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NIHR Service Delivery and Organisation programme

NHS National Institute for Health Research

Evaluating models of care closer to home for children and young people who are ill: main report

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Glossary of terms/abbreviations

A&E	Accident and Emergency
CAU	Children's Assessment Unit
CCTH	Care Closer to Home
CCN	Community Children's Nursing
CHC	Continuing Health Care
CHME	Child Health Mapping Exercise
CHS	Child Health Strategy
HAH	Hospital at Home
HES	Hospital Episode Statistics
LOS	Length of stay
NP	Nurse Practitioners
NSF	National Service Framework for Children, Young People and Maternity Services
PbR	Payment by Results
PCT	Primary Care Trust
PHC	Paediatric Home Care
RCN	Royal College of Nursing
SALT	Speech and Language Therapy
SDO	Service Delivery and Organisation
SHA	Strategic Health Authority
SON-L	Specialist Outreach Nurse *with a local remit*
SON-R	Specialist Outreach Nurse *with a regional remit*
SPRU	Social Policy Research Unit
WTE	Whole Time Equivalent

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Contribution of authors

Professor Gillian Parker (Director, SPRU) developed and wrote the original proposal, managed and directed all stages of the project, advised on methods and all stages of analysis, conducted the analysis for the trials and other comparative studies in the systematic review, wrote the systematic review, and co wrote and edited the final project report.

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Karin Lowson (York Health Economics Consortium) undertook the analysis for the health economics component of the project and co-wrote chapter 8 of the final project report and the health economics chapter in the systematic review.

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Executive Summary

Background

Providing care for children who are ill, as close to home as possible, is an objective of health care providers and policy makers nationally and internationally. The existing evidence base to support development of care closer to home (CCTH) is weak in relation to clinical effectiveness, approaches and models, potential costs and benefits to families and the health service, impact on those who use CCTH, and how CCTH is best delivered and organised.

Aims of the project

1. Identify service models currently available to provide CCTH for children who are ill
2. Explore how these models respond to need
3. Explore the benefits, drawbacks and cost implications of a shift to more CCTH for ill children
4. Establish evidence-based good practice for establishing and running CCTH

Methods

This project took a mixed methods approach. We updated and extended a previous systematic review of international evidence on paediatric home care and reviewed UK literature that described models of CCTH. The review is in a separate report, but we used its findings in our health economics analysis. A national survey of English acute and primary care trusts mapped paediatric CCTH services and collected data on their delivery and organisation (e.g. staffing, cover, budgets). We used the survey data to create a typology of CCTH services. Case studies in four PCTs in England, using in-depth interviews with 35 staff who commissioned, organised and delivered CCTH and 22 families who used the services, explored the implications and impact of CCTH. Lastly, we explored the cost effectiveness of providing CCTH. This used survey data on caseloads and costs, compared Hospital Episode Statistics in case study sites with national data, and used the results of these, alongside evidence from the systematic review, to carry out simple economic modelling. Relatively few services provided information about their costs and caseloads, limiting this element of our work.

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Key findings

Models of care closer to home

There is a wide range of CCTH services, but community children's nursing teams are predominant. Fifteen children's hospices providing CCTH services also responded, suggesting that this model of end of life care is growing.

There are three main service models: cluster 1 largely provides condition specific services, usually working from acute settings; cluster 2 predominantly provides allied health therapy input; and cluster 3 services are largely community-based and provide both acute and long-term care, usually to children with very complex needs.

Responding to need

Cluster 1 and 3 services focus on preventing hospital admission, providing care for complex health needs out of hospital, reducing length of hospital stay, and supporting early discharge. Cluster 3 services are more likely to provide ongoing nursing care, technical support, drugs administration, and palliative or end of life care. Cluster 1 services are more likely to report training, liaison, health monitoring and social/psychological support, although half also report providing ongoing nursing care, drugs administration and sample taking.

These CCTH models operate as a 'virtual' service system, providing different elements of support to children with differing needs. While their functions and focus overlap somewhat, all are arguably necessary to avoid gaps in care delivery for very vulnerable children.

Benefits, drawbacks and cost implications

Commissioners and providers see CCTH as something that is for the NHS (e.g. preventing hospital admission), and for patients and families. Many feel that CCTH is better for children and families, describing both clinical (e.g. reducing risk of infection) and social (e.g. maintaining 'normality') benefits.

However, we identified difficulties in implementing CCTH at organisational and practice levels.

Organisational level issues

A perceived lack of evidence can impede CCTH development. Inadequate systems, and problems defining and quantifying effectiveness make collecting robust data difficult. Where data are available, this can underpin developing provision.

Good relationships between commissioners and providers are vital, particularly as providers hold the 'expertise'. Some find that competition rules make good relationships more difficult. Others adopt a useful strategy of distinguishing between working with providers to develop existing services, and working with them to commission new ones.

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Practice level issues

Capacity – particularly staffing and cover – is sometimes problematic, making it difficult to provide holistic care, including social and psychological support, which both practitioners and families see as important aspects of CCTH.

Working across and within boundaries can create difficulties when there is imperfect understanding in other parts of the health service about the role and purpose CCTH.

Community working can be isolating for staff and raises issues about personal safety when working alone. Good supervision and support structures help to deal with this.

Parents recognise that sometimes their child needs to be in hospital but prefer care to be at home where possible. This reduces disruption for the child and family, and sometimes the financial impact of caring for an ill child. Some parents have good relationships with staff, receiving social and psychological support, which they value. Others feel a need for increased support. Parents' willingness to take on technical and nursing responsibilities varies. The support of CCTH services is important for those who play an enhanced role in technical care for their child.

Our health economics work used all elements of the study, including the systematic review (see separate report). The conclusion was that CCTH might offer a cost saving when compared to hospital based care, particularly for children with complex and long-term needs. This appears largely due to days of hospital care saved. Case mix, skill mix and financial disincentives for acute providers may affect the opportunities for cost saving. The inability of most survey respondents to provide information about caseload and costs for their services restricted the health economics analysis we could carry out.

Evidence-based good practice

Descriptive accounts of CCTH rarely describe service delivery and organisational characteristics of services. This made it impossible to produce advice about good practice in establishing and running CCTH services from the systematic review (see separate report). However, other elements of the project threw some light onto these issues, outlined above. We build on these below, where we bring findings from the different elements of the project together.

Implications for health care

CCTH can provide safe and effective care for a wide range of children who would previously have been in hospital, and may do so with reduced costs to the health service, and to families too. Areas that commissioners and providers will need to consider in developing CCTH include:

- **The need for negotiated and agreed care protocols**, between acute and community-based providers, and between CCTH services and primary care.
- **Good working relationships between acute and community-based health care providers to ensure continuity of care.** These relationships are also important to ensure that savings from reduced length of stay in one part of the health care system are applied in the parts that support the reduced lengths of stay.
- **Understanding among general practitioners about CCTH and its potential**. Even when care protocols are agreed, it takes time to build the trust of GPs in referral to CCTH. A sustained period of negotiation and confidence building among GPs may be necessary to help realise the full gains of CCTH.
- **The right skill mix in CCTH teams**. Having a range of nursing bands in a team, including health care assistants, may influence cost-effectiveness.
- **The importance of case mix in determining the costs and flexibility of CCTH services**. Generic teams that can deal with both short-term acute illnesses and longer-term, more complex care may be more cost-effective and find it easier to manage fluctuations in demand. Embedding nurse practitioners within generic CCTH teams seems a promising model, because it addresses both skill mix and case mix.
- **The nature of contracting with CCTH services**. Block contracts offer less flexibility to CCTH services dealing with fluctuating levels of need, while competition rules may impede planned innovation. However, given variability of caseloads in most CCTH services, setting a tariff is challenging. Cost per case seems to work well in continuing care provision and may be worth experimenting with in other types of CCTH.
- **The need to provide psychosocial support within CCTH**. This is not a luxury; it is a vital part of supporting ill children and their families, particularly those dealing with very complex health needs.
- **The need for robust data systems on activities and costs**. Using HES data to examine length of stay might be a useful starting point for many health economies that do not yet have robust systems in place.
- **Supervision and support in CCTH**. CCTH involves lone-working; good supervision and support structures within teams are essential to safe practice.
- **24 hour, seven day a week support**. For some CCTH services, this can be provided effectively through telephone support systems. For services intended as immediate alternatives to acute hospital care, it is counterproductive, for children, families and the health care system, to limit them to 'office hours'.
- **The availability of training for paediatric community nursing**. Local availability of appropriate training for nurses working in the community with ill children seems to affect recruitment and retention.

The Report

1 Introduction

1.1 What is care close to home?

Standard 6 of the National Service Framework (NSF) for Children, Young People and Maternity Services[1] described a vision for the health care of ill children[a] and their families. Markers of good practice centred on the need to ensure that care was accessible, and focused on the needs of the ill child and their family. Within this context, the guidance stated that care should be provided as *close to home* as possible. At least three drivers for this emphasis on care close to home (CCTH) in policy can be identified.

First, there is the longstanding recognition of the importance of keeping children out of hospital where possible and providing care at home; Platt's review, *Welfare of Children in Hospital*[2] is perhaps the first official signal of this. Until the publication of the NSF, however, care for ill children outside hospital predominantly meant care *at* home, as demonstrated by the literature on paediatric home care (PHC)[3]. For example, an early study in the USA by Stein and Jessop[4] evaluated a PHC programme for children with long-term and complex needs, while later, UK-based studies described teams centred on the child's home environment, providing either long-term support or care for episodes of acute, non-serious illness, or both, in the child's own home (for example, Lessing and Tatman, 1991;[5] Tatman and colleagues, 1992;[6] Tatman and Woodroffe, 1993[7]; Sartain and colleagues, 2002;[8] Davies & Dale, 2003[9]).

Secondly, the development of high technology intervention and support for children with very complex conditions means both that they survive birth and that they live longer than they would have done in the past. This poses dilemmas for health care systems that, on the one hand, are essential to the child's continued survival but which, on the other, as in the case of the UK, have been moving away from long-term hospital care for most groups since the late 1970s. The recognition that high technology care can be delivered safely at home provides a potential solution, allowing high levels of health care support at home for very ill children. Continued technological and scientific advances are likely to mean increased numbers of children in this position.

Despite the trend towards care *at* home in the literature, the NSF chose to emphasise care *close* to home. This shift in emphasis suggests the NSF saw the need for flexibility in the settings in which ill children can be cared for outside the acute hospital ward. To some extent, this reflects the third

[a] Here and throughout the report the term 'children' implies children and young people up to the age of 18 years.

policy driver– the growing interest in 'ambulatory care' for children which, while not provided at home, ensures that children with acute conditions are cared for in the most appropriate setting. Assessment and triage when children present with acute conditions, mean that some return home without an overnight hospital stay but with some form of home-based health care. This form of care has the potential both to be better for the child and family and to make better use of expensive acute hospital resources.

Later policy in relation to children confirmed and extended the duality of focus evident in the NSF; the child health strategy, *Healthy Lives, Brighter Futures*[10] (hereafter referred to as CHS) referred to the need for ill children to be cared for closer to home and extended this to education and social care settings:

> For children and young people, the concept of care close to home needs to include support to maximise their participation in education and other social and developmental activity. So thinking about the pathway and the multi-disciplinary team around the child needs to extend to education as well as social care.
>
> (ibid; p.72)

Together these policies define CCTH as the physical relocation of care previously delivered in hospital settings (whether short-stay or long-stay) into the community. A more comprehensive understanding of CCTH, however, shows that it can be defined not only in terms of where care is provided, but also in terms of the functions of such care. The philosophy of ensuring that ill children should not be in hospital unnecessarily means that CCTH is also about preventing admission to hospital or reducing hospital stay by facilitating early discharge or long-term care at home.

1.2 How is CCTH provided and by whom?

CCTH service provision varies, but can be broadly classified into a four service-type model, determined by focus and location, which has been used in various forms in the literature (for example, Parker et al., 2002;[3] Winter, 1997;[11] Whiting, 2004[12]). Thus, CCTH teams can be generic or specialist, and be based in an acute setting or in the community. They can also provide shorter- or longer-term input (figure 1).

Figure 1. Dimensions of paediatric home care provision (adapted from Parker et al., 2002[3])

	Focus			
	Specialist		*Generic*	
Location/base	Timing		Timing	
Community	Shorter	Longer	Shorter	Longer
Hospital	Shorter	Longer	Shorter	Longer

In reality, services are often hybrids of these forms. For example, generic and specialist CCTH may both provide short-term care to prevent acute hospital admission as well as long-term care to children with complex conditions. Further, services occupying different 'cells' of the model may, in reality, provide almost identical care. For example, the input of a hospital-based team providing out-reach services to ill children in the community may be virtually indistinguishable from that of a community-based team.

The provision of care for ill children outside hospital is perhaps most commonly recognised in the UK in the form of community children's nursing (CCN) teams, whose presence in the NHS reaches back to 1948 when the first home care team was established[5]. Later surveys of provision indicate growth in the 1990s, with 62 generic and 124 specialist services identified by 1999[7 13]. Almost a decade later, Forys[14] identified 124 hospital at home (HAH) and CCN teams, although it is not clear what proportion of these were generic or specialist. More recently, the Royal College of Nursing (RCN) directory of CCN teams listed 192 services in England in August 2007[15], although again, it is not clear what proportion were generic or specialist.

Whiting[16] has distinguished seven types of care provided via CCN: neonatal care, acute care, supporting planned surgery, long term care, follow-up and emergency care, care for disabled children and palliative care. While CCN teams may differ in their remit of care, most share features in terms of their coverage, base settings, referral sources and care activities. Coverage in some cases is 24-hour, but mostly more restricted than this[14 17]. Most teams are said to operate from hospital rather than community bases[13 14]. Referrals are taken from a number of sources, including the family[7 13], and care activities are likely to include (in addition to nursing care) advice and information, liaison, support and teaching[13].

While CCN teams have been the traditional model of CCTH in the UK, other forms of service provision have been defined as providing or facilitating CCTH. For example, the most recent edition of the RCN directory of CCN includes special school nursing services. At the other end of the health care spectrum, Eaton[18] includes paediatric assessment units as a form of CCN provision. Ambulatory care (as it is more usually known in the USA) aims to prevent unnecessary hospital admission for children through designated units, wards or beds. Referral to these facilities may be from a GP or from the Accident and Emergency (A&E) department, and they are often situated

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within a hospital[19 20]. Given their setting within a hospital, these services may not be *physically* closer to home. However, preventing hospital admission can result in care being provided in a setting more appropriate than an in-patient ward and thus be seen as enabling CCTH.

Regardless of how broadly one interprets *CCN* provision, the inclusion of these services into the domain of thinking around caring for ill children outside the hospital environment clearly indicates that *CCTH* provision can extend across a wide range of children's health services. In exploring CCTH provision therefore we need to adopt a flexible approach to identifying who is providing this care and how.

1.3 Who is CCTH for?

CCTH can serve four broad groups of children. Firstly, for children with longer-term, complex health conditions who are likely to need constant health care, CCTH is an alternative to long-term care in hospital. Secondly, children with chronic but less complex conditions, such as diabetes or asthma, may also benefit if repeated visits to hospital can be replaced with an outreach nurse going into the home (for example, Matthams, 2003[21]). Thirdly, children with palliative care needs may use a specialised version of CCTH, enabling services to facilitate the choice of dying at home[22]. Lastly, children with acute episodes of illness (whether associated with longer-term conditions or not) might benefit from relocated care, reducing the length of hospital stay or avoiding it all together when the condition can be safely managed elsewhere[8].

1.4 What do we already know about CCTH?

Existing literature about home care and CCN provision is predominantly descriptive. While this is valuable in understanding the potential complexity of provision, it offers little insight into questions of clinical effectiveness, approaches and models, potential costs and benefits to both families and the health services, its impact on those who use it, how it is best delivered and organised, and its implications for the NHS workforce.

A systematic review of international evidence on PHC carried out before the NSF was developed[3] indicated the evidence base was underdeveloped. It was impossible to ascertain whether home care for ill children was clinically more or less effective than routine care, or whether it was more or less cost effective.

There was also a lack of evidence on the psychosocial impact of specific home care interventions on the parents and child. Although at the time few studies had evaluated this in relation to specific interventions, we know from descriptive studies of technology dependent and other chronically ill children cared for at home that there can be an impact on parents and children, particularly in terms of caregiver burden and social isolation (for example, Ray and Ritchie, 1993;[23] Stalker et al., 2003;[24] and see Wang and Bernard, 2004[25] for a review). Further, professionals' awareness of this impact may alter their decision-making about hospital discharge[24].

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Developing CCTH may also have implications for the NHS workforce – both at the level of commissioning and in practice.

The role of commissioners in ensuring high quality services was emphasised in the aim of 'world class commissioning' driving the development of NHS services[26]. For children's health services, however, there is a recent added layer of intricacy with Children's Trusts arrangements intended to drive 'joined-up commissioning'[10]. Developing children's health services closer to home may thus involve the complexities of negotiating networks of care between different agencies. Further, the importance of incorporating the voices of children and families in service development has been rightly emphasised. Before our project, the extent to which these issues played a role in the development of CCTH was unknown. We also did not know what role commissioners were playing in developing CCTH, how they used evidence to support developments, what success they were having, and what challenges were associated with this.

At the practice level, developing and delivering CCTH may have implications for the children's workforce in the NHS, in relation to the impact on primary care, clinical responsibility, and having sufficient capacity to provide the care. For example, if care is relocated out of the hospital and into the community, how does this affect the workload of other community staff? How is the child's care communicated to relevant partners? What skills are required in a children's health care workforce working with ill children in the community? What links are necessary and appropriate with other parts of the children's workforce?

A review by Eaton[18] shows communication between community nurses and other staff can be problematic and suggests more liaison is needed between hospital and community based staff. There is also the issue of clinical responsibility. For a child receiving hospital care in the community, how are the boundaries of clinical responsibility established? Eaton[18] argues that clinical responsibility under the hospital consultant, rather than the GP, would increase continuity during home care. There is, however, little evidence about the experiences of families receiving CCTH in relation to this.

The extent of CCTH provision may also be mediated by the extent of staffing and coverage in response to need. For example, a small study of children and young people with complex health needs in hospital found insufficient provision in the community was delaying discharge from hospital for some[24]. Although no national data exist which fully describe the extent of need for ill children, emergency admission statistics show an increase of 18 percent in admissions between 1996/97 and 2006/07, with infants less than one year old having the highest rate of admissions[27]. This provides some indication that demand for care for ill children may be increasing; but we do not yet know how much of this demand could be met through CCTH and what the workforce implications of this would be.

These issues indicate there is much to be understood about children's CCTH, and scope to identify good practice evidence on which to develop this form

of care further. As Winter[11] noted, development of this type of care has been reactive rather than planned and:

> "Rather fragmented … to bridge 'gaps' between local primary and secondary care services rather than as planned strategic responses to develop an integrated child health service in order to meet identified local needs (p.24)."

For policy to be successfully implemented, best practice evidence is required. Models of CCTH can then be developed and carefully evaluated in relation to designated outcomes.

1.5 The study

1.5.1 Background

The project reported here was commissioned as part of a larger programme of research intended to support the implementation of the NSF for Children, Young People and Maternity Services. The overwhelming impression, as stated in the evidence reviewed for the NSF[1], is that CCTH services have developed 'according to local need and circumstance rather than [influenced by] an evidence-base of the most effective model of provision' (p.26). The House of Commons Select Committee[28] highlighted this issue when it recommended that the Department of Health should monitor the effectiveness of local models and structures, so that improved advice and guidance could be given to providers. However, while there is a UK literature on the development of CCTH for children and young people who are ill (see above) it has weaknesses in relation to informing policy and provision.

First, as outlined above, little of the literature is evaluative. The systematic review of paediatric home care[3] found no completed, controlled evaluation of any form of generic CCN services in the UK, although one randomised controlled trial (RCT) of a hospital at home service has been completed since[8]. The evidence base is weak in the realm of specialist provision, too. For example, while home-based support for children with long-standing conditions such as diabetes or asthma is increasingly popular, the systematic review concluded that 'there seems relatively little evidence to suggest whether or not it improves outcomes or reduces costs, for children themselves, their families or the health service'[3] (pp.71-2). The same is largely true of home-based, high technology care for children with the most complex care needs.

The second weakness is that the views of children and young people and their families are not central in much of the literature. The evidence review for Standard 6 of the NSF[29] stated that, despite the lack of evidence on clinical or cost effectiveness, 'home care is preferred by many families' (p.126). Yet, controlled studies rarely report the views of families, and even less those of children or young people.

Thirdly, descriptive accounts of individual service and local developments often contain detail of the benefits and challenges of establishing a new

model of care. However, this material has never been synthesised to provide insight into broader organisational issues around providing CCTH.

The initiative to generate evidence to inform implementation of the NSF recognised the need to strengthen the evidence-base in relation to services that provide CCTH for children and young people who are ill. Our proposal was a response to that need and aimed to tackle the three weaknesses outlined above. It offered a multi-faceted study, using mixed methods, to generate new understanding and to make best use of already available material in order to inform the development of innovatory practice in models of CCTH.

1.5.2 Aims and objectives

The aims of the proposed project were:

1. To identify service models currently available to provide care as close to home as possible for children and young people who are ill
2. To explore how these models respond to needs influenced by, for example, age, condition, ethnicity, deprivation
3. To explore the benefits, drawbacks and cost implications of a shift from hospital in-patient care to more community-based models of care for ill children and young people
4. To establish evidence-based principles of good practice in relation to establishing and running 'close to home' models of care.

The objectives of the proposed project were:

1. To update and extend an earlier systematic review of paediatric home care, to identify recent evidence on models of CCTH for children with long-term (but not necessarily disabling) conditions and extend the review to models of care for children with short-term health needs.
2. To review the descriptive literature on 'close to home' models of care in the UK for children and young people who are ill, with a focus on features of service delivery and organisation, including issues for primary care, and child and parent satisfaction.
3. To carry out a national survey and case studies to explore in more detail the implications for services and service users of providing care close to home for children and young people. This element of the project intended to have a specific focus on the implications for primary care, the ways in which different parts of the service system work together to deliver appropriate care, and the views and experiences of children and young people and their families.
4. To model the impact of providing more care close to home on hospital paediatric acute activity – emergency admissions, length of stay – and health service costs.

1.6 Structure of the report

In chapter 2 we describe the methods of the national survey and the case studies. The systematic review is published as a separate document[30], although its findings did influence and contribute to other elements of our work. This was particularly so for the health economics analysis. In chapter 3 we move onto the results of the national survey of CCTH services in England, presenting quantitative material about the type, functions, coverage, staffing, future developments and costs of the services surveyed. Chapters 4 to 6 report the qualitative findings of the case studies. Chapter 4 examines how CCTH was conceptualised by commissioners, service managers and practitioners and explores strategic barriers and enablers to commissioning and developing CCTH. In chapter 5 we then go on to describe and explore some of the practical issues that arise in delivering and developing CCTH services, while in chapter 6, the views of parents and other carers are analysed. Chapter 7 describes the methods and findings of the fourth stage of the project which examined the health economics implications of CCTH. Finally, chapter 8 includes the 'headline' conclusions we have drawn from all stages of our work including the systematic review, discusses the research approach taken, and makes suggestions about future service development and research. Appendices contain our tools for data collection, documents for participant recruitment and other supplementary information.

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2 Design and methods

2.1 National survey of care close to home services

2.1.1 Design and instruments

The aim of the national survey was to map paediatric CCTH services available in England. For each service identified, the objective was to gather information on service delivery and organisational characteristics.

Initially, we had intended to send a single questionnaire to each primary care trust (PCT) and acute trust in England. However, consultation with children's service providers and commissioners at the beginning of the project revealed two potential problems with this approach. First, some trusts had more than one CCTH service; but a single questionnaire, designed to collect information on more than one service and that would have to be completed by a range of people, would be difficult to manage. It would also appear lengthy, which might discourage participants from responding. Secondly, it became clear that the lead for children's services in each trust – the original intended recipients of the questionnaire - would be unlikely to be able to answer detailed questions about services and their organisation, without consultation with others.

We therefore decided to carry out the survey in two stages.

The first stage consisted of a screening questionnaire sent to the person in each trust that was responsible for provision of children's services (for example, a strategic director for children's services). This questionnaire provided a definition and examples of what we meant by CCTH services for children and asked if the trust provided any. If they did, the questionnaire then asked for the contact details of service managers for these services who could provide further information.

The second stage involved sending out individual questionnaires to each of the CCTH services identified in stage 1.

At the preliminary stage of development, the stage 2 questionnaire was informed by information gathered during the descriptive review of the UK literature[30]. Using this information, the questionnaire was designed to collect data on: service objectives, delivery methods, settings, staffing, population served, geographical profile and funding arrangements. Discussions with the Royal College of Nursing (RCN), the Royal College of Paediatrics and Child Health (RCPCH), and our project advisory committee also informed the content of the questionnaire.

After initial drafting, feedback on the stage 2 questionnaire was sought from the RCN, RCPCH, local children's service managers and our advisory committee. No major issues were identified at this point and thus no significant amendments were made to the draft questionnaire.

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2.1.2 Sample

A list of PCTs and acute trusts in England was obtained from http://www.nhs.uk/ServiceDirectories/ in January 2008. At that time, there were 166 acute trusts and 141 PCTs. We contacted each trust and asked for the name and contact details of the most senior individual with responsibility for delivering children's services. The individuals identified often held senior positions such as director of children's services, director of operations, paediatric matron, medical director or divisional director. In some cases, a children's commissioner was identified as being the appropriate person; we questioned this where possible, however reconfiguration of PCTs was underway during this period and this may have resulted in a lack of clarity regarding the division between commissioning and delivery.

Children's hospices are increasingly involved in providing CCTH services for children and young people with life-limiting or life-threatening conditions. These are provided by the third sector, in some cases with the support of public funding. We thought it unlikely that our screening questionnaire to trusts would identify these services so we contacted all 30 children's hospices in England directly.

2.1.3 The pilot study

2.1.3.1 Screening stage

The screening questionnaire was piloted on ten percent of the total stage 1 sample of trusts, which resulted in a pilot sample of 30 of 307 trusts (16 acute trusts and 14 PCTs). Participants in the pilot sample were informed that they were taking part in a pilot phase and were asked to give feedback on any difficulties they faced completing the questionnaire and what changes they would like to see made. All pilot screening questionnaires were sent on the same day, with a reminder letter for non-responders being sent two weeks later. After a further week, non-responders were telephoned. Twenty-five trusts responded, giving a pilot response rate of 83 per cent for the stage 1 screening questionnaire (Table 1).

Table 1. Response to pilot screening questionnaire

Number of pilot screening questionnaires sent out	**30**
Returned within two weeks	6
Returned after sending a reminder letter (two weeks from initial mail out)	8
Returned after a telephone follow up (one week from date of sending reminder letter)	11
Trusts refusing participation	1
Total number of completed responses for pilot screening questionnaire	25
Response rate (excluding refusal)	***83%***
Response rate of acute trusts (Total sent =16)	***94%***
Response rate for PCTs (Total sent = 14)	***71%***

After return of the pilot screening questionnaire, all services reported by respondents were crosschecked with services reported in the most recent Child Health Mapping Exercise (CHME)[31]. The purpose of this was to check that key CCTH services were being reported, and thus that the presented definition of CCTH in the survey was clear to respondents. It is important to note that the CHME is not exhaustive in detailing the different types of CCTH services. It was thus used as a guide in relation to community nurses, assessment units, 'hospital at home' (so defined), specialist nurses, and home care for life threatening illness.

If a screening questionnaire respondent did not mention CCTH services reported in the CHME, there were three possible explanations:

1. the person completing the form did not have sufficient knowledge of the services provided in the trust
2. the services no longer existed
3. the person completing the form did not understand the non-reported services as CCTH.

The first point had been addressed before sending the screening questionnaire, as each trust was contacted and asked for the name of the person in a position to have an overview of all children's services provided by the trust. If the third point was the reason for not reporting services, this might indicate that the definition of CCTH in the screening questionnaire did not clearly communicate the types of services in which we were interested, or that the individual felt that such services reported in the CHME were not, in fact, providing CCTH.

Crosschecking indicated that hospital based services such as day assessment units and day medical care were not being reported. Three trusts did not report these services in their response, though they were included in the CHME. We contacted the respondents and explained that such services were relevant to our national survey. The three trusts contacted were happy to provide contact details for managers of these units but said that although these services did prevent hospital admission, they did not conceptualise them as CCTH. Such services had been described in the pilot screening questionnaire, but as a result of these comments we altered the structure of the information presented to respondents so that hospital based services that prevented admission or reduced length of stay were listed before home and community based services.

From the piloting of the screening questionnaire, it was also clear that some respondents understood CCTH services to include public health services such as health visiting. Thus, changes were made to emphasise that the survey was not mapping public health services. The final version of the screening questionnaire can be found in Appendix 1.

The telephone reminder stage of the screening questionnaire also indicated that participants wanted more time to complete the questionnaire. We therefore amended the timetable so that there was a two-week interval between the reminder letter and the reminder telephone call. The protocol for follow up of the screening stage and for the main stage is in figure 2. Children's hospices were not screened, but sent questionnaire two directly (see below).

2.1.3.2 Main stage

Of the 25 returned pilot screening questionnaires, 21 trusts reported that, between them, they provided 51 CCTH services. However, we were able to use only 44 of these services as a pilot sample for the full questionnaire, due to four late returns representing seven services. These seven services were later included as part of the main survey.

For the pilot phase, 44 identified services were sent questionnaire 2. Participants were informed they were taking part in a pilot phase and, again, feedback was sought. A similar follow-up protocol to that for the screening questionnaire was used. Due to the more detailed nature of pilot questionnaire 2, reminder letters were sent to non-responders three weeks after the initial mailing, and for those not returned after an additional two weeks, a telephone call was made. The total response rate for the pilot of questionnaire 2 was 70 percent (Table 2)

Table 2. Response to pilot main stage questionnaire

Number of pilot questionnaire two sent out	**44**
Returned within three weeks	6
Returned after sending a reminder letter (three weeks from initial date of mail out)	5
Returned after a telephone follow up (two week from date of sending reminder letter)	20
Total number of responses to pilot main stage questionnaire	31
Response rate	***70%***

We also piloted a slightly amended version of questionnaire 2 with three children's hospices.

Several issues arose from the responses to the pilot questionnaire 2. Most of these concerned the wording of questions. Amendments were made and the final version is at Appendix 2.

A further issue concerned the information about deadlines given to participants completing the questionnaire. Initially, it was decided that no deadlines would be given to participants, with a reminder sent after three weeks. However, several potential respondents contacted the researchers and asked for a deadline. After further team discussion, we decided to inform participants that the team would like the questionnaire to be returned within three weeks, but that questionnaires returned after this date would still be logged and included in the survey. No change to the follow up protocol for pilot questionnaire 2 was made for the full survey.

2.1.4 Full survey

2.1.4.1 Screening stage

Given the minor changes in questions after piloting, the 30 trusts selected for the pilot phase were not resurveyed but their pilot data were analysed alongside those from the full survey. The remaining 277 trusts were sent a screening questionnaire and the amended protocol for follow up was followed (see Figure 2). The total response rate of returned and completed screening questionnaires was 64.6 percent (n=179) after the final follow up. Nine trusts declined participation at the screening stage. Further details of the response rate for the screening questionnaire are in Table 3.

Table 3. Response to full survey screening questionnaire

Number of main stage screening questionnaires sent out	**277**
Questionnaires returned within two weeks	37
Questionnaires returned after sending a reminder letter (two weeks from initial date of mail out)	60
Questionnaires returned after a telephone follow up (two weeks from date of reminder)	82
Number of trusts refusing	9
Total number of completed responses for screening questionnaire	179
Response rate (excluding refusals)	***64.6%***

Combining the responses for the pilot and main stages, 204 out of 307 trusts (66.4 percent) completed the screening questionnaire, with ten trusts declining participation (five PCTs and five acute trusts). Of the 204 returned, 115 were from acute trusts and 89 from PCTs. Of these, 168 (82.3 percent) reported that they provided CCTH services.

2.1.4.2 Main stage

From the screening questionnaires, including those from the pilot stage, 546 CCTH services were reported. Some services were excluded from the main survey at this stage, where it was obvious the service was not relevant to CCTH (for example, generic community paediatrics), where more than one respondent had reported the same service, or where the respondent had provided insufficient detail for us to send questionnaire 2.[b] In other cases, however, it was more difficult to establish whether the service was relevant based on the screening information alone. In these instances, questionnaire two was sent and a decision made after (if) the questionnaire was returned. Examples of such services included out-patient clinics (not otherwise specified) and 'specialist' health visitors.

Of the 546 services reported at the screening stage, 418 services were eventually deemed 'in scope'.

We also sent the slightly altered version of questionnaire 2 (see above) to the remaining 27 children's hospices.

[b] We contacted screening stage respondents in all cases, but lack of response to repeated telephone, email or letter requests for further details meant that we 'lost' nine services at this stage.

Table 4. Number of care close to home services reported and 'in scope'

Number services reported	**546**
Services deemed not relevant to CTH by respondent	33
Services deemed not relevant to CCTH by researchers	77
Services excluded due to duplication	10
Number of services excluded due to incorrect reporting[1]	9
Number of care close to home services identified	***417***

In addition to the follow-up stages outlined in the protocol, we sent an additional letter to all non-responders (including non-responders to questionnaire 2 in the pilot stage). This letter asked if the service that had been identified at the screening stage was, indeed, relevant to CCTH and, if not, to inform the researchers using a response slip and prepaid envelope. If the recipient felt that their service was relevant, then a final request to complete the enclosed questionnaire was made.

A total of 296 questionnaires, including those from the pilot survey, were returned from trusts (see Table 5). We also received returns from 24 children's hospices, 15 of which provided CCTH services. In total, then, we had 311 returned questionnaires.

Of the 417 services deemed 'in scope', 279 were provided by acute trusts and 138 were provided by PCTs. Of those returned, 202 were from acute trust provided services (72 percent of acute sector services 'in scope') and 94 from services provided by PCTs (68 percent of PCT services 'in scope').

Table 5. Response to main stage questionnaire (including pilot responses)

Number of services 'in scope'	**417**
Returned within three weeks	117
Returned after sending a reminder letter (three weeks from initial date of mail out)	89
Returned after a telephone follow up (two weeks from date of sending reminder letter)	57
Returned after final letter to determine relevance of service to survey	33
Trusts refusing	2
Total responses	296
Response rate (excluding refusals)	***71.0%***

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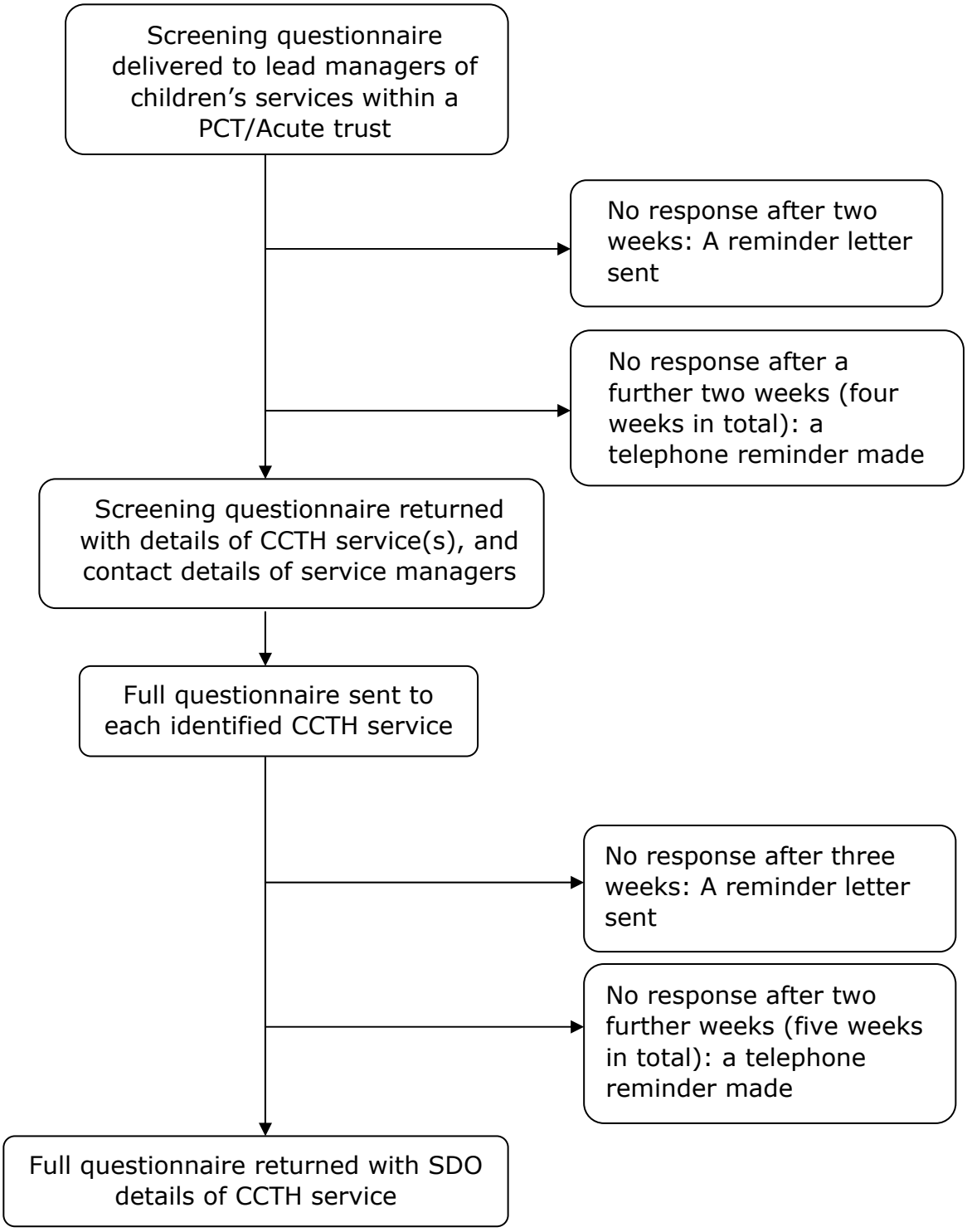
Figure 2. Follow up protocol for main stage survey



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2.1.4.3 Analysis

After cleaning and validation within an Access database, the main stage data were exported into SPSS for analysis.

The first stage of analysis involved examining the range of services reported, and assigning them to one of 13 service model categories. Bivariate analysis then compared the different service models across the other variables. More detail about the 13 categories is given in Chapter 3.

The second stage of analysis used a series of K-means cluster analyses for data reduction purposes. K-means clustering is a method of cluster analysis that aims to partition *n* observations into *k* clusters, in which each observation belongs to the cluster with the nearest mean. The first stage generates an initial set of means and classifies cases based on their distances to the centres. Next, cluster means are re-computed, using the cases assigned to the cluster. All cases are then reclassified, based on the new set of means. These steps are repeated until cluster means become relatively stable between successive steps. The final stage is to calculate the means of the clusters once again and assign the cases to their permanent clusters.

A range of variables related to the functions the service provided, whether it was generic or specialist provision, its operating base, its hours and days of operation, and whether it was condition specific, informed the cluster formation. A three-cluster model that defined relatively distinct types of services was finally adopted. Using largely non-parametric statistics, the three service clusters were then subject to bivariate analysis of provision, service objectives, staffing, and other service delivery and organisational characteristics.

2.2 The case study

2.2.1 Design and methods

The survey helped us to understand the pattern of provision of CCTH services in England, and some aspects of their delivery, organisation and financing. However, surveys cannot give an in-depth understanding of other organisational and contextual issues that were of interest, and particularly the implications of moving care closer to home for primary care and other parts of the service system. To address this we carried out a multi-site, exploratory case study design, with different models of CCTH services as the unit of analysis, in order to identify the implications for users, commissioners and providers of having CCTH services within their PCT area.

Case study design is appropriate when asking 'how' and 'why' questions about contemporary events over which the researcher has little or no control, and where context is an important contributory factor to the phenomenon being studied[32] (pp.9, 13). Within this overall design, qualitative methods, including documentary analysis and individual interviews with significant actors, were the chosen approach.

This small-scale but intensive investigation was intended to focus on the:

- implications of CCTH for primary care
- views and experiences of children and young people and their families who used the services
- ways in which developments were working with other parts of the service system to address health, social, educational and emotional needs of children and young people who were ill.

2.2.2 Identifying and securing the case study sites

The original proposal was to use five or six Strategic Health Authorities (SHAs) as the service system for study. However, by the time the project was funded, SHAs had been reorganised into larger groupings that no longer represented discrete service systems. At the same time, PCTs were being amalgamated into groupings of size comparable to the previous SHAs. We therefore decided to use PCTs as the basis for the case study, as described in our revised proposal.

As we describe below, re-organisation was a continual feature of the case study fieldwork and some PCTs, though technically amalgamated, were still operating within previous boundaries.

The original intention was to identify our sites after we had analysed the survey, in order to select different patterns of service development in relation to CCTH. For two reasons, we eventually selected areas before full analysis of the survey was complete. First, a large amount of time was taken up obtaining outline research ethics approval and then having the survey instruments approved (both of which, at both pilot and main stage, had to be returned to the committee for approval[c]). This meant that we could not wait for full analysis of the survey before embarking on ethics and research governance clearance for the case study sites, without jeopardising the project timetable. Secondly, it soon became clear that reorganisation was taking time to bed down and that recruiting sites would be more complex and time consuming than anticipated. For example, in some PCTs identified as potential sites, it was not clear for several months who within the new structures could or would take responsibility for agreeing to be a case study site.

In response to these challenges, we changed the approach to identifying potential sites, using social and demographic data to identify PCTs with higher and lower levels of deprivation[33], different sizes of minority ethnic population[34], and that covered both urban and rural settings. We then examined PCTs that fell into the four 'extremes' of the matrix – high deprivation/high minority ethnic community; high deprivation/low minority ethnic community; low deprivation/high minority ethnic community; low deprivation/low minority ethnic community – for their representation of urban and rural settings. By this stage, we also knew whether any CCTH

[c] This was despite very minor changes to the wording of very few questions between pilot and main stages.

services had been declared in the PCT and of what type, and we used this information to refine our selection of sites so that different models of CCTH were included. Based on all this information, we selected seven potential case study sites and approached them personally to discuss possible involvement in the project.

At this point, the difficulty of finding anyone empowered to make a decision about involvement became clear. Two factors were evident here. First, some PCTs were further along in the process of separating their provider and commissioning arms. Secondly, some key decision-making posts were not yet filled after reorganisation. As a result, in some PCTs we had to follow very long trails to find the right person with whom to discuss participation and, in some cases, never reached the end of that trail. The final outcome then was that the selection of case study sites was pragmatic; there were few sites in the four extremes of the matrix, which had at least one CCTH service, where a senior manager was prepared to approve their PCT's involvement and that, between them, covered both urban and rural areas and different models of CCTH.

By the end of this extended process, it was clear that we could not achieve our intended five or six case study sites, obtain research governance clearance in each,[d] carry out our intended fieldwork and keep to our planned timetable. However, one of the PCTs we identified as 'in scope' was still operating largely in its pre-reorganisation format, with a generic, community-based CCTH service serving one part of the PCT, and a specialist, hospital-based CCTH service serving the other. This gave us an opportunity to compare and contrast these models within a single PCT and meant that we could achieve five services across our four sites.

2.2.3 Selected case study sites

As described above, the four sites represented different population profiles and types of CCTH provision. Table 6 outlines their characteristics and the model of CCTH studied in each. Further details about each site are in Appendix 3. We were unable to identify and recruit a case study site that represented a high level of deprivation in a PCT that covered rural areas. Although both site X and site Z covered rural and urban areas, site Z was, overall, more rural in its geography than site X.

[d] Despite the 'research passport' being technically in place when we did this work, none of our selected case study sites was prepared to accept a passport that had been issued by another PCT. Further, different service providers within a single PCT took different approaches. As a result, we made six separate applications for research governance approval across the four sites.

Table 6. Summary Characteristics of the Case Study Sites and CCTH Services

	Urban	***Urban/Rural Mix***
High to moderate ethnic diversity	*Site W* **Deprivation:** High **Model:** Generic Children's Community Nursing (CCN) Team **Provider Trust:** PCT	*Site Xa* **Deprivation:** Low **Model:** Nurse Practitioner service for acute conditions (NP) **Provider Trust:** PCT
		Site Xb **Deprivation***:* Low **Model**: Oncology Specialist Outreach Nursing (Acute) (SON-L) **Provider Trust**: Acute
Moderate to low ethnic diversity	*Site Y* **Deprivation:** High **Model:** Oncology Specialist Outreach Nursing (SON-R) **Provider Trust:** Acute Trust	*Site Z* **Deprivation:** Low **Model:** Children's Assessment Unit (CAU) **Provider Trust:** Acute Trust

2.2.4 Samples within the case study sites

The initial focus of the case study was the commissioning arm of the PCT, and those involved in commissioning children's services. Individuals here were usually at director level and had an overview of children's and young people's services across the PCT. This subsequently led to the commissioned provider service, which in two sites was an acute trust, in one site a PCT, and in one site (two services) both. In the provider service, we focused first on the wider strategic organisation of children's services as a context for the delivery of CCTH. Individuals participating at this level were thus often directors or other senior level managers of the providing trust. The focus then narrowed to a particular service within the provider trust that delivered CCTH, and those involved in delivering such services. Individuals participating at this level were both CCTH service managers and practitioners who delivered the service face-to-face. Finally, the focus turned to the service users; here the intention was to include children and young people, and their families. For reasons explained below, the numbers of children and young people available to recruit were very small.

2.2.5 Case study methods

2.2.5.1 Interviews with staff

Semi-structured guides were developed for interviews with commissioners and for staff who manage and provide services, both at strategic and practice level. The guides were based on the questions outlined in the original proposal, and further developed from information gained from the reviews and from the survey stage of the project. In summary, they addressed some or all the following questions, depending on whose views were being sought:

- How are services for children and young people who are ill planned and developed in this PCT, and to what effect?
- How are services organised between health, social care, education and other relevant services, and to what effect?
- What is the relative balance between secondary and primary care provision, how does this work, and are there any plans for change in the future?
- What implications would (further) movement of care for ill children out of hospital have for primary care providers?
- How do children and young people and their families experience services close to home, and to what effect?
- How do services deal with diverse needs (both the diversity created by different conditions and prognoses and that created by the needs of different parts of the population)?
- Which models of service provision work best in delivering services close to home, from the perspectives of service users, their families or carers, and the professionals who deliver them?

