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Spiers, Gemma Frances [orcid.org/0000-0003-2121-4529](https://orcid.org/0000-0003-2121-4529), Allgar, Victoria Louise [orcid.org/0000-0002-5228-2623](https://orcid.org/0000-0002-5228-2623), Richardson, Gerry [orcid.org/0000-0002-2360-4566](https://orcid.org/0000-0002-2360-4566) et al. (8 more authors) (2016) *Transforming Community Health Services for Children and Young People who are Ill : A quasi-experimental evaluation*. *Health Services and Delivery Research*. ISSN 2050-4357

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# **Transforming Community Health Services for Children and Young People who are Ill: A Quasi-Experimental Evaluation**

**Gemma Spiers<sup>1\*</sup>, Victoria Allgar<sup>2</sup>, Gerry Richardson<sup>3</sup>,  
Kate Thurland<sup>4</sup>, Sebastian Hinde<sup>3</sup>, Yvonne Birks<sup>1</sup>,  
Kate Gridley<sup>1</sup>, Helen Duncan<sup>4</sup>, Susan Clarke<sup>1</sup>,  
Linda Cusworth<sup>1</sup>, Gillian Parker<sup>1</sup>**

**Social Policy Research Unit  
University of York**

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1. Social Policy Research Unit (SPRU), University of York, Heslington, York YO10 5DD  
Tel: 01904 321950; E-mail: [gemma.spiers@york.ac.uk](mailto:gemma.spiers@york.ac.uk) \*

2. Department of Health Sciences/Hull York Medical School (HYMS), University of York, Heslington, York YO10 5DD
3. Centre for Health Economics (CHE), University of York, Heslington, York YO10 5DD
4. Public Health England (PHE), West Offices, Station Rise, York YO1 6GA

\* Corresponding author

No competing interests declared.

## **Abstract**

**Background:** Children's community nursing (CCN) services support children with acute, chronic, complex and end of life care needs in the community.

**Objectives:** This research examined the impact of introducing and expanding CCN services on quality, acute care and costs.

**Methods:** A longitudinal mixed-methods, case study design in three parts. The case studies were in five localities introducing or expanding services. Part 1: An interrupted time series (ITS) analysis of Hospital Episodes Statistics on acute hospital admission for common childhood illness, and bed days and length of stay for all conditions, including a subset for complex conditions. The ITS used between 60 and 84 time points (monthly data) depending on the case site. Part 2: A cost consequence analysis using activity data from CCN services, and resource use data from a subset of families (n=32). Part 3: A process evaluation of service change with 41 NHS commissioners, managers and practitioners, using interviews, focus groups and documentary data, and depth-interviews with 31 parents of children with complex conditions using services in the case sites.

**Findings:** Part 1: The ITS analysis showed a mixed pattern of impact on acute activity, with the greatest reductions in areas that had rates above the national average before CCN services were introduced and significant reductions in some teams in acute activity for children with complex conditions. Some models of CCN appear to have more potential for impact than do others. Part 2: The cost and consequence analysis covered only part of the CCN teams' activity. It showed some potential savings from reduced admissions and bed days, but none that were greater than the total cost of the services. Part 3: Three localities implemented services as planned, one achieved partial service change, and one was not able to achieve any service change. Organisational stability, finance, medical stakeholder support, competition, integration with primary care and visibility influenced the planning and implementation of new and expanded CCN services. Feeling supported to manage their ill child at home was a key outcome of using services for parents. Various service features contributed to this and were important in different ways at different times. Other outcomes included being able to

avoid hospital care, enabling the child to stay in school, and getting respite. Whilst parents judged that care was of high quality when teams enable them to feel supported, reassured and secure in managing their ill child at home, this did not depend on a constant level of contact from teams.

**Limitations:** Delays in service reconfigurations required adaptation of research activity across sites. Use of administrative data, such as HES, for research purposes is technically difficult and imposed some limitations on both the ITS and the cost analysis.

**Conclusions:** Large, generic CCN teams that integrate acute admission avoidance for all children with support for children with complex conditions, and highly targeted teams for children with complex conditions offer the possibility of supporting children more appropriately at home while also making some difference to acute activity. This possibility remains to be tested further.

**Future work:** Further work should refine the evidence on outcomes of services by looking at outcomes in promising models, value for money, and measuring quality based outcomes.

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## List of abbreviations

Accident & Emergency	(A&E)
Children's community nursing	(CCN)
Clinical Commissioning Group	(CCG)
General Practitioner	(GP)
Interrupted Time Series	(ITS)
Joint Commissioning Unit	(JCU)
Medical Home Index	(MHI)
Medical Home Family Index	(MHFI)
National Health Service	(NHS)
National Service Framework	(NSF)
Paediatric Observation & Assessment Unit	(POAU)
Parent Consultation Group	(PCG)
Primary Care Trust	(PCT)
Quality, Innovation, Productivity and Prevention	(QIPP)
Research Ethics Committee	(REC)
Transforming Community Services	(TCS)
Whole Time Equivalent	(WTE)

# Scientific summary

## Background

Delivering health care in home and community settings is a national policy directive. The Department of Health has identified Children's Community Nursing (CCN) teams as services that can help to deliver care closer to home for children and young people who are ill. Whilst there is evidence showing that families who use these services view them positively, there is a gap in evidence in relation to costs and secondary care outcomes. Previous work shows there is a need for evidence about these outcomes.

## Aims

The aims of this research were to: (1) test whether introducing or expanding CCN services affects acute hospital admission for common childhood illness, and bed days and length of stay for all paediatric conditions (including a subset for complex conditions); (2) examine the costs of delivering and using these services; (3) understand parents' experiences of quality of care over time when they begin using CCN teams for their child and to carry out a process evaluation of service change.

## Design and Methods

We used a longitudinal case study design with mixed methods in five sites that had recently, or were currently, introducing and expanding CCN services. There were two recently introduced or expanded generic CCN teams (one community-based and one hospital based) within a single region (Sites A1 and A2) and one paediatric nurse practitioner team for complex conditions in Site D. Site B was expanding its complex care team and had advanced plans to introduce an acute home nursing team. Site C was in an advanced stage of planning for a new generic CCN team alongside standardising other CCN provision. None of the planned change took place in Site C and the acute home nursing team was not introduced in Site B. This limited the type and range of data collection and analysis possible in these sites but we used Site C as a 'control' site for the analysis of acute activity (see below).



There were three main studies:

- (1) An interrupted time series (ITS) analysis of Hospital Episodes Statistics to examine acute admissions for common childhood illnesses and bed days and length of stay for all paediatric conditions (including a subset of complex conditions), using between 60 and 84 time points;
- (2) A cost consequence analysis, drawing upon activity data from the CCN services, and resource use data from a subset of families (n=32) using the services;
- (3) A longitudinal qualitative study of change over time in experienced quality of care with 31 parents of children with complex conditions using the CCN teams, drawing upon depth-interviews. We also carried out a process evaluation with 41 commissioners, managers and practitioners across the case sites, drawing upon longitudinal depth-interviews, focus groups and documentary data.

## **Findings**

**Study 1:** The ITS analysis provided a mixed picture of change in all three indicators of activity. However, exploring these different patterns suggests some key factors for a theory of change for the introduction of CCN teams.

Site A1 was a large, community-based CCN team in an area of highest deprivation and multi-ethnicity and which, before the team was introduced, had non-elective admission rates for common childhood illnesses substantially higher than the national average, and which were growing rapidly. The team's introduction seemed to affect this rate immediately and significantly and continued to do for around three years. We do not know what caused the effect to wane, but possible factors identified included later organisational change in children's urgent care in the locality, and issues with team visibility, which may have affected referrals. Bed days also reduced from a level that, again, had been substantially higher than the national average before the team was in place.

Site A2 was part of the same redesign of children's services as Site A1; it was in the second to highest deprivation group but had a lower rate of multi-ethnicity than Site A1. Its non-elective admission rates were substantially higher than the national rates and growing rapidly before the team was introduced. Unlike Site A1, Site A2 saw no reduction but an increase in admission rates over the study period – but did see a sustained reduction in bed days over

time. What could explain these differences? Our work across the project suggested three important factors.

First, the A1 team took parent self-referrals, but the A2 team did not. Practitioners in Site A1 said that these tended to be for conditions such as chronic constipation, eczema, and asthma, where word of mouth led some parents to contact the team directly. The option of self-referral increases accessibility to the team, some of which may replace use of A&E. This may help to explain some of the lowered rate of admissions in this site.

Second, the A1 team was community (clinic) based, whereas the A2 team was hospital based. We wondered if this might explain some of the differences; given its base, did the A2 team have a predisposition to triage children to short-term admission, which might explain both the increase in admissions and the reduction in bed days in this site? The commissioner and manager in this site said that the team's priority was admission avoidance, and they had developed referral pathways from consultants and advanced paediatric nurse practitioners in A&E to the CCN team. This would suggest no particular predisposition to triage children to short-term admission. However, if A&E first referred children to the POAU before referral to the CCN team, and if POAU attendances were coded as admissions, this could help to explain the observed changes.

Third, our qualitative work with parents in site A1 highlighted the role of the team in empowering parents to care for their child and in assisting with acute episodes of illness. Whilst this part of our work focused on those with complex conditions, this philosophy may have extended across the wider caseload of those with less complex conditions. Thus, an empowering role may help to change help-seeking behaviours for episodes of acute illness, as we saw in earlier research on CCN teams.

We explored changes in our three indicators of acute activity in Site C and acute admissions for common conditions only in Site B, both of which had been unable to implement elements of planned change. This was to provide a degree of control for our findings in Sites A1 and A2. Despite high levels of deprivation, Site B's admission rates were close to the national average at the start of the analysis period and falling slightly. This fall was not sustained and admissions increased over time. Site C was different from the other case sites with low levels of deprivation and admission rates for common conditions similar to national rates. It was

difficult to interpret the HES data for Site C, with a suggestion of significant changes in data recording during the period of analysis, which showed falls in admissions and bed days but increases in average length of stay.

In summary, when admission rates for common conditions are much higher than the national average there may be more scope for CCN teams to have an impact. However, the model of CCN team may have an effect too; the more community-based and parent facing, the more scope there may be for reducing both admissions and bed days.

For children with complex conditions, there was evidence of significant impact in both Site A1 (on bed days) and Site D (on non-elective acute admission, the main outcome for this site). In both cases, rates before implementation of the CCN service had been substantially above national rates. By contrast, Site A2, with a level of bed days close to the national average, showed a smaller level of reduction. We know that Site A1 acted not only to empower parents of children with complex conditions, but also played a key role in care management in the early days after diagnosis or discharge from hospital. This may explain the reduction in bed days for complex conditions in this site. It may also be that the population of children with complex conditions in Site A1 was always larger than that in Site A2 which may have increased the scope for a reduction in bed days, but we cannot explore this in the absence of any national statistics on children with complex conditions.

Site B showed a slight increase in bed days over the period of analysis, despite already having a rate higher than the national average.

Again, then, the original level of activity may increase the scope for CCN teams to have an effect on acute activity for children with complex conditions. However, these findings also suggest that the model of CCN service is important. The teams in both Site A1 and Site A2 were ‘integrated’, in the sense that their work to avoid acute admission for all children was of a piece with their work to support children with complex conditions. Site D, was very different, but was highly targeted on a specific group of children and on a single outcome (avoiding acute admission for children with complex neurological conditions). By contrast, Site B had not developed much from its origins as a respite service, even when it had taken on responsibility for children with continuing care packages. The inability of the area to deliver the planned CCN service that would focus on acute admission may have meant that

the Site B team had no opportunity to develop the more active work with parents of children with complex conditions that was an important part of the work of the Site A1 team.

**Study 2:** Given the type of health economics analysis that was possible, it is difficult to be secure about the individual findings. Further, given the different type and costs of the four services included in this part of the work, it is difficult to synthesise the findings meaningfully.

Individually, the paediatric nurse practitioner team that targeted admissions of children with very complex conditions (Site D) was the service where costs most closely matched savings. This was a highly targeted service with only one main outcome and the small numbers involved in the ITS analysis mean that there is greater potential variability around the outcome. Given this, however, the overall conclusion is that this service has a relatively high probability of being cost saving. Parents valued the service, too.

For the community-based and hospital-based generic CCN teams (Sites A1 and A2), the health economics verdict remains unclear. We were not able to assess the impact of the disinvestment that had taken place in the acute sector before the teams were introduced, neither were we able to assign value to benefits or costs that might arise from all the other work that these teams did. For example, both sites ran a number of long-term condition clinics in the community to provide care for children that would otherwise have attended hospital out-patient clinics.

Site B was unusual in terms of CCN services more generally. The high proportion of children funded via continuing care packages meant that an analysis based on bed days was slightly out of kilter with the aims of the team. The question that should, perhaps, be asked about this team's activities is whether better value is achieved for continuing care expenditure from this model of CCN team compared with other ways of delivering continuing care (for example, via spot purchasing of services). The team had been established because spot purchasing had been problematic in the past, so that perhaps provides part of the answer.

This is the first attempt, to our knowledge, to examine the costs and consequences of a range of types of CCN team, meeting diverse types of needs. There is clearly much still to be done.

**Study 3:** The process evaluation highlighted that the development and introduction of CCN services is possible but requires dedicated resources, medical support and, where taking place across multiple providers, a mechanism to oversee changes (for example, a network). Commitment to, and views about, introducing CCN services varied among NHS stakeholders, but some appeared to be more powerful than others in influencing change. Wider instability in the NHS from the recent reforms added further difficulties in one site, with changes in commissioning arrangements compromising the leadership needed to take forward plans. Once teams were introduced, there were problems with visibility of the new services to others, and balancing the needs of different groups of children on the caseload. Teams faced pressures to demonstrate their value and impact on secondary care, but felt it was important to find ways of demonstrating quality based outcomes. The qualitative study with parents showed that positive experiences of CCN services are reflected in the teams' central role in supporting them to manage their child's ongoing health and care needs at home. Various features of CCN services contributed to this, but the importance of these features to parents could change over time if the service played an empowering role, where the responsibility of care gradually shifted from the team to parents.

Positive experiences of CCN services are also reflected in the perception that they help avoid planned and unplanned hospital stays and attendance, as well as other outcomes such as enabling the child to attend school. When CCN teams supported parents to feel secure and reassured in managing their child's health needs at home, positive experiences of using CCN services were maintained. However, this did not necessarily depend on maintaining a constant level of service input. Thus, it was not how much care was provided, but more a matter of what was provided and when.

## **Conclusions**

This project demonstrated the challenges of evaluating complex change in an unstable service environment. Use of administrative data, such as HES, for research purposes is technically difficult and imposed some limitations on both the ITS and the cost analysis.

Nonetheless, the project has added significantly to the evidence base for the costs, consequences and challenges of developing services to deliver care closer to home for

children, and the service models that might be most promising in doing so. Delivering change in children's services requires leadership, clinical commitment, dedicated resources and continued commitment to a vision over time. Higher-level restructuring can have a wasteful impact on planned change. Large, generic CCN teams that integrate acute admission avoidance for all children with support for children with complex conditions, and highly targeted teams for children with complex conditions, offer the possibility of supporting children more appropriately at home while also making some difference to acute activity. These possibilities remain to be tested in larger scale evaluation.

**Words: 2395**

## **Plain English summary**

There is a national move to deliver more health care outside hospitals and in community settings. Children's community nursing (CCN) teams can help to achieve this for children with short and long-term illnesses. We worked in five sites that had recently started CCN services or were planning to do so. We tried to understand:

- Whether the services could affect how much hospitals are used, by exploring local statistics before and after the CCN teams started work;
- The costs of these services, by gathering information from the teams and using the local statistics to put a cost on hospital activity;
- Parents' views of CCN services for their child, by talking to them about their experiences and whether these changed over time.

We found a mixed pattern of change in hospital activity. Sites where children's use of hospitals was higher than national rates seemed more likely to see a reduction after CCN services started. Some types of team seemed to reduce how often children with complex needs went into hospital and how long they stayed. In terms of hospital use, none of the services saved more money than they cost, but we did not assess the value of all the other things the CCN teams did – for example, running clinics in the community. Parents valued CCN service input as it helped them manage their child's health needs at home. These positive experiences relied less on how much support teams offered, and more on what type of support was offered and when.

**Words: 249**

# Chapter 1 Introduction and methods overview

## Background

Delivering health care 'closer to home' for children and young people who are ill was established as a policy directive in the 2004 National Service Framework (NSF) for Children, Young People and Maternity services.<sup>1</sup> It followed a long-standing view that ill children were better cared for at home where possible, and concerns about the welfare of children in hospital.<sup>2,3</sup> In the 2004 NSF, the importance placed on delivering health care close to home was linked with issues of ensuring accessible and timely services that were centred on the needs of families.

Later, the Transforming Community Services (TCS) programme reiterated the importance of care closer to home in England.<sup>4</sup> As part of an ambition to 'make everywhere as good as the best', developing services 'so that children with support from family members can choose to be cared for at home at all stages of their illness or disability' was recommended as a 'high impact' change (p.13).

Whilst care closer to home policy had its origins in concerns about appropriate settings for the ill child and their family, it later evolved to become part of the wider national agenda of containing demand for urgent care. For example, the Department of Health highlighted the importance of children's community nursing (CCN) services as a pathway to achieving Quality, Innovation, Productivity and Prevention (QIPP) plans to reduce hospitalisation.<sup>5</sup> Most recently, delivering paediatric care in the community gained traction as a possible solution to a perceived unsustainability of acute inpatient care in the NHS.<sup>6</sup>

## Realising children's health care 'closer to home' in practice

Designed to care for ill and disabled children in the community, CCN teams have been recognised by national policy as the services to achieve care closer to home.<sup>1,5,7</sup> More recently, the Royal College of Nursing described them as the 'bedrock to integrated care closer to home'<sup>8</sup> (p.4). Despite this, not every health community in England has access to a CCN team.<sup>9,10</sup> CCNs have a long history in the NHS,<sup>11</sup> and terminology has varied over



time; paediatric home care, hospital at home, and to some extent ambulatory care, can all describe types of services known in the contemporary NHS as CCN teams.

Variation in models of care closer to home are evident,<sup>12, 13</sup> and typologies have been conceptualised in a number of ways. For example, dichotomies of generic/specialist, in-reach/out-reach, community-based/hospital based, and long-term/short-term input are all described in the literature.<sup>10, 12, 14, 15</sup> However conceptualised, the key components of such services are that they are led by children's nurses and deliver nursing interventions and care in community settings, such as home and school.

Evidence shows CCN services provide health care at home for a wide range of needs,<sup>9</sup> including acute (for example, see<sup>16-20</sup>) long-term and complex (for example, see<sup>21-24</sup>) and end of life.<sup>9</sup> They undertake a range of clinical care activities (for example, home chemotherapy regimens) and, depending on skill mix, may be able to offer advanced nurse practice, such as assessing and prescribing.<sup>25</sup> They can also play a central role in non-clinical aspects of care, such as care coordination and empowering parents to support an ill child at home.<sup>16, 26</sup>

Although CCN services play a key role in facilitating care closer to home, they do not work in isolation. Often, they link with primary and secondary care services, particularly for urgent care pathways.<sup>8</sup> However, the success of these partnerships can be challenged by poor visibility and a lack of understanding more generally about the role of CCN teams in the NHS.<sup>9</sup>

### **What outcomes could CCN services achieve?**

Given the function and nature of CCN services, it is possible they might influence outcomes such as secondary care use (and the associated costs), and quality of care for families.

Secondary care use may change as a result of CCN service provision to families in two ways. First, admission avoidance is a function for some CCN services.<sup>9</sup> This, in turn, may result in a reduced rate of admissions for children. Admission avoidance may be achieved through immediate diversions from the inpatient ward following referral from A&E or primary care. It could also be achieved as a long-term consequence of CCN services empowering and educating parents, over time, to manage acute childhood illness at home. For example, in dealing with acute illness in children, parents have anxieties about making 'wrong' decisions<sup>27</sup> and the risks of longer-term harm to the child.<sup>28</sup> Parents can feel disempowered,<sup>29</sup>

and recent studies have shown a need for reliable information about recognising and managing acute childhood illness.<sup>30, 31</sup> Recent evaluations of CCN services show community nurses can counteract these issues by acting as a source of support, advice and reassurance, and increasing parents' confidence to support an ill child at home.<sup>9, 16, 17, 20, 26</sup>

Second, CCN services may reduce length of hospital stay. Although children with common conditions that resolve rapidly may not stay long in hospital, their large numbers mean that reductions in length of stay of only small amounts, and particularly avoiding a single overnight stay, would add up to changes in the individual average and total lengths of stay. There are also possibilities for shorter hospital stays when a child's condition is likely to resolve completely after treatment, or for complex care. Children with complex care needs may have longer lengths of stay in hospital when admitted for common acute illnesses, and very long lengths of stay for issues related to their complex care. For example, a study of 15 children in the South-West region dependent on long-term ventilation found that they experienced a mean length of hospital stay of 513 days before being discharged home, with one child having stayed for a total of 1460 days.<sup>32</sup>

Despite the theoretical possibility of impact of CCN services on secondary care, evidence for this is only just emerging, and is tentative at best (for example, see<sup>9, 33</sup>). Continued increases in emergency admissions lasting less than one day<sup>34</sup> mean efforts by CCN teams to fulfil admission avoidance functions are taking place against greater demand for urgent care. It is therefore important that future service evaluations try to account for this, although doing so is difficult outside the design of randomised controlled trials, an evaluation method inappropriate for this type of intervention.

Evidence for service quality is largely, but not consistently, positive. For example, studies of parental caring for ill children at home, particularly those with complex and ongoing needs, demonstrate a consistent picture of the demands associated with this.<sup>35-40</sup> The support provided by CCN services plays a critical role in supporting families in this situation,<sup>26</sup> although other evidence suggests that existing provision is not always sufficient in this respect.<sup>22</sup> However, evaluations of CCN services typically show that parents highly value these teams and are largely satisfied with provision.<sup>16, 17, 20, 26</sup>

Despite the evidence trend towards positive evaluations of CCN services, there remains a gap in understanding how views of service quality change over time. For example, the importance parents place on different aspects of service provision may change over time as families become accustomed to being supported by a CCN team at home. Such considerations may be important to managers and commissioners as they plan services. Also, in Parker et al.'s evaluation, evidence suggested that perceptions of service quality were strongly linked to the quality of relationships with healthcare staff,<sup>9, 26</sup> a finding replicated elsewhere in the context of other services.<sup>41, 42</sup> Parent-provider relationships inevitably change and develop over time, and again, this presents questions about the longitudinal experience of CCN service quality for families.

### **Organisational change in healthcare**

An extensive literature on organisational change indicates a range of factors that influence both the acceptability and sustainability of service change. For example, enabling and sustaining change requires a stable environment with capacity to acquire new knowledge.<sup>43, 44</sup>

A 'receptive context',<sup>43</sup> (p.595) reflected in strong leadership, allowance for risk taking, clear objectives, and dedicated funding is also important.<sup>43, 45, Pettigrew et al., 1992, cited in 46</sup>

Consideration should be given to the innovation itself and how it is implemented. For example, there must be compatibility between the change and the organisation in which it is taking place, and changes need to be seen as credible and vital to organisational success, with thought given to timing and order.<sup>43, 45</sup> At the person-level, the influence of key stakeholders can support or inhibit efforts to enact change, with the motivations, commitment, skills and values of others all playing a critical role.<sup>43, 45, 47</sup>

The evidence base regarding organisational change in healthcare spans both acute and community services, although no work has examined the salience of this evidence specifically for implementing CCN services. Given the national agenda to move care closer to home, which requires a degree of organisational change to introduce and expand new CCN services, understanding the factors that influence efforts to implement change in this particular context may be useful.

