided but doctors can only visit in [area]".*

Participant 26/W spoke of the challenges in involving a child's own GP: "*we would arrange [a visit at 3am] if needed. At home we would link to the GP but most children don't have a strong link to their GP. On a couple of occasions have had to call the OOH GP. We have used a GP to certify a child".*

10.5.7 Case scenario three: summary

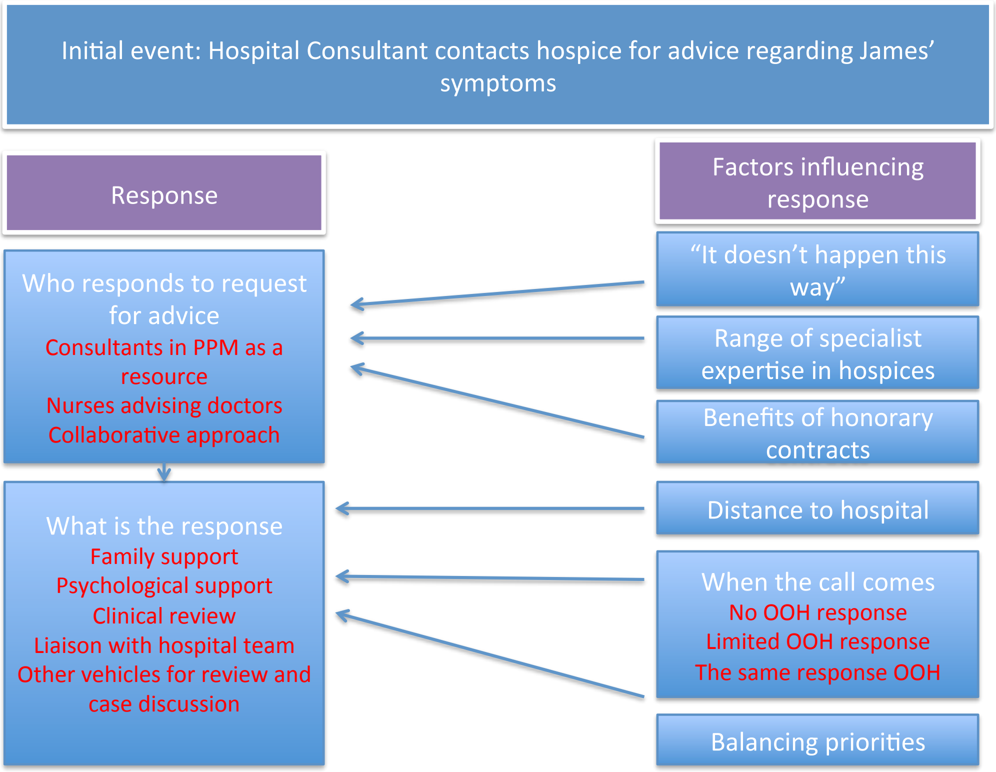
The combined analysis of data from case scenario three highlighted the decision-making process when a hospice service is asked to arrange an urgent transfer home for care for a child at the end of their life. The response of hospices to this scenario was found to be diverse and limited. Less than one quarter of the participating hospices could accept and support this urgent transfer. Other hospice services reported possibly accepting such a transfer at a later stage. The need for planning, CCN availability and confirmed medical cover affected and at times limited, the decision. The decision-making process was shown to be a collaborative process between hospice and NHS teams and supporting a dying child and their family at home required joint working. The unique challenges of care in the home were evident, with a lack 24/7 nursing, variability and inequity in resources including uncertainty in medical care provision at home. The ability for the family to access medical advice at 3am was also less certain with just under a quarter of the leaders of hospice care responding to this scenario, stating that a doctor could not be called at this time. The level of training in PPM of the doctors was again variable. Specialist PPM advice at level 3 or 4 was available in around half the cases with lower availability of Consultant PPM advice.

10.6 Case scenario four: the findings

A hospital paediatric consultant contacts the hospice on a weekday for advice regarding a patient, James, who is currently in hospital and is known to your hospice service. James is 12 years old and has a rare neurodegenerative condition with intermittent and progressive gut failure. He was admitted to hospital two days ago with abdominal pain and erratic absorption. The consultant is asking for advice on managing his pain and support in reviewing overall goals of care.

Figure 10.5 is a diagrammatic representation of the sequence of events in response to this request for symptom management advice identified by an explanation building approach.

Figure 10.5: Case scenario four. Summary of sequence of events



10.6.1 *Factors influencing the response to the request*

"It doesn't happen in this way"

When asked to describe their response to a request for advice regarding symptom control in a hospital patient a number of the hospice leaders answered: "*it doesn't happen in this way*". Respondent 22/S typified this response stating: " *We pass on the request, to be honest, I can't see it ever happening, we haven't got a consultant here".*

Interviewees indicated a need for the hospice service itself to contact professionals outside their service for this type of advice as illustrated in the following excerpts:

> 9/H “ *The consultant nurse or the clinical nurse specialist would give advice, however it would generally happen the other way round, with the CNS contacting the consultant to discuss the concerns”.*

> 23/T “*This question does not work for this model as it would be more likely to occur the other way around with the nurse team leader phoning the [tertiary hospital] consultant”.*

Range of specialist expertise

The range of specialist expertise between hospice services was evident as a factor in influencing the response given to this scenario. Where some participants reported their ability to offer a specialist PPM opinion, admission or review, other leaders of hospice care reported not being able to contribute to these aspects of PPM as demonstrated by the following contrasting responses:

> 29/Z “*We wouldn’t know about pain management”*.

> 24/U *“We would transfer the patient to the hospice for a symptom control admission”.*

For some of the hospices the respondents reported particular limitations in the services offered, for example:

> 29/Z “*We do not prescribe symptom management. Medications come from hospital children’s community nurses. We do not have a pharmacy with stock”.*

Benefits of honorary contracts

A further factor identified as influencing the response was in relation to the presence of honorary contracts with NHS services. Respondents reported the benefits of hospice nurses and doctors having honorary contracts with NHS hospitals. This was found to be an enabler in responding to this type of scenario. Hospices where staff had honorary contracts reported being able to assess and prescribe for children in a hospital setting as described by participant 8/G: *"we have an honorary contract with the hospital therefore we could review [James] and prescribe medications".*

10.6.2 Who responds to the request for advice?

Consultants in PPM as a resource

Analysis of responses to the question of who made the response to a request for symptom control advice, demonstrated the range of responses from hospice services. For those hospices with a consultant in PPM, interviewees gave examples of their role as a resource for symptom management advice for this complex patient as described by the following participants:

> 13/K *"The consultant in PPM would ring the local consultant and would offer a visit if required. The consultant in PPM would look at the symptom management and give advice and offer on-going liaison".*
>
> 17/N " *The consultant in PPM would arrange to go in and visit, provide medical review and advice on symptom management".*

Nurses advising doctors

The outworking of the fading distinction between medical and nursing roles identified through the qualitative data analysis (Chapter Eight) was again evident with many of the respondents stating that a nurse at the hospice would give advice to the hospital consultant. As participant 3/C stated: "*Advice would be given over the phone by a senior nurse".* Or as described by participant 20/Q:

> "*We put through the call to the clinical nurse specialist who could pass it on to the GP with a special interest. If the clinical nurse specialist knows the child s/he would give advice".*

The following respondent linked this giving of advice to '*confidence'* rather than competence, as shown in the following excerpt:

> 9/H “*This scenario is unlikely but if a call was received it would be answered by the clinical nurse specialist. It would depend on the confidence level of the nurse specialist giving advice to a consultant”.*

Collaborative approach

For other hospices services the giving of symptom control advice was reported to be more of a collaborative approach as described in the following extracts:

> 26/W “*Our nurse consultant would take the call. If she was not able to advise she would contact the consultant paediatrician. Telephone advice would be given or a visit in hospital by the hospice at home service”.*

> 18/O ***“****The nurse on call might go and visit or have a telephone discussion based on knowledge of the child. Or we could arrange for local children’s hospice medical director to go into hospital. Or we arrange for transfer to the hospice”.*

10.6.3 What is the response?

The response described by the participants to this request for advice varied widely ranging from family support; including care for siblings and psychological support, to clinical review and liaison with the hospital team. These responses correlate to the main theme *Hospices in action* from the cross case thematic analysis.

Family support

The holistic nature of hospice care was evident and for many of the leaders of care interviewed, the support for the whole family, including sibling support was seen as an essential part of hospice care. Participant 13/K described:
“*The family support team could offer the family social support”,* a response echoed by respondent 30/a who said: *“If appropriate a nurse on team or a caseload liaison nurse would visit for a supportive visit to give family support”.*

In many cases the support described involved caring for a child in order that parents could have a break. This was reported to be of particular importance in this scenario, where the situation was of a child on a hospital ward. As explained by participant 2/B: " *[we would] go in to see the child and support the family to give the family a break, to allow them to go home*". A response repeated by a number of participants:

> 19/P "*A nurse on hospice team would visit to offer whatever the family would like including a break for the family by providing 1 to 1 care".*

> 14/L *"Nurses would also visit to support parents. A dedicated nurse could sit with the child".*

For one respondent (29/Z) the foundation of trust was mentioned as a key part of the support offered:

> "*The named nurse will offer support care and we can also offer sibling support and emotional support. The aim is to give the family a break and provide someone the family trust".*

Psychological support

A further aspect of the holistic care offered by the hospice services was the provision for psychological support and the recognition of the need to support families emotionally as well as addressing physical aspects of care. Participants 2/B, 12/J, 17/N and 19/P all mentioned this emotional and psychological support in their responses to the case scenario.

Clinical review

The provision for clinical review of children with life-limiting conditions and planning for symptom management were demonstrated as a major part of the care offered both within inpatient hospices and as part of work with NHS colleagues in hospitals. The following extract is one of the many examples of this response:

> 7/G "*A doctor is available or clinical nurse specialist or nurse consultant to see [the patient] and examine them. They would talk to the treating team, understand what the needs are and plan how to meet them and make a symptom management plan".*

This type of clinical review was reported to involve specialist skills and on-going communication with parents in order to decide on the best options for care, as described by participant 10/H:

> "*The clinical nurse specialist would visit and assess the child, discuss the implications with parents of nutrition and pain management. And would also need to consider fluids and the role of medications."*

Participant 14/L described these discussions including consideration of the stage of a child's illness to inform decisions as to the most appropriate treatment:

> *"Yes, the consultant in PPM would visit the child in hospital. [S/he] would need to decide "is this end of life care?', "is TPN appropriate?", whether to start [TPN] and how long to continue it".*

The use of specific assessments for pain was stated to be a part of the remit of some hospice teams. The Paediatric Pain Profile being one such tool as discussed by participant 20/Q:

> "*Yes a clinical nurse specialist would visit for a discussion to talk about use of the Paediatric Pain Profile and to provide assessment and advice on strategies. [The clinical nurse specialist] would have spoken to the medical officer regarding suggesting medications".*

In the hospital setting only one interviewee (6/F) reported that the hospice team engaged in the practical aspects of clinical care stating that the hospice team: *“could also support clinical work such as subcutaneous insertion”.*

For another hospice leader (9/H), these aspects of care were reported to be beyond the hospice’s remit, reporting: *“therefore we would not set up a syringe driver in hospital even though the nurses have honorary contracts, as the on-going management would need to be by nurses in the hospital with this competency”.*

Liaison with hospital team

An essential part of the review offered in hospitals was shown to include liaison with hospital teams as discussed by interviewee 18/O who commented: *“we would visit in the hospital to give the family a break. And also to liaise with hospital staff* and *give ideas and opinions based on local knowledge of services”.* It was evident that this liaison was enabled where a doctor or nurse worked in two roles, across two settings as described by the following participants:

> 24/U “*Yes, a hospice doctor who is in the hospital for her other role as paediatric oncologist [could visit to review James]”.*
>
> 25/V “*The medical director would respond and may go and visit the child or give telephone advice. The paediatric oncologist works in two roles hospice and hospital”.*

Vehicles for review and case discussion

A growing part of the work of hospices was shown by the responses to the case scenarios to be in relation to providing a resource for symptom control advice. This symptom control advice role had been extended by some hospices to include the provision of admissions for assessment and management of symptoms. Participants 18/O and 24/U both described the ability to transfer into the hospice for a "*symptom control admission",* in response to the case scenarios. Another hospice leader (27/X) described the development of a monthly multidisciplinary meeting as a vehicle to promote discussion around individual children's needs including planning for symptom management in a discussion involving hospice, hospital and community teams led by the hospice service.

10.6.4 Factors influencing the response

When the call comes

The predominant factor influencing the response given was found to be the timing of the request. Participants were asked whether the same response could be given to this request for advice at a weekend. For some hospice services there was no difference, for others a limited response could be given and for others no response could be made at a weekend. This is illustrated in Table 10.7.

Table 10.7: Examples of range of responses to a request for symptom control advice at the weekend

No response at a weekend	*Limited response at a weekend*	*Same response at a weekend*
1/A “*We are developing a 24/7 rota for senior nurse cover at the hospice, at present this is done on good will basis by the director of care. There is no CCN OOH rota and no formal doctors on call rota”.* 18/O **“***No we can’t respond. We are not a 24/7 telephone access service”.*	2/B “*We have less resources to respond the same day and it would depend on what time of day the call came”.* 13/K “*The* weekend *would be harder if the consultant in PPM was not on call, the other doctors on the team would not be so comfortable giving advice. [It] depends on the medical cover*”. 24/U “*Difficult. If they wanted a symptom control admission we would arrange this but mostly we would apologise and direct the hospital to call the hospice doctor on a Monday morning*”.	3/C “*A senior nurse could answer the call via the on call rota of band 7/8 nurses for the hospice”.* 11/I **“***The same response as the symptom management team work 24/7”.* 16/M “*The medical team would go into hospital on a weekend.”*

Distance to hospital

A further factor cited as influencing the response was the distance to the hospital, for example participant 25/V stated: *“ to visit the tertiary children’s unit is more difficult due to travel time of over an hour”.*

Balancing priorities

The issue of balance in priorities for hospice services was again a factor. The tension that hospice leaders experienced in balancing the needs of children being cared for within inpatient units with requests from outside were illustrated by interviewee 14/L who explained: “the *visit to the hospital would be less likely as the doctor would need to prioritise in house patients”.*

10.6.5 Case scenario four: summary

The integrated analysis of data from case scenario four demonstrated a diverse range of responses by hospices when advice regarding symptom management and goals of care is requested for a young person in hospital. This ranged from hospices with the capacity to offer a ‘symptom management admission’ at the hospice or clinical review in hospital to other hospices where leaders of hospice care declared limited knowledge of symptom management. Factors influencing the response were identified including the range of specialist PPM expertise in hospices. Professionals working across NHS and hospice settings either with honorary contracts or with dual roles were seen as an enabling factor. The timing of the request was key, with responses over a weekend being more limited for most hospice services.

10.7 Chapter conclusion

This chapter presented findings from the case scenario data analysis conducted using a mixed methods comparative case study approach. The responses of the participating hospices to four case scenarios were outlined. The sequence of events around the decision-making was explored using an explanation building approach. This was integrated with findings from a cross case thematic analysis of qualitative data from the case scenarios and with case scenario quantitative data. The way in which the hospices responded to the scenarios was presented in terms of the decision making process and the outcome of the decisions. Factors influencing this decision making process and the hospices’ responses were discussed.

The way in which hospices respond in situations where a child with a life-limiting condition has unstable symptoms, is deteriorating or is dying were shown to be diverse. Of particular significance, limitations were demonstrated overall in the hospices’ abilities to accept an urgent transfer of a child who is reaching the end of their life. The outworking of the range and limitation in specialist PPM expertise in the hospices was also evident. A wide range of responses to requests for advice in managing complex symptoms in children with life-limiting conditions was reported and limited access to a consultant in PPM 24/7 was demonstrated.

11 The impact of the classification of PPM service provision: integration of findings

11.1 Chapter introduction

The previous chapter presented findings from analysis of the case scenario data, using a mixed methods comparative case study approach. This provided an overview of the way in which participating leaders of hospice care responded to hypothetical scenarios relating to a child with a life-limiting condition having unstable symptoms, deteriorating or dying. Building on this combined analysis, the current chapter investigates the third research question: Do varying approaches to PPM service provision in children's hospices impact on abilities to respond to the needs of children with life-limiting conditions and their families when a child has unstable symptoms, is deteriorating or is dying?

To examine findings in light of this question, data from across the study were integrated and cross-referenced to the geographic-specialist classification and alternative classifications of PPM service provision in children's hospices. Additional quantitative analysis correlating aspects of PPM service provision to hospices' activity and case scenario responses were undertaken. Within this small sample size it was not possible to demonstrate statistical significance, however trends in the data are explored to search for patterns in terms of the impact of varying classifications of PPM service provision.

The chapter firstly discusses the integration method followed by the overall integration by each category of the classification of PPM. Three potential areas of impact of the classification of PPM service provision within children's hospices are then reviewed: (1) Impact on activity data, (2) Impact on complexity of care needs and (3) Impact on case scenario responses.

11.2 Integration of findings: the method

For each of the hospices represented in the study, data were collated and tabulated in relation to the hospice activity in terms of the number of end of life care episodes and compassionate extubations in the past year and the complexity of care score. These were then combined by each category of the geographic-specialist and alternative classifications of PPM service provision with a calculation of the mean and median for each data point. Similarly qualitative data relating to complexity of care needs were collated for each hospice and then combined by PPM service provision classification category. In contrast to the previous chapter where case scenario data were combined for all the hospices to give an overall analysis, for the purpose of answering the third research question, the case scenario data were collated for each hospice and then combined by PPM classification category.

In view of the small total population of children's hospice services and therefore even smaller sample size of number of hospices recruited and then classified within each group, it was not possible to draw any valid statistically significant results using correlation calculations. As this was known to be the case at the outset of this integration, the aim was to provide a provisional exploration of whether the classification had any discernable impact on the response of the hospices in practice, by looking for trends in the data when reviewed in this way. Table 11.1 summarises the data collated

Table 11.1 Summary of data collated for each hospice

Hospice activity data: Quantitative data	*Qualitative data and case scenario data*
Total number of end of life care episodes over the past year, including episodes of end of life care where the child recovered, with mean and median for PPM classification category ***Number of compassionate extubations*** over past year with mean and median for PPM classification category ***Complexity of care score*** for each hospice in each PPM classification group	***Complexity of care responses*** for each PPM classification category ***Ability to respond to case scenarios:*** combined data by PPM classification category. CS1: Response to need for review of symptoms during short-break CS2: Response to request for emergency transfer for end of life care to inpatient hospice CS3: Response to request for emergency transfer for end of life care to home CS4: Response to request from hospital for symptom management advice

The summary of data by individual hospice has not been included in the appendices, in order to maintain anonymity. This data can be provided on request for the purpose of scrutiny of methodology. The alternative classification categories have only one or two examples in each but it was decided on balance that this was an essential part of the findings and therefore it was important to include these for comparison with the main geographic-specialist classification. In order to preserve anonymity the alternative classification categories are not presented by respondent number and are the only individual responses presented.

11.3 Integration of findings: summary of data

The collated data has been cross tabulated with each category of the geographic–specialist and alternative classifications of PPM service provision within children's hospices as defined in full in Chapter Nine. This is presented in a series of Tables 11.2.1 – 11.2.7.

Table 11.2.1: Integration of findings by Regional specialist classification

Quantitative data *Hospice activity data* *Complexity of care score* *N= 6*	***Qualitative Data*** *Complexity of care comments* *Case scenario responses*
End of life care episodes: 35,12,49,38,69,86 Mean = 48 Median = 43.5 **Compassionate extubations:** 20,6,2,8,6,10. Mean =8.6 Median = 7 **Complexity of care rating**: High for all except for one medium	**Complexity of care comments:** Overall reference to complex interventions and symptom management and involvement in these alongside the complex ethical decision making of palliative care. ***CS1:*** Overall a doctor with a level of specialist training is available to assess a patient receiving short break care ***CS2:*** Four out of six (the majority) of regional specialist hospice services always accept urgent referral for end of life care at inpatient hospice. The other two accept at a later stage with planning or dependent on staffing. **CS3:**Only one regional specialist hospice service could always accept urgent referral for transfer home. For all others the decision making and support offered was variable according to community services in the area **CS4*:***Advice and review offered by all regional specialist hospices by a doctor with specialist PPM training. Some offer a symptom control admission.

Table 11.2.2: Integration of findings by Regional non-specialist classification

Quantitative data *Hospice activity data* *Complexity of care score* *N=3*	***Qualitative Data*** *Complexity of care comments* *Case scenario responses*
End of life care episodes: 25, 30, missing data Mean = 27.5 Median= 27.5 **Compassionate extubations:** 3, 1, missing data Mean= 2 Mean =2 **Complexity of care score:** Missing data for two examples (one likely to be low) the other low	**Complexity of care comments:** Overall reference to the combinations of needs, neurodevelopmental conditions and step down admissions. ***CS1:*** GP covering hospice reviews the child receiving short break care ***CS2:*** Two may be able to accept depending on staffing and medical cover. One always accept. **CS3:** All never able to accept this type of request, depends on factors outside the hospice **CS4:** Comments on it being rare to have this type of request or these requests being directed to a hospital team. Can offer nurse or medical director discussion and review if asked.

Table 11.2.3 Integration of findings by Local specialist classification

Quantitative data *Hospice activity data* *Complexity of care score* *N=7*	***Qualitative Data*** *Complexity of care comments* *Case scenario responses*
End of life care episodes: 5, Missing,2,18,19,10,6 Mean =10 Median =8 **Compassionate extubations:** 0, Missing,2,0,0,1,1 Mean= 0.66 Median= 0.5 **Complexity of care score:** A range from 2 Low, 3 Medium to 2 High	**Complexity of care needs comments:** A wide range of comments: multiple needs, babies, syringe drivers, challenging behaviours, seizures, cough assist and tracheostomies. **CS1:** For the majority the hospice doctor for the day reviews, for one a consultant PPM clinic is used for review for another the review is done primarily by nurses with doctor asked if needed. In one case an emergency transfer to hospital may be needed. **CS2:** A range of responses: Two always able to respond, one of these self-described as *“a truly responsive service*”. Two able to accept at a later stage with planning, and three able to accept depending on staffing. **CS3:** A range of response. Four never able to accept. One able to accept with planning stating: “*the decision lies with the community team”.* One always able to accept. **CS4:** The majority (six) would offer telephone advice and review of patient in hospital. One reported” “*it would be the other way round”* with hospice contacting hospital PPM team for advice.