Managers and practitioners on our advisory group contributed to development of the interview guide, which is at Appendix 4.

The interviews were carried out face-to-face, during fieldwork visits to the case study sites, or over the telephone, depending on the preference of the person being interviewed. In both cases, permission was sought to record the interview; this was given in all but two cases, where detailed notes were taken instead. The material gathered was reviewed continuously so that it could inform, where necessary, subsequent interviews and information seeking.

2.2.5.2 Interviews with children and young people

There was a long period of development for the topic guides, interview methods and tools, consent form and information sheets for the children and young people.

The issues covered in the interview included children's and young people's views about services delivered at home, hospital-based services, other places where they might receive health care, and about what might make their experience of health care better.

The Social Policy Research Unit's (SPRU) permanent consultation groups of young people and of parents advised about the content of the draft interview guide, consent forms and information sheets. These were then tested in 11 pilot interviews with children and young people aged between five and 17 years. None of the children interviewed at this stage used CCTH services and all were known personally to the researchers in the team. The focus of the pilot interview was on a time the child or young person had been to either a hospital or the dentist. This ensured that the topic guide questions and interview tools were being tested on a health care issue.

Pilot participants were asked about the type and range of questions asked, and the length of the interview. The interviews lasted approximately 30 minutes and all the questions were covered within this time. Most participants felt that 30 minutes was long enough and some that a longer interview would become boring. Most participants felt that the type and range of questions were appropriate. Some participants suggested additional topics, including the timings of care and its impact on schooling and social activities, as well as more 'warm up' questions relating to the family. These were added to the final interview topic guide (see Appendix 5).

Various tools and methods were developed to facilitate discussion with children and young people, and to make the interview fun and interactive. These included:

- Playmobil® hospital sets, hospital figurines, family figurines and home sets
- pens and paper for making posters and drawing pictures
- sheets with boxes for each question to make notes and lists (see Appendix 6)
- feeling face stickers
- feelings boards (see Appendix 7)
- message box/book.

Each received positive feedback during the pilot interviews. As might be expected, the younger children tended to prefer the Playmobil®, paper, pens and stickers and the middle and older age groups preferred the feelings board and sheets with boxes for each question. However, these preferences were not always driven by chronological age.

Prior consultation with SPRU's permanent young person's consultation group had suggested three key preferences for information sheets: that information was better presented as a booklet rather than as individual pages, that information should be presented in small 'chunks', and that colour was preferred to black and white. Considering each of these factors, different information booklets for three age groups (5-7, 8-12, 13-18) were designed and tested with the pilot sample. Each contained the same information but presented differently. There was a clear preference for one particular design, which was then adapted for each age group and used as a final version (see Appendix 8). The consent form was also piloted, and a

minor wording change implemented for the final consent form (see Appendix 8).

2.2.5.3 Interviews with parents

Interviews with the parents of children and young people who used CCTH services were designed to collect information about family structure, the child's condition, and the parents' experiences of and views about using CCTH. SPRU's permanent advisory group of parents helped to develop the draft interview guide which was then piloted with three volunteer parents from the group who used local CCTH services. The final version of the guide is at Appendix 9.

2.2.6 Case study samples

2.2.6.1 Staff

Senior level, strategic managers and commissioners were recruited in the first instance through links made with trusts at the start of the case study stage, where we identified the individual with ultimate responsibility, either for commissioning or delivering services for children and young people. Snowballing from these strategic level interviewees led, in some cases, to other strategic stakeholders. We then approached the CCTH services and identified relevant practice level managers and staff. We identified and interviewed individuals until it was clear that we had learned most of what there was to know about the history, strategic direction, delivery and future development of CCTH services in the site.

All staff invited to take part were given information about the research, the implications of taking part, and their rights as participants. Recruitment letters, information sheets and consent forms are at Appendix 10. Written consent was obtained face-to-face or, for telephone interviews, by post and then confirmed verbally before the interview started.

2.2.6.2 Parents

We liaised with the CCTH services in the sites about how best to identify and recruit parents whose children used their services and whom we could interview. In each service, a member of staff was identified who was responsible for distributing recruitment packs to parents who had used or were using the service. The only instructions we gave about which parents should be approached were that children receiving end of life care were excluded and that we were keen to gather the views of all types of parents, children and families using the service, not just those who were most 'engaged'.

Recruitment packs included information about the research, the implications of taking part, participants' rights, a form to indicate whether they wished to participate (with their contact details if they were giving a positive response) and a prepaid envelope to return the form directly to the researchers (see Appendix 11). Parents who responded and indicated that they were interested in participating were contacted by the researchers and interviews arranged. Written consent to the interview was obtained face-to-face.

2.2.6.3 Children and young people

Children and young people aged between five and 18 years were eligible for inclusion in the case study, after their parents had consented to their own participation. After parents had been interviewed we gave them an information pack regarding the child's possible participation in the research. This included separate information for parents and children about the research and the implications of the child's participation, response forms for both, and a pre-paid envelope (see Appendix 8). If both parents and children indicated interest in the child being involved, a researcher contacted them to discuss participation and, if consent was forthcoming, arrange an interview.

2.2.6.4 Ex gratia tokens

After participating in the research, we gave parents a £10 voucher as a token of appreciation. Parents did not know prior to their decision to participate or during their participation that they would receive a voucher afterwards. There was thus no monetary incentive to participate. Further, when parents had children old enough for participation, they did not receive the voucher until their child returned a response form or, if the child did not respond, four to five weeks after the parents' interview. This avoided the voucher being construed as an incentive for the child's participation.

After participation, child participants also received a voucher, this time for £5, but did not know about this before they participated.

2.2.6.5 Achieved samples

Staff

Thirty-five PCT or acute trust staff across the four sites were interviewed. Table 7 describes them by trust, function and level in the organisation.

Table 7. Numbers of staff interviewed in each case study site

	Primary Care Trust			**Acute Trust**		
	Commissi-oner	*Strategic Provider Manager*	*Service managers and practitioners*	*Strategic Provider Manager*	*Service managers and practitioners*	*Total in each site*
Site W	1	1	8	-	-	10
Site Xa	3[a]	1	4	-	-	8
Site Xb		-	-	1	3	4
Site Y	1	-	-	1	3	5
Site Z	1	1	-	1	5	8
Total	***6***	***3***	***12***	***3***	***11***	***35***

a. These commissioners were interviewed about the CCTH services in both sites within the PCT.

In addition to the staff described in the table, a GP in site Xa was interviewed about the CCTH service and its impact on primary care activity.

Parents

Ninety information packs were distributed to parents across the four sites; there were no responses to 61 of these, six outright refusals, and 22 achieved interviews, with 27 parents and carers (one was a grandmother). In five cases, two parents/carers chose to be interviewed together. The distribution of the interviews across sites is summarised in Table 8. As the table shows, the yield of interviews to packs sent varied substantially between sites, from almost a half in one case to only one in 20 in another.

Table 8. Recruitment for parent interviews

Site	Packs sent	No response	Refusal	Achieved interviews	Number of parents interviewed
W	14	8	2	4	6
Xa	15	5	3	7	9
Xb	16	10	1	5	6
Y	25	19	0	5	6
Z	20	19	0	1	1
Total	***90***	***61***	***6***	***22***	***28***

The ethical requirements of this project meant that the research team was entirely dependent on practitioners to hand out packs to parents whose children used the CCTH services, and had no way of contacting parents directly in the first instance. This had a number of consequences. First, it is possible that not all the packs that the research team provided were actually distributed. This seems most likely in site Z, which was providing a triage service in an acute setting, where children and their families might spend relatively little time before being discharged home or admitted to hospital. Secondly, there is no way of knowing how representative those interviewed were of the total parent group. Thirdly, the low response meant that this stage of the case study took longer than had been planned and it was further extended in an attempt to increase the numbers recruited.

Despite these challenges, the richness and degree of saturation of the material obtained from the parents' accounts compensated for the somewhat lower than planned numbers of interviews. A total of 28 parents/carers took part in the research across the four case study sites. The majority (20) were mothers, 7 were fathers and 1 was another family member. The age range of the sample was 21-52 years. Seven of the parent/carers were in full time work, 10 worked part time and 11 were not currently in employment. The majority of parents/carers were not in any education; however a small proportion (4) were. Nineteen of the parents/carers were married.

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Children and young people

Despite the careful preparation of materials for children and young people, and the lengths we went to in obtaining ethical approval for these, in the end only one young person was interviewed. The majority of children of the parents who were interviewed were under the age of five, and therefore ineligible for the study. Of the remainder, four were eligible and one consented to participation. Details of the ages and health conditions of children whose parents participated are in Appendix 12.

2.2.7 Analysis

The material from all sites and all participants was analysed using the framework approach[35]. This is a method of qualitative analysis developed specifically for applied policy research of the sort carried out here. The process of developing a framework for analysis was similar for each group interviewed, although the final frameworks were, as might be expected, different for staff and parents.

For the staff interviews, members of the team involved in the case study read a selection of transcripts, and made notes of common themes. The team discussed these and then grouped and refined them into a framework. This was done separately for transcripts for commissioners, provider managers and practice level staff. The team then worked together with the three frameworks to refine them further into one framework that could accommodate the material from all three groups. The two team members who took main responsibility for analysing the case study material piloted the framework, using the same transcript, so that they could develop common understandings of the meanings of the themes. Material from the interview transcripts was then extracted into charts, using the identified themes, with repeated discussion between the two team members to maintain common approaches and understanding.

The same approach was used with material from the parents' interviews, although in this case there was a single framework from the outset.

The themes and sub-themes from both frameworks are at Appendix 13.

The single interview from a young person was charted with the parents/ carers interviews, and the material has been used for contextual purposes only.

3 Results of national survey of care close to home services

3.1 Introduction

The methods used to generate a sample for the national survey of CCTH services and to develop the screening and main questionnaires were described in chapter 2. We also gave a detailed account there of response rates and the approach to analysis that we adopted. In this chapter, we present a summary analysis of the data gathered from the 311 returned questionnaires, the results of the cluster analysis applied to the data, and the subsequent exploration of similarities and differences between three distinct models of CCTH services that the cluster analysis identified.

3.2 Summary analysis of data gathered

The main questionnaire was designed to collect information about the functions that CCTH services provided. We used this approach because service titles can sometimes be poor indicators of what services actually do. For example, a 'community children's nursing team' might provide services to children and young people to prevent acute admission, facilitate early discharge from hospital, provide long-term care for children with complex conditions, care for children at the end of life, or a combination of these. However, taking a function-based approach to the questionnaire design meant that material could be analysed only after a process of data reduction which we did using cluster analysis (see below).

However, we were also keen to place our findings alongside the existing descriptive literature on CCTH services; our initial objective in the analysis was, therefore, to classify services into recognisable groupings. This was done 'by eye' and involved examining both the title of the service (where this made clear what the basis of the service was) and the descriptive information from the questionnaire. Using this approach, 13 categories of CCTH services recognisable from the existing literature were identified. These are listed below, with their definitions.

Generic community children's nursing/home care team

This included all paediatric home nursing teams, or community children's nursing teams that were generic, in that they served children and young people with a wide range of conditions.

Condition specific services

This included any service, other than a specialist nurse/s (so defined) that was specific to a particular medical condition or specialty, and included home care teams and community children's nursing teams. An example of a service in this category would be a diabetes home care team.

Specialist nurses/nursing

This included all single, and teams of, specialist nurses.

Assessment/short stay units

This included all ambulatory short stay units, such as short stay wards, assessment units, and observation units.

Therapy services

This included all allied health therapy services facilitating CCTH and covered occupational therapy, physiotherapy, and speech and language therapy (SALT) services for complex needs. Mainstream SALT was not included here or in the survey.

Neonatal services

This included all CCTH services specifically for neonatal care, including home care teams. This was defined separately from 'condition specific' services because of the specific demands of neonatal care.

Continuing/complex care

This included all teams reported as specifically and exclusively for continuing or complex care.

Technological care

This included teams or services providing exclusively technological care in the home or community. Examples included services supporting intravenous therapy or ventilation at home.

Palliative care

This covered services exclusively providing palliative CCTH for children and young people, and included home care teams. These services were distinct from 'hospice at home' services (see below)

Specialist health visitors/specialist school nursing

Specialist school nursing and specialist health visiting (for children with complex health care needs) were included here when it was clear that they were providing some type of care for children or young people that prevented admission to hospital.

Hospice at home

This category was for hospice services that also provided care in a child's or young person's home.

Day surgery units

This category included units that provided services specific to children and young people that prevented overnight stays in hospital when they required

surgery. Units that also provided services for adults were excluded, because their focus was not exclusively paediatric[e].

Other

Any services that could not be categorised into one of the above or further distinguished into a useable category were included here. Sometimes this included services that were difficult to classify because of partial completion of the questionnaire.

One researcher applied the classifications initially, with a second researcher double-checking them at the data entry stage. Table 9 shows the number of reported services placed into each category.

Table 9. Reported services in each category

Service type	N of services	% of reported services
Generic CCN/Home care	102	32.8
Condition Specific Services	44	14.1
Specialist Nurses	39	12.5
Assessment/Short Stay Units	20	6.4
Therapy Services	19	6.1
Neonatal	18	5.8
Continuing/complex care	16	5.1
Hospice at home	15	4.8
Technological care	12	3.9
Palliative care	9	2.9
Specialist health visiting/ school nursing	7	2.3
Day surgery units	2	0.6
Other	8	2.6
Total	***311***	***100****

*May not sum to 100 because of rounding

The most frequently reported category was generic community children's nursing/home care; in line with current literature, this suggests that this is the dominant model of CCTH services in England. In addition to these models providing CCTH for a wide range of conditions, specialist CCTH services (related to a speciality or condition, or to a specific part of the care pathway, such as complex or palliative care) were also reported. In total,

[e] Despite our encouraging inclusion of these units at the screening stage (see chapter 2) we suspect that this form of CCTH may be underrepresented in the responses to the survey.

then, at least 56 percent of reported services involved some form of community-delivered children's nursing.

Other services, which may not currently be recognised in the literature as providing a distinct form of CCTH, were also reported, such as therapy services, and specialist health visitors.

3.3 Cluster analysis

The exercise reported above was helpful in providing an initial description of the nature of CCTH services currently being provided in England. However, as is clear from even a cursory examination of the categories, the potential for significant overlap of *function* across these services is considerable. We therefore spent time exploring the inter-relationships between descriptive data as an initial stage in building a typology of CCTH services based on their reported function, services provided, and their delivery and organisational characteristics. We then used cluster analysis to explore how well we could group the services, based on these variables.

3.3.1 Developing the cluster analysis

A series of k-means cluster analyses was carried out, adapting them until a model was obtained which could distinguish between groups of services (see Chapter 2).

Variables were included to represent the types of services provided, whether the service was a generic CCN, whether they were hospital-based, whether they offered daytime weekday cover only, and whether they were condition specific. The variables included and the number of clusters used was adapted until a model was obtained that could be used to distinguish helpfully between groups of services. Cluster analysis does not produce goodness of fit statistics, so one model cannot be deemed 'better' than another can. However, the three cluster model that we finally adopted defined three descriptively different groups of services, using the least number of variables.

Although being a generic CCN (or not) was included in the model, it can be seen from the final cluster centres in Appendix 14 that not all generic CCNs were captured in the same cluster, nor did that cluster identify only generic CCN services.

One service had missing data for the variables used in the cluster analysis and therefore was not included in the final cluster model. This service was a specialist health visiting/school nursing service.

The three clusters defined in the final cluster analysis can be broadly characterised[f] as:

1. hospital based, condition specific services, accounting for 36.1 percent of all services included in the analysis
2. other services, accounting for 18.7 percent of all services

[f] Although these broad characterisations should not be taken to describe every service in a cluster.

3. community children's nursing and community services, accounting for 45.2 per cent of all services.

3.3.2 Cluster 1

This cluster contained 112 services, including 84.6 percent of the reported specialist nurses, 75 percent of the reported condition specific services, 88.9 percent of the reported neonatal services and 55.6 percent of the reported palliative services. The services were most likely to be based in hospital and to be condition specific. The services they were most likely to offer were training, social and psychological support, health monitoring and liaison services.

3.3.3 Cluster 2

This cluster contained 58 services, including all but one of the therapy services, both of the day surgery services, and half of services described as 'other'. It was the smallest cluster, and was comprised of services most likely to report 'other' functions and to be available for weekday cover only.

3.3.4 Cluster 3

This cluster contained 140 services, including the majority of the generic home care and community nursing teams, three-quarters of the continuing and complex care teams, around two thirds of the specialist health visiting and school nursing services, and just under half of the hospice services. The services in the cluster were most likely to be community children's nursing teams and other community services (for example, continuing care teams), offering a wide range of functions, and less likely to have a hospital base.

Table 10 shows how the clusters related to the 14 categories developed in this first stage of analysis.

Table 10. Service type by cluster membership

	Cluster membership			
Service type	*1* *n (%)*	*2* *n (%)*	*3* *n (%)*	*Total (100%)*
Generic CCN/Home care	5 (4.9)	3 (2.9)	94 (92.2)	102
Therapy services	0	18 (94.7)	1 (5.3)	19
Specialist Nurses	33 (84.6)	4 (10.3)	2 (5.1)	39
Condition Specific Services	33 (75)	7 (15.9)	4 (9.1)	44
Continuing/complex care	1 (6.3)	3 (18.8)	12 (75)	16
Day surgery	0	2 (100)	0	2
Assessment/Day units	8 (40)	6 (30)	6 (30)	20
Technological Care	3 (25)	5 (41.7)	4 (33.3)	12
Specialist Health Visiting and School Nursing	0	2 (33.3)	4 (66.7)	6
Neonatal	16 (88.9)	0	2 (11.1)	18
Palliative care	5 (55.6)	1 (11.1)	3 (33.3)	9
Hospice at home	5 (33.3)	3 (20)	7 (46.7)	15
Other	3 (37.5)	4 (50)	1 (12.5)	8
Total	***112 (36.1)***	***58 (18.7)***	***140 (45.2)***	***310 (100)***

3.4 Analysis by cluster membership

After finalising the clusters, we used chi square analysis to explore the relationships between clusters and descriptive variables relating to service characteristics.

3.4.1 Service functions

Respondents were asked what the objectives (functions) of their service were and to tick all options that applied. Thus, responses were not mutually exclusive. Table 11 shows the four most commonly reported service objectives. There were statistically significant differences in the functions of services in different clusters. Thus, services in cluster 1 and cluster 3 were more likely than those in cluster 2 were to have the objective of preventing hospital admission, providing care for complex health needs out of hospital, reducing length of hospital stay, and supporting early discharge.

As well as these four functions included in the questionnaires, some respondents reported other functions. Sixteen services (5.2 percent) reported providing an alternative to accident and emergency care, four (1.3 percent) an alternative to out-patient or day care, one pre-operative care, and 49 (15.8 percent) a range of 'other' functions, most of which were actually sub-groups of the main categories.

Table 11. Service functions by cluster

	Services in cluster:				
Function	*1*	*2*	*3*	*All services*	X^2
	n (%)	*n (%)*	*n (%)*	*n (%)*	
Prevention of hospital admission	95 (84.8)	37 (63.8)	127 (90.7)	259 (83.5)	21.831, df = 2, p<0.001
Provision of care for complex health needs	90 (80.4)	37 (63.8)	133 (95.0)	260 (83.9)	31.124, df = 2, p<0.001
Reduce length of hospital stay	86 (76.8)	30 (51.7)	120 (85.7)	236 (76.1)	26.114, df = 2, p<0.001
Support early discharge	85 (75.9)	29 (50.0)	121 (86.4)	235 (75.8)	29.674, df = 2, p<0.001
N (100%)	***112***	***58***	***140***	***310***	

3.4.2 Specific services

The questionnaire asked respondents to report the specific input that their CCTH service was able to provide. As Table 12 shows, the most frequently reported specific service was liaison with other professionals, followed by training for the child, family or other carer, and monitoring health. However, as the table also shows (and as would be expected, given how the clusters were developed) there was substantial variation in patterns of provision between clusters. Ongoing nursing care, technical support (for example with ventilation, IV therapy, parenteral and enteral feeding), drugs administration, palliative or end of life care, training and liaison were all reported by more than 90 per cent of services in cluster 3. Services in this cluster were also more likely than those in others to report providing post-operative care. By contrast, services in cluster 1 were more likely to report training, liaison, health monitoring and social/psychological support than other activities, although around a half also reported providing ongoing nursing care, drugs administration and sample taking.

Table 12. Specific services provided by cluster

Specific service provided	**Services in cluster:** *1* n (%)	*2* n (%)	*3* n (%)	*All services* n (%)	X^2
Post-operative care *	10 (8.9)	17 (29.3)	101 (72.1)	128 (41.3)	106.794, df=2, p<0.001
Ongoing nursing care*	67 (59.8)	6 (10.3)	137 (97.9)	210 (67.7)	148.759, df=2, p<0.001
Drug administration *	61 (54.5)	12 (20.7)	131 (93.6)	204 (65.8)	106.834, df=2, p<0.001
Palliative/end of life care*	26 (23.2)	11 (19.0)	128 (91.4)	165 (52.3)	149.936, df=2 p<0.001
Technical support *	41 (36.6)	14 (24.1)	134 (95.7)	189 (61.0)	132.018 df=2, p<0.001
Training for child, family or carer *	107 (95.5)	37 (63.8)	135 (96.4)	279 (90.0)	54.503, df=2, p<0.001
Taking samples for routine investigation *	65 (58.0)	8 (13.8)	124 (88.6)	197 (63.5)	101.297, df=2, p<0.001
Short-term breaks *	6 (5.4)	5 (8.6)	43 (30.7)	54 (17.4)	31.652, df=2, p<0.001
Social/psychological support for family/carer *	97 (86.6)	14 (24.1)	124 (88.6)	235 (75.8)	103.988, df=2, p<0.001
Managing transition to adult services *	71 (63.4)	16 (27.6)	113 (80.7)	200 (64.5)	50.660, df=2, p<0.001
Monitoring health *	106 (94.6)	23 (39.7)	120 (85.7)	249 (80.3)	77.796, df=2, p<0.001
Liaison with other professionals *	108 (96.4)	35 (60.3)	137 (97.9)	280 (90.3)	73.501, df=2, p<0.001
Other: case management	1 (0.9)	4 (6.9)	2 (1.4)	7 (2.3)	7.036, df=2, p=0.030
Other: assessment	3 (2.7)	12 (20.7)	0	15 (4.8)	39.902, df=2, p<0.001
Other: other	18 (16.1)	18 (31.0)	14 (10.0)	50 (16.1)	13.414, df=2, p=0.001
N (100%)	***112***	***58***	***140***	***310***	

*Service variables included in cluster analysis. The 'other' variables were amalgamated for a single 'other' variable for the cluster analysis.

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3.4.3 Settings of service delivery

Two questions asked respondents where their service was based and in what settings it was delivered.

A hospital base for CCTH services was most common, followed by a community base (Table 13). Multiple and 'other' bases accounted for only 11 per cent of CCTH services reported. There were significant differences between clusters, as Table 13 also shows.

Table 13. Service base by cluster

Service base	**Services in cluster:** *1* n (%)	*2* n (%)	*3* n (%)	*All services* n (%)
Hospital	87 (77.7)	26 (44.8)	71 (50.7)	184 (59.4)
Community	18 (16.1)	20 (34.5)	54 (38.6)	92 (29.7)
Multiple	4 (3.6)	6 (10.3)	11 (7.9)	21 (6.8)
Other	3 (2.7)	6 (10.3)	4 (2.9)	13 (4.2)
N (100%)	***112***	***58***	***140***	***310***

*'Hospital-based' used in cluster analysis

$X^2 = 30.801$, df=6, $p<0.001$

The most common setting for care delivery was, as would be expected, the home, with 87.7 percent of all reported services providing care here (Table 14). The next most common settings (for around two-thirds or over of all services) were schools and out-patient clinics. Around a third or fewer of services delivered care in day nurseries, community clinics, child development centres, day units, children's centres or primary care settings. Respondents also listed 89 'other' settings where they might deliver care, including in-patient settings (40), respite care (14), hospices (11), and other community settings (7). Another 17 'other other' settings were also mentioned.

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Table 14. Where service was delivered by cluster

Service settings	Services in cluster: 1 n (%)	2 n (%)	3 n (%)	All services n (%)	X^2
Home	99 (88.4)	44 (75.9)	129 (92.1)	272 (87.7)	10.176, df=2, p=0.006
School	69 (61.6)	30 (51.7)	117 (83.6)	216 (69.7)	25.092, df=2, p<0.001
Out-patient clinic	84 (75.0)	27 (46.6)	80 (57.1)	191 (61.6)	15.232, df=2, p<0.001
Day Nursery	31 (27.7)	15 (25.9)	69 (49.3)	115 (37.1)	16.308, df=2, p<0.001
Community Clinic	20 (17.9)	16 (27.6)	29 (20.7)	65 (21.0)	2.193, df=2, p=0.334
Child Development Centre	15 (13.4)	14 (24.1)	33 (23.6)	62 (20.00	4.793, df=2, p=.0.091
Day unit	24 (21.4)	9 (15.5)	25 (17.9)	58 (18.7)	1.000, df=2, p=0.607
Children's Centre	14 (12.5)	15 (25.9)	28 (20)	57 (18.4)	4.989, df=2, p=0.083
Primary Care	11 (9.8)	5 (8.6)	19 (13.6)	35 (11.3)	1.381, df=2, p=0.501

Although home was reported by the majority of services as a setting for delivering care in each of the three clusters, cluster 3 services were significantly more likely than others were to deliver care at home. They were also more likely than services in other clusters were to operate in the children's schools and day nurseries. By contrast, services in cluster 1 were significantly more likely than others were to deliver services in out-patient settings. No other differences between the clusters reached conventional levels of statistical significance.

3.4.4 Alternatives to CCTH

The questionnaire asked where care would be provided if the service being reported was not available. Three options were given, along with an 'other' category that respondents completed themselves. Table 15 shows that CCTH was seen as an alternative to in-patient care in almost nine out of ten services, particularly for those in clusters 3 and 1. Cluster 3 services were also significantly more likely than other services were to be reported as an alternative to day unit care. No other significant differences between clusters were evident.

As well as the 'other' alternatives provided by respondents, some of them (24, 7.7 per cent) chose to comment that no service would be provided at all, if their CCTH service were not available. This was most often reported by cluster 2 services, and the difference between these and the other clusters reached statistical significance (χ^2 = 9.725, df=2, p=0.008).

Table 15. Where care would be delivered if CCTH was not available by cluster

	Services in cluster:				
Where care would be delivered	*1 n (%)*	*2 n (%)*	*3 n (%)*	*All services n (%)*	*X^2*
In-patient unit	97 (89.0)	38 (67.9)	126 (92.6)	261 (86.7)	21.926, df=2, p<0.001
Day unit	19 (17.4)	9 (16.1)	55 (40.4)	83 (27.6)	20.600, df=2, p<0.001
Out-patient clinic	60 (55.0)	25 (44.6)	73 (53.7)	158 (52.5)	1.745, df=2, p=0.418
Other: A&E	3 (2.7)	2 (3.4)	2 (1.4)	7 (2.3)	0.898, df=2, p=0.638
Other: hospice	3 (2.7)	2 (3.4)	9 (6.4)	14 (4.5)	2.218, df=2, p=0.330
Other: other	15 (13.4)	7 (12.1)	24 (17.1)	46 (14.8)	1.126, df=2, p=0.570
N (100%)[a]	***112***	***57***	***140***	***309***	

a. N for hospice and 'other' was 310; cluster 1 n = 112, cluster 2 n =58, cluster 3 n =140. Missing cases for all other categories = 1

3.4.5 Referrals

Services were asked about their sources of referrals, and were given the option of hospital-based team, GPs, school-based team, community nurse, community-based team, child/family, social care services, and other.

As Table 16 shows, the most common source of referral for all services was hospital-based teams, followed by general practitioners, community-based teams and community nurses. Fewer than half of all CCTH services took referrals directly from children and young people and their families.

Services in clusters 1 and 3 were more likely than were those in cluster 2 to receive referrals from hospital-based teams. Cluster 3 services were also significantly more likely than those in other clusters to receive referrals from community based teams, community nurses, children, young people and their families, social care services and schools. Cluster 3 services were thus taking referrals from a wider range of sources in total. There were no

statistically significant differences between the clusters in referrals from GPs, hospices and other sources.

Table 16. Sources of referrals by cluster

	Services in cluster:				
Sources of referrals	*1 n (%)*	*2 n (%)*	*3 n (%)*	*All services n (%)*	X^2
Hospital-based team	107 (95.5)	50 (87.7)	135 (96.4)	292 (94.5)	6.274, df=2, p=0.043
GP	66 (58.9)	38 (66.7)	87 (62.1)	191 (61.8)	0.970, df=2, p=0.616
Community-based team	45 (40.2)	34 (59.6)	105 (75.0)	184 (59.9)	31.321, df=2, p<0.001
Community Nurse	41 (36.6)	31 (54.4)	99 (70.7)	171 (55.3)	29.313, df=2, p<0.001
Child/Family	46 (41.1)	21 (36.8)	76 (54.3)	143 (46.3)	6.873, df=2, p=0.032
Social care services	32 (28.6)	21 (36.8)	81 (57.9)	134 (43.4)	22.940, df=2, p<0.001
School	29 (25.9)	19 (33.3)	81 (57.9)	129 (41.7)	28.176, df=2, p<0.001
Other: Hospice	2 (1.8)	1 (1.7)	5 (3.6)	8 (2.6)	0.997, df=2, p=0.607
Other: other	16 (14.3)	7 (12.1)	26 (18.6)	49 (15.8)	1.608, df=2, p=0.448
N (100%)	***112***	***57***	***140***	***309***	

Missing cases=1

3.4.6 Groups served

The questionnaire asked which groups of children and young people services cared for, giving the options of children with life limiting conditions, children with life threatening conditions, children with an acute condition, children with ongoing complex conditions and 'other'. The options were not mutually exclusive.

Table 17 shows that the most common groups of children being cared for were those with complex conditions, followed by life-limiting or life-threatening conditions. Acute conditions were the least frequently mentioned group, but nonetheless were served by almost six in ten services.

Cluster 3 services were significantly more likely than were cluster 1 and 2 services to serve children with any of the listed conditions, indicating that, overall, they were serving more groups in each service.

Table 17. Groups of children and young people served by cluster

	Services in cluster:				
	1 *n (%)*	*2* *n (%)*	*3* *n (%)*	*All services* *n (%)*	X^2
Complex conditions	90 (81.1)	41 (70.7)	130 (92.9)	261 (84.5)	16.872, df=2, p<0.001
Life limiting conditions	61 (55.0)	38 (65.5)	135 (96.4)	234 (75.7)	61.988, df=2, p<0.001
Life threatening conditions[a]	45 (45.5)	30 (58.8)	118 (92.9)	193 (69.7)	62.788, df=2, p<0.001
Acute conditions	49 (44.1)	31 (53.4)	103 (73.6)	183 (59.2)	23.187, df=2, p<0.001
N (100%)	***111***	***58***	***140***	***309[b]***	

a. N for life-threatening conditions was 277 because of missing data. Cluster 1 n=99, cluster 2 n=51, cluster 3 n=127.

b. Missing cases for other conditions =1

Respondents also gave 46 'other' responses to this question: 30 referred to groups of children and young people with ongoing chronic conditions, two to elective day surgery, and 14 to 'other' other conditions. Services in cluster 1 were somewhat more likely to refer to ongoing chronic conditions (13.5 percent, compared to 8.6 percent in cluster 2 and 7.2 per cent in cluster 3) but this difference was not statistically significant.

A further question asked whether the reported CCTH services were specific to a particular condition or speciality, and was used in the cluster formation. Some 121 services in all (39 percent) reported that they were. This was significantly more likely in cluster 1 services (81.3 percent compared to 24.1 percent in cluster 2 and 11.4 percent in cluster 3, χ^2=132.119, df=2, p<.001). Among the condition-specific services, endocrinology-related conditions were mentioned most frequently (22.3 percent of condition-specific services), followed by palliative medicine (19.0 percent), neonatal medicine (14.9 per cent), respiratory medicine (10.7 percent) and neurology (6.6 percent). No other condition or speciality accounted for more than five per cent of the condition-specific CCTH services.

3.4.7 Ethnic background of caseload

Services were asked about the ethnic background of their caseload. Just over half of services (51.9 per cent) reported the caseload was a mixture of both White British and minority ethnic populations (Table 18). There were

no significant differences between clusters in the reported ethnic backgrounds of their caseloads.

Table 18. Ethnic background of population by cluster

	Services in cluster:			
Ethnic background	*1 n (%)*	*2 n (%)*	*3 n (%)*	*All services n (%)*
Predominantly White British	49 (43.8)	20 (35.1)	67 (48.2)	136 (44.2)
Predominantly minority ethnic populations	5 (4.5)	4 (7.0)	3 (2.2)	12 (3.9)
A mixture of both	58 (51.8)	33 (57.9)	69 (49.6)	160 (51.9)
N (100%)	***112***	***57***	***67***	***308***

Missing cases=2

3.4.8 Geographical coverage

The questionnaire asked about the geographical location and coverage of the CCTH services, offering the options of local, regional and national. These options were not mutually exclusive. Table 19 shows that most services provided at least local coverage, with relatively few operating at regional or national levels. Cluster 3 services showed a trend towards providing more local services than other clusters, but this difference was not statistically significant. By contrast, cluster 1 services were significantly more likely than other services to provide regional or national coverage.

Table 19. Geographical coverage of service by cluster

Coverage of service	Services in cluster: *1* n (%)	*2* n (%)	*3* n (%)	*All services* n (%)	X^2
Local	96 (86.5)	52 (89.7)	129 (93.5)	277 (90.2)	3.437, df=2, p=0.179
Regional	28 (25.2)	8 (13.8)	8 (5.8)	44 (14.3)	19.120, df=2, p<0.000
National	13 (11.7)	2 (3.4)	4 (2.9)	19 (6.1)	9.314, df=2, p=0.009
N (100%)					
Local	***111***	***58***	***138***	***307***	
Regional	***111***	***58***	***139***	***308***	
National	***111***	***58***	***140***	***309***	

Missing cases: local = 3, regional = 2, national = 1

As is clear from Table 19, some services provided coverage at more than one level.

3.4.9 Profile of area served

Services were asked about the geographical profile of the area served, with urban (population >200, 000), large town (population 50,000 to 200,000), small town (population <50,000) and rural as options. These options were not mutually exclusive. Over half of all services served an urban population, while just over a third served a rural population (Table 20). Cluster 3 services were more likely to serve rural areas than cluster 1 and 2 services (chi-square = 9.676, df = 2, p = 0.008). There were no other statistically significant differences between clusters.

Table 20. Geographical profile of area served by cluster

	Services in cluster:			
Profile of area served	*1 n (%)*	*2 n (%)*	*3 n (%)*	*All services n (%)*
Urban	66 (60)	35 (64.8)	71 (53.8)	172 (58.1)
Large Town	55 (50)	28 (51.9)	53 (40.2)	136 (45.9)
Small Town	24 (21.8)	18 (33.3)	34 (25.8)	76 (25.7)
Rural	28 (25.5)	19 (35.2)	59 (44.7)	106 (35.8)
N (100%)	***110***	***54***	***132***	***296***

Missing cases=14

3.4.10 Exclusion criteria

Services were asked if, apart from any issues of geographical coverage, they had any explicit criteria for excluding children from their service. Over half (54.7 percent) of all services did not report using exclusion criteria (Table 21). Cluster 3 services were more likely than were others to report using exclusion criteria (chi-square = 12.443, df = 2, p = 0.002).

Table 21. Exclusion criteria by cluster

	Services in cluster:			
Uses exclusion criteria?	*1 n (%)*	*2 n (%)*	*3 n (%)*	*All services n (%)*
No	72 (65.5)	35 (60.3)	61 (43.9)	168 (54.7)
Yes	38 (34.5)	23 (39.7)	78 (56.1)	139 (45.3)
N (100%)	***110***	***58***	***139***	***307***

Missing cases=3

Of those with exclusion criteria (n=139) the most common were condition (34.6 percent) and area (31.6 percent), followed by severity (12.5 percent), age (7.4 percent) and complexity of condition (6.6 percent). Few services referred to parents' (un)willingness to care for the child (1.5 percent).

3.4.11 Hard to reach groups

The questionnaire asked whether respondents were aware of any groups of children or families who were not using their services. Examples were given, including children from minority communities, travellers, asylum seekers, and others. An open-ended follow-up question asked about any strategies in place for reaching hard to reach groups.

Very few respondents overall (14.7 percent) reported that they were aware of any groups not using their service, and there was very little difference

between clusters (Table 22). Where issues of access were recognised, this was most often in relation to families from minority ethnic communities (mentioned by 15 services who reported access issues) and travelling families (mentioned by 14 services).

Table 22. Whether any groups were not accessing service by cluster

	Services in cluster:			
Any groups not accessing the service?	*1 n (%)*	*2 n (%)*	*3 n (%)*	*All services n (%)*
Yes	16 (14.3)	9 (15.8)	20 (14.5)	45 (14.7)
No	96 (85.7)	48 (84.2)	118 (85.5)	262 (85.3)
N (100%)	***112***	***57***	***138***	***307***

Missing cases=3

Around a third of all services (32.5 percent) said they had strategies to reach hard to reach groups. Although this differed by cluster, with fewer cluster 3 services reporting they had strategies in place, these differences were not statistically significant (Table 23).

Table 23. Strategies in place to enhance access to services by cluster

	Services in cluster:			
Strategies to enhance access?	*1 n (%)*	*2 n (%)*	*3 n (%)*	*All services n (%)*
Yes	38 (34.9)	21 (38.2)	37 (28.2)	96 (32.5)
No	71 (65.1)	34 (61.8)	94 (71.8)	199 (67.5)
N (100%)	***109***	***55***	***131***	***295***

Missing cases=15

3.4.12 Staffing

3.4.12.1 Nursing staff

The total whole time equivalent (WTE) number of nursing staff was calculated for each service, and the mean WTE compared across the three clusters of services. The mean WTE for cluster 1 services was 2.58 (SD = 5.10, N = 112), for cluster 2 services 1.93 (SD = 3.96, N = 58) and for cluster 3 services 7.76 (SD = 8.23, N = 140). One way analysis of variance was significant ($F = 26.41$, $df = 2$, $p<0.001$), and post hoc tests showed

that cluster 3 had a higher mean WTE nursing staff than cluster 1 services (mean difference = 5.21, SE = 0.83, p<0.001) and cluster 2 services (mean difference = 5.83, SE = 1.02, p<0.001).

3.4.12.2 Allied health staff

Just under a third of all services had an allied health therapist as part of the team (Table 24). Cluster 2 services were more likely than cluster 1 and 3 services to do so (chi-square = 13.745, df = 2, p = 0.001), which reflects the nature of many cluster 2 services (see above).

Table 24. Teams with an allied health therapist by cluster

	Services in cluster:			
	1 *n(%)*	*2* *n(%)*	*3* *n(%)*	*All services* *n(%)*
Teams with an allied health therapist	32 (28.6)	29 (51.8)	35 (25.2)	96 (31.3)
N (100%)	***112***	***56***	***139***	***307***

Missing cases=3

Services that reported allied health therapists were asked what categories of therapist were part of the team. Table 25 shows that the most commonly reported allied health therapists across all services were physiotherapists, followed closely by dieticians and play therapists.

Cluster 1 services were significantly more likely to have a dietician than were cluster 2 and 3 services, while cluster 2 services were significantly more likely to have a physiotherapist, an occupational therapist or speech and language therapist as part of the team. Cluster 2 services were also the most likely to have a play therapist on the team, but this difference did not reach statistical significance.

Table 25. Types of allied health therapists in all teams by cluster

	Services in cluster:				
Type of therapist	*1* *n (%)*	*2* *n (%)*	*3* *n (%)*	*All services* *n (%)*	X^2
Dietician	19 (17.0)	4 (7.4)	10 (7.2)	33 (10.9)	6.840, df=2, p=0.033
Occupational therapist	3 (2.7)	9 (16.7)	10 (7.2)	22 (7.2)	10.619, df=2, p=0.005
Play therapist	8 (7.1)	7 (13.0)	17 (12.3)	32 (10.5)	2.173, df=2, p=0.337
Physiotherapist	10 (8.9)	14 (25.9)	11 (8.0)	35 (11.5)	13.455, df=2, p=0.001
Speech and language therapist	3 (2.7)	7 (13.0)	8 (5.8)	18 (5.9)	6.925, df=2, p=0.031
Other	2 (1.8)	3 (5.6)	5 (3.6)	10 (3.3)	1.716, df=2, p=0.424
N (100%)	***112***	***54***	***138***	***304***	

Missing cases=6

If we confine analysis only to those teams that had *any* allied health therapist (Table 26), slightly different patterns emerge. Cluster 1 services were still significantly more likely to have dieticians on the team. However, it also becomes clear that, when cluster 3 services did have therapists involved, they were as likely as cluster 2 services to have occupational therapists or speech and language therapists, and more likely to have play therapists.

Table 26. Types of therapists in teams with any allied health therapists by cluster

	Services in cluster:				
Type of therapist	*1 n (%)*	*2 n (%)*	*3 n (%)*	*All services n (%)*	X^2
Dietician	19 (59.4)	4 (14.9)	10 (29.4)	33 (33.5)	13.565, df=2, p=0.001
Occupational therapist	3 (9.4)	9 (33.3)	10 (29.4)	22 (23.7)	5.637, df=2, p=0.06
Play therapist	8 (25.0)	7 (25.8)	17 (50.0)	32 (34.4.)	5.778, df=2, p=0.056
Physiotherapist	10 (31.3)	14 (51.9)	11 (32.4)	35 (37.6)	3.385, df=2, p=0.193
Speech and language therapist	3 (9.4)	7 (25.9)	8 (23.5)	18 (19.4)	3.168, df=2, p=0.205
Other	2 (6.3)	3 (11.1)	5 (14.7)	10 (10.8)	1.233, df=2, p=0.540
N (100%)	***32***	***27***	***34***	***93***	

Missing cases=3

The total whole time equivalent (WTE) number of allied health therapists was calculated for each service, and the mean WTE compared across the three clusters of services. The mean WTE for cluster 1 services was 0.15 (SD = 0.42, N=112), for cluster 2 services was 1.28 (SD = 2.65, N = 58) and for cluster 3 services was 0.32 (SD = 1.19, N = 140). One-way analysis of variance was significant (F = 13.04, df = 2, p<0.001), and post-hoc tests showed that cluster 2 services had higher mean WTE allied health therapists than cluster 1 services (mean difference = 1.13, SE = 0.23, p<0.001) and cluster 3 services (mean difference = 0.96, SE = 0.22, p<0.001).

3.4.12.3 Social workers

Almost 12 percent of services had a social worker as part of their team (Table 27) but there was no statistically significant difference between the clusters (χ^2 = 2.520. df=2, p=0.284)

Table 27. Teams with a social worker by cluster

	Services in cluster:			
	1 *n(%)*	*2* *n(%)*	*3* *n(%)*	*All services* *n(%)*
Teams with a social worker	16 (14.5)	8 (14.8)	12 (8.7)	36 (11.9)
N (100%)	***110***	***54***	***138***	***302***

Missing cases=8

3.4.12.4 Other staff

Almost one in five services (66, 21.8 percent, N=303) reported other types of staff on their team. Although cluster 3 services were somewhat more likely to report other staff members (26.8 percent, compared to 17.9 percent in cluster 1 and 17.0 percent in cluster 2) the difference between them was not statistically significant.

Psychologists were the most common type of other staff on teams (reported by 9.4 percent of respondents overall), but there were no statistically significant differences between the clusters. Very few services had home care workers (2.0 percent) or administrative staff (3.3 percent). Just under one in ten (9.4 percent) services reported having 'other' staff as part of their team; these included a school teacher, technical instructor and family support worker. Cluster 3 services were significantly more likely than cluster 1 and 2 services were to have 'other' other staff (14.6 percent compared with 5.9 percent cluster 2 and 4.5 percent cluster 1 (chi-square = 8.239, df = 2, p = 0.016).

3.4.12.5 Involvement of medical doctors

Services were asked about the level of involvement of paediatricians and other doctors in the team providing CCTH (Table 28). They were categorised into those with a paediatrician as a member of the team, those who had a named doctor they could contact for clinical support and advice (whether a paediatrician, GP, or other doctor) and those with neither form of support. As might be expected, given their likelihood of being based in hospitals, cluster 1 services were more likely than other clusters were to have paediatricians on the team or a named doctor available (chi-square = 22.49, df = 4, p<0.001).

Table 28. Doctor involvement by cluster

	Services in cluster:			
Level of involvement	*1 n(%)*	*2 n(%)*	*3 n(%)*	*All services n(%)*
Paediatrician on team	36 (32.7)	15 (27.3)	26 (18.6)	77 (25.2)
Named doctor available	71 (64.5)	28 (50.9)	85 (60.7)	184 (60.3)
Neither	3 (2.7)	12 (21.8)	29 (20.7)	44 (14.4)
N (100%)	***110***	***55***	***140***	***305***

Missing cases=5

3.4.12.6 Other agency staff

Finally, in the section of the questionnaire that covered team membership, respondents were asked about other agencies providing input to the CCTH service. The options were another NHS provider, local authority provider, community or voluntary sector provider, private agency and 'other'. Overall, 40.1 percent of respondents reported the involvement of other agencies; cluster 2 services were somewhat less likely to report this than were the others (35.2 percent, compared to 39.6 percent in cluster 1 and 42.4 percent in cluster 3) but this difference was not statistically significant.

When other agencies were involved, the most commonly cited were another NHS provider, followed by a third sector provider (Table 29). Cluster 1 services were significantly less likely than other clusters were to involve local authority or private agency providers.