### **The need for research and background to the NIHR call**

Despite the national policy direction of moving care closer to home, commissioners have stated a need for evidence about the costs and secondary care outcomes of these types of

services.<sup>9</sup> The tentative evidence about such outcomes warrants a need for further research in this respect. In addition, questions remain about the longitudinal aspects of perceived service quality for families.

Typically, CCN services have not been formally evaluated using ‘gold standard’ experimental approaches, not least because of the methodological and ethical challenges of doing so. A 2011 NIHR call for quasi-experimental evaluations presented the opportunity for robust quasi-experimental evaluation of organisational innovations to develop CCN teams. Such evaluation would make a substantial and timely contribution to evidence, addressing the gaps outlined above. In response to this call, we designed a research project to answer the following questions:

1. Does redesigning children’s health care services by introducing CCN teams affect acute hospital admission rates for common childhood illnesses and length of stay for all conditions?
2. What changes in the quality of care do families caring for children with complex health care needs experience when CCN teams are introduced?
3. What benefits and challenges do commissioners and providers experience, as the new services are planned, implemented and established?
4. What are the costs and outcomes of the new services compared to those achieved by alternative service configurations?

As the research was taking place during structural changes in commissioning arrangements, a supplementary research aim addressed how these changes affected the planning, implementation and establishment of services (as part of question 3, above).

## **Overview of the research**

The research took place between 2012 and 2015, using a mixed methods, multi-site case study approach. A mixed methods approach of this sort is recommended when additional

information is needed to interpret quantitative measurements,<sup>48</sup> allowing us to understand how service redesign has worked, for whom and in what context (that is, providing a ‘realistic evaluation’<sup>49</sup>). Case studies are useful for understanding the wider contextual factors that may influence the phenomena being studied, with multiple case studies generally being preferred to single case studies.<sup>50</sup> Health communities aligned to the local primary care trust (and later in the research, clinical commissioning group) and NHS provider trusts acted as the ‘cases’. Selection of these case sites was based on our previous work, where we were aware of areas that were planning CCN services that would fit in with the timetable of the proposed research. For those sites that went on to secure these services, each had a slightly different approach to this type of provision. However, the key features across these teams were that they each focused on managing aspects of the child’s condition in the community (mostly, the home), and were nurse led. Two of the case site teams were ‘generic’; that is, they provided clinical nursing input to children with a range of needs (acute, chronic, complex and end of life) and conditions. Two of the case site teams were ‘specialist’; that is, they supported children with complex (mainly neurological) conditions only. One of these specialist teams was oriented to home respite care, whilst the second focused on managing acute illness through assessment and prescribing. More detail of the case site CCN services is provided in chapter 2. Previous work indicates that generic CCN teams, similar to the two studied in this research, are the most typical form of CCN provision.<sup>13</sup>

Across the sites, there were four strands of research activity.

**Strand 1: A longitudinal qualitative study of service change over time,:**

- Longitudinal in-depth, semi-structured interviews and focus groups with 41 commissioners, managers, practitioners
- Documents pertaining to the local service reconfigurations
- Field notes
- Thematic analysis using the Framework approach<sup>51</sup>

**Strand 2: An interrupted time series (ITS) analysis to explore the impact of introducing CCN services on acute hospital admission and length of stay:**

- Use of Hospital Episodes Statistics (HES) data to examine trends in secondary care activity by case site.

- Time series using between 60 and 84 monthly data points
- Looking at impact on acute admissions for common childhood illnesses and bed days and length of stay for all paediatric conditions (including a subset of complex conditions)

**Strand 3: A cost-consequence analysis to assess whether the introduction of CCN teams is likely to provide value for money compared with current service provision:**

- Data from resource use questionnaires and the translated Medical Home Family Index (MHFI) (see below) from 32 parents using the case site CCN services
- 
- Cost questionnaires for case site CCN teams
- Data on acute activity from the ITS analysis.

**Strand 4: A longitudinal qualitative study of changes in quality of care, with parents of children with complex health care receiving CCN services:**

- Longitudinal in-depth, semi-structured interviews with 31 parents of children using the case site CCN services.
  - Thematic analysis using the Framework approach<sup>51</sup>

In addition to the four studies, we translated two service assessment tools, the Medical Home Index (MHI) (Pediatric) and the MHFI,<sup>52</sup> as part of the research. The purpose and process of translating these tools are described in Appendix 4f and 4g.

Detailed methods and analysis for each strand are described in the chapters that follow.

**Ethical review**

The study was approved by an NHS ethics committee in 2012, and all relevant local governance approvals obtained.

**Summary of changes to the original protocol**

Five key changes were made to the original protocol:

1. One case site (Site A) represented a regional approach to service change and there were several CCN services introduced within the same period. Although our site contact (an NHS manager) had identified one team to participate, a second team were also keen to take part in the research. Thus, this case site resulted in two ‘arms’, with two CCN services being studied. One of these teams, however, declined participation in the qualitative study with practitioners and parents (though their managers and commissioners participated). Table 1 summarises the research activity across sites.
2. We had developed the research in partnership with three health communities, and thus, had intended to carry out the research with three case sites. However, due to delays with service reconfiguration in one case site (Site C), a fourth (Site D) was recruited so that we could undertake the parts of the research we were unable to in the delayed site. Because the service changes in Site D were complete with no further expansions or developments, we did not undertake the longitudinal qualitative component with service staff, instead carrying out one set of interviews.
3. We had intended to look at time of admission and discharge as part of the ITS analysis. However, this information was not available within the HES data, and thus we could not examine this as intended.
4. Due to difficulties recruiting newly referred parents, we amended our approach to recruit ‘established’ parent users of the CCN teams. Details of these changes are described in Chapter 5.
5. We had intended to collect data with commissioners and managers from the translated MHI<sup>52</sup> (now the CCN development tool). However, during the process of translating the tool with our NHS partners, quantification of responses was removed, as this was felt to make the translated tool more useful and meaningful in practice. Thus, we were no longer able to collect data using the tool. This did not affect the wider project, as originally, data collected with the MHI was to be analysed descriptively, and compared to interview data to examine face validity. Thus, whilst we could not provide a descriptive analysis of change to compare with interview data, our ability to meet the wider project aims was not affected. The intensive feedback gained from NHS staff

about the tool has enhanced its validity as a service development instrument. Full details of the translation and final tool are in Appendix 4.



**Table 1: Research activity across case sites**

<b>Case Site</b>	<b>Strand 1: Qualitative study with NHS staff</b>	<b>Strand 2: ITS analysis</b>	<b>Strand 3: Cost-consequence</b>	<b>Strand 4: Qualitative study with parents</b>
<b>A1</b>	Yes	Yes	Yes	Yes
<b>A2</b>	Yes (limited)	Yes	Yes	No
<b>B</b>	Yes	Yes	Yes	Yes
<b>C</b>	Yes	No	No	No
<b>D</b>	Yes	Yes	Yes	Yes

### **Patient and Public Involvement**

A dedicated project steering group, which consisted of representatives from the Royal College of Nursing and the voluntary sector, a paediatrician and community nursing practitioners, advised on the research process as well as the development of the MHI tool (see Appendix 4f). The group met five times through the three year project. SPRU's Parent Consultation Group (PCG) also advised on the materials developed for the qualitative study with parents.

### **Learning Days**

Three learning days were also incorporated into the management of the project, where representatives from the case sites came together with the research team to discuss the research and developments in services. These learning days also provided an opportunity to develop and translate the MHI tool.

### **Production of an analytical toolkit**

Any area undertaking a review of health services for children is likely to have the aim of preventing unplanned hospital admissions for children, or reducing the length of time children spend in hospital following admission.

The **Improving Services Toolkit: Improving services for children and young people who are ill** is aimed at commissioners and service managers who are aiming to redesign acute

services for ill children. It provides evidence and data which can be used to help develop strategies and business cases. It examines emergency hospital admissions for children with common childhood conditions, such as respiratory and gastric conditions. It also looks at how long children spend in hospital, and presents similar information specifically for children who have complex conditions, such as congenital heart conditions, cerebral palsy or metabolic disorders. The toolkit is available at the following link: <http://www.chimat.org.uk/istoolkits>

## **Structure of the report**

The following chapter presents details of the case sites taking part in this research. Given the mixed methods design of the project, detailed methods and findings for each study are presented in Chapters 3-7. Chapter 8 addresses the strengths and limitations of the project and pulls together the findings of each study to answer the four research questions, and Chapter 9 discusses the implications of the evidence for policy and practice, and outlines future research recommendations.

## **Chapter 2      Case site overview**

This chapter presents an overview of the case sites, including the background to the intended service change, the approaches to service change, and whether service change was achieved. References to rural/urban profiles in this chapter are sourced from the Rural Urban Classification Index (<https://www.gov.uk/government/statistics/2001-rural-urban-definition-la-classification-and-other-geographies>). To describe area level deprivation, the 152 Primary Care Trusts (PCT) ranked by deprivation in the 2001 Indices of Deprivation were split into quintiles, where: 1 = very high deprivation; 2= high deprivation; 3 = average deprivation; 4 = low deprivation; and 5 = very low deprivation.

### **Description of case sites and background to service changes**

#### **Site A: Generic CCN teams**

Prior to service change in the region, a number of inpatient units and small community or outreach nursing services existed. Across the region, workforce changes meant that inpatient services had to be reduced in order to be sustainable, and this, in turn, meant that more care was to be provided in the community. Thus, existing CCN teams were expanded and new CCN teams introduced to: support nursing care in the community for children with acute and chronic conditions; reduce multiplicity of care; and prevent acute admissions to, and facilitate early discharge from, hospital. Newly expanded or introduced community services were expected to be in place with evidence of competency prior to the closure of inpatient services. In addition to the changes in inpatient and community services, a new children's hospital was built for the region. We studied two health communities within this region, both of which introduced either new (area 1), or expanded existing (area 2), CCN provision in line with the regional reconfigurations outlined above.

#### **Area A1: Generic CCN team (community based)**

This community is a major urban area with a population of around 210, 000, of which between 15-20% are from black and minority ethnic groups. The area falls with the highest deprivation quintile (1). There were two provider NHS trusts in the PCT area, one an acute hospital trust and one a community healthcare trust. Prior to the reconfigurations in this area,

there was a small outreach service of two community nurses. As part of the reconfigurations, a large new generic CCN service was introduced. The team was community based, and anyone could make a referral, including parents. Self-referrals tended to be from parents of children with chronic conditions, such as constipation, eczema and asthma. Around three years after the CCN team was introduced, the local children's inpatient ward and A&E department were closed, and a GP-led urgent care centre introduced.

### **Area A2: Generic CCN team (hospital based)**

This community is a major urban area with a population of around 250,000. The area falls within the 'high' deprivation quintile (2), and fewer than 10% of the population are from black and minority ethnic groups. There was one provider NHS trust in the PCT area, which was an acute hospital trust. Prior to the reconfigurations in this area, there was a small generic CCN team of around five nurses. As part of the reconfigurations to move care closer to home, this team expanded its existing provision. The CCN team was hospital based, and worked closely with the hospital's A&E department (where there was also a consultant in paediatric emergency medicine and advanced paediatric nurse practitioners), the inpatient unit and the paediatric observation and assessment unit (POAU).

### **Site B: Acute and complex care teams**

Prior to the service changes, this site, a children's hospital, had a number of specialist services with outreach nurses and a complex home care team for children with neurological conditions, but no generic children's community nursing team or provision of acute care 'closer to home'. Continuing health care (CHC) packages for children were an ad-hoc commissioned arrangement, drawing upon agency resources and, as a result, were seen to delay discharge from hospital. These two issues – an absence of an acute home nursing team, and the ad-hoc commissioning of CHC packages – led to two proposed service changes. The first was the introduction of an acute home nursing team, intended to reduce hospital admissions, attendances and length of stay, and offer families a choice of care at home, school or nursery. The team would support a strategic aim of the commissioner and provider in providing care closer to home.

The second proposed service change was the expansion of the complex home care team, through an increase in nurses and clinical support workers, to accommodate 'in-house' provision of CHC packages. It was intended this change would allow more nursing care (for

CHC packages) to be provided in the community through the existing home care team rather than through an agency. It was expected that this would enable packages to be in place much more quickly (due to staff already being in place), therefore reducing length of stay.

Alongside this, a discharge coordinator role was created for the High Dependency Unit (HDU) in the hospital, where children with CHC packages tended to reside prior to discharge. The coordinator was intended to work closely with the expanded team to facilitate discharge of the child. Finally, it was proposed that the assessment of CHC would take place through a single point of assessment, in the form of a newly employed nurse assessor and coordinator.

The area served by the PCT here is a large urban community with a population of just over half a million. Just over 10% of this population are from black and minority ethnic groups, and the PCT rank falls within the high deprivation quintile (2). In addition to the children's hospital, there were two NHS providers locally – a hospital trust and a health and social care trust.

### **Site C: Children's community services in development**

This site, which at the start of the research was a large PCT, had historically comprised a number of smaller PCTs, not all of which had CCN provision. When these trusts came together to form one larger PCT, the different models of CCN provision were highlighted. It also resulted in a 'patch' that had no access to CCN services except for an acute trust discharge team for children under the care of the trust's consultant. Thus, children with a consultant in another trust (for example, a regional centre) would not access this service. This led to plans to standardise existing CCN provision, and ensure equity of access for all children and families by introducing a fourth team to cover the patch that had no provision. These proposed changes were embedded within a wider drive to reconfigure a number of other children's community services in the local area, including continuing healthcare, school nursing, health visiting and advanced paediatric nurse practitioner-led urgent care pathways.

The area served by the PCT is a mix of both urban and rural geographies, with a population of around 750,000. It has low levels of deprivation, falling within the 'very low' classification (5), and fewer than 10% of the population are from black and minority ethnic groups. Within the PCT boundary there are a number of NHS provider trusts, all acute hospital trusts except one, which is a community provider. The community provider was leading the bid to transform the local CCN services.

### **Site D: Nurse practitioners for complex conditions**

In this site, prior to service change, there was an existing CCN team providing clinical nursing care for children. A team of advanced nurse practitioners was proposed to complement this existing CCN team and support children with complex health care needs who were frequently attending the local hospital for acute care. There was no case management of children with long-term complex conditions, who had tended to rely on the local hospital instead of primary care for this. The new team of advanced nurse practitioners would address this by taking on the case management role, alongside assessing and prescribing. It was also intended that the case management would reduce multiplicity of care for families. The model was to be based on a model of adult community matrons that had previously been introduced, and which was felt to be successful by trust staff.

The area served by the PCT is a major urban community with a population of around 440,000, fewer than 10% of which are from black and minority ethnic groups. The PCT rank falls within the very high deprivation quintile (5). Within the PCT boundary there are two NHS provider trusts, one an acute hospital trust and one a community provider. The service change was located in the community provider trust.

Table 2 summarises the intended changes to CCN services across each case site.

**Table 2: Intended changes to CCN services**

<b>Site</b>	<b>Intended change to CCN services</b>
<b>Site A1</b>	Introduction of a generic CCN service
<b>Site A2</b>	Introduction of a generic CCN service
<b>Site B</b>	Introduction of an acute home nursing team and expansion of a complex care team
<b>Site C</b>	Introduction of a generic CCN service, standardise existing CCN provision, reconfigure continuing healthcare, school nursing, health visiting and urgent care
<b>Site D</b>	Introduction of a nurse practitioner team for children with complex conditions

## **Approaches to service change**

The approaches to the service changes taking place across the four case sites differed. These differences encompassed: whether or not it was a ‘whole-system’ change (that is, whether all children’s services were reconfigured); whether service change was an expansion of an existing service, or introduction of a new service; if there was more than one intended service change; and if change took place across more than one provider trust.

In Site A, a coordinated whole-system service change took place, in which all children’s services (both inpatient and community) were redesigned. Part of this was the introduction and expansion of CCN teams, closure of inpatient units, and the introduction of a new hospital. This whole-systems reconfiguration took place across a number of NHS trusts, and was led by a single network.

In Site B, there were two intended strands of service change (see above). These intended services changes were not part of a wider ‘whole-systems’ change. The intended and achieved changes took place within one NHS trust. In Site C, a broad set of reconfigurations encompassing a number of community based children’s services were intended (see above). These intended changes reached across a number of provider trusts in the area, but were led by one trust.

In Site D, the service change was the introduction of a new advanced nurse practitioner team. Whilst other new children’s community services had also been introduced earlier, these were isolated changes and not part of a coordinated whole-systems approach to change. The service change took place within one trust.

Table 3 summarises these approaches to service change.

**Table 3: Approaches to service change**

<b>Site</b>	<b>Whole-systems change (i.e. changing all children’s services)?</b>	<b>(Intended) changes to single or multiple services</b>	<b>Did (intended) service change take place across more than one provider trust?</b>	<b>(Intended) expansion to existing service, introduction of new service, or both?</b>
<b>A</b>	Yes	Multiple	Yes	Both
<b>B</b>	No	Multiple	No	Both
<b>C</b>	No	Multiple	Yes	Both
<b>D</b>	No	Single	No	Introduction of new service

### **Achieving service change**

Each of the four case sites intended to change their CCN services, either through introducing new services and/or changing existing services. In two of the four sites (A and D), service change was achieved. That is, both of the areas studied in Site A introduced or expanded their generic CCN teams, and in Site D, they introduced a nurse practitioner service as planned. In Site B, service change was partially achieved, with the expansion of the complex home care team set in motion. However, plans to introduce an acute home nursing team were abandoned. In Site C, plans for service change were ongoing for much of the duration of the research, before most of the intended reconfigurations were terminated towards the end. Thus, not all were able to achieve the service changes they intended.

Table 4 summarises the achieved CCN services across each site.

In the next chapter, we present findings from the staff qualitative study about the factors that influenced their efforts to plan and achieve the intended reconfigurations to CCN services. Chapter 4 discusses the challenges and issues faced by the teams once they were implemented.



**Table 4: Summary of CCN services across case sites**

<b>Site</b>	<b>Generic/ Specialist</b>	<b>Summary of intended intervention and functions</b>	<b>Needs covered</b>	<b>Settings of care</b>	<b>Coverage</b>	<b>Referrals to team</b>	<b>Team size, skill mix and banding<sup>a</sup></b>	<b>Years of operation at end of research period</b>
<b>A1</b>	Generic	Acute admission avoidance and facilitate early discharge. Case management for children with complex needs	Acute, long-term, complex, palliative and end of life	Home, school, nurse-led clinics	8am-8pm, seven days. On-call for end of life care	Anyone can refer, including parents. Self-referrals tend to be those with chronic conditions (e.g. constipation, eczema, asthma).	Around 19 WTE, bands 5-7 children's nurses with some specialist nurses, some with non-medical prescribing	7
<b>A2</b>	Generic	Acute admission avoidance and facilitate early discharge. Admission avoidance is prioritised	Acute, long-term, complex, palliative	Home, nurse-led clinics	8am-8pm, seven days. On-call for end of life care	Consultants, GPs, allied health professionals. No self-	Around 11 WTE, bands 4-7, health care assistant and children's nurses with some specialists	7

			and end of life			referrals from parents. Works closely with A&E, POAU and children's unit.	nurses	
<b>B</b>	Specialist (Complex, mostly neurological conditions)	Home respite by trained band 3 support workers, and children's nurses supporting child at home. Primary function to facilitate early discharge. Intensively support child with acute illness at home (for existing caseload children)	Complex	Home, school	On-call 24/7 nursing, home respite variable	Anyone can refer, including parents if they have a consultant in the trust	Around 12-28 WTE (growing with the accumulation of continuing care packages), bands 3 (support worker), 6 and 7 (children's nurses), some with non-medical prescribing	Expanded element – 4 years
<b>D</b>	Specialist (Complex, neurological conditions)	Acute admission avoidance and case management for children with complex	Acute needs for children with	Home, school	Monday-Friday, 9am-5pm	Neonatal unit, intensive care, social care, children's	Around 3 WTE  All band 8, advanced nurse practitioners (1	7

		needs	complex conditions			community nursing team	paediatric).	
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<sup>a</sup> There were some fluctuations in team size throughout the research period due to, for example, sickness. Thus, WTE and staff numbers should not be considered static representations over time.

## Chapter 3      Planning children's community nursing services: perspectives of NHS staff

### Key messages:

- i. The development and introduction of CCN services is possible but requires dedicated resources, medical support and, where taking place across multiple providers, a mechanism to oversee changes (for example, a network)
- ii. Commitment to, and views about, introducing CCN services vary among NHS stakeholders, but some stakeholders appear to be more powerful than others in influencing change
- iii. A lack of dedicated financing can lead to competition where multiple providers are involved, which hinders efforts to plan services
- iv. Wider instability in the NHS from the recent reforms adds further difficulties, with changes in commissioning arrangements compromising the leadership needed to take forward plans
- v. The 'magnitude' of service change does not necessarily correspond to whether plans to implement change are successful.

### Introduction

In this chapter, we draw upon the data collected through the staff qualitative study to present findings about the contextual factors that staff felt mediated their efforts to introduce or expand CCN services in the case sites. As per the realist approach to evaluation, such contextual factors are important for understanding the process and outcomes of service change.<sup>49, 53</sup> We begin with a description of the methods used for the staff qualitative study.

## **Methods**

### **In-depth, semi-structured interviews with NHS staff involved in developing**

#### **CCN services**

In-depth, semi-structured interviews are a widely used qualitative data collection tool.<sup>54</sup> Semi-structured interviews allow set topics to be covered, but with the participants' responses determining 'the kinds of information produced about those topics, and the relative importance of each of them'.<sup>55 p.94</sup> They were used here to capture the experiences and views of staff involved in the strategic development of CCN services. These staff included NHS commissioners, senior managers (for example, heads of nursing, heads of children's services), and in one case site (C), a senior nurse. We undertook these interviews longitudinally to understand the drivers, context, and planning for service change, the factors enabling and inhibiting service change, and perceived outcomes of service change (where applicable) as they occurred. A topic guide was used for interviews (see Appendix 4c), and all interviews were audio recorded and transcribed. A record of informed consent was taken prior to all interviews (see Appendix 4b). We treated consent as 'ongoing', and thus a record of consent was sought prior to each interview where a participant took part in multiple interviews across data collection waves.

#### **Sampling and recruitment**

A snowball approach to sampling was used, where an initial interview was undertaken with our key contact in each case site. This person then identified, either independently or as part of the interview, other relevant people to approach. Subsequent participants were also asked to identify any other NHS staff that we could approach for interview. All staff invited to participate in an interview were sent an information sheet about the research and a response form to record their participation decision (see Appendix 4a). Staff members were contacted either via email or post, depending on the contact details provided. Responses to invitations were given either by response form (returned to the researcher) or via email. If no response was received after 2-3 weeks, a reminder letter/email was sent. No further reminders were sent if a response was not received. In one case, a reminder letter was not sent due to organisational sensitivity in the case site at the time. We felt sending a reminder letter about the research and possible participation in an interview might aggravate researcher-observed tensions between staff.

In line with the longitudinal approach, all staff members who participated in an interview were contacted for a further interview approximately six months later. The information leaflet was resent along with an opt-out form. If an opt-out form was received, or a participant made contact to decline a subsequent interview, we asked if they could recommend anyone else for us to approach for an interview. If no opt-out form was received after approximately two weeks, a researcher made contact with the participant to arrange an interview.