Table 11.2.4 Integration of findings by Local non-specialist classification

Quantitative data *Hospice activity data* *Complexity of care score* *N=8*	***Qualitative Data*** *Complexity of care comments* *Case scenario responses*
End of life care episodes: 4,8,8,7,0,7,6 and Missing. Mean= 5.7 Median= 7 **Compassionate extubations:** Missing, 0,2,0,0,0,1,1 Mean = 0.6 Median=0 **Complexity of care score:** 4 medium, 2 high, 1 missing.	**Complex care comments:** A range including: jejunostomy /gastrostomy, epilepsy and complex neuro-disability, blended diet, tracheostomy, transplant, neonates, challenging behaviours. **CS1:** A range of responses, from speaking to parents or young person, to GP or hospice doctor review. Three mention possible need for 999 hospital transfer. **CS2:** A range of responses. One always accept. Two, may accept depending on staffing and medical cover. One may be able to accept at a later stage with planning. Four with no inpatient unit, therefore not applicable. **CE3:** Three hospices never able to accept this request. Four maybe able to accept depending on staffing and medical cover. Only one always able to accept. **CS4:** A range of responses: for three of the hospices, comments that they would not receive this type of request. For two general advice and family support but not medical advice. For one, nurse gives advice and can arrange transfer to an inpatient hospice for symptom control stay. One can arrange symptom control stay or give telephone advice.

Table 11.2.5 Integration of findings by Rural classification

Quantitative data *Hospice activity data* *Complexity of care score* *N=2*	***Qualitative Data*** *Complexity of care comments* *Case scenario responses*
End of life care episodes: 5, 11 Mean = 8 Median = 8 **Compassionate extubations:** 1, 0 Mean = 0.5 Median= 0.5 **Complexity of care score:** 1 Low and 1 High	**Complex care comments:** Epilepsy complicated by distance to hospital. Combination of needs in one child **CS1:** Parents called then hospice doctor or GP **CS2:** Accept at later stage with planning/staffing, and May be able to accept depending on medical cover if the one doctor is not on leave. **CS3:** One could support but not able to accept and lead. One may be able to accept depending on medical cover. **CS4:** One would pass the request on to the consultant in the area with a special interest in PPM. The other would give nursing and GP advice

Table 11.2.6 Integration of findings by one-person pioneer classification

Quantitative data *Hospice activity data* *Complexity of care score* *N=1*	***Qualitative Data*** *Complexity of care comments* *Case scenario responses*
End of life care episodes: 30 **Compassionate extubations:** 5 **Complexity of care score:** Missing data	**Complex care comments:** Complex ventilation **CS1:** Call medical director or child's consultant **CS2:** Always accept " 100%" **CS3:** Always accept **CS4:** Telephone advice and visit. Family and clinical support such as subcutaneous infusion insertion

11.2.7: Integration of findings by Nurse-led 24/7 PPM classification

Quantitative data *Hospice activity data* *Complexity of care score* *N=1*	***Qualitative Data*** *Complexity of care comments* *Case scenario responses*
End of life care episodes: 21 **Compassionate extubations:** 4 **Complexity of care score** Medium	**Complex care comments:** Use a dependency score Have noticed an increase complexity over the past 12 months. TPN, Unstable diabetics **CS1:** On call senior nurse responds and review by nurse practitioner **CS2:** Always accept and whole scenario covered by on call senior nursing team who are all nurse prescribers **CS3:** Always. Scenario covered by nurse on call team. **CS4:** Nurse Consultant gives advice, if not able to pass on to Consultant Paediatrician

11.4 Integration of findings discussion

The use of this data can be critiqued in many ways. The total population size is small, therefore the recruited sample is small and each category of the classification of PPM service provision in children's hospices smaller still. A critique of this stage of the methodology is provided in the following chapter.

Therefore any comments regarding the impact of the classification of PPM service provision in children's hospices are provisional and require further exploration. The aim of this integration was to use data from this study to provide a preliminary view on whether there are trends in the way children's hospices with different classifications of PPM service provision respond to situations where a child with a life-limiting condition has unstable symptoms, is deteriorating or is dying. This is discussed under the headings of (1) Impact on activity data, (2) Impact on complexity of care needs and (3) Impact on case scenario responses.

11.4.1 Impact of classification of PPM service provision on activity data

In terms of the caseload and activity data for participating hospices, information was provided on the number of episodes of end of life care in the past year, both for those children who died and for those who recovered for a period after an episode of end of life care and the number of compassionate extubations supported over the past year. This narrow data field by no means gives a measure of the overall activity of the hospices but is data gathered routinely by hospices and therefore enabled comparison. It is important to note that participating hospices were found to have a wide variation in size of caseload of children and young people. This ranged from 38 to 700 with a median of 174 and a mean of 215. End of life care episodes and compassionate extubations have not been stratified for caseload size in view of the small total sample size. Therefore the comparisons are made between regional services and between local services to allow for the impact of caseload size.

Table 11.3 summaries the ranges, medians and means of end of life care episodes and compassionate extubations by geographical-specialist classification in comparison to the overall study population data.

Table 11.3: Comparison of hospice activity data by PPM geographic-specialist classification

Hospice activity data	*Study population*	*Regional specialist*	*Regional non-specialist*	*Local specialist*	*Local non-specialist*
Range of end of life care episodes in past year	0 - 88	12- 86	25 - 30	2 -19	0-8
Median for end of life care episodes	10	43.5	27.5	8	7
Mean for end of life care episodes	20	48	27.5	10	5.7
Range of compassionate extubations in past year	0 - 20	2 - 20	1-3	0 - 2	0-2
Median for compassionate extubations	1	2.6	2	0.5	0
Mean for compassionate extubations	2.9	7	2	0.66	0.6

Comparing the regional categories, the regional specialist category has a higher range of end of life care episodes with a correspondingly higher mean and median than the regional non-specialist category. In comparison to the overall study population of hospices, the regional specialist group has a higher mean and median for end of life care episodes. For compassionate extubations, although the range is higher for the regional specialist category than the regional non- specialist, the median is similar as the range is skewed by one hospice facilitating the highest number of compassionate extubations in a year. This illustrates the problems faced in analysis of data from a small total sample size.

Comparing the local categories there is similarity in data relating to the end of life care episodes, with a comparable median. The compassionate extubation data is also similar. It is not possible to draw any statistical significance from this summary but in terms of trends in the data, it appears that the hospices which have been classified regional specialist have a higher activity in terms of caring for children who are dying, than those which have been classified as regional non-specialist.

The alternative classification has not been included in this comparison Table (11.3) as for the one-person pioneer and the nurse led 24/7 PPM categories there is only one example for each. However it is interesting to note that the number of end of life care episodes over the past year for the one person pioneer category is higher than the median and mean for the study population. For the nurse led 24/7 PPM category this number is higher than the median and similar to the mean for the overall study population. The compassionate extubations for these alternative classifications are both higher than the median and the mean for the study population. This raises questions as to whether these alternative classifications provide a different perspective on possible recommendations for PPM service provision within children's hospices. This is discussed further in the following chapter.

Correlation calculations: impact of number of doctors and doctor hours on number of end of life care episodes.

In order to investigate whether there was a statistically significant relationship between aspects of the classifications of PPM in the hospices and the hospice activity data, non-parametric correlation calculations were performed using the SPSS^{TM} database. The results of the spearman's rank correlation calculation between number of end of life care episodes and the total number of doctors at the hospice and the number of end of life care episodes and the number of doctor hours per week for the hospices is available in Appendix H. As anticipated the results of these were not significant.

11.4.2 Impact of classification of PPM service provision on complexity of care needs

The complexity of care needs score was developed from the study data to give one measure of the complexity of health care needs for the children on participating hospices' caseloads (see Chapter Seven). Comparing regional categories, the complexity of care scores for the regional specialist category were predominantly high and the regional non-specialist low. However missing data in this section limits the value of this comparison. For the local categories both specialist and non-specialist have a range of complexity of care scores from low to high.

Reviewing qualitative data from the responses given to an open-ended question on what contributes to the complexity of care needs, there was overall evidence of an increasing complexity of care needs as discussed in detail in the eponymous overarching theme in the qualitative findings in Chapter Eight. The responses were compared by PPM classification to search for patterns within the data. In terms of a comparison of the regional specialist category, the respondents for these hospices commented on the involvement in complex symptom management in a way that was not evident in the responses from the other categories of the geographic-specialist classification.

11.4.3 Impact of classification of PPM service provision on case scenario responses

Case scenario one comparison: need for review during short break stay

For the regional specialist hospice category, this review was reported as provided by a doctor with a level of specialist PPM training. In contrast, for the regional non-specialist category, a GP was reported to be available to conduct a review. For both the local specialist and local non-specialist categories a range of professionals were reported to review the young person but it appeared more likely that for the local non-specialist category, the review could result in an emergency transfer to hospital.

*Case scenario two comparison**:** Response to request for emergency transfer to hospice for end of life care*

For the regional specialist category the majority of these reported always accepting an urgent end of life care referral with the others accepting at a later stage or dependent on staffing. For the regional non-specialist category, one hospice service was always able to accept with the other hospice services abilities to accept being dependent on staffing and medical cover. For the local categories there were no discernable patterns with a range of responses regarding acceptance of this referral for both.

Correlation calculation: Impact of number of doctors on acceptance of end of life care referral.

In order to investigate the impact of the classification of PPM service provision within children's hospices on the urgent acceptance of an end of life care referral, a correlation calculation between number of doctors and end of life care acceptance was conducted. The number of doctors was chosen as one measurable aspect of the classification. Data from case example two were recoded into a binary response to acceptance of the referral: Always (10) or Other (14). Therefore separating those hospices answering that they could always accept an urgent transfer for end of life care at the hospice from any other response. The results are summarised Appendix H and are not statistically significant.

Case scenario three comparison: Response to request for emergency transfer home for end of life care

In line with findings from the overall analysis of case scenario data presented in the previous chapter, all the classification categories of PPM service provision demonstrated challenges in acceptance of urgent referrals to support the care of a child at the end of their life at home. The hospices which reported always being able to accept such a referral represent all categories of the classification with no one approach showing a pattern of being more able to respond. Both the alternative classifications of one-person pioneer and nurse led 24/7 PPM gave responses of being confident in being able to respond and reported always accepting an urgent referral for transfer home for end of life care.

Case scenario four comparison: Response to hospital request for symptom management advice

Comparison between the regional categories demonstrated different patterns of response to this scenario. Respondents within the regional specialist category all commented on a doctor with specialist training in PPM being able to review the child in hospital and give advice. Some of these hospices also offered the facility for a ‘symptom control admission’. In contrast, respondents within the regional non-specialist category reported that this type of request would be unlikely. For the local specialist hospice category the majority could offer a review of the child in hospital, whereas for the local non-specialist category, a number reported that this type of request is not received and for those who reported a response this ranged from family support to one hospice service being able to offer admission for symptom review and management. Another reported offering to arrange an admission at another inpatient hospice demonstrating integration of hospice services in practice with a local non-specialist service supported by a regional specialist hospice service.

11.5 Chapter conclusion

The analysis presented in this chapter represents an integration of data from across the study, collated for each of the categories of the geographical-specialist and alternative classifications of PPM service provision within children’s hospices. This integration was conducted in order to address the third research aim: to determine if and how varying approaches to PPM service provision in children’s hospices impact on abilities to respond when a child with a life-limiting condition has unstable symptoms, is deteriorating or is dying. To this end, hospice activity data, complexity of care scores, qualitative data in relation to complexity of care and case scenario data were compared for each classification category.

The impact of the different classifications was discussed in these key areas of (1) Impact on activity data, (2) Impact on complexity of care needs and (3) Impact on case scenario responses. Whilst the conclusions on the impact of the classifications of PPM service provision were limited by the total population of children's hospice services and therefore small sample size under analysis, patterns of differences in the hospices' abilities to respond were observed. In particular, the role and activity of the regional specialist children's hospices were observed as being distinct from the role and activity of hospice services classified in the other categories. The following discussion chapters review all aspects of the research findings in relation to the original research questions and aims. This includes a discussion of the impact of specialist CPC services and the role of children's hospices as specialist CPC services.

12 Contribution to knowledge and theoretical development

12.1 Chapter introduction

The research presented in this thesis explored the role of PPM in children's hospices. At the outset, the history of children's hospice care and PPM set the context for this study. Findings from analysis of the mixed methods survey conducted by telephone interview with leaders of children's hospice care across the UK provided a viewpoint from which to understand the position of medical service provision within children's hospices and the interaction with PPM at the point of data collection.

This thesis began by examining the history of the fear of medicalisation of death and specifically medicalisation of hospice care (Field 1994). The consequent tensions between the hospice movement and palliative medicine were outlined. Concerns were identified that the holistic philosophy of the hospice movement would, over time be subverted by the introduction of palliative medicine (Field 1994). These concerns have been mirrored in the children's hospice movement as described in Chapter Two and explored further in this chapter.

At the beginning of this chapter the absence of an existing theoretical perspective for PPM service provision within children's hospices is discussed. The use of a theoretical framework based on concepts in CPC is reviewed and the contribution of these findings to a foundation of knowledge in this field is outlined. The outcome of the development of a research-based classification of PPM in children's hospices is reviewed. The main geographic-specialist classification of approaches to PPM service provision within children's hospices in the UK is contrasted to the alternative classifications, developed based on identified 'outlier' approaches. This novel classification is discussed in light of historical concerns in relation to a 'medical model' (Farre and Rapley 2017) and children's hospice care. Development over time, of the medical model to a biopsychosocial model is explored, with its application within palliative care. Emerging approaches to hospice and palliative care within current literature are presented and the place of the classification from this study is reviewed.

The contribution of this study to knowledge of the role of children's hospices as specialised CPC services is discussed. On-going questions around the definition of a specialist CPC service are raised and the application of the study findings to this debate is considered. What this study adds to the evidence base on the impact of specialist CPC services is also explored.

12.2 Theoretical development

In the absence of an existing theoretical perspective relevant to the research questions posed in this study the research was positioned at the intersection of a number of important theoretical strands. These were: the holistic philosophy foundational to children's hospice care (Chambers 2018), the position of medical care within this philosophy (Hain et al. 2012), theory concerning the definition of 'specialist' services developed through research into the role of POONs both in terms of the defining 'specialist' (Hunt 1999) and the impact of geographical location on models of practice (Hunt 1995). Finally, a concept relating to breadth and depth of specialist CPC services (Hain 2013) completed the framework.

This research contributes to theoretical development in progressing knowledge of PPM within children's hospices at the time of data collection. This provides a foundation of knowledge, not previously evidenced, with respect to the detail of the diversity of approaches to PPM service provision within children's hospices. Research findings from this study demonstrated that overall PPM is strikingly absent in children's hospices. Both in terms of a limited involvement of consultants in PPM and a lack of specialist training in PPM of the doctors working in children's hospices. PPM and children's hospice care are two of the foundational pillars of CPC and these findings indicate a lack of integration between these services.

Based on these findings a classification of the range of approaches to PPM within children's hospices was developed. The application of the theoretical framework to the development of this classification is discussed in the following section. The classification provides a differentiation between the parameters and function of regional and local children's hospices and specialist and non-specialist children's hospices. These geographical factors and PPM specialist factors were integrated to define regional-specialist, regional non-specialist, local specialist and local non-specialist children's hospices. This classification could be used in practice and applied to a networked approach to PPM within children's hospices in order to promote integration of these services as discussed in subsequent chapters.

Exploration of the impact of the different classifications contributes to the evidence base regarding the impact of specialist CPC services. The participating hospices classified as regional-specialist were found to have a distinct role and activity in terms of their contribution to the care of children with life-limiting conditions at times of unstable symptoms, deterioration and at the end of life. These hospices also acted as a resource in specialist PPM for the region providing in reach into hospitals and at times forming alliances with smaller local children's hospices services. This contribution to the debate on the impact of specialist CPC is critiqued in section 12.7 of this chapter.

In contrast the findings also raise questions as to the definition and impact of specialist CPC services. Throughout the study the role of nurses in PPM with a blurring of the boundaries between medical and nursing roles was evidenced. Multi-professional working has always been at the heart of children's hospice care and this extension in nursing roles and responsibilities raises the question of whether it makes a difference if the specialist PPM is provided by nurses or doctors. This is discussed in full in section 13.6 of the following chapter.

In terms the definition of specialist CPC services, applying the definition of the presence of a consultant in PPM, few of the children's hospices participating in the study could be classified as specialist. However the geographic- specialist classification of PPM in children's hospices takes into account the differing needs of regional and local children's hospices in relation to specialist PPM. This classification argues for an integrated approach whereby consultants in PPM within regional-specialist children's hospices or tertiary children's hospitals inter-relate with local-specialist children's hospices. This approach recognises and promotes the training of the existing hospice doctor workforce in PPM so that those working on a local level develop and maintain the skills to care for children with life- limiting conditions at times of unstable symptoms, deterioration and at the end of life, with the support of a consultant in PPM when required.

The contentious issue of when a children's hospice can be classified as a local non-specialist hospice and in effect what the minimum requirement is for a service to be named a "hospice" requires delineation. Findings from this research included instances of the leaders of hospice care declaring a lack of knowledge of symptom management, or of limited or no involvement in the care of dying children. The need to introduce standard expectations and guidelines for children's hospice services as discussed in sections 13.2 and 14.2 is one of the key recommendations arising from this research.

12.3 Classification of PPM service provision in children's hospices

One of the main outcomes of this study has been the classification of PPM service provision in children's hospices. This classification is based on 'what is' or 'what was' at the time of data collection but could be used to contribute to the development of an aspirational classification of 'what could be' as discussed in Chapter Fourteen in relation to recommendations arising from these research findings. Children's hospices were classified at the intersection of geographical factors and specialist PPM service provision as outlined in Chapter Nine. There were many challenges in giving parameters to this classification in view of the diversity of approaches to PPM service provision in children's hospices. The classification developed was a 'best fit' taking into account multiple data points from the research findings and applying existing theory and concepts from the proposed theoretical framework.

Geographical location has been found to influence models of practice in children's cancer services (Hunt 1995) and this delineation in practice between regional and local services was echoed in the findings in relation to children's hospices. Location of hospice services was not intended at the outset of the children's hospice movement to influence their function and no external boundaries have been set around where new children's hospice services are cited. However, the findings demonstrate a link between geographical location, in particular proximity to a tertiary children's hospital and approaches to PPM and service delivery. This was evident in the sub-theme: *Defining the overall hospice classification* (Chapter Eight) where participants self-defined their hospice service as being either a regional or a local service. The geographical distinction was also clear when quantitative and qualitative findings were integrated (Chapter Nine) to give definition to the classification. Data in relation to caseload, number of doctors, doctors' working hours and provision for 24/7 PPM advice led to differentiation between local and regional services.

Understanding of 'specialist' in terms of children's cancer nursing has been shown to be an area of variability, with components of 'specialist status' conferred including: formal qualifications, hands-on clinical skills, previous 'specialist' work experience, in-depth medical knowledge or insight into family dynamics (Hunt 1999). Confusion and concerns around the definition of 'specialist' in terms of PPM service provision were demonstrated in the findings. The sub-theme: *The specialist question* (Chapter Eight) highlighted respondents' concerns, whilst analysis of quantitative data demonstrated confusion. There was a marked difference in comparing specialist PPM qualifications of doctors to respondents' answers in terms of their contribution to specialist PPM roles and 24/7 PPM advice (Chapter Seven). Whilst analysis of what respondents perceived as contributing to 'specialist' PPM knowledge was outside the scope of this study, there was evidence of variability in the perceptions of what constitutes 'specialist' PPM.

The intersection of geographical location and specialist function has been evidenced in the role of POONs (Hunt 1999), with different components of 'specialist' knowledge conferred on these nurses depending on their work location. The interaction of geographical location and specialist PPM service provision in participating hospices was seen at the point of integration of qualitative and quantitative data. This informed development of a classification at the intersection of these factors. The difference between the provision and need for specialist PPM at a local level in comparison to a regional level was therefore encompassed in this classification. The contribution of these findings to the debate on specialist CPC is considered in the later section of this chapter.

Alternative classifications were also presented based on identified ‘outliers’ with significantly different approaches. One of these, the *One-person pioneer* approach could be seen as a developmental stage in the evolution of children’s hospices, which many of the participating hospices may have passed through at a time of reliance on one pioneering individual doctor providing the majority or entirety of the medical service provision. This developmental stage was epitomised by Cicely Saunders at the inception of the hospice movement (Saunders 1978; Clark 2001; Clark 2018) and mirrored to some extent in children’s hospice care by the pioneering work of Sister Frances Dominica (Dominica 1982; Worswick 2000a).

12.4 Concerns regarding a ‘medical model’

The application of a classification of medical service provision as a guiding factor in the delineation of children’s hospice services may contribute to the tensions between children’s hospice care and PPM. One of the founders of the first children’s hospice (Worswick 2000c) warned of the danger of a “*medical backwash*” from hospitals into children’s hospices. The following quotation would appear to be in opposition to using PPM service provision as a defining factor in the future of children’s hospices:

> *“Inappropriate medicalisation of their service is perhaps something that children’s hospices need to guard against. The hospices, of course, need to draw on medical expertise but medical input should have a supportive not directional function.” (Worswick 2000b)*

However in the 20 years since this was written, a perhaps unforeseen escalation in the medical and ethical complexity of this population has taken place, as evidenced by the literature and corroborated by these study findings. The complex health care needs of children with life-limiting conditions necessitate a wide-ranging and responsive provision, achieved by the collaboration of many professionals and services. As discussed in detail in Chapter Eight’s qualitative findings, the blurring of the roles of doctors and nurses within the PPM service provision of children’s hospices indicates that supporting these children’s complex health care needs is not limited to the work of doctors. Therefore what was framed in 2000 by Worswisk as "*inappropriate medicalisation"* is not solely the consequence of doctors involvement but has become a complicated debate around how best to meet children's medical needs whilst always acknowledging that this is part of a child-centred and family-focused provision.

Worswick (2000) did clarify these comments on medical involvement in children's hospices, stating that, *"it would be foolish to suggest that the use of even sophisticated medical practices constitutes per se a subversion of the principles of children's hospice care"* (Worswick 2000b). However the following statement makes specific reference to the perceived dangers of a "*medical model"*, a caution of which I have been aware in conducting this study:

> *"We need to beware of a shift to an "interventionist approach" with the risk of palliative care practice adopting a disease –centered medical model which might direct the focus away from the fundamental philosophy of holistic care. In sensitive paediatric palliative care, the child remains the focus not the illness" (Worswick 2000b).*

The term medical model is synonymous with "*biomedical model"*, a historical definition of the practice of medicine as focused on the treatment of disease (Farre and Rapley 2017). This was critiqued from the 1970's onwards, principally by Engel (Engel 1978, 1980) who proposed a biopsychosocial model (Engel 1980; Farre and Rapley 2017). This adaptation of the biomedical model encompassed the social, behavioural and psychological aspects of health and disease. In spite of recurrent criticisms (Farre and Rapley 2017), principles of the biopsychosocial model have been used and adapted over the past four decades (Engel 1997; Farre and Rapley 2017). In the field of adult palliative care the application of the biopsychosocial model has been recommended as a way to broaden the scope of quality measures in palliative care, particularly when evaluating outcomes of hospice care (Webb and Kamal 2014).