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Table 29. Services where another agency provides input by cluster

	Services in cluster:				
Agencies providing input to the service	*1 n (%)*	*2 n (%)*	*3 n (%)*	*All services n (%)*	X^2
Other NHS Provider	28 (63.6)	11 (57.9)	30 (50.8)	69 (56.6)	1.694, df=2, p=0.429
LA Provider	6 (13.6)	10 (52.6)	19 (32.2)	35 (28.7)	10.553, df=2, p=0.005
Community/ Voluntary Provider	16 (36.4)	7 (36.8)	26 (44.1)	49 (40.2)	0.726, df=2, p=0.696
Private Agency	3 (6.8)	5 (26.3)	18 (30.5)	26 (21.3)	8.771, df=2, p=0.012
Other	7 (15.9)	0	7 (11.9)	14 (11.5)	3.323, df=2, p=0.190
N (100%)	***44***	***19***	***59***	***122***	

Overall, teams containing only nursing staff were the predominant (48.4 percent of the 275 teams that provided all relevant information). This was followed by a multi-disciplinary team without paediatric support (26.2 percent), and finally a multi-disciplinary team with paediatric support (18.9 percent). The least common model was uni-professional (nursing) with paediatric support (6.5 percent). There were no statistically significant differences between clusters, although cluster 3 services were the most likely to involve only nursing staff (51.9 percent of services, compared to 45.7 percent of cluster 1 and 42.9 percent of cluster 2 services).

3.4.13 Recruitment and retention of staff

Services were asked about recruitment and retention issues, starting with a question about any unfilled posts over the past year. Almost a quarter of all services (23.5 percent) reported having unfilled posts in the past year, with cluster 3 services more likely to report this than cluster 1 and 2 services (32.8 percent, compared with 24.1 percent in cluster 2 and 11.7 percent in cluster , $\chi^2 = 15.243$, df = 2, $p<0.001$).

Of the 71 services reporting unfilled posts, 56 (78.9 percent) reported having one vacancy, 11 (15.5 percent) reported having two vacancies and four (5.6 percent) reported having three vacancies. Cluster 3 services were more likely to have two or more vacancies than were the others (31.1 percent, compared with 7.7 percent in cluster 1 and 0 percent in cluster 2).

The most common reason given for having unfilled posts was difficulty recruiting to posts (reported by 46 services overall). Only five services reported financial constraints as a significant factor in this.

3.4.14 Service history and origins

Just over a quarter of services (26.9 percent) had been in operation for over 16 years, while 3.2 percent had been in operation for less than a year (Table 30). Cluster 1 and 3 services were more likely to have been in operation for over ten years than were cluster 2 services; as a corollary, cluster 2 services were more likely to have been in operation for five years or fewer. Overall, six in ten cluster 3 services had been operational for over ten years, followed by almost half of cluster 1 services. These differences were statistically significant ($\chi^2 = 25.480$, df = 2, $p<0.001$).

Table 30. Length of service by cluster

	Services in cluster:			
Length of service	*1* *N (%)*	*2* *N (%)*	*3* *N (%)*	*All services* *N (%)*
<1 year	2 (1.9)	3 (6.8)	4 (3)	9 (3.2)
1-5 years	21 (19.6)	16 (36.4)	14 (10.6)	51 (18)
6-10 years	31 (29.0)	11 (25)	34 (25.8)	76 (26.9)
11-15 years	29 (27.1)	2 (4.5)	40 (30.3)	71 (25.1)
16 + years	24 (22.4)	12 (27.3)	40 (30.3)	76 (26.9)
N (100%)	***107***	***44***	***132***	***283***

Missing cases=27

The questionnaire asked if the CCTH service had been initiated in response to a policy initiative and, if so, which. Overall, 17.5 percent of respondents indicated that their service had been a response to a policy initiative. While not statistically significant, cluster 2 services tended to report this more than other clusters (Table 31).

Table 31. CCTH service started in response to a policy initiative

	Services in cluster:			
	1 *n (%)*	*2* *n (%)*	*3* *n (%)*	*All services* *n (%)*
Service started in response to policy initiative	17 (16.0)	14 (27.5)	19 (14.7)	50 (17.5)
N (100%)	***106***	***51***	***129***	***286***

Missing cases=24

Among the services that reported starting in response to a policy initiative, responding to national guidelines was mentioned most often (11 cases),

followed by New Opportunities Funding (ten), and specific mention of the NSF (seven). Seventeen, very varied 'other' initiatives were also mentioned.

3.4.15 Future plans and aspirations

Services were asked if there were any services they would like to provide but were unable to do so currently. Almost 80 percent (79.2 percent) reported there were, although there were no significant differences between clusters. Those who responded 'yes' were then asked to say what additional services they would like to provide. Responses to this question were open-ended and analysed descriptively only.

Responses fell into four main categories here: increased service cover (55 responses); increased staffing (64); psychological input and support, including play therapy (49); and (expanded) respite (26). The details of increased service cover included the need for 24 hour, seven day a week cover, 24-hour cover for palliative care, increased weekend, overnight and on-call cover, and the need to provide more time per visit for existing service users. The responses about the need for increased staffing were sometimes related to increased cover, but the need for specific clinical input, including therapies, and staff able to provide formal psychosocial support were also mentioned. The need for psychological input and support was mentioned in relation both to specific conditions (for example, cancer) and to the more generic needs of children with complex and long-term conditions. This category also included the need for formal play therapy support.

The questionnaire also asked if the service had any innovations planned (as opposed to wished for). Over four in ten (43.2 percent) reported that they did, but there was no significant difference between clusters. An open-ended question asked respondents to detail these plans and, again, a descriptive analysis was carried out. The responses varied, but three main groupings were evident. First, a group of responses referred to changes in staffing, including recruiting nurse specialists, and extending staffing to provide new services (for example, a specialist pump service) or types of input (for example, dietetics, pharmacy). A second set of responses, related to the first, referred to plans to change services. Examples included CCTH for teenagers with cancer, improved transition services, psycho-oncology support, enhanced respite provision, and a new splinting service. Finally, a group of responses referred to planned strategic change. This included developing urgent and ambulatory care pathways, investment in information technology to improve communication between acute and community professionals, and overall review of community nursing services.

3.4.16 Service funding and costs

In the final section of the questionnaire, services were asked a series of questions about their sources of funding and the costs of the service provided.

First, they were asked if they received funding other than through a PCT. Only 289 respondents provided an answer to this question, and just over a

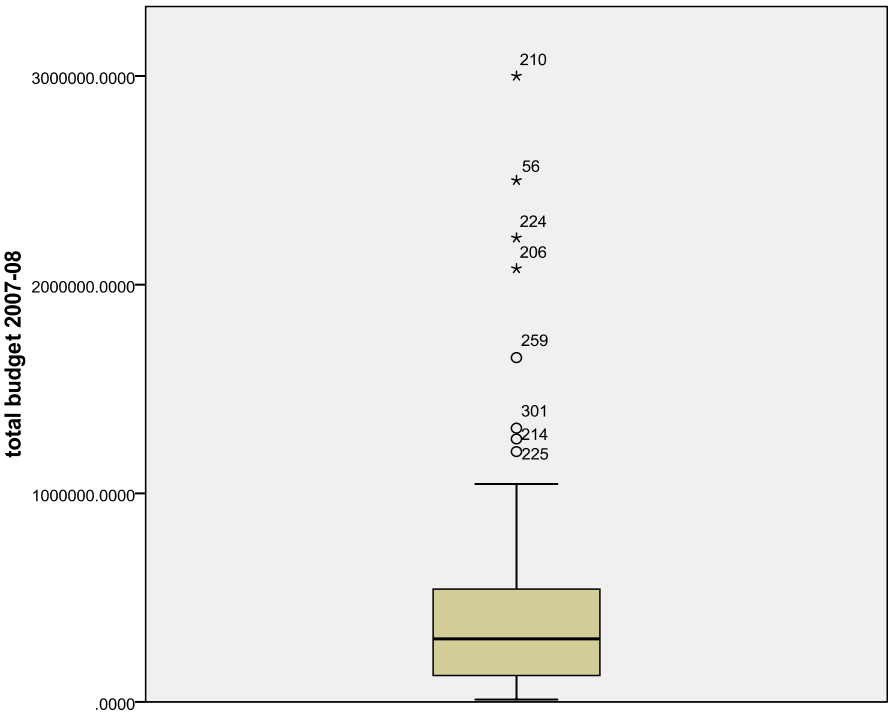
fifth of these (21.5 percent) reported other sources of funding. Cluster 3 services were slightly more likely to report this than were the others (25.0 percent, compared to 17.3 percent in cluster 1 and 20.8 percent in cluster 2) although the difference was not statistically significant.

Under a half of respondents (42.8 percent) reported that their CCTH budgets were separate from those of other services, and another 14.1 per cent did not answer the question. Cluster 3 services were more likely to report separate budgets than were cluster 1 and 2 services (66.9 percent, compared to 27.7 percent in cluster 1 and 41.2 percent in cluster 2, χ^2 = 35.409, df = 2, p<0.001, N=276).

Further detail about service budgets (where these were separate) and anticipated change for the coming year was asked for. Only 96 services in total (30.8 percent of all services; 72.1 percent of those who said that they had separate budgets) were able to provide information about their current budget. A majority of these (65) were in cluster 3. This material is analysed in more detail in Chapter 7, where we discuss the health economics of CCTH services. This chapter examines only the central distribution of reported costs.

The mean reported annual budget was £462,156, with a standard deviation of £532,108. The median value was £302,438, with three-quarters of the total budgets falling below £551,529. The service budget figures were skewed, the vast majority being less than £1m, with a small number of outlying, high figures (outliers), as shown in the box plot (Figure 3).

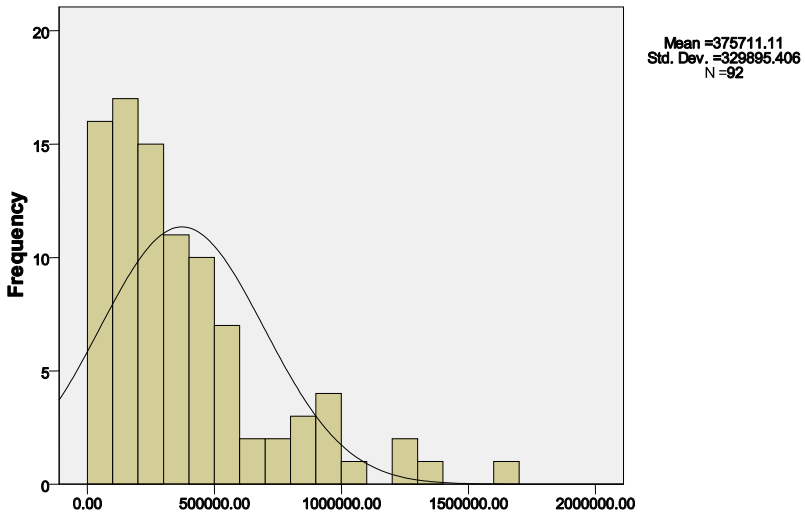
Figure 3. Box plot of reported budgets for CCTH services



These extreme values or outliers, statistically defined as cases with standardized scores in excess of 3.29 (p<0.001, two-tailed test)[36] were then removed

from the analysis. This reduced the standard deviation to £329,895, but the distribution of mean annual budgets remained skewed (see Figure 4).

Figure 4. Histogram and central tendency statistics for reported annual budgets of CCTH services, outliers removed



Mean total annual budgets (with outliers removed) were then compared across the three clusters using analysis of variance (see Figure 5). The mean budget for cluster 1 services was £135,507 (SD £121,650), for cluster 2 services £243,838 (SD £221,925), and for cluster 3 services £476,471 (SD £345,717). There does appear to be a difference between the clusters ($F=10.731$, $df=91$, $p<0.001$), although the mean differences between the individual clusters were not statistically significant. Further, as we saw above, different clusters had different staffing complements.

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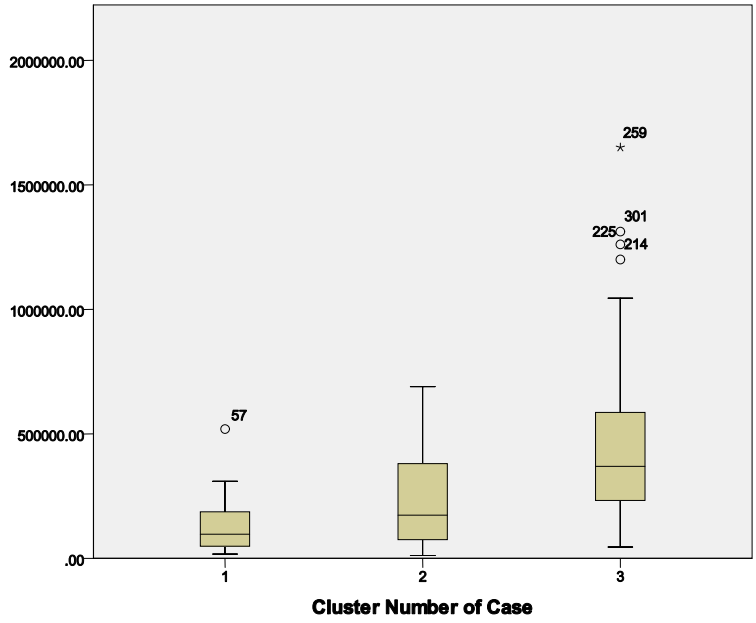
Figure 5. Box plot of mean total annual budgets (with outliers removed) by cluster



3.5 Discussion

Although we did not get a full response to our survey, we have no reason to assume that non-response was systematic in terms of national geography. Thus while we are unable to present a full picture of *local* provision of CCTH services, we are able to present a *national* picture of the range, types and service delivery and organisational features of CCTH services.

The analysis of the national survey suggests three models of CCTH, distinguished by their service delivery and organisational characteristics. Two of these (cluster 1 and cluster 3) are predominant, and appear to serve different purposes and different geographies (local, regional and national). Services in cluster 3 are most closely associated with the functions of prevention of hospital admission, providing care for complex health needs, reducing hospital stays and facilitating hospital discharge. They are also heavily involved in providing post-operative care, on-going nursing care, drug administration, palliative and end-of-life care, and support for technological care to children with complex, life limiting and life-threatening conditions. Cluster 1 services also provide functions related to reducing acute health service use, mostly in relation to children with complex needs, but they are more likely to be doing this through training children and their families or carers, health monitoring, and liaison with other professionals. Cluster 2 services, by contrast, are closely linked with therapeutic input to children with complex conditions.

Cluster 3 services are most likely to consist only of nursing staff, although this difference did not reach statistical significance. However, services in

this cluster also contained the highest numbers of nursing staff and this difference was statistically significant.

A surprising proportion of respondents were unable to give us any detail about their service budgets. In some cases, this was because the CCTH service did not have a budget separate from that of other services. In others, it was because the respondent appeared not to know the answer. This was despite vigorous follow-up from the research team to obtain missing data. Given that some teams *were* able to give detailed information in response to the budget questions, this suggests that some providers may be lagging behind others in the sophistication of their financial systems.

4 Meaning and commissioning in care close to home

This chapter presents qualitative material from the four case study areas and explores how practitioners, service managers, and commissioners viewed, commissioned and practised care close to home (CCTH). This specifically addresses the project's aim of exploring the implications for services and families of providing CCTH for children. The chapter is in three parts. First, we explore how our respondents defined CCTH and, in doing so, provide insight into its potential. Secondly, we explore the issues raised by commissioning in order to realise this potential, particularly within the changing context of NHS relationships. Thirdly, we explore some of the practical difficulties faced by practitioners and mangers when delivering CCTH, as well as the potential solutions they identity.

4.1 What is care close to home?

An important aspect of our qualitative work was to explore the meaning and potential of CCTH. This section explores the views of front line staff and their managers and in particular their reflections on the nature of CCTH for children. It provides insight into the broader normative values and assumptions informing CCTH and shows that CCTH was conceptualised by professionals in two broad ways. First, it was seen as something that is 'for' the NHS. Here the concern was with organisational issues such as reducing the child's length of stay in hospital and preventing admissions. Second, it was seen as something that happens to and for the child's family; here the emphasis was on it being better for children to be at home, and on access and accessibility, choice, empowerment, quality of care, and added value. However, areas of tension related to managing risk and children 'being different' emerged, as practitioners attempted to reflect these aspirations in their practice.

4.1.1 Something that is 'for' the NHS

CCTH was conceptualised by respondents as something that is 'for' NHS. It was seen as an alternative to out-patient care, as a means of preventing admission to hospital or reducing length of stay, thereby releasing in-patient beds, as well as an interface between secondary and primary care. The Children's Assessment Unit (CAU) in site Z, for example, helped the acute trust to manage its caseload. Previously, children with acute illnesses were admitted directly onto the in-patient ward and this was felt by a senior member of staff to be *'a less efficient way to manage these acute patients*'. The CAU was intended to relieve pressure on the in-patient ward, and it sometimes acted as a handy 'overflow' space too. CCN teams were also seen as a means of facilitating earlier discharge, with hospital staff feeling more confident about releasing children because they knew community support was on hand. CCTH services were also seen to have a role in

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supporting primary care to manage ill children in the community, thereby providing an alternative to hospital.

4.1.2 Something that happens to and for the child and their family

4.1.2.1 Being better at home

Most practitioners agreed that it was 'better' for both children and their families to be at home when they were ill. Some staff referred specifically to an underlying 'philosophy' that underpinned their desire to keep children out of hospital:

> "So I think our driver was very much about offering that choice … because … you know, our underlying philosophy is that we, we shouldn't, children shouldn't have to go into hospital unless they absolutely need to."
>
> (PCT strategic manager)

For some this was for straightforward clinical reasons - avoiding exposing already sick, and in some cases immuno-compromised, children to infection. For others, the benefit assumed a more social meaning, linked to maintaining a sense of routine and normality for families. Going into hospital created disruption, splitting sibling from sibling and parent from parent. One senior Trust manager compared the logistical complexity of bringing a child into hospital with the relatively 'straightforward' task of a nurse visiting them:

> "… you know, mum might need a morning off work, how do we take the child out of school, dad's working away, I haven't even got the care and grandma hasn't got my other child, can I bring my other child in, where do I park the car and where do I put, all that for something that, from a professional point of view, is quite simple and straightforward."

Many staff emphasised the general importance of maximising normality for children who in other ways had the usual trajectory of childhood disrupted. One element of hospital-based care identified as particularly unacceptable concerned children missing school. CCTH services could be more flexible by organising home visits outside school hours, thereby giving greater scope for children to fulfil their potential. The importance of this went beyond academic achievement and enabled children to maintain a normal social life, although as we shall see, this was sometimes difficult to achieve in practice. CCTH was also felt to offer a more familiar environment for the child, where family routines could be maintained. Even CCTH provided outside the home could be seen to promote 'normality' when compared to traditional in-patient care. Further, length of stay was kept to a minimum and children could be quickly returned to their home environment. Protecting family life and maximising 'quality family time' was considered to be particularly important for children with long-term or life threatening conditions. One nurse explained:

> "The group of children that we're working with have to spend a lot of time in hospital just because of the nature of, of their

problems, so time at home is, is bonus to them really. So if we can stop them coming into hospital or get them home quicker or minimise the number of contacts they have that's obviously better for family life."

4.1.2.2 Access, accessibility and choice

The practicalities of bringing a child into hospital meant that many staff viewed CCTH as a preferable alternative for children and their families. Regular travel to hospital could be expensive, particularly for parents without access to a car. Parking could be problematic and expensive, as could access to food and the practicalities of feeding young children away from home. Respondents therefore saw CCTH as improving access to healthcare, particularly for families without their own transport or those whose circumstances made getting to hospital difficult.

Practitioners saw CCTH services as particularly accessible. Some CCN services in the case study sites took referrals from multiple sources, including self-referrals, and had an open telephone service. Others had more restricted referral routes but, once part of the service, families were provided with easily accessible support and advice, sometimes late at night. CCTH services were also seen to be more responsive than hospital services, with advice obtained and children seen more quickly than they would be through mainstream acute care.

CCTH was thus seen to facilitate choice by offering alternatives to hospital care. This, however, began to raise an interesting tension in how CCTH was framed. Often participants discussed choice in relation to the family rather than the child, sometimes confusing the two or seeing them as essentially the same. At the same time, there was frequent reference to the needs and importance of the *child* being nursed at home. While the support of an ill child at home was therefore ascribed importance, it was the family that ultimately determined its implementation. This comment from a nurse captures this:

> "We think that children have a right to be nursed at home, that children should be comfortable in the environment that, that they're in, and usually that's home, and we feel that we should be able to provide that if that's what the family want. We're very much family centred care."

While this tension is perhaps inevitable, it has important implications in relation to who exercises choice, and under what circumstances. Parents were said to have a choice about the settings of care (usually a choice between home and hospital, although sometime care was available in other community settings such as schools and nurseries). Then there was a further choice about what nursing tasks parents would take on. Practitioners' accounts reflected a concern with the former (choice of settings), rather than the latter (level of parental involvement). In most cases, practitioners tended to assume that CCTH would be the most acceptable option for parents and therefore thought it was unlikely to be turned down. Exceptions to this assumption were usually found in relation to end of life or specialist oncology care. There appeared to be little actual

negotiation between parents and service practitioners and, to some extent, practitioners seemed to assess whether CCTH was a viable option for families before offering it to them. The focus of our work meant parents who were not using CCTH - perhaps because of practitioner assessment of their inability to cope or the unsuitability of their home environment - were not in our sample. This makes it difficult to explore this issue further.

4.1.2.3 Empowering families

Closely related to the idea of choice was how CCTH was seen to empower families. Staff, for example, talked of 'supporting' families in the home, 'following' families into the community and 'working with' families. This suggests that families led the care, with CCTH services facilitating and supporting this. 'Empowerment' was talked about as part of a process by which parents were provided with the skills needed to manage more of their child's care at home:

> "It's about empowering the parents to not be so afraid, you know, a lot of parents are afraid of a pyrexia. So it's empowering them to, to realise that there are things they can do to minimise those symptoms and to recognise when symptoms are becoming dangerous, and if the symptoms are becoming dangerous of course we're going to send them into hospital. But if they're not and they're run of the mill everyday illnesses then they're teaching the parents how to deal with those."

This was as much about building parents' confidence as it was about training them to administer particular treatments. Some staff also aimed to empower parents to be stronger advocates for their children. For example, a senior nurse explained: *'…* we're nurturing very proactive dynamic parents to actually shout their child's corner in the future'. This of course, would have a direct benefit for a child. It was also talked about as giving parents the expertise and confidence to recognise when their child needed medical attention, thereby reducing anxiety.

There was also a hope, especially from the nurse practitioner (NP) service, that such empowerment would reduce dependency on the NHS.

Empowerment of children, by contrast, was far less likely to be addressed by practitioners. Only one member of staff explicitly talked about building the expertise of children to manage their own care.

4.1.2.4 The added value of care close to home

Practitioners' views on the potential (and actual) benefits of CCTH were not solely concerned with the practical issues of offering care in a setting other than hospital. More social and psychological benefits, such as flexibility, holistic management and continuity of care were also reported. As one commissioner explained, "… it's more than just, you know, you can be treated at home, it's all the add-ons to that."

Greater flexibility enabled outreach teams to tailor care to the needs of individual children and families. This included planning home visits to fit

around families' existing commitments, as well as adapting treatment plans to fit individual trajectories, as a nurse observed:

> "We try and offer a very individual service to families, 'cos each family is very different and each child is very different and, you know, pathways, you know, their journey through the diagnosis and treatment's very different. It's about adapting a lot, you know, for the families."

The flexibility of CCTH services also allowed some practitioners to liaise with other agencies on behalf of service users or advise families on further support, with the potential for enhancing continuity.

Staff also felt that CCTH provided valuable psycho-social support, which would not normally be available in hospital environments. One interviewee, for example, described oncology outreach nursing as largely a 'befriending service', helping families to get through the cancer journey. Some practitioners also took on an advocacy role, helping parents to negotiate with doctors and understand technical language. However, it was acknowledged that providing this type of psycho-social support was dependent upon the ratio of staff to families and this differed for different teams.

While some services operated time limits for their input or strict inclusion criteria, most staff maintained that children were viewed more holistically than they would be in hospital (although this was not without its tensions, as aspirations were sometimes difficult to realise in practice, as we see in the next section). Children using traditional hospital services might see a different practitioner each time they had treatment, potentially adding to their stress. By contrast, the same practitioner or group of practitioners generally saw those using CCTH services, whenever they received care. In addition to making things easier for families, this continuity was felt to contribute to relationship building, which in turn enabled staff to better understand and meet the individual needs of children and families.

Even where services provided only short-term intervention continuity of care could be achieved. For example, in the time-limited NP service in one case study, nurses were able to spend as long as they needed with families on each visit. Moreover, if children needed further care after the usual five-day period was over, they could be transferred to the connected CCN team and parents might not even notice the transition.

CCTH providers felt they had a privileged insight into family life, entering the family home and spending extended periods with family members. Staff argued that, through this, they gained a better understanding of the child's environment and a greater awareness of the impact of their illness on family life. In one case study area, a family support worker who spoke four local languages was able to build relationships where mainstream services using interpreters would have struggled. Staff who worked with this person emphasised how s/he provided a vital link to families whose first language was not English, not only helping to facilitate care, but also to meet social, cultural and spiritual needs.

If CCTH services do have the potential to provide individually tailored, flexible services that ensure continuity of care for children and families, part of their added value could be to meet the needs of groups traditionally subject to health inequalities and disadvantage. For example, it was felt that the CCN team in site Z reduced the incidence of 'did not attends', which are traditionally spread unevenly across different social groups. Similarly, in another site a nurse commented:

> "We've had quite a few pretty poor, you know, deprived, deprived families. Those families it is more important that the outreach team is there, 'cos they can go out and see them, 'cos those families tend not to have cars."

4.1.3 Managing risk

Up to now we have focused on how practitioners view the potential of CCTH and in particular its practical advantages over traditional hospital care. However, an element of practitioner accounts acknowledged that CCTH requires a different way of working. This raised issues about what was possible when delivering CCTH. Many staff – as we have seen - felt strongly that children *should* be nursed at home. To this extent, CCTH was seen as a good thing, but some practitioners expressed concerns about what it was possible to deliver. There was, for example, some disagreement over the potential for moving more care outside the hospital environment. One nurse said that some procedures in paediatric oncology should always be provided in hospital. Another, however, felt that with the right approach there might be no limit to what could be provided in the home: "You can do almost anything at home if you've got the will and you've got the staff."

A commissioner in one area expressed the need for more evidence on what it was safe to deliver closer to home, and said he had so far limited development of CCTH services to things he 'knew' to be safe. Other service managers shared these concerns, and this was also raised by some practitioners.

Clinical risks were identified within different contexts. Risk and safety, for example, were talked about in terms of procedures and care that could not be given at home. It was argued that home care should only be given when safe, and when the child was well enough to be out of hospital. In determining this, practitioners could not help comparing CCTH to hospital care. In particular, hospital was viewed as generally a safe(r) place, better suited for some types of treatment and care. In hospital there were safety nets (specialist equipment and the expertise of more senior clinicians) less readily available to staff working in the home or community settings. Viewing hospitals as safer than the community, when caring for ill children, generates an important challenge for future development of CCTH.

Nevertheless, many front line staff emphasised that managing risk was possible, given sufficient staffing and support. Some services did this through establishing clear protocols and direct links with specialist support. Many practitioners were also aware that risk was more apparent at key times, and this could be managed by choosing a care pathway for the child

that balanced considerations of the potential severity of the illness against considerations of the most appropriate setting. Ultimately, then, clinical risk or *perceptions* of clinical risk appeared to mediate the extent to which CCTH was supported and implemented.

4.1.4 Children are different

Much material from staff framed the child - and childhood illness - as requiring a different way of working. Staff often talked of their CCTH services being not just for individual patients - as is usually the focus in traditional adult care - but for whole families. Although in some cases children were distinguished from the family, the logistics of caring for children naturally encompassed parents and other family members. Interviewees noted that nurses going into children's homes were entering environments influenced not only by the patient's health, but also by other family circumstances. Thus, extra support might be needed to help them manage this.

Despite emphasising the advantages of CCTH over hospital care, practitioners were aware it could also cause stress for parents. Care can be tiring, create emotional distress and have consequences for other family members, especially siblings. Providing psycho-social support for the whole family, therefore, could be key to good quality care. One staff member for complex care argued that a family should be supported psychologically to care for the child at home, while a nurse providing palliative care highlighted how there were unmet psychological needs often associated with CCTH. Comments from other staff supported this, as did remarks from parents (see Chapter 6).

As well as increased responsibility for the family and the associated challenges that may bring, families may have to make other sacrifices while receiving CCTH. Employment, for example, may be affected, with related financial implications. Although recognising the need for support, some practitioners felt their capacity to meet such needs was limited (see Chapter 5).

4.2 Commissioning care close to home: strategic level barriers and enablers

This section explores some of the issues faced by commissioners and service managers when developing CCTH. The main issues that emerged from the data were how commissioners interpreted and engaged with national policy, the role of evidence in commissioning service provision, the commissioning process from different stakeholders' perspectives, and the ways in which different understandings of CCTH influenced its development.

4.2.1 Interpreting and engaging with national policy

The National Service Framework for Children, Young People and Maternity Services emphasised the need to provide care away from hospitals and suggested ways of achieving this[1]. In many ways, the aspirations identified

in the NSF accorded with practitioner accounts on the potential of CCTH (see above). We asked commissioners whether the NSF, along with other national guidance such as the Child Health Strategy (CHS)[10] - had been useful in the development of CCTH.

By describing CCTH as good practice, both the NSF and the CHS were felt to have lent support to existing CCTH services and backed the case for further development. However, their usefulness was mitigated by the absence of additional money to fund service development or performance management mechanisms to penalise those who did not follow the guidance. A PCT commissioner explained:

> "So it's a bit of a 'yes it would be nice to, wouldn't it' kind of approach … but if you don't do it is anybody going to get sacked? Probably not."

One way around the absence of dedicated funding was to bid for 'one-off' grant funding or become part of a national pilot. The problem remained, however, about who would pick up the funding, when the initiative ended. More generally, it was left to individuals in some areas to try to drive the development of CCTH forward. This could prove difficult when funds were limited or the introduction of new programmes of work and competing priorities threatened to push CCTH off 'the radar'. A senior nurse, working in a PCT said:

> "I think priorities change very much according to the Government agenda. ... And I think that's quite difficult because you may really be on a, an area where you're very supported and everybody wants this ... situation to happen and they want you to see lots of children, and then another agenda can come along and that changes the drivers and that's, that's quite difficult I think, because then something that you were doing well you might struggle to continue with and I think that's quite frustrating really."

A range of other guidance and initiatives were currently seen to have higher priority than the NSF and CHS, or at least as having greater impact. *Aiming High for Disabled Children*[37], for example, came with substantial funding and a time-limited period for implementation. This gave the impetus to move quickly. Areas of work where services faced assessment or impending peer review were also given priority. Staff commented that this tended to encourage children's services to be reactive rather than proactive, responding to Safeguarding 'scandals', for example, more readily than they did to good practice guidelines. This, as we shall see, was a concern of practitioners too. Further, it was noted that some models of CCTH, in particular CCN, targeted relatively small numbers of people when compared to, for example, children's learning disability teams or health services for older people. They could be considered a lower priority, therefore.

4.2.2 The role of evidence in commissioning care close to home

Commissioners in each of our case study areas talked about not having sufficient evidence about the types of interventions that could be provided

successfully outside of hospital or how cost effective these would be. However, it was also clear that some commissioners had a limited understanding of CCTH as a concept, even if they did not explicitly acknowledge this. These commissioners often had a generic health service background and little understanding of the complexities of developing CCTH or the evidence to support it. There was also some concern, from both commissioners and providers, that the views of children and families were not well understood or especially well reflected in practice. These two issues could create tensions. In one area, for example, a CCN team leader felt under pressure to extend the operating hours of her service because it was assumed that parents would prefer this, but she felt there was little evidence to support longer hours. Others were concerned that the risks of providing care outside hospital were not well understood. The business case for a CCN team in one area, for example, had been turned down repeatedly because commissioners were unsure of the associated risks.

Some service managers reported that information about population needs and service use had been a catalyst for the development of CCTH services. This was seen as a positive development. In one area a specialist children's nursing service was set up in response to local pressure about the unmet needs of a particular group of children (backed also by a powerful champion). In another, the NP service was introduced after an audit of hospital activity showed that the majority of children were staying for fewer than 12 hours. Closer inspection of case files confirmed that many of these children had conditions that could have been managed at home, if support had been on hand and protocols in place to manage risk. This site then looked to examples of existing CCTH services in other areas of the country to help them design their own. Similarly, the CAU in our study was based on a model already operating in another area of the country. However, not all commissioning decisions were grounded explicitly in existing models or evidence. Use of evidence or learning from existing models was the exception rather than the rule. For example, when asked what evidence they had used to develop the new model of continuing healthcare (CHC) planned in one of our case sites, the commissioner said:

> "There's ample evidence out there really, isn't there, about short breaks and supporting parents?"

but continued

> "I mean I suppose the, the short answer is (sighs) we probably haven't looked."

Evidence collected about the activity and cost effectiveness of existing CCTH services could act as a powerful enabler for their further development. In one area, for example, evaluation of the home nursing for neurological conditions pilot showed it to be a successful model and as a result, service managers and commissioners were looking to expand it to a wider group of patients. Similarly, in another area, data collected on the numbers of children using the NP service who would previously have been referred to hospital demonstrated to commissioners that the service was reducing

admissions. As a result, further resources were allocated to expand it across the PCT.

Nevertheless, commissioners and service managers - in all case study sites – acknowledged that collecting robust data about the effectiveness of CCTH services was difficult. This is because systems are often not in place to capture service activity and because effectiveness in CCTH services is hard to define and quantify. Where services used narrow definitions, based on numbers of admissions avoided or reduced length of stays, they encountered unreliable systems of data collection and difficulty in identifying directly attributable costs and outcomes. In three of our four sites, work was currently underway to improve data collection systems and unpick CCTH activity.

When success was defined more broadly as the overall value of a service and its acceptability to service users, demonstrating effectiveness could be even more problematic. Most areas had some system for collecting the views of children and families (including satisfaction surveys and parents' forums) and in site Y it was felt that this had helped to dispel service providers' assumptions about the needs of different groups. However, in other areas it was felt that satisfaction surveys did not adequately capture parents' or children's views. More qualitative data collection was considered desirable, but prohibitively labour intensive. An issue flagged up in one area was the risk of raising families' expectations about what services they could receive outside of hospital. An oncology nurse said she did not collect views on whether her patients would prefer care in hospital or at home because "sometimes with the oncology children those options are not open."

Service managers did not always expect commissioners to have the information and expertise necessary to design CCTH services. Indeed, one of the commissioners we spoke to argued that it was the clinicians' responsibility to know what was clinically safe and to keep up to date with new developments. He would look into and verify their suggestions but, as he did not have a clinical background himself, he was dependent upon their expert knowledge. From a provider perspective, there was concern that commissioners might not fully understand the services being provided, which could have serious ramifications when reviewing what was provided. As seen above, some commissioners may not have been best placed to develop CCTH. Even when this was not the case, commissioners often had to balance many different priorities and be responsible for several other clinical areas. Good relationships and effective communication between all parties could thus be crucial to high quality commissioning; it is to this issue that we now turn.

4.2.3 Commissioning relationships

Different case sites in our study approached children's service commissioning in different ways and commissioners told us about a number of issues affecting the development of CCTH. One of these was to do with the size and 'unwieldiness' of PCTs, particularly since mergers following the most recent reorganisation[38]. In one large PCT, formed from four smaller ones, commissioning structures appeared fragmented, with numerous

people, across different work streams, involved in different aspects of children's commissioning. The commissioner here talked about the impact of this fragmentation on communication with partners, who sometimes did not know with whom to liaise. There was also a danger of work being duplicated or gaps appearing because different areas of the system did not know what others were doing. Moreover, this PCT covered two Local Authorities (LAs) that historically, according to the commissioner, had not worked well together. This caused further problems:

> "I would actually sort of highlight the, the size of the PCT and the two Local Authorities as real major sort of barriers for us …"

> "… well it's like we've got two, we've got two Children and Young People's plans. So in terms of the, in terms of the production of those and the involvement in those you're, you're, you're, you're doing it twice so that's quite sort of difficult."

In another large site, there was a complex commissioning structure involving a number of PCTs and interviewees told us that working across the boundaries between the different commissioning arms could be problematic, as could joint commissioning with the LA. In contrast, a PCT that was coterminous with its LA and covered a more manageable area appeared to have a more organised approach to commissioning. Here joint commissioning arrangements were in place through the Children's Trust, which had a clear governance structure in place for decision making around children's health services.

Commissioners referred to the difficulties inherent in dividing up and managing the children's commissioning remit, commenting that the needs of children themselves were so broad that they could become unwieldy. In some instances, it could be hard to determine where children fitted into commissioning structures, particularly where these were designed primarily with adult services in mind. It was noted in one site, for example, that neither the acute nor the long-term conditions 'Darzi' work-streams, included children. This left a single children's work-stream to cover all aspects of children's health. Consequently, the children's work-stream was large and operated quite separately from all other agendas, increasing the risk of discontinuity between adults' and children's services.

All sites noted that the quality of the relationships between commissioners and providers affected the development of CCTH services. In some sites, key individuals in provider organisations had been central to the development of CCTH. In one area, the children's CHC and the specialist nursing services were set up in response to the efforts of individual provider champions. In the case of specialist nursing, a 'forward thinking nurse' developed the service in collaboration with an acute sector consultant. In the case of CHC, the service manager persuaded 'the powers that be' that there was a need for a substantive in-house team, and that this model would be more cost effective than the alternatives. However, it was noted that in order to influence service development effectively in this way, clinicians needed supportive management, and managers in turn needed

good relationships with commissioners to ensure services were adequately funded and supported:

> "If you don't have a good relationship with your commissioners you're going to struggle now. Luckily we do, I think, have a, a very good relationship and we have people we can say, look we'd really like to do this, would you help us."
>
> (PCT service manager)

These relationships were influenced by wider commissioning structures, especially the introduction of competition rules, which meant commissioners and providers were finding it more difficult to maintain these close working relationships. A commissioner commented:

> "The medical staff and the nursing staff have got far more knowledge than I've got and, and really it should be about utilising their expert, expertise."

But then he added that this was "quite a difficult thing at the moment" and explained:

> "We've got to be very careful when we obviously move forward to what we're going to do with the strategy, that we're not being seen to favour any particular providers as we go forward."

Commissioners often found themselves in a 'catch 22' position. They felt the need to communicate with provider organisations because their clinicians had valuable expertise, but they could not be seen to be influenced by any particular organisation as this would go against competition rules. In one site, a distinction was made between working with providers to develop existing services and working with them to commission new services (including service re-commissioning). For the former, commissioners felt that some involvement of existing providers was acceptable 'because there's no commercial sensitivity', but when commissioning new services:

> "It's difficult because like I say, with it, with it becoming more of a competitive market and a sort of going out to tender."

Similarly, a commissioner in another area stressed that, while it was important to work with clinicians when redesigning services, this was about making use of expertise not engaging potential providers.

Providers were feeling the effects of these constraints. In one area a team leader commented that commissioners did not listen as much as they should. In another site, there was a feeling that the new arrangements had had a detrimental impact on both the acute trust's relationship with commissioners, and their relationships with other provider organisations with whom they now found themselves in competition.

One of the commissioners we interviewed felt strongly that the introduction of competition should not inhibit collaboration between providers, since the opportunity for providers to propose delivering services in partnership remained open. However, some of the providers did feel under threat and mentioned how this could lead to defensiveness and sensitivity over

information sharing. One team said that they purposefully kept a low profile with their PCT because they were 'a bit wary that they might want to take us over at some point'.

Where relationships between providers and commissioners were poor, PCTs could be seen by providers as barriers, rather than enablers, to service development. In one such area, CCTH services had been developed by front line staff, with support from managers and the help of some external, 'one off' funding which the PCT 'rather reluctantly' continued. The manager of the service explained:

> "Although occasionally they challenged what we're doing and why, there's been no sort of, oh yes this is a good thing, we need to support that, and is there more you could be doing and how can we work together to achieve this type of event. We've just got on and done it ourselves. I mean my personal view is that if we were waiting for the PCT we would have still been waiting."

For commissioners, front line innovations appeared to be welcomed in theory. However, if they did not feel sufficiently well informed about the nature of these developments they were less inclined to support them. One commissioner complained:

> "There's not the control the PCT would like, but equally ... they would argue back that they're being innovative and they probably are, but they need to share with the commissioners the innovation as well, so."

This commissioner attributed much of this lack of control to block contracting. Indeed, the type of contract could noticeably affect the development of CCTH services. The majority of CCTH services we looked at came under block contracts, either specifically for those services, or as part of broader acute trust contracts. The exceptions were children's continuing healthcare (CHC), where funding for packages was determined on a case by case basis[g]; and a CAU, where activity came under a cost per case tariff as part of 'payment by results' (PbR). The staff we talked to highlighted both positives and negatives about block contracts. Commissioners explained that they were useful for PCTs because they enabled them to set budgets and targets in advance.

However, there was recognition on both sides that such security came at the cost of inhibiting services from responding to changes in demand. Two of the CCN teams we spoke to said that they could increase the numbers of children receiving CCTH by raising awareness of the service, but neither intended to do this as they could not handle an increase in demand without a corresponding increase in staffing. As one senior nurse explained:

> "The worry is you go out and do that [publicity work] and you get inundated and then you can't provide, can you, 'cos you've got to

[g] Note that children's continuing healthcare was not the primary focus of any of our case studies, but that some of the CCN teams we focussed on did have CHC as part of their remit.

> prioritise everything, you've only got so much resources and funds and things."

With cost per case contracts, mechanisms are in place to respond to changes in activity without renegotiation of the contract. If demand increases, so does funding and additional staff can be brought in to meet the additional activity. In theory, block contracts can also be renegotiated in response to real or anticipated changes in activity; however, this is a slower process and there has to be the will on the side of the PCT to commit additional funds. This was something that providers felt was not always in evidence. In one site, for example, a provider manager told us:

> "The only real problem I've got with that service is, is if I wanted to do more I might be able to do more, but nobody quite, in, interestingly, feel they want to pay us for it, and so, so therefore I have to try and fight them [the PCT], and the team is quite small as a result …"

Block contracts, despite the financial certainty they provide, can also cause difficulties for commissioners. In particular, services that had developed 'bottom up' as part of large acute block contracts could appear elusive to commissioners who had not, themselves, set the service specifications. Commissioners talked of having 'less of a handle' on these services, not knowing exactly what they were getting for their money and not being able to control how they developed. A commissioner explained:

> "Quite often, if it's within the block it's sort of, not necessarily been left but it will be, it, it's more likely to be provider led in its development. But there's certain areas in the block that we've clearly specified and we clearly performance monitor and, you know, we're, we're clear about what's in and what they do and we've set the, the activity levels. But there's a whole bundle of work that isn't, and until it comes up the list in terms of it being a priority I suppose, you know, it, it's not all clearly specified and clearly performance monitored."

One of the benefits of many acute services now coming under PbR is that much more can be known about the activity of a particular service. However, some commissioners felt that having a tariff for a service was 'a double edged sword'. On the one hand, it ensured that all activity was appropriately recompensed and that PCTs could clearly see where their money was going; on the other, it encouraged providers to see as many patients as possible and commissioners feared that this could lead to spiralling costs.

As it stood, community children's nursing activity, even that of acute trusts, did not come under PbR in any of our case study areas. Such activity was too difficult to put a procedural price on, as one commissioner explained:

> "Once you move away from your sort of regular like hip replacements where you know there's a cost of a, of a hip and the surgeon's time and da-da-da-da, which is quite straightforward, it [costing activity] then becomes much more difficult."

Such difficulties meant that different systems of funding continued to operate in tandem, leading to perverse incentives and inequities between services. Thus it was pointed out that, if children were discharged early from hospital needing support, commissioners or acute trusts could see reduced costs[h], but community provided CCN teams would be expected to pick up the children's care without receiving additional funding.

In one area, an acute service manager actively redistributed money from the ward budgets to the acute sector based CCN budget, even though financially there was a disincentive for him to do this. He knew that if he invested in the CCN service and kept more children out of hospital, the PCT would not reimburse the extra work the CCNs did and the ward budget could be reduced. However, he had 'a sort of philosophy' that children should be in hospital for as short a time as possible. It was not, however, always possible for service providers to operate in a similar way. In another area, the CCNs said they would like to be able to support enteral feeding in the home, but the PCT would not fund the development of this service because it would not lead to reduced hospital bed stays. This demonstrates the primacy of the 'invest to save' argument when commissioning CCTH services and we move onto this issue in the next section.

4.2.4 Financial pressures and incentives

The argument that developing CCTH services would enable PCTs to spend less on hospital services (and thus reduce spending overall) was instrumental in the development of some of the CCTH services in our sites. In one site, the business case for a home-based, sleep diagnostic service was successfully made on the premise that this model would result in significant cost savings to the PCT (by preventing in-patient admission for diagnostics). We noted above that the nurse practitioner service in one area was developed after an audit of hospital admissions showed that many of the children admitted could have been treated at home, given the appropriate support. Service providers in this site told us that their driver for developing this service had been 'about offering a real alternative to hospital admission'. However, the PCT strategic manager also acknowledged that:

> "Sometimes it's not as easy as saying, we think this'll be a really good alternative, you have to prove well actually is it financially viable."

Consequently, the provider made the case to the PCT that if they invested in a nurse practitioner service they would save money. The commissioner from this site confirmed that this financial argument persuaded them to commission the service:

> "The original driver from the clinicians was that that's what they wanted to do, they felt that was an appropriate thing, you shouldn't be taking children into hospital when they don't need to go into hospital. The reason we did it was financial."

[h] Depending on their specific contracting arrangements for acute children's care.

This commissioner told us that the nurse practitioners had succeeded in reducing hospital admissions and consequently there were plans to roll out the service across the whole county.

In other case sites there did not seem to be the same motivation to invest in CCTH services. Service providers across our four sites highlighted lack of investment as a key barrier to the development of CCTH. In one area staff felt more children could be supported in the community but currently were not because resources were lacking:

> "I still think there's times when children go into hospital unnecessarily when they don't need to, and, but I mean, you know, ultimately that's down to resource and, and it comes down to money."

The commissioner in this locality was aware that more could be done to promote CCTH, but felt that this was largely because providers had not done enough in the community to avoid admissions and facilitate early discharge. By contrast, the provider felt unable to develop services because of lack of funds. An impasse had therefore arisen, whereby the commissioners would provide no extra funding, and the provider organisation could not extend the reach or scope of its CCTH service. As one of the nurse managers in this area pointed out, this stalemate did not only affect the amount of care that could be provided outside of hospital, but also the type and quality of that care. In particular, the team wanted to provide more psycho-social support and felt that there was a real need for this amongst their service users, but the view of the commissioners was that this was a 'luxury' they could not afford. As one senior nurse from a different field work site put it: 'It's quality versus the economy really'. The commissioner in this area, however, said that this was not a problem unique to CCTH services, describing the PCT as 'financially challenged' overall and explaining that the focus on financial recovery had been a barrier to commissioning across all children's services.