We intended to carry out interviews with willing participants at six-monthly intervals. Based on the timetable, we anticipated approximately five waves of interviews. However, sometimes the intervals between waves of data collection were longer than six months. There were three reasons for this:

- Sometimes participants asked us to delay the interview until after a particular meeting, when they felt they would be in a better position to tell us about service change plans.
- The six-month interval expanded if a participant declined a further interview but recommended another person, or persons, to speak to, as this meant having to approach the new individual and arrange an interview.
- There were sometimes delays in participants responding to contact about the subsequent interview.

Due to expanded intervals (as well as longer than anticipated processes of getting local research governance approvals in some NHS trusts, which delayed the start of data collection with staff), we were able to undertake three waves of interviews with staff involved in developing CCN services.

Due to the variation in service structures in each case site, we did not set out to recruit a defined number of commissioners and managers involved in service development. Rather, we set out to recruit and interview as many key informants<sup>56</sup> as necessary in order to build up a picture of service change in each case site. In the first wave of interviews, we approached 17 individuals to participate in an interview (four of these staff were in Site D, where we did not undertake longitudinal interviews – see Chapter 1). Of these, 13 agreed to participate, and 12 took part in an interview. One participant who originally agreed to participate did not respond to later emails attempting to arrange the interview. We received no responses from three individuals, and a decline from one individual (who recommended another person to approach).

In the second wave of interviews, five of the participants interviewed at wave one declined participation. In three cases, this was due to a change of job following the reconfiguration of NHS commissioning structures. In one case, the participant felt unable to add anything further, but was happy to be contacted later if needed. Three individuals who participated at wave one gave a further interview at wave two, and a further three new individuals were approached and agreed to participate. This gave a total of six interviews (from eleven approached) at the second wave of data collection.

At wave three, nine individuals were approached for an interview. Five of these were those who had been interviewed at wave two, and one individual who participated at wave one but not two (but was happy to be contacted again later). Three were new individuals identified at this wave. Of the nine individuals approached, four agreed and took part in an interview, and five declined or gave no response. We attempted a fourth wave of interviews to further explore the perceived outcomes of service change in Sites A and B (partly explored at wave 3). However, we did not receive any response to the invitations to participate in Site B, and in Site A we were informed there was nothing new to add. Table 25 in Appendix 1 summarises this recruitment and attrition across waves 1 to 3.

Across all waves of data collection, a total of 22 interviews were undertaken with 17 staff involved in strategic service development, across sites. Participants included those involved in commissioning children’s health services within the trust, and those with a management role (for example, heads of CCN services, operational leads, associate directors of children’s services).

Table 5 summarises the recruitment by site across waves, Table 6 gives details of the number of staff approached and interviewed in total by case site, and Table 7 gives this information by job designation.

**Table 5: Number of staff involved in developing services approached and interviewed by site and wave**

	Wave 1	Wave 2	Wave 3	Wave 4
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	Approached	Participated	Approached	Participated	Approached	Participated	Approached	Participated
<b>A</b>	3	3	4	1	1	1	1	0
<b>B</b>	4	2	2	1	4	2	2	0
<b>C</b>	6	4	5	4	4	1	1	0
<b>D</b>	4	3	-	-	-	-	-	-
<b>Total</b>	17	12	11	6	9	4	4	0



**Table 6: Number of staff involved in developing services approached and participated by site overall**

Site	Number of unique individuals approached across waves	Number of unique individuals interviewed across waves	Total number of interviews
A	4	4	5
B	6	4	5
C	9	6	9
D	4	3	3
<b>Total</b>	23	17	22

**Table 7: Number of staff involved in developing services approached and participated by job designation**

Job designation	Number of individuals approached	Number of individuals interviewed
Commissioners <sup>a</sup>	11	5
Managerial role	12	12

<sup>a</sup> Pre April 2013, these were Primary Care Trust commissioners.

### Use of documents

Documents are valuable sources of data for case study designs <sup>(51)</sup>, as they ‘play an important role in organizational life’.<sup>57p.389</sup> We used them here to provide contextual insight into the case site area and its service developments. Alongside interviews, we asked participants for copies of any documents that would help us to understand the development and reconfiguration of services and wider contextual developments in children’s health services in their locale. We also asked for copies of documents that participants referenced in interviews. All documents obtained were numbered and

read. Any information in the documents that would provide helpful context was used to supplement the analysis. Across the sites, we obtained 34 documents.

### **Field notes**

Field notes are used to provide additional context to data collected from participants in interview studies.<sup>51</sup> They were used here primarily to record observations about service changes between staff interviews, and to record notes from any informal discussions or meetings the researchers held with case site staff. These notes were sometimes used to inform later interviews with staff in the case sites.

### **Non-participant observations**

We had intended to use this method as part of the qualitative study, to observe key meetings about the services being developed. Although we identified some meetings that we could potentially observe that may offer some insight into the development of services, these often involved staff members from multiple trusts, including trusts for which we did not have local governance approvals (we had governance approvals from the key trusts involved, but meetings often involved those from other trusts beyond the immediate coverage of the research case site). Thus, in order to carry out these observations, we would have needed to obtain governance approvals from these other trusts, which was not possible given the time this process takes. As an alternative, we followed up the content and outcomes of these meetings with participants in subsequent interviews, where possible. In another case, we identified a meeting that we could observe and we contacted those attending to seek permission. However, despite reminders, not all of those attending responded or gave permission for the observation. Thus, we were unable to carry out the observations as planned.

### **Analysis**

The longitudinal data was managed using the Framework approach<sup>51</sup> and analysed thematically. For full details of the analysis, please see the analytical plan and summary in Appendix 4e.

## **Findings**

As described in the previous chapter, the intended services were agreed, financed, set up and implemented as planned in Sites A and D, partially in Site B and not at all in Site C. Interviews with commissioners and managers indicated there were four main factors that influenced their efforts to introduce or expand the services they intended. These were: financing, medical support for the CCN services, NHS reforms, and managing change across multiple providers. Each of these is discussed in turn below.

### **Financing service change**

A theme emerging in the data across all case sites was that of financing service change. In Sites A and D, staff reported having money to invest in the service transformations, and therefore initially, they did not face financial challenges:

“Obviously we did this growth when we had money, in PCTs, we don’t have money now” (Commissioner, Site A)

“I think, you know, fortunate we’re, we’re, at that time, in a position where we, we did have money to invest” (Manager, Site D)

Accessing additional investment for further CCN service expansions at a later stage was reported as difficult for some teams in Site A, because there was no longer an allocated budget as there had been initially. Instead, they had to go through the process of bidding to local commissioners and not all were successful in securing such additional funds.

In Site C, where the initial stages of service change were taking place during the research, it was reported that there was no dedicated money to finance the proposed service change. The lack of available new funds to invest meant existing resources in the local NHS had to be reinvested. This meant a lengthy process of getting different NHS organisations in the local area together to review these existing resources. This was reportedly challenging, as organisations were trying to protect their income in a constrained financial climate. Tensions around withdrawing funds from acute trusts to fund community services were also reported:

“So we need to find a system that will enable us to have that open dialogue and find a way forward because the secret to success is releasing funding from the acute sector to support children in their communities” (Manager, Site C)

In the later stages of planning in Site C, the commissioners’ consideration of the proposed service plans for children’s community services was thought to be triggered by the financial viability of some parts of the local health service, although this, in the end, did not facilitate the intended service change.

In Site B, there was initial caution about funding expansions to the complex home care team, due to concerns about potential fluctuations of demand for the service. This evidently did not prevent the team expansion, but it was reported that such caution did delay getting the workforce in place. We later learned that the trust had responded to these concerns through an agreement where, if support workers in the expanded team were released through the termination of a package, they would transfer to the HDU and ICU until a new package was agreed. Therefore, this staff resource would always be in use, regardless of demand for the complex home care team. Further funding requests from the team to managers and commissioners for packages were apparently supported by the trust’s clinical director.

### **Medical support for CCN services**

The support of medical colleagues appeared to mediate the process of service transformation, with such buy-in supporting the planning, development and implementing of CCN services, and a lack of buy-in inhibiting plans for change. For example, in Site B, there were plans to pilot and introduce an acute home nursing team to reduce secondary care activity and deliver care closer to home for families. However, this intended service did not materialise due to a lack of ‘medical’ support for it locally. Concerns were raised by the medical directorate about the risks of this care being delivered through a community nursing function. At a later stage of data collection in Site B, the theme of medical support arose again, but in relation to the complex home care team. Here, one nurse reported the value of having a senior consultant that gave legitimacy to the team by supporting them with bids for further funding and working closely with, and having confidence in, the team nurses:

“He [consultant] values our opinions and gives us that, you know, confidence to be able to provide the service that we provide... Plus, if there’s any issue with the team, or we want to go forward for further funding or anything like that, then [he] is our clinical lead who will support us in doing that.” (Senior Nurse, Site B)

It is not explicitly clear in the available data why there was this contrast in reported level of medical support for the intended acute home nursing service, and the current complex home care team. One possible reason may be due to the complex home care team already being in existence (and therefore known and trusted) when it expanded to incorporate continuing care. In contrast, the intended acute home nursing team was a complete innovation, and to our knowledge, this site had never had a service like this before. The lack of support for it may have stemmed from a lack of familiarity with, and trust in, this kind of service.

In Site A, the network which oversaw the reconfigurations reportedly won backing from the medical workforce for the proposed changes during the planning stages. In Site C, the proposed service changes had some medical support, with a GP lead working closely with commissioners and practitioners to support change. However, this support did not overcome the other barriers this site faced, such as the impact of the NHS reforms, and a lack of dedicated finance combined with local competition for business (see below). Issues were also highlighted in this site around how some local acute trusts were supportive of CCN services, but others were not, and that this had prevented a cross-provider partnership working to develop a possible service. In Site D, it was reported that whilst GPs were not involved in the development of the new nurse practitioner team, they did support it.

### **NHS reforms**

The changes to CCN services in Sites B and C were taking place during the recent NHS reforms, where new commissioning arrangements, in the form of clinical commissioning groups (CCG), were being set up. The planning stages of transformation in Site C, and some aspects of service development in Site B, straddled both sides of 1<sup>st</sup> April 2013, when these new commissioning arrangements officially came into place.

In Site C, the NHS reforms were felt to be particularly problematic for the planning of new CCN services in the period before 1<sup>st</sup> April 2013. Commissioning in this preceding period was characterised as being in a state of flux, with changes to job roles and people. This, it was felt, contributed to the delays in progressing with plans for service change. Others reported the reforms were ‘stifling’, making people less open to change. In subsequent data collection that took place in this site after the 1<sup>st</sup> April 2013 (between July and September 2013), these challenges continued. With new people coming into post as a result of the reforms, it was felt to be difficult to know who to talk to and when regarding the proposed new services:

“I think what seems to have made, made it sort of not quite so clear, in terms of moving forward, is, you know, all the new CCG setting up and people getting into posts and knowing who, who we need to talk to when” (Manager, Site C)

At the later stage of data collection, it was also apparent how the broader set of plans for changing CCN services (for example, continuing care, CCNs, urgent care pathway) had been split following the changing commissioning arrangements. The urgent care pathway changes now sat with the CCG and the remainder with the Joint Commissioning Unit (JCU). Whilst the two were reportedly working closely on these changes, this, we were told, could sometimes be challenging. Around November 2013, seven months after 1<sup>st</sup> April, there was still uncertainty about who was leading the commissioning arrangements locally, with concerns expressed that this would further delay service change plans. Approximately one year later in October 2014, the complexity of local commissioning arrangements between the local CCGs and JCU persisted, with the new arrangements described as a ‘minefield’.

In Site B, the NHS reforms were reported to have affected the original plans for supporting children receiving CHC packages (through the complex care team) in schools. Originally, it was intended that the local special school nursing resource would be used to support these children in schools. However, following the NHS reforms, the contracts for special school nursing moved to the local authority and it was no longer possible to go ahead with these plans. At the first round of data collection, it was reported that discussions about this issue between health and education commissioners were ‘uncomfortable’, stalling progress in securing the special school nursing resource. However, at later data collection it was reported this was now progressing and the two commissioners were working together to develop the school support for children with CHC packages. Later, the team suggested school support was not particularly problematic, with support workers and teaching assistants in school working together for the child’s care.

### **Managing change across multiple NHS providers**

In both Sites A and C, the service reconfigurations were taking place across a number of provider trusts, but the nature of this multiple trust involvement differed between the two. In Site A, the multiple provider trusts involved were each the recipient of financial investment and their own service change was led by a network. In contrast, the proposed changes in Site C were being advanced by one particular provider trust. However, with no new money to invest, existing provision across a range of providers in the local area had to be reviewed, leading to cross-provider talks to address this. These cross-provider talks appeared to be in the form of a clinical group established by a former commissioner who had initiated the original proposal for service change. A lack of clinical consensus was cited as a factor delaying progress with service plans, which may reflect competition for business between the different provider trusts, a factor cited in later data collection in this site. Such competition may have been exacerbated by the lack of new funds to invest and the need to use and review existing NHS resource (see earlier).

In Site A, a network had centralised the service change, and oversaw all contracting, (initial) recruitment and monitoring. The network was felt to be particularly beneficial to the reconfigurations. It was reported to help standardise the process across participating NHS trusts, it created a high profile locally to communicate the changes effectively (“the network was very key in it getting the priority it needed locally”), and it enabled children’s commissioners to come together, creating opportunities for shared learning.

Such macro level structures were not reported in Site B and D, and this probably reflects that in these sites, service changes were isolated to one provider trust and thus no macro structures were required.

### **Termination of reconfigurations in the planning stage (Sites B and C)**

As noted earlier, service change was not achieved in Site C, and only partially in Site B. In Site B, a lack of medical support was cited as the reason why the introduction of the acute home nursing team was not achieved. We learned of this early in the research, but it was unclear from interviews and available documentation how much work had been invested in the planning for this service. We know it got as far as a service specification from the commissioner, but as the planning for this appeared to take place before the research we were unable to capture it in detail, and in ‘real time’.

By contrast, in Site C much of the planning for the intended service change took place during the course of the research, and we were able to capture this ‘as it happened’, including the decision to terminate much of the reconfiguration plan. This provided an opportunity to describe the extent of the work, time and effort invested in the planning of a service change that was not achieved. In previous sections, we have described the factors that participants in Site C felt influenced the planning. In this section, we describe these to provide a chronology of events and factors and offer an overarching picture of the difficulties in achieving service change in this case site.

Prior to the research, we had been in touch with this case site in 2010, when the then commissioner was proposing plans to redesign children’s community nursing services. The commissioner knew of our previous work in this area<sup>9</sup> and wanted to use the learning from the research to inform planning in the site. By the time the current project got under way in 2012, these proposals were ongoing, and with the appointment of a new head of nursing, work was underway to plan and research the proposed redesign. For example, we received copies of draft commissioning intentions, and the first round of interviews in late 2012 indicated there was work being done on business cases, auditing existing services and workforce planning with other local providers. In 2013, further planning work was being done, including a review of services, a public consultation, continued discussions and workforce planning with other provider trusts, and the development and submission of a business case following a service specification from commissioners.

Across these first and second rounds of interviews, there was discussion of tensions and competition with other providers. These discussions indicated that it was not simply a case of one provider negotiating with a commissioner, but multiple providers negotiating with each other as well as



commissioners about resources and future service provision. Perhaps most prominent in the discussions were the difficulties of continuing such service planning with the change in commissioning arrangements. This was felt to play a significant role in delaying service change, and was mentioned at each stage of data collection (see above for more detail – NHS reforms).

It was also apparent there was much interdependency between stages of planning, with certain aspects or events holding up the progression of others. For example, in 2013 the planning of the new service model became dependent on the outcomes of a public consultation on existing provision. This was because the new service model partly depended on the resources released by the decommissioning of the existing provision. Another example was that the new intended service was dependent on the appointment of a new nursing post in a different trust, to facilitate discussions across providers about workforce planning.

Despite these difficulties, in late 2013, it was reported that the submitted business case had verbal go-ahead, with the provider now planning the phased implementation of the proposed service. These service changes aligned with outcomes of the public consultation regarding existing provision in the area. However, by early 2014, we learnt that this decision had been reversed by the commissioners. It was reported this was because of a lack of financial planning around the redesign. In October 2014, it was reported that despite persisting complexities around the new commissioning arrangements, there was some progress. A number of factors were felt to be responsible. First, the appointment of a new commissioner allowed someone to look at the proposed redesign and the issue of inequity of CCN provision with ‘fresh eyes’. Second, the CCGs were felt to be giving more thought to the redesign. As noted earlier in this chapter, following the new commissioning arrangements, it was the JCU that had largely led the commissioning for the redesign of CCN services in this area. However, by October 2014, it was reported that the CCGs were beginning to grapple with the issues around CCN services, though it was still felt that children’s services more generally was a low priority for them. Third, neighbouring health communities were also redesigning their CCN services as a priority, and this was felt to have influenced the commissioners in this case site in thinking about the possibilities of their own CCN services.

The plans and intentions for the service change in this site had started at least as far back as 2010, and continued into 2014. This represents four years of planning for a service change that was eventually abandoned.

### **Influence of changing commissioning arrangements**

As this research was taking place during major NHS reforms, we included a secondary research question about whether there would be an impact of changing commissioning arrangements on the intended service reconfigurations. An impact was most evident in Site C, and to some extent Site B, which we have already described above. As expected, in Sites A and D where the services were established, there was no evidence of impact on service reconfigurations in terms of planning and early implementation (such as that seen in Site C and B respectively). However, when we asked staff in these sites about the changing commissioning arrangements on existing CCN provision, a common issue raised in Site A was how urgent and secondary care was a priority for the CCGs. Findings about this are presented in Chapter 4, where we discuss the issues teams faced in practice.

### **Summary**

The findings reported here highlight the complexities of achieving service change to move care closer to home. There was clearly a commitment from both providers and commissioners to develop and introduce these services, but other factors were influential in determining the ‘success’ of their plans. Whether or not the plans had the support of medical staff appeared to play a role, to varying extents, in whether services were achieved. This suggests that there may be conflicting views about the acceptability of CCN services as a means of delivering care closer to home, but also that the views of some NHS stakeholders hold more ‘weight’ than others. When service reconfiguration takes place across a number of providers (as was the case in Sites A and C), a centralised network appears useful for ‘powering’ change. However, smaller, isolated service changes are also possible, as was the case in Site D. Thus, the magnitude of the reconfiguration does not necessarily correspond to whether service change is successful.

Dedicated finance without the need to disinvest elsewhere in the system was observed in those sites where service change was achieved. By contrast, a lack of dedicated finances and the need to disinvest in existing services can exacerbate competition between providers, making service planning and

development time consuming. Changing, unstable environments add further difficulties. Nonetheless, some were able to implement the services they intended. In the Chapters 6 and 7, we present findings about the impact of the implemented services on secondary care, costs and quality. In the next chapter we present findings from practitioners about the issues they faced once services were implemented, and the perceived outcomes of their provision.

## **Chapter 4      Implementing children’s community nursing services: perspectives of NHS staff**

### **Key messages:**

- i.**      Poor visibility of new and expanded CCN services can affect take up by primary and secondary care. Maintaining this visibility can be difficult to do alongside the day-to-day demands of delivering care
- ii.**     Balancing needs of different groups of children on the caseload can be a challenge, particularly when resources are constrained in times of staff absence or when acute need increases during winter months
- iii.**    Demonstrating impact and value is difficult using outcomes relating to secondary care activity. Teams are looking for ways to measure meaningful outcomes relating to quality.

### **Introduction**

In the sites where service change intentions were realised (Sites A, D and partially B), implementing and embedding these new services did not come without challenges. There were some common themes across sites in this respect, but some implementation issues were specific to the individual team and their service context. In this chapter, we draw upon data collected from the teams who delivered the services to present findings about the key challenges faced when implementing the new or expanded services. We begin with a description of the methods used.

## **Methods**

### **Focus groups and in-depth, semi-structured interviews with CCN team practitioners**

Focus groups are particularly useful for exploiting group interaction to generate information <sup>(58)</sup>. To understand issues associated with the implementation of new or expanded services, we undertook focus groups, and some supplementary in-depth interviews, with the practitioners in the CCN teams in Sites A1, B and D. As with the data collection with managers and commissioners, we planned to undertake longitudinal focus groups with practitioners to understand expectations and reflections about the changes to practice. For Sites B and C, where the teams were to be introduced during the research period, we expected to undertake the first focus group soon after implementation, and the second approximately six months later. We were able to do this for Site B, where we explored issues associated with their recent expansion to incorporate CHC provision. However, as the intended new CCN team in Site C did not go ahead, it meant we were unable to collect data in this site for this component.

For Site A, where the team was already established, we also undertook two focus groups. The first retrospectively examined the earlier phase of implementation as well as expectations about new developments in the team. The second, approximately six months later, examined reflections about these new developments. Topic guides were used for each focus group (see Appendix 4c). In Site D, which was a late addition to the research to compensate for the loss of research activity in Site C (because of the delays to service change), we undertook one focus group to explore issues associated implementation retrospectively. A second focus group was not necessary, given that there were no further service changes or developments taking place.

### **Sampling and recruitment**

Because of variation in local service structures, a set sample size was not feasible. Rather we intended to recruit as many team members as possible across the three sites. Thus, all available practitioners (n=35) across sites were approached to participate in focus groups at wave 1. Of these, 21 agreed and took part, and a further individual who had not been approached joined a focus group on the day (Site B). Fourteen individuals either declined participation or did not respond. In Site A we were advised it would be difficult to find a date where everyone could attend due to rostering of shift work. Instead, we were advised to set a date for the focus group and those who were present and willing to participate could join in. At wave two, we

approached all those who had participated at wave one in Sites A and B (n=18). Of these, twelve agreed to participate (thus, there was an attrition rate of one third of the original sample). An additional three individuals, who had not been approached because they had not taken part at wave one, joined the focus group in Site A on the day. At wave two in Site B, two participants requested an individual interview due to scheduling conflicts with the date set for the focus group.

Participants across the sites were nurses (n=20) and clinical support workers (n=4), all of whom worked as part of the teams. Nurses included generic CCNs, specialist nurses, and those with advanced practice qualifications. Table 8 details the number of participants approached and the number who took part in a focus group or interview, at each wave of data collection, by site.

**Table 8: Number of participants approached and who took part across waves**

Site	Wave 1		Wave 2	
	Number of staff approached	Number of staff participating	Number of staff approached	Number of staff participating
<b>A</b>	23	9	9	8
<b>B</b>	9	10 (an additional team member joined the focus group on the day)	10	7
<b>D</b>	3	3	Not applicable – one focus group undertaken	

A record of consent was obtained prior to data collection for participants taking part in both the focus groups and interviews, and for each wave of data collection.

As described in Chapter 1, we also drew upon relevant documents for context, and contemporaneous field notes.

### **Analysis**

Focus group and interviews were audio recorded in all cases, transcribed, and data managed and analysed using the Framework approach.<sup>51</sup> In one case, the audio recording of an interview failed and notes of the interview were made and sent to the participant for confirmation. For full details of the analysis, please see the analytical plan (Appendix 4e).

## **Findings**

Across the three sites, there were three overarching themes about the challenges faced when implementing the new or expanded services. These were: the visibility and legitimacy of CCN services, balancing different caseload demands, and demonstrating impact and value. Alongside these, there were issues specific to individual services and their context. In this next section, we present findings about the implementation challenges faced, starting with the three overarching themes.