However in spite of this progression to a biopsychosocial model more in keeping with CPC, the old connotations of the medical model persist and have been experienced as barriers when conducting and presenting this research

(Frost 2017; Frost 2018). In view of the history of concerns around the ‘medical model’ and the desire to remain true to the philosophy of the children’s hospice movement and the position of medical care within this, I chose to use the term ‘classification of approaches to PPM service provision’ rather than ‘models of PPM service provision’ within this study.

12.5 Alternative emerging models of palliative care

Alternative emerging models of palliative care may be at odds with a medical approach to classification of children’s hospices. The most prominent of these in adult palliative care in recent years is the public health approach (Martins Pereira et al. 2015), supported by compassionate communities (Kellehear 2015). The WHO has pioneered a public health strategy as a global model for palliative care (Stjernswärd et al. 2007; Callaway et al. 2018). This involves the whole of society, all levels of health care systems and must be owned by local communities (Stjernswärd et al. 2007). A compassionate community has been defined as one that understands the care of those living with a life-threatening condition to be the responsibility of all citizens (Kellehear 2015). This model from adult palliative care is being introduced within CPC with communities now considered as part of universal CPC services (Chambers 2018).

However, the biopyschosocial model and the public health model as applied to CPC need not be in opposition to or exclude PPM. The approach of PPM is intended to encompass physical, emotional, social and spiritual elements (Hain et al. 2012) In line with the holistic and multidisciplinary philosophy of children’s hospice care (Hunter 2017), it is important for CPC to embrace both the need for community focused palliative care in which everyone can participate and the highest standards and equity in PPM. In one sense, the direction of travel for the definition of specialised CPC services has already been set by the introduction of guidance and agreed national and European recommendations (European Association for Palliative Care 2007; NICE 2016c), with the link to funding in the palliative care services review (Hughes-Hallet et al. 2011) acting as a driver for this direction of development. There is therefore a place for a research-based approach to classifying children’s hospices in relation to PPM service provision with acknowledgment of the need to position this carefully within the holistic, family-centred approach foundational to CPC.

12.6 Children's hospices: specialised CPC services?

This research demonstrates that at the time of data collection only 27.5% of doctors working in participating children's hospices had attained a specialist level of training in PPM, at either level three (20%) or four (7.5%) as defined in the combined curriculum (APPM Education Subgroup and RCPCH 2015). Historically, best practice and policy have recommended access to 24/7 specialist CPC advice for all CPC services (Craft and Killen 2007; ACT 2009) although until recently, what constituted specialist advice was undefined. Current guidance is more specific recommending that a specialist CPC team includes a consultant in PPM and that for a child cared for at home at the end of life there should be access to 24/7 telephone advice from a consultant in PPM (NICE 2016c; Aidoo and Rajapakse 2018). In spite of these recommendations there is a lack of research into the delivery of CPC 24/7 (Maynard and Lynn 2016b), with only a small number of single institution studies (Craig 2003; Bradford et al. 2012). One 2016 study describes how a regional service has addressed the need for 24/7 symptom management, charting the development and evaluation of a service for children with life-limiting conditions (Maynard and Lynn 2016b).

Findings from the study presented in this thesis add to the evidence base regarding access to 24/7 PPM advice, demonstrating a lack of this provision in many children's hospices in the UK. As evidenced in quantitative findings in Chapter Seven, only half of the hospices in the study had 24/7 access to specialist PPM advice. For a number of these there were inadequacies in the provision: in two of these one person with a specialism in PPM was covering 24/7 and in another the PPM specialist provision covered a subsection of the hospice patients only.

The challenges inherent to providing this specialist advice 24/7 were demonstrated in the qualitative analysis presented in Chapter Eight within the main theme: *Challenges facing medical service provision*, with sustainability and the variable workload at the fore. Having grown up over the past 30 years, the medical service provision within hospices now approaches a ‘change of guard’. The pioneering doctors who established and provided medical care in its entirety are reaching retirement and a new generation of hospice doctors are facing new challenges. Patterns of working which have been sustained in the past are becoming unsustainable in the face of growing numbers of children, increasing complexity of need and a challenging ethical and legal landscape. Where once a ‘one person’ system was sustainable, this approach is fast becoming untenable.

Variability of need for medical input across the whole spectrum of palliative care makes planning difficult (Spathis et al. 2012). A medical emergency in relation to palliative care could arise at any time and the logistics of preparing to meet such a need are therefore hard to resolve. The need for responsive hours was evident from the data in this study, quantitative data (Chapter Seven) demonstrated that for half of the participating hospices, doctors’ working patterns did not fit within the predefined categories and the need for responsive hours was frequently cited. Qualitative findings (Chapter Eight) within the subtheme: *Variable workload*, described this need for responsive hours as most evident when a child is cared for at the end of their life. Analysis of data presented in Chapter Seven found that children’s hospices have developed a variety of approaches to meeting the need for access to ‘specialist’ advice. This included ways of augmenting medical service provision to support end of life care. Innovative responses by local palliative care services in order to implement the NICE end of life care guidance (Aidoo and Rajapakse 2018) have been recognised and collated in a recent report by TfSL (TfSL 2018).

Recommendations as to what constitutes a specialist CPC service were introduced without an evidence base; therefore evidence as to the impact of specialist CPC services has been sought in hindsight (Mitchell et al. 2017). Mitchell’s systematic review to identify the distinct benefits of specialised CPC services to children and their families identified little and low quality evidence (Mitchell et al. 2017). There was suggestion that specialised CPC services may improve quality of life for life-limited children and their families (Gesa Groh

2013; Friedrichsdorf and Positer 2015), may improve symptom control (Gesa Groh 2013; Sheetz and Bowman 2013) and may reduce burden of care and psychological distress for families (Gesa Groh 2013). However it is not clear from the limited research which aspects of these specialised CPC services led to these improvements, how this occurs or what the presence of a consultant in PPM contributes (Mitchell et al. 2017). Studies relating to CPC services led by nurses or children's hospices without a consultant in PPM were excluded from the systematic review and therefore could not be compared (Mitchell et al. 2017). One study has shown a nurse- led CPC service to improve choice of place of care, coordination of care and family support (Sastry J et al. 2014).

As part of the CPC sector's response to the Commission into the Future of Hospice Care (Help the Hospices Commission 2013) the issue of specialisation was discussed. This debate was summarised by Hain (2013) in terms of needing a broader understanding of the concept of specialisation in the context of CPC:

> *"It is about having the right breadth as well as depth in specialist skills. Providers need to be able to deliver a wide ranging set of services across their multi-disciplinary team as well as providing access to consultant level medical expertise".*

In light of this thinking, reducing the definition of specialist CPC to the presence of a consultant in PPM would seem to be a narrowing of the philosophy of CPC. The classification of PPM service provision within children's hospices presented in Chapter Nine is only one aspect of specialised children's hospice care. The definition of 'specialist' PPM has been broadened for this classification in terms of the difference in PPM service provision at a local and regional level and the interaction of these services. This classification could be considered alongside other aspects of service provision which contribute breath in specialist skills as alluded to by Hain (2013).

12.7 The impact of specialised CPC services

As discussed, there is limited evidence as to the benefits of specialised CPC services (Mitchell et al. 2017) and specifically the impact of doctors with specialist training in PPM. Chapter Eleven presented the results of an integration of data from across the study collated by the geographic-specialist and alternative classifications of approaches to PPM service provision within children’s hospices. The findings of this integration contribute to knowledge regarding the impact of specialised CPC services. Before this contribution is stated it is important to acknowledge the limitations inherent to the process of integration.

Firstly the classification itself can be critiqued as it involved pragmatic decisions in order to classify hospices with a range of diverse configurations of PPM service provision. Secondly in looking for patterns in the responses by this classification it cannot be concluded which aspect of the hospice service leads to the response. Thirdly the method of assessing the hospices response is limited by the methodology of hypothetical case scenarios. This was chosen as a foundation to investigating the work of children’s hospices in view of the ethical and methodological challenges in exploring the response of hospices across the country in clinical situations in reality. Research data gathered based on hypothetical responses is likely to be subjective and dependent on the interviewee. Fourthly in terms of the measures of hospice activity used these were limited to data routinely gathered by hospices and are not necessarily the best or most pertinent measures of the medical work of the participating hospices. The activity data chosen for the integration of analysis were the number of episodes of end of life care in the past year (including those when a child was thought to be dying but recovered following an episode of care), the number of compassionate extubations in the past year and the complexity of care score for the whole caseload, a measure developed for this research study, as described in Chapter Seven.

Taking into consideration these limitations, interpretation of the integration of analysis was based on looking for patterns by hospice classification. In comparing the regional specialist and regional non-specialist approaches it appears that the regional specialist hospices are distinctly different from the non-specialist regional hospices with higher activity levels in terms of numbers of children supported whilst they are dying, higher numbers of compassionate extubations and with overall high complexity of care scores.

Reviewing and comparing the case scenario data the hospices classified as regional specialist seem to be serving a distinct function in the provision for situations where a child with a life-limiting condition has unstable symptoms and is deteriorating, arranging admission for symptom management and acting as a resource for advice and clinical review. In comparing abilities to respond when a child is dying and urgent transfer to an inpatient hospice is requested, the regional specialist hospices appear to be more able to respond to this request immediately and consistently. Importantly neither regional specialist or regional non-specialist hospices reported being able to give an immediate or consistent response when the request is for a child who is dying to be transferred home. The implications of findings in relation to end of life care at home are discussed in the following chapter.

Reviewing the integration data for local specialist and local non-specialist hospices there are fewer distinctions with broadly similar activity data for numbers of children supported when they are dying, numbers of compassionate extubations and a similar range of complexity of care needs scores. Comparing the case scenario responses there were no clear patterns with a diverse range of responses in situations where a child with a life-limiting condition has unstable symptoms or is deteriorating. In terms of the response to request for urgent transfer to an inpatient hospice unit when a child is dying there are again range of responses with no clear distinction between specialist and non-specialist local hospices. It is again important to note that a significant number of these hospices are never able to respond when this request is for a child who is dying to be transferred home.

Integration of analysis of the responses for alternative classifications raises questions as to the impact of PPM service provision within children's hospices. For two of these: the One-person pioneer approach and the Nurse led 24/7 PPM approach, activity levels based on numbers of children supported when they are dying and compassionate extubations, these figures are overall higher than for the whole study population. This is of interest as these are primarily nurse run services with a higher level of involvement in situations of end of life care than many of the services with doctors trained in PPM. It is not possible within the confines of this research to comment on whether there is a difference in the end of life care given in these alternative approaches. It is interesting to note that although there is only one example of each, they are the only hospices which report always being able to accept urgent requests for transfer of a dying child, both to an inpatient hospice and to home. This may indicate a more robust approach to planning for capacity to respond to these requests 24/7, made possible by comprehensive 24/7 cover by nurses able to work across inpatient hospice and community settings.

In summary it has been possible to draw some conclusions on the impact of specialist PPM in children's hospices from the study findings. The integration of findings has strengthened the classification of hospices as regional specialist and regional non-specialist showing distinct differences in activity and response. As one of the defining features in distinguishing these services was the level of specialism in PPM of the doctors, as well as the numbers of doctors and doctors' working hours, it could be hypothesised that the difference in their response and activity is a result of the increased level of specialist PPM. However, in order to accurately assess the impact of the different classifications of PPM service provision it would be necessary to use validated outcome measures of CPC, either prospectively or retrospectively if sufficient data were available. Such outcome measures are being developed and there is a growing body of evidence around their importance and usage (Downing et al. 2018). Gathering parents', children's and young people's views would be paramount as discussed in Chapter Fourteen. It would also be important to quantify and describe the contribution a doctor trained in PPM makes in practice in these situations within the holistic, family focused care offered by children's hospices. Only then could definitive conclusions be drawn as to the impact of PPM within children's hospices.

12.8 Chapter summary

This chapter provided a discussion of the contribution the research findings make towards knowledge and theoretical development in relation to the role of medical care within children’s hospices. The contribution of a foundational evidence base regarding detail of PPM service provision within UK-based children’s hospices at the time of data collection and development of a classification of PPM service provision within children’s hospices were discussed. Historical concerns around the *“over medicalisation”* of children’s hospice care were reviewed and progression of the biomedical model to a biopsychosocial model of relevance to palliative care explored. Current thinking on new models of palliative care were referenced, with a critique of the place for a PPM based classification of children’s hospices.

A case was made for the position of these research findings within the on-going debate as to the definition of specialist CPC services. An attempt was made to reconcile the issue of whether children’s hospices can be considered ‘specialist’ with the low level of specialist PPM training of their doctors identified within this study. Finally the contribution of the findings in relation to the impact of PPM on the response and activity of children’s hospices was reviewed with particular reference to the distinct role of the regional-specialist children’s hospices. The following chapter goes on to discuss findings in detail with reference to the implications in practice, development of services and education in children’s hospice care.

13 Implications of findings on the development of practice, services and education

13.1 Chapter introduction

This chapter discusses the key findings from the qualitative, quantitative and case scenario mixed methods analysis, exploring the relevance to the current climate in CPC. Firstly, the diversity of medical provision within children's hospices is discussed highlighting implications for equity. The relevance of findings in relation to the workforce of children's hospices is presented noting the predominance of GPs and exploring the role of nurses in medical service provision.

In Chapter Three the numbers and needs of children who could benefit from children's hospice care were reviewed. Most recent estimates suggest there to be 49,000 children (0 – 18 years) in the UK with a life-limiting or life threatening condition (Fraser 2012; Chambers 2018). However, in England and Scotland the prevalence of children with these conditions has been shown to be rising year on year (Fraser et al. 2012; Fraser et al. 2015). A recently published report (Fraser et al. 2020) confirms a further increase in prevalence of children with life-limiting conditions in England to 66.4 per 10,000 population of 0 – 19 year olds. This chapter goes on to discuss the findings from this study supporting widespread anecdotal and limited research evidence of the increasing complexity of care needs of these children.

The medical service provision that children's hospices offer in practice is explored with particular relevance to phases where a child with a life-limiting condition becomes unstable, is deteriorating or dying The unique challenges of caring for a child at the end of life at home and the limitations of children's hospices' involvement are a striking finding from the study and are contrasted with national guidance and policy.

The implications of these research findings in practice are discussed throughout. Finally a rationale is laid out for the need to preserve the holistic, multidisciplinary philosophy of children's hospices whilst positioning excellent medical care at the heart. The importance of integration of CPC services is discussed, including suggesting the possible application of the geographical-specialist classification of PPM in children's hospices to a networked approach to CPC.

13.2 Diversity in PPM service provision in children's hospices

The children's hospice movement has been led by individual initiative and independent pioneering, predominantly supported by charitable fundraising. This has led to the diversity in approaches to PPM service provision as evidenced by this study. Although it is accepted that there is not one 'right way' to provide CPC (Jones and Wolfe 2014) there is a recognised need for equitable provision of services (DH 2008). The original guidelines for good practice in children's hospices (Worswick 1995; Worswisk 2000) appear to have become redundant following the merger between the Association of Children's palliative care (ACT) and Children's Hospice UK in 2011(TfSL 2011). Detailed documents now exist in relation to standards in CPC (Chambers 2018) and end of life care (NICE 2016c). However, although under a system of governance and regular inspection by the Care Quality Commission (Help the Hospices Commission 2013) there are currently no agreed standards or expectations specifically for children's hospices. Therefore with a lack of steering and clarity at a national level, particularly in their early years of operation, children's hospices have developed a wide range of approaches to service delivery, including PPM service provision.

Findings from this research study evidenced diversity in PPM service provision in participating children's hospices across all aspects of data collection: the numbers of doctors employed, the hours worked, the level of specialism and access to 24/7 specialist PPM advice. Quantitative data (Chapter Seven) demonstrated that participating hospices employed 0-13 doctors each, providing 0-120 hours medical presence weekly plus on call. 159 doctors were identified as working in children's hospices, of these only 27.5% had specialist training in PPM. The majority of children's hospices (67.9%) did not have involvement from a PPM consultant. Qualitative data provided a picture of the depth and detail of this diversity, within the overarching theme: *Diversity in approaches to PPM service provision* (Chapter Eight). This covered the configuration of the participating hospice services, the approach to accessing 24/7 PPM advice and the diversity in approaches to outreach.

Given national guidance and policy recommendations for integrated CPC services with access to PPM advice (Craft and Killen 2007; Aidoo and Rajapakse 2018; Chambers 2018), it is of note that half of the standalone community hospice services interviewed had no formal arrangement for medical service provision either at a generalist or specialist level. All the inpatient units participating reported a system for medical service provision but quantitative and qualitative data (Chapters Seven and Eight) from this study demonstrated a vast diversity in configurations of these services. Based on a previously collated and analysed survey (Frost 2013), possible configurations of medical service provision were predefined. Over a quarter of participating hospice services did not fit into the predefined configurations, and for those that did, none of the service configurations were alike.

The need for a classification of approaches to PPM service provision in children's hospices as discussed in Chapter Nine was therefore evident. This could be developed and used in practice as a foundation to ensuring both equity in access to PPM within children's hospices and consistency in expectations for service delivery. The original guidance for children's hospices included statements of the need for symptom control to aim to provide comfort and to improve quality of life and for care to be continued when child is dying (Worswick 2000c). This study evidenced limitations and at times an absence in the ability of some of the participating hospices to provide this care. One of the fundamental needs for the children's hospice sector is to be clear in the expectation that for a service to be termed a children's "hospice" there must be the intention and capacity to respond to the these needs for symptom control and for end of life care for children with life-limiting conditions in their local population. This recommendation is highlighted in Chapter Fourteen, section 14.2.

13.3 Inequity in children’s hospice and PPM service provision

In addition to overall diversity, an inequity in numbers of children’s hospices and PPM resources across the UK were identified through quantitative data analysis presented in Chapter Seven. Findings from this study determined more PPM resources in the south of the UK compared to the north. This included a higher number of children’s hospice services, doctors trained to level three and level four in PPM and consultants in PPM in the south of the UK (Chapter Seven, Table 7.25).

Socio-economic inequalities are observed in almost all aspects of child physical and mental health (Pearce et al. 2019). Children living in more disadvantaged socioeconomic circumstances are known to experience worse health than their peers (Pearce et al. 2019). Social determinants of health (Bronfenbrenner 1979) are multi-layered, healthcare resources are a factor but are considered of secondary importance to parenting, the health of parents, household and community resources (Pearce et al. 2019). The presence of a north-south divide the UK as a whole and England in particular, is well evidenced in terms of economic and health-related disparities (Buchan et al. 2017; Kontopantelis et al. 2018). Inequity in NHS funding is topical, particularly concerning primary care, with perception of a north-south divide (Burch 2018). Advocating for more equitable resource provision is recommended as a strategy to tackle these inequities in child health (Pearce et al. 2019).

Findings in relation to inequity in children’s hospices and PPM service provision (Chapter Seven) evidence a further dimension to the north-south divide in healthcare resources, within the field of CPC. This adds weight to the argument for a classification of PPM service provision within children’s hospices to be developed and applied in practice. This could include coordination of the numbers and location of children’s hospices and the distribution of PPM resources into the future, to ensure a more equitable and standardised provision.

13.4 The workforce of children's hospices

One of the standout findings from this study was that in spite of the recognition of PPM as a sub-specialty of paediatrics in 2009 (Hain et al. 2012) in reality the medical workforce of children's hospices predominantly comprises of GPs. In addition general practice organisations are the highest employer of doctors working in children's hospices. In contrast, as demonstrated in the quantitative findings in Chapter Seven, the majority of children's hospice services (67.9%) in the study did not have a working relationship with a consultant in PPM.

NICE (2017) guidance for end of life care for children (Aidoo and Rajapakse 2018) was introduced in the lifetime of this project, with specific recommendations regarding access to specialist PPM provision. This study gives a benchmark of the involvement of consultants in PPM in children's hospices prior to this guidance. Findings will therefore enable comparison following the introduction NICE quality standards (NICE 2016b) regarding children's hospices' access to specialist PPM provision. The findings support the need for consultants in PPM and children's hospices to consider how their services inter-relate, in order to achieve a fully integrated approach to CPC. This would enable a return to the original vision for specialist PPM service provision to be positioned within holistic, child-centred, family-focused care (Hain 2004).

At the time of data collection there were 15.7 whole time equivalent consultant posts in PPM (Hunter 2017). Given that the number of children's hospice organisations at this time was 38 and has subsequently risen to 54 (Chambers 2018), numbers of children's hospices remain significantly higher than consultants in PPM. The resulting shortfall in consultants in PPM, is a challenge which is likely to be on-going, as training posts have been limited (Mellor et al. 2012). This was reflected in the qualitative data in the main theme: *Challenges facing medical service provision* (Chapter Eight). The discrepancy between number of consultants in PPM and numbers of children's hospice services mean that innovative and integrated approaches will be needed to enable fulfilment of the quality standards set out by NICE (2017).

13.5 Implications for education and training

The findings have important implications for the training and education of doctors working in the field of CPC. Until now the focus has been on specialist training (RCPCH 2010). Data from this study demonstrated a high proportion of GPs and limited specialist training in PPM of doctors working in children's hospices (Chapter Seven). Therefore there is now a clear mandate for improved access to resources for training and education for all doctors working in children's hospices, in particular GPs.

It is now 15 years since the landmark study into the educational needs of children's hospice doctors (Amery and Lapwood 2004). This led to the development of the combined curriculum that has subsequently been reviewed and updated to a second edition in 2015 (APPM Education Subgroup and RCPCH 2015). The combined curriculum was developed jointly by the APPM and RCPCH and provided the first recognised educational framework in PPM for use by doctors from all backgrounds working in the field of CPC (APPM Education Subgroup and RCPCH 2015). Although this combined curriculum has in some respects been super-ceded by the RCPCH sub-specialty curriculum (RCPCH 2018, 2010) this applies only to paediatricians training to be consultants in PPM and does not address the range of doctors from different backgrounds and specialisms, such as general practice, working in CPC as evidenced by this study. This research demonstrates a high number of non-paediatricians working in children's hospices and their relative lack of specialist training. These findings give a clear imperative to consider the educational needs of children's hospice doctors with recognised, accessible training opportunities, applicable to both GPs and doctors from a wide range of professional backgrounds working in children's hospices.

13.6 The role of nurses in PPM service provision

Since the opening of the first children's hospice, nurses have made up the majority of the workforce and have provided leadership in this and subsequent children's hospices (Devanney and Bradley 2012). In many aspects of this study, the way in which nursing leadership is intrinsically linked with medical leadership and service provision was apparent. From the recruitment of participants, to the way in which questions regarding medical service provision were answered, a blurring of boundaries between nursing and medical roles in PPM was demonstrated. The subtheme: *The nursing versus medical role: A fading distinction?* (Chapter Eight) described the way in which questions regarding medical service provision were answered in relation to nursing roles and the delivery of medical care was shown to be dependent in many cases on nurses.