Another site pointed out that an increase in funding would enable them to enhance the safety of their nurses by making it possible to do home visits in pairs, but there was currently no funding available for such a move (particularly since no direct 'invest to save' argument could be made to justify it).

4.3 Conclusions

Staff views on the nature of CCTH and its potential benefits, emphasised the value of providing a family centred, flexible service, informed by the principles of holistic care, as an alternative to hospital care. However, aspirations sometimes proved difficult to realise in practice and this created tensions. The problems associated with providing CCTH begin to indicate some of the difficulties commissioners, service managers and practitioners have to negotiate in practice. The role of commissioning is of primary importance here.

Commissioners noted that different policy initiatives mediated the development of CCTH. The NSF and CHS were felt to have supported existing provision, but the lack of monies associated with such policies was a problem when it came to developing existing and commissioning new services. Commissioners and providers, therefore, had to be creative in accessing funds. Both bemoaned the lack of evidence about the sorts of interventions that could be developed outside hospital settings. Data, when available, was an important driver in establishing provision. Nonetheless, in some cases, commissioners' understanding of CCTH created problems. Commissioning structures and relationships further exacerbated this situation. Good relationships between commissioners and providers were especially important in the successful development of CCTH. However, commissioners needed to access the expertise of provider organisations to design services, but in a way that did not breach competition rules. Sustaining a distinction between working with providers to develop existing services, and working with them to commission new ones, offered a useful strategy in negotiating this problem.

Block contracts were seen to have both advantages and disadvantages. Some commissioners liked them, as they enabled PCTs to establish costs and targets in advance. However, if services had evolved under existing block contracts they might not have clearly defined service specifications that commissioners could monitor. Service managers, for their part, felt block contacts could inhibit services developing in response to demand.

Proving the potential cost savings to hospital care when developing CCTH proved especially difficult. More generally, financial pressures, on both commissioners and providers, risked undermining the entire process, affecting the amount, as well as the types and quality, of care that could be provided closer to home.

As we see in the next chapter, a focus on day-to-day practice of CCTH services illustrated these tensions. However, it also provided ideas for solutions, which could facilitate more accessible and appropriate CCTH.

5 The practicalities of providing care close to home

This chapter discusses the experiences of staff managing and providing CCTH and the specific practical challenges they identified in their everyday work. The previous chapter explored the meaning and potential of CCTH and the tensions involved when commissioning support. Here we discuss challenges practitioners had to negotiate in their day-to-day role, as well as organisational practices that helped facilitate their work. Admittedly, most participants reflected more on the challenges they faced than on facilitators. Nonetheless, in exploring these difficulties, implications for service development emerged, particularly since practitioners were aware of the tension between what they would have liked to have provided for families and what they actually did provide.

5.1 Managing team capacity

Two main issues related to team capacity emerged from the case studies. First, there was what might be achieved if teams were larger and thereby could meet the needs of more families, or more of the needs of families already using CCTH services. The second issue was about difficulties running teams at *existing* capacity – whether because of unfilled posts, sickness or related factors.

Practitioners reported that both types of capacity issues had an impact on the service they were able to offer. The ability to provide support over and above clinical input was predominant here. When capacity was limited, clinical input took priority over psycho-social forms of intervention, meaning that services were not able to offer additional support that would benefit the child's quality of life more generally. As we saw in Chapter 4, providers felt that commissioners often saw this broader, more socially orientated support as 'a luxury'. However, capacity issues could also hinder clinical support. For example, one practitioner spoke of how lack of capacity made it impossible *routinely* to administer IV antibiotics in the home. Several staff also commented on how staff shortages created stress for them.

Unfilled vacancies were identified as a particular problem and this directly affected families when visits were cancelled because of staff shortages. More generally, many staff commented on how a lack of capacity made it difficult to meet demand. For one team, this meant being reactive, responding to crisis management, rather than offering a pro-active, planned response. A senior member of this team explained:

> "You tend to focus your care on the families that shout the loudest or are, are in crisis, and the ones that don't contact you, you know, months go by without you really being aware of what's happening for them. You just assume that all must be well or they'd contact you if they didn't, if it wasn't."

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Another nurse manager was aware of how the current lack of capacity meant the 'neediest' families got the most service, referring to both those with more needs and those who were better able to express needs. As a consequence, some children were admitted to hospital, even though CCTH would be appropriate to their needs. In other cases, waiting lists were necessary, thus reducing the ability of practitioners to be responsive.

A constant need to prioritise, therefore, characterised many practitioners' work. They were equally aware of how such strategies could undermine equity of provision, and talked about this also in relation to policy change:

> Q: Right. And is that, is that quite a big issue then, giving an equitable service, if you're, you're, you're under-staffed?
>
> A: Well it is, because if, if we have to take on huge projects, you know, that, that, that have to, that have to be undertaken, I mean that takes us away from being able to do the clinical things that we need to do. So ..., I mean I'm supposed to be sixty/forty, sixty per cent manager, I'm probably the other way round, sixty per cent clinical/forty per cent management, if not more clinical than that. It's just because of the amount of visits that we do. So ... it would be nice to say that we can do it all, but if I'm really honest about it we just, we need more staff to be able to be, you know ... to do everything that needs to be done.

The implication here is that policy cannot be reflected in practice if it is not met with sufficient resources. Services that were understaffed and unable to meet demand meant that some families would be unable to access CCTH.

Given the above, it was not surprising that increased staffing was seen as a priority by many. Those who had seen additional staff employed confirmed its value as it had enabled them to provide more time and psychosocial support to parents.

Staff shortages and a lack of capacity not only affected current provision, but also meant there was limited scope to develop the service. Measuring activity, which could help extend the scope of the service, was sometimes difficult to do when there were what practitioners regarded as more pressing priorities such as clinical care. One senior nurse specifically described how her large caseload had potential for development, but she had been unable to instigate such development due to lack of capacity:

> "We've got, you know, quite significant caseloads ... and you can, I can see where ... the development could be, but obviously we need to have, we need to have some strategies to be able to put into place so that we can actually look at service line development and, you know, and mapping really and where we want the services to go."
>
> "Q: Right. And do you, are those strategies in place at the moment?
>
> A: No. ... Ever since I've started we've only really tended to do fire fighting, because of, because of, you know, not as a criticism

> of the Trust at all but just because of situations that occur with sickness and people leaving and then, you know, not being able to recruit into post and, do you know what I mean?"

Capacity was a particular problem for the CAU during winter, when staff sickness combined with an increased caseload required the increased use of bank staff, which came at an additional cost.

Recruitment and retention of staff represented a greater problem for some teams than for others. This pattern was evident in the national survey, where around a quarter of services reported they had unfilled posts in the past year (see Chapter 3).

Some case study teams reported difficulties in recruiting staff, particularly in relation to appropriate banding, qualifications and experience. For the generic community nursing team, the problem was specifically related to recruiting Band 5 nurses. Their perception was that reduced training opportunities meant there were fewer Band 5 nurses available to work in the community, and that Band 5 staff in the hospital sector were attracted to other posts in the community in search of promotion. Suitability of candidates was also related to the general inexperience among nursing staff of working in the home and community; one team had overcome the problem by ensuring experience was gained on the job, through shadowing and mentoring. Access to appropriate training was mentioned as a frequent problem, exacerbated by a lack of financial resources, which meant it was difficult to send people on training courses. Some nurses, however, wondered whether courses relevant to CCTH were actually available.

Some teams also faced difficulties retaining staff, the general impact of which was a reduced quality of service provision. One senior nurse explained how anticipated vacancies would:

> "... bring the service to a standstill. At the moment I've got one nurse that's on, off sick and it literally leaves us with one, two, possibly three members of staff on per shift …"

> "… and that's with, on Mondays and Tuesdays and Fridays we can have up to twenty-five visits a day."

However, recruitment and retention were not necessarily problems everywhere. Comments from staff in site Z may be significant here, as recruitment and retention were reported as unproblematic, and reference was made both to the resource of the local university, which trained children's nurses, and to the desirability of the area for living in.

5.2 Service availability

As well as affecting the extent and types of support that CCTH services could provide, participants also explicitly linked capacity to service coverage and the time available within the team. A lack of capacity could thus reduce the hours or days CCTH was available.

For most staff, insufficient capacity was the norm and this had knock-on effects, both for children and families and for the health service more generally.

Fitting in visits with children around the school day could be difficult for the generic CCN team, who struggled to offer flexible support. This could result in a child leaving school early to fit in with the team's working patterns. Several practitioners explicitly felt the restrictions associated with working 'office' hours were incompatible with normal family routines. In contrast, the CAU did not seem to have these problems, with operating hours (9am – 10pm) that helped accommodate visits after school hours. Staffing later shifts, however, could be a problem and one CAU nurse highlighted how this meant acutely ill children were then admitted directly as in-patients, which created a strain on the in-patient ward. Other services also commented on how insufficient coverage meant that some children received aspects of their care in hospital, when they could have easily been cared for at home.

For the local specialist oncology outreach nurse (SON-L) team, the problem was addressed by adopting a flexible approach in their hours of work. The NP service recognised that 24-hour care did not always have to mean visiting the home and that support could be offered by a 'reassuring' telephone service. The regional specialist oncology outreach service (SON-R) offered a partial weekend service to prevent children from being admitted to hospital, which in turn offered more continuity to families. This increased service resulted from increased staffing:

> "We're wanting, because we've now got the extra person in post, that on a Saturday and Sunday there will be, always be one of them on call, available who could go out and give, you know, an, IV antibiotics in the home to save the family coming back in."

Nonetheless, offering extended care, outside usual hours, often relied on the goodwill of staff.

Team leaders were more likely to be aware that potential solutions to the problem of capacity could create additional difficulties. Too much staff rotation or excessive use of bank nurses could undermine continuity of care. For a continuing health care team, having substantive and directly employed staff as opposed to using bank and agency staff was a strength: it offered a more flexible service and one better able to meet the needs of children in the home. Having continuity in staffing was felt to be advantageous in guaranteeing quality of care, although some nurse managers admitted that having regular bank staff could overcome some of these problems, especially when demand for the service was high. Such continuity also benefitted staff, as practitioners came to know one another. Specialist and smaller teams - the regional and local SONs – felt that they offered more continuity for families.

More generally, the problems associated with maintaining sufficient coverage meant, in some instances, practitioners felt CCTH was underdeveloped and not realising its potential (see previous section). This led some team leaders to question the extent to which the service was actually driven by the needs of families; organisational priorities seemed to

take precedence, leading to a service that was reactive rather than pro-active

5.3 Skill mix and working with and across multi-disciplinary teams

In some localities, skill mix was mentioned as a potential way of overcoming capacity difficulties. In the CAU, a healthcare assistant was seen as a particularly valuable resource in providing clinical support and freeing up the time of nursing staff, especially in the context of the unpredictable nature of acute admissions, which made it difficult to define an appropriate team size. Staff in other localities supported the increased use of care assistants, too. Some nurses also mentioned the role of trained carers, particularly in developing care packages, when the nurse could act as educator rather than provider. However, one site experienced problems retaining and recruiting trained carers. This is a reminder of how the ability to achieve skill mix may be mediated by recruitment and training opportunities.

At the other end of the nursing grade spectrum, some practitioners reflected on the potential value of nurse practitioners, especially those who had a prescribing role. Some teams were developing this role. Relying on GPs to write prescriptions did not seem an efficient use of resources and potentially undermined the effectiveness of the care pathway. The cost of employing a nurse practitioner, however, could be a barrier, and a strategic manager mentioned that ensuring a nurse practitioner's employment was cost-effective was important. The difficulties of accessing training relevant to nursing children was another difficulty faced by team mangers.

Working across teams and boundaries also made practitioners aware of tensions between policy expectations and practice. For example, the SON-R team worked in partnership with local CCN teams to support and educate staff in how to deliver care to families. Local provision, however, was not always consistent. One practitioner from this team said:

> "You know, personally I think there should be paediatric community nurses sort of nationwide, like we have district nurses nationwide ... but that's a, a Government issue. And if they want, you know, more children treated at home, if that's the bottom line from the Government, then they have to provide the community paediatric nurses to do that and so far that doesn't seem to be very forthcoming."

Not having other types of suitably qualified staff, such as play therapists, psychologists and social workers in the team could also affect capacity. Many practitioners, for example, talked about the need for a play specialist. Such support could be especially valuable in combating needle phobia. Having to access such therapy in hospital could prolong the stay of the child. The CAU did have access to the hospital's play therapy team and team members saw this positively. Community-based teams, on the other hand, regretted how care at home was interrupted when play therapy could be accessed only in a hospital setting.

Nurses from different case study sites also highlighted the need for formal psychological support. These nurses worked in teams where the burden of care for the family was likely to be high, for example in relation to palliative and continuing care:

> "So it's just kind of, you know, enabling a child with really complex health needs, I think, to be cared for by their family and what we would need to put in for that, and the support we would need to give the family, not just by doing the care, but I think also that psychological support to a family so that they have their care in the home."
>
> (Practitioner)

Another potentially valuable team member, identified by nurses, was the social worker. Social work support was regarded as particularly valuable in facilitating integrated working in complex care, particularly when trying to arrange care packages for families. One palliative care team reflected on the difficulties of attracting a social worker to the team and instead employed a band 2 family support worker. This worker was highly valued by the staff, providing support to families, in addition to having the skills to be a link for families from culturally diverse families.

5.4 Capacity issues specific to care close to home

Many of the problems described above perhaps raise generic issues, which all NHS staff would identify. However, there is something different about CCTH, especially its association with care *in* the home (see Chapter 4). Consequently, family dynamics, in addition to social and material circumstances, assume significance for the nurse when negotiating care. In a hospital setting it is, of course, important to support the family; but this assumes a different meaning when the nurse has direct, face-to-face contact with parents, in their own homes. Parents also play a key role in the child's healthcare, often taking on increased responsibility. Nurses needed to respond to this, in addition to meeting the clinical needs of the child.

Family support needs could be relatively uncomplicated and related to advice and education about monitoring the child's health. Alternatively, support needs could be more complex, particularly since community nursing in the home could be an isolating task for practitioners, who felt they sometimes lacked adequate support mechanisms. As we saw above, practitioners were aware of the psychosocial needs of families receiving CCTH, but felt they were sometimes unable to meet such needs.

The material circumstances in which care was provided were also important. This raised the obvious issue of appropriate housing. Other needs might also be observed when the child was cared for at home, such as the needs of their siblings. These accumulating needs associated with care in the home indicated the potential scope of the nursing role A senior nurse from site W remarked:

> "'… once they're in our care we take a holistic approach to their needs really."

However, as we have seen, nurses sometimes struggled to deliver these wider support needs.

Providing this sense of holistic care was seen to place extra demands on practitioners, when compared to providing care in the hospital and was explicitly linked to providing a *better* service. To this extent, the nature of CCTH could sometimes give rise to inflated expectations about care among nursing staff because the needs of families were directly visible to them. This, however, raised a now familiar theme and created a potential discrepancy between expectations and the actual experiences of care, which nurses had to negotiate. Capacity issues made it difficult to meet these holistic needs and this often created frustration for nurses. They were aware of what needed to be done, but struggled to secure resources that ensured it was done.

The circumstances in which care was provided were also implicated in the capacity to provide appropriate care. Nurses talked about negotiating difficult family and household circumstances that, as one manager noted, is not seen as so necessary during hospital care. Some nurses also perceived a lack of confidence in some parents when providing care. A GP supported this view and noted how this sometimes meant parents requested inappropriate referrals, especially to the nurse practitioner service. To this extent, parental confidence could directly influence their use of health resources, particularly in relation to the types of care they wished to access. Changing family structures might be particularly influential here. For example, a nurse in the CAU noted how not having family nearby meant parents did not have an immediate source of advice regarding their child's condition:

> "They go to the GP, they turn up, cos they haven't got their mum in [City] or their mum next door, or they haven't got a mum, they're a, you know, don't see their family or whatever, so, just to give them some reassurance."

The use of CCTH to increase parents' confidence, and its subsequent impact on demand in primary care and accident and emergency services, was seen as part of the role of CCTH.

Confidence could also influence how much of a role parents assumed in providing CCTH, which again affected the types of service parents felt appropriate to their situation. One senior nurse reflected on how 'confidence' had an important role to play on the referral process:

> "That's part of our referral criteria, is to talk to parents about ... not just the, the, that aspect, OK, we are going to go in and do the IVs, but how do you feel, actually, about each day checking their temperature, how generally are they, because they're having that done for them while they're an in-patient. You know, a doctor sees them at least once a day and check them over and ... for some parents, if they've had a very serious acute episode of illness, they may not quite be ready to step outside of that hospital environment. So part, that's part of our own ... our, our own referral, but we would go."

Teams were willing to train parents to perform certain nursing procedures, such as flushing lines or passing naso-gastric tubes (as was the case in site W). Material from the parents in this study however, suggested they did not always wish to take on this role (see Chapter 6). While this reluctance would probably not prevent the child receiving CCTH, it could create additional involvement for practitioners.

Nurses were also aware that CCTH might not always be acceptable to a family or not acceptable to all family members within a household. Negotiation was, therefore, sometimes necessary. For end of life care, practitioners specifically reflected on the difficulty of making early contact with a family, who might not want to think about their potential need for palliative care. Practitioners were equally aware that parents had views on who should be delivering CCTH. A nurse in the CAU described how some families preferred to see senior doctors immediately, rather than a nurse.

This material shows that teams face challenges to service provision relating to family and household circumstances, the confidence of families and the acceptability of the care to families. While household and family circumstances and lack of acceptability to families may pose a significant barrier to providing CCTH, they are all issues that can be addressed through sensitive practice. Parents can be trained to take on part of their child's care should they wish to, yet practitioners were uneasy about putting too much pressure on families. A balance had to be struck.

Earlier in this section, we mentioned practitioner concerns about the isolating experience of providing CCTH and a feeling of 'being more on your own', when compared to working in a hospital setting. Practitioners spoke of several psychological challenges they faced when working in the home. End of life care was seen as especially challenging and emotionally demanding, and made more difficult, when there was no *immediate* support from colleagues. Such problems were compounded when practitioners were aware that they could be doing much to help families, but felt prevented from doing so, because of a perceived lack of capacity (see above).

Other, more practical, difficulties when working in the community included the need for good supervision and clear support structures, in addition to sustainable lone working policies. Personal safety was a particular issue for the teams in sites W and Xa. Some staff doubled up for home visits, however for the community team (including the nurse practitioner service) in site Xa, this was not always possible due to cost.

5.5 Geography

Home visits can involve much travel time, either when there are large distances to cover or inner-city traffic to negotiate. Distance was a particular issue in large geographically dispersed settlements, such as rural communities or where the service remit was regional rather than local. Travelling long distances to give an injection was not usually seen as cost-effective and regional teams preferred to liaise with local CCN teams and train them to carry out such procedures. Time-intensive travel also affected how many patients a nurse could see in one day and this could be an

important consideration in discussion about extending the geographical remit of the service. Some teams split their caseload geographically, helping to cut down on travel time. However, this did not always work as well as it might; if all referrals came from one patch then one nurse could be overloaded.

5.6 Language and culture

Cultural and language barriers were cited as a problem when delivering CCTH. This was especially in the case study sites where there was greater ethnic diversity among the population (W and Y) but to a somewhat lesser extent in site X and much less in site Z. Language and communication barriers were commonly cited, and although interpreters were used by services, some reported problems with this. Long-standing problems, well covered in the literature[39], were evident, for example, the need for interpreters to have an understanding of health care issues, consistency among interpreters in how they interpreted, and less delay in accessing interpreters. Specific issues included interpreters lacking experience in and understanding of CCTH and that using an interpreting service did not give the same degree of continuity for the family as using a family support worker. Interpreters also had to be booked in advance, meaning that families who did not speak English as a first language might experience a delay in receiving the service. The CAU used a telephone interpreting service and this was felt to be helpful by some staff, but problematic by others. For example, one CAU staff member suggested a trained staff member who was aware of the issues and whose role it was to interpret would be more appropriate:

> "There's a role for somebody to act as an advocate for a family who might not understand the health system here ... to enable them to get the best access to the treatment they need."

Language barriers could affect the relationship with the family. One nurse from the SON-R team described how difficulties with language resulted in a child being cared for in hospital instead of at home:

> "They probably don't get the best outreach care just because it's so difficult for the outreach team to communicate with them in their home. So very often they'll just be advised to come back to the hospital, because we can at least get interpreters in and things like that more easily in the hospital setting than they can out in the community."

This led some staff to wonder if their services, despite their best efforts to accommodate language differences, were largely inaccessible to those who spoke languages other than English. This of course had implications for equity of provision.

Some teams, however, had attempted to overcome these problems. The palliative care team from site W used a family support worker successfully and in another team texting families about appointments and similar issues was reported to have worked well.

In addition to language barriers, staff highlighted cultural issues as a barrier to equitable care. Nurses regarded these issues as being more evident when caring for a child at home compared to in hospital. There was a genuine desire among nurses to understand different cultures, and this was felt to be important so that everyone received the same standard of service. Nonetheless, cultural issues might present a conflict between what services could offer and what was required by the family. One nurse described how the service tried to take into account gender preferences for nurses in some families by doubling up, but this is not always possible due to workload issues. Travelling families were highlighted as being a particularly hard to reach group, especially in providing long-term care. Some nurses noted how such families are often not registered with a GP. Strategies were put in place, however, to adapt and provide care, such as building relationships with traveller families.

5.7 Visibility and integration

Integration of the CCTH service with other services posed some challenges, particularly in relation to patient referrals, transition to adult services, general communication and joint working. PCT-based services had problems being 'visible' because of poor awareness and understanding of CCTH. More generally, visibility and understanding about the roles of the teams by other services and families appeared to generate referral problems. Services, for example, could get inappropriate referrals, when there was an incorrect assumption about what the team did. One nurse observed:

> "Sometimes it's things like, they ask if you'll just, the, the wound's healed but could we just go and check that the wound's all right ... and we wouldn't do anything, if, we wouldn't just go in to check if a wound's all right, because really the parents can do that."

Staff working for acute trusts did not report as many problems with poor understanding of their services; perhaps being provided by an acute hospital trust increased their visibility.

This lack of understanding about the role of community-based CCTH services had other consequences. Teams might face an increased workload due to inappropriate expectations, hostility from families who felt the service was not responding to their needs, or a lack of clarity about who was responsible for the care of the child in relation to joint packages for complex care. Conflicts over responsibilities were seen to affect families directly and it was suggested that having a social worker work alongside the complex care team, or a routine panel to aid decisions might help to resolve these issues. In site Y, such a panel was used to assess health and social care needs for joint packages of care and this was felt to offer an example of good practice. In another site, there were good relationships between the continuing care team and the local authority, which meant there was a good understanding of each other's respective responsibilities.

Transitions from children's to adults' services caused particular problems for joint working. The pathway appeared especially underdeveloped in some

areas, causing problems when transferring the child to adult care. A strategic development manager pointed out how the 'set up' for adult services was very different from that for children's provision and nurses noted how adult district nurses were not used to some clinical procedures, such as passing naso-gastric tubes, that were common in providing CCTH for children. Nurses were also aware that the level of care in adult provision was much less, when compared to that available in children's services.

Other general problems associated with working across service sectors included communication with other trusts; between different types of service support such as between a ward and an outreach team; and with social services. Further, overlapping with different services in care provision sometimes resulted in duplication of effort. There were also more immediate difficulties associated with being able to get hold of other staff, which could be time consuming and there were specific difficulties arising from working and communicating with primary care.

While integration and joint working were clearly problematic for some, in other instances there were reports of good working relationships. For example, while GP referrals were generally described as problematic, staff reported good working relationships with some. Other practitioners reported positive experiences of liaising with specialist nurses in the local hospital or within the same hospital. Such joint working between generic and specialist nurse teams helped address specific and complex problems as they arose. One manager of a generic team remarked that it was, "just too hard for us to be experts in all the areas." As seen above, other examples of good joint working concerned the joint assessment of need between health and social services, when organising joint packages of care. Another team reflected on how working closely with a CLIC (Cancer and Leukaemia in Children) social work team helped ensure families received the best package of care available. The SON-R team also worked in partnership with local CCN provision, helping to combat the cost issues associated with providing care for a family who needed outreach, but who lived some distance away:

> "But ... obviously driving out to [distant town] to give one injection is perhaps not always most cost effective. But, you know, so we do have ... not in all areas but certainly in some of the areas that we cover, we have local children's community nurses who can obviously administer chemo."

These examples demonstrate the positive outcomes of joint working. Many participants felt that such good joint working contributed to continuity of care, facilitated earlier discharge of children from hospital into a community nursing team, helped deal with the diversity of conditions, and ensured a holistic view of the child's needs.

5.8 Different organisational models

Our fieldwork sites used different organisational models, when delivering CCTH. Each had its positive and negative points. Both specialist nursing teams (sites Y and Xb) were hospital based and employed by acute trusts, as was the CAU in site Z. The CCN teams, on the other hand, were both run

by PCTs. Those services run by acute trusts argued that they were in a better position to provide care at the interface between home and hospital because they had a track record of working with acutely ill children and had close links with other teams in hospital. Participants made direct comparisons between the more generalist approach of community-provided services and their specialist expertise and experience. One of the benefits staff in site Z saw in the hospital-based CAU model was its dedicated children's focus, coupled with its easy access to specialist equipment and senior doctors:

> "The children are seen by a group who are all children's nurses and doctors. They've got a lot of experience in looking out for signs of more serious illness, which is very helpful. The equipment that we need to do tests is at hand and they've got better access to the senior doctors who are very close to the child assessment unit and often walking through."

Staff identified other advantages of providing community nursing via an acute trust. A manager in one site, for example, explained that many children using the hospital-based CCN team were already under hospital-based consultants, which improved continuity and coordination between home and hospital. In sites Xb and Z, being part of the acute provider trust was felt to improve communication and joint working between acute services and CCTH teams. By contrast, PCT-based CCNs in site W reported considerable difficulties coordinating with hospital services and said children were sometimes discharged early without support as a result. A senior manager in another acute trust explained that there was 'free flow' through the health system for families using the acute provided CCN and specialist nursing services. He contrasted this with what he had heard about places where CCTH services were not part of the acute trust:

> "It's almost like you get to the barrier between acute and the community and you have to, the, the family and, and the child pass through that. But, but somehow or another the rest of it doesn't, and they like come into a new world and then they go back out again and hit the barrier and they go out again."

This manager felt that the vertical integration of community services and the acute trust worked '*fantastically*'. CCNs had easy access to all the acute trust provided services and could set up and run care pathways to meet individual children's needs. Moreover, the doctors on the wards knew the CCNs, and he argued that knowing what they were capable of made doctors more likely to discharge children into their care. The lead CCN in this area similarly felt that their integration with the acute trust worked well, facilitating multi-disciplinary working as follows:

> "The child doesn't just come to see the paediatrician, they're also seeing the psychologist, the dietician, the physio, whoever else they need to and that's the model that we have always followed. So actually the child, and we can refer to all of those other professionals, we don't have to go, we don't have to ask a GP to refer for physio, we haven't had to have someone else referring

> to the Child Development Centre, we, we have a working relationship with everyone involved, and so we can directly refer to all of these other departments."

Here, however, the implication is that children will come *in* to the hospital to see the multi-disciplinary team. This begs a question about whether this really is multi-disciplinary CCTH, or whether there is a trade off between greater access to acute based specialists apparently afforded by this model of vertical integration, and the provision of care closer to or in the home, which is said to be the objective of the services in question. Some participants suggested that acute based services could be more '*inward thinking*' and '*medically driven*' than those run by community providers. For example, a participant from a community provider compared an acute provided and PCT provided service and said of the latter:

> "I think they're much more community focused. So they focus much more on the home, providing that in, in the, in the home, and .. their communication [with families] is really ... I think, excellent …"

Moreover, CCTH staff from site Y did not necessarily feel that being part of the acute trust improved their links with other hospital services:

> Nurse: I think communication's usually a big difficulty. You tend to find communication's like a bit of a one way street and that can be quite difficult and quite frustrating.
>
> Q: Is this with other services rather than …?
>
> Nurse: Other services, yeah. But certainly, well in-house really as well, not so much within our team, but sort of communication between the ward and, and us and out-patients and us could sometimes be, not as good as it could be, and I think it's something we all strive to be a lot better at (laughs) and to improve.

While acute based staff talked at length about their links with other *acute health* services, much less was said about communication with professionals from the wider service system. In Xb, a manager said that the CCTH teams had good working relationships with education, social services and the voluntary sector, but also said that when CAMHS were contracted out to a different provider it became more difficult to liaise with them, implying that services beyond the boundaries of the acute trust were harder to reach. In site Z, one interviewee commented that communication with other agencies was good, but another complained that just finding out who a child's health visitor was could be a 'lengthy process'. In site Y, it was noted that working relationships with other agencies had deteriorated since the introduction of competition rules (see Chapter 4).

Staff from PCT-provided services, on the other hand, had a lot more to say about their experiences of liaising with different agencies. CCNs in site W told us much about the problems they faced trying to work with a range of different providers, including social care, other community health services, and the acute hospitals trust. In site Xa, the experience appeared to be

more positive, with staff reporting strong links with the LA through various routes, including the Children's Disabilities Team and a multi-agency Early Support Team. Protocols were also in place for the fast track referral of children under the NP service to the paediatric assessment unit, and similarly this unit referred into the NP service.

One barrier to inward referral for community provided CCTH services was the perceived risk entailed in not referring acutely ill children directly to hospital and the care of a consultant. As a commissioner explained about the NP service in Xa:

> "One of the main issues that we had when we tried to set up the service in the [Town] end of the county was that GPs didn't want to use it because it's very safe for them if they ring up a consultant and say, will you have a look at this child I'm not sure about .. and I think that GPs are perhaps lacking some skills around, or sort of in themselves lacking the skills around managing paediatric cases where the risk can be that little bit higher with children going downhill a lot quicker and doing unpredictable things."

This was not solely about a lack of confidence in the skills of the nurse practitioners, but also about who was accountable for the ill child and what would happen if something went wrong. The team felt that they had partially overcome such concerns through the agreement of protocols and fast track referral to the acute paediatric team, and by building up a reputation for providing high quality care. Nevertheless, gaining the trust of GPs was a slow process and a number of practices still did not refer.

The NP model was unique in our study in its aim of preventing the admission of acutely ill children *before* they reached hospital. It therefore functioned directly to replace care previously provided by hospitals and, since it was provided by the PCT, it operated in direct competition to the acute trust. If we refer back to the centrality of the 'invest to save' argument in the commissioning of CCTH services, the idea that CCTH services will *replace* some services previously provided by acute trusts makes sense. However, if CCTH services are to be provided by community organisations separate from acute trusts this introduces financial disincentives to joint working and the potential for rivalry between providers. The alternative, however, of acute trusts providing CCTH services in addition to their in- and out-patient services is no less subject to financial disincentive, since reducing admissions under the current system would reduce a trust's income. Staff members from acute trusts, however, told us that in practice such disincentives did not influence their behaviour, as their primary focus was providing care in the most appropriate settings for the child:

> "We wouldn't describe ourselves as a hospital. We, we have a hospital but that's only part of what, what we do and who we are. We would provide ourselves, we would describe ourselves as a children's healthcare provider in whatever, in whatever setting that child needs that care."

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5.9 Conclusions

This chapter has concentrated on service delivery and organisational issues that could enhance or impede delivery of CCTH.

Capacity and skill mix issues could compromise the type, extent and quality of care offered. The specific difficulties of offering social and psychological support were common themes, particularly since nurses were aware of how they could become secondary to meeting clinical needs, especially when there were capacity issues. Staff were aware of how they were often providing a reactive service rather than a proactive one. It could be difficult to provide holistic care and this caused particular frustrations for some practitioners, who were aware both of what they 'should' be providing and of the problems they faced in trying to deliver what they regarded as appropriate care. Capacity issues could also affect equity, when problems were apparently more difficult to overcome in more deprived areas. Capacity also fundamentally affected the amount of CCTH it was possible to provide. Out-of-hours working offered a specific example of the dilemmas faced by practitioners in delivering CCTH. Recruitment and retention problems, alongside a lack of training opportunities, further limited the opportunity to develop CCTH services.

Practitioners were also aware of the particular issues raised by providing care in a child's home, compared to providing it in hospitals. More immediate contact with the family could raise issues that were sometimes invisible in hospital care. Negotiation and diplomacy were needed, and improving parental confidence was seen as especially important in delivering successful CCTH, although this did not mean practitioners expected parents to perform complex nursing tasks. Practitioners felt increasing parental confidence also helped in managing expectations.

Working across and within service boundaries was challenging, particularly when other health and social care agencies, and particularly primary care, struggled to understand the role of CCTH. Practitioners were also aware of how much they could benefit from working alongside play therapists, psychologists and social workers. While this was rarely achieved in practice examples of good practice did exist, suggesting problems can be overcome.

Different organisational forms were evident in our case study areas. Practitioners working in acute trusts felt they were in a better position to provide care at the interface between home and hospital than those working in community settings, mainly because they believed they had better access to specialist advice and support. On the other hand, those working more in community settings, suggested that those working from acute settings were less likely to see the wider circumstances in which the child lived.

Issues about commissioning and competition that have the potential to slow the development of CCTH services were raised during our fieldwork. These seemed particularly evident in relation to community-based services that strove to prevent acute admission to hospital.

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6 Parents' experiences of care close to home

This chapter explores the experiences of parents in our case study sites, examining their views about both hospital care and CCTH for their children. It provides context for some of the organisational issues raised in Chapters 5 and 6 and, as becomes clear, parents' experiences embody some of the struggles outlined in practitioners' and commissioners' accounts. The interviews with parents were striking for their consistency in reported experiences and perspective, regardless of the model of CCTH their child used. As a result, the analysis presented here is less complex than that in Chapters 4 and 5.

We begin by exploring parents' experience of hospital care, which we use as a point of comparison for their experience of CCTH. We then move on to explore the psychosocial impact of CCTH and end by exploring parents' views on how current provision might be improved.

6.1 Parents' experience of hospital care

Parents' accounts of hospital care for their children mainly focused on the practicalities of getting to hospital, the environment in which care was provided, and the impact of hospital-based care on the family.

For many, getting to hospital involved long periods of travelling or multiple journeys. Parents commented on the difficulties of travelling such distances with a sick child or if the parent was unable to drive. Once at the hospital, parking could be difficult, adding to their stress, and more generally expenses accumulated for travel, parking, petrol and food.

Parents' largely related negative experiences of being in hospital with their child, particularly since they were often there for long periods. However, a few parents did mention examples of good practice, particularly valuing the use of 'private' rooms. Some parents who used specialist care also described how there were other parents on in-patient wards, with whom they could talk and share advice. This indicates that the presence of parents on specialist wards creates a social resource that may be valuable. These positive experiences, however, proved the exception rather than the rule. Parents described long periods of waiting, while some expressed specific concerns about exposing children to infection. Where children were admitted over night, usually at least one parent chose to stay with them, but facilities for this were generally poor. Often, there was nowhere to cook or heat up food, and inadequate sleeping arrangements meant sleeping in chairs or on their child's bed. When beds *were* provided, this was usually for one parent only, which meant families being split.

Most parents felt their children had similarly negative experiences, although a few did report positive ward environments or that their child was unaffected by hospital. One parent, for example, described how their child

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was able to access play therapy when in hospital, a service that otherwise would be unavailable. Generally, however, parents reported that their children disliked hospital, with several parents describing in-patient stays as 'horrible'. For some, the environment was physically uncomfortable, while others described how their children became 'fed up'. Some reflected on how time spent in hospital was stressful for their child, with one parent, for example, reporting how she would see a change in her child's personality, when in the hospital environment.

Parents were equally aware of how being in hospital affected the child and the family more broadly. For some children, hospital visits meant missing school. In other cases, the need to visit hospital could disrupt the routines of siblings, as well as the amount of time parents could spend with them. Parents' employment could be disrupted, with many having to use annual or unpaid leave when their child had to attend or be admitted to hospital.

6.2 The advantages of care close to home

Hospital care, therefore, could create difficulties for families of ill children. This explains why all parents who had experienced[i] it preferred care closer to, or in, the home. They did recognise that CCTH might not always be possible and there were instances where parents felt their child would be more appropriately cared for in what they regarded as the 'safer' hospital environment. This was seen as especially relevant in the early stages of treatment or when children were particularly poorly. When parents were initially coming to terms with their child's illness or it had not yet stabilised, they did, as one mother said, feel '*more secure'* in hospital. When the child began to recover, however, parents felt support in the home should always be offered:

> "Like there was times when she was feeling really ill and she'd say 'I want to go to hospital' 'cos she felt safe and everything was there and, and I was there and that was it, it was, she was good. So it wasn't all bad going in, but the, definitely, when, when you're over the worst and you're just dealing, cos it's two, two, two and a half years of treatment and it's a, it's a long haul and it's a pain in the arse having to be away from home. So sort of once you've sort of come to terms with it and you're dealing with it and you've had the worst of the treatment then just the maintenance of it is, to, to do as much as possible as local as possible or at home is, I think makes a big difference."

There was thus a strong consensus that any care that *could* be provided in the home, *should* be. This is not to say, parents did not experience problems, but generally CCTH was looked on favourably, particularly when compared to hospital care. The most strongly stated benefit of receiving CCTH – irrespective of the model of care - was the convenience it afforded. From a parents' point of view, when a child required healthcare on a regular basis over a period of months or years, the difference between receiving

[i] All parents but one in the sample received care closer to home – see Chapter 2.

care in the home compared to the challenges of travelling to hospital several times a week was considerable. Families receiving CCTH could stay together and get on with their daily lives. As one parent explained:

> "[when you're with a child in hospital] you're not available to take your [other] daughter to swimming lessons or whatever, to, to be out of the sort of loop doing that. So even, you know, just, just a blood test, the fact that they come here and do it and then you can get on and do, cook the tea even or just get on with your life, it, it's, it's such a small thing but it makes ... a massive difference."

Parents and children might wait hours in hospital to have minor procedures carried out, whereas these often took only a matter of minutes in the home. Nurses sometimes stayed longer, to chat to parents or to spend time with children, and parents valued this, particularly since they felt they did not receive such support when in hospital. Where CCTH prevented or shortened in-patient care, parents valued being in a familiar environment:

> "At least if you're at home it's a bit more normal, you can get on with things."

They felt their child preferred this too. At home, children had their own things around them and could see more of their friends and siblings. They were also more likely to be able to attend school, and the flexibility of the CCTH services facilitated this. (As we saw in chapter 5, however, there was some difficulty accommodating after school visits as this was a time of peak demand.) Services also appeared flexible in relation to the timing of parents' other activities, accommodating their employment and other commitments, and in some cases visiting schools or babysitters' houses to enable parents to go to work.

A few parents did say that it was a little '*weird*' at first, having someone come into the house, or that they were '*embarrassed with the mess'*, but this soon wore off. Parents frequently mentioned examples of good practice. One mother explained that, when her child first got an infection, the nurse practitioner telephoned every three hours and visited twice a day, easing off the contact as the child recovered but not withdrawing until she was fully better. This was over a two-week period, which was considerably longer than the official five-day limit on contact specified in the service protocol. When asked if anything could have been done to improve this service, the mother replied:

> "Not really, it was fantastic, or I found it fantastic. The, the nurses were friendly, they was there, they was like, when you needed them, answered any questions, like looked at anything that I wasn't sure of, helped me like give her medicine, showed me how the easiest way to give her medicine was. It was fantastic."

Being able to ring CCTH services for advice and support was viewed favourably, especially if nurses were flexible enough to be able to follow this up with a home visit. Parents particularly valued evening and weekend

support, when available. The NP service in site Xa operated seven days a week and in site W a reduced team was available at weekends to respond to emergencies. In these sites, the ability of services to respond immediately to calls for support was highly valued, particularly where this was outside office hours:

> "I was really concerned and I phoned at, well you have a dedicated number for the [nurse practitioner] and I phoned and she answered the phone at ten o'clock at night and was willing to come up at, at that time of night."

This experience contrasted with that of parents in site Xb, where the CCTH service made only pre-scheduled visits and operated only in office hours. Parents could ring the ward if they had a concern, but to be assessed the child had to be taken into hospital and some parents would have appreciated a more responsive home service:

> "It'd be good if you could phone and them send someone out rather than you going up there."

There was also a desire for scheduled interventions to be provided at home over the weekends. For example, parents had to take children into hospital for chemotherapy at weekends, when on weekdays the same treatment was administered by a nurse in the home. They found this frustrating, particularly since they valued weekends, for spending time with the family. In instances where parents were trained to provide care themselves, this could help protect families' weekends:

> "At weekends obviously when, you know, I want to sort of spend time with my boys and I'd rather spend it doing something more enjoyable than, you know, driving an hour and a half in the car (laughter) and, you know, for what amounts to a five minute, five minute treatment. I mean I didn't really mind particularly because I thought well, you know, it's part of his treatment and it needs to be done, but it was certainly more convenient once I was trained up and I could just quickly get it done myself."

However, parents were aware that considerable responsibility came with administering treatments and were equally aware of how important the support of services was to them.

Most parents got on well with the CCTH staff and said that their children did too (both those receiving care and their siblings). In most cases, the same nurse or group of nurses had cared for children over a prolonged period. This meant nurses came to know individual children and families well, which was reassuring for parents. When one parent was asked if there was anything particularly good about the SON-L service, she responded:

> "I think the, the continuity, the fact that it's the same nurses …I suppose all children are different and [daughter's] got her own way of doing things and dealing with things and, and we don't need to explain anything."

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The nurses' knowledge of individual circumstances also gave them credibility when advocating on families' behalf. CCTH nurses – irrespective of locality – assumed some degree of responsibility for coordinating care: acting as a first port of call, dealing with issues themselves, or linking parents with other agencies. Nurses went into schools to inform staff, as well as pupils and parents, about children's needs. Most also picked up and dropped off samples for parents, chased up test results and fed them back. In some cases, this support extended beyond clinical care, with nurses helping parents to fill out forms, understand official letters and resolve problems with other agencies. One parent said (through an interpreter):

> "Because I can't speak English, and last time my bathroom was, something wrong with my bathrooms, and the nurse help me to ring the Housing."

As we saw in Chapter 5, nurses themselves valued such holistic care, but felt it was becoming increasingly difficult to deliver because of capacity issues. This could create future tension in the development of CCTH, particularly since such support was rarely available in hospital settings. We discuss this further below.

In sites Xa and Xb, parents appreciated the close links nurses had with hospital teams. These served to reassure parents that should their child's health deteriorate, they had easy access to the clinical expertise of hospital doctors. It also put parents and children at ease to see the same faces in hospital clinics and at home, or to be visited by the community nurses during an episode of in-patient care. However, it was noted that this continuity could be lost if children were sent to tertiary hospitals for in-patient care when their CCTH service was based around or provided by the district general hospital.

That parents in *both* these areas reported good continuity between home and hospital services was interesting. In Xb, staff had highlighted the CCTH service's integration with the acute trust as a particular benefit of their service model over community provided models. In Xa, however, the provider arm of the PCT delivered the service, yet parents still reported good continuity between home and hospital services.

Generally, parents were extremely satisfied with the CCTH services they received, however a few did recount less positive experiences. In one area, the parent of a child who had regular seizures, and a number of other problems, was advised to use CCTH services as her first port of call, rather than taking her child to hospital. The mother said she would have been happy with this arrangement had she had direct access to the CCTH service. However, referral was dependent on a GP decision and sometimes her GP would opt not to refer the child, resulting in the family being 'left with her at home, poorly and not sure what's going to happen with her.' The mother had medication for the child's seizures, but was not sure how to use it and reported receiving no training:

> "I mean they've said to me there's instructions, but obviously I need to, I need to be sure as well that I'm, I'm giving her it at the

right time and in the right amount and things, 'cos you have to mix it all up."

This mother did feel that it was better for children to be cared for at home, but stressed that there must to be adequate support available for parents to facilitate this. She gave another example of her child being discharged from hospital under the care of the CCNs, which was 'great', but said there had also been times when she had been 'rushed' out without the support of the CCNs and advised to come back to the ward if her child deteriorated, which she felt was insufficient:

"Obviously I don't want her to spend, her to stay a long time in hospital, it's better for her to be at home. [But] she needs to have the care at home and people to keep an eye on her."

Most parents emphasised that if they were caring for children outside of hospital they needed appropriate support. This meant adequate training, as well as accessible telephone and/or face-to-face advice. In some ways, this is a reflection of the social and psychological impact of caring for a child with a long-term or complex condition experienced by parents, which we turn to in the next section.

6.3 The psychosocial impact of care close to home

When reflecting on CCTH, parents often talked about the relationships they developed with staff, the confidence they had in the service, the type and level of support they received, their sense of responsibility and their feelings of competence when managing their child's healthcare. All these had implications for parents' psychosocial wellbeing.

Parents perceived the relationships they developed with staff as an important and integral aspect of the child's care. Relationships were often - although not always - described positively and were clearly valued. In these instances, there appeared to be three types of relationships between parents and practitioners: therapeutic, social and advocacy-related. Some parents for example, mentioned how talking to community nurses, feeling supported emotionally, discussing concerns, and being reassured and understood were important; all appeared to serve a therapeutic function. Parents also valued more social aspects of their relationships with nurses, and to this extent CCTH staff could be seen as an important social resource, helping parents in their role. The nurse was often referred to by parents as a friend, or as part of the family. One mother said:

"She was just like my best friend, you know, she was fantastic, and she still keeps in contact now. So we, we've built up a really good friendship."

Parents were also aware of how community-based nurses advocated on their behalf and described how they provided additional support, such as arranging equipment, getting appropriate transport, addressing housing issues, liaising with other staff on the parents' behalf, getting additional funding and helping with financial issues.

These relationships demonstrated not only the multi-facetted needs of families but also the extended role the CCTH nurse can play. In the relatively few instances where parents described less positive relationships, this seemed to be about a lack of social and psychological support. Relationships may also have been influenced by whether parents had confidence in the staff's expertise and competence: the few who lacked confidence in the service described less positive relationships with nursing staff. The relationships parents had with staff and their sense of being supported emotionally and socially were, therefore, closely linked. Practitioners, however, felt such broader, holistic care was constantly under threat due to capacity issues and unsupportive commissioners (see chapter 4). This, again, might create potential tensions in the development of CCTH; the more clinically focused such care becomes, the less valuable it could be for parents.