### **Visibility and legitimacy of CCN services**

Once services became operational, there were immediate and ongoing issues about how visible the teams were to others. For example, when the nurse practitioner team in Site D was initially introduced, it sat alongside a CCN team in the acute trust. Later, when acquired by a different NHS trust, their base was moved into the community. Though the team preferred being based in the community, visibility to acute trust consultants was felt to be compromised, affecting consultant referrals to the team:

“we’re not utmost in people’s, in consultants’ minds for when they’re looking at, you know, care for these children” (Focus group, Site D)

Problems with visibility were thought to be partly a result of the team being so small at just three advanced nurses, and partly a lack of marketing on their behalf. Whilst the introduction of a similar team in adult services was preceded by a marketing exercise at the senior management level, this did not happen for the nurse practitioner team. When the service was first set up, there was ‘suspicion’ from other services, and a lack of clarity about what the team would do. In response, they had to raise their own profile with others through educating them about the service. The team reported that others’ learning about their team continued in every day practice through joint working, but they still struggled to find time to continually maintain their profile whilst delivering the service.

Similar accounts were found with the Site A generic CCN team, particularly with regards to how they were used and understood by GPs, where referral rates had been low. In response, the team implemented a liaison post to increase visibility of the service to, referrals from, and to improve relationships with, primary care. This involved close working with local GP practices, sometimes sitting in on GP consultations to advise on which children could be safely managed by the team. This post was felt to have worked well; referrals from GPs had doubled, and GPs better understood and valued the role of the team. Face-to-face contact between the team nurses and GPs was thought to be a significant part of the liaison post’s success.

Despite this success, visibility of the service to others remained a concern for the team. Earlier implementation was accompanied by a publicity drive, coordinated by the network that had overseen the wider reconfigurations (see Chapter 3). Thus, the new service was ‘marketed’, which the team felt

was valuable for creating awareness of what they could provide to others in the NHS as well as to the public. However, the network ceased during the period of research, and there was no longer anyone to do this marketing. Having a dedicated person to do this was deemed important to raise and maintain awareness of the service to ensure its continued use:

“we need a marketing bod for everything we do really” (Site A, Focus Group 2)

Both the accounts of those in the nurse practitioner and the generic CCN team highlight not only difficulties with being visible to and understood by others but also a wider issue about how the teams struggle to achieve legitimacy within the local NHS. They had to prove themselves to the GPs and consultants that would refer to them, in order to ensure their use and success.

Problems regarding visibility and understanding were also reported with the complex care team in Site B. However, unlike those reported in Sites A and D, these appeared to be temporary problems following the expansion of the service to incorporate the provision of CHC packages alongside their original remit (home nursing and respite for children with complex medical conditions). In the first focus group, the team saw a division between the two sorts of provision, with “*the same staff... doing two different roles*”. There was, they felt, some confusion among other professionals and families about this division in the newly expanded team and what it provided. However, when we followed this up six months on, it was clear this issue had largely disappeared, with the team no longer seeing any sort of division in the care they provided. Other professionals were becoming more informed about them as a team because more were initiating contact with them. This suggests the service expansion had become embedded in a relatively short period of time, and did not face the same longer-term pressures to establish themselves as seen in Sites A and D. One explanation for this may be that the complex care team was not brand new (like the teams in Sites A and D), but an expansion of an existing team that was already largely visible to those that used it.

### **Balancing different caseload demands**

Another implementation challenge faced by the generic CCN team in Site A was that of balancing the needs of different groups of children on their caseload. The intention of the new team was to offer provision for those with acute, long-term and complex needs. However, there was, immediately, a substantial population of children with complex needs being referred, resulting in a large caseload for this group. Balancing the needs of this group with the needs of those with acute illness could be particularly challenging in winter, when referrals for acute cases typically increased. It was anticipated that a newly created post, dedicated to children with complex, continuing and palliative care needs, would help to address this.

Indeed, later data collection with the team confirmed that the appointment of a complex needs coordinator had been beneficial in this respect, although the large caseload of children with complex needs still presented an ongoing concern. Coordinating care for children with complex needs was felt to be time consuming, but the nurse who had taken on the post was felt to be particularly knowledgeable about local services for this group of children due to her extensive experience, and could make these links much more quickly than a nurse without this experience:

“I found it dead helpful, cos I’ve got a few that are complex needs, and it, I could spend days and days and days on just like that patient, and she’s [complex needs coordinator] come in and took a lot off me so I can carry on with all my acute stuff as well” (Site A Focus Group 2)

The post was also seen as a resource for the wider team, with the nurse being able to offer advice and training regarding care of children with complex conditions.

The teams in Sites B and D did not face issues about balancing demands between those with acute and complex needs, but that is likely because their caseloads included only those with complex needs. However, the expansion of the Site B complex care team had resulted in two different caseloads – those with and without NHS funded CHC packages – and concerns were raised about balancing the needs of both within finite team resources. There were suggestions that the newly incorporated CHC service component could potentially dominate provision, with those families on the team’s original

caseload who did not have a CHC package being ‘neglected’. Upon following this up at later data collection point, there were mixed views among team staff. Some felt this was not problematic currently, whereas others felt it was an issue in times of staff absence, where priority was given to children with CHC packages. Some suggested addressing staff absence by having a floating nurse to step in and provide cover, but also noted that it was unlikely such a post would be funded.

### **Demonstrating impact and value**

The generic CCN team in Site A believed they were helping to keep children with complex needs out of hospital by intensively managing them at home, but reported it was difficult to demonstrate or evidence this. They collected data about the activities they undertook, but they also required data about secondary care use. However, this was difficult to achieve. First, they did not have the resources to audit the hospital use of every child on their caseload. Secondly, population level secondary care data (that is, HES) was deemed problematic, as potentially high-volume attendances at the local Paediatric Observation & Assessment Unit were counted as inpatient admissions within this data. Thus, staff felt it was not accurately representing trends in inpatient admissions (an issue also seen to be part of a wider trend nationally) and was a poor measure of their impact on this activity. Other forms of data collection, designed to show impact on secondary care, had been attempted at the caseload level. Whilst this showed a patient-reported decreased use of secondary care, this had not corresponded with decreases in activity in the secondary care data used by commissioners (typically HES data). Similarly, whilst the team could demonstrate an impact on primary care through increased referrals from this source, which was felt to be a precursor to deflecting hospital attendance, there was no visible corresponding effect in the secondary care data.

Team members felt that there was also too much focus on contact activity, rather than service quality, for demonstrating impact. However, this had begun to change by the time of our second data collection, where the team reported plans to start collecting data on quality outcomes and patient satisfaction. Despite this, there were still concerns that patient satisfaction outcomes would not be sufficient to demonstrate the team’s value to commissioners.

Similar concerns were raised by the nurse practitioner team in Site D. The team were keen to collect data to evaluate their service, but it was felt that the current IT system did not adequately capture their activity. It was also anticipated that attributing outcomes to the team could be a challenge, given the close working and interdependency between the team and other services. Impacts on A&E and school attendance were outcomes being examined using data reported from families using the service. Work was underway with the acute trust to seek more robust data on A&E outcomes.

Concerns around demonstrating impact and value were not raised by the complex care team in Site B. However, it was raised by the commissioner who was unable to access patient level data, due to recent legislation, to examine the impact of increasing team activity on length of stay locally.

## **Site specific issues**

In addition to the overarching themes presented above, the teams in Sites B and D also reported challenges that were specific to their own services and context. These are reported in turn below.

### **Site B: Complex Care Team**

The expansion of the complex care team in Site B to incorporate provision of CHC packages meant that new band 3 clinical support workers were brought into the team to staff these packages. Initially, the team used temporary one-year contracts for support workers, which offered flexibility to determine 'fit' between the worker and the family to whom they were allocated for a package. We later learned, however, that this caused problems in attracting high-calibre applicants, and created job insecurity meaning existing support workers would look for other work towards the end of the contract. To address this, permanent contracts were introduced, and 'fit' between families and support workers was addressed through moving the worker to a different package. It was reported they now had enough packages in place to allow this. Securing the permanent contracts was difficult initially, due to the financial implications. However, this was addressed through an agreement whereby if a package ended, thus releasing the support worker, they would work at the children's hospital in the interim until a new package became available. Retaining staff through these permanent

contracts reportedly contributed to more efficient processes in getting care packages in place. It was also thought to save money in training, as the team no longer needed to train new workers replacing those on temporary contracts.

Another issue faced by the team was about how best to staff the care packages. A model of core care teams was used, where a core set of staff in the team was allocated to a package, and peripheral staff acted as a back-up in the event of staff sickness. This offered continuity to, and was reportedly desired by, parents. However, this approach also had challenges, in that staff could become very knowledgeable about one particular child to whom they are allocated, and less knowledgeable about others. This, in turn, made it difficult to move staff around at times of staff sickness and absence:

“Because if, if you, you know a lot about one particular child because you work with them a lot, it does mean that you tend to know less about others, and some of our children are really complex so it means that we can’t always move them around quite as flexibly, you know, as we could before” (Nurse, Site B)

Practitioners had also expressed a desire to work with different children to allow them to maintain a professional relationship with the family, avoiding relationships that might become too emotionally close with one family, which may tax their own emotional resilience. The use of core care teams thus continued, but with more crossover of staff onto different care packages to address these issues:

“it works for both, parents become, don’t come as dependent on other small groups of people and you, the support workers keep their skills up” (Site B Focus Group 2)

#### **Site D: Nurse Practitioner team for children with complex conditions**

The development and introduction of the nurse practitioner team required staff to have advanced practice qualifications, either generic or paediatric. All staff that had worked in this team did so, and whilst it was felt that having this qualification was necessary, clinical practice and experience were also important to undertake the role. Having an experienced advanced paediatric nurse practitioner in the team was thought to be beneficial in helping newly qualified advanced practitioners develop into their role through supervision, support and mentoring:

“we wouldn’t have been able to do the post without [other nurse practitioners] already having come in with their APNP because they acted as, you know, supervisors, mentors, etc, supporting us to, for us to develop into the role” (Site D Focus Group)

Maintaining an advanced skill set for assessing, diagnosing and treating acute illness required regular use of such skills, but time spent on team management and tasks for ongoing nursing needs (such as managing portacaths, gastrostomy tubes) could potentially limit opportunities for this. However, in this case, the team felt that the existence of a local children’s community nursing team, which dealt with these other ongoing nursing needs, enabled them to focus on assessing, diagnosing and treating and thus helped them to maintain their skills.

One of the most prominent issues that arose in the discussion with this team was the role of GPs in the care of children on their caseload. The team described positively their working arrangements with primary care services such as health visitors and school nurses. However, whilst they tried to keep GPs informed about the child’s care, they noted that GPs had little actual involvement with the child. The team attributed this partly to the fact that parents tended to contact the nurse practitioner team for supporting their child during acute episodes of illness, instead of the GP. Given the focus of the team is to address acute illness through assessing and prescribing, this would make sense. Indeed, as we see in Chapter 5, parents told us they typically chose the nurse practitioner team over GPs when their child was acutely ill. The consequence of this, however, was that when young people were ready to transition to adult services, a GP may have seen the child very few times and thus would be unfamiliar with their care needs. The nurse practitioner team were keen to do more to involve GPs in preparation for when the young person transferred to their care in adult services. However, even if the nurse practitioner team did not exist, it is possible that GP involvement in the child’s care would still be limited. The team were

designed in response to a population of children with very complex health needs, who typically used the local hospital for acute illnesses such as fever and infections. Thus, parents were bypassing primary care anyway, suggesting that the absence of GP involvement is not a result of the nurse practitioner team, but a demonstration of the difficulties primary care has in dealing with a group of very complex children with highly specialised needs.

## **Summary**

Once CCN services are implemented or expanded, becoming visible to and understood, accepted and utilised by other NHS services was considered challenging. There was a need for continued marketing with dedicated resources for this, as undertaking this work alongside the delivery of care was difficult. In one context, a specific post was deemed successful for increasing awareness to, and building relationships with, primary care. Ongoing pressures to establish and embed services was not observed in Site B, which may reflect the team's existing known role in the local service landscape prior to expanding. Balancing demand between different groups was observed in two sites but appeared different in a context where the nurse practitioner team had a very particular focus in their remit. Demonstrating impact and value was also challenging, and the findings presented here raise questions about identification of the most meaningful outcomes measures, and the most robust and appropriate data to capture this.



## Chapter 5      Experience of quality of care when using Children's Community Nursing services

### Key messages:

- i. Parents' positive experiences of CCN services are reflected in the team's central role in supporting them to manage their child's ongoing health and care needs at home
- ii. Various features of CCN services help to achieve this, though the importance of these features to parents may change over time if they become more confident in caring whilst the team becomes less involved
- iii. Positive experiences of CCN services are also reflected in the perception that they help avoid planned and unplanned hospital stays and attendance
- iv. Quality of care is maintained when CCN teams are able to offer provision that enables parents to feel supported in managing their child at home. However, supporting parents is not necessarily dependent on maintaining a constant level of service input.

In this chapter, we present findings from the qualitative study with parents. The aim of this part of the research was to examine parents' experiences of changes in quality of care when using CCN services. NHS England's definition of quality encompasses three things: clinically effective care, safe care and a positive experience of care.<sup>58</sup> This study component focused on the latter of these - positive experience - by examining the ways in which parents used the services for their child, what they valued, and what positive outcomes they felt were achieved as a result. As noted in Chapter 1, this part of the research focused on the community based generic CCN team (Site A1), the complex care team (B) and the nurse practitioner team for complex conditions (D). We begin with a description of the methods.

## **Methods**

### **In-depth, semi-structured interviews**

We undertook two waves of in-depth interviews with parents of children with complex health needs using the teams. The first interview explored the parents' early experiences of using the team for their child, from when they were referred, including: how the team was used, views of care quality, and expectations for future use of the team. The second interview explored if and how their use of the team had changed since the first interview, and again views on quality of care. Topic guides are in Appendix 4c. Interviews were audio recorded with permission and transcribed in all but two cases, where detailed notes were taken instead (at the request of the participant). At the same time as the interview, the researcher administered the cost questionnaire for study 3 (see Chapter 7 and Appendix 4i), and parents self-completed the MHFI. A record of informed consent was obtained prior to each interview.

### **Intended sample**

For this part of the study, we chose to recruit parents of children with complex health needs. There were two reasons for this. First, this group of children are those who are likely to be intense users of secondary care and where the support of a CCN team may be particularly important. Second, we wanted to understand changes in experience of care over time, and it was most likely that those with complex needs would be using the team over longer periods of time, as opposed to those using the team for one-off episodes of care (for example, children with acute needs with no underlying complexity). As we wanted to understand change over time, we intended to recruit parents who were newly referred to the services. This would enable us to capture their early experiences and their expectations of using the team for their child. A second interview approximately six months later would allow us to see if and how use of the team had changed over time, and if and how experience of quality of care changed over time.

Parents were eligible to participate if they: had a child with a complex health condition, were newly referred to the team (within six months of referral), and were likely to use the team again one or more times in the six months from referral. We excluded those who were receiving end of life care.

Children with complex health needs constituted just one part of the caseload for the team in Site A1, who also provided care for children with chronic

conditions and acute conditions with no underlying complexity. The teams in Sites B and D catered only for children with complex health needs. We intended to recruit between 25-35 parents across the three case sites. At the start of the research, the case sites were planned to be A1, B and C. Due to the delays in Site C, described in Chapters 1 and 3, the research activity transferred to the newly recruited Site D. However, because new referrals per month were few in Site D, we compromised and recruited the most recent referrals.

In addition to interviewing parents, we intended to interview, where possible, their child. This would draw upon the interview facilitation materials that were developed, piloted and used in the previous project.<sup>9</sup> Children were eligible to participate if they were aged over five years, and were cognitively able to give informed consent and participate in an interview. We intended to adapt the mode of interview to suit the young person's communication style.

## **Recruitment**

For parents, we prepared invitation-to-participate packs, which included a covering letter, an information sheet explaining the research, a response form that parents could return directly to the research team, and a pre-paid return envelope. We asked the teams to distribute these packs to parents meeting the eligibility criteria. If we received no response from the parent after three weeks, we prepared reminder letters and asked the team to send these on our behalf. For data protection reasons, we were not able to directly contact families who were using the teams. For children, we explored with parents at the second interview whether it would be possible for their child to take part in an interview, and if we could approach them with an invitation to participate. We explained that we would adapt the interview to suit the young person's communication needs, and information packs for the parent and child were given. These included a response form to return to us. As we could not approach children directly, we do not know for certain whether parents chose to pass on the information to their child. All final recruitment materials used are in Appendix 4.

### **Achieved sample, and attrition**

A total of 32 parents were recruited to the study, of whom, 31 took part in an interview. One parent wanted to participate but did not have time to be interviewed. This parent asked to complete the questionnaires instead, and we agreed. Thus, interview data is from 31 parents. Cost and MHFI data is from 32 parents.

Initially, we experienced difficulties with recruitment; we had few responses from those parents contacted. We adapted the materials in two ways to improve our recruitment. First, we added the option of texting a response, so that parents could use this method to respond instead of mailing back a response form. Second, we reduced the amount of information we sent in the invitation pack to make it easier for parents to go through the material. For this protocol revision, the invitation packs included a combined covering letter and response form, and a pre-paid envelope, while the information sheet was sent separately to those who responded stating they were interested in participating. Although we were giving parent participants a £10 shopping voucher as a thank you for their participation, we did not reveal this initially, due to concerns around financial incentives. Later, in an attempt to increase participation, we did include this financial incentive in the revised covering letter. All of these revisions were implemented following consultation with SPRU's Parent Consultation Group (PCG). Regarding the financial incentive issue, the PCG advised that this was simply recognition of the time given by parents who are very busy. All revisions were given ethical approval from the NHS REC.

Following these revisions, we still struggled to recruit parents. We suspected this might be due to parents being newly referred, and this was likely to be soon after diagnosis. Thus, parents might feel unable to participate if adapting to numerous changes that would follow this. Discussions with CCN team members confirmed that newly referred parents are often experiencing a chaotic and difficult time. With this in mind, we adapted our recruitment strategy. Whilst we continued to try to recruit newly referred parents (meeting the eligibility criteria described above), we also began to recruit 'established team users', that is, parents of children with complex health needs who had been using the team for longer than six months. In Site A1, at the time when we began recruiting established team users, the responsibility of handing out invitation packs was transferred from the team to a research nurse in the trust.

For the established team users, we conducted only one interview, which aimed to understand how parents' experience of quality of care had changed over the time they had been using the team. Thus, it was a retrospective account. Whilst this presents a limitation to the study, it was necessary to help us achieve the sample we needed to undertake meaningful analysis. Not only this did approach increase the population from which it was possible to recruit, but it also increased our response rate and we were able to meet our minimum target.

Of the 32 parents recruited, 18 were established users, where one point of data collection took place, and 14 were newly referred, where two data collection points took place, approximately six months apart. One of these newly referred parents was the person who did not take part in an interview, but who completed the questionnaires. Of the 13 newly referred parent participants taking part in round one interview, 10 took part in a round two interview. Of the three who did not take part in a round two interview, one opted out, one could not be contacted, and in one case the team asked us not to contact the parent due to the death of the child and other difficulties in the parents' circumstances (we did not disclose parents' participation to the team, although some parents told us they had chosen to tell them). Table 9 gives details of recruitment by site.

**Table 9: Number of parents approached and recruited**

		New Referrals		
	Approached	Recruited and interviewed wave 1	Recruited and interviewed wave 2 (from wave 1 sample)	Recruited (established users)
<b>A</b>	89	5	3	12
<b>B</b>	43	4	4	4
<b>D</b>	36	4	3	2
<b>Total</b>	168	13	10	18
<b>Total recruited and interviewed across new and established users</b>	-	31		

Of the 32 parents who participated, most (n=30) were mothers. Parents' ages ranged between 23 and 67, with most falling in the 30-39 years (n=13) or 40-49 (n=11) bracket. The ethnicity of those participating were White British (n=25), Asian (n=2) or 'other' (n=5). Just over half of parents were married or living with a partner (n=18), whilst the remainder (n=13) were either widowed or single.

Most of the children of parents interviewed had multiple diagnoses and health conditions. These included epilepsy, including West Syndrome (n=10), cerebral palsy or cerebral spinal conditions (n=9), rare metabolic or chromosomal conditions (n=6), brain injury or brain related conditions, such as encephalitis (n=5), chronic lung or respiratory conditions, excluding asthma (n=4), and other conditions we cannot name specifically in order to protect anonymity of participants (n=5). Some children also had a learning disability or developmental delay, and/or sensory impairments. Alongside these conditions, some children had chronic health problems, such as asthma, eczema, constipation and diabetes, which, if taken in isolation, may not be considered medically complex. However, these appeared alongside other diagnoses, and thus added to the complexity of the child's overall health needs. Nearly all (n=31) were in receipt of Disability Living Allowance. Children were aged four months to 18 years.

Of the 31 parents recruited and interviewed, most of their children (n=23) were not eligible or could not be invited to participate. The reasons for this were: the child was not able to communicate to a level that they could comprehend and answer questions (n=13), age (n=6), the child had died (n=2), the parent declined (n=1), or the parent had withdrawn prior to the second interview (n=1). In one case, we were unable to explore the child's participation with the parent at the time of interview, and a letter was sent to enquire about this afterwards. However, we received no response. This resulted in seven eligible children. We received responses from two of these children, one of whom declined. The remainder (n=5) did not return the form, or it was possible the parent chose not to pass the information on. Thus, just one child was interviewed.

## **Analysis**

The longitudinal data was managed using the Framework approach<sup>51</sup> and analysed thematically. Full details of the analysis are in the analytical plan in Appendix 4e.

## Findings

### Access to and initial experience of the team

For the majority of those interviewed, their child's entry to the CCN service followed a period in hospital. Where this was the case, some, but not all, made comparisons in terms of care quality between hospital and CCN care. These comparisons suggest that experienced quality of care changes in response to the shifting needs of the child and family when moving from hospital to home. In hospital, input is focused on the more immediate medical intervention required to address the child's illness. Once home, input centres on managing ongoing nursing and health needs. Parents valued different aspects of both hospital-based and CCN care, indicating that mostly, quality of care was experienced as no better or worse between the two.

Not all parents accessed the CCN service following hospital discharge. There were some parents and children who had, in a sense, slipped through the net, and were managing their child in the community with no nursing assistance or support before being referred to the teams. Where this was the case, the input of CCN services helped them get the support they needed to manage their child's care. Being without such support was described as a 'struggle' and a 'no-man's land'. These cases highlight what it is like to care for a child at home with little support, and the role a community nursing service can play:

**Interview 3:** *"It's a weight off my shoulders because we just literally felt that we'd been abandoned and it feels like there's somebody there that I can call on."*

A minority of parents reported coming into contact with the CCN team after a period of using another team after moving from another area.

Once referred to the teams, parents used them for their child's care in different ways, summarised in Table 10. These different uses reflect the nature of the service models (see Chapter 2 for a summary of these). For example, parents used the nurse practitioner team (Site D) typically when their child was acutely ill, whilst parents used the complex care team (Site B) as part of an allocated nursing and home respite care package.