The original recruitment strategy was for the lead doctor for each hospice to be interviewed as outlined in Chapter Five. During the data collection phase of the study it was found that not all participating children's hospices had a lead doctor and where they did, a nurse in the role of leader of care appeared to act as gatekeeper to their involvement in the research, often asking to be interviewed in addition to or with the lead doctor. Of the 31 interviews, 18 were conducted with nurses.

Gatekeeping in CPC research is well recognised as a barrier to recruitment but is generally reported to be in relation to lead clinicians acting as gatekeepers for the children and families under their care (Peake et al. 2018). This barrier to recruitment of doctors with nurses acting as gatekeepers in CPC has not previously been reported on but may represent one aspect of the historical power dynamic between doctors and nurses (Stein 1967; Stein 1990; Holyoake 2011). This power dynamic was first described by Stein (1967) as *"the doctor-nurse game"*. Stein later revisited this concept and considered "*the game"* to be redundant (Stein 1990). However the interaction and power dynamic between nurses, doctors and other member of multi-disciplinary teams has been found to be an important factor in collaboration to deliver effective multi-disciplinary care (McDonald et al. 2012) and in enabling job satisfaction (Zwarenstein and Bryant 2001; Khowaja-Punjwani and Smardo 2017).

Qualitative and case scenario findings (Chapters Eight and Ten) demonstrated the role of nurses as key to the delivery not only of overall children's hospice care but as perceived to be part of specialist PPM service provision within children's hospices. In the qualitative analysis in Chapter Eight within the subtheme: *Defining the overall hospice classification,* the hospice services were frequently self-defined by participants as *"nurse-led".* In this same chapter the subtheme: *The specialist question* gave evidence of interviewees' perceptions of nurses as part of specialist PPM service provision. A novel approach to the delivery of PPM was identified and described within the alternative classification in Chapter Nine, defined as Nurse led 24/7 PPM, this approach involved a team of nurse consultants and prescribers as an alternative to doctors.

The outworking of the roles of nurses in PPM in practice was seen in the case scenario analysis by using an explanation building approach. Table 10.1 in Chapter Ten presented a *spectrum of involvement in decision-making,* relating to the process by which a decision regarding a request for urgent transfer of a child to the hospice for end of life care was made. At one extreme the decision was reported by respondents to be a nursing decision without a doctor's involvement. In the middle of the spectrum there were frequent comments of a doctor needing to be "*informed but not involved"* in the decision, a further demonstration of the power dynamics at work in this situation. The case scenario analysis relating to aspects of the emergency transfer for care at the end of a child's life, gave evidence of nurses in medical roles in practice, in contrast to either joint working or traditional nursing and medical roles as presented in Table 10.3, Chapter Ten.

The creation of new posts and novel roles for nurses present alternative opportunities for the future of PPM service provision in children's hospice care. However, it is well recognised in national reports that nursing shortages are sadly endemic in the field of CPC (Devanney and Bradley 2012). This was demonstrated in the qualitative analysis in Chapter Eight summarised in the sub-theme: *Workforce challenges* and was reported to impact on the potential to deliver palliative care and to limit developments.

The pattern of nurses taking on roles akin to medicine has been recognised as part of the progression of the dynamic between nursing and medicine, with the remit of nursing extended and expanded to take on roles previously performed by doctors (Holyoake 2011). At the start of the decade this progression of the nursing profession by emulation of the medical profession was viewed by some as raising its status *"through extension of role rather than expanding its caring definition"* (Holyoake 2011). Holyoake (2011, page 14) went on to give this blunt critique:

> *"Nursing has been so intent on mirroring medicine that it has turned itself into little more than a clone… put bluntly nursing is not medicine and if it was it just would not be as good".*

Since this was written the expansion of nursing into traditionally medical roles has continued and is well documented in the literature in specialist fields related to CPC such as children's cancer care (Hunt 1999). In CPC the roles of nurse consultant, clinical nurse specialist and advanced nurse practitioner are becoming more prevalent but there has been minimal specific evidence in the literature of their impact on patient, professional or organisational outcomes (Maynard and Lynn 2016b). Research describing one "*specialist palliative care, nurse led service*" providing a 24/7 symptom management service has shown positive outcomes (Maynard and Lynn 2016b). An evaluation demonstrated promotion of choice in place of care and positive feedback on the role from families with service standards met and exceeded (Maynard and Lynn 2016b). Authors have previously proposed that specialist palliative care delivered in this way "*challenges the tertiary cancer model of biomedical power*" in the way described by Skilbeck and Payne (2005) and is perhaps a further demonstration of the nursing-medicine power dynamic at work. However this study related to adult palliative care in cancer services where there are distinct differences in service provision required by adults with terminal cancer in contrast to the diverse and complex population of children accessing children's hospice care.

The practice of non-medical prescribing is one of the key aspects of nurses stepping into traditionally medical roles (Tatterton 2017). The UK has been described as a world leader in non-medical prescribing (Ziegler et al. 2015) and non-medical prescribers now have equal prescribing rights to doctors following changes in legislation (Tatterton 2017). This has recently been taken a step further with non-medical prescribing being written into current standards published by the Nursing and Midwifery Council (NMC) for pre-registration nurse education so that all nursing students must have achieved this skill at the point of registration (NMC 2018a, 2018b). A survey into independent non-medical prescribing in children's hospices using an internet-based questionnaire sent to 55 hospices, received responses from 29 staff representing 20 hospices (Tatterton 2017). 28 respondents were registered nurses and one a pharmacist. Fourteen of the participating hospices had non-medical prescribers with a total of 39 non-medical prescribers (Tatterton 2017). Comparing this to the findings of the study reported in this thesis, 10 of the 28 participating hospice services had at least one non-medical prescriber with a total of 39 non-medical prescribers.

Tatterton's (2017) study found that the non-medical prescribers most frequently prescribed in relation to symptom management, with pain, anxiety, constipation and nausea most frequently cited (Tatterton 2017). Of the respondents, 37.5% reported prescribing independently for symptom management and 31.3% during end of life care. The benefits perceived by participants of this non-medical prescribing included possible improvements to service sustainability and choice in place of care (Tatterton 2017). Associated barriers related to confidence of non-medical prescribers in prescribing for children with a wide range of ages and conditions, use of off label medications and a lack of evidence base for prescribing. Additionally the impact on nurses' workload and a lack of supervision, peer support and on-going professional development were found to be issues (Tatterton 2017). Interestingly an organisational culture of prescribing being seen as a medical role and strategic concerns regarding the impact on the role of GPs in children's hospice care were raised by respondents (Tatterton 2017).

The data from the study presented in this thesis leads to questions as to where the dividing line between medical and nursing roles lies within PPM service provision. Further to this, the logical next question of whether a nurse compared to a doctor delivering care akin to PPM service provision has an impact on the care given needs exploration. For example is it better to have one consultant in PPM or a team of nurse consultants with specialist training able to prescribe. These questions are outside the scope of this study but have implications for future recommendations for PPM service provision within children's hospices. Within the scope of this study the intention was to explore the role and impact of doctors delivering PPM service provision within children's hospices. One of the key unexpected findings was in relation to the way in which nurses are delivering care akin to PPM and the extent, impact and implications of this warrant further research.

13.7 Access to children's hospice care for children with life-limiting conditions and their families

Taking the estimated figure of 49,000 children aged 0 – 18 years living with a life-limiting condition in the UK (Fraser 2012; Chambers 2018), findings indicate that a large proportion of these children and their families are not accessing hospice care. Quantitative data presented in Chapter Seven indicates that the total caseload for participating children's hospices (5,806) is a fraction of the estimated total number of children who require access to children's hospice care. This is the case even when taking into account that the figures represent the caseloads of 66% of all children's hospice organisations in the UK at the time of data collection and included young adults.

Studies in the US have echoed this finding with reports of limited access to children's hospice care (Johnston et al. 2008; Vesel and Beveridge 2018). One early study identified that of the children in need of hospice care only 10% received this care (ChiPPS 2001). One recent study cites possible reasons for this as including limited availability and adequacy of CPC and logistical challenges, alongside factors in relation to families, in particular their cultural values and priorities (Pentaris et al. 2018). The words 'hospice' and 'palliative' have been recognised as barriers that can prevent families accessing much needed support (Harrop and Edwards 2013; Twamley et al. 2014).

Professionals participating in this research study spoke of finding an acceptable 'way in' to enable hospice care to be provided. Qualitative data presented in the main theme: *Developing the delivery of children's hospice care* (Chapter Eight), demonstrated that this has resulted in innovations that are accessible to families, without them having come to the point of acceptance normally required for referral to a hospice. Professionals, in particular lead clinicians, can be the barrier to early integration of CPC and hospice care (Twamley et al. 2014;

Dalberg et al. 2018). This has been identified to be in relation to professionals equating palliative care to end of life care, resulting in late or missed opportunity for referral (Twamley et al. 2014). Dalberg's (2018) study concluded that there is a need for education of both families and providers of care in the benefits of children's hospice and palliative care.

Qualitative findings from the sub-theme: *innovations in hospice services* within the main theme: *Developing the delivery of children's hospice care* (Chapter Eight), indicate that some groups of children have been targeted as a focus for children's hospice care. Particularly evidenced in this study were children with cancer and neonates. In contrast, other groups of children's access to hospice care appears to have been deliberately reduced as shown in the subtheme: *changing parameters of care* within the overarching theme: *Increasing complexity of care needs* (Chapter Eight). This has been done through the introduction of specific criteria within ACT category four (ACT 1997; Harrop and Edwards 2013) where it can be difficult to predict whether or not a child will survive into adulthood. In the past these children made up a significant proportion of children's hospice provision (Worswick 1995) therefore this represents a definite change in the parameters of care in some services.

This balance between providing short-break care for children with life-limiting but longer-term conditions with providing care for children at the end of life was identified as one of the on-going tensions for children's hospices. This was evident in the case scenario analysis presented in Chapter Ten where responses to case scenario two were shown by an explanation building approach to be influenced by *conflicting priorities*, namely the conflict in providing short break care versus responding to requests for emergency transfer when a child is dying. This raises the fundamental question as to whether it is possible to sustain this dual intention set out by founders of the first children's hospice to provide both care at the end of a child's life and short-break care for children with severe long-term illness (Burne et al. 1984). Or indeed whether providing this short-break care as part of children's hospice care is the best and most equitable approach in terms of the wider need for short-break care for children with complex health care needs.

All of the children's hospices represented in this study provided a mixture of short-break care, either within an inpatient hospice or in the community, alongside some form of emergency provision for when a child is unstable, deteriorating or dying. However as previously discussed, the qualitative and quantitative findings demonstrated wide ranging PPM service provision, epitomised in the overarching theme *Diversity in approaches to PPM service provision* (Chapter Eight). In addition, as discussed further later in this chapter the case scenario analysis (Chapter Ten) showed a diversity in responses by hospice services to situations where a child is unstable, is deteriorating or is dying. This diversity in provision and response may relate to the balance of the two strands of short-break care and responsive care within children's hospices, and could be either a cause or an effect of the PPM service provision.

13.8 Increasing complexity of children in need of hospice care

The data gathered in this research study aligns with published data around the increasing numbers of babies, children and young adults who require palliative care and are therefore in need of the support of children's hospices (Fraser 2012; Fraser et al. 2012; Chambers 2018; Fraser et al. 2020). The analysis concurs with national recognition of the increasing medical complexity of this population of children (Craft and Killen 2007; Pinney 2017), which is often alluded to but is difficult to capture in routine data collection or in research.

The hospice services in this study were shown to support children dependent on a range of technology, as presented in Chapter Seven, the most frequent of which was non-invasive ventilation, with 96.4% of participating hospices supporting children with this care need and up to 40% of the children on the hospices' caseload requiring non-invasive ventilation. This finding resonates with literature confirming a global increase in technology-dependent children, in particular children dependent on ventilatory support (Tearl et al. 2006; Wallis et al. 2011). Wallis's (2011) publication cited an eight-fold increase in children dependent on long-term ventilation at home over ten years between 1998 and 2008. This data was collected by a single point UK wide census and confirmed non-invasive ventilation as the most frequent form of ventilatory support (Wallis et al. 2011).

Respondents in the study reported on in this thesis commented on the role of hospices as part of a ‘step down’ process for these technology dependent children, providing a transition in place of care from hospital to hospice and finally to home. This was described in the subtheme: *changing parameters of care,* within the overarching theme: *Increasing complexity of care needs* (Chapter Eight). Published research based in one UK hospice evaluated this practice for children dependent on ventilation and identified multiple benefits perceived by parents and professionals (Price et al. 2018). However a tragic incident in relation to management of a young person on ventilatory support in a children’s hospice has highlighted the risks, governance and training paramount to ensuring safety in the care of technology dependent children (Care Quality Commission 2017).

The complexity of life-limited children’s health care needs is reflected in literature regarding the PICU population. A recent national UK-based study concluded that life-limited children are a large proportion of the PICU population (Fraser and Parslow 2018). The study demonstrated that children with life-limiting conditions made up 57.6% of admissions and 72.9% of deaths on PICUs. In addition children with life-limiting conditions were found to be 75% more likely to die on a PICU than children without a life-limiting condition.

The diversity in children’s hospice provision was again demonstrated with a wide range in services offered and the caseloads supported. Whereas some hospices supported children with multiple complex health care needs, others reported a less medically complex caseload. This was encapsulated in the complexity score for hospice caseloads developed and presented in Chapter Seven. The complexity scoring evidenced a range in caseload complexity from low to high across the participating hospices. Qualitative data in Chapter Eight demonstrated the interplay of factors contributing to complexity within the overarching theme: *Increasing complexity of care needs,* with respondents describing increasingly complex conditions, interventions, expectations of choice of treatment and place of care and escalating ethical issues.

Reasons for this increase in numbers and needs of children with life-limiting conditions were also highlighted by the findings. Literature cites an increased life expectancy as one reason for rising prevalence of children with life-limiting conditions (Fraser et al. 2012). This was perceived to be a factor by participants in the study presented in this thesis. It has been recognised for some time that infants have the highest mortality rate of all ages under 25 years (Sidebotham et al. 2014) and that they have historically been under represented in the provision of CPC. Qualitative findings from this study within the subtheme: *changing parameters of care* (Chapter Eight), suggested that this is changing over time with increasing use of hospice care by infants and their families. This assertion is supported by one US study that identified more than 15% of infants with life-threatening conditions in one state accessed hospice care between 2007 and 2010 (Lc Fau - Newnam 2017). In the past those working in children's hospices were rarely involved with a child and family at the time of diagnosis, but this is increasingly becoming a possibility with both earlier referrals and antenatal diagnosis, as described in a perinatal initiative by one UK based hospice (TfSL 2018).

As the limits of what is possible expand, new questions arise concerning ethical decision-making in initiating, withholding and withdrawal of interventions (Larcher et al. 2015). The findings, presented within the sub-theme: *Ethical issues and facilitated decision making* (Chapter Eight) evidence requests for hospices to be involved in the ethical decision making process and at times in the practical enactment of a decision to withdraw a treatment. There were no reports in this study of hospice involvement in decisions to initiate long-term ventilation. Research into the perspectives of doctors involved in decisions regarding long-term ventilation, highlight the physical, emotional and social burden of this intervention and the need for interdisciplinary supported decision making, focused on families' goals (Edwards et al. 2017). These ethical decisions are sensitive and challenging for all concerned (Larcher et al. 2015) and are part of the changing climate in which children's hospices now operate. It is recommended that decisions are made in partnership between parents and all members of the child health team and are based on forming a consensus using an ethical and legal framework (Larcher et al. 2015). The guiding principle remains that of a child's "*best interests*" (Larcher et al. 2015). Sadly, breakdown of relationship between parents and the medical profession in decisions around with-holding or with-drawing life-sustaining treatments has been frequently reported in recent years (Hain 2018). Hain's (2018) article proposes a national Children's Interests Panel to agree what is in a child's best interests for these situations.

Findings from this study in relation to the increasing complexity of care needs of children receiving children's hospice care and the associated ethical decision -making, highlight the need for doctors with specialist training in PPM to be integrated within children's hospices care. PPM education and training involves developing knowledge and clinical competencies in the field of ethical decision making in partnership with parents (RCPCH 2010). As evidenced these are becoming essential skills within CPC, the need for which has been reported by leaders of hospice care participating in this study. Without such specialist knowledge and skills in complex ethical dilemmas, children's hospices may find themselves out of their depth in an increasingly challenging ethical climate.

13.9 Abilities of children's hospices to respond to the medical needs of children with life-limiting conditions

As children's hospice care and PPM have 'come of age' there have been numerous review articles published in relation to the work of symptom management and care at the end of a child's life (Harrop and Edwards 2013; Hunter 2017; Aidoo and Rajapakse 2018). There is however, a dearth of published research into the response and role of children's hospices in these situations. Although it is widely acknowledged that children's hospices take part in these aspects of PPM (Chambers 2018), little is known about the degree to which the hospices contribute and the parameters or delivery of this provision. Since the published analysis of the first year of the world's first children's hospice (Burne et al. 1984) there have been a few single hospice studies (Taylor et al. 2010; Postier 2014) but these have focused on demographics, survival and mortality (Taylor et al. 2010) or on the impact of hospice and palliative care on hospital admissions (Postier et al. 2014). There have been no other studies investigating the responses of UK or international children's hospices in clinical scenarios and comparing these responses across the hospices.

Overall the case scenario findings presented in Chapter Ten demonstrated the outworking in practice of the diversity in PPM service provision in children's hospices across the UK. This was evidenced in the cross case analysis themes outlined in Chapter Ten: *Hospices in Action* which covered the extent and limits of the hospices' responses and: *The importance of planning*, which demonstrated the use of symptom management plans, advanced care plans and parallel planning in practice.

The diversity in responses by the hospices to the case scenarios was evident in all the defined phases of illness. In the management of unstable or deteriorating symptoms there were considerable contrasts in the responses, indicating markedly different contributions by children's hospices to the PPM delivered in practice and also an inequity in the access to PPM advice for children with life-limiting conditions. Where one hospice reported arranging a "*symptom control admission"* and leading complex aspects of medical management, other hospices stated a need to transfer a child receiving short-break care with unstable symptoms to hospital. The range of specialist PPM skills in doctors working in hospices was seen in practice with a range of professionals with a varying level of PPM training assessing children, taking part in advance care planning and symptom management plans and prescribing medications. The potential for consultants in PPM as a resource for symptom management advice and clinical review was evident but this was by no means equitably distributed in practice. As demonstrated in the previous chapter, a children's hospice classified as regional-specialist, with an increased level of PPM service provision did have an impact on the response, enabling the hospice service to provide specialist advice, review and at times admission in these phases of instability and deterioration.

Abilities for children's hospices to respond to the dying phase of a child's illness have been found through this research to be diverse and limited. Less than half (41.7%) of the participating in-patient hospices could accept an urgent request to accommodate a child at the end of their life. Significantly fewer (17.8%) could accept an urgent request to care for a child at home at this time and importantly 14.2% reported that they could never respond to this type of request. As outlined in the previous chapter, hospices classified as regional-specialist did have an impact on the response to these urgent referrals for children in the dying phase, with a greater ability to accept the referrals and a higher activity level in terms of caring for dying children in an inpatient hospice setting. Importantly different geographic-specialist classifications of PPM service provision did not impact on hospices' abilities to respond to urgent referral to support a child at this time in the home environment. This is discussed further in the later section on the challenges of end of life care in the home.

It was in these scenarios that the tension of providing short-break care alongside emergency care was most evident, in particular in responses to the phases of deterioration or dying. As discussed above this calls into question the uncomfortable issue as to whether children's hospices can continue to successfully fulfil this dual purpose of acting as providers of short-break care alongside responsive care when a child with a life-limiting condition is deteriorating or dying. The data collected for this study did not enable an analysis of the balance of these types of provision and further research is needed into the balance and flexibility of capacity in children's hospices for short-break care and responsive care.

In relation to the provision of specialist PPM advice 24/7 in practice, the scenarios confirmed the outworking of the quantitative and qualitative findings concerning the limitations of this 24/7 provision discussed in full in the previous chapter. For a child cared for during the dying phase in an inpatient children's hospice the recommended provision of 24/7 consultant PPM advice was available for only 8.3%. For a child cared for at home this figure was 17.6% of the smaller group of participating hospices able to support this care. That these figures are so low raises questions as to the wisdom of the implementation of the guidelines prior to research based evidence as to the need for or impact of provision with such vast resource implications (Mitchell et al. 2017). It also raises the question as to whether this recommendation should be aspired to and is possible to achieve sustainably and equitably or whether other approaches should be sought, including improved training of existing hospice doctors with utilisation of regional clinical networks for integration of consultant PPM advice.

The theme: *the importance of planning* from the cross case thematic analysis (Chapter Ten) runs throughout the research findings and gives evidence of the ways in which children's hospices use the tools of advance care planning and symptom management plans in practice. The use of these plans and the concept of parallel planning have been widely discussed (Harrop and Edwards 2013; Bluebond-Langner et al. 2017; Harrop et al. 2017; Lotz et al. 2017; Popejoy et al. 2017). However there is limited published evidence as to their use in children's hospices and their impact on palliative care in these settings. The case scenario data demonstrates that these tools are vital to the work of children's hospices in supporting children with life-limited conditions at times of instability, deterioration or dying.

It is an obvious, but important point that those hospices able to respond to requests for emergency transfer or to situations where a child has unstable or deteriorating symptoms were found to be those that had planned to do so. This planning was seen to be in the form of overall strategy, collaborative working and in the details of provision of emergency capacity in terms or staffing and beds with a robust system for 24/7 PPM advice. The contrasting issues of 24/7 cover provided by just one person, or a lack of planning, were evident as limiting factors in enabling a response. It was also clear that a number of the hospices represented in the study were not intended to be 24/7 responsive services and the tension of this in responding to children with unpredictable and 24/7 needs was palpable. Application of the classification of PPM service provision in children's hospices in practice would enable clarity in provision of 24/7 PPM advice and adherence to NICE guidance. On a practical level this would enable a family receiving children's hospice care to have a clear expectation as to whether the hospice will be able to respond to their child's needs at times of unstable symptoms, deterioration or at the end of their life.

Prescribing was found to be an important issue in the case scenario responses as described in the cross case analysis theme: *Prescribing and Prescribers* (Chapter Ten). The diversity of responses in practice was evident in the range of prescribers. Particular challenges in relation to planning in prescribing, professional boundaries and safety were raised. As described above, 39 non-medical prescribers were identified in this study and research confirms an increasing number of non-medical prescribers in children's hospices (Tatterton 2017). As the numbers and complexity of children with life-limiting conditions have increased the associated increase in complexity of medication regimens, modes of delivery and new medications was evidenced in the qualitative findings in the subtheme: *Increasing complexity of interventions* within the overarching theme: *Increasing complexity of care needs* (Chapter Eight). This has implications for the need for specialist training of prescribers in this field and raises concern in relation to the evidence presented in this study of a lack of specialist training of doctors working in children's hospices.