Not all parents in our study, however, felt that they were supported adequately via CCTH services, and some noted the need for additional support (see below).

While many parents in our study had not assumed clinical or nursing responsibilities, a small proportion had. There were mixed views among parents about the level of responsibility they were willing to take on, with some not keen on an increased role, and some feeling they would like to do more. For the latter, this might have been about taking on more care to avoid hospital visits. One parent explained:

> "If there was a way that we could do more at home, even like you [other parent] say with the temperatures, checking through the night and stuff like that, then we'd be happy to take on that responsibility."

On the other hand, two mothers reported they did not want to be trained to take on clinical roles. One justified this by pointing out she is not a nurse, while the other felt uncomfortable about administering a process that caused her child distress.

Those parents who had assumed clinical responsibilities for their child's care expressed different views about the support they received. One mother felt highly supported by community nurses:

> "I never felt under any pressure whatsoever to ... to go for this sort of training ... and I was never once made sort of to feel as if, you know, if I decided ooh no, you know, I'm not happy with that ... that they would sort of think oh God, you know, it means we're gonna have to keep trailing out to [town] every day or whatever. I mean it just, they, you know, they were great in that respect they really were. They instilled some confidence into me."

Another family described how they were initially 'daunted' at having to administer gastronomy feeds at home. The support received from the CCTH service helped overcome their difficulties. By contrast, two parents of children diagnosed with cancer felt they had assumed considerable responsibility for administering a complex regimen of medicines to their

child at home, including oral chemotherapy. These parents valued the input from the CCTH services, although one would have appreciated additional support, which she felt might "make you feel a bit more secure in what you're doing". She went on to describe using a mental coping strategy:

> "… when you're giving something every day, you know, it's like you have to mentally, 'I did give it to him today, didn't I? I did', and so we feel that is quite a lot of responsibility."

Nevertheless, both these parents valued being able to give treatment at home, rather than having to go in to hospital. This was despite the difficulties they experienced and suggests that parents are carefully balancing their options. Administering complex treatments in the home might not be ideal, but it is preferable to the alternative of hospital care. This is the context in which parents exercise choice.

CCTH can play an important role in building parents' confidence when managing their child's illness, irrespective of whether clinical tasks are involved. Many parents, for example, received considerable reassurance from the nurse practitioner service and appreciated the availability of a telephone support line, as this mother noted: "They're just always there on the end of a phone." Positive relationships which improved parental skills and confidence could also lead to a more appropriate use of services, particularly from the viewpoint of practitioners. As we saw in chapter 5, some practitioners felt some parents overly depended on health services because they did not have the confidence to manage their child's illness. Parents confirmed that talking to a nurse practitioner often meant they no longer felt the need to contact their GP or take their child to hospital.

6.4 What do parents do when CCTH is not available?

None of the services in our case study provided 24 hours 'hands-on' coverage, although the nurse practitioner service offered a 24-hour telephone line for children active on the caseload. Parents described difficulties when need arose outside operational hours, when they would use out-of-hours primary care services, access Accident and Emergency care or, for those with open access, take them directly to an in-patient ward. This last group could also ring the ward if they were concerned, but the success of this and other forms of telephone support was dependent on how well a nurse or doctor could assess the child's symptoms over the telephone. Therefore, hospital admission might not always be avoided.

If parents did not have open access, their use of hospital outside CCTH service hours tended to be of two sorts. First, they used hospitals for technical and unplanned needs (for example, re-passing a naso-gastric tube that had come out). Secondly, they used hospitals for technical and planned needs where there was no formal provision (for example, administering chemotherapy intravenously at the weekend, when CCTH services were not operational). Both types of use pose questions about cost-effectiveness of acute hospital care, whether for relatively quick procedures requiring a small amount of nursing input or for planned procedures delivered safely and effectively at home during the week, but not at weekends.

6.5 Improving service support

Parents were asked whether there was anything that could be done to improve current support. Most of their responses focused on the range and coverage of provision. Parents living in sites Y, W and Xb explicitly commented on the need to increase the range of procedures on offer outside of hospital. They would prefer more to be done at home. A father in site W, for example, said the nurses came out to flush his daughter's line, but if she had any other problems he would have to take her to hospital, which was time consuming and less convenient. Some parents using the SON services also said they would like more chemotherapy at home, with nurses available to provide regular, accessible support. A father explained:

> "In an ideal world, [son]'d stay at home and a nurse would come out every day and hook him up for his chemotherapy and there'd be a nurse for us to ring if, in emergencies, for 'em to come and in [son], if that could have, you know if that scenario could have taken place [son] would have been a lot happier and I'm sure most other kids would be."

In Xb, parents felt that the time their children spent as in-patients when they had an infection should be reduced. They expressed particular frustration about the seemingly arbitrary timings of these stays: for example, the minimum stay when children had a temperature was 48 hours, but the 'clock was not started' until a doctor saw the child, which in turn depended on the timings of ward rounds. Parents also wondered why their child had to stay in hospital when receiving antibiotics, but were in other ways quite well. As one mother complained:

> "But I don't understand why we can't take her in and them do the cultures [and then let us] bring her home and give us the antibiotics to give her, I don't understand."

Staff from this site said they did not provide daily antibiotics routinely in the home because they did not have enough capacity. By contrast, another area, did administer IV antibiotics routinely in the home.

In sites, W, Xb and Y parents felt the hours of CCTH should be extended to cover weekends. As we have seen, several parents expressed frustration that they had to take their children into hospital at weekends for procedures that on weekdays were delivered at home. Parents in these sites also wanted the service to be extended to include night and emergency cover, as getting children to hospital at night often meant disrupting the whole family.

Parents living in sites Xa, Y and Z specifically wanted to see an increase in the size of CCTH teams. Parents recognised that nurses' time was limited, which in turn limited what they could deliver. A mother explained:

> Mother: It's a good service, I just wish like maybe they have like more people, you know, I don't know whether they will be able to come with it more staff so that they will be able to sort of like offer these visits a lot more…

Interviewer: More often?

Mother: To other people more often. Because I think [there] probably is just about four, four practitioner nurses cover [area].

Those living in Y, Xa and Xb also expressed a particular desire for the service to increase the level of psychosocial support on offer. This seemed particularly important for parents of children with long-term or life-threatening conditions; this may not be surprising given the value parents ascribed to such support. One couple, for example, suggested that their own needs might have been overlooked because of the limited amount of time available to the nurses:

Father: Like you're sitting down here now saying, you know, interviewing us whereas somebody could have perhaps sat down and said well, you know, what, what are your needs, what are your requirements.

Mother: Mm, mm. It would have been nice, wouldn't it?

Father: You know, and perhaps you could have expressed what you felt and whereas we're so busy caring for, for [child] that, you know, our needs perhaps didn't come into it too much, did they?

Another parent felt that a support group for parents would be useful, explaining that she would find it helpful to meet other parents in a similar position. This reflects earlier comments from parents who valued speaking to other parents at the in-patient ward. When parents received care at home, they no longer had access to this informal source of support from those with whom they shared a common experience. This further underlines the need to integrate psychosocial support into CCTH.

Parents living in Xa wanted to see the service offered to more people, in addition to allowing self-referrals for known families. As we have seen, the nurse practitioner service in site Xa was highly valued by parents, but many felt it would be improved if known families could re-enter the service without needing a fresh referral:

"It would be nice if there was someone like that that you didn't have to wait to see the doctor, you know, if you'd got something that was similar again, if they could hold your case notes and, you know, maybe that was a step before you got to the doctor even**."**

There was also consensus amongst users of this service that more people should be told about the service and be offered access to it:

"I think it should be a bit more like, not many people know about the service … I know like some of my friends have had their babies quite ill and they've never, like their GP has never referred them, I don't think all GPs do it. They're not, they're quite reluctant to do it."

6.6 Conclusions

Parents' experience of hospital care meant CCTH was an attractive option for them. They did recognise that there were instances where hospital was a more appropriate environment for the care of their child, but there was a strong consensus that any care that *could* be provided in the home should be.

Parents generally built up good relationships with nurses who visited the home and valued the support they received above and beyond clinical care. Parents especially appreciated the emotional and social support offered by nurses, in addition to their role in advocating for them. To this extent, CCTH did seem to offer some degree of holistic care, although as we have seen practitioners felt such care was constantly under threat due to a lack of resources and unsupportive commissioners. The balance between clinical input and psychosocial care, as we saw in earlier chapters, may thus pose challenges for the development of CCTH.

Despite some staff emphasizing the benefits for continuity of acute trusts providing CCTH, we found no evidence from the parents' material to suggest that their experience of continuity between home and hospital care was impaired by PCT provision. This is in contrast to what managers and practitioners said in chapter 5.

Parents varied in their views about how much clinical responsibility they were prepared to take on. Some were happy to assume greater responsibilities, especially if it meant keeping their child out of hospital, while others did not wish to become 'a nurse' or expressed discomfort administering a procedure that caused their child distress. Balancing the need to keep their child out of hospital, with the need to take on considerable responsibilities, did create tensions for parents. Despite the difficulties experienced by some parents, however, in administering complex clinical procedures in the home, they felt it was preferable to the alternative of hospital care. Parents thus exercised choice in this context.

When CCTH was not available, such as at weekends or outside office hours, parents largely relied on hospital care rather than primary care, although they expressed frustration at this, particularly when they were aware of how easily such procedures could be carried out in the home. This is why parents wanted to see the range and scope of service support improved, specifically wanting services to offer more procedures in the home, extended periods when cover was available, more social and psychological support, and greater opportunities for self-referral.

7 Health economics of care closer to home

This section of the report investigates the costs of services for children closer to home. It analyses data from the national survey in respect of resource utilisation and caseload, provides some comparative analysis of

data from hospital episode statistics, and demonstrates the implications of options using simple economic modelling. Tables supporting the information presented in this section are shown in appendix 15.[j] Most of the analysis presented here concentrates on services in clusters 1 (predominantly specialist or condition-specific services) and 3 (predominantly generic CCTH or continuing care services) (see chapter 3) as the predominant models of CCTH provided in England.

7.1 Analysis of survey data

This section of the report discusses the survey findings in respect of resources used, examining caseload, staffing levels and budgets.

7.1.1 Caseload and staffing

Respondents were asked to indicate the annual expected caseload for their service, a question to which 66 percent responded. Of these, 73.4 percent reported having a caseload of under 300. Using the service clusters developed for analysis of the survey (see chapter 3), 80.9 percent of services in cluster 1 reported caseloads under 300 compared to only 65.8 percent of those in cluster 2. Two teams in cluster 3 reported that they had annual caseloads of over 10,000 but were working in acute assessment units. The mean caseload across all services was 627.2, with a mean for cluster 1 of 400.7, compared to 834.2 for teams in cluster 3. Table 35 in appendix 15 provides the detail.

Examining the total number of staff (WTE) by the cluster types shows that, on average, the teams in cluster 1 had fewer staff, with an average of 2.9 WTE compared to the cluster 3 teams with 8.8 WTE, almost a three-fold difference. Almost two-thirds (64.3 percent) of the cluster 1 teams reported having fewer than 3 WTE staff, whilst 28.1 percent of the cluster 3 teams reported having between ten and 50 WTE staff. Table 36 in appendix 15 provides the detail.

One hundred and ninety three respondents (62 percent of the total) gave information about both caseload and staffing, enabling us to calculate staff to caseload ratio. The ratio of staff (WTE) to children overall was one WTE to 201.3 children. The cluster 3 teams had an average ratio one WTE to 108.4. However, since a small number of teams had very large caseloads (see above), it is more appropriate to use the median to calculate the ratio of staff to caseload. For all teams this was one WTE to 46.5. The ratio for cluster 3 teams using this approach was one WTE to 82.0 and for cluster 1 teams one WTE to 30.1. These figures, however, are only indicators, as some hospital-based teams did not report medical staff on their teams, because they were staffed in rotation. By contrast, other teams did include

[j] Graphs displaying the findings are given in this section. However, it should be noted that means shown are calculated over all replies, where a valid figure was available for both the variables used in the graph, therefore these means may be different to those reported throughout the costing findings.

medical staff in their complement. Table 37 in appendix 15 provides the detail.

7.1.2 Analysis of costs and budgets

Teams were asked to provide information about the annual budget for their team (if separate from budgets from other services). We received usable data about budgets size from only 96 respondents (31 percent of the total).

As shown in Table 38 in appendix 15, overall 73.9 percent of all the reported budgets were between £100,001 and £1,000,000. Of the cluster 1 teams who provided information, 89.5 percent had budgets of under £200,000, compared to the teams in clusters 2 and 3 who had larger budgets. Across all teams, the mean budget was £462,156, before any outliers or exclusions were made. However, because nine (13.8 percent of the usable returns) of the cluster 3 teams reported having budgets over £1,000,000, this skews the overall mean. If teams with a total budget of over £1 million pounds are excluded, the recalculated mean budget is £322,965. The effect of excluding the outliers from the analysis can be seen in Table 39 in appendix 15.

The 'cost per case' was calculated using the total budget and the total caseload size (Table 41). This could be calculated only where a valid response was received for both questions. We were thus able to calculate 'cost per case' for only 67 respondents (21 percent of the whole sample, and 69.8 percent of those who provided budget information). Very large standard deviations for mean values suggest that the median is a more appropriate indicator of central distribution. The lowest median 'cost per case' was for cluster 1 (£747.65, range 42208.40), followed by cluster 2 (£794.48, range 6175.51) and then cluster 3 (£1970.30, range 95732.96). We saw in chapter 3 that cluster 3 teams were providing a wider range of technological care, to children with more complex conditions. It is likely, therefore, that the higher 'cost per case' reflects both more complex caseloads and the delivery of more 'hands on' care. By contrast, cluster 1 teams tended to provide less 'hands on' care and more advice, support and training. It is also possible that cluster 1 teams see children less frequently.

If respondents had indicated that their service had a separate budget, the questionnaire asked how much of that budget was for staffing. Eighty-four respondents, (27 percent of all respondents and 87.5 percent of those who provided budget information) responded. Just over half of the respondents (54 percent) regardless of the cluster type reported the staff budget as being less than 20 percent of the total budget; 70 percent of cluster 2, 78 percent of cluster 1, but only 53 percent of cluster 3 reported that the staff budget was less than 20 percent. It is important to note that 70 percent of respondents that were able to report both sorts of information were from cluster 3.

7.1.3 Combining findings

Using the survey data, where a valid response was reported for both the variables required, analysis was undertaken to examine relationships

around pairs of variables. We examined the relationship between the total staff wte and total budget, the size of the caseloads and the total budgets and the size of the caselaod and the cost per case. This analysis was carried out using the existing defined clusters. Outliers for costs and caseload sizes were omitted from this analysis using a cut-off point of standardised scores in excess of 3.29 (see chapter 3). Table 40 in the appendices details these calculations. New means and standard deviations were calculated on the new data set. The results are presented graphically in figures 6, 7 and 8.

Figure 6 shows the total staff number by total budget by cluster. Most teams are in the bottom left quadrant, i.e. with a budget of lower than £300,000 and fewer than 9.85 WTE. Staff WTE in Cluster 1 is entirely to the left of the mean, whereas Cluster 3 has a wider spread for staff WTE and budgets. Of the valid 89 cases, 58 are below the mean of 9.85 WTE staff time with 49 of these having below average total budgets. The sites that appear to have above average staff numbers and budgets are from cluster 3.

Figure 7 shows caseload by budget, and again there is a preponderance of teams in the bottom left quadrant, but with a wide spread (also note that there are fewer respondents). For the 68 who gave a valid response to both variables, 51 have a lower than average caseload size and 33 of these also have below average budgets.

Figure 8 shows the relationship between size of caseload and cost per case, with data for 68 teams (16 percent of total respondents, 53 percent of those who provided budget data). Fifty–three of the sites had below average cost per case and 36 of these also had below average caseloads. The graph therefore shows that the majority of teams are in the bottom left and top left quadrants with very few having high cost per case and case load.

Figure 6. Total staff numbers by total budget by cluster

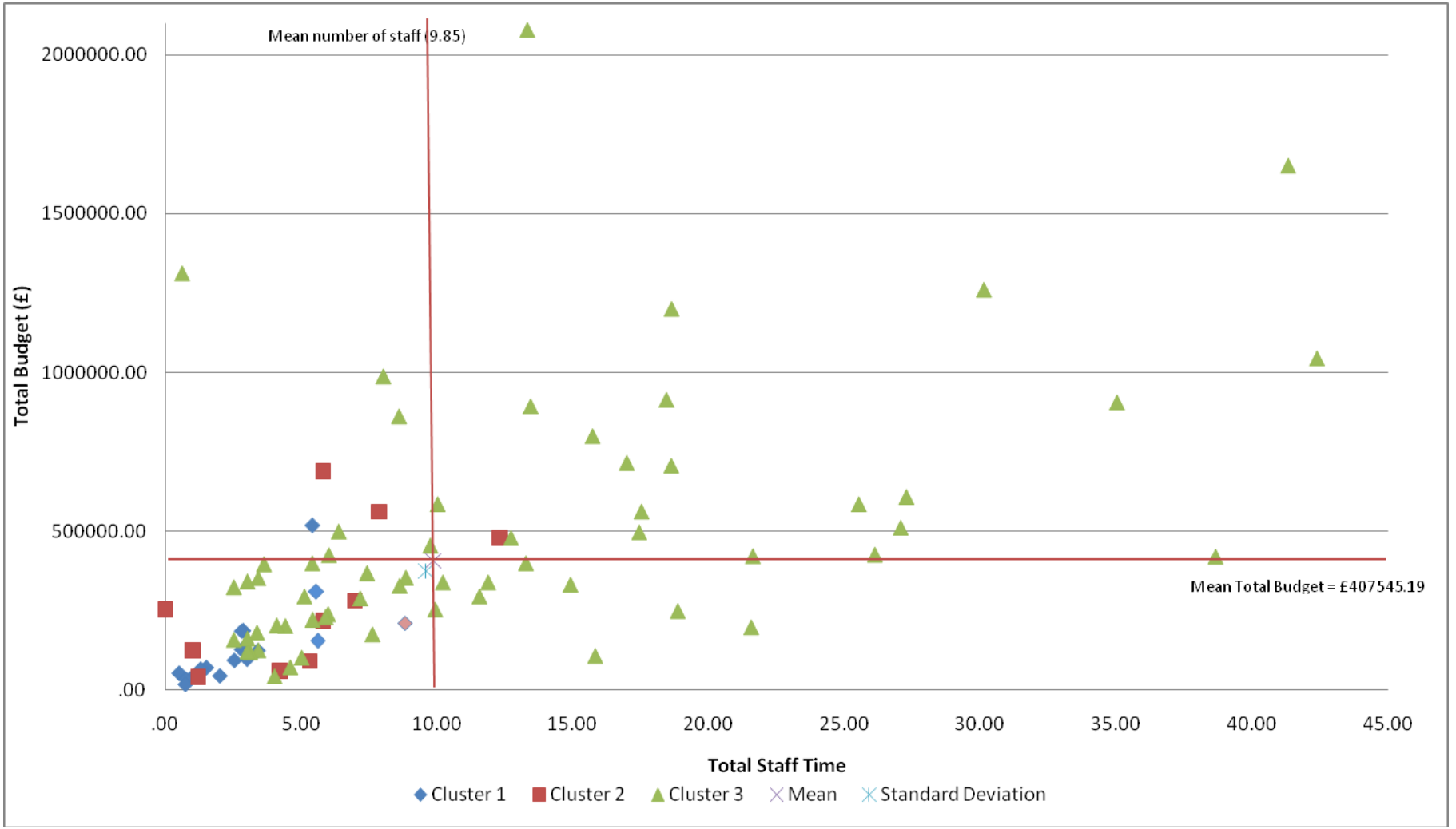


Figure 7. Caseload number by total budget by cluster

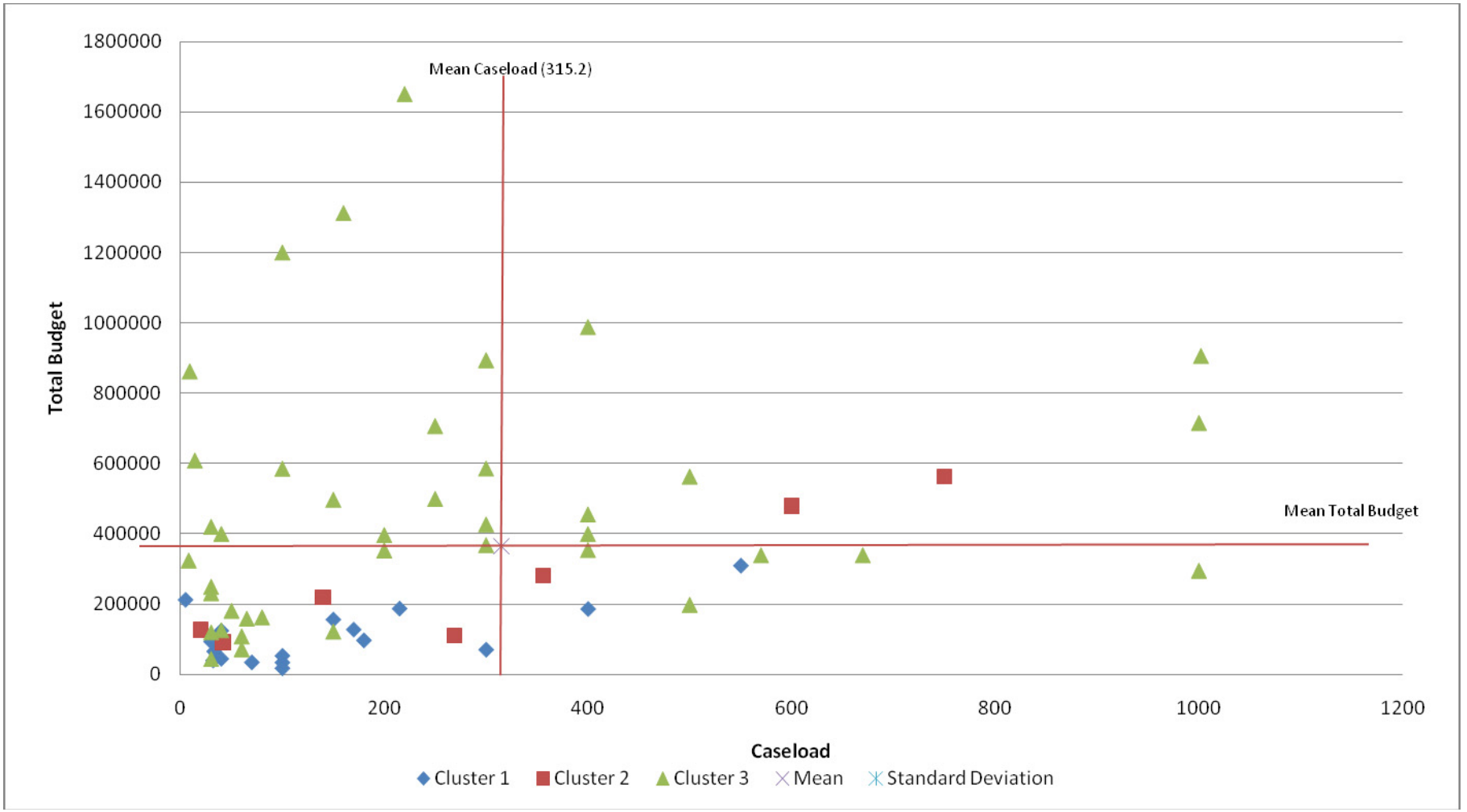
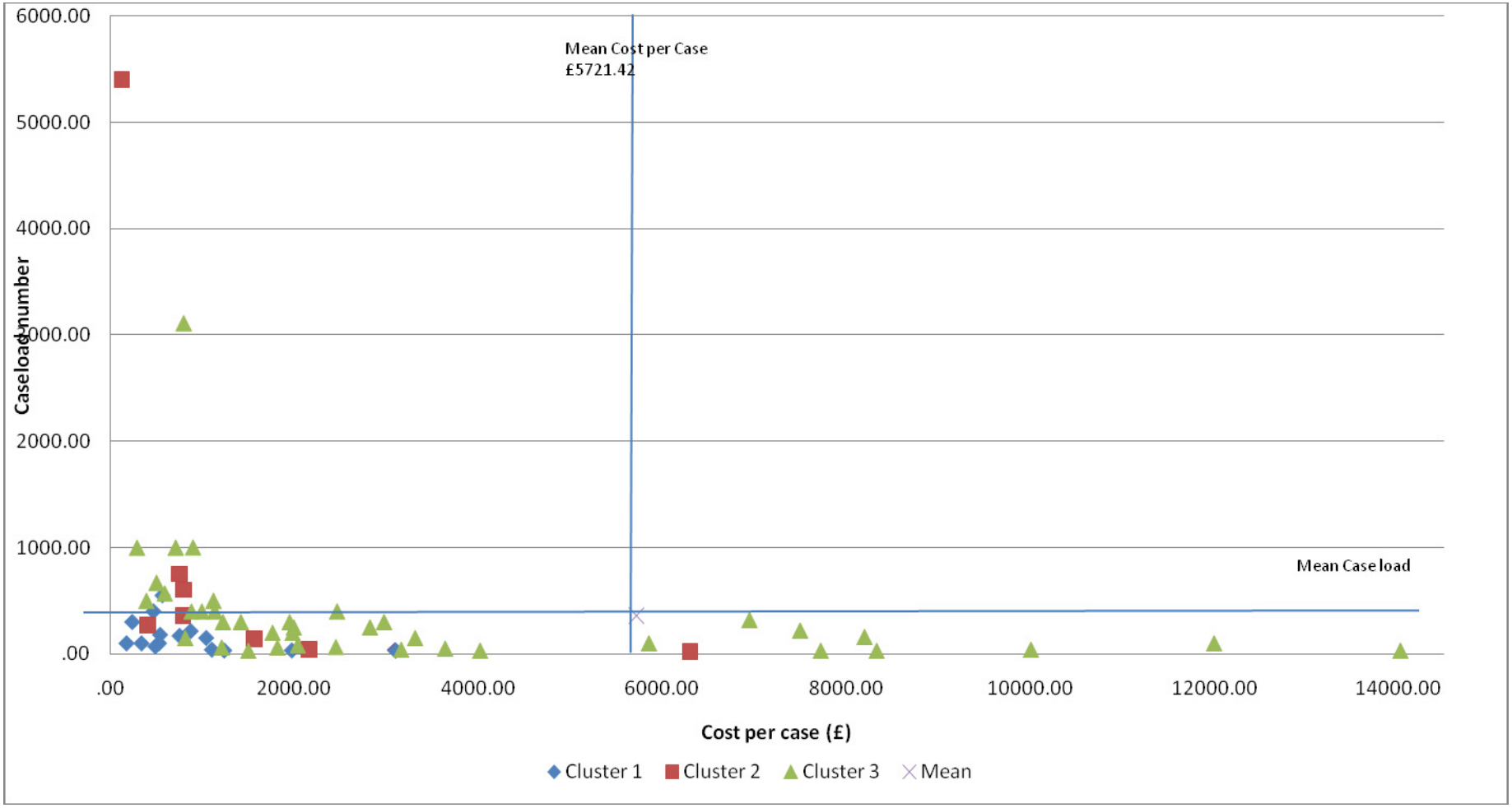


Figure 8. Caseload number compared to cost per case by cluster



7.1.4 Analysis of funding

We asked respondents from what sources they received funding and the majority were able to provide this information, as shown in Tables 32 and 33. Twenty percent of respondents reported having funding other than through the PCT. Examining this by clusters indicates that 33 of the cluster 3 teams (predominantly generic CCTH or continuing care services) reported funding from other sources, of which 18 received charitable funding, and 14 Local Authority funding (more than one additional funding source could be reported). Charitable funding was also the most important source of additional funding in the other clusters, received by 11 teams in cluster 1 (predominantly specialist or condition-specific services) and five in cluster 2 (predominantly therapy services).

Table 32. Additional funding for CCTH services

Funding other than through PCT	Cluster 1		Cluster 2		Cluster 3		Total	
No	86	76.8%	42	72.4%	99	70.7%	227	73.2%
Yes	18	16.1%	11	19.0%	33	23.6%	62	20.0%
No response	8	7.1%	5	8.6%	8	5.7%	21	6.8%
Total	***112***	***100.0%***	***58***	***100.0%***	***140***	***100.0%***	***310***	***100.0%***

Table 33. Other sources of funding

Other Funding	Cluster 1		Cluster 2		Cluster 3		Total	
	N	*%*	*N*	*%*	*N*	*%*	*N*	*%*
Specialist commissioning	2	3.9%	1	3.3%	3	3.1%	6	3.4%
Charitable funding	11	21.6%	5	16.7%	18	18.8%	34	19.2%
Local authority	1	2.0%	3	10.0%	14	14.6%	18	10.2%
Provider resources	4	7.8%	0	0.0%	0	0.0%	4	2.3%
Other	2	3.9%	3	10.0%	5	5.2%	10	5.7%
Not applicable	31	60.8%	18	60.0%	56	58.3%	105	59.3%
Total	***51***	***100.0%***	***30***	***100.0%***	***96***	***100.0%***	***177***	***100.0%***

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7.2 Hospital Episode Statistics analysis

Hospital Episode Statistics Data (HES), covering the year from 2007 to 2008, were analysed using Predictive Analytics SoftWare (PASW) Statistics 18. Data for non-elective in-patient admissions for children under 18 were selected. The purpose was to investigate whether there were differences across the case study sites, some of which had community based teams, and national data. All tables are shown in appendix 15.

7.2.1 Length of stay

Length of stay for all emergency admissions of children to acute trusts based in the relevant case study sites was compared against the mean for all acute trusts in the rest of England. Table 44 shows the number of admissions, the mean length of stay (LOS) and standard deviation.

Nationally, the average LOS of all emergency admissions for children is 1.9 days. In all but two of the acute hospitals serving the case study sites, the mean length of stay was below this figure (figure 9). Site WCH, a tertiary referral centre, had an average LOS of 4.7 days above the national figure, at 6.6 days. Site Xb had an average LOS of 0.2 days above the mean.

All the case study PCTs had an average length of stay below that of the national figure, the lowest being site Y at 1.6 days compared to 1.9 days (figure 10).

Table 44 refers to all admissions to acute trusts regardless of the PCT of residence of the patient. We then examined these data confining our analysis only to children living in the PCT where the CCTH service we had studied was based. Further analysis of the data looking at admissions to acute trusts from children living in the PCTs where our case study CCTH services were based can be seen in Table 45. This table also details the percentage of admissions to each trust from its relevant PCT.

Looking at only the patients who reside in PCT case study sites, mean LOS in acute trusts is over the national average of 1.9 days again in WCH (3.0 days) and Xb (2.1 days). However, the mean LOS in WCH for residents of the PCT is three days shorter than the length of stay for all admissions. Acute trust Xb is not affected by the removal of out of PCT area admissions, however 97.8 percent of the admissions to this acute trust were from the local PCT. The results for the length of stays for acute trusts and admissions from the local PCT are shown graphically in figure 11.

7.2.2 Day of admission and discharge

None of our case study CCTH services provided care 24 hours a day, seven days a week, although others (Xa and Y) provided partial weekend cover for specific services. If more generic CCTH services divert admission during their working hours, one might expect to see a 'rebound effect' at weekends, when admissions return to levels that might be expected without CCTH services. We therefore explored the day of admission and discharge for children living in the case study PCTs. Tables 47 and 48 show

the distribution of the admissions and discharge data and the data are displayed graphically in figures 12, 13, 14 and 15.

These figures do suggest that site X, which had a generic CCN team serving part of the PCT, may have experienced a rebound effect of the sort hypothesised above. On the one hand, this site experienced a lower percentage of weekday admissions than other case study sites. On the other hand, it had a higher percentage of weekend admissions. Site Z, which had a CAU that operated five days a week (though not 24 hours a day) had a relatively low percentage of admissions on Sundays.

7.2.3 Reason for admission

As outlined above, two of our case study sites, Xa and Z, provided services intended to prevent acute admission for children who could be safely managed at home. In site Xa, there was a CCN team, within which there was a dedicated admission avoidance section. In site Z, the CAU, although based in an acute setting, triaged children after assessment and worked closely with the CCN team. One might, therefore, hope to see some impact on admissions to hospital for common childhood illnesses. In order to explore this, we looked at the national HES data on primary diagnoses of all emergency admissions, ordered them by their frequency and selected the most common ICD 10 codes (International Classification of Diseases version 10). We then looked at the equivalent data for acute trusts in these two case study sites. The mean length of stay is in Table 49.

The table shows that the two case study sites each had shorter average length of stay for eight common conditions, compared to the national average. There were five common conditions where both case study sites had lower lengths of stay. These were acute upper respiratory infection, acute bronchiolitis, asthma, noninfective gastroenteritis and colitis, and nausea and vomiting. There are other factors that influence length of stay, for example, the referral status (tertiary) of hospitals in the PCT and socio-economic deprivation. For reasons explained in chapter 2, we were not able to carry out the more sophisticated statistical modelling, based on the national survey data, that would have allowed us to explore the influence of these other sorts of factors in addition to the existence of CCTH services. The comparison we have presented here is thus interesting but not conclusive, and deserves further exploration in subsequent work.

Figure 9. Average length of stay in acute trusts based in case study sites

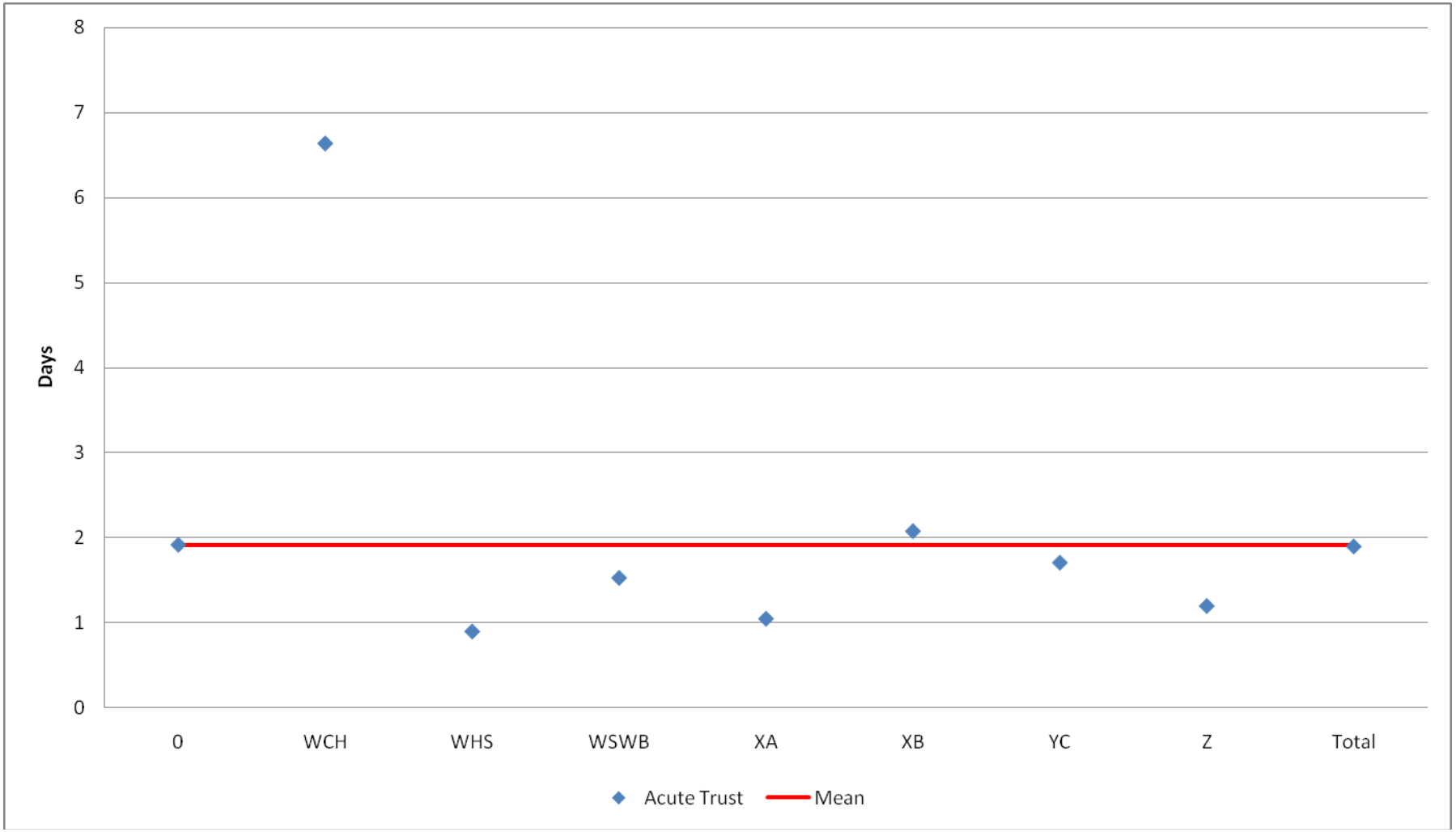

Figure 10. Average length of stay by PCTs in which case study CCTH services were based

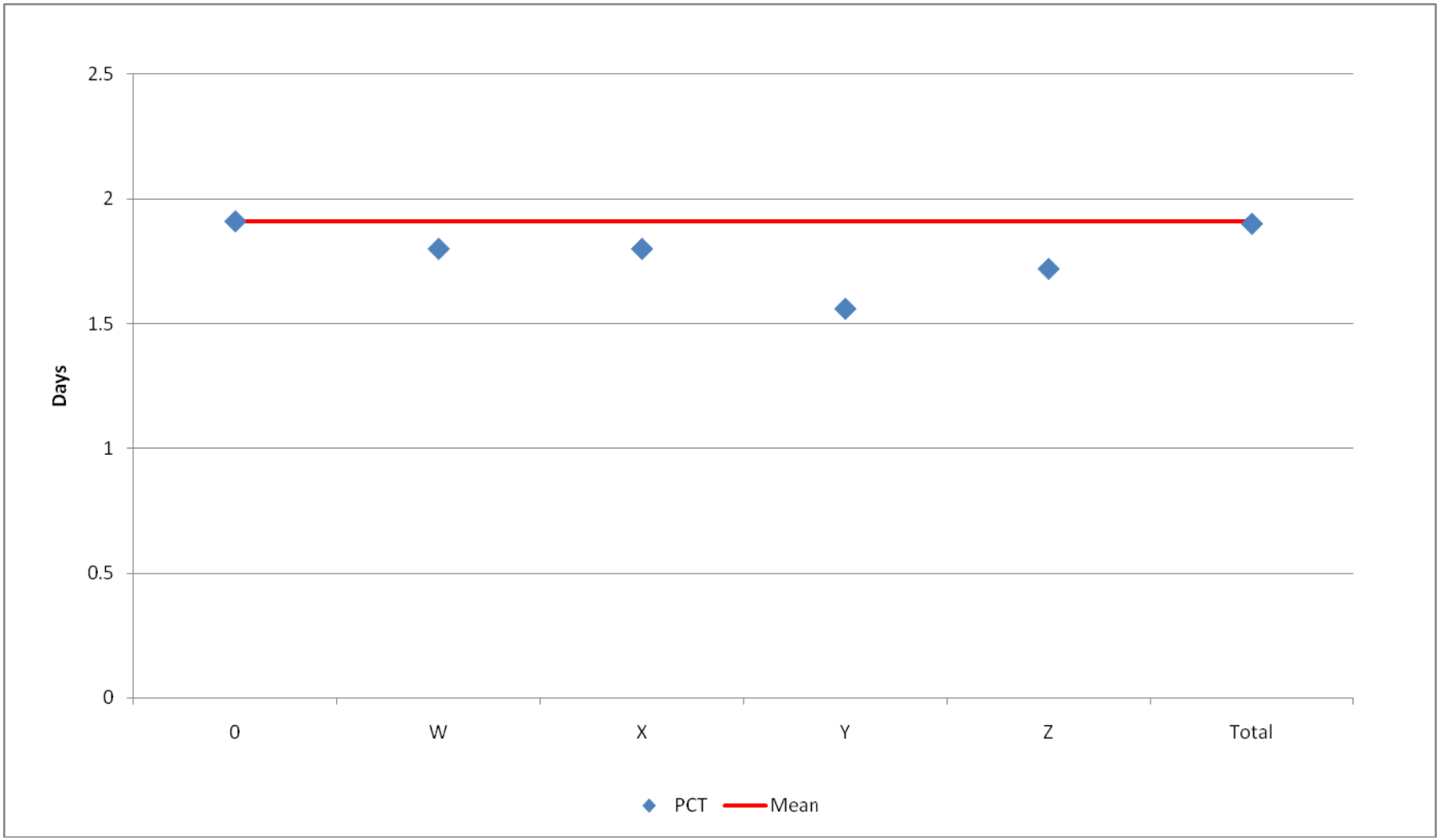

Figure 11. Average length of stay in acute trusts for in-patients who live in case study area PCT

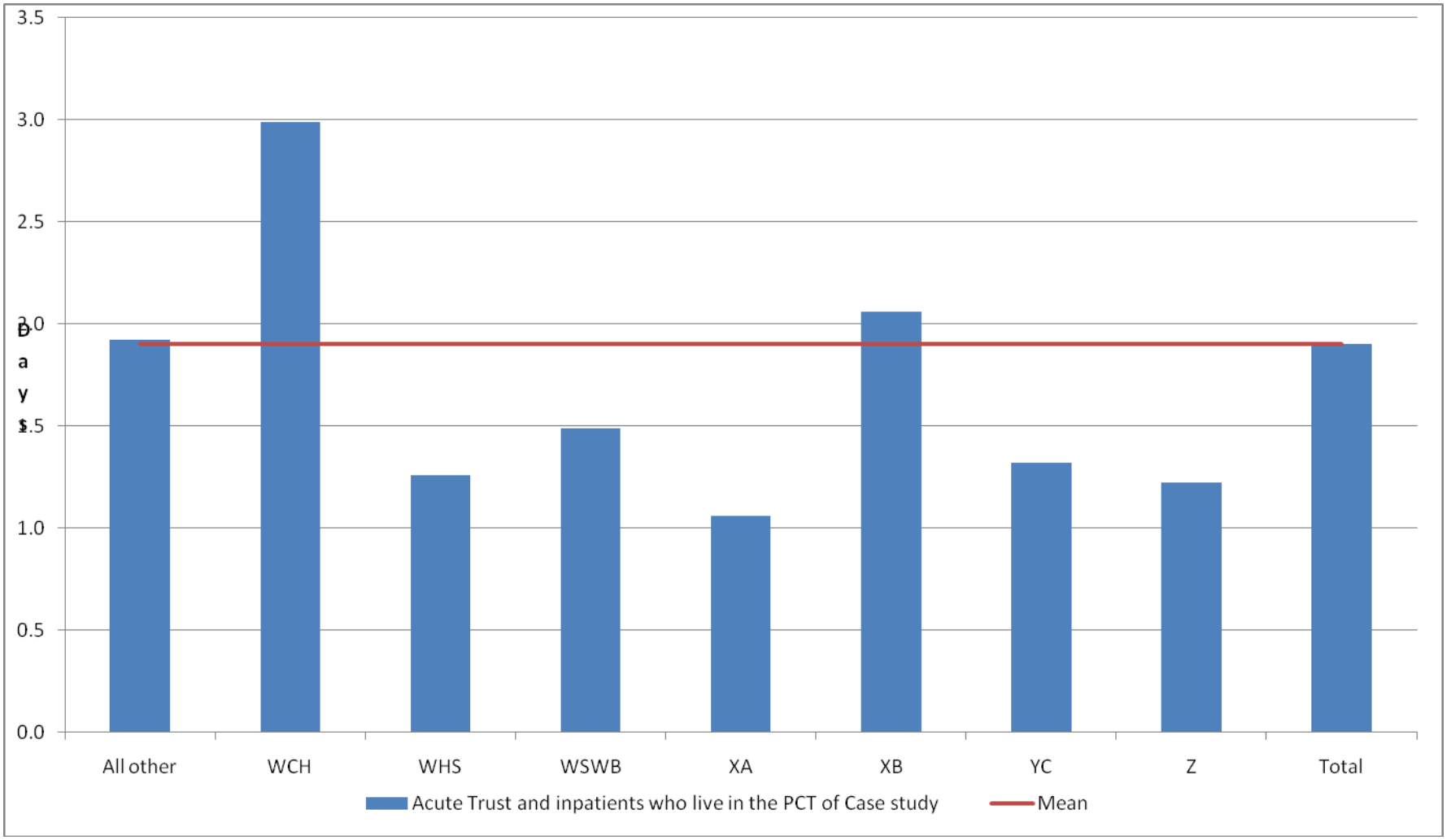

Figure 12. Admission day of the week for acute trusts based in case study sites

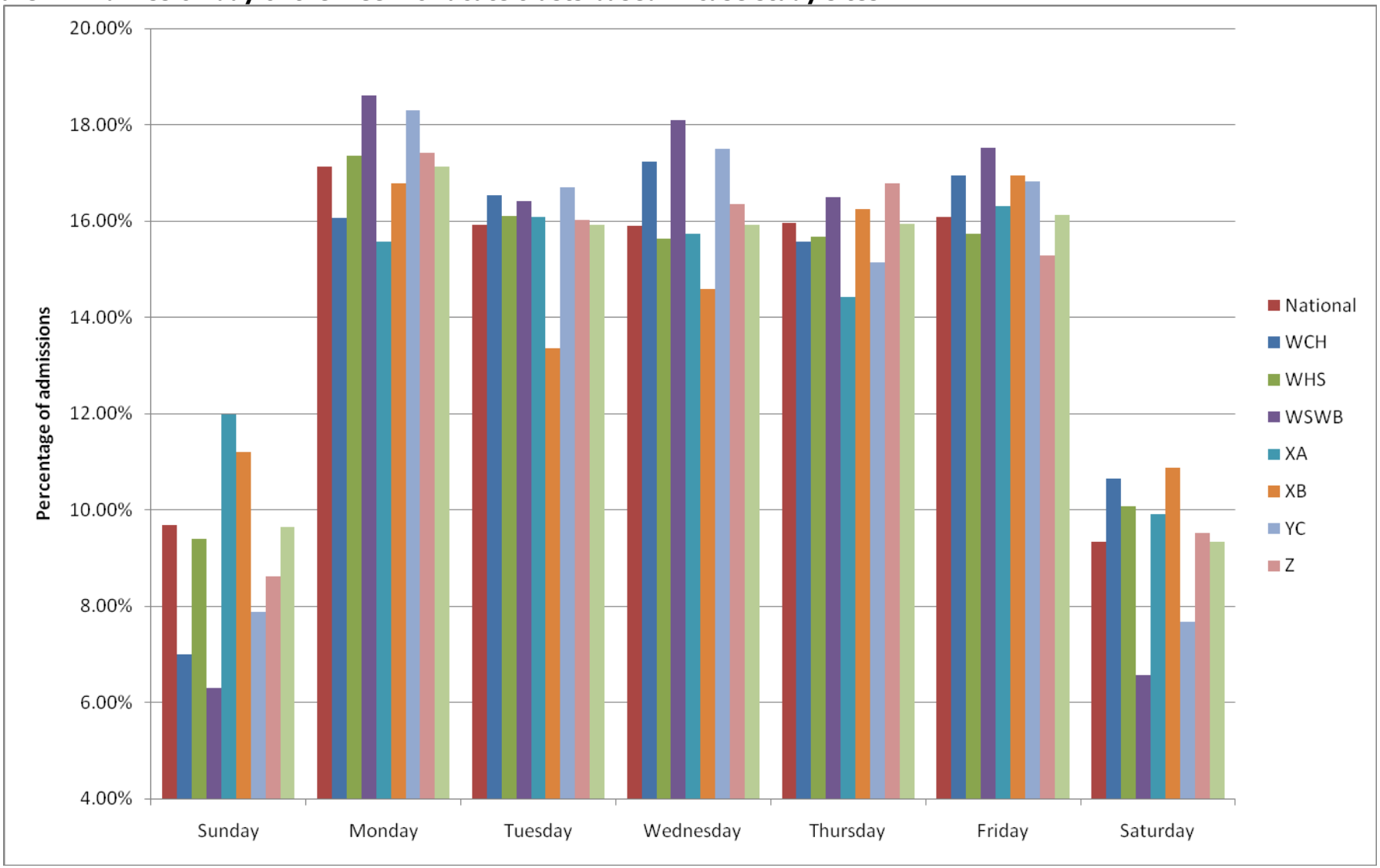

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Figure 13. Discharge day of the week for acute trusts week based in case study sites