**Table 10: Summary of how parents used the three services**

<p><b>Site A:</b> <b>Generic CCN team</b> <b>(community based)</b></p>	<p>Of those interviewed in this site, the majority were using this team for: clinical nursing care (for example, administering treatment, passing naso-gastric tubes, changing gastrostomy tubes); advice and support about the child’s health and care; varying levels of care coordination; input for acute episodes of care; general monitoring; provision of supplies; and in a few cases, prescribing.</p>
<p><b>Site B: Complex Care team</b></p>	<p>Home respite was the primary team function used by families, usually (but not always) as an NHS funded continuing care package staffed by the team’s clinical support workers. The allocated care packages varied, but usually involved staff being in the home or school with the child for a number of hours at a time, and in shifts. In addition to this, parents used the team for advice and support about the child’s care, and to a lesser extent, episodic nursing input outside allocated respite care shifts (for example, flushing portacaths), care coordination, prescribing, provision of supplies, and input for acute episodes of care.</p>
<p><b>Site D:</b> <b>Nurse Practitioner team</b></p>	<p>Parents primarily used the nurse practitioner team for assessing the child when acutely ill and prescribing medication. This was done through home and school visits. For some of the parents interviewed, the team was used for coordinating the child’s care, and to a lesser extent, advice and support with their child’s condition. Other clinical nursing care, such as changing gastrostomy tubes and IV medication, was not performed by this team, and was instead provided by the local generic CCN service.</p>

**Ongoing experiences and outcomes**

The accounts of those interviewed suggest a largely positive experience, both in terms of the positive outcomes that occurred or were achieved as a result of the team’s input, and in terms of what they were able to offer families. The most predominant theme was about how perceived quality of the CCN services – that is, positive experiences of care – was largely rooted in whether parents felt confident and supported by the teams to manage their

child's care in the community. CCN services were vital in this respect, and the support they offered helped to avoid the feeling of being 'abandoned' that we saw with those who previously had no support in the community (see above). Secondary to this was how using the teams enabled the child to remain at home by avoiding planned and unplanned hospital visits. Other outcomes across sites were also reported, but to a much lesser extent. In this section, we present findings about parents experiences of what the team's did to achieve these outcomes.

### **Feeling supported and confident to manage the child's care in the community**

The accounts of parents in each of the three sites show how feeling supported to manage their child's care in the community was a key outcome of using these services, both in terms of what was expected and what was, in most cases, achieved. However, the aspects of provision that were offered to achieve this outcome differed somewhat across the three services studied. Not only did the services appear to differ in what they did to achieve this outcome, but they also differed in how these valued aspects of service provision changed, or not, over time. Each of these is described in turn below.

### **Being able to contact someone in the team for support, advice and reassurance**

Managing a child with complex health needs at home was a daunting task, and parents across all three sites often spoke positively of having someone at the end of the telephone they could contact for advice, support and reassurance regarding their child's health and nursing care needs. This function of the community nurses gave parents confidence to support their child at home. In Site A, the way parents viewed and valued this service function appeared to differ depending on how long they had been at home with their child. When new to care (for example, when recently discharged from hospital), it acted as a buffer against the anxiety of the unknown:

**Interview 2:** *“When we first come out the hospital, you're so anxious and you're so unaware of what does need doing and what is involved and what's more to come that it's just really helpful for somebody to be there and to, just to give you a bit of guidance on what can happen and what will happen, and they can, and just to know that someone's there if you need 'em. It's just really helpful that way.”*

When parents had grown more confident with their child at home over time, having the team in the background was valued as a ‘back up’:

**Interview 17:** *“They’ve given me that confidence, because they have that belief in me that I can do it, you know, so, and it’s, it’s made a big difference that; when I’ve got to bring him home on certain things, I’m quite happy doing it and I know that I’ve got a good community team here.”*

This worked both ways. So, not only was it important for parents to know the team were there as a back-up, but they also valued the fact that the team would sometimes contact them to check in:

**Interview 13:** *“And they do phone, you know, even if I’ve not been in touch for like a few weeks if I’m fine, you know, appointments are fine, and they’ll phone just to make sure, am I OK, is [child] OK and everything, and I’ll say yeah, you know, and that’s it really, which is good, it’s good reassurance for me.”*

In Site B, parents valued being able to access support and advice from both the nurses and support workers about nursing care (for example, passing naso-gastric tubes), equipment and supplies, responding to acute illness, and general concerns about their child’s health and condition management. Just knowing the team were there to call for advice if needed made parents feel secure. As in Site A, this was especially the case in the earlier stages of managing the child at home, where the team’s support provided reassurance:

**Interview 25:** *“I did know that I could ring them and someone would come out, even if it was just to watch me do it [passing naso-gastric tube], so that, you know, in case I thought I was doing it wrong, or they could just reassure me.”*

Whereas in Sites A and B, the use and value of being able to contact the team for advice, support and reassurance was about a wide range of issues relating to the child’s care and health, in Site D, this function was described in relation to managing acute episodes of need, reflecting the nurse

practitioner team's focus on acute care. Parents in this site valued being able to contact the nurse practitioners for advice about when an acute exacerbation of illness could be managed at home, or when a hospital visit was required.

### **Care coordination**

Coordinating care across primary and secondary care, education and social care was an aspect of CCN provision used by some, but not all, parents in Sites A and B. Where teams offered this resource, parents valued the team's knowledge of the service landscape and their ability to secure other services for the child (through, for example, facilitating referrals):

**Interview 23:** *“If you need anything, like referring to see anybody, you're concerned about anything, it just cuts through all the red tape and for us it's a fantastic service; couldn't manage without it.”*

Having the community nursing team coordinate care was helpful when parents felt uninformed about where and how to access other supports, were overwhelmed by the amount of input required for their child, or struggled to find time to do it themselves. For some in Site A, care coordination was more important in the earlier stages of using the team, when a child was recently discharged from hospital into the community, or the family was new to the area. This could help to get services and supports in place around the child to manage their care in the community. Once these services were set up, nurses could take a step back in this role, and care coordination became less important. However, for others, there was a need for ongoing liaison (for example, liaising with consultants and primary care about medications), which was valued by parents.

### **Continuity of care and staffing**

Continuity of staffing was described as an important feature of care in both Sites A and B, and in a slightly different incarnation in Site D. Having the same nurses, and in Site B, support workers, involved in the child's care was important for: ensuring familiarity with their child's clinical care needs (for example, distinguishing when the child 'looked' well and unwell, and thus advising parents on courses of action); a growing child becoming more aware of those around them; knowledge and experience of the child's communication needs; building trust between both the child/parent and team

members; and avoiding time-consuming repetition of information exchanges about the child's care needs. This continuity appeared to be most predominant as a valued aspect of care for the parents we interviewed in Site B, though the extent to which this was achieved varied. Not all felt they had the continuity of staffing they desired, and this was sometimes attributed to perceived problems of staffing and resources. Some felt continuity was better in their earlier use of the service, whilst others felt this had improved over time.

In Site D, parents did not talk so much about the importance of having the same nurses visit them and their child, but the importance of whichever nurse was visiting to be familiar with their child's acute clinical needs:

**Interview 27:** *“Even the tiniest change in her breathing or anything like that, they [the team] just know because they know her so well, which with [child] you've sort of got to act sooner than later with things, rather than like letting infection get hold of her.”*

Indeed, parents felt this was a key benefit of using the nurse practitioner team, because they had this clinical familiarity with the child's needs, whereas others performing the same functions (for example, General Practitioners) did not.

Linked with this was the importance of having good relationships with the nurses that visited, which allowed trust to develop between parent and nurse for managing the child's care needs. The importance of good relationships between nurse and child were also described by parents, although to a much lesser extent. Where it was noted as being important, it was felt to facilitate trust with, and ease anxiety for, the child. One child interviewed for the study also confirmed this.

Although parents' accounts indicated these good relationships were built over time, there was no indication that the value of good relationships changed over time – that is, they appeared to be important regardless of how long parents had been using the services.

### **Other service features**

These three components of CCN provision, being able to contacting the team for support, advice and reassurance, care coordination and continuity of care and staffing, were those that emerged in the accounts of parents across the three sites as contributing to their feeling supported to manage their child's care in the community. In Sites A and D, other components of the service were also linked to this outcome. In Site A, value was ascribed to the fast response that could be expected of the nurses, which was felt to make care more accessible:

**Interview 6:** *"I can't get in the doctors for like a week, whereas I can get, ring them [the team], say that I've got a problem, I'm really worried, and they'll, they'll either get him in at the doctors, or they'll say "Right, we're on our way, we'll come.""*

Regular contact with parents was also important to parents in this site, until they felt more confident in the child's care, as were 'check ins' by the team when they had not been used for a while. The opportunity to be trained in certain aspects of their child's technical care was also valued by some in Site A, and gave parents confidence to manage their child's needs at home. For example, in some instances the team trained parents to care for and use gastrostomy and nasogastric tubes. Where this was the case, having the support of the team as a back-up for advice, or to have them come to check if there were concerns, meant parents felt supported in this aspect of care. It was equally important that any training was ongoing, and not a one-off occurrence at the start of the parent and child's use of the CCN team:

**Interview 12:** *"[Training] needs to be reviewed...So training has been done, I'm not gonna say I've not had it, but you forget, you easily forget."*

In Site D, nearly all those interviewed cited the team's ability to assess their child when acutely ill and then prescribe medicine(s), through home or school visits, as an aspect of the service they particularly valued. It helped to avoid A&E visits, thus enabling their child to stay at home, which was in all cases the preferred option where possible. A&E visits could be a 'hassle' for what culminated in a prescription and thus it was felt to be easier to *"just get the [nurse] out and check her over at home"* (**Interview 30**). Accessing primary care could also be difficult, and the ability of the team to *"do*

the same as what a GP can do” (**Interview 31**) at home and school was easier and made care more accessible for parents. They also valued that the team could spend longer assessing their child at home, whereas a visit to the GP would result in a shorter, and what was perceived to be a less thorough, examination.

### **Avoiding planned and unplanned hospital visits and stays**

A second outcome was discussed by parents – avoiding planned and unplanned hospital visits and stays. As with the first outcome, the value of being able to avoid hospital where possible was described positively, but the ways in which the CCN services facilitated this differed by model.

This outcome was typically described in Sites A and D, and to a much lesser extent Site B. Across all sites, being able to contact the team for advice and support, as described above, helped parents decide whether to take their child to hospital. Beyond this, the teams in Site A and D each offered different approaches to preventing unnecessary hospital visits and stays. In Site A, this reflected their role in providing clinical care at home or school for the child; this was, for most, a key component of care by the CCN team in Site A. This clinical input could be planned administration of treatment at home, maintaining technological care (for example, passing a naso-gastric tube, caring for gastrostomy tubes), monitoring and observations, or assessing and advising parents whether to take the child to hospital. Some described the team’s clinical input as helping to avoid unplanned visits to hospital, whilst others observed their input as being in place of planned hospital care:

**Interview 12:** *“Rather than me take him back to [hospital] daily, for his daily dose of IV antibiotics, the community nurses’ll come out and do that. So that, that helps, ‘cos [it] stops us from, either him being in hospital for days when he doesn’t really need to be, and he’s bored and at risk of catching something else, and then it saves me having to drive to [hospital].”*

By having this clinical input in the community, parents felt it avoided hospital visits, which could be time consuming, costly, logistically difficult in terms of travelling, harmful to the child’s physical (for example, exposure to infections) and emotional (for example, stressful) health, and result in family separation, lost work and missed school:

**Interview 2:** *“If we hadn’t have had it, like I say, it would have just meant more and more trips down to the hospital for what takes all of five/ten minutes in total to do, but it just seems a total waste really. So it, it, it was just really, I found it beneficial to us.”*

**Interview 14:** *“It’s distressing for [child] when she’s in hospital... they mess about with her, it’s like even when she does sleep they’re here prodding her, taking her temperature and things like that, it’s, then I’m there up with her, it just turns everything upside down. So being able to care for her actually in the home is so much easier, and [child’s] more comfortable at home, so she gets everything that she needs.”*

Being trained to manage clinical care at home was also a part of this, helping to avoid trips to hospital for the parent and child:

**Interview 14:** *“I was glad that they did the training [for gastrostomy button], because before they actually trained me, if [child’s] button went or anything like that, or the feeds weren’t going down, I’d have to take her into hospital, which then meant a stay in hospital; now that I can change the button myself and things like that it does make life a lot easier.”*

By contrast, in Site D, it was the role of the team in assessing and prescribing (see above) that parents valued, and which they felt largely helped to avoid visits to A&E when their child showed signs of illness.

### **Other positive outcomes from using the CCN services**

Feeling confident and supported to manage the child’s care in the community and avoiding planned and unplanned hospital visits were the main outcomes reported by parents across the three sites. Other outcomes were reported to a lesser degree, and only in relation to certain teams. For example, some parents in Site A felt the team’s active management of the child’s health and nursing needs and their availability in the evening had enabled children to remain in school. In Site B, the home nursing care packages provided by the team gave parents respite – something which they greatly valued.



### **Change in experienced quality of care over time**

So far, we have described the service features that parents valued when using the CCN services, and the positive outcomes they felt were achieved as a result of this input. We were also interested in how these positive experiences, as indicators of care quality, changed over time. The accounts of parents suggest there are two key issues here; the first is about change in what is valued and when, and the second is about change (or absence of it) in perceived level of overall care quality over time. Each is discussed further below.

### **Changes in what is valued and when, over time**

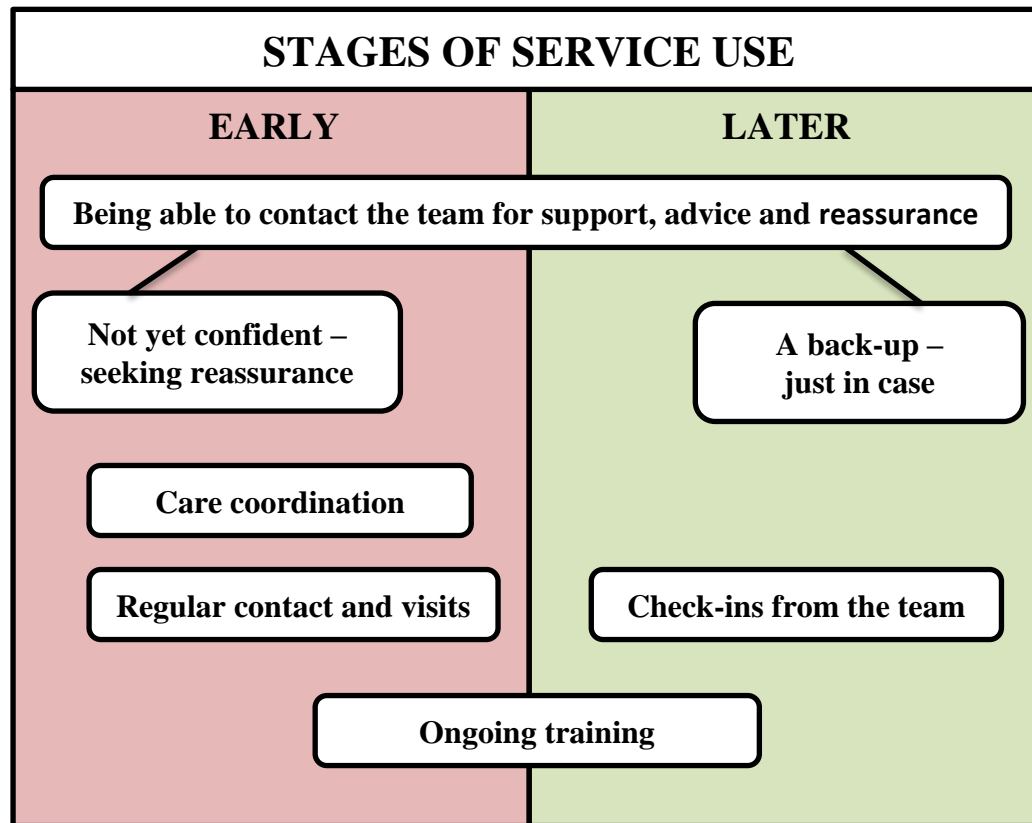
First, the importance and value that parents attach to some features of CCN provision appears to change depending on ‘where’ they are at in their journey of care and how confident they feel in managing their child at home. This is not a change in the perceived ‘level’ of quality in relation to the valued service features, but simply a change in the ways they are important. This was most noticeable in Site A, in relation to being able to contact the team for advice and support, care coordination, frequency of contact, and training. Being able to contact the team for advice and support was important in the early stages of using the CCN team, when the child was recently discharged. This was a time of anxiety and the ‘unknown’, and being able to contact the team was a way of accessing reassurance and advice when parents were not yet feeling confident about managing their child at home. Knowing the team were there at the end of the telephone continued to be important for parents even as they grew more confident in their child’s care, but it seemed to act as more of a back-up, a ‘just-in-case’ rather than an actively used resource:

**Interview 11:** *“I needed her services more initially, but now we’re on an even keel and we’re just plodding along, things are fine, but I know that she’s just there at the end of a phone if I need any advice or help.”*

Similarly, frequent contact was valued at the ‘daunting’ initial stages of being at home, and became less important when parents grew confident in care.

Coordination of care was valued when the child was initially referred to the team (typically following hospital discharge), as this helped to get services in place for the child in the community. Over time and once services were in place, this became less important: "...[named nurse's] probably stepped back a little bit more 'cos obviously she's set everybody up, everybody's on board kinda thing now" (Interview 5). Training was also valued for its ability to empower parents and take control of their child's care, and this continued to be important in the form of 'refresher training' in the longer-term. Figure 1 summarises these changes in what was valued and when for the Site A1 team.

**Figure 1: What is valued and when (Site A1)**



In Site B, there were, for some, similar discourses about the importance attached to being able to contact the team for advice and support – it was important at all stages of care but was used more actively in the earlier stages of being at home, and was valued as a back-up later in care. However, this was the only service feature in this site where the value attached differed over time. For other service features in this site, and all service features in Site D, parents' accounts suggested that there were no changes in what was valued and when in their journeys of care. In Site B, this may be explained by the nature of their input, which was intended to be 'static', reflecting the allocated care package each family received. For example, a child might be allocated seven hours a week of nursing care, which would remain unchanged until they were reassessed. Thus, unlike the Site A team where input typically decreased over time, input from the Site B team meant that the intended level of contact remained more or less the same over time. This might explain why there was little difference in what parents valued and when in Site B – because there was little change in the basic component of provision over time. In Site D, the absence of change in what was valued and when may be explained by the fact that parents were using the team for a very particular aspect of their child's care (acute illness), which tends to be episodic rather than ongoing.

### **Changes in perceived level of quality of care over time**

As described above, for most of the parents we interviewed using the generic CCN team in Site A, the team was more involved when parents first began using the service for their child, where the team fulfilled clinical, care coordination and advisory roles for the family. Over time, the team's involvement changed to be one more of 'maintenance', where less care coordination was required, visits became less frequent, and they were used mainly for supplies and advice as and when needed. For a smaller number of parents, use of the team did not follow this trajectory, with some reporting that the team had become more involved over time, and others reporting that their input had remained steady. Team involvement also reflected significant changes in the child's needs, for example, for end of life care.

Where the team's involvement had gradually decreased over time, this was mostly viewed positively. Parents reported that they had become more confident in managing their child's care over time, but valued that they still had access to the team for support and advice when needed. In these cases,

parents' accounts indicated that despite the reduced involvement of the service, they still felt supported by the team and were still satisfied with the input received. This suggests that the perceived level of care quality remained positive and static over time, even though input had changed, and was linked to the 'empowering' role played by the team. This may explain why certain service features are valued more at the earlier and later stages of care.

However, there were two cases in Site A1 where the diminished involvement of the team over time was seen to be a result of heavy workloads, rather than a planned reduction of input. In these two cases, both parents felt that they did not need the team for their child as much as they had at first and still valued them as a source of reassurance and advice. Still, these two parents had concerns and frustrations about the impact of these perceived heavy workloads. For example, one parent described how the quality of the Site A1 team was better in the beginning, when they were "*very on the ball*" with her child's care (**Interview 7**). More recently, this had been lost somewhat because the team had become so busy, meaning that she was chasing them for information and test results: "*a lot of the time now it's me phoning, me checking and me making sure*". In another case, a parent described how the "*personal touch*" of the team had waned, which was attributed to the team's heavy workload. This 'personal touch' was reflected in having a regular nurse that knew her son's health and needs. Without this, the mother was concerned about how it would affect his care:

**Interview 12:** "*I don't want them to forget [son], I don't want them to come and go, oh hang on, let me read his notes. Who he is, what's he got again, what does he need, what have we give him in the past. I think it's [continuity] good, I think it's good for [son], so he won't be frightened.*"

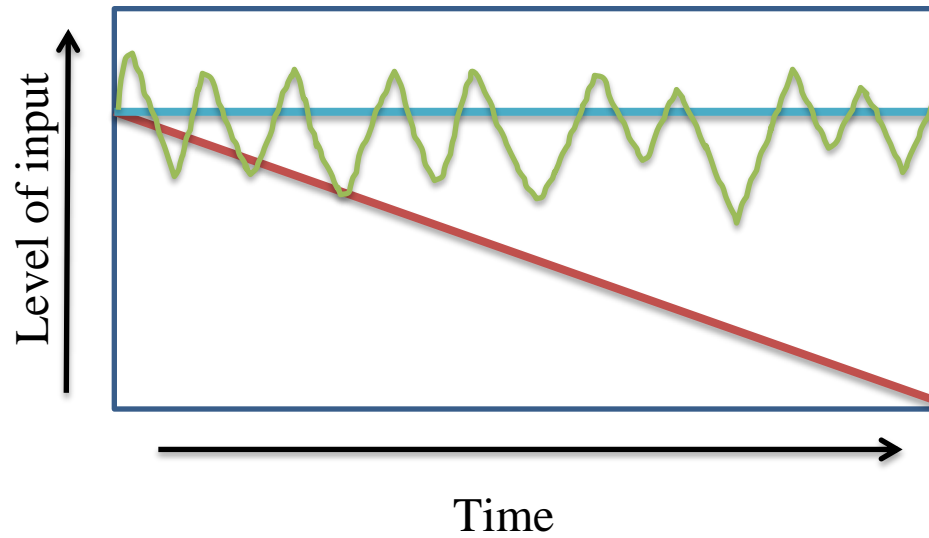
As noted above, the level of input from the team in Site B was intended to be fixed, reflecting an allocated package of care. But even within this fixed allocation of hours, there were reports of losses and gains in what the team delivered to the child and parent, and these were closely tied to experiences of satisfaction with the service. Thus, valuations of quality tended to fluctuate, depending on whether parents felt the service was doing what it was meant to and to a sufficient standard. For example, there were reports of both lost and enhanced continuity of staffing. Some felt continuity had been lost over time as the team grew bigger, which could be a source of frustration, whilst others reported their 'core care' teams had become more

established over time, which was viewed positively. There were reports of losing keyworkers, which were then not replaced, as well as reports of getting new keyworkers who were able to coordinate their child's care. Both were linked with negative and positive views respectively. There was also a loss of input and support at times when allocated hours of respite care were not achieved due to what was apparently staff absence or shortages. Thus, whilst parents in this site had a global view of the service – that, overall, it played a critical support role – assessments of quality depended on whether they felt individual service processes, such as staffing continuity, were being adequately delivered.

For those interviewed in Site D, service use either increased over time as the child's condition worsened, or remained constant and matched fluctuations in the child's acute health needs. Use of the team was mostly for when the child was acutely ill, and so largely reflected patterns of the child's illness. Some parents reported that they had developed positive, trusting relationships with the nurses over time, and that the nurses had grown familiar with the child's clinical signs and symptoms when acutely ill. This, combined with other factors (for example, the perceived inaccessibility of primary care) sometimes appeared to correspond to a preference, developed over time, for using the team when their child was acutely ill where possible. Evaluations of the service were all positive and none of those interviewed described any loss in quality of care in their use of the team over time. One felt the team was less 'hands on' than it used to be but still felt the quality of the service was excellent, whilst another felt that quality had improved over time as they used the service more for their child. Thus, the perceived level of care quality appears to be linked to what the service offers to parents in terms of managing acute illness.