13.10 Challenges and limitations in end of life care at home

Over the past twenty years there has been an increasing drive from policy-makers to increase the numbers of children cared for in the community and to support the parents of children requiring palliative care in their choice of place of care (Craft and Killen 2007). This applies most importantly to end of life care but also for care throughout life. The recommendation for home as the preferred place of death was made without a valid evidence base. Further rigorous research has been recommended with parents, children and young people and their siblings (Bluebond-Langner et al. 2013) and is one of five NICE research recommendations (NICE 2016a). Current guidelines recommend that where possible children should be cared for in the place of the family's choice and as previously discussed a quality standard now exists for end of life care of children and young people at home (NICE 2016b).

One of the standout aspects of the case scenario responses was the limitation in participating hospices' abilities to support the urgent transfer of a child to home for care at the end of their life. This was demonstrated clearly in that of the 28 participating hospice services, 17 (60.7%) gave responses to the case scenario relating to their response to a request to support the urgent transfer of a child to their home for end of life care. Of these only 17.8% were always able to respond to this type of request. The responses presented within the cross case analysis theme: *The unique challenges of care in the home* (Chapter Ten) showed inconsistency, inequity and confusion around provision of this end of life care at home which related to all aspects of care in particular the PPM service provision. As referred to in the previous section, findings give strong evidence that at the time of data collection the equitable access to 24/7 advice from a consultant in PPM for children dying at home falls far short of the quality standard (NICE 2016b).

13.11 Children's hospice care: a rapidly changing field

In contrast to some of the limitations in children's hospice care identified by this research, qualitative data analysis demonstrated a 'can do' approach evidenced in the overarching theme: *Increasing complexity of care needs* with a vast number of developments in children's hospice services reported within the main theme: *Developing the delivery of children's hospice care* (Chapter Eight). In Figure 8.1 relating to the overall story of the qualitative analysis this was described as: *a dynamic system with a constantly developing approach to hospice care.* The developments described were multifaceted and included an increasing interconnectedness both between hospice services and with NHS CPC teams described within the main theme: *Relationships between services and professionals* (Chapter Eight). It is likely that the increasing complexity of the population of children in need of hospice care identified in these findings will further hasten the speed of change.

One of the main criticisms of this study is how quickly the findings will have become out of date. The data presented in this thesis gives a 'snap shot' of the PPM service provision within children's hospices at the point of data collection. This would undoubtedly look different if repeated. However in view of the major gap in any evidence base in this area, the research provides a foundation for developing this evidence and in line with the pragmatic underpinning philosophy could enable positive change within the field of children's hospice care.

13.12 A need for integration of services: the role of managed clinical networks

It has long been agreed that to meet the needs of life-limited children a comprehensive, multi-disciplinary team, working in a coordinated, cooperative and integrated manner is needed (Maynard and Lynn 2016b). The development of clinical networks aims to ensure equitable provision of services and improve the care for the child by enhancing collaboration between primary, secondary and tertiary professionals and their organisations (Baker and Lorimer 2000; Cosh 2012; RCPCH 2012). In England it is recommended that specialist CPC services be commissioned and delivered within managed clinical networks (RCPCH 2012; Maynard and Lynn 2016b). It has been proposed that children’s hospices are best placed to lead this network development (Vickers et al. 2007). This suggestion was made in view of the established relationship between children’s hospices, commissioners and statutory services and their status as independent organisations unimpeded by formal statutory boundaries (Maynard and Lynn 2016b).

The research findings presented in this thesis have shown examples of where children’s hospices are part of this developing network of CPC provision. However overall, the findings demonstrate that there is still a long way to go to achieve genuine integration of PPM and children’s hospice services to ensure equity in all aspects of provision. One of the clear needs identified is for pragmatic solutions to ensuring equitable access to consultants in PPM whilst enabling GPs and paediatricians working locally to achieve and maintain training, recognition and practice in PPM. At a time when services are perceived to be in competition for funding it is vital to strive to hold together the holistic, child and family centred, multidisciplinary philosophy foundational to the children’s hospice movement with the timely integration of PPM. The geographical-specialist classification of PPM service provision within children’s hospices could be used as a foundation for future recommendations for a networked approach to PPM within children’s hospices in order to promote equity and maximum positive impact for children with life-limited conditions. This is discussed in the final chapter regarding conclusions and recommendations arising from this study.

13.13 Chapter conclusion

This chapter provided a discussion of findings from across the study in terms of their implications for practice, service development and education. Firstly the diversity of PPM service provision in children's hospices and the evidence of inequity across the UK were positioned as arguments for the research-based classification arising from this study to be developed and applied in practice. Findings were reviewed in relation to the workforce of children's hospices with particular reference to a mandate for the development of education and training for GPs and other hospice doctors. The unexpected findings in relation to the dynamic between nurses and doctors within PPM provision were considered including presenting a historical perspective and highlighting a need for future research. The implications of the evidence of increasing numbers and complexity of care needs of children with life-limiting conditions were considered in terms of both access to children's hospice care and implications for children's hospice PPM provision.

The contribution of this study to a foundational evidence base, regarding how children's hospices contribute to the care of life-limited children in phases of instability, deterioration and dying was discussed. The significant limitations exposed by the study in relation to participating hospices' responses were explored. In particular the gap between policy, guidelines and current practice in the children's hospice-based provision of care for children who are dying was highlighted. The question as to how to address the shortfall in access to 24/7 PPM advice was posed with suggestion of the application of the geographic-specialist classification to a networked approach to PPM within children's hospices. This and other recommendations arising from this research study are discussed in the following chapter.

14 Conclusions and recommendations

14.1 Introduction

This study used a convergent mixed methods design to explore the role of PPM in children's hospices across the UK. The mixed methods design enabled an investigation of the approaches to PPM service provision within participating children's hospices. Quantitative, qualitative and case scenario data regarding the individual hospices' activity, detail of the medical service provision and responses to hypothetical clinical case scenarios were collected in parallel using a mixed methods survey conducted by telephone interview with leaders of hospice care. Analysis and subsequent integration of quantitative and qualitative findings led to the development of a geographic-specialist and alternative classifications of PPM service provision within children's hospices. Analysis of case scenario data using a comparative case study approach enabled exploration of the hospices' responses at times when a child with a life-limiting condition has unstable symptoms, is deteriorating or is dying. Combining the geographic-specialist and alternative classifications with data relating to the hospices' activity and case scenario responses gave an evaluation of the impact of PPM service provision.

Findings overall indicate a diversity in approaches to PPM service provision within children's hospices across the UK alongside an increasingly complex population of children with life-limiting conditions in need of hospice care. Inequity was demonstrated both in terms of resources across the country and a limited and diverse response from hospices to situations where a child with a life-limiting condition has unstable symptoms, is deteriorating or is dying. In view of these findings, this concluding chapter builds upon the previous chapter's discussion of implications of findings and makes recommendations relevant to policy, practice, guidelines, education, training and future research before finally summarising how the initial research aims were addressed.

14.2 Recommendations for policy, practice and guidelines

14.2.1 *Re- thinking the definition of specialist CPC services*

The tensions between the children's hospice movement and PPM may have been fuelled by a definition of specialised CPC that focuses predominantly on the presence of a consultant in PPM (NICE 2016c). Although The NICE (2016b) quality standard also includes a nurse with expertise in CPC, a pharmacist with expertise in specialist CPC and experts in child and family support as members of a specialist CPC team, the focus in terms of guidelines, commissioning and research has been on consultants in PPM (NHS England 2013; Mitchell et al. 2017; Chambers 2018).

As outlined in Chapter Nine and discussed in Chapter Twelve the definition used for specialist children's hospice services developed within this study related not only the presence of a consultant in PPM but the overall hours of medical presence, the level of specialism in PPM (APPM Education Subgroup and RCPCH 2015) for all doctors, the ability to access PPM advice 24/7 and in terms of regional services the ability to act as a resource for PPM advice and review and the way in which the hospice interacts with NHS services. In intersecting with a geographical classification, the definition of specialist PPM included the way in which regional and local services are intended to interact in a networked approach (RCPCH 2012). Whilst regional specialist children's hospices were predominantly defined as those with a consultant or level 4 PPM trained doctor, local specialist children's hospices were defined as those with a link to a consultant in PPM with level 3 trained PPM doctors at the hospice.

The research based geographic –specialist classification of PPM service provision within children's hospices therefore provides a broader, integrated definition of the PPM aspect of a specialist children's hospice. As this relates to only one aspect of specialised children's hospice care it could be developed and considered alongside other aspects of service provision giving a definition for a breath and depth in specialist skills in children's hospice care (Hain 2013).

14.2.2 *Recommendation for standards and guidelines in children's hospice care*

In the past decade it has been recommended that children's hospices consider their '*core offer*' and debate has been on-going as to the balance of emergency and short-break care (Help the Hospices Commission 2013; TfSL 2013). These research findings indicate that at the time of data collection there was no resolution to these issues and personal experience indicates that this has not changed. The call for a "*co-ordinated national approach to regulation of the number, location and professional accountability of children's hospices" (Hain et al. 2012)* remains unanswered. This research has shed light on inequities across the UK and between individual children's hospice services. Such that whether a child with a life-limiting condition can access children's hospice care, whether they encounter specialist PPM within that children's hospice and ultimately whether they can benefit from children's hospice care at times when they are unstable, deteriorating or dying is a matter of great uncertainty, dependent on where they happen to live.

Whilst the 2018 Guide to Children's Palliative care (Chambers 2018) states that *"all children's hospices provide end of life care"* the findings from this research suggest that this is not the case and there is no mechanism to ensure that this care is provided responsively and equitably by children's hospices across the UK. Quality standards (Aidoo and Rajapakse 2018) will not impact on real children and families unless there is co-ordinated response from the children's hospice sector. The recommendation arising from this research is for a return to clear expectations and guidelines for children's hospice services, developed in discussion with the families and children who are in need of children's hospice care and professionals working within CPC.

A "*co-ordinated national approach to children's hospice provision"* (Hain et al. 2012) could be enabled by the application of the geographic-specialist classification of PPM service provision within children's hospices. In this way clarity would be provided as to the role and remit of regional-specialist, regional-non-specialist, local-specialist and local non-specialist children's hospices. Including a minimum requirement for a service to be classified as a hospice in the ability to provide symptom control and end of life care for children with life-limiting conditions in the local population. This co-ordination of children's hospice care could be supported by a networked approach to PPM service provision within children's hospices as described in the later section of this chapter.

The debate around the balance of short break care and emergency or responsive care at times when a child with a life-limiting condition has unstable symptoms, is deteriorating or is dying could also be addressed by clear guidance and expectations. For some children's hospices it could be that in their operation and provision they are more akin to short break services for children with life-limiting conditions and it would be beneficial to classify them as such.

The use of the geographic-specialist classification would also be a way of promoting an increased level of education and training in PPM for doctors working in children's hospices (as recommended in section 14.3), such that over time local non-specialist and regional non-specialist children's hospices could evolve to regional specialist and local specialist services or make a decision to become dedicated short break services for children with life-limiting conditions.

14.2.3 *Urgent need to review services for supporting end of life care in the home*

One of the standout findings from this research was the limitations and challenges faced by the majority of participating hospices' in supporting care of a child dying at home. Findings also evidenced that at the time of data collection access to 24/7 advice from a consultant in PPM for children dying at home fell far short of the quality standard (NICE 2016b). NICE recommends research to explore factors important to the preferred place of care and place of death (NICE 2016a). Based on evidence from this study, significant inequity in access to PPM and nursing resources in the home may be a factor in the choice of place of care for the family of a dying child. Findings demonstrated a considerable gap between policy, standards and guidelines in relation to choice of place of care as a child is reaching the end of their life and the care available

(Craft and Killen 2007; DH 2008; Chambers 2018). There is therefore an urgent need to review services supporting children at home at this time and to consider the role of children's hospice services in delivery of end of life care at home in collaboration with other services.

14.3 Recommendations for education and training

This research has important implications for the education and training of doctors working in children's hospices. There was overwhelming evidence of a lack of specialist education and training in PPM of doctors working in participating children's hospices at the time of data collection. Presentation of findings at two national conferences (Frost 2017; Frost 2018) has prompted consideration of the educational needs of children's hospice doctors. There is a clear mandate to review the current combined curriculum (APPM Education Subgroup and RCPCH 2015) and a need for recognised and accessible training applicable for both GPs and doctors from a wide range of professional backgrounds working in children's hospices.

14.4 Recommendations for future research

14.4.1 Research to explore the experiences and views of children, young people and their families concerning PPM service provision within children's hospices

The study presented in this thesis was originally intended as a two-stage project with a second phase planned to include in-depth interviews with parents and ideally children and young people. In view of the high response rate and volume of data gathered in the first stage of the research, it was decided that a convergent study design focused on the views and experiences of leaders of children's hospice care was better suited to the research aims. However the primary recommendation for future research is that the experiences of parents, children and young people be explored. These views are vital to the development of high quality services and should inform all other recommendations arising from this study. The following research recommendations are made with the acknowledgement that ascertaining the views of parents, children and young people is paramount.

14.4.2 *Further research into the impact of PPM service provision within children's hospices*

Exploration of the impact of the different classifications developed within this study on the hospices' activity and response both contributes to the evidence base regarding the impact of specialist CPC services and raises questions about the current recommendations as to what constitutes specialist CPC. There is a need for further research as to the impact of PPM service provision within children's hospices in a prospective mixed methods study using validated outcome measures of CPC and in-depth qualitative interviews with parents, young people and ideally including the voice of children with life-limiting conditions. The impact of PPM service provision could be evaluated at times of instability, deterioration and end of life care. This would require further development of measures of these phases as relevant to children's hospice care as discussed in the following section. The geographic-specialist and alternative classifications could be developed and used as a basis for assigning children's hospices to different study groups and comparing quantitative and qualitative findings between groups.

14.4.3 *Research to develop descriptions of the phases of instability, deterioration and dying relevant to children's hospice care*

The use of phases of illness has become topical in recent years in relation to NHS England's (2017) "Guidance for using Children's Palliative Care Currency", and in research into the scale of need for specialist CPC services (Jarvis et al. 2016). The four case scenarios used in this study to equate to phases of instability, deterioration and dying could be refined and tested using a Delphi-method to gather the opinion of experts in the field of CPC. The resultant descriptions could be used in research, to advocate for funding and to evidence need for services.

14.4.4 *Research into the role of nursing in PPM*

The blurring of the boundaries between nursing and medical roles in the delivery of PPM within children's hospices was a standout finding. Research is needed to explore the impact of nurses on the delivery of PPM service provision in children's hospices. Further studies could focus on the perspective of both the nurses working in children's hospices and the children, young-people and families receiving children's hospice care. Research to assess the impact of nursing led PPM in comparison to other approaches to PPM service provision is encompassed within the recommendations for research into the impact of PPM service provision using alternative classifications in comparison to the geographic-specialist classification described above.

14.4.5 *Research into the balance of short-break and emergency care provided by children's hospices*

This research highlights a need to assess the balance of short-break care and responsive care provided by children's hospices. The last data-mapping project (Devanney and Bradley 2012) identified a range in provision for short-break care with 34% of hospices offering short-breaks in the home and hospice. Of the remaining hospices, 64% offered short-breaks in the hospice and 2% in the home. There has been no study to identify whether the amount and form of short-break provision by hospices impacts on the emergency and responsive provision, or vice versa. This issue is closely related to the need for clear guidance as to the expectations of children's hospices outlined in the earlier section of this chapter. There is a wider issue in relation to equity of the provision of short-break care for children with complex health care needs that is outside the scope of recommendations arising from this study. However as there is an overlap between children with life-limiting conditions and those with complex health care needs and finite resources for short-break care this should be borne in mind as the context for further research in this area.

14.5 Application of the geographic-specialist classification to a networked approach to PPM within children’s hospices

The justification for the application of a classification of PPM service provision within children’s hospices was made throughout the previous chapter. Findings support the role and impact of consultants in PPM within the holistic provision of children’s hospice care but show that their involvement within children’s hospices has been limited. Therefore recommendations are needed as to how children’s hospices and consultants in PPM inter-relate and innovative, integrated approaches are needed to enable fulfilment of the quality standards set out by NICE (2016b). In line with existing recommendations for a networked approach to CPC (RCPCH 2012; Maynard and Lynn 2016b; NICE 2016c) the geographic- specialist classification of children’s hospices could be developed and applied in practice. This would enable the work of consultants in PPM within regional-specialist children’s hospices or tertiary children’s hospitals to be integrated with local children’s hospices and also give a motivation for doctors working within the local hospices to achieve and maintain a level of PPM education and training. It would overlap with the development of expectations and standards in children’s hospice care, providing a pragmatic solution to the need to access 24/7 advice from a consultant in PPM and to improving all hospices’ abilities to respond in situations when a child with a life-limiting condition becomes unstable, is deteriorating or dying. This recommendation aligns with the NICE guidance for managed clinical networks in CPC (NICE 2016c) and would represent one aspect of a managed clinical network facilitating the integration of PPM within children’s hospice services.

This recommendation would involve debate and further evaluation of the research- based classification developed within this study. As stated in Chapter Twelve this is a pragmatic classification based on ‘what is’ or ‘what was’ at the time of data collection. It could be used to form the basis for development of an aspirational classification or ‘what could be’, in terms of a networked approach to PPM provision within children’s hospices across the UK. The challenges inherent to this would include integrating independent charitable organisations with all the barriers that entails and consideration of a strategy to include policy and commissioning in line with this aspiration would be essential.

This recommendation is linked to the section above in relation to further research into the impact of PPM service provision within children's hospices. Findings from this study strengthened the classification of a regional-specialist children's hospice service by demonstrating the impact and role of this type of hospice in situations where a child with a life-limiting condition is unstable, deteriorating or dying. Further research, as discussed above, could inform the development of the local specialist and local non-specialist classifications. In addition, research comparing the geographic-specialist classification to alternative classifications could demonstrate the impact of PPM service provision within children's hospices delivered by teams of nurse consultants who are non-medical prescribers. This could potentially open up an alternative direction in the approach to the delivery of PPM within children's hospices, one that, as evidenced by this study, is already being used in practice.

14.6 Answering the research questions

14.6.1 *What are the current approaches to PPM service provision in children's and young adults' hospices across the UK?*

The approaches to PPM within children's hospices at the time of data collection were found to be diverse, with a low level of specialism in PPM of doctors working in children's hospices who were predominantly GPs. Inequity was demonstrated between participating hospice services and across the UK in terms of PPM resources. These diverse approaches were defined and classified based on the intersection of geographic and specialist factors. This led to the development of a geographic-specialist classification. This was contrasted to outlier approaches developed as an alternative classification.

14.6.2 *How do children's and young adults' hospices respond in situations when a child with a life-limiting or life-threatening condition has unstable symptoms, is deteriorating or is dying?*

The responses of children's hospices in these phases were found to be diverse and at times limited with demonstration of the inequity of specialist PPM in practice. In particular the response of children's hospices in supporting children to be transferred home for care at the end of life was found to be limited.

14.6.3 *Do varying approaches to PPM service provision in children's and young adults' hospices impact on abilities to respond to the needs of children with life-limiting or life-threatening conditions and their families when a child has unstable symptoms, is deteriorating or is dying?*

Comparison of the impact of the different classifications of PPM service provision within children's hospices demonstrated a distinct impact and role of hospices classified as regional-specialist in the provision for situations where a child with a life-limiting condition has unstable symptoms and is deteriorating, arranging admission for symptom management and acting as a resource for advice and clinical review in these situations. In comparing abilities to respond when a child is dying and urgent transfer to an inpatient hospice is requested, the regional specialist hospices were able to respond to this request immediately and consistently. There is need for further research to assess the impact of the classification of approaches to PPM.

14.7 Concluding remarks

This PhD study set out to explore the role of PPM in children's and young adults' hospices. This thesis began by exploring the tensions between PPM and children's hospice care. With evidence of the increasing numbers and needs of children with life-limiting conditions, it has never been more important to hold these two pillars of CPC together. A picture of the diversity of ways in which PPM service provision has developed in children's hospices and the associated inequity and impact were revealed in the research findings. The statement that:

“We are still a very long way from being able to offer children the same access to the best quality palliative care that adults can already expect” (Hain 2013), still holds true. The study has important implications for the future development of children’s hospice services. The recommendations arising from this research suggest a strategic pathway for this development, in order to ensure that all children with life-limiting conditions and their families can access the best of both children’s hospice care and specialist PPM.

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Appendix A: Invitation email template

Dear Leader of care/ Medical lead,

You are invited to take part in a telephone survey interview as part of a research project looking at the medical service provision in children's and young adults' hospices across the UK. This is the first stage in a three-phase PhD research project, building on preliminary work undertaken by Together for Short Lives and the Association of Paediatric Palliative Medicine.

The attached information sheet outlines the purpose and details of the project to enable you to decide whether or not you wish to take part.

It is anticipated that this project will contribute to an evidence base to influence policy developments and conclusions as to the future of medical services within children's hospices over the next decade.

If you would like to take part please email Jo.Frost@bournemouth.ac.uk to arrange a telephone interview at a time convenient for you.

If no reply is received a follow up telephone call will be made to ensure that you have the opportunity to participate should you wish to do so.

Yours sincerely,

Dr Jo Frost

Children's Hospice South West Post Graduate Research Fellow / PhD student Bournemouth University / Palliative Care Paediatrician.

Appendix B: Participant Information Sheet

Title of research project: Palliative care for life limited children and young people: the role of medical care in the development of children's hospice services.

You are invited to take part in a telephone survey interview. This is the first stage of a three-phase PhD research project, building on preliminary work undertaken by Together for Short Lives (TFSL) and the Association of Paediatric Palliative Medicine. The following information outlines the purpose and details of the project to enable you to decide whether or not you wish to take part.

What is the purpose of the project?

The specialty of Paediatric Palliative Medicine has only evolved in recent years and therefore little is understood about how services develop. This research aims to identify and classify the range of current models of medical provision in children's hospices across the UK. It also aims to determine parents' perceptions of the medical care received during their child's palliative care and how different models of medical service provision impact on the quality of palliative care from parents' and professionals' perspectives.

The research project begins with a national survey of children's hospices to identify and classify current models of medical service provision. This first stage will identify the range of models of medical service provision within hospice services on which further work will be based.

Why have I been chosen?

In collaboration with TFSL one lead professional from each of the children's and young people's hospice services across the UK has been identified and you have been chosen as that person to take part in the survey. (If you don't think you fit this description please do pass this request on to the person from your hospice service who you think would be best placed to respond).

Do I have to take part?

No. Your participation is entirely voluntary.

What will happen to me if I take part?

If you agree to take part in the project, you will be asked to participate in a survey via telephone interview, which will focus on the medical service provision within your hospice organisation. The survey can be completed in under an hour.

Will I need to prepare for the interview?

The majority of questions can be answered without preparation and relate to the medical service provision for your hospice. It would be helpful to have available current data for the caseload of the hospice including the area covered for referrals, numbers of children and young people on your case load, number of bereaved families on your case load and numbers of children and young people supported through end of life care in the past year for which you collect this data.