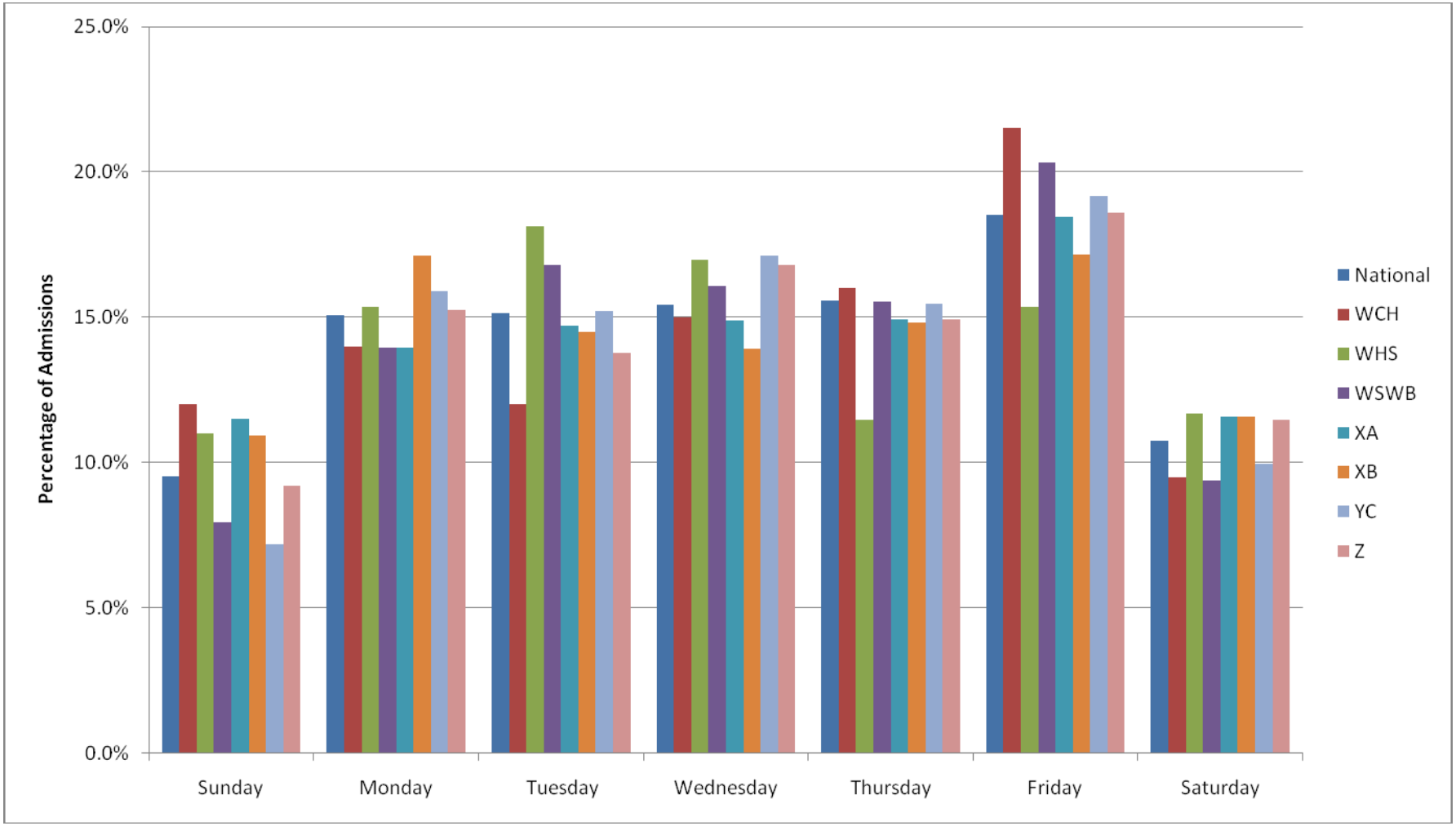

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Figure 14. Admission day of the week by acute trust: children who live in case study PCTs

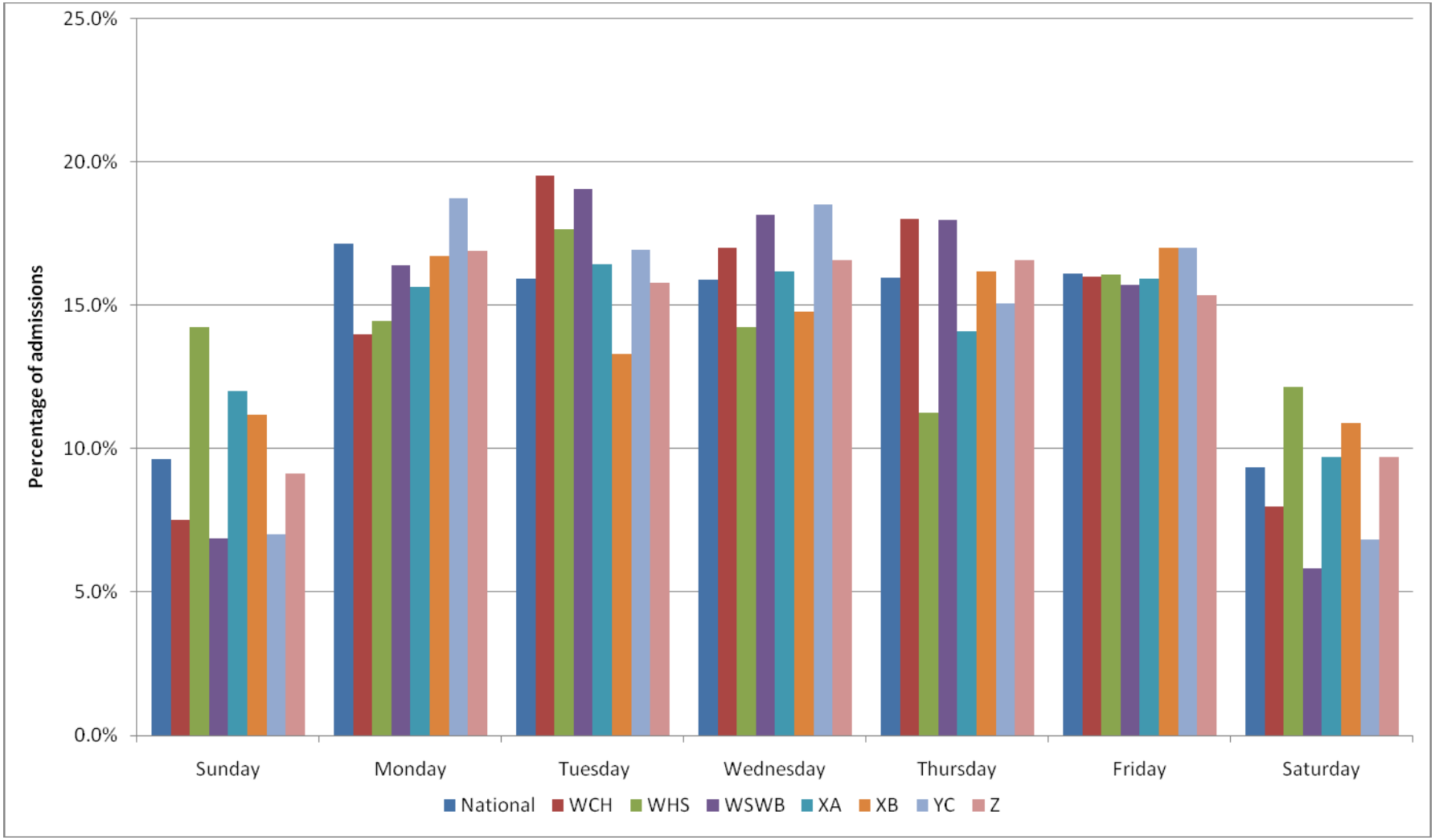

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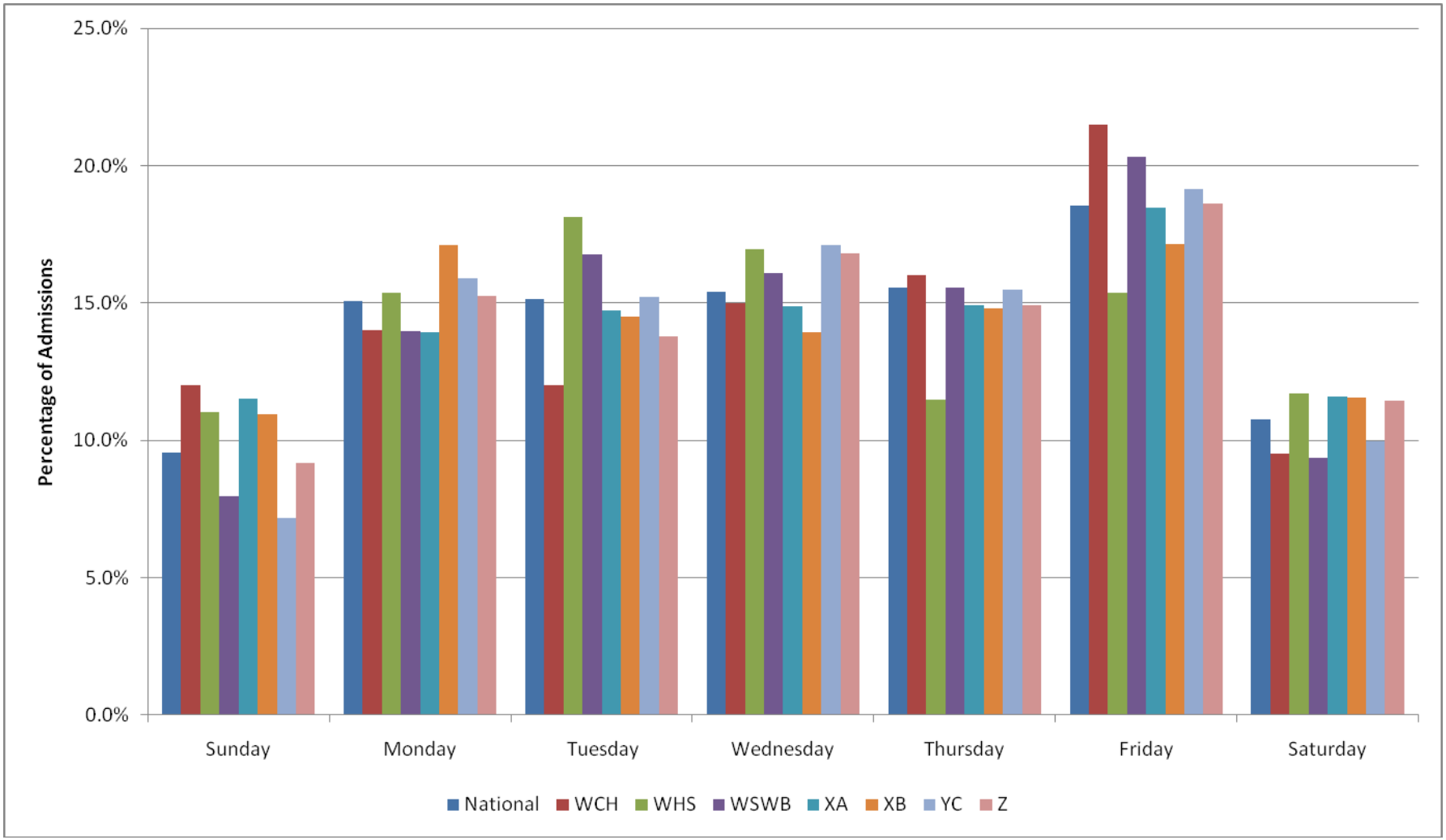
Figure 15. Discharge day of the week by acute trusts: children who live in case study PCT



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7.3 Economic modelling

We have investigated whether there are differences in costs and caseload across the different models, and have observed that there is great variation in, for example, cost per case and caseload for teams in cluster 3 (predominantly generic CCTH or continuing care services). We know that teams who manage children close to home can manage children with very complex needs, and they can provide care and management for children and their families which avoids them having to attend, for example, hospitals for inpatient or outpatient care.

The systematic review undertaken as part of this study[30], indicated that community based teams could deliver a wide variety of care, for example diabetes management, or the management of small babies who could be discharged early from neonatal units. Much of the literature demonstrated that savings could be made, mostly by reducing length of stay in hospital settings. This evidence on the usefulness of children's community nursing thus suggests that:

- Acute illnesses in children with breathing problems, fever, or diarrhoea and vomiting can be managed at home and may avoid a hospital admission
- Parents and children prefer management at home to hospital admission
- Length of stay in hospitals may be reduced by community nursing, but the overall length of care (i.e. hospital plus community) may be longer
- There is no difference in re-admission rates to hospital

We also know from our survey that in response to the question 'where would care be provided if this service was not available', 83 percent of respondents said inpatient care, 27 percent said day unit care, and 51 percent said outpatient care. Other options included a hospice or that care would not be provided at all. Thus we know that care closer to home is already an alternative to more expensive hospital care.

PCTs may wish to commission care closer to home for two reasons: not only to provide care that is more acceptable to and is preferred by children and families, but also because it is perceived to be more cost effective. With careful planning, it may be possible, under Payment by Results, to remove costs from hospitals and invest in teams that are closer to home. Our analysis of HES data offers some suggestion that an effect of this sort is evident when PCTs have access to CCN teams with a specific remit to avoid admission. However, it is also possible that we are seeing here the effect of some local health economies having thought strategically about options for care for children and young people who are ill.

Looking simply at national reference costs, we can see that CCTH might well offer a cost effective alternative under certain circumstances. For

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example, the costs[k] of an inpatient bed day, depending on the condition, can vary between around £200-£400. Inpatient care for a child with cystic fibrosis can vary from £2,500 to £5,000, and the delivery of chemotherapy can cost around £200-£300. The cost for community nursing services for children is around £100 per attendance, a similar cost to a consultant-led outpatient first attendance, with follow-up being slightly lower. Thus a community based nurse, seeing 4-8 children per day, could in theory, not just be covering the cost of her or his salary, but could be *saving* the equivalent of her or his salary, if each child seen would otherwise have been managed in a hospital setting. By reducing the length of stay of a child in hospital by one-day, and delivering that care in a community-based setting, that care would cost around £100 less. Four of the PCTs in which our case studies were undertaken exhibited a lower length of stay than the national average, of between 0.2 and 0.5 days, and five of the hospitals in these PCTs also had lower lengths of stay of between 0.2 and one day (of course other factors may also have influenced the length of stay).

Evidence from a previous study[l] indicated that a generic community team of eight WTE supporting children with a range of complex conditions, including children with cancer and cystic fibrosis, can prevent inpatient and outpatient episodes. For example, home-based IV management, blood tests and even chemotherapy, can be provided at home. Thus, a team may prevent on an annual basis around nine outpatient or ward visits per child with cancer at a cost of around £900 per child, and two inpatient episodes per child with cystic fibrosis at a cost of around £3,000 per episode.

We have also calculated in a previous study[m] that the average number of GP consultations with children per annum per GP is around 1600, of which around 15 percent are with a practice nurse. Therefore, the increased management of children by community nursing teams or paediatric nurses attached to GP practices can also reduce the direct burden on GPs.

Further, as we saw from the systematic review[30] and as was suggested by the national survey, potential cost savings are sensitive to case mix and to skill mix. However, the maturity of CCTH options and the ability to achieve savings in acute care were also important. Moreover, the case studies suggested that new commissioning arrangements, under competition rules, might militate against local health communities working together in order to realise the benefits that developing CCTH options can bring.

[k] All costs quoted here are from the national reference costs for 2007-08, available at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_098945

[l] York Health Economics Consortium (2007) Independent Review of Palliative Care Services for Children and Young People: Economic Study for Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074459

[m] For the Working in Partnership Project, for the Department of Health

8 Conclusions

Standard 6 of the NSF for Children, Young People and Maternity Services[1] has established a vision for the future of services for children who are ill. At its broadest, this requires providing timely, high quality and effective care, as close to home as possible, within a locally co-ordinated system of health, social care and education, and that meets individual needs. Attaining this vision requires substantial change and development in existing patterns of services. Our study constitutes the first major, national study of the current state of development of one element of this vision – care as close to home as possible. In this final chapter, we summarise the headline findings from our work and their implications for health care, reflect on the strengths and limitations of our research approach and methods, and outline suggestions for future research that is needed.

8.1 Headline findings and implications for health care

8.1.1 Models of CCTH

Three main types of CCTH services for children are evident in the English NHS, based on their delivery and organisational features. First, there are those that are broadly hospital-based and condition-related. The specific services that these CCTH services are most likely to offer are training, social and psychological support, health monitoring and liaison. Secondly, a small group of CCTH services includes most of those providing therapy services and services providing 'other' functions. The third and largest group of CCTH services is largely comprised of children's nursing services and other community-based provision for children with continuing, complex or end-of-life health care needs as well as those with acute need because of common childhood illnesses.

The third grouping provides a wide range of technological and other clinical care, including ventilation support, IV therapy, parenteral and enteral feeding, in children's own homes, schools and nurseries. Most of the services in the first and third groups clearly provide an alternative to in-patient or out-patient care. Group three services also serve as an alternative to day unit care. These are also the ones most likely to be dealing with children with complex, life-threatening or life-limiting conditions, as well as children with acute conditions that will resolve.

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Services in the first grouping were more likely than others to be operating regionally or nationally, while services in the third grouping were almost all operating locally.

Group 3 services had higher staffing complements, dealt with more children annually and had higher staff to caseload ratios than services in the other groups. Only 67 respondents were able to provide us with both caseload and budget information, and the majority of these were in the third grouping. This made it difficult to compare cost per case across the three groups with any certainty.

8.1.2 Commissioning CCTH

There is a clear desire to commission and provide CCTH, because commissioners, providers and families alike recognise it as a family-centred, flexible, holistic alternative to hospital care for children. However, three main issues may impede further development. First, unlike earlier NSFs, monies for implementation did not accompany the NSF for Children, Young People and Maternity Services. Thus, while policy supported the 'rightness' of CCTH services already in place, it did not offer the resources to commission new, or extend existing, provision. The lack of high quality evidence about the costs and effectiveness of CCTH services also meant that it was more difficult to argue for (further) development against other priorities. There is, further, a danger that risk aversion might prevent commissioners who are not specialists in child health services from seeing CCTH as clinically safe. Competition rules could further exacerbate this, if interpreted as 'forbidding' access to the clinical and service expertise of providers that might provide reassurance about safety.

8.1.3 Delivering CCTH

When a child receives care close to or in their home, rather than in a hospital, issues become active which, in a hospital setting, are largely quiescent. Adequacy of the physical environment within which a child will be cared for, parents' or carers' ability and willingness to assume responsibility for what may be complex care at home, the impact on siblings and other family members, boundaries between home, school and other parts of the child's life, and other factors become a living part of delivering care. Providing CCTH thus takes on a complexity that is additional to that of caring for an ill child in more formal surroundings.

Yet, the NHS has been moving away from provision of long-term care in hospital settings since the 1970s, particularly in relation to children and young people. For children with complex and long-term conditions, there is thus no acceptable alternative option to providing CCTH, regardless of how challenging the technical and clinical needs of the child may be.

These factors are perhaps the reason capacity figured strongly in the accounts of service providers in the case studies and also in families'

accounts. For providers this was about capacity to meet the needs of all children and families who could benefit from CCTH and capacity to meet the *specific* needs of those who were already using services. For families already using services, capacity was raised in relation to the hours and days during which care was available and how responsive a service could be to their needs.

Capacity to provide enough, and the right sort, of care is clearly related to commitment from commissioners and to funding, as we discussed above. However, other issues also prevent providers from giving the quality of service that they feel is possible. First, restricted training opportunities for nurses, in particular, who could work both with children and in the community, limit the numbers of suitable professionals available to staff teams. This national issue is impeding development in some areas in particular, where it is proving difficult to attract qualified and experienced staff. Both the case studies and the national survey underlined this. Secondly, because of the additional complexity of delivering CCTH, even when nurses with both paediatric and community training are available, the lack of professionals in teams who can provide psychosocial support to both children and parents limits the ability to provide holistic care. Both providers and parents expressed the need for this sort of support to be available and, again, the national survey underlined the need.

Whether CCTH services have the right skill mix is another factor that might influence capacity. Evidence from the health economics element of the systematic review showed clearly that case mix and skill mix, and the interaction between them, influence whether CCTH can and does deliver cost benefits to the health service.

8.1.4 The role of CCTH in the lives of families and children

Our interviews with providers of CCTH services and the families who use them are clear about their contribution to keeping life as 'normal' as possible for ill children. CCTH keeps disruption to children's routines and schooling to minimum, and relationships with siblings and friends can be maintained more easily. The family as a whole benefits, too. CCTH has potentially less impact on parental employment and family income, removes the need for the costs associated with hospital attendance, and enables parents to care for their other children and maintain other aspects of family life. In addition, CCTH was simply more convenient for families and children. When families are dealing with the substantial challenges of caring for a child with long-term and complex or life-threatening conditions, this is a significant gain.

These findings are an important contribution to our understanding of the benefits of CCTH, and highlight the inadequacies of the existing literature on effectiveness that, still, rarely includes such outcomes.

However, CCTH can also pose challenges for families and children. The people we interviewed were, by definition, those who were coping with caring for their children at home. When CCTH is for acute ill health that is not coupled with a longer-term condition, then the relatively short period of disruption at home while a child recovers is one thing. It is entirely another thing when the child is dependent on complicated technological care at home, and for many years. Not all families are able or willing to take on this type of responsibility, and some live in conditions that do not allow care to be provided safely. Evidence from our case studies shows how CCTH needs to be negotiated between families and services. All elements of our study show that, with support, many children who would previously have been cared for in hospital for many months or years can be safely cared for at home. However, this requires both commitment to services that have the same night and weekend coverage as hospital services, and formal methods within services for addressing the significant psychosocial challenges that care at home can create for families and children.

8.1.5 Implications for health care

The finding across all elements of our project, including the systematic review[30] suggest that providing CCTH for children and young people who are ill is achievable, safe and probably cost-effective. CCTH is also highly regarded by the families whose children use it.

Given the policy emphasis on keeping children out of hospital wherever possible or ensuring that their stay is as short as feasible, it is surprising to find that some commissioners are still hesitant about CCTH as a service model. In part, this seems related to their feelings that there is an insufficient evidence base to support CCTH. Our study suggests that this is no longer the case and that the weight of evidence does underline the value and safety of CCTH services.

Our evidence suggests a number of areas that commissioners and providers might need to consider in developing CCTH:

- **The need for negotiated and agreed care protocols**, both between acute and community-based providers, and between CCTH services and primary care.
- **The key role that good working relationships between acute and community-based health care providers play in ensuring continuity of care for children and their families.** These relationships are also a key issue in ensuring that savings in one part of the health care system, achieved from reduced length of stay, are applied in other parts of the health care system that work to produce the reduced lengths of stay.
- **The overall understanding among general practitioners about CCTH and its potential**. Our evidence suggests that even when care protocols were agreed, it could take a lot of time to build the

trust of GPs in referral to CCTH. This suggests that a sustained period of negotiation and confidence building among GPs may be necessary if the full gains of CCTH are to be realised.

- **The importance of the right skill mix in CCTH teams**. Having a range of nursing bands in a team, including health care assistants, may influence cost-effectiveness.
- **The importance of case mix in determining the costs and flexibility of CCTH services**. Generic teams that can deal with both short-term acute illnesses and longer-term, more complex care may be more cost-effective and find it easier to manage fluctuations in demand. Embedded nurse practitioners within generic CCTH teams seem a promising model here, because it addresses both skill mix and case mix issues.
- **The nature of contracting with CCTH services**. Block contracts seem to offer less flexibility to CCTH services dealing with fluctuating levels of need, while competition rules may run the danger of impeding planned innovation. However, given the variability of case loads in most CCTH services, setting a tariff is well-nigh impossible. Cost per case seems to work well in continuing care provision and would seem to be worth experimenting with in other types of CCTH.
- **The provision of psychosocial support within CCTH**. This is not a luxury; it is a vital part of supporting ill children and their families, particularly those dealing with very complex health needs. This form of support empowers families and enables them, often, to participate more fully in their child's care.
- **The need for robust data systems on both activities and costs**. Our use of HES data to examine length of stay in our case study PCTs does suggest that this might be a useful starting point for many health economies that, our survey findings suggest, do not yet have such robust systems in place.
- **Supervision and support in CCTH**. By its nature, CCTH involves lone-working; good supervision and support structures within teams are thus essential to safe practice.
- **The importance of 24 hour, seven day a week support**. For some CCTH services this can be provided effectively through telephone support systems. For other services that are intended as real alternatives to acute hospital care, our evidence suggests that it is counterproductive, both for children and families and for the health care system, to limit them to 'office hours'.
- **The availability of training for paediatric community nursing**. Local availability of appropriate training for nurses working in the community with ill children seemed to affect recruitment and retention in our case study sites.

8.2 Reflections on research approach and methods

The project reported here used a multi-method approach to examine a multi-faceted and developing form of health service delivery and organisation for children and young people who are ill. The use of different research approaches allowed us to: map the development of services nationally; understand in detail the benefits and challenges of commissioning and delivering CCTH services; explore the perceptions of families who received these services; make some initial assumptions about costs and impact; and to place all this in the context of international evidence about CCTH. As such, it constitutes a substantial contribution to the evidence base about models of care not extensively researched to date.

A challenge throughout the project was defining CCTH. As outlined in chapter 1, a combination of policy imperatives, technological development and apparent increases in demand for care for ill children has increased the impetus to provide that care, wherever possible, away from hospital settings. However, the language used to describe alternative service models, which has changed over time and differs across the world, makes it difficult to bring an accurate focus to the topic. We took a pragmatic and operational approach to defining 'care close to home' that was somewhat wider than that taken in our previous work on 'paediatric home care'[3] but which, we believed, reflected the focus of the NSF.

A practical consequence of using operational definitions of CCTH, in an environment where the concept itself is rapidly evolving, meant that we did not use pre-defined categories of service models in the national survey. We added a screening stage that involved open questioning, with some examples of ways in which CCTH might be provided, so that respondents could think widely about their services. The focus, both in the screening questionnaire and the main stage, was therefore on functions[n] related to CCTH, and settings where this might be provided, rather than on 'titles', such as 'hospital at home', 'early discharge co-ordinator', 'community children's nursing teams'. We have used this successfully in previous survey research where potentially novel service models were being developed in response to demographic and/or policy drivers[40] and believe that this flexible approach has captured the diversity of CCTH services.

The main benefit of the screening approach was the potential it offered to identify all forms of CCTH as defined by respondents, not just forms of CCTH pre-defined by the research team. It thus allowed us to see the diverse ways in which care is being delivered close to home. The primary limitation was that respondents often reported the same type of service in a variety of ways. For example, teams typically known as community children's nursing teams could be reported as home care teams, children's home nursing, or paediatric outreach nursing. This meant that post-hoc

[n] Such as avoidance of hospital admission, early discharge, etc

classification (as opposed to pre-imposed classification in a closed question approach) was needed before we could analyse data. Further, inclusion and exclusion criteria were difficult to implement until full questionnaires were returned and we could understand the service's nature from the information reported.

Basic inclusion criteria were:

- services specially for children and young people only
- services for a physical illness (whether acute, complex, chronic, life limiting or life threatening)
- services that provided some element of care closer to, or in the home
- services that aimed to prevent admission, reduce length of stay, facilitate early discharge, or provide care in the community for complex health care needs.

The survey *did not* map: child and adolescent mental health services (which had been subject to relatively recent national research)[41];key worker services; public health interventions; universal services; bereavement services; midwifery services; general paediatrics; outpatient clinics for routine follow-up; respite and short break services that were not part of a CCTH service; services exclusively for disabled children such as Portage schemes; and services that provided care for both children and adults.

Other researchers might have chosen to draw the line between CCTH and other services elsewhere, but both the limitations and strengths of our approach are inextricably linked with the broader challenges of conducting research into a concept as undefined as 'care close to home'.

We achieved a relatively high response rate for both the screening and the main stages of the survey. This was largely due to careful follow-up. However, we have no way of knowing definitively whether non-response at the screening stage meant that there were no CCTH services in the relevant trust, or whether it meant that the questionnaire was never completed. As a result, we have not been able to provide a complete map of CCTH services in England. The geographical patchiness of response restricted our ability to give a clear picture of the depth and breadth of service development across the country. It also meant that we were unable to carry out the proposed multi-variate analysis of provision, taking into account population characteristics. Instead, we used HES data to explore service use data in our case study sites, where we did have a complete picture of provision. This is reported with the health economics analysis in chapter 8.

There was a higher response rate from acute trusts than from PCTs at both the screening and main stages of the survey. The survey was conducted during the reconfiguration of PCTs into commissioning and provider arms and this undoubtedly affected the response of PCTs at the screening stage. This in turn was reflected in the lower proportion of reported services provided by PCTs and the response rate from them at the main stage.

Despite the challenges of the national survey, it gives the first detailed picture of the functions, coverage, organisation, and, in some cases, costs of CCTH provision in England. It has also distinguished three main models of CCTH services, based on their delivery and organisational features, using cluster analysis. We believe that this use of cluster analysis may constitute a methodological development in service delivery and organisational research.

We had originally intended to have six case study sites for our in-depth qualitative exploration of different models of CCTH. As we explain in chapter 2, we eventually achieved four case study sites, and studied in detail five different CCTH services within them. Given the depth of the material we gathered and the consistency of the messages that emerged from our interviews with commissioners, practitioners and, particularly, parents, we believe that the qualitative findings have applicability in a wide context.

We spent much time in the early stages of the project developing and piloting age-appropriate recruitment materials and interview techniques to enable children to give their views and experiences of using CCTH services. In the event, most of children using the service whose parents were recruited to the case studies were under five years, and thus excluded. Only one of the few children over this age consented to involvement. This is a disappointment, but a not uncommon experience in research with ill children.

The inability of most respondents to provide information about both caseload and costs restricted the health economic analysis that we were able to carry out. We compensated for this to a degree by exploring HES data for non-elective admissions in our case study sites.

8.3 Research priorities

A number of further research questions have arisen as a result of this research; we have prioritised and listed below.

1. Social and psychological support is a valued and important component of CCTH. Our research suggests however, there are relatively few professionals to provide this support (for example, social workers, psychologists). More work is needed to further understand the psychosocial needs of children and their families receiving CCTH, how current service provision attempts to meet these needs, and to what effect.

2. Our research shows that GPs are a common referral source to CCTH services, and thus their decisions about referral may mediate how effectively CCTH services are utilised. Further research should explore what factors affect GPs' decisions to refer to CCTH services, how they understand CCTH services, what types of conditions they

are likely to refer to hospital and what types of conditions they are likely to refer to a CCTH service. This will become an even more important issue as GP commissioning becomes a reality.

3. Another common referral source to CCTH services is hospitals; however our research indicates that community based teams sometimes had difficulties with referrals from hospitals. Further work to understand the experience of hospital staff when they refer a family into the care of a CCTH service may help to understand how the process can be improved.

4. Recruitment and retention issues in CCTH services affect capacity. Future research should explore how capacity issues affect the well-being of CCTH staff, especially given the demanding and, at times, isolating nature of their role.

5. Similarly, work should also explore the experience of families whose children are being discharged from hospital into the care of a CCTH service. Do families feel ready to go home and have a community nurse visit them? What are their expectations? If and when children are readmitted to hospital during CCTH, how does this affect the quality and continuity of care for the family?

6. Transition from CCTH services to adult services was highlighted as being problematic in our research, due to not being able to plan transition far enough in advance and adult community nurses being inexperienced with some types of care. Our research also shows that CCTH for children and their families is often holistic, yet we do not know if and how this holistic care is continued in adult community care. Future research should further explore the transition pathway between children's CCTH services and adult community care, in relation to the difficulties faced by CCTH services, the difficulties faced by adult's services, and most importantly the experiences and needs of families during the transition period.

7. Our research suggests that priorities for children's commissioners differ across trusts. Obtaining a national picture of priorities for children's commissioners to understand where ill children and CCTH 'fit' in these priorities would help to identify where areas may be progressing in developing CCTH.

8. Some staff in our case studies suggested that sometimes parents may use health services, particularly CCTH services, because of a lack of confidence in being able to manage their child's acute illness. It was felt this was exacerbated by parents often not having family nearby to access support and advice. Future research should

investigate how changing family structures may influence parents help seeking behaviours when their child is acutely ill and how CCTH services help to deal with this.

9. For parents who perform clinical procedures which can be distressing for their child, further work should investigate the impact this may have on the parent, how it may affect the child, and how it may affect the relationship between the parent and the child.

10. For children who experience CCTH over long periods, future research should investigate how educational needs are met.

11. For children who receive CCTH in school settings, further work should explore how this affects the child's social development.

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Appendix 1 Screening Questionnaire

THE UNIVERSITY of York

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The Provision of Paediatric Health Care Closer to Home

Questionnaire 1

Name of trust: ……

Name and work address of person completing this form

Name: …….

Address: …….

…….

……..

Telephone: …….

Email: …….

The questionnaire is about services that prevent children from being admitted to hospital, or reduce the time they spend in hospital as inpatients, by bringing care closer to home.

Please note, these services may be delivered in a wide range of settings. For example, day assessment units, outpatient settings, community based clinics, children's centres, GP/primary care settings, schools, nurseries, or the child's home.

These services may also be provided to a wide range of children, including those with an injury, an acute illness, a chronic condition, a life-threatening condition, a degenerative condition, technology dependent children, children having surgery, and babies who are medically fragile or of very low birth weight.

We use the term 'children' to refer to the age range of 0-19 years.

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Please note: we do not require information on CAMHS or public health interventions for this survey

Does your trust provide any 'care closer to home' services?

Please note, we are interested in services that are provided, not commissioned.

Please tick:

❑ **No, this trust does not provide such services**

↳ *If no,* please return this questionnaire in the pre-paid envelope provided.

❑ **Yes, this trust does provide such services**

↳ *If yes,* we would be grateful if you could provide further information overleaf.

Further details of service provided

1. Name of service: ……

Manager of this service is: ……..

Address: ……..

……..

……..

Telephone number: ……

2. Name of service: ……

Manager of this service is: ……..

Address: ……..

……..

……..

Telephone number: ……

3. Name of service: ……

Manager of this service is: ……..

Address: ……..

……..

……..

Telephone number: ……

4. Name of service: ……

Manager of this service is: ……..

Address: ……..

……..

……..

Telephone number: ……

5. Name of service: ……

Manager of this service is: ……..

Address: ……..

……..

……..

Telephone number: ……

6. Name of service: ……

Manager of this service is: ……..

Address: ……..

……..

……..

Telephone number: ……

7. Name of service: ……

Manager of this service is: ……..

Address: ……..

……..

……..

Telephone number: ……

8. Name of service: ……

Manager of this service is: ……..

Address: ……..

……..

……..

Telephone number: ……

9. Name of service: ……

Manager of this service is: ……..

Address: ……..

……..

……..

Telephone number: ……

10. Name of service: ……

Manager of this service is: ……..

Address: ……..

……..

……..

Telephone number: ……

11. Name of service: ……

Manager of this service is: ……..

Address: ……..

……..

……..

Telephone number: ……

12. Name of service: ……

Manager of this service is: ……..

Address: ……..

……..

……..

Telephone number: ……

13. Name of service: ……

Manager of this service is: ……..

Address: ……..

……..

……..

Telephone number: ……

If there is insufficient space on this form to list all the care closer to home services you provide, please feel free to attach additional pages.

A summary of the research findings will be made available to all those who take part in the research. Please let us know if you would like a copy of these findings by ticking the appropriate box below.

❑ **Yes** I would like a copy of the survey findings

❑ **No** I would not like a copy of the survey findings

Thank you for taking the time to complete this questionnaire.

Please return the questionnaire in the pre-paid envelope provided, or to:

Social Policy Research Unit, University of York, FREEPOST YO378

Heslington, York YO10 1GY

Appendix 2: Phase 2 questionnaire

THE UNIVERSITY of York

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The Provision of Paediatric Health Care Closer to Home Questionnaire 2

This questionnaire is about services that prevent children from being admitted to hospital, or reduce the time they spend in hospital as inpatients, by bringing care closer to home. You have been identified by a senior manager within your NHS trust as having knowledge about such a service. We would therefore be very grateful if you could complete this questionnaire and return it in the pre-paid envelope provided.

The service in question is:

The questionnaire should take approximately 30 minutes to complete. It asks about the characteristics of the service you provide, the population served and funding arrangements. All information provided will be treated as strictly confidential. If you feel you are ***not*** the appropriate person to complete this questionnaire, please pass the

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questionnaire on to the person you feel is best placed to complete it.

A summary of the survey findings will be made available to all those who take part in the research. Please let us know if you would like a copy of these findings by ticking the appropriate box below.

❑ Yes, I would like a copy of the survey findings

❑ No, I would not like a copy of the survey findings

Thank you for your help

The research team

Professor Gillian Parker

Miss Kate Gridley

Dr Suzanne Mukherjee

Miss Gemma Spiers

For help with completing this questionnaire please contact Gemma Spiers on 01904 321950 or e-mail: gs525@york.ac.uk

THE SERVICE PROVIDED

1. What are the objectives of the service? *(Please tick as many options as appropriate)*

- ❑ Prevention of hospital admission
- ❑ To reduce length of hospital stay
- ❑ To support early discharge
- ❑ Provision of care for complex health needs out of hospital
- ❑ Other *(please describe)* ……..

2. What services are provided? *(Please tick as many options as appropriate)*

- ❑ Post-operative care
- ❑ Ongoing nursing care
- ❑ Drug administration
- ❑ Palliative/terminal care
- ❑ Technical support (e.g. assisted (to child, ventilation, intravenous therapy, enteral or parenteral nutrition)
- ❑ Training and advice family and/or carer)
- ❑ Taking samples for routine investigations
- ❑ Short term breaks
- ❑ Social and psychological support family and/or carer)
- ❑ Managing transition to adult services
- ❑ Monitoring of health
- ❑ Liaison with other professionals
- ❑ Other *(please describe)* ……..

3. Where is the service based (i.e. where does the team work from)? (*Please tick the appropriate box below)*

- ❑ Based in the community
- ❑ Based in hospital
- ❑ Other (*please describe)* ……..

4. In which of the following settings is the service delivered? *(Please tick all the options below that apply to this service)*

- ❑ Outpatient clinics
- ❑ Day units
- ❑ Community based clinics
- ❑ GP/Primary care settings
- ❑ Schools and/or nursery schools
- ❑ Day nurseries
- ❑ Children's centres
- ❑ Child's home
- ❑ Child Development Centre
- ❑ Other *(please describe)* ……..

5. Which of the following levels of cover does the service provide? *(Please tick the appropriate box below)*

- ❑ Weekday cover
- ❑ Weekday cover *plus* emergency out of hours care
- ❑ 24 hour care, seven days a week

6. What is the annual expected caseload for this service?

……...

7. Is the amount of time designated to each child limited/capped to a pre-specified number of sessions/ time period? *(Please tick the appropriate box below)*

- ❑ No
- ❑ Yes
  - ↳ *If yes, please describe* ……..

8. Where would care be provided if this service was not available? *(Please tick as many options as appropriate)*

- ❑ Inpatient unit
- ❑ Day unit
- ❑ Outpatient clinic
- ❑ Other *(please describe)* …….

9. Who refers children to the service? *(Please tick all the options below that apply to this service)*

- ❑ Hospital based team member
- ❑ General practitioner
- ❑ School based team member
- ❑ Community nurse
- ❑ Community based team member
- ❑ Child/family
- ❑ Social care services
- ❑ Other *(please state who)*. ……

THE POPULATION SERVED

10. Which of the following groups does the service cater for? *(Please tick all the options below that apply to this service)*

- ❑ Children with a life-limiting condition
- ❑ Children with a life-threatening condition
- ❑ Children with an acute condition
- ❑ Children with ongoing, complex conditions
- ❑ Other *(please describe)*. ……..

11. Is this service specific to ONE condition only?

- ❑ No (please go to question 12)
- ❑ Yes

↳ *If yes, please indicate which condition by ticking **ONE** box below*

- ❑ A & E
- ❑ Audiology
- ❑ Cardiology
- ❑ Dermatology
- ❑ Ear, nose & throat
- ❑ Endocrinology
- ❑ Gastroenterology
- ❑ General surgery
- ❑ Infectious disease, allergy
- ❑ Neuro-disability
- ❑ Oncology & haematology
- ❑ Ophthalmology
- ❑ Orthopaedics
- ❑ Palliative care
- ❑ Plastic surgery
- ❑ Renal medicine
- ❑ Respiratory medicine
- ❑ Rheumatology & immunology

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❑ Neonatal medicine ❑ Neurology

❑ Other (*please specify)* …….. ……..

12. How would you describe the ethnic background of the service caseload? *(Please tick the appropriate box below)*

❑ Predominantly White British

❑ Predominantly ethnic minority populations

❑ A mix of both

13. Would you describe the service as local, regional or national? *(Please tick all the appropriate boxes below)*

❑ Local

↳ *If local, please name all the PCTs you provide services for*

……..
……..
……..
……..
……..

❑ Regional

↳ *If regional, please name all strategic health authorities and/or PCTs which you provide services for*

……..
……..
……..
……..
……..

❑ National

↳ *If national, please name all the strategic health authorities which you provide services for*

…….
…….
…….
…….
…….

14. What is the geographical profile of the population served by your service? *(Please tick all the appropriate boxes below)*

❑ Urban (population >200, 000)

❑ Large town (population 50,000 to 200,000)

❑ Small town (population <50,000)

❑ Rural

15. Aside from age and geographical boundaries, do you have any explicit criteria for *excluding* children from the service? *(Please tick the appropriate box below)*

❑ No

❑ Yes

↳ *If yes, please provide details below*

…….
…….
…….
…….....
…….

16. **Are you aware of any groups of children/families who are *not* using the service?** (For example, children with particular health needs, travelling families, families who do not use English as a first language, ethnic minority populations, asylum seekers, socially/economically disadvantaged groups, recent migrants)

❑ No

❑ Yes

↳ *If yes, please provide further details of who these groups are*

…….
…….
…….
…….

17. **Do you have strategies in place to help "hard to reach" groups access this service?**

❑ No

❑ Yes

↳ *If yes, please provide further details*

…….
…….
…….

THE STAFF

This section asks about the staff involved with the care closer to home service. It begins by asking about team members. It then goes on to ask about staff from other agencies providing input to the service, and about any difficulties with staff recruitment and retention.

18. Are there any nurses in the team providing care closer to home?

❑ No

❑ Yes

↳ *If yes, please provide details below*

Members of the care closer to home team: Nurses			
Staff	**Type of nurse** *(e.g. specialist, advanced, community etc.)*	**Band**	**Number of whole-time equivalent hours devoted to providing this service- exclude time devoted to other services** *Please express as 1.0 for full time, 0.6, 0.8 etc.*
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			
9.			
10.			

19. Are there any allied health professionals in the team providing care closer to home?

❑ No

❑ Yes

↳ *If yes, please provide details below*

Members of the care closer to home team: Allied health professionals			
Staff	**Type of allied health professional** *Please specify type of therapist (e.g. play, occupational, physio, speech etc.)*	**Band**	**Number of whole-time-** **equivalent hours devoted to providing this service- exclude time devoted to other services** *Please express as 1.0 for full time, 0.6, 0.8 etc.*
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			

20. Are there any paediatricians in the team providing care closer to home?

❑ Yes (please go to question 20a)

❑ No

↳ ***If no, do you have a named doctor you can contact for clinical support and advice?***

❑ No (if no, please go to question 21)

❑ Yes

↳ *If yes, please specify which type of doctor by ticking the appropriate boxes below*

❑ Paediatrician
❑ GP
❑ Other *(please specify)*…….

↳ **Please go to question 21**

20a. Please provide details of the paediatricians in your team in the box below.

Members of the care closer to home team: Paediatricians			
Staff	**Type of paediatrician** *(e.g. consultant, community, specialist, general etc.)*	**Level** *Please specify whether junior doctor, staff grade/associate specialist or consultant*	**Number of sessions per week - devoted to providing this service- exclude time devoted to other services**
1.			
2.			
3.			
4.			
5.			