In summary, the three services each offered different trajectories of service use, as summarised in Figure 2. Typically, input from the generic CCN team in Site A decreased over time; input from the complex care team in Site B was intended to be static, reflecting an allocated package of care; contact from the nurse practitioner team in Site D fluctuated depending on acute episodes of illness. Despite these changing trajectories of input, assessments of quality of care did not align to these. That is, parents mostly held positive views of the Site A team, despite decreasing input over time. In Site D, fluctuating, 'irregular' input was also matched by positive evaluations. In Site B, despite the set allocated hours of input, perceived quality was closely tied to whether aspects of care within the allocated input were delivered and thus tended to be more variable.

**Figure 2: Trajectories of service use**



-  Site A
-  Site B
-  Site D

### **Suggestions and improvements**

Although valuations of the three services were largely positive, a minority felt there was scope for improvement in the care they were offered. These included, by site:

- Site A: having a 24 hour on call service so that that the community nurses were accessible at night, a play therapist within the team, regular reviews of training needs, having a core team of nurses for continuity, and advertising the team more widely (for example, through health visitors and GP surgeries) so they can become involved in care sooner
- Site B: improved continuity of staffing, having a single health and social care team; knowing the names of shift staff in advance; having someone to coordinate different aspects of their child's care; having a named nurse; and the administration of intravenous medications at home
- Site D: a weekend service.

It appears there is a desire for increased availability in Sites A and D, enhanced continuity in Sites A and B, and components of care in Site B that we tended to see from the Site A team (for example, care coordination, administration of IV medications at home).

## **Summary**

The objective of this study component was to examine parents' experiences of quality of care and how this changes when they use CCN services. Three points can be drawn from the findings presented. First, when moving from hospital to home, hospital and community care are not comparable in terms of quality or input because they are each meeting different sets of children's and families' needs.

When moving from no previous community support to a CCN service, a change of experience from struggle and abandonment to feeling supported is evident, suggesting that a change in perceived quality of life accompanied referral to the CCN service. Second, where CCN service provision and use decreases over time (as typically seen in Site A), change is evident in what aspects of provision are important for feeling supported over time. This does not appear to be the case so much where provision follows a 'constant' trajectory (as per Site B) or is episodic (as per Site D). Third, perceived quality of care is maintained if CCN teams are able to offer provision that enables parents to feel supported and confident in managing their child's health and care at home. However, maintaining quality of care is not necessarily dependent on maintaining a constant level of input.



## **Chapter 6      Exploring the impact of CCN services on acute hospital activity**

### **Key messages:**

- i. For the generic team (site A1) we observed a significant reduction in admissions for common childhood conditions after the introduction of the service, but this was not sustained over time. A reduction in bed days for all children was also observed over time.
- ii. For the nurse practitioner team (Site D), we observed a reduction in admissions for children with neurological conditions, who were the focus of the service in this site. However, apparent discontinuities in the HES data mean that we cannot be sure whether this effect is real or an anomaly.
- iii. We observed no significant impact on admissions or bed days for the other sites.

This chapter presents the findings from the Interrupted Time Series (ITS) analysis of Hospital Episode Statistics (HES) data to explore the impact of introducing CCN services on acute hospital activity. The aim of this analysis was to explore whether redesigning children's health care services, by introducing CCN teams, affected acute hospital admission rates for common childhood illnesses and length of stay for all conditions.

### **Methodology**

#### **Outcome measures**

Data was extracted from HES to explore the impact of introducing CCN services on acute hospital activity. The measures of hospital activity were:

- **Rate of admissions per 100,000** for the twelve most frequently occurring, common childhood conditions requiring an emergency admission to hospital. For the purposes of our analysis we identified the ‘top twelve’ primary diagnoses in each site for the twenty-four month period prior to implementation of the CCN services and used this grouping throughout. Data was extracted on the number of finished emergency admissions for infants (excluding neonates/new-borns) and children in the age range between 14 days and 15 years inclusive. The rate of admissions was calculated by taking number of admissions in each month divided by the appropriate ONS mid-year population estimates for PCTs multiplied by 100,000. The resident population figure was used as opposed to the population of PCT/Commissioning area service users, in order to ensure that all hospital activity for residents was captured rather than just activity in that locality.
- **Bed days per 100,000 and average length of stay (LOS)** for all diagnoses, whether elective or non-elective, that were reported HES inpatient care data. Data was extracted for infants (excluding neonates/newborns) and children (the age range was between 14 days and 15 years inclusive). Bed days per 100,000 was calculated by taking the total number of bed days in each month and divided by appropriate ONS mid-year population estimates for PCTs, multiplied by 100,000. Length of stay was calculated by taking the total number of bed days divided by the number of discharges in that month.
- **Childhood conditions associated with highest average and highest total length of stay in inpatient care (Complex Care).** For each site, HES data for the period of twenty-four months before implementation of CCN services was used to identify these conditions and use them for subgroup analysis to explore the impact of CCN services on complex care patients. The primary and all secondary diagnoses codes were used to identify children with complex conditions. Rate of bed days per 100,000 and LOS were the outcome measures used in this analysis, with the exception of Site D, where the rate of admission per 100,000 was the only outcome measure as the aim of the team was to reduce admissions. The age range was between 14 days and 15 years inclusive.
- For the analysis of impact in children with complex conditions, we explored the HES data and discussed the choice of a group of conditions with experts and with our project advisory group. We identified three main groups usually found in CCN teams that served children with complex conditions :

- Congenital malformations, deformations and chromosomal abnormalities;
- Diseases of the nervous system;
- Metabolic disorders. (E70 to E90).

In addition, the above data were extracted for following sub-groups.

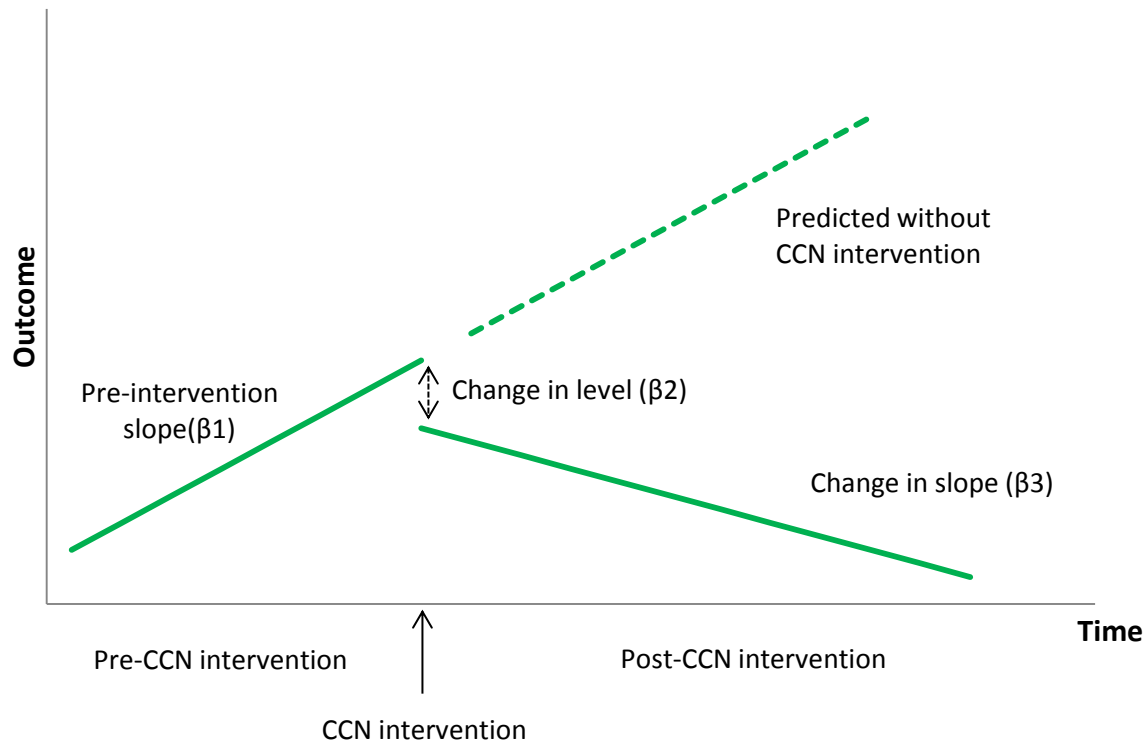
- Age on admission (rates were based on actual age profile of resident population):
  - 2 weeks – 1 year
  - 1 year – 4 years
  - 5 years – 11 years
  - 12 years – 15 years.
- Ethnic group:
  - White (British, Irish, Any other White background)
  - Asian or Asian British, Black or Black British, Mixed, Other
  - Not stated
- Gender: Male/female (Rates based on actual gender profile):
- Local authority lower super output area data to provide a link to area deprivation data (1=most deprived, 2, 3, 4&5= least deprived).
- Primary diagnosis using ICD 10 Block (Admission rates only).
- Speciality
  - Paediatrics
  - Other
- Day of admission
- Day of discharge
- Elective or non-elective (For bed days and LOS)

In the sub-group analyses, suppression of data is made when there are between 1 and 5 admissions in a particular month. This is to ensure individual children cannot be identified. Where categories were suppressed a figure of 2.5 was inputted. This was to ensure there was no missing data in the time series.

### **Statistical analysis**

Interrupted time series (ITS) analysis is arguably the strongest quasi-experimental research design and is particularly useful when a randomised trial is infeasible or unethical.<sup>59</sup> This design is appropriate when randomisation is not feasible – for example, when evaluating organisational change of health care delivery - and when a time series is available – as here, from HES data.<sup>60</sup> Although randomised trials maybe considered the gold standard of causal evidence, quasi-experimental designs informed by extensive qualitative work about decision making, are argued to be likely the best way to move the discipline of quality improvement and implementation science forward.<sup>59</sup> ITS analysis allows assessment, in statistical terms of how much an intervention changed an outcome of interest, immediately and over time. When a separate control group is not available, the analysis of the outcome of interest in the study group does not allow control for other events that may have influenced the outcome.<sup>61</sup> Nonetheless, the level and trend of the pre-intervention segment serve as control for the post-intervention segment in single group time series, still address important threats to internal validity, and represent a methodologically acceptable design for measuring the impact of interventions.<sup>61</sup> Figure 3 demonstrates graphically the ITS analysis.

**Figure 3: Interrupted Time Series Analysis**



The first step in interrupted time series studies is visual inspection of the series over time. Visually, this allows comparison of the time series pattern before the intervention with the pattern after the intervention to assess if, after the intervention, the time series pattern has changed noticeably in relation to the pre-intervention pattern.

This is followed by a segmented regression model to fit a least squares regression line to each segment of the independent variable, time, and thus assumes a linear relationship between time and the outcome within each segment. The following linear segmented regression model (Equation 1) is used to estimate the level and trend before the intervention and the changes in level and trend following intervention:

### **Equation 1: Segmented regression model**

$$Y_t = \beta_0 + \beta_1 \times \text{Time}_t + \beta_2 * \text{Intervention} + \beta_3 * \text{Time after intervention}_t + e_t$$

The components of the model outlined above are:

- $Y_t$  is the outcome in month  $t$ ;
- Time is a continuous variable indicating time in months at time  $t$  from the start of the observation period;
- Intervention is an indicator for time  $t$  occurring before (intervention = 0) or after (intervention = 1) the intervention, which was implemented at specific month in the series;
- Time after intervention is a continuous variable counting the number of months after the intervention at time  $t$ , coded 0 before the intervention and (1, 2, 3...) after the intervention.

In the model the parameter estimates can be explained as follows (Equation 1):

- $\beta_0$  estimates the baseline level of the outcome at time zero;
- $\beta_1$  estimates the change in the outcome that occurs with each month before the intervention (that is, the pre-intervention slope);
- $\beta_2$  estimates the change in level in the outcome immediately after the intervention, that is, from the end of the preceding segment;
- $\beta_3$  estimates the change in slope after the intervention, compared with the slope before the intervention.
- The sum of  $\beta_1$  and  $\beta_3$  is the post-intervention slope.

- The error term  $e_t$  at time  $t$  represents the random variability not explained by the model. It consists of a normally distributed random error and an error term at time  $t$  that may be correlated to errors at preceding or subsequent time points.

Using the model to estimate level and slope changes associated with the intervention, this allows control for baseline level and slope, a major strength of segmented regression analysis.

In the analysis undertaken here, the parameter estimates and p-values from the linear segmented regression model are presented for the total models and sub-group analyses. The 95% confidence intervals of the parameter estimates were calculated using the methodology of Zhang et al., 2008.<sup>62</sup>

Table S1 (in Supplementary document) illustrates the data structure for the segmented regression analysis for Site A.

ITS analysis was undertaken for each outcome measure at each site (Total model), followed by ITS for each sub-group outlined above. The sub-group analysis was undertaken to investigate further whether certain sub-groups had more or less change on the outcome measures. For example, were certain diagnostic groups more likely to see a fall in admission rate after the introduction of a CCN team?

To summarise, the key outcomes of interest in this ITS analysis are:

- (i) Change in level immediately after the intervention;
- (ii) Difference between pre-intervention and post-intervention slopes.

The findings from the segmented regression were used to predict the post-CCN monthly values that would have been expected if the pre-CCN trends had continued. This was calculated using Equation 2. It was then possible to compare the values derived from the Equation 1 model to investigate the difference between what was predicted without CCN intervention and predicted with CCN.

## Equation 2: Model for prediction of post CCN, assuming pre CCN trend

$$Y_t = \beta_0 + \beta_1 \times \text{time}_t$$

Data were extracted for each site for at least two years before and at least two years after the intervention in order to minimize the effect of seasonal variation.<sup>63</sup> Early analysis indicated that there were serious discontinuities in the HES data before April 2006, due to introduction of Payment by Results so no data were extracted before this date for any site. Data were extracted up to March 2013 for all but one site; in Site B data were extracted from April 2009 to March 2014, due to the later intervention date (October 2011).

Data were adjusted for autocorrelation if required. Correcting for autocorrelation avoids underestimating standard errors and overestimating significance of the effects of an intervention. There may be seasonal patterns in monthly time series, where the rate of admissions in January of one year is more similar to rate of admissions a year previously than to rate of admissions in other months. This is an example of higher-order autocorrelation. For estimating seasonal autocorrelation, the autoregression model needs to evaluate correlations between error terms separated by multiples of 12 months. Accounting for seasonally correlated errors usually requires at least 24 monthly data points.<sup>63</sup>

To assess the fit of the final model, the residuals were examined around the predicted regression lines. Residuals that are normally distributed and that follow no observable pattern over time indicate that the assumptions underlying the linear model are met. PACF and ACF residual plots were examined. The Durbin-Watson statistic was then used to assess remaining auto-correlation. This statistic tests for serial autocorrelation of the error terms in the regression model; values close to 2 indicate no serious autocorrelation.

Table 11 shows the specific analyses undertaken for each site for the main analysis and Table 12 for the complex condition analysis.

### Table 11: Guide to the main analysis undertaken for each site



	<b>Site A1</b> Intervention date: April 2008	<b>Site A2</b> Intervention date: February 2008	<b>Site B</b> Intervention date: None – using April 2008 as a control	<b>Site C</b> Intervention date: None – April 2008 as a control
Caseload	Acute, chronic, complex, palliative	Acute, chronic, complex, palliative	Complex conditions (mostly neurological)	N/A
Rate of admissions per 100,000	Yes	Yes	Yes	Yes
Length of stay for all conditions (elective and non- elective)	Yes	Yes		Yes
Bed days per 100,000 for all conditions (elective and non- elective)	Yes	Yes		Yes

**Table 12: Guide to the complex conditions analysis undertaken for each site**

<b>ICD 10 codes used</b>	<b>Site A1</b> Q code, G code and E70-E90 codes	<b>Site A2</b> Q code, G code and E70-E90 codes	<b>Site B</b> Q code, G code and E70-E90 codes	<b>Site D</b> G codes only
Intervention date	April 2008	February 2008	October 2011	March 2008
Length of stay (elective and non-elective)	Yes	Yes	Yes	-
Bed days per 100,000 (elective and non-elective)	Yes	Yes	Yes	-
Rate of admissions per 100,000	-	-	-	Yes

A p-value of <0.05 was considered to indicate statistical significance. The p-values for each model are presented with no adjustments for multiple significance testing. Due to the large number of models, the analysis has resulted in a large numbers of significance tests and these may be difficult to interpret because, if we go on testing long enough, we will inevitably find something which is “significant.” Therefore, caution should be made in attaching too much importance to a lone significant result among a mass of non-significant ones. It may be the one in 20 which we expect by chance alone.<sup>64</sup> Simply describing what was done and why, and discussing the possible interpretations of each result informed by the qualitative data to understand the nature of and changes to services, should enable the reader to reach a reasonable conclusion without the help of Bonferroni adjustments.<sup>65</sup>

All analyses were undertaken on SPSS (v22). A sample of the SPSS syntax used is shown in Appendix 2.

## **Results**

The findings are in two sections. First, we present the analysis that explored the impact of introducing generic CCN teams (Sites A1 and A2) on non-elective admissions, bed days and length of stay. The analysis for non-elective admissions is based on the twelve 'most common' physical conditions found in such admissions for children. This part of the analysis also includes data from the two sites that had not been able to implement planned generic CCN teams, in order to provide a contrast with the sites that had.

The second part of the analysis relates only to children with complex conditions and explores, for Sites A1, A2 and B the impact on bed days and length of stay for all three groups of complex conditions outlined earlier. For Site D, which was established only to prevent non-elective admissions in children with a limited range of conditions, the analysis is restricted to such admissions and to a single group of conditions.

### **Site A1**

The introduction of the CCN team was in April 2008. Data were extracted from April 2006 through to March 2013.

#### **Rate of admissions per 100,000**

The number of admissions was examined between April 2006 and March 2008, covering the two-year timeframe prior to the introduction of CCN. In total there were 8267 admissions. Table 13 shows the top 12 admissions. These are based on the primary diagnoses grouped into ICD10 code blocks. This represents 63.5% of the total non-elective admissions.

The most common reason for admission was an acute upper respiratory infection, which represents 15% of the 'top 12'. Injuries to the head and injuries to the elbow and forearm were also in the top twelve primary diagnoses. The research team did discuss whether or not these should be retained as they may or may not be within the remit of the CCN teams. For example, minor head injuries not requiring sustained observation might be susceptible to CCN intervention, while major head injuries clearly would not, at least in relation to non-elective admission. However, CCN teams

might influence how long a child with a significant head injury remains in acute care. We decided to retain these conditions in the top-12 analysis as a form of control, allowing the sub-group analysis to demonstrate whether admission rates for these might change, alongside those for other conditions.

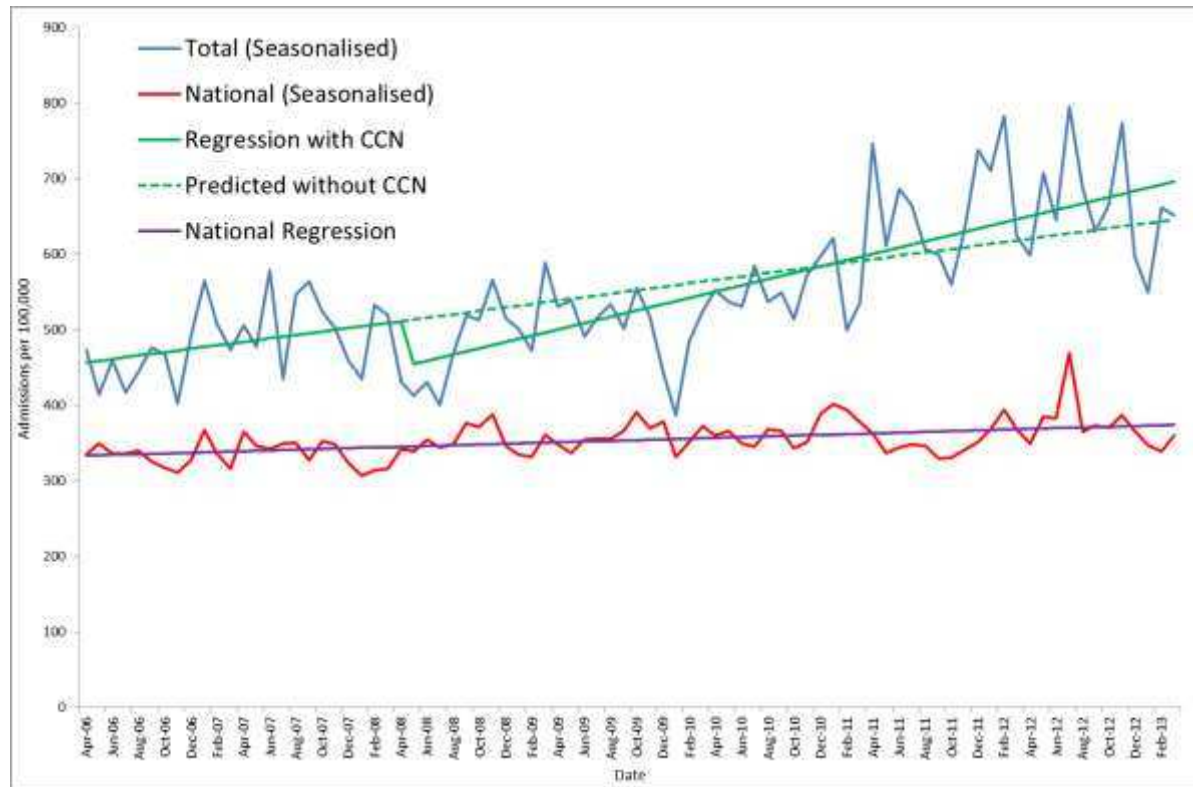
**Table 13: Site A1: top 12 number of finished emergency admissions in 12 months prior to introduction of CCN**

<b>Primary Diagnosis</b>	<b>Number of finished emergency admissions</b>	<b>%</b>
J00-J06: Acute upper respiratory infections	798	15.2%
R50-R69: General symptoms and signs	689	13.1%
R10-R19: Symptoms and signs involving the digestive system and abdomen	615	11.7%
B25-B34: Other viral diseases	567	10.8%
J20-J22: Other acute lower respiratory infections	430	8.2%
R00-R09: Symptoms and signs involving the circulatory and respiratory systems	381	7.3%
S00-S09: Injuries to the head	376	7.2%
J40-J47: Chronic lower respiratory diseases	362	6.9%
A00-A09: Intestinal infectious diseases	327	6.2%
K50-K52: Non-infective enteritis and colitis	312	5.9%
S50-S59: Injuries to the elbow and forearm	211	4.0%
R20-R23: Symptoms and signs involving the skin and subcutaneous tissue	179	3.4%
Total top 12	5247	100.0%

Figure 4 shows the seasonalised monthly rate of admissions per 100,000, along with the regression lines pre and post the introduction of CCN (April 2008). It also shows the national data and the national regression line. The overall trend in the national rate shows an increasing admission rate of 0.49

per month (95% CI: 0.30, 0.68) over the whole time period, which was a statistically significant increase ( $p < 0.001$ ). The rate of admissions per 100,000 in Site A1 was higher than the national rate throughout the period covered.

**Figure 4: Site A1: overall admission rate by month (per 100,000)**



At the start of the analysis period in April 2006 the rate of admission per 100,000 was 455. Prior to the introduction of CCN in April 2008 there was a rise of 2.28 (95% CI: -0.91, 5.47) in the rate of admissions per 100,000 per month but this was not statistically significant ( $p=0.165$ ). There was a statistically significant fall of 60.70 (95% CI: -144.67, -6.73) in the admission rate immediately after the intervention ( $p=0.030$ ). Overall, however, after the intervention, the magnitude of the underlying trend increased by 1.89 (95% CI: -1.42, 5.20,  $p=0.226$ ), with no statistically significant difference between pre-intervention and post-intervention slopes. Following the introduction of CCN, the rate of increase of admissions was thus 4.17 ( $2.28 + 1.89$ ) per 100,000 per month.