Will my taking part in this project be kept confidential?

Yes. The survey is confidential. In any future publications all data will be anonymised and specific comments will not be personally attributable.

What will happen to the results of the research project?

Research findings from all three stages will form the basis of a PhD thesis; publications in academic journals, conference presentations and a summary will be available to participants and families of children with life limiting conditions.
All data collected throughout the project will be coded, stored on a password-protected computer and subsequently destroyed in line with the Data Protection Act.

Who is organising/funding the research?

The research is conducted by Dr Jo Frost, a PhD student at Bournemouth University (BU) and postgraduate research fellow for Children's Hospice South West (CHSW). Fees for the research are funded by a Vice Chancellor scholarship at BU; a research grant from CHSW also part supports this project.

Contact for further information

If you require more information or have any concerns about the project please contact one of the following researchers:

Dr Jo Frost: Postgraduate research fellow CHSW/ PhD student BU/ Palliative Care Paediatrician	jo.frost@bournemouth.ac.uk
Dr Jane Hunt: Senior Lecturer Children's and Young People's Nursing Bournemouth University.	jhunt@bournemouth.ac.uk

If you would be willing to take part in a telephone interview please email:
Jo.Frost@bournemouth.ac.uk.

Appendix C: Survey schedule

Participant’s details

1. What is your job title?

2. What role do your have within your hospice?

3. What professional qualifications do you have to enable you to undertake your post? (Please include both a) generalist and b) specialist qualifications)

4. How long have you been in your current children’s palliative care post (in months)?

Hospice details

5. In which region is your hospice located:

a. Scotland
b. North East
c. North West
d. Yorkshire and Humber
e. East Midlands
f. West Midlands
g. East of England
h. London
i. South West
j. South East
k. South Central
l. Wales
m. Northern Ireland

6. What is the geographical area from which your hospice service takes referrals?

a. Regional catchment area

Yes / No

6ai. If yes how many regions does your hospice service accept referrals from

b. A Clinical commissioning group catchment area (Or Health board area for Wales and Scotland or Trust area for Northern Ireland)

Yes/ No

6bi. If yes how many CCG's/ health board areas or Trust areas does your hospice take referrals from?

7. What is the age range of children and young people for whom your hospice service accepts referrals?

a. Please give the formal referral criteria for age range.

b. In practice what is the age of the oldest young adult on your case-load at the current time?

8. How many children and young people are currently on the active caseload of your hospice service (please exclude bereaved families)?

9. How many bereaved families are currently on the caseload of your hospice service?

Care needs

10.a. Over the past year, how many children and/or young people have been provided with end of life care by your hospice service? (For the past year for which you collect this data). Please include all admissions/support for end of life care even for those children/young people whose condition improved.

b. Over the past year, how many children and/or young people provided with end of life care died?

c. Over the past year how many children and/or young people were supported during compassionate extubation by your hospice service.

Q11a. At the current time estimate the % of children on your hospice case load who have the following care needs.

11b. Can these care needs be supported in your hospice/by your hospice team in other settings, either within your own team of with the support of other professionals?

Care need	A. % Estimate of proportion of children on case load	B. Can this care need be supported by your hospice service Yes/No
a. Intravenous medications		
b. TPN		
c. Any type of assisted ventilation (including Cpap and Bipap)		
d. Blood or platelet transfusion		
e. Peritoneal dialysis		
f. Full ventilation in the community (a child or young person discharged from hospital with full ventilation via tracheostomy).		

12. Are there any other forms of care needs for children/young people on your hospice case load you would like to add?

Overall model of medical service provision

13a. Which of the following broad categories describes the **overall model of your hospice service?** *Please indicate one which best applies*

a. Community hospice service (i.e. mainly supporting patients and families in their own homes).

b. Hospice with inpatient beds for children
c. Hospice with inpatient beds for children and young adults
d. Joint inpatient bed unit and community /outreach service for children.
e. Joint inpatient bed unit and community/ outreach service for children and young adults.
f. Children's hospice unit as part of an adult hospice

Defining children as up to 18 yrs of age and young adults as 18yrs – 25yrs.

13bi. How many inpatient hospice bed units does this interview represent?

13bii: How many community hospice services does this data represent?

13biii: Are any of these services currently being developed or recently built?

14. Which of the following best describes the **model of medical service provision** for your hospice?

14a **For Community Children's Hospice services (no inpatient beds):**

a. Nurse led community hospice service with no formal arrangement for medical service provision.
b. Nurse led community hospice service with formal arrangement with a General Practice surgery.
c. Nurse led community hospice service with formal arrangement with one or more G.Ps with special interest in PPM.
d. Nurse led community hospice service with Service Level Agreement (SLA) with another hospice for medical service provision.
e. Nurse led service with SLA with a hospital trust for medical service provision
f. Not applicable (hospice has inpatient bed)

14b **For children and young person's hospice service with inpatient beds unit**

a. Nurse led multidisciplinary team with formal arrangement with a General Practice surgery.
b. Nurse led multidisciplinary team with formal arrangement with one or more G.P with Special interest in PPM.
c. Consultant in PPM employed by hospice working with a team of doctors.
d. Consultant in PPM employed by hospital providing in reach into hospice as part of formal arrangement.
e. Team of doctors from a range of backgrounds providing daily sessions at the hospice (but no level 4 doctor integral to the team).
f. Not applicable (hospice has no inpatient beds)
g. Combination of above models (state which in free text description box)
h. None of above (describe below)

15. Please give any further description of the model of medical service provision for your hospice organisation that you think would be of help.

Free text description box.

Details of doctors working at the hospice

16. How many doctors are employed by your hospice?

17. How many doctors working at your hospice are employed by other organisations?

18. For doctors employed by organisations other than the hospice which organisation are they employed by?

Please state how many doctors working at the hospice are employed by the following organisations:

a. General practice

b. NHS: District general hospital

c. NHS: Tertiary children's hospital

d. Community Trust

19a. How many hours per week do doctors work at the hospice/ for the hospice service in work directly related to the care of children and families (either in the hospice, home or hospital) excluding on call?
(*Multiply number of hours by number of doctors if more than one doctor working).*

19b. What pattern of work do your doctors have for their regular hours (not on call)?

a. A session per day (2 – 4 hours)
b. Full 9 – 5 days on weekdays
c. Full 9 – 5 days every weekday plus as required visits out of hours and at weekends.
d. Full 9 – 5 days every day
e. No regular hours: responsive to need

19c. Is there anything else you would like to add about the way in which your doctors work that you would like to add?

20a. How many hours per week are doctors working for the hospice available for telephone advice to nursing and other multidisciplinary team members if needed?

20b What is the pattern of doctor's availability for telephone advice?

a. Weekdays 9 – 5
b. Everyday 9 – 5
c. 24 hours a day on weekdays, not at weekends
d. 24/7 (all the time)

e. No fixed pattern (as needed/ad hoc)

21a. How many hours per week are doctors working for the hospice available to see patients face-to-face as requested by nursing and other multidisciplinary team members?

21b What is the pattern of doctors availability to see patients face to face on request.

a. Weekdays 9 – 5
b. Everyday 9 – 5
c. 24 hours a day on weekdays, not weekends
d. 24/7 (all the time)
e. No fixed pattern (ad hoc/as needed)

22. How many Consultants in PPM **work at the hospice?

*** Definition of Consultant in PPM*

23. Who is or are s/he /they employed by for their hospice work? (state the number of Consultants for each)

a. Hospice

b. Hospital

c. Joint post

d. Clinical commissioning group

24. What is the pattern of work for Consultants in PPM at the hospice? (indicate all that apply)

a. Specified hospice sessions including face to face patient / family contact and medical review

b. Available for telephone advice

c. Available to visit if requested

d. Other (specify)

e. Not applicable (No consultant post)

Availability and type of 24/7 medical advice

25. Does the hospice service have access to medical advice 24/7?

Yes/ No/ Don't know

26.Which of the following best describes the arrangement for 24/7 medical advice at your hospice organisation?

a. 24/7 on call rota of doctors run by hospice
b. Service Level Agreement (SLA) with a G.P practice or cooperative
c. SLA with another children's hospice service
d. SLA with an adult hospice service
e. SLA with secondary children's hospital
f. SLA with tertiary children's hospital
g. No access to medical advice
h. 24/7 but one person therefore not sustainable 24/7

27. What type of advice does the on call system cover? Please tick all relevant options.

a. Telephone advice
b. Face to face patient / family review in hospice
c. Face to face patient / family review in hospital
d. Face to face patient / family review in community

28. What medical advice are the doctors providing 24/7 medical advice giving? Please tick all relevant options.

a. Medical advice on general issues
b. General Paediatric Palliative medical advice
c. Specialist paediatric palliative medical advice

29. What is the training level in PPM of the Doctors giving advice? * for definition of levels

a. Levels 1 and 2
b. Level 3
c. Level 4
d. Both level 3 and 4 (a two tier system of advice as needed)
e. Don't know
f. Not applicable (no access to medical advice)
g. Level 1 , 2 and 3 (depending who is on call)

*Definition of levels **

30. If the hospice runs a 24/7 on call rota which patients are covered?
Please indicate all that apply.

a. Children/ young people at home who are already known to the hospice service
b. Children /young people at home not yet known to the hospice service
c. Children/ young people in inpatient bed hospice unit
d. Children/ young people in hospital who are already known to the hospice service
e. Children/young people in hospital who are not yet known to the hospice service

31. If the hospice runs a 24/7 on call rota who can normally contact medical staff for advice? Please tick all relevant options

a. Nurses working for the hospice
b. All multidisciplinary team working for the hospice
c. Parents whose child is under the care of the hospice service
d. Parents whose child is not under the care of the hospice service
e. Professionals outside of hospice service

Training, experience and roles of doctors working for the hospice

32. How many of the doctors working for your hospice have developed the following level of competency?

a. Level three Paediatric Palliative Medicine *

b. Level four Paediatric Palliative Medicine *

33. Which medical specialties do doctors working at the hospice come from? (indicate the core specialism for each doctor)
Please indicate the number of doctors for all that apply:

a. G.P

b. G.P with special interest in PPM

c. Community paediatrics

d. Adult palliative medicine

e. Paediatric palliative medicine

f. Paediatric oncology

g. Paediatric intensive care

h. Paediatrics (of any specialty) with special interest in PPM

i. Other e.g. neurology, learning disability (please specify):

34. Do doctors who work for the hospice provide in reach into hospital(s)?

Yes/ No/don’t know

35. How many of each of the following types of hospital do the doctors provide in reach for?

a. District general hospital

b. Tertiary children’s hospital

c. Neonatal Unit

36. If the doctors working for the hospice provide in reach what are the arrangements for this?

a. Formal arrangement with honorary contract, funded
b. Formal arrangement with honorary contract, non-funded
c. Informal arrangement with no contract or funding
d. No in reach
e. Don’t know
f. Employed by hospital in main post

37. Do doctors who work for the hospice provide outreach into the community?

Yes/ No/don’t know

38. What are the arrangements for this out reach?

a. Formal arrangement with honorary contract, funded
b. Formal arrangement with honorary contract, non funded
c. Informal arrangement with no contract or funding
d. No outreach
e. Don't know

39. Which of the following roles do doctors working at the hospice (in any capacity) undertake?

Please indicate all that apply.

a. Writing of medication charts
b. Prescribing new medications for patients
c. General medical review of patients (for issues not directly related to palliative care)
d. General PPM review of patients
e. Specialist PPM review of patients
f. Advice on symptom management
g. Writing and circulating symptom management plans
h. Writing discharge summaries following hospice admissions.
i. Discussion of advance care plans and end of life care plans with parent/ guardian and/or young person and /or the wider care team.
j. Arranging and providing medical input for admission to hospice for symptom control or end of life care.
k. Arranging and providing medical input for stepped discharge from hospital via hospice.
l. Arranging and providing medical input for emergency admissions to hospice (medical or social)
m. Medical review for family members (siblings/ parents)
n. Certification of death of patient
o. Contributing to ongoing extended team review of a patient.
p. Contributing to clinical governance and clinical policy development for the hospice.
q. Teaching and training at the hospice (both formal and informal)
r. Contributing to strategy and development in the wider medical community

Senior nursing posts

40a. Does your hospice have a nurse consultant or advanced nurse practitioner post?

Yes / No/Don't know

40bi. Does your hospice have any non-medical prescribers.

Yes/No/Don't know

40 bii: Number of non medical prescribers
40c. If yes what is their professional background:

a. Nursing
b. Pharmacist
c. Other (please specify)

41. If your hospice has an advanced nurse practitioner or consultant nurse what roles does s/he undertake?

Select all that apply

a. Signing of medication charts
b. Prescribing new medications for patients
c. General health review of patients (for issues not directly related to palliative care)
d. General PPM review of patients (for issues relating to palliative care)
e. Specialist PPM review
f. Advice on symptom management
g. Writing symptom management plans
h. Discussion of advance care plans and emergency / end of life care plans with parent/ guardian or young person and/or the wider care team.
i. Arranging admission to hospice for symptom control or end of life care
j. Medical review for family members (siblings/ parents)
k. Certification of death of patient

42. Case examples

Case example one: Response to need for symptom review during respite care

14 year old Mark is under the care of your hospice service with a neurodegenerative condition. He experiences a deterioration in symptom control during a period of respite care (either at home or in your hospice). Mark is in distress but it is unclear whether this is due to muscle spasm, seizures or pain of another cause.

Questions:

1.1 Who would the respite carer call for advice in the first instance?

1.2 Would a doctor be contacted for advice?

1.3 If so who would this be and what is their level of PPM training?

1.4 If Mark needed review by a doctor how would this be arranged?

1.5 Mark needed a change in medication who would prescribe this?

Case example two: Response to need for rapid discharge from hospital to hospice for end of life care

Your hospice service receives a call from the local hospital's oncology team at 3pm on a Friday afternoon. The call is regarding Megan, an 8 year old girl, with a diffuse pontine glioma. She has completed 1 year of treatment and is known to your hospice service. She has a VP shunt in situ, is in hospital and has headaches, can no longer swallow and has a chest infection. The opinion of her lead oncologist is that she is in the last weeks of her life. Her family would like to be transferred to the hospice for end of life care, supported by your hospice service. It is a bank holiday weekend and they do not want to remain in hospital any longer.

Questions:

2.0 Overall how likely would it be that your hospice service could accept this referral and arrange transfer at this time:

a. Always
b. At a later stage with planning
c. May be able to accept but would depend on staffing
d. May be able to accept depending on medical cover
e. Never able to accept this type of request.

2.1 Who would take this initial call?

2.2 How would a decision be made about whether the hospice service can facilitate her rapid discharge from hospital?

2.3 Would a hospice doctor normally be involved in this decision?

2.4a If so, who?

2.4b And what is their level of PPM training?

2.5 Would a doctor or nurse from the hospice service be available and likely to visit? Megan and her family in hospital prior to discharge?

2.6 On arrival at the hospice who would be available to assess Megan?

2.7 Who would be most likely to lead on discussions about a symptom control plan with the family and document this plan?

2.8 Who might discuss and document an advance care plan / end of life care plan?

2.9 Who would prescribe medications?

At 3am on Sunday morning Megan's symptoms deteriorate with increased headaches and development of muscle spasms.

2.11 Who would be called for advice in the first instance?

2.12Would a doctor be available to give telephone advice?

2.13If so who would this be and what is their level of PPM training?

2.14 Would a doctor be available to visit and assess Megan?

Case example three: Response to need for rapid discharge from hospital to home for end of life care

Your hospice service receives a call from the local hospital's oncology team at 3pm on a Friday afternoon regarding Megan, an 8 year old girl, with a diffuse pontine glioma. She has completed 1 yr of treatment and is known to your hospice service. She has a VP shunt in situ, is in hospital, has headaches, can no longer swallow and has a chest infection. The opinion of her lead oncologist is that she is in the last weeks of her life. Her family would like to be discharged home for end of life care supported by your hospice service. It is a Bank Holiday weekend and they do not want to remain in hospital any longer.

Questions:

3.0 Overall how likely would it be that your hospice service could accept this referral and arrange transfer at this time:

a. Always
b. At a later stage with planning
c. May be able to accept but would depend on staffing
d. May be able to accept depending on medical cover
e. Never able to accept this type of request.

3.1 Who would take this initial call?

3.2 How would a decision be made about whether the hospice service can facilitate her rapid discharge from hospital?

3.3 Would a hospice doctor normally be involved in this decision

3.4a If so, who?

3.4b And what is their level of PPM training?

3.4 Would a doctor or nurse from the hospice service be available and likely to visit Megan and her family in hospital prior to discharge?

3.5 On arrival at home who would be available to assess Megan?

3.7 Who would be most likely to lead on discussions about a symptom control plan with the family and document this plan?

3.8 Who might discuss and document an advance care plan / end of life care plan for Megan?

3.9 Who would prescribe medications?

3.10 Who would ensure that a supply of emergency medicine is available in the home?

At 3am on Sunday morning Megan's symptoms deteriorate with increased headaches and development of muscle spasms.

3.11Who would parents call for advice in the first instance?

3.12Would a hospice doctor be available to give telephone advice?

3.13If so who would this be and what is their level of PPM training?

3.14Would a hospice doctor be available to visit and assess Megan if required?

Case example four: Response to requests for advice from a hospital Consultant

A hospital paediatric consultant contacts the hospice on a weekday for advice regarding a patient, James, who is currently in hospital and is known to your hospice service. James is 12 years old and has a rare neurodegenerative condition with intermittent and progressive gut failure. He was admitted to hospital 2 days ago with abdominal pain and erratic absorption. The consultant is asking for advice on managing his pain and support in reviewing overall goals of care.

4.1Who would respond to this request for advice?

4.2How would the request be responded to?

4.3 Would a member of the hospice team be available to visit James and his family in hospital?

4.4aIf yes, who is this likely to be?

4.4b And what form would the visit take?

4.5How would the hospice team respond to this request on a weekend?

Appendix D: Definitions of Levels of PPM education and training

Full description of Levels of competency in PPM from the Combined Curriculum (APPM Education Subgroup and RCPCH 2015)

For paediatricians, these would correspond to:

- Level 1 : a doctor just completing a medical degree,
- Level 2: a paediatric SpR who has completed core paediatric training
- Level 3: a consultant paediatrician who has gone on to general or subspecialty training in a related field and developed a special interest in paediatric palliative medicine
- Level 4: a consultant in specialist paediatric palliative medicine.

For children's hospice doctors, these would correspond to:

- Level 1: a doctor just completing a medical degree,
- Level 2: a children's hospice doctor after one year of experience,
- Level 3: a children's hospice medical director, or other established children's hospice doctor who has gained the Cardiff Diploma in Palliative Medicine (paeds) or similar validated qualification ,
- Level 4: a few hospice medical directors (mainly historical leaders in subspecialty formation and development, with roles beyond the local hospice). Likely to have been awarded FRCPCH or similar distinction.

While the specific standards for each competency would, of course, depend on its nature, the following general principles were used to define the different levels:

- Level 1. Understand the basic principles, of paediatric palliative care
- Level 2. Apply basic principles of palliative medicine to the care of children specifically. Recognise reversible causes of symptoms in children, whether with a life-limiting condition or not.
- Level 3. Be able to manage most common symptoms safely and effectively. Be prepared to recognise need for specialist help and access it where necessary.
- Level 4. Manage uncommon symptoms; understand principles in order to develop a logical approach even where there is no evidence basis. Considerable emphasis on leading and developing services within and beyond the local hospice, and on supporting and teaching other professionals involved with children with life-limiting conditions who are not trained in palliative medicine. This level will probably only be seen to be achieved if the doctor has obtained FRCPCH or similar distinction.