21. Are there any social workers in the team providing care closer to home?

❑ No

❑ Yes

↳ *If yes, please provide details below*

Member of care closer to home team: Social workers			
Staff	**Type of social worker** *Please specify type of social worker (e.g. Specialist, advanced)*	**Grade** *(e.g. social worker, senior social worker)*	**Number of whole-time-** **equivalent hours devoted to providing this service- exclude time devoted to other services** *Please express as 1.0 for full time, 0.6, 0.8 etc.*
1.			
2.			
3.			

22. Are there any staff from other professional backgrounds (e.g. nursery nurse, play worker, teacher etc.) in the team providing care closer to home?

❑ No

❑ Yes

↳ *If yes, please provide details below*

Member of care closer to home team: Other (e.g. nursery nurse, play worker, teacher etc.)			
Staff	**Type of other**	**Band/Grade**	**Number of whole-time-** **equivalent hours devoted to providing this service- exclude time**

			devoted to other services *Please express as 1.0 for full time, 0.6, 0.8 etc..*
1.			
2.			
3.			
4.			
5.			

23. Do staff from any agencies other than your trust provide input to this service? *(please tick the appropriate box below)*

❑ No

❑ Yes

↳ *If yes, please provide details of these organisations and staff by ticking the appropriate boxes below*

❑ Other NHS provider (PCT or NHS acute trust)

❑ Local authority provider

❑ Community and voluntary sector provider

❑ Private

❑ Other *(please describe)* …….

24. We are also interested in whether you have difficulties with recruitment and retention of staff within the service. Have you had any unfilled posts over the past year?

❑ No

❑ Yes

↳ *If yes, please provide further details below*

Staff vacancy	Profession	Band/ Level / Grade	What has been the vacancy rate over the past year?	Please state the main reason for unfilled post
1.				
2.				
3.				
4.				
5.				

THE ORIGIN OF THE SERVICE

25. How long has the service been in operation? ……years ……months

26. Was it developed in response to a government initiative? *(Please tick the appropriate box below)*

❑ No

❑ Yes

↳ *If yes, please specify which government initiative below*

…….. ……..

PLANS FOR THE FUTURE

27. Are there any services you would like to provide but are currently unable to offer to families?

❑ No

❑ Yes

↳ *If yes, please describe these services below*

…….. …….. …….. ……..

28. Are there any special services or innovations planned for the future that you would like to tell us about? If so, please provide details below.

…….. …….. …….. ……..

FUNDING AND BUDGETS

29. Is there any other funding for the service other than through direct PCT commissioning? *(Please tick the appropriate box below)*

❑ No

❑ Yes

↳ *If yes, please give details below*

…….. …….. ……..

30. Is the total budget for this service separate from budgets for other services?

❑ No

↳ *If no, please go to question 34*

❑ Yes

↳ *If yes, please state the total budget for this service for the Last financial year (2007-2008):* **£**

_____

31. Please can you tell us how much of this budget was for *staffing?*

In the last financial year (2007-2008), the budget available for staffing was:

£ _____

32. We are also interested in any changes in budgets for *this* care closer to home service in the next financial year (2008-2009). It would therefore be helpful if you could tell us about the budget for the next financial year.

The total budget for the next financial year (2008-2009) is: **£**

_____

33. If your budget has changed, please can you tell us why this has happened in the space provided below.

……

……

……

……

……

……

……

……

……

……

……

……

The service budget has changed for the following reasons:

N.B. If you are *unable* to answer the questions on funding and budgets (questions 30- 33), please provide details of the manager we should contact to obtain this information.

Contact details of manager with information on funding of the service

Name: ……

Address: ……

……

……

Email: ……

Tel. number: ……

SERVICE EVALUATION

34. Has any evaluation or audit of the service been carried out? *(Please tick the appropriate box below)*

❑ No

❑ Yes

↳ *If yes, please provide details of who we should contact to obtain the evaluation or audit report*

Name: ……

Address: ……

……

……

Email: ……

Tel. number: ……

Alternatively, feel free to return the report with this questionnaire

FURTHER COMMENTS

35. If you would like to make any further comments about the provision of paediatric health care closer to home, or this survey, please feel free to do so on the next page.

Further comments:

……

……

……

……

……

……

……

……

……

……

Thank you for taking the time to complete the questionnaire

YOUR ORGANISATION AND CONTACT DETAILS

Please can you confirm which NHS trust you are responding on behalf of

Name of trust:

_____

It would be helpful if you could provide us with your contact details in case we have any questions about your response to the survey.

Name: _____

Telephone number: _____

Email: _____

Please return the questionnaire in the pre-paid envelope provided, or to:

Social Policy Research Unit, University of York, FREEPOST YO378

Heslington, York YO10 1GY

Please note all information provided will be treated as strictly confidential

Appendix 3: Case study site profiles

Site W

Socio-demographic context[15]

Site W was a large city with a population of just under 1 million. Around a quarter is aged 0-17 years[16] and the average age of the population is slightly lower than the national average. It has an ethnically diverse population, with just over a third classed as being from black and ethnic minority groups (i.e. non 'White-British'). The area is ranked highly among the Indices of Deprivation (IMD, 2007). The city covers three PCTs, one of which (see below) is the focus of this case study. When looking at the data for the population of this PCT alone, rather than the whole city, there are some subtle differences in the socio-demographic context. The age profile of the PCT shows a greater bias towards young people compared to the age profile of the whole city, with just under a third of the population aged 0-17 years[17]. Ethnic diversity increases substantially with around a quarter classed as White British. There are a range of ethnic groups among the population within this PCT, with relatively large groups of residents from Indian, Pakistani and Caribbean backgrounds.

Local organisational context

The case study in this site began initially with one PCT (A), however due to its strategic links with two other local PCTs both in terms of provision and commissioning, the two additional PCTs (B and C) were included for contextual purposes. The focus of the case study however remained with the provision for the population of PCT A. Across the three PCTs, commissioning for children's services is done on two levels. The first level of commissioning is for universal services, which is done individually by each PCT for their own population. The second level of commissioning is for specialist services for ill children, which is led by PCT A on behalf of all three PCTs. The provider arm of PCT C hosted specialist services for children for all three PCTs. Figure # demonstrates this. Secondary care for children within the boundaries of PCT A is provided by one acute trust. In the broader city area, secondary care for children is also provided by two other acute trusts.

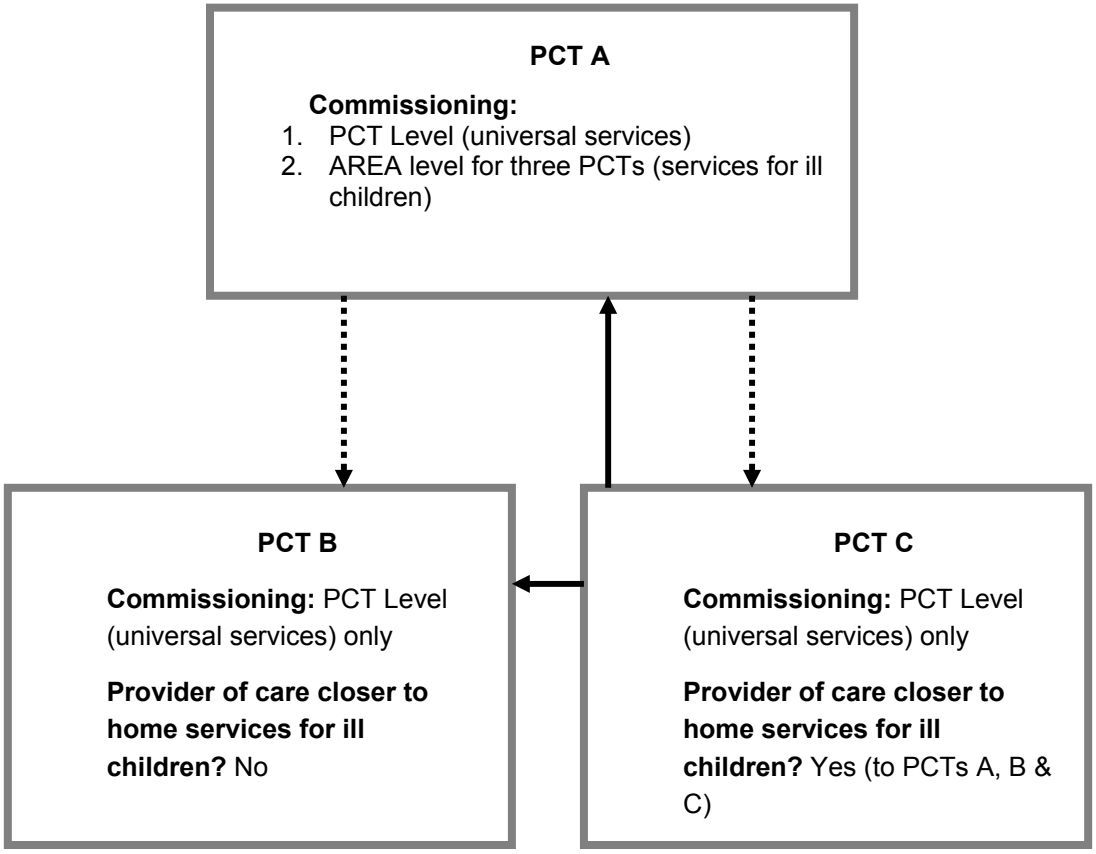
The service model

The case study looked at a large Community Children's Nursing Team provided by PCT C for the population within its own PCT boundary as well as the populations of PCTs A and B. The team consists of five smaller teams. Two of these teams are specialist (palliative care and complex

[15] Based on data from the 2001 census
[16] Calculated by us based on 2001 census data
[17] Calculated by us based on 2001 census data

care) and provide services to children within all three PCTS, and the remaining three are generic teams aligned to the three PCTs in the area. The focus then narrowed to the generic team (hereafter referred to as the generic CCN team) provided for the population of PCT A. The objective of this team is to keep children out hospital where appropriate, and any child with a clinical need can be referred. Service hours are 8.30am-6pm Monday to Friday, however there is also a reduced service at weekends for emergencies provided by two nurses taken from the larger CCN team and provided for the whole city. The generic CCN team is comprised of 7 community children's nurses, including five band 6, one band 5 and led by a band 7. They have a caseload of approximately 150 patients (excluding dressings) and perform a wide range of care activities, including dressings, naso-gastric tube support, line flushes, blood taking, button changes, IV antibiotics, injections, enteral feeding, and maintenance for oncology treatment. Anyone can refer to the service; health professionals can call through to the team, while self referrals from parents go through a message service. The generic CCN team will take children up to 16 years of age, or 19 years of age if in a special school. Care settings include the home, school, nurseries and refuges. When the child comes to the end of treatment or no longer has a clinical need, they will be discharged from the team. Children with complex needs are transferred to adult services.

Figure A.1 Commissioning and provider structures



Site X

Socio-demographic context[18]

Site X PCT covered a mixed rural and urban area and, in 2001, had a total **population of around 600,000. The mean age of residents at this time was slightly younger than the national average and just under a quarter of the population was under 18 years old**. Census figures show the area to have lower than average ethnic diversity, but more

[18] Based on data from the 2001 census http://www.neighbourhood.statistics.gov.uk/dissemination/ unless otherwise stated. 'National average' or 'average' in this section refers to the national average for England.

recently there has been an increase in the number of migrants from minority ethnic groups, particularly from eastern European countries. The area has relatively low levels of deprivation overall, with the majority of the population living in the least deprived or second least deprived areas in the country (IMD 2007[19]). However, pockets of deprivation and relatively low life expectancy remain, particularly in urban areas.

Local organisational context

This PCT had been formed through the merger of 3 previously existing PCTs, and some variation in service provision reflecting the old PCT boundaries still existed. Two acute hospital trusts operated in the PCT area, one in the south of the county and one in the north. PCT provider services were notionally split from commissioning and the PCT provider arm delivered most universal services uniformly across the county. However, separate models of community paediatrics and CCN provision remained. In the north of the county, community children's nursing was provided by the PCT provider arm, although most of the nurses were based at the district general hospital. In the south, most children's CCTH services were provided directly by the acute hospital trust.

The service models

In light of the clear distinction between the two CCTH services in operation across the county, each of which had its own model of service delivery and an entirely separate caseload, it was decided that this site should be split into two separate case studies, one focussing on a service in the north of the county (hereafter Xa), and one in the south (hereafter Xb).

Xa (north of the county) – Nurse practitioner service for acutely ill children

This service was part of a larger CCN service consisting of 3 teams under the management of a single nurse facilitator. One team provided children's continuing healthcare, one team provided CCN services for children with long-term conditions, and the final nurse practitioner team provided short-term interventions for children who were acutely ill. This nurse practitioner team provided the focus for our case study. It was the newest of the CCTH teams, set up about 3 years prior to our fieldwork, and was explicitly aimed at reducing acute admissions to hospital. The team consisted of 4 full-time band 7 nurses and one band 6 nurse 30 hours per week. Children could be referred to the nurses by a GP or other health professional, but self-referrals would not be accepted. Intensive support was provided to referred families for up to 5 days, including telephone assessment and advice, as well as home visits and frequent monitoring. Strict protocols were in place to manage risk and the nurses could refer directly to hospital if children

19 http://www.communities.gov.uk/communities/neighbourhoodrenewal/deprivation/deprivation07/

deteriorated whilst at home. Hours of operation were 8am – 9pm, 7 days a week, and 24 hour telephone support was also available.

Xb (south of the county)– Oncology Specialist Nursing Service

As in the north of the county, there were 3 arms to the CCN service in the south of the county, one facilitating children's continuing healthcare, one providing generic CCN services and CCTH for children with long-term conditions, and one made up of specialist nurses. These services were provided by the acute trust as part of an integrated Child Health Directorate and based on site at the hospital in the south of the county. The focus for our case study was the specialist oncology outreach nursing service, part of the specialist nursing team, but linked closely with the acute oncology service. There were 2 oncology nurse specialists, one band 7 nurse working 30 hours per week, and one band 6 nurse, also for 30 hours. The nurses' primary focus was supporting children with cancer and other haematological conditions who used the district general hospital in the south of the PCT. However, shared care arrangements with tertiary hospitals outside the PCT area meant they also provided care for some children with cancer in the north of the PCT. The service operated within office hours, Monday to Friday, and provided planned interventions such as taking blood or maintaining Hickman lines. Nurses did administer some home chemotherapy, but there was an emphasis on skilling up parents and children to self-manage and thus they also trained parents to give chemotherapy medication themselves. As with the oncology service in site Y, psycho-social support was seen as an important element of the service.

Site Y

Socio-demographic context[20]

Site Y PCT covered a city that had a population of around half a million people at **the time of the 2001 census. The mean age of the population was close to the national average at that time, and just over one fifth of its residents were under 18. In 2001 the city had below** average levels of ethnic diversity, but city council figures suggest that the numbers of people from non-white British backgrounds has increased considerably since then. The city has relatively high levels of deprivation, with over a quarter of its neighbourhoods ranking in the top 10% most deprived in the country (IMD 2007[21]).

[20] Based on data from the 2001 census http://www.neighbourhood.statistics.gov.uk/dissemination/ unless otherwise stated. 'National average' or 'average' in this section refers to the national average for England.
[21] http://www.communities.gov.uk/communities/neighbourhoodrenewal/deprivation/deprivation07/

Local organisational context

Site Y PCT was coterminous with the city council boundaries at the time of our research (2008/9) and had both an acute teaching hospitals trust and a children's hospital trust within its boundaries. Children's Trust arrangements were still developing at the time of our fieldwork and the focus initially was on aligning universal health and LA services. Services for *ill* children were thus largely unaffected at this time. PCT provider and commissioning roles had been clearly split and the PCT provider arm offered mainly universal services. Most specialist community, as well as acute, children's services were provided by the children's hospital trust, including the oncology outreach service which was the focus of this case study. The children's hospital provided a tertiary service to the region as well as district general hospital services for children living in site Y.

The service model

Our case study focussed on the paediatric oncology outreach service provided by the children's hospital trust. This was one of several specialist nursing outreach services that had developed out of acute children's hospital services in the absence of a more general CCN team. The service had broad regional coverage, with the aim of bringing care closer to home for all children under the care of site Y paediatric oncologists, and took on about 60 new referrals per year. For children who lived outside the PCT boundaries, this often meant liaising with district general hospitals and CCN teams in their local areas, although nurses also provided care directly into the home. For children living within site Y, care usually took this latter, more direct form. For all families, however, the nurses assumed a 'key worker' role and aimed to provide a bridge between the home and hospital. The team was made up of four band 7 nurses, two part-time and two full-time. Interventions provided in the home ranged from administering chemotherapy and intravenous antibiotics, to blood transfusions and gastronomy care. Nurses would also train parents to administer some elements of care themselves, such as central line care. There was a strong emphasis on psychosocial support, and nurses had a role in palliative care. The palliative care service operated around the clock, but for all other services the team operated office hours Monday to Friday, with additional half-day weekend cover.

Site Z

The socio-demographic context[22]

Site Z was a small city with a population of approximately 180,000.The Indices of Deprivation indicate the area has relatively low levels of deprivation, and data sources show that just under a third of households are owned outright. Approximately two fifths of households are owned with a mortgage or loan. The average age is slightly higher than the average

[22] Based on data from the 2001 census

age nationally, and just under a fifth of the population is aged 0-17 years[23]. It has relatively low levels of ethnic diversity with most of the population classed as White British. The city is located within a large PCT which has a mix of rural and urban areas and has a similar socio-demographic profile. For example, the Indices of Deprivation again indicate relatively low levels of deprivation for the whole PCT and a population predominantly classed as White British. Just over a third of households are owned outright and just under two fifths are owned with a mortgage or loan.

The organisational context

The focus of the case study began initially with the PCT, which covers the city described above as well as a number of large, medium and small towns and large rural areas. The commissioning structure for the PCT at the time of the study was divided into three work streams (Children and Young People, Urgent & Unplanned Care, and Continuing Care). This structure however, has since changed and operates using a different commissioning framework. The PCT also works jointly with two local authorities for the Children's Trust arrangements. Services for ill children are provided by both the provider arm of the PCT and six acute trusts[24]. Provision from the provider arm of the PCT is in the form of a Community Children's Nursing Team. This service is for children with complex and life limiting conditions, and is provided to just one area of the PCT and not the PCT as a whole. Of the six acute trusts, one provided Child and Adolescent Mental Health Services only, while the remaining five provided a range of paediatric services. Across these five trusts, care closer to home services included Community Children's Nursing and a Children's Assessment Unit (CAU). The CAU was the focus of the case study, and is based in a hospital located in the city described above.

The service model

Although not physically closer to home, the CAU plays a key role in preventing inpatient admission to hospital so that children can be sent home more quickly and length of stay is reduced. The unit operates 9am-10pm Monday-Friday, and referral can be made by GPs, A&E, and walk-in centres. Where the child has previously been discharged from the CAU within the last 24-48 hours, the parents can call the CAU if required and may be advised to return to unit. It is staffed by up to two nurses and one healthcare assistant per shift, plus a consultant for acute on call. The consultant is one of six who work on a rota basis. The nurse staffing are taken from a larger group of nurses who are rotated between the paediatric inpatient ward and the CAU. Within the nurse staffing, there are four deputy sisters. The caseload is split between unplanned and planned visits, takes over 300 admissions a month, and has a capacity of 8 bed spaces. The acute unplanned portion of the caseload includes children with fever,

[23] Calculated by us based on 2001 census data
[24] This does not include care trusts or ambulance services

respiratory presentations (asthma, pneumonia, bronchiolitis, croup) gastroenteritis, vomiting, fits, seizures, abdominal pain, kidney conditions, bleeding disorders, and feeding problems in neonates. Whilst in the CAU, children will be assessed by a nurse and junior doctor and then a registrar. After assessment (including observations and investigations) a decision will be made as to whether the child should be sent home, treated, admitted to the inpatient ward or undergo further observation.

Table 34. Characteristics of the services in our case studies

Service	Settings of care	Referral Sources	Discharge	Staffing	Cover	Caseload	Clinical Care Activities
Generic Children's Community Nursing Team (site W CCN team)	Wherever the child goes, including, home, school, nurseries, refuges	Hospitals, GPs, Social Services, Schools, Self-referral	Children are discharged when there is no longer a clinical nursing need	Band 7 x1 Band 6 x 5 (F/T & P/T) Band 5 x 1 (P/T)	8.30-6pm Monday-Friday. Weekends: reduced emergency service covering all three PCTs in the area.	150 (excluding dressings); up to 25 visits a day	Any clinical need (e.g. changing NG tubes, line flushes, IV antibiotics, enteral feeding, dressings)
Nurse Practitioner Service (site Xa NP service)	Wherever the child is living or staying at the time: home, grandparents' house, etc.	GP (inc practice nurses), out of hours service and hospital practitioners. Do not take self-referrals.	Short term intervention – usually 3-5 days. If children need longer term care they may be transferred to the 'core' CCN team.	Band 7x4 (F/T) Band 6 (30hpw)	8am – 9pm, 7 days a week (including bank holidays) plus 24 hour telephone line	499 referrals in2008/9 571 referrals in 2009/10 (this includes re-referral of the same child)	Manage and monitor children with acute illnesses including (but not limited to) gastroenteritis, bronchiolitis, asthma, children who are febrile, etc.
Specialist Outreach Nurses (Oncology) (site Xb SON-L service)	CCTH delivered at home, but nurses also see children on the ward and in outpatient clinics. Also school (for teaching and advice)	Via paediatrician	Keep patients on active caseload throughout the whole treatment, and longer if they need further blood testing or treatments	Band 7 (30hpw) Band 6 (30hpw)	9am-5pm Monday - Friday	22 children on active chemotherapy 75 on long-term follow-up 50 other haematological conditions (Sickle Cell Disease, thallasaemia, congenital neutropenias)	Administer some chemotherapy, order medications, do routine maintenance of Hickman lines, give counselling, physiotherapy, take bloods, GCSF, some palliative care.

Service	Settings of care	Referral Sources	Discharge	Staffing	Cover	Caseload	Clinical Care Activities
Specialist Outreach Nurses (Oncology) (site Y SON-R service)	Home, schools (for teaching and advice)	Inpatient ward, out-patient clinic	Involvement of the outreach team stops at the end of treatment	Band 7 x 4 (F/T & P/T)	24/7 for end of life care, Monday-Friday, and half-day weekends	60 new referrals a year	Chemotherapy, IV antibiotics, dressings, blood tests, passing NG tubes, training families in central line care, gastronomy care, palliative care, transfusions, infusion pumps
Children's Assessment Unit (site Z CAU)	CAU (separate unit on hospital site)	GPs, A&E, Walk in centre, self referral for known children only	At discharge, family is given open access for between 24-48 hours during which time they can call the CAU	Up to 2 nurses and 1 HCA per shift, with a Paediatric Consultant on call. Nursing staff shared with the inpatient ward	9am-10pm Monday-Friday	300+ admissions a month	Assessment, investigations, observations, treatment

Appendix 4: Topic guide for staff

Service Commissioners

Introduction & consent process

- Introduce self
- Go through information sheet
- Answer any questions
- Go through consent form and ask participant to sign consent form

Background

- Explore information about the PCT
    - Geographic boundaries of the PCT
    - Structure - directorates, provider/commissioner split, model of PCT provision (social enterprise/ arms length provider org etc)
    - Key providers (hospitals, children's trusts, etc)
    - Key partners (local authority, other PCTs, etc)
    - Recent history (reconfigurations/mergers/deficits, etc)
    - Demographics of local population/ particular needs (discuss sources of information and any gaps in information, etc)

Commissioning structure

- Explore details of the commissioning structure
    - Where/how are decisions about commissioning children's health services made (boards, planning rounds, etc)?
    - Who leads?
    - Who else is involved (agencies and individual roles)?

- What is the history of these structures?

Defining 'care closer to home'

- What is understood by the term "care closer to home" (in the context of children's services)?
- What would/does care closer to home for children look like?
- What has influenced this understanding (i.e. where did it come from)?
- What services does the PCT commission that fit this definition?

Commissioning care closer to home for children and young people

- Explore where/how commissioning for care closer to home fits into the commissioning structure (runs through whole thing/ is a separate strand, etc)
- What processes are/have been involved in commissioning care closer to home for children (audits/needs assessment/business case submission etc)?
- Service user involvement in these processes
- Types of contract (for each care closer to home service)
- Budgets (for each care closer to home service) if known (if not known/not clear, discuss reasons)

Drivers/Priorities

- Explore PCT's current commissioning priorities for children's services.
- Key drivers involved (policies/targets/financial issues, etc) and how?
- Relative priority of commissioning care closer to home services in this context (i.e. against other policies/strategies)
- Again, what key drivers are involved?

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- Sources of (extra) funding for care closer to home services (explore issues such as ring fencing, etc)
- Impact of the NSF for CYP&MS? Why? What factors have influenced this?
- Kind of policy needed to further develop and improve commissioning for care closer to home? Why?

Evidence

- Evidence used to influence decisions about commissioning children's care closer to home.
- What kinds of evidence are missing/what would be useful? Why?
- Any evaluations/audits of existing models/services?

Barriers

- Explore any barriers/blocks to commissioning care closer to home services for children.
- What are they?
- Impact of barriers/block on commissioning/development of these services.
- What is needed to overcome these barriers?

Future plans

- Plans in place to commission new care closer to home services in the future
- Plans in place to develop/make changes to existing care closer to home services for children? Again, please tell us about these.
- Other anticipated changes (locally, regionally or nationally) that could affect the commissioning or provision of care closer to homes services for children

- Anything else?

END OF INTERVIEW

Service Providers

Introduction & consent process

- Introduce self
- Go through information sheet
- Answer any questions
- Go through consent form and ask participant to sign consent form

Describing the service

- Explore information about the service
    - Objectives of the service
    - Referral to service
    - Care pathway to service from initial entry into health service
    - Staff in the team (numbers, general roles)
    - Staff not in team but who team liaise with
    - What services/treatments are offered (clarify what each of these are, and how these meet the objectives)
    - Settings of care/delivery
    - How is discharge organised and facilitated
    - Budget/costs of service
    - How many children cared for (weekly caseload)

Service origins

NOTE: for strategic managers ask in the context of the wider service system

- When was the service set up
- Did it evolve from another service
- Initial aim of service (is this still part of current objectives)?
- Why the service was set up (in response to unmet need, patient

demand, restructuring)

- What evidence, if any, was used to support the setup of this service (other models of good practice)

Workforce

- Additional training/accreditation of staff
- Recruitment & retention issues – why, and impact of this.
- Roles of the team (specialism, skill mix, supervision etc) and how they have evolved since the start of the service

Service users/patients

- How the service deals with condition diversity/need
    - Which conditions?
- How the service deals with population diversity
    - Which populations?
- What the service cannot provide based on condition/population need
- Difficulties in providing the service in certain settings (e.g. home, clinics)
- Difficulties in reaching patients who live in hard to reach areas
- Problems with accessing/pathway to service
- Continuity of care – how this is done
- How patients are involved in the development of the service

Challenges of providing the service

NOTE: When asking this of senior level manager, the question should be asked in context of the provider agency; when asked of staff/service managers, it should be asked in terms of service level provision

- Difficulties of providing this service.
- How difficulties are addressed
- Difficulties liaising with other agencies, and impact of this

Benefits of the service

- How the service improves patient experience
- How need would be met if the service was not available
- Meeting the needs of patients
- Patients views/opinions of the service

Impact of policy

- Impact of Children's NSF on the provision and delivery of the service
- Impact of other policy on the provision and delivery of the service
- Policy needed to further develop and improve the service

Changes to the service, future plans and restructuring

- New developments planned for the service
- How new developments will improve the service?
- Impact of the new developments on this service and other services/the department
- Anticipated changes to the service that may have a negative impact
- Other comments

END OF INTERVIEW

Appendix 5: Topic guide for children and young people

Topic Guide: Children & Young People

NOTE: The topics presented below will be used to guide the interviews; however it is important to note that the methods for *facilitating* the discussion will vary depending on the child. A flexible approach will be taken for the children's interviews, where different methods will be used depending on the child's age, abilities and personal preferences. These methods include drawings, making posters, making lists, and using figurines to help the child express their views. Previous experience of doing interviews with children show that a flexible approach is needed, as some children may wish to talk, but other children may wish to express their views through drawings, creating scenes with dolls, writing messages etc. In addition where a child does not communicate verbally, or uses english as a second language, alternative methods of communication (e.g., translators, 'Talking Mats') will be used as appropriate. For all interviews, parent's advice will be sought on how best to conduct the interview with the child. Please also note that for convenience, [x] refers to the health condition of the interviewee and [y] refers to the service they are in receipt of.

Materials:

- Digital recorder
- Digital camera (to take pictures of any posters/drawings done by child)
- Pens, crayons, paper, stickers (for children/young people to make posters, draw pictures during interview)
- Question dice with warm up questions
- Post box for children to write and post messages about the help they get
- Graffiti book for older children to write messages about the help they get
- Playmobil (for children to use to help when explain situations)
- Stop/pause/start cards to facilitate the interview
- Cardboard figures for children to colour in during interview
- Consent form
- Information sheet

Introduction to interview & consent process

INTRODUCTIONS

- Introduce self
- Explain what project is about and the importance of young people's views
- Explain that you will be talking to other child who use the same service as the interviewee
- Explain what you would like to talk about
    - *You*
    - *Your family*
    - *The places you get help with [insert name of condition/injury as appropriate following discussion with parent]*
    - *What you liked and didn't like about the help you get*
    - *Ideas about how the help could be improved*
- Show child some of the resources they can use during the interview (e.g. coloured paper, pens, stickers etc.)
- Emphasise that there are no right or wrong answers

CONSENT AND CONFIDENTIALITY

- Explain confidentiality, including when researcher would have to break it.
- Explain what will happen to the information collected and how researcher will maintain confidentiality
- Emphasise that child can skip questions, take a break, or stop the interview whenever s/he wants *(Where appropriate use traffic light cards to practice stopping/starting, taking a break, skipping a question, don't understand*).
- Check child is happy to take part and ask child to sign consent form
- Researcher to sign promise of confidentiality on the consent form
- Ask permission to use tape recorder and set it up with child
- Discuss with parent and child what parent is going to do during the interview

Warm up questions

YOUR FAMILY

- People the child lives with
- Ages of brothers and sisters
- Pets

Draw map of house/ family members

A BIT ABOUT YOU

- About the child
- Likes and dislikes
- School

Questions about the care closer to home service

Your Mum/Dad tells me you have something called X/ that X happened, and that you go to Y/ that Y comes to see you to help you with that.

I don't know a lot about X and I have never been to Y/ never meet Y, so today I would really like to find out what that is like.

- What it is like having X

FOR SERVICES DELIVERED IN THE HOME

Do you think we could talk for a bit about what it is like when Y comes to see you at home because you have X?

- Who comes to visit
- Same/different person on different occasions
- What happens during visit

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- What other people in family do when Y visits (Mum/Dad/brothers/sisters?)
- How they feel about Y visiting them
- Parts they like about Y visiting them
- Parts they don't like about Y visiting them

FOR SERVICES DELIVERED IN HOSPITAL/OTHER SETTINGS

Do you think we could talk for a bit about what it is like when you go to Y?

- Transport to place
- Who goes with them
- What the family does when they get to place
- Where the child goes when they get to place
- Who they see, and if it's the same person every time
- How the child feels when they get there
- Parts they like about going to Y for help
- Parts they don't like about going to Y for help

OTHER PLACES YOU HAVE GONE FOR HELP

- Other places the child might have gone to get help with X?
    - *Prompt: Hospital, health centre etc*
- Transport to this place
- Who goes
- What the rest of your family does when at the place
- Where the child goes
- Who the child sees
- How the child feels about going to this place
- Parts they like about going to Y to get help
- Parts they don't like about going Y to get help

IDEAS ABOUT HOW TO MAKE THE HELP BETTER

So you have told me all about the help you get and what you like and don't like about, now I would like to talk about how to make the help you get better than it is at the moment. [Possibly refer to the list of things they didn't like].

- So we are going to pretend for a minute, that you are in charge of the help children get when they have X. If you were the boss, what would you do to make it better/improve it?

COOL DOWN

We are going to finish by sending a message to the people who are in charge of the help you get. I have a box here, where all the children who have taken part in the project can post these letters/messages. Do you want send a message?

OK so that's all the questions I have, is there is anything else you wanted to tell me that we haven't talked about so far?

END OF INTERVIEW

- Thank child for taking part in the project.
- Remind child what you are going to do with audio-tape & that you will send them a report.
- Ask child what they would like to do with anything they have made during the interview (leave it with the child/ have the researcher take it with them/ have the researcher take photographs of what they have made)

Appendix 6: Children's interview materials 1: sheets with boxes to make lists and notes (intended to be used on A3

The places I get help are:

Things that happen when I get help are:

I get to this place by:

The people who help me are:

When I get help in this place I feel:

The things that I like about the help and care I get are:

The things I don't like about the help and care I get are:

These are the things that I would change about my care:

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Appendix 7: Feelings board

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Appendix 8: Case study materials for children and young people's participation

A8.a Letter of invitation to parents re. child taking part in the study

ON LETTER HEADED PAPER

Name and address

Dear Parent

Earlier this year you were good enough to take part in a research project about your experiences in receiving care closer to home for your child. The information you provided was very useful to the project – thank you. As I mentioned when we met, we would also like to invite your child to take part in the project. Enclosed with this letter is an information leaflet which tells you more about this part of the project.

Once you have read the information leaflet, we would be very grateful if you could return the enclosed response form in the pre-paid envelope provided, so that we know whether or not you are considering letting your child take part. If you are interested in your child taking part in this part of the project, we will then telephone you to answer any questions you might have.

We look forward to hearing from you.

With thanks for your help.

Yours sincerely

[Name of researcher]
Research Fellow
Enc Information leaflet for parent for child (Case Study)
Response form
Pre-paid envelope

Social Policy Research Unit, University of York, Heslington, York YO10 5DD

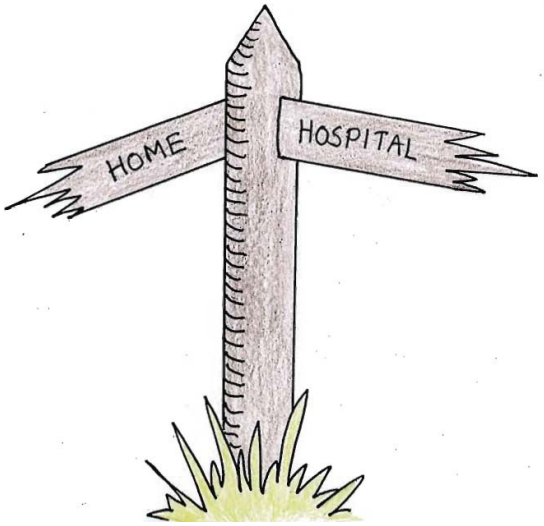
Tel: 01904 321950 Fax: 01904 321953 E-mail: spru@york.ac.uk

A8.b(1) Information sheet for children and young people (younger age group)

THE UNIVERSITY of York

spru | Social Policy Research Unit

Getting help when you are ill or injured: where is best?



Where should children get help when they are ill?

Have you been to hospital?

Does someone visit you at home to help you with an illness or injury?

Hello,

This is a letter from Gemma and Kate. We are doing a project about the places children get help when they have an illness or an injury.

We would like to ask you about the places you go to get help. Do you go to the hospital? Does someone visit you at home?

Can one of us visit you at home and ask you some questions about the places you get help?

If you want, we can do some drawing and make things.

If you think you would like one of us to visit, just tick 'YES' on the form and send it back to us.

One of us will then call you on the telephone to tell you more.

If you don't want one of us to visit you, just tick 'NO' on the form and send it back to us.

Thanks for reading this letter.

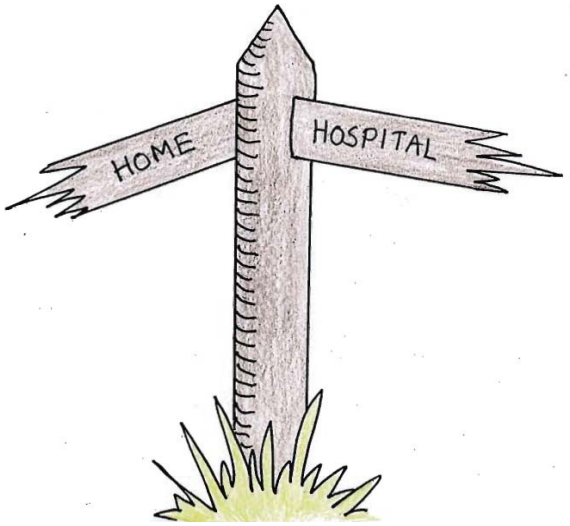
Kate & Gemma.

A8.b(2) Information sheet for children and young people (older age group)

THE UNIVERSITY of York

spru | Social Policy Research Unit

Getting help when you are ill or injured: where is best?



Where should young people get help when they are ill or injured?

Have you been to hospital?

Does someone visit you at home to help you with an illness or an injury?

What's it like?

What would make it better?

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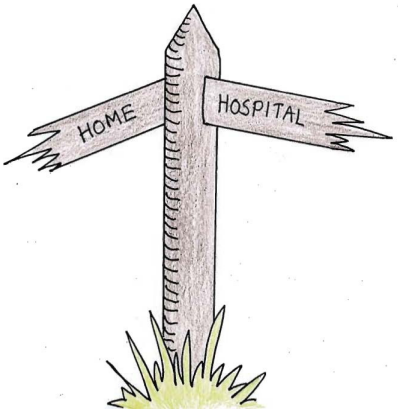
Project 08/1704/151

- Hi, we are researchers from the University of York. We're doing a project about the different places young people get help when they have an illness or an injury.

- We want to find out about the help you get when you are ill or injured, and what it was like for you.

- If you want to join in with this project, one of us will arrange to visit you at your house.

- We will stay for about an hour to talk about you, your family and the places you get help when you are ill or injured. We will also ask about what it was like. There are no right or wrong answers, we just want to hear what you think.



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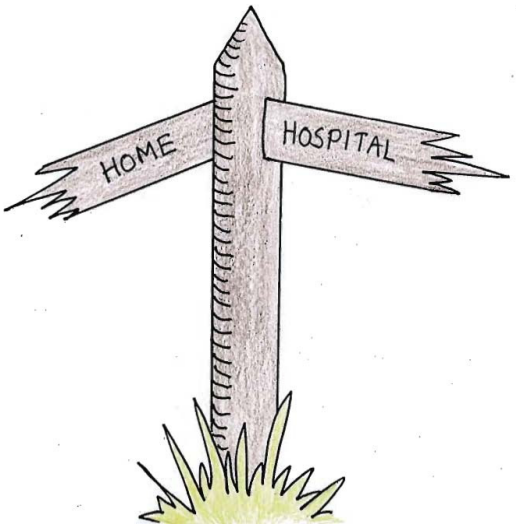
Project 08/1704/151

- We would like to record what we talk about so we don't forget any of it. We will do this using a digital recorder.

- We won't tell anyone else what you say (but you can if you want). We will write a report about what all the young people have told us, but we will *not* put any names in this report.

- Joining in with the project will not change anything about the help you get. When the project is over, we will send you a short report about what all the young people have told us, but we won't come back to your house.



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Project 08/1704/151

- **If you don't want to join in with the project, that's okay. If you don't want to join in just tick the box that says 'NO' on the reply slip and send it back to us.**

- **If you think you might like to join in just tick the box that says 'YES' on the reply slip and send it back to us. We will then telephone you to tell you more about the project and arrange a time to meet.**

Thanks for reading this leaflet.

Kate & Gemma.

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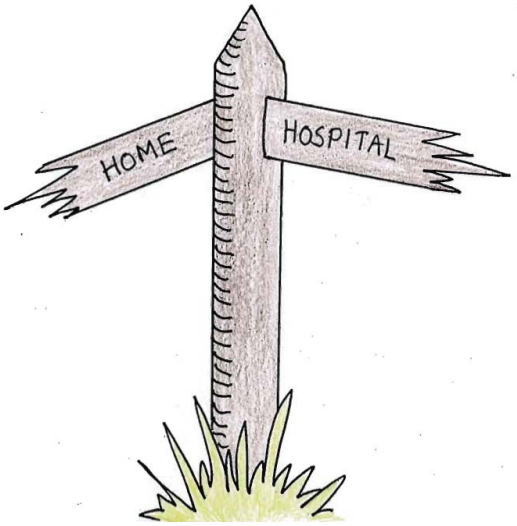


A8.b(3) Information sheet for children and young

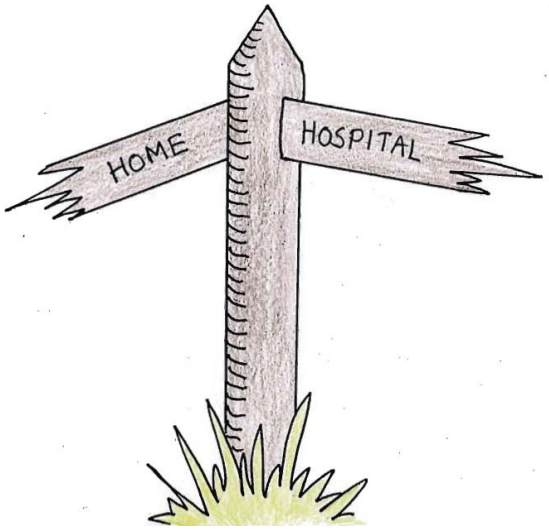
THE UNIVERSITY of York

spru | Social Policy Research Unit

people
age group)

(middle

Getting help when you are ill or injured: where is best?



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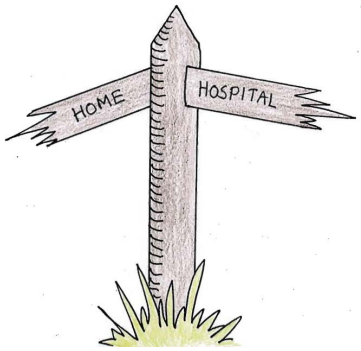
Hi, we are Gemma and Kate. We want to find out where children would like to get help when they have an illness or an injury. It's part of a project we are doing.



We would like to talk about the help you get and what you think of it.

Where should children get help when they are ill?

Have you been to hospital?

Does someone visit you at home to help you with an illness or injury?

What's it like?

What would make it better?

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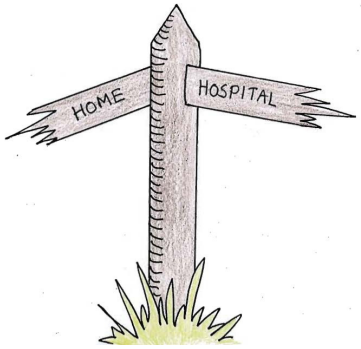

If you want to join in with this project, one of us will come to your house to meet you. We will stay for about an hour to talk about you, your family and the help you get. If you want, we can also do some drawing and make things.

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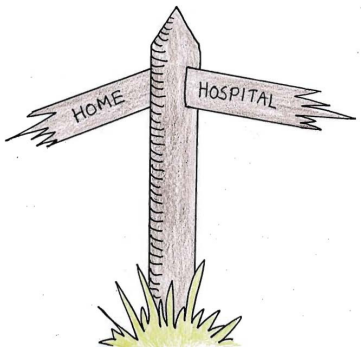
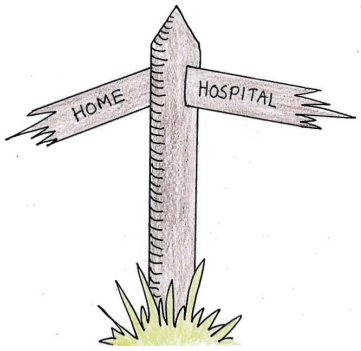
We would like to tape record what we talk about so we don't forget any of it. We would also like to take photographs of things you draw or make.



We won't tell anyone else what you say (but you can if you want). We will write a book about what all the children have told us, but we will *not* put any names in this book.



Joining in with the project will not change anything about the help you get. When the project is over, we will send you a book about what all the children have told us, but we won't come back to your house.

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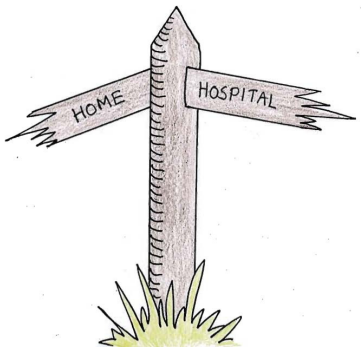
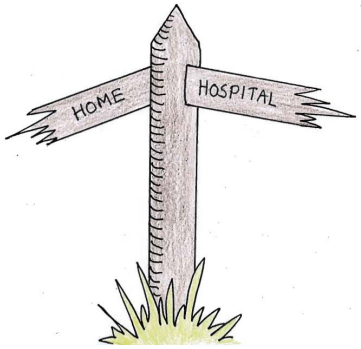
If you don't want to join in with the project, that's okay. If you don't want to join in just tick the box that says 'NO' on the reply slip and send it back to us.



If you think you might like to join in just tick the box that says 'YES' on the reply slip and send it back to us. We will then telephone you to tell you more about the project and arrange a time to meet.



Thanks for reading this leaflet.

Kate & Gemma.

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A8.c Information sheet for parents re child's participation

spru | Social Policy Research Unit

THE UNIVERSITY of York

The Help Children Get from Health Staff

A Research Study Funded by the NHS Service Delivery and Organisation Research and Development Programme

What is the purpose of the research project?

The purpose of the research is to find out about the views and experiences of children who receive heath care closer to home. We would like to know what they like and dislike about the help they receive, and any changes they would like made to such services. The aim of the study is to provide information for staff in the NHS who are in a position to improve children's health services.

What does taking part mean for my child?

Taking part in the project would involve your child meeting with a researcher for an interview about the health services they have received, particularly any health care closer to home. The interview will be informal. In other words, it should feel like having 'a chat'. We want to make taking part as fun as possible. Younger children will be asked if they want to do some drawing or use stickers to describe their experiences. Older children might want to draw diagrams, fill in charts, or do some writing. The length of the interview will vary depending on how much your child has to say. Interviews with younger children may take as little as twenty minutes. Interviews will be no longer than one and a half hours.

Where and when will the interview take place?

The researcher can meet with your child in your home, or anywhere else that suits you and your child. The interviews will also be arranged at a time that suits you and your child. Parents can be present during interviews if this is what they and their child would like. Older children can be interviewed over the telephone if this is what they prefer.

What will the researcher talk to my child about?

The interview will begin with a general chat about school, hobbies etc. The researcher will then ask about the help your child receives from health staff, how they feel about it, and anything they would like to change about it.