As can be seen in Figure 4, from April 2008 through to January 2011, the regression line with CCN was below the regression line predicted without CCN. This indicates a lower number of admissions with CCN that would have been expected without CCN. Just looking at a two year timeframe post CCN, this difference represents 399 fewer admissions than would have been predicted without CCN.

Table S2 (in Supplementary document) shows the parameter estimates from the linear segmented regression models for the total and sub-group.

In the overall model, the Durban Watson statistic was 1.54, which is close to 2 indicating no serious autocorrelation in this site. There were statistically significant falls in the admission rates immediately after CCN for:

- Males: Statistically significant fall in admissions immediately after the intervention (p=0.035).
- Age group one year to four years: Statistically significant fall in admissions immediately after the intervention (p=0.012).
- Other speciality: Statistically significant fall in admissions immediately after the intervention (p=0.001).
- White ethnic group: Statistically significant fall in admissions immediately after the intervention (p=0.019).
- A00-A09: Intestinal infectious diseases: Statistically significant fall in admissions immediately after the intervention (p=0.005).
- R50-R69: General symptoms and signs: Statistically significant fall in admissions immediately after the intervention (p=0.003)
- Sunday admissions: Statistically significant fall in admissions immediately after the intervention (p=0.011)
- Sunday discharges: Statistically significant fall in admissions immediately after the intervention (p=0.010).

Within the other sub-groups, there were no statistically significant findings.

### **Bed days per 100,000**

Figure 5 shows the monthly number of bed days per 100,000, along with the regression lines pre- and post- the introduction of CCN (April 2008). It also shows the national data and the national regression line. The overall trend in the national rate shows a flat rate, with the regression giving a small

monthly fall in the number of bed days per 100,000 of 0.20 per month (95% CI: -1.00, 0.60), which was not statistically significant ( $p=0.623$ ). The number of bed days per 100,000 in Site A1 was higher than the national rate throughout the reporting period.

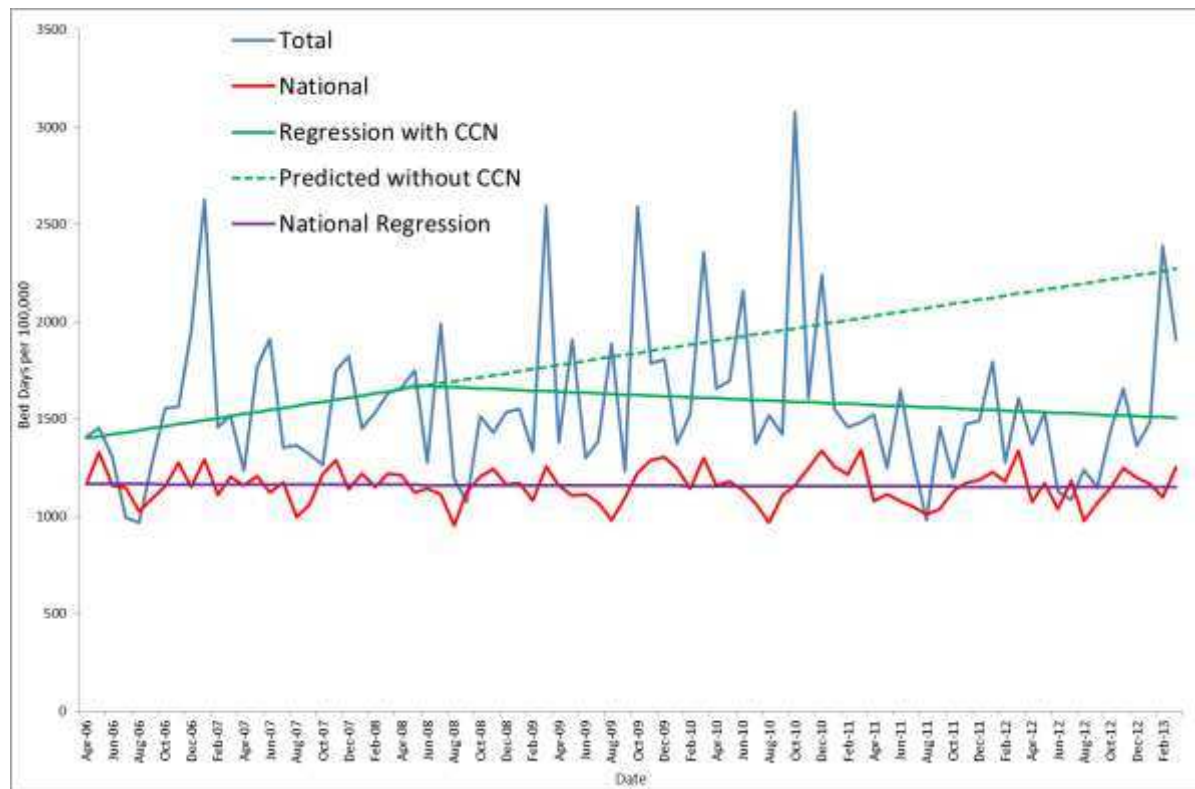
Table S3 shows the parameter estimates from the linear segmented regression models. In the overall model, the Durban Watson statistic was 1.874, which is close to 2, indicating no serious autocorrelation.

At the start of the analysis period in April 2006 the number of bed days in the site was 1390 per 100,000. Prior to the introduction of CCN there was an annual rise of 10.49 (95% CI: -0.33, 21.31) in the number of bed days per 100,000 per month ( $p=0.335$ ). There was a fall of 22.98 (95% CI: -160.18, 206.15) immediately after the intervention, but this was not a statistically significant change ( $p=0.900$ ). After the intervention, the magnitude of the underlying trend was reduced by 13.34 (95% CI: -35.34, 8.67,  $p=0.238$ ), bringing it much closer to the national average. Following the introduction of CCN, there was thus a decrease of 2.85 bed days per 100,000 per month (10.49-13.14), although this change did not reach statistical significance. There were no statistically significant findings in any of the sub-group analyses.

In the two year timeframe after the introduction of CCN, the regression models suggest that there were 1548 fewer bed days than would have been predicted without CCN.



**Figure 5: Site A1 analysis for bed days by month (per 100,000)**

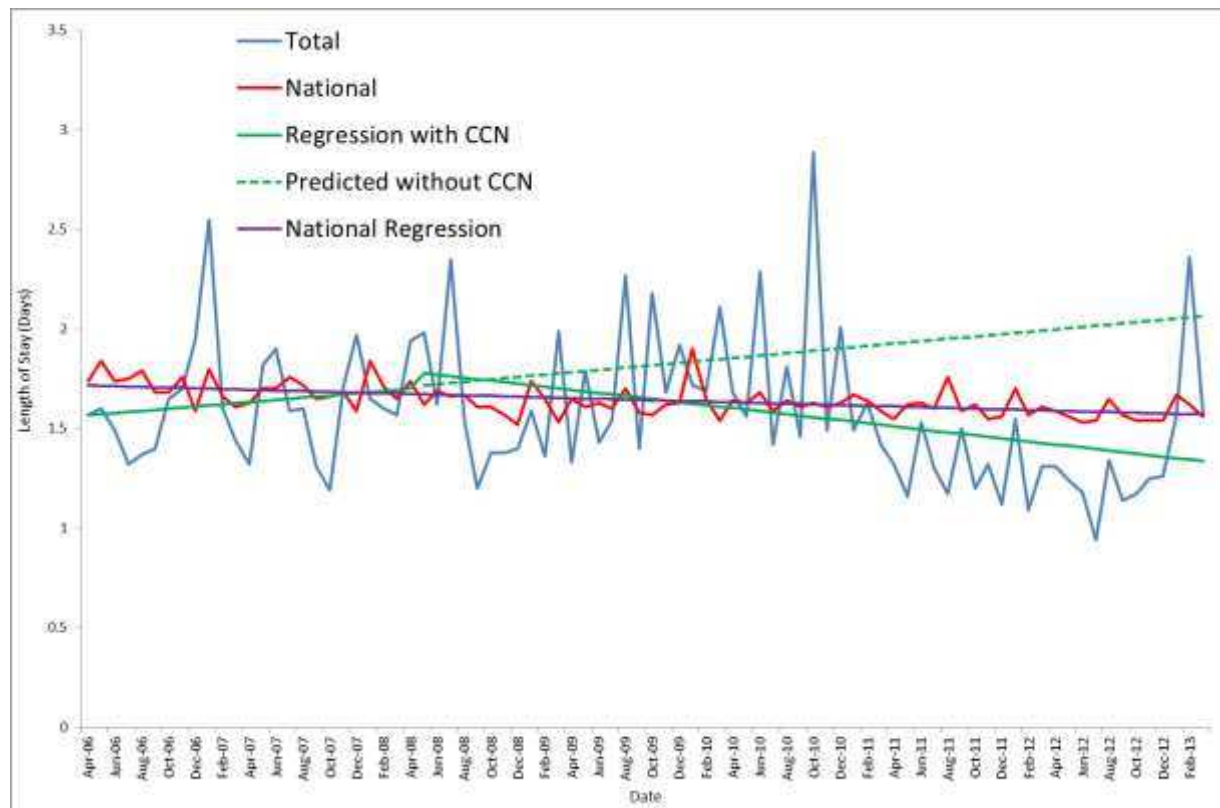


**Length of stay**

Figure 6 shows the average length of stay in this site, along with the regression lines pre and post the introduction of CCN (April 2008). It also shows the national data and the national regression line. The overall trend in the national rate is flat, with the regression giving a small monthly fall in the length of stay of 0.002 days per month (95% CI: -0.002,- 0.001), which was a statistically significant fall ( $p < 0.001$ ). The average length of stay in Site A1 was similar to the national rate throughout the reporting period.



**Figure 6: Site A1: average length of stay by month**



At the start of the analysis period (April 2006) the average length of stay in the site was 1.561 days. Prior to the introduction of CCN there was very small increase in LOS of 0.006 per month (95% CI: -0.013, 0.024,  $p=0.558$ ). There was an increase of 0.086 days (95% CI: -0.228, 0.401) immediately after the intervention, but this was not statistically significant ( $p=0.593$ ). After the intervention, the magnitude of the underlying trend was reduced by 0.013 (95% CI: -0.032, 0.007,  $p=0.183$ ), but this change was not statistically significant. Following the introduction of CCN there was thus a decrease of 0.007 days in average length of stay per month, bringing it below the national average.

Table A4 shows the parameter estimates from the linear segmented regression models. In the overall model, the Durban Watson statistic was 1.561, which is close to 2 indicating no serious autocorrelation. None of the sub-group analyses showed any statistically significant findings.

## Site A2

The introduction of the CCN team in this site was in February 2008. Data was extracted from April 2006 through to March 2013.

### Rate of admissions per 100,000

Between February 2006 and January 2008 - the two year timeframe prior to the introduction of CCN - the total number of non-elective admissions was 9147. Table 14 shows the top 12 numbers of admissions, which represents 63.1% of the total. Although in a slightly different order, these top 12 are the same as was seen in Site A1.

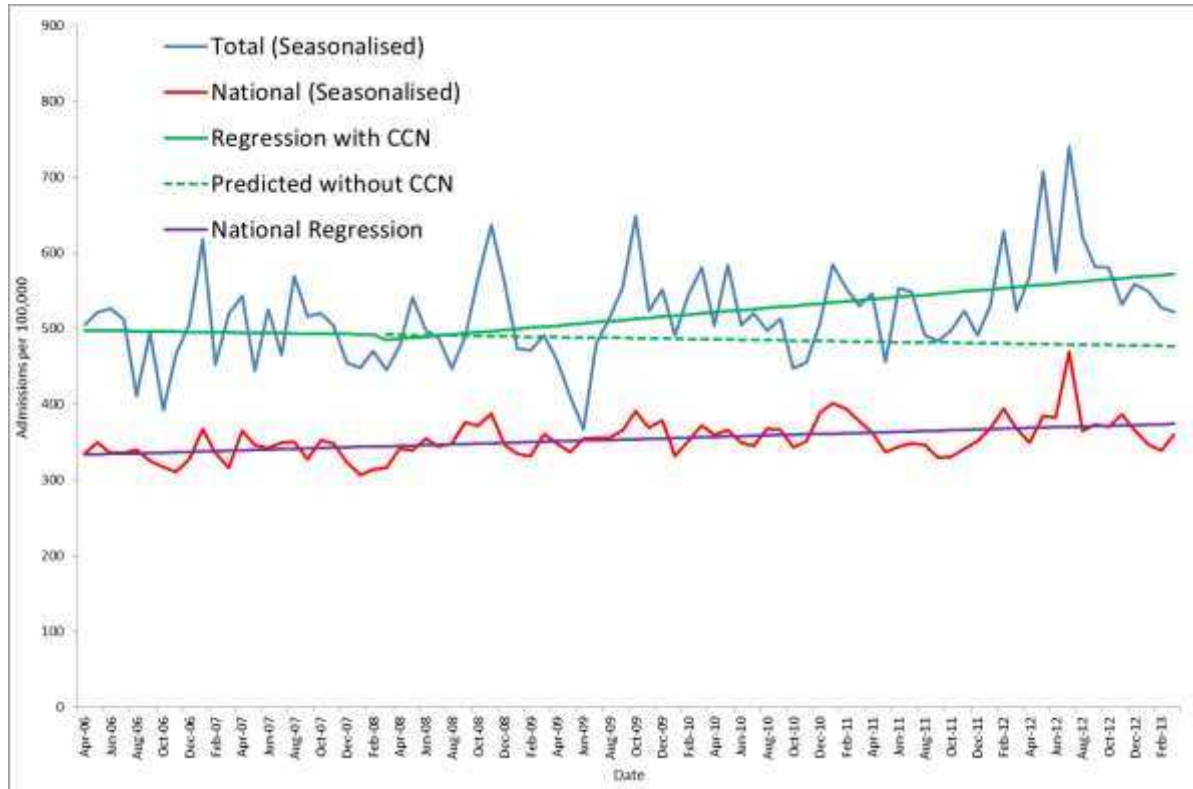
**Table 14: Site A2 top 12 number of finished emergency admissions**

Primary diagnosis	Number of finished emergency admissions	%
J00-J06: Acute upper respiratory infections	1329	23.0%
B25-B34: Other viral diseases	600	10.4%
A00-A09: Intestinal infectious diseases	541	9.4%
R50-R69: General symptoms and signs	511	8.9%
J20-J22: Other acute lower respiratory infections	498	8.6%
R10-R19: Symptoms and signs involving the digestive system and abdomen	454	7.9%
S00-S09: Injuries to the head	431	7.5%
J40-J47: Chronic lower respiratory diseases	381	6.6%
R00-R09: Symptoms and signs involving the circulatory and respiratory systems	329	5.7%

S50-S59: Injuries to the elbow and forearm	251	4.4%
K50-K52: Non-infective enteritis and colitis	232	4.0%
R20-R23: Symptoms and signs involving the skin and subcutaneous tissue	212	3.7%
Total top 12	5769	100.0%

Figure 7 shows the seasonalised monthly rate of admissions per 100,000, along with the regression lines pre and post the introduction of CCN. It also shows the national data and the national regression line. As can be seen, the rate of admissions per 100,000 in this site was higher than the national rates throughout the reporting period. See Site A1 analysis for regression model for the national data.

**Figure 7: Site A2: overall admission rate by month (per 100,000)**



The total rate of admissions per 100,000 in this site, at the start of the analysis period in April 2006, was 498 per 100,000. Prior to the introduction of CCN in February 2008 there was an annual fall of 0.25 (95% CI: -3.80, 3.30) in the rate of admissions per 100,000 per month, but this was not statistically significant ( $p=0.891$ ). There was a small fall in the rate of admissions immediately after the intervention of 8.46 (95% CI: -62.58, 43.66), but this was not statistically significant ( $p=0.760$ ). Overall, after the intervention, the magnitude of the underlying trend was increased by 1.70 (95% CI: -1.94, 5.34,  $p=0.363$ ). Thus, after the intervention there was a rise in the rate of increase of admissions of 1.45 ( $-0.25 + 1.70$ ) per 100,000 per month.

As can be seen in Figure 7, the post-intervention regression line was above the regression line predicted without CCN. This indicates a higher number of admissions with CCN than would have been expected without CCN. In the two-year timeframe after the CCN team was introduced, this represents 150 more admissions than would have been predicted without CCN.

Table A5 shows the parameter estimates from the linear segmented regression models and the parameter estimates from the linear segmented regression models for each sub-group analysis.

Despite the overall absence of statistically significant change in total admissions, there were statistically significant findings for the change immediately after the intervention for some sub-groups:

- Unknown ethnic group: Statistically significant rise in admissions immediately after the intervention ( $p < 0.001$ ).
- A00-A09: Intestinal infectious diseases: Statistically significant fall in admissions immediately after the intervention ( $p = 0.016$ ).
- J00-J06: Acute upper respiratory infections: Statistically significant fall in admissions immediately after the intervention ( $p = 0.041$ ).
- R00-R09: Symptoms and signs involving the circulatory and respiratory systems: Statistically significant rise in admissions immediately after the intervention ( $p < 0.001$ ).
- Tuesday admission: Statistically significant fall in admissions immediately after the intervention ( $p = 0.005$ ).

Within the other sub-groups there were no statistically significant findings.

### **Bed days per 100,000**

Figure 8 shows the monthly number of bed days per 100,000 in Site A2, along with the regression lines pre- and post- the introduction of CCN (February 2008). It also shows the national data and the national regression line. The number of bed days per 100,000 was slightly higher in Site A2 than the national rate throughout the reporting period.





**Figure 8: Site A2 bed days by month (per 100,000)**

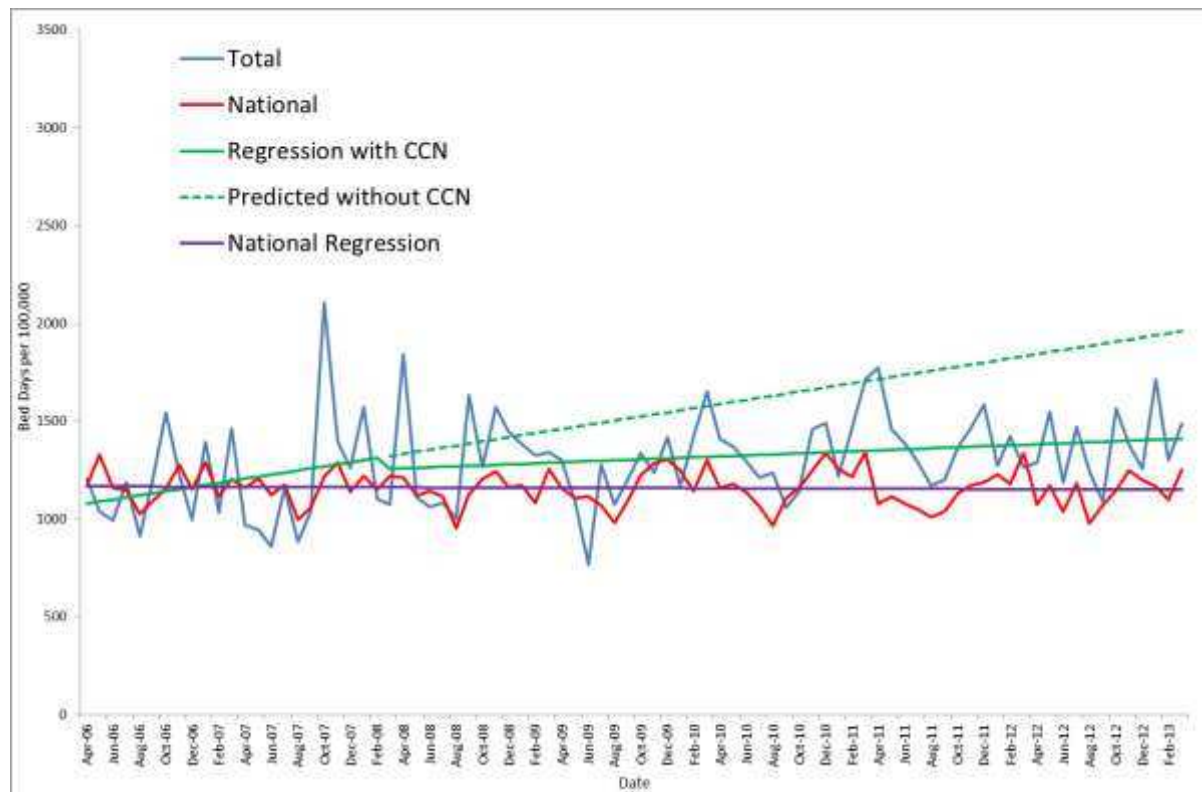


Table A6 shows the parameter estimates from the total and sub-group linear segmented regression models. For the total, at the start of the analysis period in April 2006, there were 1068 bed days per 100,000. Prior to the introduction of CCN in February 2008 there was an annual rise of 10.62 (95% CI: -3.33, 24.57) in the number of bed days per 100,000 per month, but this trend was not statistically significant ( $p=0.140$ ). There was a fall in bed days immediately after the intervention of 58.20 (95% CI: -271.15, 154.75), but this was not statistically significant ( $p=0.594$ ). Overall, after the intervention, the magnitude of the underlying trend was decreased by 8.05 (95% CI: -22.37, 6.27,  $p=0.274$ ). Thus, after the intervention, bed days per 100,000 were increasing by 2.57 ( $+10.62-8.05$ ) per month that is much more slowly than before the intervention.

As can be seen in Figure 8, the post-intervention regression line was below the regression line predicted without CCN. This indicates a lower number of bed days per 100,000 with CCN than would have been expected without CCN. In the two-year timeframe after the introduction of CCN, this represents 1864 fewer bed days than would have been predicted without CCN.

There were no statistically significant changes evident in any of the sub-group analyses.

### **Length of stay**

Figure 9 shows the average length of stay for Site A2, along with the regression lines pre- and post- the introduction of CCN (February 2008). It also shows the national data and the national regression line. The average length of stay in Site A2 was lower than the national length of stay throughout the reporting period.