Appendix E: Code book for survey

Codes for survey

SPSS Variable name	Variable details	Coding instructions
ID_Hospice	Letter Code	Letter as string data
ID_Participant	Number	Numeric
Q1_Job	Job title as string data	String data
Q1a_Job	Code for job	1=Nursing lead 2= Medical lead 3=Other
Q2_Role	Role	String data *
Q3a_Primaryqual	Primary professional qualification code	1=Primary nursing qualification 2=Primary medical qualification 3=Social work qualification *
Q3b_Specialistqual	Specialist professional qualification code	1=PPM qualification 2=PC qualification 3=Specialist medical training in PPM 4=Other
Q4_Months	Number of months in post	Actual number in months
Q5_Region	Region code	1=Scotland 2=NorthEast 3=Northwest 4=Yorkshireand humber 5=EastMidlands 6=Westmidlands 7=East of England 8=London 9=SouthWest 10=SouthEast 11=Southcentral 12=Wales 13=NorthernIreland
Q6a_Referralregion	Regional catchment area.	0= No 1= Yes D/K = 88
Q6ai_Numberregions	Number of regions	Number 99=N/A
Q6b_ReferralCCG	CCG or Health Board catchment area	0=No 1=Yes D/K =88
Q6bi_NumberCCG	Number of CCG's or Health boards	Number 99=N/A 88=D/K
Q7a_Agerange	Age range code	0-18yrs=1 0-19yrs=2 0-25yrs=3 0-35yrs=4 0-40+=5
Q7b_Oldest	Age of oldest young adult	Age as number in years
Q8_Caseload	Number of children	Number
Q9_Bereavedcaseload	Number of bereaved families	Number
Q10a_Endoflife	Number of end of life care (All)	Number
Q10b_EoLdeaths	Number provided with EoL care who died	Number
Q10c_Extubations	Number of compassionate	Number

	extubations	
Q11ai-fi	%estimate care need: actual number	String data of actual number given
Q11Aa - f	% estimate of proportion of children on case load coded into %range	0=0% 1=<1% 2=1-2% 3=2 – 5% 4=5-10% 5= 10 -15% 6=15-20% 7=20 – 25% 8=25-30% 9=>30% 88=D/K
Q11B a-f	Can hospice support child with these needs.	0=No 1=Yes 88=DK 88= DK
Q12	Free text Qualitative information: other complex care needs	String data *
13a	Model of hospice service code.	1= Community hospice service (i.e. mainly supporting patients and families in their own homes). 2= Hospice with inpatient beds for children 3= Hospice with inpatient beds for children and young adults 4= Joint inpatient bed unit and community /outreach service for children. 5= Joint inpatient bed unit and community/ outreach service for children and young adults. 6= Children's hospice unit as part of an adult hospice 7= Other (specify)
13ai	Other model specified	String data *
13bi	Number of inpatient bed hospices represented	Number
13bii	Number of community hospice services represented	Number
13biii	Free text: Qualitative data : are any of these hospices currently being developed/recently built.	String data*
14a	Model of medical service provision code for community hospice teams (With no inpatient beds)	1= Nurse led community hospice service with no formal arrangement for medical service provision. 2= Nurse led community

		hospice service with formal arrangement with a General Practice surgery. 3= Nurse led community hospice service with formal arrangement with one or more G.Ps with special interest in PPM. 4= Nurse led community hospice service with Service Level Agreement (SLA) with another hospice for medical service provision. 5= Nurse led service with SLA with a hospital trust for medical service provision 6= Combination of above models (state which in free description) 7=Other (Specify) f=99= Not applicable (hospice has inpatient bed)
14ai	Description of other models	String data *
14b	Model of medical service provision for hospices with inpatient beds	1= Nurse led multidisciplinary team with formal arrangement with a General Practice surgery. 2= Nurse led multidisciplinary team with formal arrangement with one or more G.P with Special interest in PPM. 3= Consultant in PPM employed by hospice working with a team of doctors. 4= Consultant in PPM employed by hospital providing in reach into hospice as part of formal arrangement. 5= Team of doctors from a range of backgrounds providing daily sessions at the hospice (but no level 4 doctor integral to the team). 6= Combination of models (specify) 7= Other (specify) 99=Not applicable (No inpatient beds)
14bi	Other inpatient medical model description	String*
15	Free text Qualitative information on Medical	String*

	models: no code	
16	Number of doctors	Number
17	Number of doctors employed by other organisations	Number
18a	Number of doctors employed by General practice	Number ?use99=N/A
18b	Number of doctors employed by DGH	Number ?99=N/A
18c	Number of doctors employed by Tertiary hospital	Number ?99=N/A
18d	Number of doctors employed by community trust	Number ?99=N/A
19a	Total Doctor hours	Number in hours
19b	Overall pattern of work code	1= A session per day (2 – 4 hours) 2= Full 9 – 5 days on weekdays 3= Full 9 – 5 days every weekday plus as required visits out of hours and at weekends. 4= Full 9 – 5 days every day 5= No Regular hours, responsive to need 6=Other (Specify) 99=N/A No Drs at hospice
19c	Free text description box: Qualitative information on patterns of work	String*
20a	Doctor hours for telephone advice	Number in hours
20b	Overall pattern of availability for telephone advice code	1= Weekdays 9 – 5 2= Everyday 9 – 5 3=24 hours a day on weekdays, not at weekends 4=24/7 (all the time) 5= No fixed pattern (ad hoc/as needed) 6=Other (Specify) 99=N/A Drs not available for telephone advice
20bi	Description of other models of telephone advice	String*
21a	Doctor hours availability to see patients face to face	Number in hours
21b	Overall pattern of availability code	1= Weekdays 9 – 5 2= Everyday 9 – 5

		3=24 hours a day on weekdays, not weekends 4=24/7 (all the time) 5= No fixed pattern (ad hoc/as needed) 6= Other (Specify) 99=N/A (No doctors)
21bi	Otherpatterndecription	String*
22	Number of Consultants	Number 99=N/A
23a	Number of Consultants employed by Hospice	Number 99=N/A
23b	Number of Consultants employed by Hospital	Number 99=N/A
23c	Number of Consultants employed Jointly	Number 99=N/A
23d	Number of Consultants employed by CCG	Number 99=N/A
24	Pattern of work for Consultants code: f. Specified hospice sessions including face to face patient / family contact and medical review g. Available for telephone advice h. Available to visit if requested	For each a- c: 0 = No 1 = Yes 99 = Not applicable
25	Access to 24/7 advice: Yes/ No /DK code	No= 0 Yes =1 Don’t know=88
26	Arrangement for 24/7 advice code:	1=24/7 on call rota of doctors run by hospice 2= Service Level Agreement (SLA) with a G.P practice or cooperative 3= SLA with another children’s hospice service 4= SLA with an adult hospice service 5= SLA with secondary children’s hospital 6= SLA with tertiary children’s hospital 8= One person 24/7 99= No access to medical advice (not applicable)

27a	Telephone advice	No = 0 Yes=1 N/A =99
27b	Hospice review	No=0 Yes=1 N/A =99
27c	Hospital review	No =0 Yes=1 N/A =99
27d	Community review	No = 0 Yes = 1 N/A =99
28 a	General issues advice	No=0 Yes=1 N/A =99
28b	General PPM advice	No=0 Yes=1 N/A=99
28c	Specialist PPM advice	No =0 Yes=1 N/A =99
29.	Training level for advice givers code:	1= Levels 1 and 2 2= Level 3 3= Level 4 4= Both level 3 and 4 (a two tier system of advice as needed) 5= Level 1 , 2 or3 (depending who is on call) 6= Level 3 or 4 depending who is on call 88= Don’t know 99= Not applicable (no access to medical advice)
30a	Covers home (patients who are known to hospice) *(where N/A means there is no hospice run 24/7 on call for all of Q30 and Q31)*	No =0 Yes=1 N/A =99
30b	Covers home (patient not yet known to hospice)	No =0 Yes=1 N/A =99
30c	Covers hospice	No =0 Yes=1 N/A =99
30d	Covers hospital (patients who are known to hospice)	No =0 Yes=1 N/A =99
30e	Covers hospital (patients who are not known to hospice)	No =0 Yes=1 N/A =99

31a	Nurse can call	No =0 Yes=1 N/A =99
31b	MDT can call	No =0 Yes=1 N/A =99
31c	Parents under hospice care can call	No =0 Yes=1 N/A =99
31d	Parents not under hospice care can call	No =0 Yes=1 N/A =99
31e	Professionals outside hospice	No =0 Yes=1 N/A =99
32a	Number of doctors at Level 3	Number
32b	Number of doctors at Level 4	Number
33a	Number of doctors G.P background	Number
33b	Number of doctors G.P SIPPM	Number
33c	Number of doctors Community Paeds	Number
33d	Number of doctors Adult PM	Number
33e	Number of doctors PPM	Number
33 f	Number of doctors Paediatric Oncology	Number
33g	Number of doctors intensive care	Number
33h	Number of doctors Special interest PPM	Number
33i	Number Other (Specify)	Number
33ii	Other background decription	String
34	In reach:	No=0 Yes=1 D/K=88
35a	Number of DGH	Number
35b	Number Tertiary hospitals	Number
35c	Number of neonatal units	Number
36	Arrangement for in reach code	1= Formal arrangement with honorary contract, funded 2= Formal arrangement with honorary contract, non-funded 3= Informal arrangement with no contract or funding 4= Employed by hospital in main post 99= No in reach/ not applicable 88= Don't know f. 4
37	Outreach to community:	No=0 Yes=1 D/K=88
38	Arrangement for outreach code	1= Formal arrangement with

		honorary contract, funded 2= Formal arrangement with honorary contract, non funded 3= Informal arrangement with no contract or funding 99= No outreach /not applicable 88= Don't know
39a	Writing medication charts	No=0 Yes=1
39 b	Prescribing new medication	No=0 Yes=1
39c	General medical review	No=0 Yes=1
39d	General PPM review	No=0 Yes=1
39e	Specialist PPM review	No=0 Yes=1
39f	Advice on symptom management	No=0 Yes=1
39g	Writing and circulating symptom management plans	No=0 Yes=1
39h	Writing d/c summaries	No=0 Yes=1
39i	Discussion of EoL care plan	No=0 Yes=1
39j	Arranging admission to hospice	No=0 Yes=1
39k	Arranging stepped d/c to hospice	No=0 Yes=1
39l	Arranging emergency admission	No=0 Yes=1
39m	Medical review of family members	No=0 Yes=1
39n	Certification of death	No=0 Yes=1
39o	Ongoing team review	No=0 Yes=1
39p	Clinical governance and policy	No=0 Yes=1
39q	Teaching and training	No=0 Yes=1
39r	Strategy an development	No=0 Yes=1
40a	Nurse Consultant post	No=0 Yes=1 D/K=88
40bi	Non medical prescriber	No=0 Yes=1 D/K=88
40bii	Number of non medical	Number

	prescribers	
40cA	Nurse non medical prescriber	No =0 Yes=1 N/A =99
40cB	Pharmacist non medical prescriber	No =0 Yes=1 N/A =99
40cC	Other non-medical prescriber Specify. No code: qualitative data	
41a	Signing medication charts	No=0 Yes=1
41b	Prescribing new medications	No=0 Yes=1
41c	General health review	No=0 Yes=1
41d	General PPM review	No=0 Yes=1
41e	Specialist PPM review	No=0 Yes=1
41f	Advice on symptom management	No=0 Yes=1
41g	Writing symptom management plans	No=0 Yes=1
41h	Discussing EoL plans	No=0 Yes=1
41i	Arranging admission to hospice for symptom management or EoL	No=0 Yes=1
41j	Review of family members	No=0 Yes=1
41k	Verification of death	No=0 Yes=1
CE1.1a	Who is called	String data
CE1.1b	Who is called code	1= Nurse consultant 2= Nurse team manager 3= Nurse on hospice care team 4=. Doctor working for hospice 5= Consultant in PPM 6= Local G.P on call 7=. Administrator at hospice 8= Other member of hospice MDT (not a nurse) 9= Child's hospital Consultant 10=. Child's Community Consultant
CE1.2	Doctor contacted for advice	No=0 Yes=1 If needed= 2
CE1.3a	Who code.	1= Doctor working for hospice 2= Local G.P on call 3= Child's hospital Consultant 4= Child's Community Consultant

		5= Consultant PPM 6= Medical Director Hospice 7=Other
CE 1.3b	Level of PPM training code:	1= Level 1 and 2 2.= Level 3 3= Level 4 4=Level 3 or 4 5= Level 1,2 or 3
CE1.4	How review arranged: Qualitative data	String Data*
CE1.5a	Who prescribes code:	1= Nurse consultant 2= Doctor working for hospice 3= G.P on call 4= Child' Hospital Consultant 5=. Child's Community Consultant 6= Pharmacist 7= Consultant in PPM 8 =. Medical Director hospice 9=Other
CE 1.5b	Who prescribes (other)	String
CE 2.0a	Acceptance of referral:	1= Always 2= At a later stage with planning 3= May be able to accept but depends on staffing 4= May be able to accept but depends on medical cover 5= Never able to accept.
CE2.0b	Description of acceptance of emergency referral	String *
CE2.1	Who takes call code:	1= Nurse consultant 2= Nurse team manager 3= Nurse on hospice care team 4= Doctor working for hospice. 5= Consultant in PPM 6=. Local G.P on call 7= Administrator at hospice 8= Other member of hospice MDT (not a nurse) 9= Child's hospital Consultant 10= Child's Community Consultant 11=Other

CE 2.2	How is a decision made: Qualitative data	String*
CE 2.3	Doctor involved	No=0 Yes=1
CE 2.4a	Which Doctor is involved?	1= Consultant PPM 2= Medical Director 3= G.P on call for hospice 4= Hospice doctor for the day. 5=Other
CE 2.4b	Level of PPM training code:	1= Level 1 and 2 2.= Level 3 3= Level 4 4=Level 3 or 4 5= Level 1,2 or 3
CE2.5a	Doctor or nurse available	No=0 Yes=1
CE2.5b	Likely to visit	No=0 Yes=1 If needed=2
CE2.6	Who would assess code:	1= Nurse consultant 2= Nurse team manager 3= Nurse on hospice care team 4= Doctor working for hospice. 5= Consultant in PPM 6=. Local G.P on call 7= Other member of hospice MDT (not a nurse) 8= Child's hospital Consultant 9= Child's Community Consultant 10=Other
CE2.7	Who leads symptom control discussions code:	1= Nurse consultant 2= Nurse team manager 3= Nurse on hospice care team 4= Doctor working for hospice. 5= Consultant in PPM 6=. Local G.P on call 7= Other member of hospice MDT (not a nurse) 8= Child's hospital Consultant 9= Child's Community Consultant 10=Other
CE 2.8	Who leads EoL discussions	1= Nurse consultant 2= Nurse team manager 3= Nurse on hospice care team 4= Doctor working for hospice. 5= Consultant in PPM

		6=. Local G.P on call 7= Other member of hospice MDT (not a nurse) 8= Child's hospital Consultant 9= Child's Community Consultant 10=Other
CE 2.9	Who prescribes code:	1= Nurse consultant 2= Doctor working for hospice 3=. G.P on call 4=. Child' Hospital Consultant 5= Child's Community Consultant 6= Pharmacist 7= Consultant in PPM 8= Medical Director hospice 9=Other
CE2.11	Who is called code:	1= Nurse consultant 2= Nurse team manager 3= Nurse on hospice care team 4= Doctor working for hospice. 5= Consultant in PPM 6=. Local G.P on call 7= Administrator at hospice 8= Other member of hospice MDT (not a nurse) 9= Child's hospital Consultant 10= Child's Community Consultant 11=Other
CE2.12	Doctor available on phone	No=0 Yes=1
CE2.13a	Who is the doctor	1= Doctor on call for hospice 2= G.P on call for hospice 3= Consultant PPM 4= Medical Director 5=Other
CE2.13b	Level of PPM training code:	1= Level 1 and 2 2.= Level 3 3= Level 4 4=Level 3 or 4 5= Level 1,2 or 3
CE2.14	Doctor available to visit:	No=0 Yes=1
CE 3.0a	Acceptance of referral	1= Always 2= At a later stage with

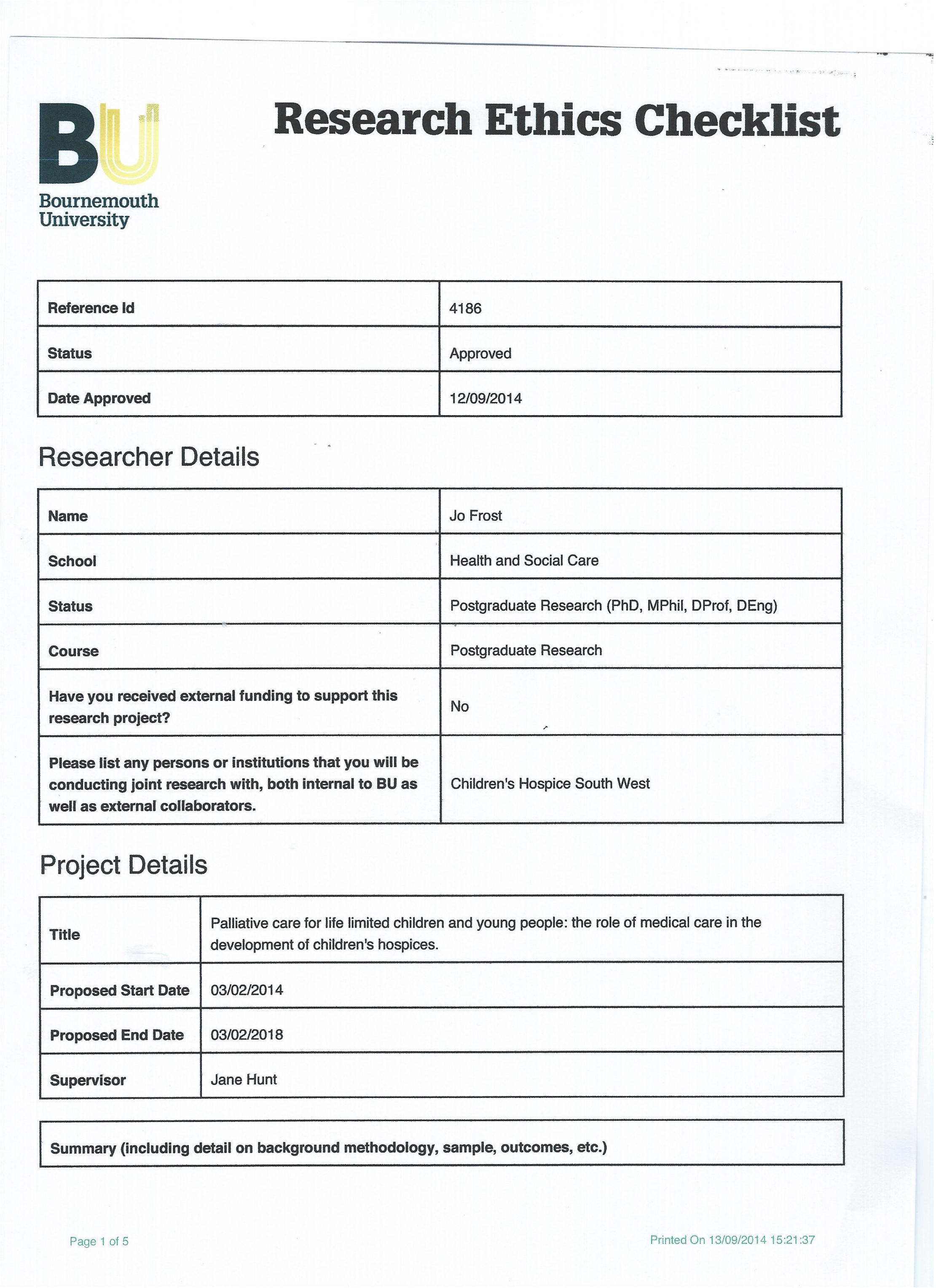
		planning 3= May be able to accept but depends on staffing 4= May be able to accept but depends on medical cover 5= Never able to accept.
CE 3.0b	Description of acceptance	String*
CE 3.1	Who takes call code:	1= Nurse consultant 2= Nurse team manager 3= Nurse on hospice care team 4= Doctor working for hospice. 5= Consultant in PPM 6=. Local G.P on call 7= Administrator at hospice 8= Other member of hospice MDT (not a nurse) 9= Child's hospital Consultant 10= Child's Community Consultant 11=Other
CE3.2	How is a decision made: Qualitative data	String*
CE3.3	Hospice doctor involved	No=0 Yes=1
CE3.4a	Doctor involved.	1= Consultant PPM 2= Medical Director 3= G.P on call for hospice 4= Hospice doctor for the day. 5=Other
CE3.4b	Level of PPM training code:	1= Level 1 and 2 2.= Level 3 3= Level 4 4=Level 3 or 4 5= Level 1,2 or 3
CE3.5	Doctor or nurse available to visit	No=0 Yes=1 If needed=2
CE3.6	Who would assess code:	1= Nurse consultant 2= Nurse team manager 3= Nurse on hospice care team 4= Doctor working for hospice. 5= Consultant in PPM 6=. Local G.P on call 7= Other member of hospice MDT (not a nurse)

		8= Child's hospital Consultant 9= Child's Community Consultant 10=Other
CE3.7	Who leads symptom control discussions code:	1= Nurse consultant 2= Nurse team manager 3= Nurse on hospice care team 4= Doctor working for hospice. 5= Consultant in PPM 6=. Local G.P on call 7= Other member of hospice MDT (not a nurse) 8= Child's hospital Consultant 9= Child's Community Consultant 10=Other
CE 3.8	Who leads EoL plan discussions code:	1= Nurse consultant 2= Nurse team manager 3= Nurse on hospice care team 4= Doctor working for hospice. 5= Consultant in PPM 6=. Local G.P on call 7= Other member of hospice MDT (not a nurse) 8= Child's hospital Consultant 9= Child's Community Consultant 10=Other
CE3.9	Who prescribes code:	1= Nurse consultant 2= Doctor working for hospice 3=. G.P on call 4=. Child' Hospital Consultant 5= Child's Community Consultant 6= Pharmacist 7= Consultant in PPM 8= Medical Director hospice 9=Other
CE3.10	Who ensures medication available code:	1 =. Nurse consultant 2=. Doctor working for hospice 3= G.P on call 4= Child' Hospital Consultant 5= Child's Community Consultant.6= Pharmacist 7=. Consultant in PPM 8= Medical Director hospice 9=Other
CE3.11	Who do parents call code:	1= Nurse consultant 2= Nurse team manager 3= Nurse on hospice care team 4= Doctor working for hospice. 5= Consultant in PPM 6=. Local G.P on call 7= Administrator at hospice 8= Other member of hospice MDT (not a nurse)

		9= Child's hospital Consultant 10= Child's Community Consultant 11=Other
CE3.12	Would hospice doctor be available:	No=0 Yes=1
CE3.13a	Who is the doctor	1= Doctor on call for hospice 2= G.P on call for hospice 3= Consultant PPM 4= Medical Director 5=Other
CE3.13b	Level of PPM training code:	1= Level 1 and 2 2.= Level 3 3= Level 4 4=Level 3 or 4 5= Level 1,2 or 3
CE3.14	Hospice Doctor available to visit?	No=0 Yes=1
CE 4.1	Who responds code: a.	1= Nurse Consultant 2= Nurse team manager 3= Nurse on hospice care team 4= Hospice Doctor for the day 5= Consultant PPM 6= G.P on call 7= G.P on call 8= Other member of hospice MDT 9= Hospital Consultant 10= Community Consultant 11=Other
CE 4.2	How would request be responded to: Qualitative data	String *
CE 4.3	Hospice team visit in hospital:	No=0 Yes=1
CE4.4a	Who visits code:	1= Nurse consultant 2= Nurse team manager 3= Nurse on hospice care team 4= Doctor working for hospice 5= Consultant in PPM

		6= f. Local G.P on call 7= Other member of hospice MDT (not a nurse) 8=.Medical Director hospice
CE4.4b	What form would visit take: Qualitative data	String*
CE 4.5	How respond to request at weekend: Qualitative data	String*

Appendix F: Ethical Approval



Bournemouth
University

Research Ethics Checklist

Reference Id	4186
Status	Approved
Date Approved	12/09/2014

Researcher Details

Name	Jo Frost
School	Health and Social Care
Status	Postgraduate Research (PhD, MPhil, DProf, DEng)
Course	Postgraduate Research
Have you received external funding to support this research project?	No
Please list any persons or institutions that you will be conducting joint research with, both internal to BU as well as external collaborators.	Children's Hospice South West

Project Details

Title	Palliative care for life limited children and young people: the role of medical care in the development of children's hospices.
Proposed Start Date	03/02/2014
Proposed End Date	03/02/2018
Supervisor	Jane Hunt

Summary (including detail on background methodology, sample, outcomes, etc.)