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Before the researcher begins talking to your child, she will spend some time explaining that everything discussed is confidential, that your child can skip any questions s/he doesn't want to answer, and that s/he can stop the interview at any time. Both you and your child will be asked to sign a form consenting to taking part and you will each be given a copy to keep.

Who is carrying out the research?

The research and the interviews will be carried out by the same researchers who interviewed parents earlier this year. Their names and addresses are given below. These researchers are all trained in carrying out research with children. You can find out more about them by going to the SPRU website - http:///www.york.ac.uk/spru/.

Will anyone be told what my child says?

No. Everything discussed will be confidential. His/her name will not be used in any reports on the research. It also means that anything a child tells a researcher cannot be discussed with others, such as parents, other family members, or health staff, without their

permission. The only time confidentiality would be broken is if a child tells a researcher something which suggests that s/he is in danger of being harmed by others.

Does my child have to participate?

No. Participation in this project is entirely voluntary. Whether or not your child takes part will have no influence on the care they receive from health services.

What are the benefits of taking part?

At the end of the project, your child will receive a report describing what children and young people think about the help they receive from health staff. This report will be colourful, including examples of drawing, writing, and art work by children who have taken part in the project. Children and young people who have taken part in previous research project have enjoyed receiving such reports.

Who cannot participate?

If your child has difficulty understanding that they are being asked to take part in a research project, and what taking part in the project involves, then s/he will not be able to participate. If you think this is likely, please let us know and we can discuss this further. In most cases we are able to explain the project to children using simple words so that even very young children are able to take part.

What happens next?

I would be grateful if you could pass on the enclosed information pack to your child.

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If they are definitely not interested in take part … That's fine, I understand. Please ask them to tick the 'No' box on the response form and return it to the researcher using the pre-paid envelope.

If they might be interested in taking part … Please make sure they tick the 'Yes' box on the response form and return it to the researcher in the pre-paid envelope. I will then contact them to answer any questions they have about the research. If they decide they want to participate, I will arrange a time to meet.

Further information

If you would like further information on this research, or have any questions before you decide whether or not you would like to participate, please do not hesitate to contact us using the details below. Please use Gemma as you primary contact point.
Many thanks

The research team

Lead researcher

Professor Gillian Parker 01904 321982 (gmp501@york.ac.uk)

Researchers

Miss Gemma Spiers 01904 321984 (gs525@york.ac.uk)
Miss Kate Gridley 01904 321988 (kg518@york.ac.uk)
Dr Janet Heaton 01904 321950 (jh35@york.ac.uk)

If you would like independent advice about this research, you can contact Dr Robert McMurray, Chair of the Humanities and Social Sciences Ethics Committee at the University of York: 01904 433432 (univ-hssec@york.ac.uk)

Social Policy Research Unit, University of York, Heslington, York YO10 5DD
Tel: 01904 321950 Fax: 01904 321953 E-mail: spru@york.ac.uk

A8.d Response form for parent re child's participation

THE UNIVERSITY of York

spru | Social Policy Research Unit

The Help Children Get from Health Staff

Parent's Response Form

Name: _____

❑ **Yes, I am interested in my child taking part in this research and have passed on the project information pack. Please contact me and tell me more about it.**

Please complete the information below so we can contact you about this project:

Contact Telephone:

_____

Contact E-mail:

_____

Contact Address:

_____

_____

_____

❑ **No, I would not like my child to participate in this research.**

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Project 08/1704/151

Please return this form to the research team using the pre-paid envelope attached.

Many thanks for your help

Social Policy Research Unit, University of York, Heslington, York YO10 5DD

Tel: 01904 321950 Fax: 01904 321953 E-mail: spru@york.ac.uk

THE UNIVERSITY of York

spru | Social Policy Research Unit

A8.e Response form for child/young person

Getting Help When You Are Ill or Injured: Where is Best?

Young Person's Response Form

Name: _____ Age:_____

Address: _____

_____

_____

_____

Please tick one of the following:

❒ I am interested in taking part in this project

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If you think you might like to take part in this project, please tell me your telephone number, so I can contact you and tell you more about it (please tell us either your house landline number or your parents number only).

My telephone number is: _____

The best time to call me is: _____

❒ **I am not interested in taking part in this project**

A8.f Parent's consent form for child's participation

spru | Social Policy Research Unit

THE UNIVERSITY of York

The Help Children Get from Health Staff

Consent Form

Please tick as appropriate

☐ **Yes, I consent to my child's participation in this research**

☐ I have read and understood the information provided.

☐ I am willing for my child to be interviewed about his/her experiences of using health care services closer to home.

☐ I understand that the information collected during the interview will be used to write up a report on the project, as well as articles for journals and newsletters.

☐ I understand that the information collected during the interview will be treated as confidential.

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☐ I understand that the information my child provides is subject to the Data Protection Act.

☐ **No, I do not consent to my child's participation in this research**

Please sign and date below to indicate your participation in this research:

Name: _____

Signature: _____ Date: _____ /_____ /_____

Contact Telephone: _____ Contact E-mail: _____

Contact Address: _____

_____

_____ Postcode: _____

Signature of researcher: _____Date: _____ /_____ /_____

There are two copies of this consent form. Please return one copy to the researcher and retain one for your own records.

Many thanks for your help

Social Policy Research Unit, University of York, Heslington, York YO10 5DD
Tel: 01904 321950 Fax: 01904 321953 E-mail: spru@york.ac.uk

A8.g Consent form for child/young person

spru Social Policy Research Unit

THE UNIVERSITY of York

Getting Help When You are Ill or Injured:

Where is Best?

Young Person's Consent Form

Please tick a box below

Have you read the project information sheet?	Yes ☐	No ☐
Do you know what taking part in this project involves?	Yes ☐	No ☐
Do you understand that you can change your mind about taking part at any time?	Yes ☐	No ☐

The person who talks to you will ONLY tell someone else what you

say if they think you are unsafe or being hurt. (Otherwise, everything will be private). Do you understand what this means? Yes ❒ No ❒

Can I [the researcher] record what you tell me using a digital recorder? Yes ❒ No ❒

Do you understand I will write down things that you tell me in a report? (But I will not used your name). Yes ❒ No ❒

Do you understand that I will not tell anyone that you have taken part in this project? Yes ❒ No ❒

Do you want to take part in the interview? Yes ❒ No ❒

Please write your name here: _____

Date: _____

I [the researcher] agree to keep all interview data confidential and anonymised.
Name of researcher: _____ Date:_____
Signature:_____

Appendix 9: Topic guide for parents

Topic Guide: Parents

Materials:

- Digital recorder
- Consent form
- Information form

NOTE: As it is likely that interview participants will be recipients of different types of services, questions will be asked relating to the topics below, but will be tailored to the service being used. For example, a question about how long a parent and child have been using the service may be relevant to individuals who have a long term illness that requires continuous use of a service, but not an individual who uses a service in a one-off capacity (e.g. an assessment unit).

Consent process & introduction

- Introduce self and explain purpose of the project
- Explain what topics the interview will cover
- Explain confidentiality
- Go through information sheet
- Answer any questions
- Ask parent if they would like us to inform their GP of their participation
- Go through consent form and ask parent to sign consent form
- Ask how much time the parent has for the interview

Family Background

- Who is in the family/house
- Ages of other children
- Family members nearby
- Involvement of parents and other family members in care of child

Background to child's condition

- Confirm child's illness/injury
- Length of illness/injury, & when diagnosed
- Duration of involvement with health services
- Impact of child's illness/injury on day to day life

About the service

- Start of using service - when
- Finding out about the service
    - Other services used for child's particular condition instead of service in question
- Accessing the service (referral)

Using the service

- What happened when using the service
    - Place
    - Staff
    - What the staff did
    - Who else went with the child

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- Parents - what they did while child was receiving treatment/therapy

Feelings about the service

- Using the service initially
- Using the service after a while
- Using the service now
- How the service met needs of family
- Aspects of the service that were helpful
- Favourable aspects of the service
- Aspects of the service that were not helpful
- Unfavourable aspects of the service
  - Possible changes to service
- Other places for getting health care
- How does current service compare with alternative services experienced?

Recommendations

- Suggested improvements for service and support

Conclusion

- Thank parent for interview
- Remind parent what will happen to audio recording and that we will send them a report

END OF INTERVIEW

Appendix 10: Staff participant materials

A10.a Staff participant materials (covering letter)

ON LETTER HEADED PAPER

Insert name and address here

Dear [Name]

I am contacting you about the possibility of your involvement with some research currently being undertaken by the Social Policy Research Unit, at the University of York. The research is looking at how children's health care services are delivered closer to home.

[Name of Trust] has been chosen as an area of study and as part of this, the research team would like to interview you about your experiences of providing children's health care services closer to home. I have enclosed an information pack about the research and what is involved, however if you have any questions, please do not hesitate to contact me.

I look forward to hearing from you.

Yours sincerely

Professor Gillian Parker

Director

Enc Information pack

A10.b Staff participant materials (information sheet)

THE UNIVERSITY of York

spru Social Policy Research Unit

Evaluating Models of Care Closer to Home for Children and Young People who are Ill

A Research Study Funded by the NHS Service Delivery and Organisation

Research and Development Programme

What is the research about?

This study is researching health care services closer to home in the NHS for children and young people who are ill. While the National Service Framework for children emphasises the importance of providing care closer to home for children and young people, the extent to which these services are available is unknown. The purpose of this study therefore is to examine if and how these services are delivered, whilst also identifying examples of good practice and ways in which service delivery can be improved.

What do you mean by care closer to home?

'Care closer to home' refers to services which are provided close to or in the home, so that children do not have to be admitted to hospital, or so that the hospital stay can be as short as possible. These services may be provided to a wide range of children, including those who have undergone surgery, those with an injury, an acute illness, a chronic condition, a life-threatening condition, a degenerative condition, technology dependent children, and babies who are medically fragile or of very low birth weight. They may be delivered in a range of settings, such as the child's home, outpatient clinics, day hospitals, GP practices, day nurseries, or schools.

Who is carrying out the research?

The project is being carried out by researchers from the Social Policy Research Unit (SPRU) at the University of York. Our names and contact details are provided below. SPRU has a lot of experience in undertaking

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research with children, families, and service providers. You can find out more about SPRU by visiting our website at http://www.york.ac.uk/spru.

Why have I been asked to take part in this research?

The NHS trust you work in has been chosen as a study site for the project. This means that we will be asking various members of staff working in this trust who are involved in providing care closer to home to participate in the research. As you are involved in providing health care closer to home for children and young people who are ill, you may be able to help us understand how such services are delivered, what works well, and how they can be improved in the future.

What does taking part in this research involve?

Taking part in this research will involve an interview with you. The interview will take part in a location of your choice (e.g. your office, place of work or a public place) and will last approximately one hour. Alternatively, you can be interviewed over the telephone. The interview will be about your experience of providing care closer to home. All questions are optional and you are not required to answer any questions you do not feel comfortable with.

What happens to the information I provide?

The information you and other participants provide will be used to write a report on care closer to home, as well as short articles for professional and academic journals. The information collected will only be used for the purpose of this study and will not be used for any other project. All the data collected will be treated as strictly confidential and will only be accessed by the research team. You will also remain anonymous and will not be identified in any of the project reports.

Do I have to participate?

No. Your participation in this project is entirely voluntary and you are under no obligation to take part

What are the benefits of participating?

By participating in this study, you have the opportunity to express your views on the services you help deliver. It can help us identify the benefits and challenges of delivering care closer to home, which in turn will be fed back to all those who manage and provide services for children, and to national policy makers. At the end of the project you will receive a summary of the project findings.

I am interested in participating. What do I do next?

If you think you might be willing to participate, please fill in the enclosed response form and return it to us using the pre-paid envelope. We will then contact you to tell you more about the project and answer any questions you might have. If you decide you would like to participate, we will arrange an interview.

I don't want to participate. What do I do?

If you would not like to participate, please let us know by ticking the 'No' box on the enclosed response form, and return it to us using the pre-paid envelope. If you return this to us we will not contact you again.

If I agree to take part, can I withdraw later?

Yes. If you decide to participate in this research, but later decide you wish to withdraw, you may do this at any time by contacting the research team using the details below.

Further information:

If you would like further information on this research, or have any questions before you decide whether or not you would like to participate, please do not hesitate to contact us using the details below. Please use Gemma as you primary contact point.

Many thanks

The research team

Lead researcher

Professor Gillian Parker 01904 321982 (gmp501@york.ac.uk)

Researchers

Miss Gemma Spiers 01904 321984 (gs525@york.ac.uk)
Miss Kate Gridley 01904 321988 (kg518@york.ac.uk)
Dr Janet Heaton 01904 321950 (jh35@york.ac.uk)

If you would like independent advice about this research, you can contact Dr Robert McMurray, Chair of the Humanities and Social Sciences Ethics Committee at the University of York: 01904 433432 (univ-hssec@york.ac.uk)

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A10.c Staff participant materials (consent form)

THE UNIVERSITY of York

spru | Social Policy Research Unit

Evaluating Models of Care Closer to Home for Children and Young People who are Ill

Service Provider's Consent Form

Please tick as appropriate

☐ **Yes, I would like to participate in this research**

☐ I have read and understood the information provided.

☐ I am willing to be interviewed about my experiences of delivering health care services closer to home for children.

☐ I understand that my participation is entirely voluntary and that I am free to withdraw from the research at any time and that I do not have to give a reason.

☐ I understand that the information collected during the interview will be used to write up a report on the project, as well as articles for journals and newsletters.

☐ I understand that the information collected during the interview will be treated as confidential. This means that my name, or any other information that could identify me, will not be included in anything written as a result of this research.

☐ I consent to my interview being audio-recorded

☐ I consent to the interviewer writing down what I say during the interview

☐ I understand that the information I provide is subject to the Data Protection Act.

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☐ **No, I would not like to participate in this research**

Please sign and date below to indicate your participation in this research:

Signature: _____ Date: __ /__ /_____

Signature of researcher: _____ Date: __/__/_____

Name:_____

Contact Telephone:_____ E-Mail: _____

Contact

Address:_____

_____

_____

There are two copies of this consent form. Please return one copy to the researcher and retain one for your own records.

Many thanks for your help

Social Policy Research Unit, University of York, Heslington, York YO10 5DD

Tel: 01904 321950 Fax: 01904 321953 E-mail: spru@york.ac.uk

Appendix 11: Parent participant materials

A11.a Parent participant materials (covering letter)

TO BE PRINTED ON SERVICE PROVIDER HEADED PAPER

Name and Address

Dear Parent/Carer

I am writing to you with some information about a research project being carried out by the University of York. The project is about health services provided close to or at home so that children do not have to be admitted to hospital for treatment and care, or so that the hospital stays can be as short as possible. It will provide us with valuable information about health services for children and how they can be improved. This study does *not* involve your child in any tests or treatment alterations. An information leaflet enclosed with this letter tells you more about the project and what taking part would involve.

The [name of service/team] are happy to support the project and hope very much that you will be able to find the time to take part. However, your decision will not influence the care your child receives from our health staff in any way. All the information you provide to the research team will be treated as strictly confidential, and will only be seen by the researchers.

Yours sincerely

[Name of service manager]

Enc. Information leaflet for parents

Response form

Social Policy Research Unit, University of York, Heslington, York YO10 5DD

Tel: 01904 321950 Fax: 01904 321953 E-mail: spru@york.ac.uk

A11.b Parent participant materials (information sheet)

THE UNIVERSITY of York

spru | Social Policy Research Unit

Providing Children and Young People with Health Care Closer to Home

A Research Study Funded by the NHS Service Delivery and Organisation Research and Development Programme

What is the research about?

This study is about health services for children which are provided close to or in the home, so that children do not have to be admitted to hospital, or so that the hospital stay can be as short as possible. We would like to learn more about these services, including what is working well and how they might be improved in the future. The aim of the study is to provide information for staff in the NHS who are in a position to improve children's health services.

Who is carrying out the research?

The project is being carried out by researchers from the Social Policy Research Unit (SPRU) at the University of York. Our names and contact details are provided below. SPRU has a lot of experience of research with children and families, and particularly about their views of health services. You can find out more about SPRU by visiting our website at http://www.york.ac.uk/spru.

Why have I been asked to take part in this research?

You are being asked to take part in this research because your child receives health care close to or in your home. We would like to know more about what you think of these health services.

What does taking part in this research involve?

Taking part in this research will involve an interview with you. The interview will take place at a time and place that is convenient for you. For example, a researcher can visit you at home, or in a public place. It will last approximately one and a half hours. The interviews will be about the health services your child receives, particularly those that are provided close to or in your home. All questions are optional and you do not need to answer any questions you do not feel comfortable with.

What will happen to the information I provide?

The information you provide will be kept confidential and will be seen only by the research team. The information collected during interviews will be used to write reports on care closer to home. None of the people who take part in the research will be named in these reports. The information collected will only be used for the purpose of this study and will not be used for any other project.

Do I have to take part?

No. Your participation in this project is entirely voluntary and you are under no obligation to take part. Your decision will not influence the help your child receives from health services in any way.

What are the benefits of taking part?

The are no direct benefits for you or your child. However, at the end of the project you will receive a report describing what parents think of the health services their children receive. The project will also provide health staff with information on how they can improve children's health services.

I am interested in taking part. What do I do next?

If you think you might like to take part, please fill in the response form we have enclosed and return it to us using the pre-paid envelope. This envelope does not need a stamp. A member of the research team will then contact you to talk about the project and answer any questions you might have. If you then decide you would like to take part, we will arrange an interview at a time and place that suits you.

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I don't want to take part. What do I do?

If you would not like to take part, please let us know by ticking the 'No' box on the form we have enclosed, and return it to us using the pre-paid envelope. If you return this to us we will not contact you again.

If I agree to take part, can I change my mind later?

Yes. You can change your mind about taking part at any time.

Further information

If you would like further information on this research, or have any questions before you decide whether or not you would like to take part, please do not hesitate to contact us using the details below. Please use Gemma as you first contact.

Many thanks

The Research Team

Lead Researcher

Prof Gillian Parker	01904 321982 (gmp501@york.ac.uk)

Researchers:

Miss Gemma Spiers	01904 321984 (gs525@york.ac.uk)
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A11.c Parent participation materials (response form)

THE UNIVERSITY of York

spru | Social Policy Research Unit

Providing Children and Young People with Health Care Closer to Home

Parent's Response Form

Name: _____

❑ **Yes, I would be interested in participating in this research. Please contact me and tell me more about it.**

Please complete the information below so we can contact you about this project:

Contact Telephone:_____

Contact Email:_____

Contact Address:_____

_____

_____

❑ **No, I would not like to participate in this research.**

Please return this form to the research team using the pre-paid envelope provided

Many thanks for your help

Social Policy Research Unit, University of York, Heslington, York YO10 5DD

Tel: 01904 321950 Fax: 01904 321953 E-mail: spru@york.ac.uk

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A11.d Parent participant materials (consent form)

THE UNIVERSITY of York

spru | Social Policy Research Unit

Providing Children and Young People with Health Care Closer to Home

Parent's Consent Form

Please tick as appropriate

☐ **Yes, I would like to participate in this research**

☐ I have read and understood the information provided

☐ I am willing to be interviewed about my experiences of using health care services closer to home for my child

☐ I understand that my participation is entirely voluntary and that I am free to withdraw from the research at any time and that I do not have to give a reason

☐ I understand that the information collected during the interview will be used to write up a report on the project, as well as articles for journals and newsletters.

☐ I understand that the information collected during the interview will be treated as confidential. This means that my name, or any other information that could identify me, will not be included in anything written as a result of this research.

☐ I consent to my interview being audio-recorded

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☐ I consent to the interviewer writing down what I say during the interview

☐ I understand that the information I provide is subject to the Data Protection Act.

☐ **No, I would not like to participate in this research**

Parent's signature: _____ Date: __/__/____

Researcher's signature: _____ Date: __/__/____

There are two copies of this consent form. Please return one copy to the researcher and keep one for yourself.

Many thanks for your help

Social Policy Research Unit, University of York, Heslington, York YO10 5DD

Tel: 01904 321950 Fax: 01904 321953 E-mail: spru@york.ac.uk

Appendix 12: Description of the conditions and age range of children of parents participating in the research

The children of parents taking part in this study had a range of health conditions – from acute to very complex. None of the children were receiving end of life care. Eleven children were, or had been, receiving treatment for oncology conditions. Eight children had ongoing conditions, some of whom had multiple health problems and thus very complex needs. Two children had short term acute needs (e.g. infections). The age range of the children was 9 months – 16 years. Fourteen of the children were aged 4 years or less, and three were aged 1 year or less. Four were aged between 5-11 years and four were aged 12-16 years.

Appendix 13: Framework data

A13.a Framework for staff data

1. What is care closer to home?

1.1. History
- 1.1.1. National/policy
- 1.1.2. Local
  - 1.1.2.1. 'It just grew
  - *1.1.2.2.* It was a response to something

1.2. Awareness/understanding/views of purpose and objectives
- 1.2.1. Professionals
- 1.2.2. Professional's views of what parents think

1.3. Children are different
- 1.3.1. What is possible (can/should be done)
- 1.3.2. Risk/clinical picture
- 1.3.3. 'it's the families as well'
- 1.3.4. Age range – span of need
- 1.3.5. 'tag on' to national policy

1.4. Other

2. Enablers

2.1. 'High level'
- 2.1.1. National policy
- 2.1.2. Evidence
  - 2.1.2.1. Need
  - 2.1.2.2. Cost effectiveness
  - 2.1.2.3. User feedback
- 2.1.3. Commissioners' knowledge and commitment
- 2.1.4. Championship
- 2.1.5. Finance issues
  - 2.1.5.1. Resource levels
  - 2.1.5.2. Flexibility
- 2.1.6. Risk/trust and accountability

2.2. 'Practice level'
- 2.2.1. Capacity
  - 2.2.1.1. Staffing
  - 2.2.1.2. Coverage
  - 2.2.1.3. Recruitment
  - 2.2.1.4. Skill mix
  - 2.2.1.5. Retention
- 2.2.2. Integration/joint working and communication across boundaries
- 2.2.3. Visibility and understanding locally inc. families
- 2.2.4. Training and development
- 2.2.5. Management practice

2.3. What they see as strengths of their service
- 2.3.1. Culturally competence practice
- 2.3.2. Referral systems
- 2.3.3. Specialist vs. generic

2.3.4. Psychosocial support
2.3.5. Size, management and composition of the team
2.3.6. User centred care
2.3.7. Benefits of this service 9to family and NHS)
2.4. Other Enablers

3. Barriers

3.1. 'High level'
3.1.1. Lack of a definition (vagueness)
3.1.2. Finance
3.1.3. Commissioner's attitudes
3.1.4. Wider strategic structures
3.1.5. Wider service structures
3.1.6. Lack of evidence
3.1.6.1. Effectiveness
3.1.6.2. Need
3.1.7. Risk/trust and accountability
3.1.8. Competing priorities
3.1.8.1. National
3.1.8.2. Local

3.2. 'Practice level'
3.2.1. Capacity
3.2.1.1. Staffing
3.2.1.2. Coverage
3.2.1.3. Recruitment
3.2.1.4. Skill mix
3.2.1.5. Retention
3.2.2. Geography
3.2.3. Integration/joint working and communication across boundaries
3.2.4. Language/culture
3.2.5. Visibility and understanding locally (staff and families)
3.2.6. Training and Development

3.3. What do they see as challenges to good service provision?
3.3.1. Family circumstances
3.3.1.1. Hygiene/conditions
3.3.1.2. Competence
3.3.1.3. Confidence
3.3.1.4. Acceptability to family
3.3.2. Poor communication about individual service users
3.3.3. Safety issues
3.3.4. Psychological challenges to staff
3.3.5. Reliance on goodwill
3.3.6. Local knowledge – keeping up
3.4. Other Barriers

4. Future directions of care closer to home
4.1. Real Plans
4.2. A vision for the future
4.3. Other

5. Impact on primary care

A13.b Framework for parent data

1. **Experience of hospital**
   - **1.1.** Logistics of getting to hospital
     - **1.1.1.** Travel
     - **1.1.2.** Parking
     - **1.1.3.** Costs
     - **1.1.4.** Organising other families members
     - **1.1.5.** Other logistics
   - **1.2.** Impact on employment
   - **1.3.** Impact on parent(s)
   - **1.4.** Impact on other family members & family life (e.g. siblings, grandparents)
   - **1.5.** Impact on child's life (e.g. education, social)
   - **1.6.** Length of stay/time spent in hospital
   - **1.7.** The hospital environment
     - **1.7.1.** For parents
       - **1.7.1.1.** Practicalities
       - **1.7.1.2.** Feelings
     - **1.7.2.** For children (ill child and their siblings; parent reported)
       - **1.7.2.1.** Practicalities
       - **1.7.2.2.** Feelings
   - **1.8.** Other

2. **Experience of care closer to home**

   - **2.1.** Commencement of care closer to home
   - **2.2.** How is CCTH facilitated?
   - **2.3.** Care closer to home procedures experienced (e.g. changing NG tube, chemotherapy at home etc)
   - **2.4.** Level of contact (e.g. home visits only or with telephone contact too; daily, weekly?)
   - **2.5.** Care co-ordination
   - **2.6.** Feelings of having someone come into the home
   - **2.7.** Getting on with staff
   - **2.8.** Developing relationships
   - **2.9.** Helpful aspects
     - **2.9.1.** Maintaining normality/being in home environment/family routine
     - **2.9.2.** Timely
       - **2.9.2.1.** Accessibility/convenience
       - **2.9.2.2.** Length of time taken for care (see 1e above)
       - **2.9.2.3.** Responsiveness
     - **2.9.3.** Emotional support (e.g. reassurance)
       - **2.9.3.1.** Parents
       - **2.9.3.2.** Child (parent reported)
     - **2.9.4.** Social support (e.g. arranging financial support, filling in forms etc)
     - **2.9.5.** [Staff] Liaising with other professionals/agencies
     - **2.9.6.** Continuity
       - **2.9.6.1.** Between hospital and home

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2.9.6.2. Staffing over time

2.9.7. Training and advice

2.9.8. Being informed

2.10. Unhelpful aspects

2.10.1. Accessibility

2.10.2. Coverage/Hours

2.10.3. Poor communication between staff about service user

2.10.4. Presence of equipment in the home

2.10.5. Other

2.11. Having confidence in the service

2.12. Increased responsibility on parent and other family members

2.13. Parent competence and expertise

2.14. Contact with other services during CCTH

2.15. What do they do when CCTH is not available?

2.16. Outcomes of care closer to home

2.16.1. Parent

2.16.2. Child

2.17. Other

3. Improvements

3.1. Other procedures/care they'd like to be done at home

3.2. Coverage

3.3. Contact/telephone advice

3.4. Additional support

3.5. Other

4. Preferred setting of care

4.1. Home

4.2. Hospital

4.3. Other

Appendix 14: Final cluster centres

	Cluster		
	1	2	3
service - post-op care	0.09	0.29	0.72
service - nursing care	0.60	0.10	0.98
service - drug admin	0.54	0.21	0.94
service - pall care	0.23	0.19	0.91
service - technical support	0.37	0.24	0.96
service - training	0.96	0.64	0.96
service - testing samples	0.58	0.14	0.89
service - short-term breaks	0.05	0.09	0.31
service - soc or psyc support	0.87	0.24	0.89
service - managing transition	0.63	0.28	0.81
service - monitoring health	0.95	0.40	0.86
service - liaison	0.96	0.60	0.98
Other services provided	0.18	0.48	0.11
CCN service	0.04	0.05	0.67
based in hospital	0.79	0.53	0.54
weekday cover only	0.63	0.74	0.41
Specific to one condition only	0.81	0.24	0.11

Appendix 15: Health economics survey analysis

Table 35. Total caseload by cluster type

Caseload	Cluster 1		Cluster 2		Cluster 3		Total	
	Number	%	Number	%	Number	%	Number	%
0-50	14	16.7%	10	26.3%	21	24.7%	**45**	**21.7%**
51-100	18	21.4%	3	7.9%	11	12.9%	**32**	**15.5%**
101-200	25	29.8%	7	18.4%	11	12.9%	**43**	**20.8%**
201-300	11	13.1%	5	13.2%	16	18.8%	**32**	**15.5%**
301-400	4	4.8%	1	2.6%	6	7.1%	**11**	**5.3%**
401-500	2	2.4%	0	0.0%	5	5.9%	**7**	**3.4%**
501-1,000	3	3.6%	5	13.2%	6	7.1%	**14**	**6.8%**
1,001-2,000	1	1.2%	4	10.5%	3	3.5%	**8**	**3.9%**
2001-10,000	6	7.1%	3	7.9%	4	4.7%	**13**	**6.3%**
10,001 +	0	0.0%	0	0.0%	2	2.4%	**2**	**1.0%**
Total	**84**	**100.0%**	**38**	**100.0%**	**85**	**100.0%**	**207**	**100.0%**
Mean	400.7		665.0		834.2		627.2	
Standard Deviation	806.8		1225.8		3088.5		2112.0	
Median	150		185		200		170	

Table 36. Total staff time (whole time equivalents) grouped by cluster type

Total Staff whole time equivalents	Cluster 1		Cluster 2		Cluster 3		Total	
0	13	11.6%	13	22.4%	7	5.0%	**33**	**10.7%**
Under 1	24	21.4%	13	22.4%	2	1.4%	**39**	**12.6%**
1.001 - 2	30	26.8%	5	8.6%	9	6.5%	**44**	**14.2%**
2.001 - 3	18	16.1%	4	6.9%	17	12.2%	**39**	**12.6%**
3.001 - 4	9	8.0%	5	8.6%	17	12.2%	**31**	**10.0%**
4.001 - 5	4	3.6%	4	6.9%	9	6.5%	**17**	**5.5%**
5.001 - 6	6	5.4%	4	6.9%	14	10.1%	**24**	**7.8%**
6.001 - 7	0	0.0%	3	5.2%	4	2.9%	**7**	**2.3%**
7.001 - 8	1	0.9%	2	3.5%	9	6.5%	**12**	**3.9%**
8.001 - 9	2	1.8%	0	0.0%	7	5.0%	**9**	**2.9%**
9.001 -10	0	0.0%	1	1.7%	5	3.6%	**6**	**1.9%**
10.001 - 15	3	2.7%	3	5.2%	16	11.5%	**22**	**7.1%**
15.001 - 20	1	0.9%	0	0.0%	9	6.5%	**10**	**3.2%**
20.001 - 30	0	0.0%	1	1.7%	8	5.8%	**9**	**2.9%**
30.001 - 40	0	0.0%	0	0.0%	3	2.2%	**3**	**1.0%**
40.001 - 50	0	0.0%	0	0.0%	3	2.2%	**3**	**1.0%**
50.001 +	1	0.9%	0	0.0%	0	0.0%	**1**	**0.3%**
Total	**112**	**100.0%**	**58**	**100.0%**	**139**	**100.0%**	**309**	**100.0%**
Mean	2.88		3.37		8.81		5.65	
SD	5.60		4.38		8.96		7.69	
Median	1.60		1.80		5.70		3.00	

Table 37. Staff to caseload ratio by cluster type

Staff to Caseload Group	Cluster 1		Cluster 2		Cluster 3		Total	
Under 1	1	1.3%	1	2.9%	3	3.8%	**5**	**2.6%**
1.01 to 5	1	1.3%	2	5.7%	10	12.5%	**13**	**6.7%**
5.01 to 10	3	3.9%	1	2.9%	8	10.0%	**12**	**6.2%**
10.01 to 15	5	6.4%	1	2.9%	6	7.5%	**12**	**6.2%**
15.01 to 20.00	5	6.4%	4	11.4%	4	5.0%	**13**	**6.7%**
20.01 to 30.00	5	6.4%	3	8.6%	9	11.3%	**17**	**8.8%**
30.01 to 40.00	5	6.4%	3	8.6%	9	11.3%	**17**	**8.8%**
40.01 to 50.00	1	1.3%	4	11.4%	8	10.0%	**13**	**6.7%**
50.01 to 75.00	8	10.3%	3	8.6%	11	13.8%	**22**	**11.4%**
75.01 to 100.00	16	20.5%	3	8.6%	5	6.3%	**24**	**12.4%**
100.01 to 150.00	9	11.5%	1	2.9%	0	0.0%	**10**	**5.2%**
150.01 to 200.00	3	3.9%	1	2.9%	1	1.3%	**5**	**2.6%**
Over 200.01	16	20.5%	8	22.9%	6	7.5%	**30**	**15.5%**
Total	**78**	**100.0%**	**35**	**100.0%**	**80**	**100.0%**	**193**	**100.0%**
Mean	233.89		341.52		108.36		201.34	
SD	512.24		1030.56		388.89		602.61	
Median	82.00		48.78		30.14		46.51	

Table 38. Total budget grouped by cluster type

Total Budget Group	Cluster 1		Cluster 2		Cluster 3		Total	
10,001 - 50,000	5	26.3%	2	16.7%	1	1.5%	8	8.3%
50,001 - 100,000	5	26.3%	2	16.7%	1	1.5%	8	8.3%
100,001 - 200,000	5	26.3%	2	16.7%	10	15.4%	17	17.7%
200,001 - 300,000	2	10.5%	3	25.0%	10	15.4%	15	15.6%
300,001 - 400,000	1	5.3%	0	0.0%	10	15.4%	11	11.5%
400,001 - 500,000	0	0.0%	1	8.3%	10	15.4%	11	11.5%
500,001 - 1,000,000	1	5.3%	2	16.7%	14	21.5%	17	17.7%
1,000,001 - 2,000,000	0	0.0%	0	0.0%	5	7.7%	5	5.2%
2,000,001 - 3,000,000	0	0.0%	0	0.0%	4	6.2%	4	4.2%
Total	**19**	**100.0%**	**12**	**100.0%**	**65**	**100.0%**	**96**	**100.0%**

Table 39. Effect of excluding the outliers from the analysis

		Total Budget less £1,000,000					Total Budget less £2,000,000				
		Cost Per Case	**Total staff time**	**Staff to caseload**	**Annual caseload**	**Total budget 2007-08**	**Cost Per Case**	**Total staff time**	**Staff to caseload**	**Annual caseload**	**Total budget 2007-08**
	Mean	£3,461.7	2.7	80.2	147.9	£135,507.1	£3,461.7	2.7	80.2	147.9	£135,507.1
	N	17	19	16	17	19	17	19	16	17	19
	Median	£747.6	2.5	67.9	100.0	£96,581.0	£747.6	2.5	67.9	100.0	£96,581.0
	Std. Deviation	10068.6	2.3	65.8	148.2	121650.0	10068.6	2.3	65.8	148.2	121650.0
Cluster 1	Range	42208.4	8.8	199.4	545.0	502229.0	42208.4	8.8	199.4	545.0	502229.0
	Mean	£1,613.3	4.2	168.3	947.1	£243,837.8	£1,613.3	4.2	168.3	947.1	£243,837.8
	N	8	12	7	8	12	8	12	7	8	12
	Median	£794.5	4.8	48.8	312.5	£172,779.5	£794.5	4.8	48.8	312.5	£172,779.5
	Std. Deviation	2001.4	3.9	337.5	1817.7	221925.0	2001.4	3.9	337.5	1817.7	221925.0
Cluster 2	Range	6175.5	12.3	923.1	5380.0	678151.0	6175.5	12.3	923.1	5380.0	678151.0
	Mean	£7,268.4	11.2	46.6	568.9	£403,522.6	£7,412.3	12.7	43.7	539.0	£476,471.0
	N	38	56	38	38	56	41	61	41	41	61
	Median	£1,970.3	8.6	27.6	200.0	£348,375.0	£2,000.0	9.7	26.0	200.0	£368,798.0
	Std. Deviation	17469.8	8.7	106.4	1875.6	246282.0	16818.6	10.3	102.9	1807.1	345717.0
Cluster 3	Range	95732.9	38.0	668.0	11692.0	942836.0	95732.9	41.76	668.05	11692.0	1605236.0
Total	**Mean**	**£5,523.1**	**8.4**	**69.4**	**503.3**	**£322,965.0**	**£5,691.8**	**9.5**	**66.4**	**487.7**	**£375,711.1**
	N	**63**	**87**	**61**	**63**	**87**	**66**	**92**	**64**	**66**	**92**
	Median	**£1,234.4**	**5.6**	**30.3**	**150.0**	**£255,000.0**	**£1,464.9**	**5.8**	**29.4**	**155.0**	**£292,900.0**
	Std. Deviation	**14620.2**	**8.1**	**144.8**	**1594.0**	**247085.0**	**14306.4**	**9.6**	**141.9**	**1558.4**	**329895.0**
	Range	**95732.9**	**38.6**	**930.5**	**11695.0**	**976600.0**	**95732.9**	**42.4**	**930.5**	**11695.0**	**1639000.0**

Table 40. Standard deviation to 3.29 outlier calculations

	Total Budget	Caseload
Mean	462155.7292	627.1980676
Std. Deviation	532108.4754	2112.035914
3.29 Standard Deviation	1750636.9	6948.6
Upper Outlier Limit	2212792.6	7575.8
Lower outlier limit	-1288481.2	-6948.6

Table 41. Cost per case group by cluster type

Cost Per Case Group	Cluster 1		Cluster 2		Cluster 3		Total	
Under £500	5	29.4%	2	25.0%	3	67.0%	**10**	**14.9%**
£501-£1000	5	29.4%	3	37.5%	7	16.3%	**15**	**22.4%**
£1001 - £1500	3	17.7%	0	0.0%	6	14.0%	**8**	**11.9%**
£1501 - £2000	1	5.9%	1	12.5%	6	14.0%	**8**	**11.9%**
£2001 - £3000	0	0.0%	1	12.5%	5	11.6%	**6**	**9.0%**
£3001 - £4000	2	11.8%	0	0.0%	3	7.0%	**5**	**7.5%**
£4001 - £5000	0	0.0%	0	0.0%	1	2.3%	**1**	**1.5%**
£5001 - £6000	0	0.0%	0	0.0%	1	2.3%	**1**	**1.5%**
£6001 - £7000	0	0.0%	1	12.5%	1	2.3%	**2**	**3.0%**
£7001 - £8000	0	0.0%	0	0.0%	2	4.7%	**2**	**3.0%**
£8001 - £9000	0	0.0%	0	0.0%	2	4.7%	**2**	**3.0%**
Over £10000	1	5.9%	0	0.0%	6	14.0%	**7**	**10.5%**
Total	**17**	**100.0%**	**8**	**100.0%**	**43**	**100.0%**	**67**	**100.00%**
Mean	3461.73		1613.27		7274.85		5638.43	
SD	10068.6		2001.45		16444.2		14104.6	
Median	747.7		794.5		2000.0		1464.9	

Table 42. Staff budget as a percentage of the total budget

Staff Budget Percentage Group	Cluster 1		Cluster 2		Cluster 3		Total	
	No	%	No	%	No	%	No	%
0.0 - 10	6	66.7%	6	60.0%	14	23.7%	26	31.0%
10.1 - 20	1	11.1%	1	10.0%	17	28.8%	19	22.6%
20.1 - 30	0	0.0%	0	0.0%	10	16.9%	10	11.9%
30.1 - 40	1	11.1%	0	0.0%	4	6.8%	5	6.0%
40.1 - 50	0	0.0%	0	0.0%	4	6.8%	4	4.8%
50.1 - 60	1	11.1%	0	0.0%	2	3.4%	3	3.6%
60.1 -70	0	0.0%	0	0.0%	2	3.4%	2	2.4%
70.1 - 80	0	0.0%	0	0.0%	1	1.7%	1	1.2%
100.1 - 150	0	0.0%	0	0.0%	1	1.7%	1	1.2%
Greater than 200	0	0.0%	0	0.0%	1	1.7%	1	1.2%
Total	9	100.0%	10	100.0%	59	100.0%	84	100.0%

Table 43. Percentage change in budget

Percentage Change	Cluster 1		Cluster 2		Cluster 3		Total	
Reduction in budget	N	%	N	%	N	%	N	%
Over 10.1%	1	6.6%	0	0.0%	2	3.9%	3	3.9%
Between 5.01 and 10%	0	0.0%	0	0.0%	2	3.9%	2	2.6%
Between 0 and 5%	1	6.3%	0	0.0%	3	5.9%	4	5.2%
No Change in Budget	4	25.0%	3	30.0%	2	3.9%	9	11.7%
Increase in budget								
0.0 - 10	6	37.5%	4	40.0%	19	37.3%	29	37.7%
10.1 - 20	2	12.5%	3	30.0%	7	13.7%	12	15.6%
20.1 - 30	0	0.0%	0	0.0%	4	7.8%	4	5.2%
30.01 - 40	1	6.3%	0	0.0%	6	11.8%	7	9.1%
40.1 - 50	0	0.0%	0	0.0%	3	5.9%	3	3.9%
60.1 -70	0	0.0%	0	0.0%	1	2.0%	1	1.3%
80.1 - 90	0	0.0%	0	0.0%	1	2.0%	1	1.3%
90.1 - 100	0	0.0%	0	0.0%	1	2.0%	1	1.3%
150.1 – 200	1	6.3%	0	0.0%	0	0.0%	1	1.3%
Total	16	100.0%	10	100.0%	51	100.0%	77	100.0%

HES Analysis

Table 44. Length of stay, number of emergency admissions and proportion of national admissions in acute trusts serving case study site PCTs and in England (all children)

Case study acute trust	Mean length of stay (SD)	Number of emergency admissions	Percentage of national admissions
All other	1.9 (34.6)	328593	93.3%
WCH	6.6 (30.0)	1445	0.4%
WHS	0.9 (2.3)	5904	1.7%
WSWB	1.5 (3.8)	2527	0.7%
XA	1.0 (1.9)	2606	0.7%
XB	2.1 (6.6)	3619	1.0%
Y	1.7 (6.0)	5049	1.4%
Z	1.2 (2.6)	2354	0.7%
Total	**1.9 (33.5)**	**352097**	**100.00%**

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Table 45. Length of stay, number of emergency admissions, proportion of national admissions, and proportion of admissions from case study PCT in acute trusts serving case study site PCTs and in England (children who live in case study PCTs)

Acute Trust	Mean length of stay (SD)	Number of emergency admissions	Percentage of national admissions	Percentage of Trust admissions from relevant PCT
All other	1.9 (34.1)	338968	96.3%	N/R
WCH	3.0 (5.9)	200	0.1%	15.3%
WHS	1.3 (2.5)	436	0.1%	33.4%
WSWB	1.5 (3.0)	567	0.2%	43.5%
XA	1.1 (1.9)	2460	0.7%	94.4%
XB	2.1(6.5)	3539	1.0%	97.8%
Y	1.3 (5.8)	3815	1.1%	75.6%
Z	1.2	2112	0.6%	89.7%
Total	**1.9**	**352097**	**100.0%**	15.3%

Table 46. Length of stay, number of emergency admissions and percentage of national admissions in case study PCTs and for all children in England

PCT	Mean length of stay (SD)	Number of emergency admissions	Percentage of national admissions
All other	1.9 (34.3)	333689	94.8%
W	1.8 (4.9)	1305	0.4%
X	1.8 (6.4)	6623	1.9%
Y	1.6 (6.6)	4397	1.3%
Z	1.7 (8.6)	6083	1.7%
Total	**1.9**	**352097**	**100.0%**

Table 47. Day of week of emergency admissions for children living in case study PCT sites and for all England

PCT of Patient Admission Day of the week	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Total
England	9.6%	17.1%	15.9%	15.9%	16.0%	16.1%	9.3%	100.0%
W	9.7%	15.0%	18.6%	16.6%	15.8%	16.1%	8.9%	100.0%
X	11.3%	16.5%	14.6%	15.3%	15.5%	16.5%	10.4%	100.0%
Y	7.3%	18.4%	16.6%	18.5%	14.9%	17.1%	7.2%	100.0%
Z	9.6%	17.1%	15.9%	17.0%	15.4%	15.7%	9.2%	100.0%

Table 48. Day of week of discharge of emergency admissions for children living in case study PCT sites and for all England

PCT of Patient Discharge Day of the week	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Total
England	9.5%	15.1%	15.2%	15.4%	15.6%	18.6%	10.7%	100.0%
W	9.7%	14.5%	16.1%	16.1%	14.0%	18.7%	10.9%	100.0%
X	11.0%	15.8%	14.4%	14.7%	14.9%	17.5%	11.6%	100.0%
Y	7.4%	15.7%	15.4%	16.9%	15.5%	18.5%	10.7%	100.0%
Z	9.4%	14.7%	14.7%	16.5%	15.5%	17.7%	11.6%	100.0%

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Table 49. Mean length of stay for the most common reasons for admission to acute trusts for children living in case study PCTs with generic admission avoidance CCTH services and for all children in England

Reason for admission	Mean (SD) length of stay Site XA	Mean (SD) length of stay Site Z	Mean (SD) length of stay England
A084 Viral intestinal infection, unspecified	0.5 (0.9)	0.6 (0.8)	0.6 (1.4)
B349 Viral infection, unspecified	0.5 (0.7)	0.7 (0.8)	0.7 (1.5)
J039 Acute tonsillitis, unspecified	0.9 (1.2)	0.7 (1.0)	0.7 (1.2)
J069 Acute upper respiratory infection, unspecified	0.4 (0.7)	0.4 (0.6)	0.5 (2.0)
J219 Acute bronchiolitis, unspecified	1.3 (2.0)	1.2 (2.0)	1.5 (2.6)
J22X Unspecified acute lower respiratory infection	1.9 (4.2)	1.7 (2.8)	1.9 (6.3)
J459 Asthma, unspecified	0.7 (0.7)	1.0 (1.0)	1.1 (1.9)
K529 Noninfective gastroenteritis and colitis, unspecified	0.7 (0.9)	0.7 (0.8)	0.9 (2.8)
K590 Constipation	1.6 (2.2)	0.6 (1.7)	0.9 (2.0)
P599 Neonatal jaundice, unspecified	2.2 (2.0)	0.7 (1.3)	1.2 (1.8)
R062 Wheezing	0.4 (0.5)	0.8 (1.0)	0.8 (3.1)
R104 Other and unspecified abdominal pain	1.0 (1.1)	0.8 (1.1)	0.8 (1.4)
R11X Nausea and vomiting	0.8 (1.2)	0.9 (1.1)	1.0 (2.2)
Total	0.8 (1.5)	0.8 (1.3)	0.9 (2.5)

Addendum:

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme whilst it was managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) at the London School of Hygiene & Tropical Medicine. The NIHR SDO programme is now managed by the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton.

Although NETSCC, SDO has managed the project and conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.