Appendix G: Diagrams of themes with coding frameworks

Diagram for overarching theme: Increasing complexity of care needs

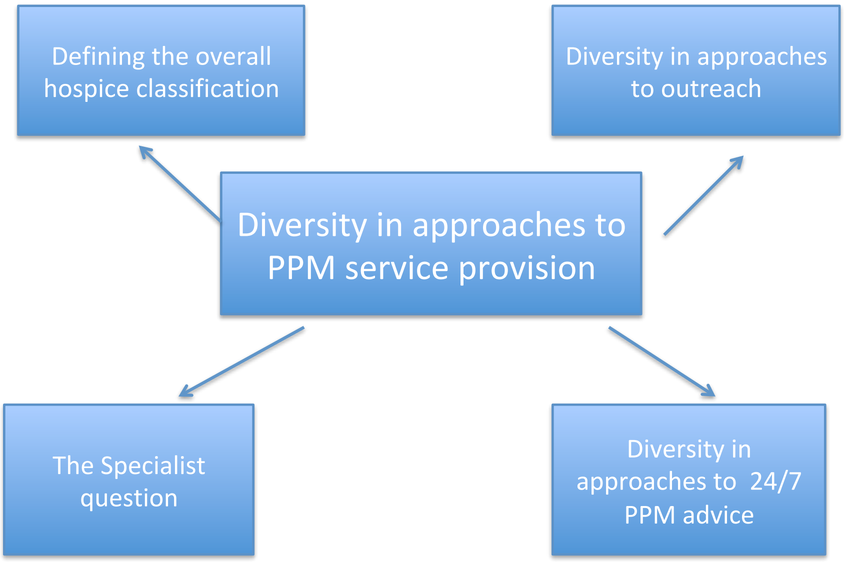
Coding framework for the overarching theme: *Increasing complexity of care needs*

Subtheme	Code name	Description	Example
Increasing complexity of conditions	The whole picture	The whole picture will refer to any reference to a combination of multiple needs within one child	*“It is not one individual care need but the combination that leads to complexity…not the individual pieces but the whole picture”*
Increasing complexity of conditions	Complex symptoms	Complex symptoms will refer to any reference to the symptoms experienced by the child increasing in complexity	*‘Unstable symptoms, managing symptoms and juggling medications’*
Increasing complexity of conditions	Challenging behaviours	To refer to any reference to challenging behavior contributing to increasing complexity of care	*12/J “Neurodevelopmental conditions with behavioural needs such as autism spectrum disorder and challenging*

			behaviour"
Increasing complexity of conditions	Epilepsy care	To refer to any reference to the management of epilepsy increasing the complexity of care	19/P "*Seizure management is challenging, for example seizures leading to ITU admission"*
Increasing complexity of interventions	Developments in technology	To refer to any reference to a technological intervention increasing the complexity of care including respiratory, ostomies, haemodialysis, catheters	13/K "*Stoma care [adds to the complexity of care], often multiple stoma care, for example; urostomy, ileal conduit, nephrostomy. Increasingly children have complex combinations of these."*
Increasing complexity of interventions	Medications	To refer to any reference to the use of medications as an intervention increasing the complexity of care: including new medication, new modes of delivery of medication and rotation of opiates.	"*admission for opiate rotation including on to methadone and the use of ketamine. We arrange admission [to the hospice] to initiate… we also arrange admissions to establish medications"*
Changing parameters of care	Changing place of care	To refer to any reference to a change in the place a child is cared for adding to the complex care at a hospice	28/Y "*In the past these children would never have come out of hospital"*
Changing parameters of care	Changing age profile	To refer to any reference to a change in the age of children receiving hospice care	21/R *" There is a changing dynamic, previously we provided respite and play therapy. [The hospice] started with 120 children and now 80 -90% are less than 3yrs old therefore there is a different profile, including antenatal referrals.'*

Changing parameters of care	Changing goals of care	To refer to any reference to a change in the expected outcome of an illness for child	9/H "*Initially this child [at hospice requiring haemodialysis] was for palliation but is now on the transplant list.*"
Changing parameters of care	Changing referral patterns	To refer to any reference to a change in a the way in which referrals to hospices are influencing the complexity of care	5/E *"We have been working with oncology services around referrals. Previously we only accepted when a child was terminally ill. We have changed our criteria to emphasise the life threatened group of children with cancer."*
Ethical issues and facilitated decision making	Ethical issues and facilitated decision making	To refer to any reference to ethics or involvement in ethical decisions such as withdrawal of treatment	7/G *" Other admissions occur for withdrawal of other types of treatment for high dependency unit, oncology patients."*
Hospice related factors	A can do approach	To refer to any reference to the hospice adapting to meet new needs	21/R "*We would rise to any challenge*".
Hospice related factors	Distance to hospital/ transport issues	To refer to any reference to the distance to hospital or issues with transport impacting on the complexity of care	22/Q ""*For children with epilepsy and major seizures or status. The care provided is complicated by the distance to hospital. There has been consideration of giving one patient a port for IV access for this reason*"

Diagram for overarching theme: *Diversity in approaches to PPM service provision*



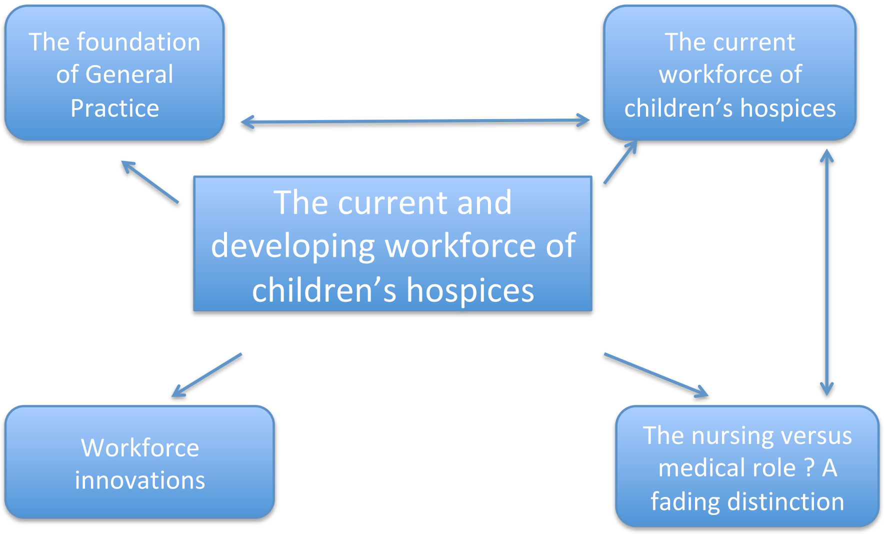
Coding framework for overarching theme: *Diversity in approaches to PPM service provision*

Subtheme	Code name	Description	Example
Defining the overall hospice classification	Geographical models (includes regional, local and rural)	To refer to any reference to geography as a defining factor in the hospice classification	25/V *" the children's hospice is described as a local children's hospice as opposed to a regional hospice."*
Defining the overall hospice classification	Linked children's and adults hospice	To refer to any reference to a children's hospice linked to an adult hospice	27/X *"A five bedded inpatient hospice attached to an adult hospice. From the care point of view the adult and children's hospices support each other as one hospice that takes all ages. The hospices were built independently in he same grounds and ten years ago came together."*
Defining the overall hospice classification	Profession led models (includes nurse led, one person pioneer and medical teams)	To refer to any reference to the profession of the leader of care as defining the hospice model	*3/C "nurse led with a link to local GPs."*

Diversity in approaches to 24/7 PPM advice	Service Level agreement models	To refer to any reference to a method of providing 24/7 medical advice	20/Q “We have an *SLA with a GP Coop for medical advice on general issues level one and two”*
Diversity in approaches to 24/7 PPM advice	In house models	To refer to any reference to the provision of 24/7 medical advice by the regular hospice doctors	13/K *“A team of doctors doing daily sessions and covering on call. 2- 4 hour sessions on weekdays covered by GPs and paediatricians. Regular sessions in weekends”*
Diversity in approaches to 24/7 PPM advice	Augmented for end of life care models	To refer to any reference to an increase in 24/7 medical cover for end of life care	24/U *“A 24/7 on call rota is run by the hospice, this is set up responsively for end of life care with doctors from the hospice”*
Diversity in approaches to 24/7 PPM advice	Multi-layer models	To refer to any reference to a combination of different levels of 24/7 medical advice for one hospice service	27/X *“A 24/7 on call rota of doctors is run by the hospice and we have an SLA with a tertiary children’s hospital. This is a two tier system: a rota by regular doctors and back up by [Tertiary children’s hospital] 24/7.”*
Diversity in approaches to 24/7 PPM advice	Regional models	To refer to any reference to a hospice providing medical advice (usually PPM advice) for a region	9/H *“A managed clinical network run a 24/7 rota. There is a 24/7 nurse on call rota of nurse specialists and a doctor on call rota of Level three PPM doctors.”*
Diversity in approaches to 24/7 PPM advice	No 24/7 medical advice models	To refer to any reference to a hospice with no formal system for access to 24/7 medical advice	*26/W “we have no access to 24/7 medical advice. There is a nurse led 24/7 on call rota of senior nurses all prescribers”.*

The specialist question	Concerns regarding a specialist model	To refer to any reference to a concern in relation to specialist PPM	1/A . *“ [I am] not convinced that having a PPM consultant is the only way to deliver the expertise needed. Local expertise also needs to be utilised. I’m concerned about the palliative care funding pilot and whether only Level four services will have access to specialist funding.”*
The specialist question	Who delivers specialist PPM care?	To refer to any reference to a professionals as being specialist in PPM and therefore involved in the delivery of PPM	1/A *“The lead for medical service provision by the hospice service is a paediatrician with a special interest in PPM, level three trained, contracted by the hospice.”*
Diversity in approaches to outreach	Type of outreach	Refers to any reference to the practical focus of the outreach ie nursing, respite, play therapy, sibling support	26/W *“The complexity of the child depends on who is sent home. Visits can be play support, nursing outreach or sibling support. We can also use family volunteer support workers.”*
Diversity in approaches to outreach	Configuration of outreach services	Refers to any reference to the way in which the outreach service operates	26/W “*A Nurse and therapist lead a team that is integrated and works across inpatient and community settings. 70 % of our work is in the community”*

Diagram for main theme: ***The current and developing workforce of children's hospices***

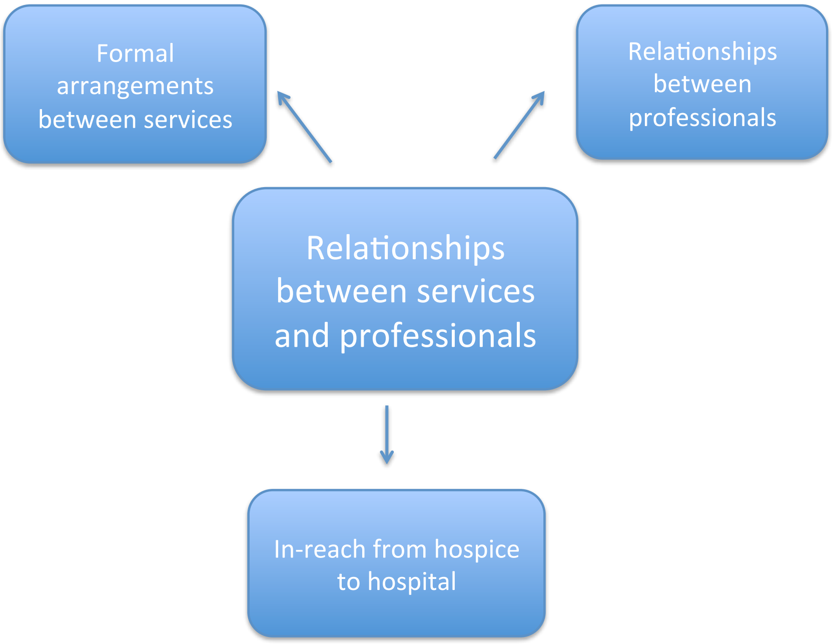


Coding framework for main theme: ***The current and developing workforce of children's hospices***

Subtheme	Code name	Description	Example
The foundation of General practice	The foundation of General Practice (NB this code was so significant it became a subtheme)	To refer to any reference to GPs or a general practice playing a part in the medical cover for a hospice	2/B ***"****The hospice has a link with a local General Practice, it is a three man GP surgery and one of the GPs works for the hospice and is very dedicated."*
The nursing versus medical role. A fading distinction?	The nursing versus medical role. A fading distinction? This code became a subtheme	To refer to any reference to nurses in medical or specialist PPM roles	7/G "*The nurse Consultant has an honorary contract with hospitals. The specialist PPM review is done with support of the [hospice] medical team."*

The current workforce of children’s hospices	Medical teams	To refer to any reference to a team of doctors as part of the current workforce at a hospice	7/G *“The team is a mixture of GPs and Paediatricians. Regular clinical sessions are; Consultant PPM: (6 ½ sessions), Consultant PM (6 sessions), Level 4 doctor with research interest (6 hours), Consultant PPM (6 hours), Oncology Staff Grade (6 hours) Adult PM Consultant (18 hours), GP with special interest (24 hours) and a registrar from PICU. “*
The current workforce of children’s hospices	Consultants in PPM and adult PM	To refer to any reference to consultants in PPM or adult PM consultants as part of the current workforce	6/F ***“**The Hospital employs the PPM* consultant *and has an SLA with the hospice. The consultant post had college approval as a PPM post”*
The current workforce of children’s hospices	Allied professionals	To refer to any reference to allied professionals as part of the current workforce	14/L“*A part time psychologist works 32 hours a week and gives holistic support. She is a vital part of the team.”*
Workforce innovations	Workforce innovations: includes review of medical services, creation of new posts.	To refer to any new development in the hospice workforce	20/Q *“We have a lead nurse in transition who is working with adult services. 18months ago we appointed a lead nurse for neonates who is building relationships with NICU as neonatal services have developed”.*

Diagram for main theme: Relationships between services and professionals

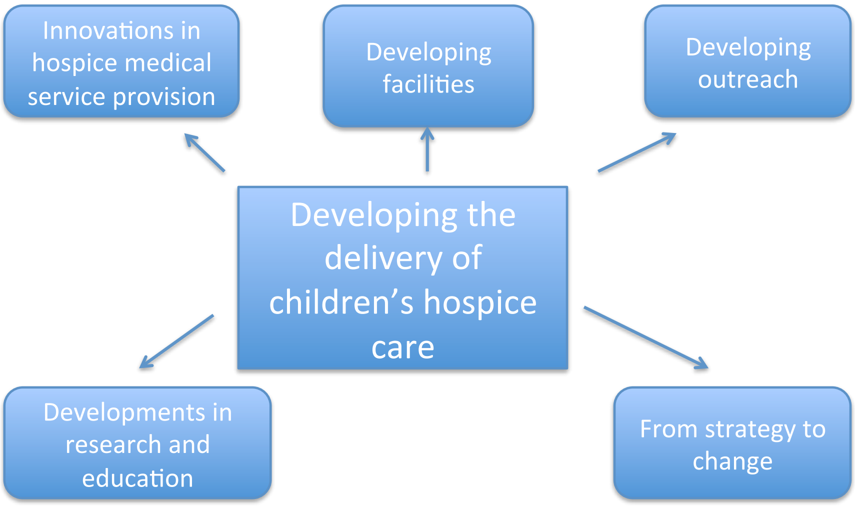


Coding framework for main theme: *Relationships between services*

Subtheme	Code name	Description	Example
Formal arrangements between services	Service level agreements	To refer to any reference to an SLA linking two palliative care services	11/I "There is an *SLA with [Tertiary children's hospital] for OOH telephone support for the children under [Tertiary children's hospital]"*
Formal arrangements between services	Operational pathways	To refer to any reference to a formal pathway to support services working together	10/H "*There is a pathway for rapid transfer from PICU and NICU"*
Formal arrangements between services	Communication between services	To refer to any formal strategies for supporting communication between services	26/W *"We are developing a children's multi disciplinary team meeting to discuss all palliative children"*

Relationships between professionals	Professional boundaries and medical leadership	To refer to any reference to systems to ensure professional boundaries and clear medical leadership	9/H “*There is a principle within the team that each child has a lead consultant and it is their patient, we provide palliative care input for them under the lead consultant. This is part of the organisational boundaries and governance. For end of life plans the clinical accountability is with the lead consultant”*
Relationships between professionals	The importance of good working relationships	To refer to any reference to good working relationships supporting care delivered	10/H *“We do not have formal agreements with hospitals but good relationships based on positive outcomes. We’ve done good stuff together”*
In reach from hospice to hospital	In reach from hospice to hospital	To refer to any reference to the hospice providing a service in an NHS hospital or for an NHS hospital	15/M “*There is in reach into [hospital] and we have three honorary* contracts *but they are not NHS funded”*

Diagram of main theme: Developing the delivery of children’s hospice care



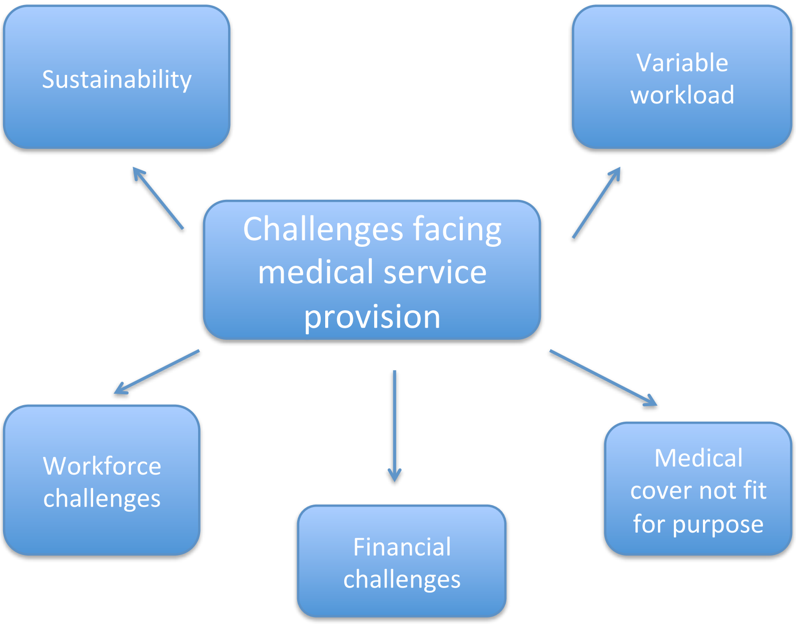
Coding framework for main theme: Developing the delivery of children’s hospice care

Subtheme	Code name	Description	Example
Innovations in hospice services	Acceptability of hospice care “A way in”	To refer to any reference to a development in service delivery to improve the acceptability of hospice care	20/Q “From *oncology we previously had last minute end of life referrals. We have developed links with the oncology team. Now most children are referred through the counseling service and sibling support”*
Innovations in hospice services	Clinics	To refer to any reference to a hospice led clinic	23/T “[Tertiary Hospital] *Consultant in PPM runs a clinic with a social worker, a physiotherapist and a specialist nurse, who is a nurse prescriber.* [Tertiary Hospital] Consultants in PPM cover different sides of [region] At clinic we see four children in a day.”

Innovations in hospice services	Telephone advice	To refer to any reference to a development in telephone advice	*21/K "It is our aspiration to run 24/7 advice with access for the whole of [Region] for medical advice"*
Innovations in hospice services	Allied and holistic care	To refer to any reference to a development in allied or holistic care	*23/T "We are developing a holistic centre for yoga and music"*
Innovations in hospice services	Targeting specific groups	To refer to any reference to a development focused on targeting specific groups of children	7/G "*Populations of children in NICU and Oncology are being targeted."*
Innovations in hospice services	Referral developments	To refer to any development or innovation in the area of referrals	19/P "*We are expanding the catchment area in line with adult service"*
Developments in facilities	Developments in facilities	To refer to any reference to a development of hospice facilities and buildings	1/A: *"A build for an inpatient unit in progress and registered with CQC [Care Quality Commission] for an inpatient unit and community hospice care"*
Developments in outreach services	Developments in outreach services	To refer to any reference to a development in hospice outreach services	7/G "*The outreach service in its current form has only been running for two years. It is actively being developed."*
Developments in education and research	Developments in education and research	To refer to any reference to new initiatives in education or research	15/M "*We are increasingly involved in research by [University] under [lead researcher] aiming to find out the number of children and young people with palliative care needs in [Region] and where are they. The [University] work identified 4000 under 25 yr olds"*

From strategy to change	From strategy to change	To refer to any reference to strategy as a driver for development	3/C " *We are actively trying to change the current situation where there is no specialist PPM input. This is by the publication of a [region] children's palliative care strategy and appointment of a consultant in PPM"*
From strategy to change	The use of pilots	To refer to any reference to the use of a pilot for service developments	26/W "*We are looking for funding to pilot children's register"*

Diagram of main theme: Challenges facing medical service provision



Coding framework for main theme Challenges facing medical service provision within hospices

Subtheme	Code name	Description	Example
Sustainability	Unsustainable 24/7 medical advice	To refer to any reference to a unsustainable provision of 24/7 advice	21/R *“We have 24/7 cover but this is one person therefore not sustainable 24/7”*
Sustainability	Reliance on goodwill	To refer to any reference to goodwill as a factor in hospice doctors work	11/I “*The system relies on the good will of one person.”*
Variable workload	Responsive hours	To refer to any reference to doctors working responsively	21/R “*the doctors regular hours are eight and a half hours but they are responsive to need.”*
Variable workload	Supporting end of life care	To refer to any reference to the variable workload in supporting end of life care	2/B outlined, “the *doctors hours are variable depending on if there is end of life care at the hospice. For end of life care one hour a day is needed* and *therefore seven hours a week. If there is no end of life care they do pop in visits.”*
Workforce challenges	Maintaining competencies	To refer to any reference to the challenge of maintaining staff competencies	9/H “*It is very difficult to do [haemodialysis] with respect to governance, competencies and difficult to maintain.”*
Workforce challenges	Need for increased staffing ratios	To refer to any reference to a need for increased staff ratios	24/U “*Challenging behaviours lead to significant training needed for restraint. And a need for 2 to 1 staff”*
Workforce challenges	Need for peer review	To refer to any reference to needing advice/ support from peers	15/M “*Sometimes need to call on national colleagues for advice*”
Workforce challenges	Recruitment difficulties	To refer to any reference to difficulty in recruitment	2/B **“***It has eight bed inpatient unit but is only running five beds currently in view of staff shortages.”*

Workforce challenges	Lack of training posts	To refer to any reference to the challenge of lack of training posts	3/C "*We have no Consultant in PPM in [Region] and no SpR training posts so it is difficult for interested registrars to develop a special interest*."
Medical cover not fit for purpose	Medical cover not fit for purpose	To refer to any reference to problems with the current medical service provision	3/C "*The current medical model does not serve us well… We need someone bringing something to the table, we have to lead the GPs 99% of the time and they are not proactive. We find in terms of the medical model that we can't actively offer as much symptom management as we want to*"
Financial challenges	Financial challenges	To refer to any reference to finances as a challenge in children's hospice care	

Appendix H: Correlation calculations

Non-parametric correlation calculation: end of life care episodes in past year and total number of doctors at hospice

Calculations	Number of end of life care episodes	Total doctors at hospice
Number of end of life care episodes: Correlation coefficient Significance (2 tailed) Number	1.0 25	0.384 0.64 24
Total doctors at hospice Correlation coefficient Significance (2 tailed) Number	0.384 0.64 24	1.0 27

Non-parametric correlation calculation: end of life care episodes in past year and doctor hours per week at hospice

Calculations	Number of end of life care episodes	Total number of doctor hours
Number of end of life care episodes Correlation coefficient Significance (2 tailed) Number	1.0 25	0.367 0.78 24
Total number of doctor hours Correlation coefficient Significance Number	0.367 0.78 24	1.0 27

Correlation calculation: acceptance of urgent referral for end of life care and total number of doctors at the hospice

	Total number of doctors at the hospice
Mann-Whitney U	67.000
Wilcoxon W	172.000
Z	- 0.176 -
Asymp. Sig (2 tailed)	0.86
Exact significance (1 tailed)	0.886