### **Figure 9: Site A2 length of stay by month**

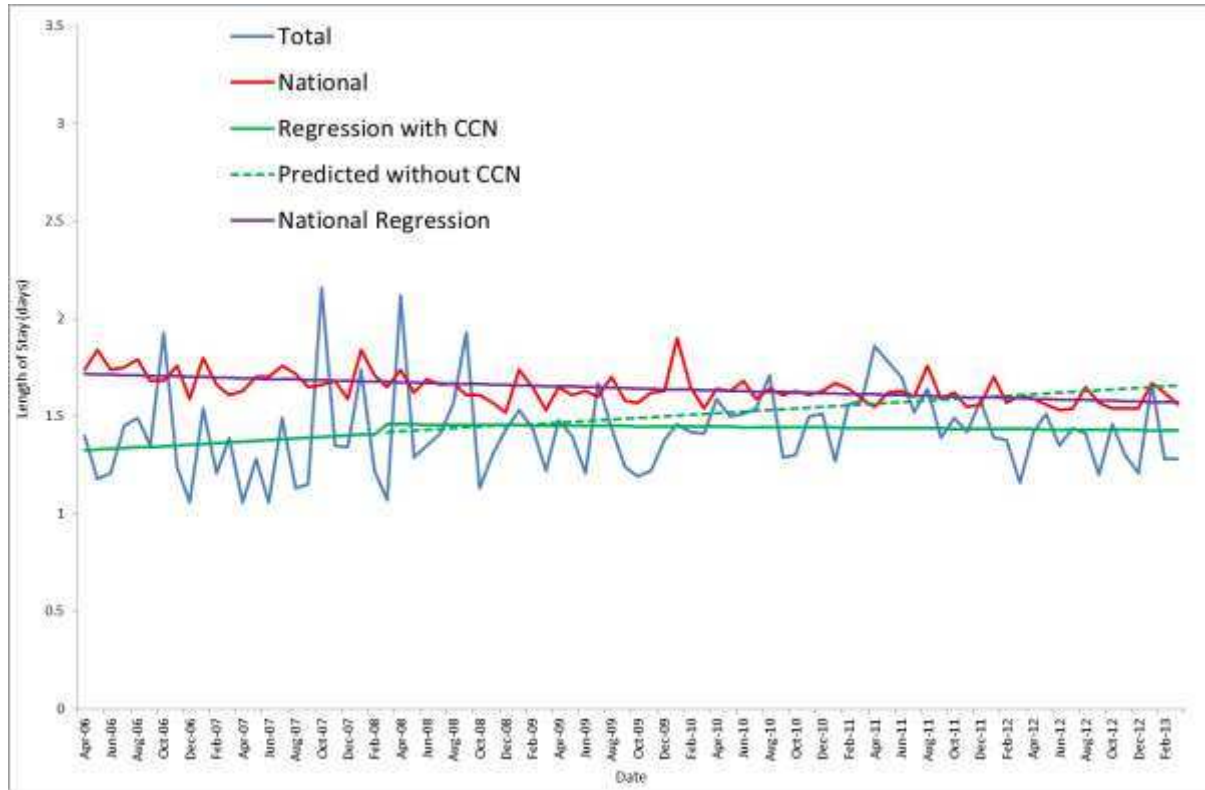


Table A7 shows the parameter estimates from the linear segmented regression models total and sub-group.

At the start of the analysis period in April 2006 the average length of stay was 1.321 days. Prior to the introduction of CCN in February 2008 there was a very small increase in length of stay of 0.004 per month (95% CI: -0.010, 0.018), but this was not statistically significant ( $p=0.588$ ). There was a slight rise of 0.050 (95% CI: -0.159, 0.260) immediately after the intervention, but this was not statistically significant ( $p=0.639$ ). After the intervention, the magnitude of the underlying trend was decreased by 0.004 (95% CI: -0.018, 0.010,  $p=0.550$ ). Overall, therefore, following the introduction of CCN there was no increase per month in average length of stay (0.004 - 0.004).

A single sub-group analysis (for deprivation group 3) showed a small increase in average length of stay of 0.047 days after the introduction of CCN ( $p = 0.049$ ).

### **Site C**

This site was used as a control site as it had not been able to introduce the planned CCN service change during the period of our project. A dummy intervention date, which was the same as Site A1 (April 2008) was used. The rationale for this was to explore change in a site that had not implemented change with those that had.

### **Rate of admissions per 100,000**

The number of admissions was examined during the time period between April 2006 and March 2008, which is the two year timeframe prior to the dummy introduction of CCN in April 2008. The total number of admission was 20,434. Table 15 shows the top 12 number of finished emergency admissions by primary diagnosis which represents 57.9% of the total. The top 12 were the same as seen in Sites A1 and A2.

**Table 15: Site C top 12 number of finished emergency admissions**

<b>Primary Diagnosis</b>	<b>Number of finished emergency admissions</b>	<b>%</b>
J00-J06: Acute upper respiratory infections	2002	16.9%
R50-R69: General symptoms and signs	1593	13.5%
R00-R09: Symptoms and signs involving the circulatory and respiratory systems	1293	10.9%
R10-R19: Symptoms and signs involving the digestive system and abdomen	1153	9.7%
S00-S09: Injuries to the head	1017	8.6%
J20-J22: Other acute lower respiratory infections	1015	8.6%
J40-J47: Chronic lower respiratory diseases	772	6.5%
B25-B34: Other viral diseases	665	5.6%
S50-S59: Injuries to the elbow and forearm	659	5.6%
A00-A09: Intestinal infectious diseases	647	5.5%
K50-K52: Non-infective enteritis and colitis	589	5.0%
R20-R23: Symptoms and signs involving the skin and subcutaneous tissue	426	3.6%
<b>Total top 12</b>	<b>11831</b>	<b>100.0%</b>

Figure 10 shows the seasonalised monthly rate of admissions per 100,000, along with the regression lines pre- and post- the dummy introduction of CCN in April 2008. It also shows the national data and the national regression line. The admission rate per 100,000 was similar to the national rate throughout the study period.

**Figure 10: Site C overall admission rate by month (per 100,000)**

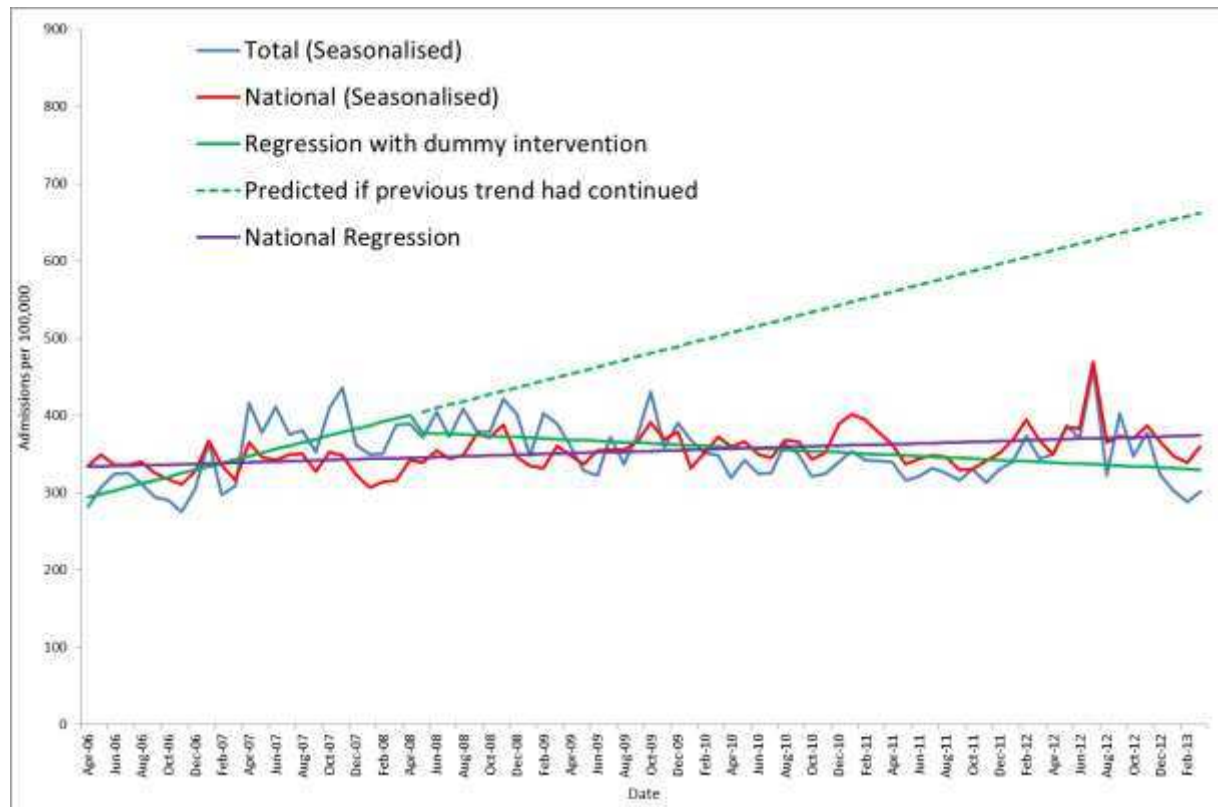


Table A8 shows the parameter estimates from the linear segmented regression models total and sub-group.

At the beginning of the observation period, there were 290 admissions per 100,000. Before the intervention date, there was a statistically significant month-to-month increase in the rate of admissions of 4.44 per month (95% CI: 2.66, 6.21,  $p < 0.001$ ). Immediately after the dummy intervention date, the rate of admissions dropped abruptly by 22.06 (95% CI: -52.09, 7.96), but this was not statistically significant ( $p = 0.154$ ). After the mock intervention point, it is estimated that the magnitude of the underlying trend decreased by 5.26 (95% CI: -7.10, 3.42,  $p < 0.001$ ), indicating a statistically

significant difference between pre-intervention and post-intervention slopes. Overall, following the mock intervention point, there was a decrease of 0.82 admissions per month per 100,000 (4.44 – 5.26).

Within all sub-groups there were some statistically significant findings for the pre-intervention increase in the rate of admissions per 100,000 and between pre-intervention and post-intervention slopes, but not for the change after the mock intervention point. These sub-group results, alongside the total results, suggest some change in the way that HES data were recorded in Site C before and after the mock intervention point of April 2008.

### **Bed days by month (per 100,000)**

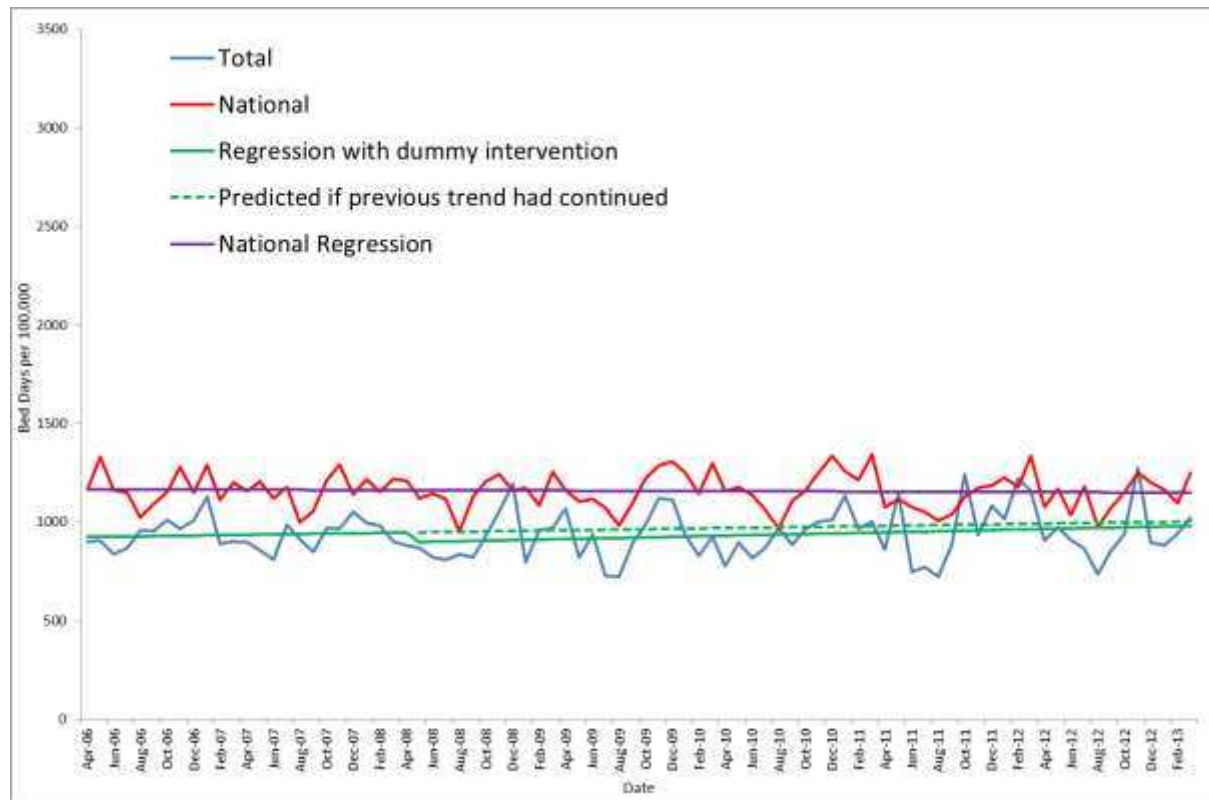
Figure 11 shows the monthly number of bed days per 100,000, along with the regression lines pre and post the dummy introduction of CCN (April 2008) in Site C. It also shows the national data and the national regression line. The number of bed days per 100,000 was slightly lower than the national rate throughout.

Table A9 shows the parameter estimates from the total and sub-group linear segmented regression models.

Before the dummy intervention date, there was a slight but not statistically significant increase month to month in the number of bed days per 100,000 (0.95 days, 95% CI: -5.56, 7.46 p=0.776). Immediately after the dummy intervention, the number of bed days per 100,000 fell by 49.98 (95% CI: -160.14, 60.19), but this was not statistically significant (p=0.377). After April 2008, the magnitude of the underlying trend was increased by 0.47 (95% CI: -6.69, 7.22, p=0.893). Post-intervention there was an increase in number of bed days per month per 100,000 of 1.41 (0.95+0.47).



**Figure 11: Site C bed days by month (per 100,000)**



Unlike the analysis of the admissions data for this site, there was no evidence of any statistically significant change in any of the sub-group analyses.

### **Length of stay**

Figure 12 shows the average length of stay, along with the regression lines pre- and post- the mock intervention point (April 2008). It also shows the national data and the national regression line. The average length of stay in Site C was lower than the national length of stay throughout.

**Figure 12: Site C length of stay by month**

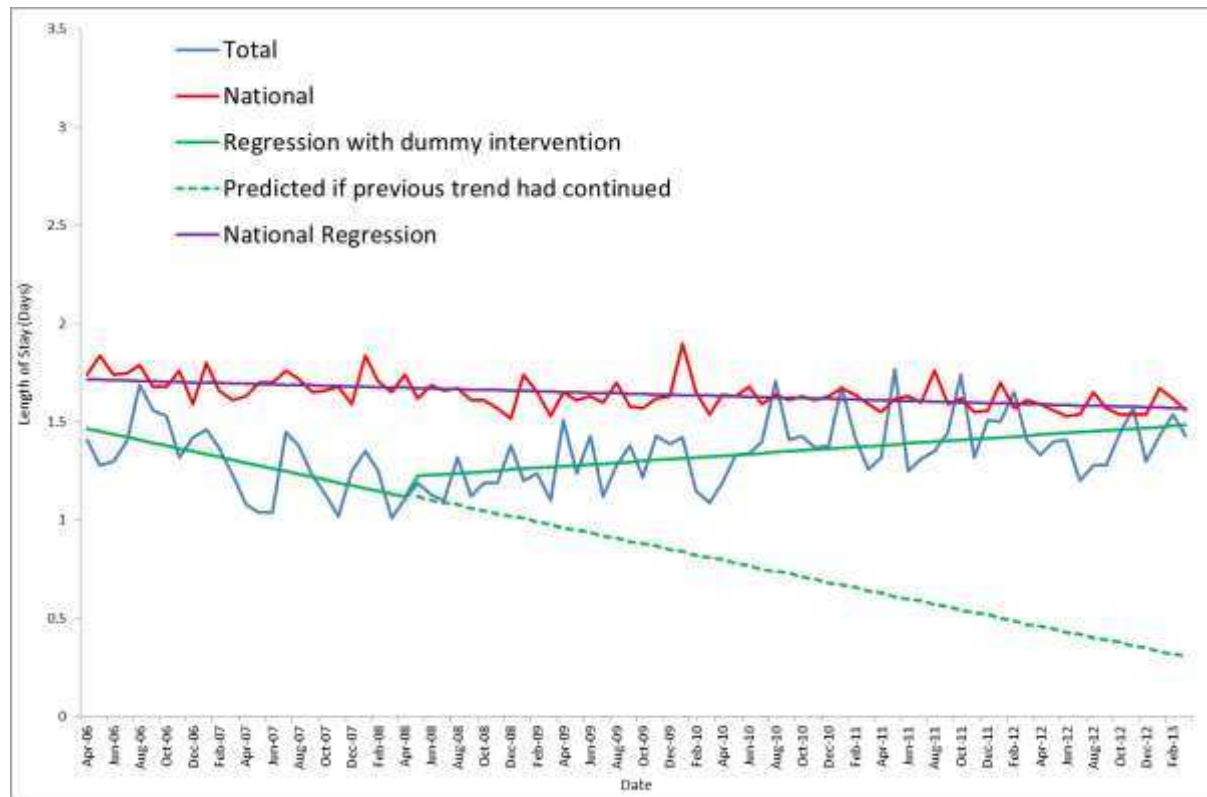


Table S10 shows the parameter estimates from the total and sub-group linear segmented regression models.

At the beginning of the observation period, the average length of stay was 1.481 days. Before the mock intervention point length of stay was decreasing by 0.014 days per month (95% CI: -0.022, -0.007) which was statistically significant ( $p=0.001$ ). Immediately after this point, the average length of stay rose by 0.101 days (95% CI: -0.033, 0.236), but this was not statistically significant ( $p=0.142$ ). After April 2008, the magnitude of the

underlying trend increased by 0.019 (95% CI: 0.011, 0.027,  $p < 0.001$ ), showing a statistically significant difference between pre-intervention and post-intervention slopes. Overall, then, after the mock intervention point, there was an increase of 0.005 in average length of stay per month (-0.014+0.019).

As with the admission data, within each sub-group there were some statistically significant findings for the pre-intervention increase in length of stay and between mock pre-intervention and post-intervention slopes, but not for after April 2008.

### **Site B**

This was the second site where a planned CCN team targeting acute activity had not been implemented. We used the same dummy intervention date of April 2008, as in the Site C analysis. The ITS was undertaken only on rate of admissions per 100,000 as this site already had a CCN service for children with complex conditions, the impact of which it was felt might be evident on bed days and length of stay.

### **Rate of admissions per 100,000**

The number of admissions was examined during the time period between April 2006 and March 2008, which is the two year timeframe prior to the dummy introduction of CCN in April 2008. In total there were 14,189 admissions. Table 16 shows the top 12 number of admissions by primary diagnosis which represent 60.6% of the total. There is one difference in the top 12 compared to Sites A1, A2 and C. R20-R23: Symptoms and signs involving the skin and subcutaneous tissue are replaced by J10-J18: Influenza and pneumonia.

**Table 16: Site B: top 12 number of finished emergency admissions**

<b>Primary Diagnosis</b>	<b>Number of finished emergency admissions</b>	<b>%</b>
J00-J06: Acute upper respiratory infections	1506	17.5%
J20-J22: Other acute lower respiratory infections	998	11.6%
B25-B34: Other viral diseases	916	10.7%
R50-R69: General symptoms and signs	852	9.9%
R10-R19: Symptoms and signs involving the digestive system and abdomen	847	9.9%
R00-R09: Symptoms and signs involving the circulatory and respiratory systems	716	8.3%
A00-A09: Intestinal infectious diseases	500	5.8%
S00-S09: Injuries to the head	494	5.7%
J10-J18: Influenza and pneumonia	492	5.7%
S50-S59: Injuries to the elbow and forearm	474	5.5%
K50-K52: Non-infective enteritis and colitis	408	4.7%
J40-J47: Chronic lower respiratory diseases	394	4.6%
Total top 12	8597	100.0%

Figure 13 shows the seasonalised monthly rate of admissions per 100,000, along with the regression lines pre- and post- the dummy intervention point in April 2008. It also shows the national data and the national regression line. The admission rate per 100,000 in Site B was slightly higher than the national rate throughout.

**Figure 13: Site B overall admission rate by month (per 100,000)**

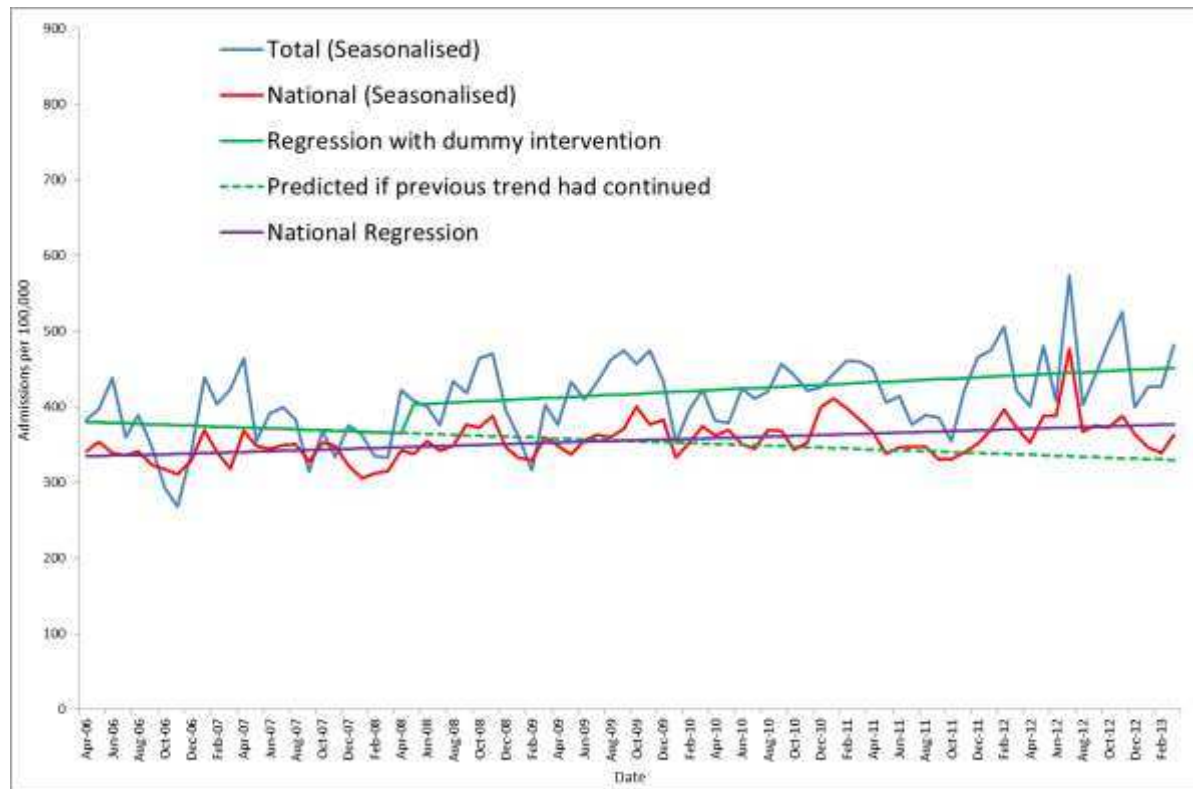


Table S11 shows the parameter estimates from the linear segmented regression models.

At the beginning of the observation period, the rate of admissions was 381 per 100,000. Before the intervention date, there was a small but not statistically significant fall in the rate of admissions (-0.60, 95% CI: -3.005, 1.80,  $p=0.62$ ). Immediately after the mock intervention date, the rate of admissions rose abruptly by 36.90 (95% CI: -3.01, 1.80), but this was not statistically significant ( $p=0.079$ ). After April 2008, the magnitude of the

underlying trend increased by 1.44 (95% CI: -1.05, 3.93, p=0.260). Overall, after April 2008, the rate of admissions per 100,000 rose by 0.84 per 100,000 per month (-0.604 + 1.441).

Table S11 also shows the parameter estimates from the linear segmented regression models for each sub-group. There were some statistically significant findings within sub-groups: increases for those aged 1-4, for those from BME groups, for Saturday, Sunday and Monday admissions and for Thursday discharges, and for three disease groups (infective enteritis and colitis; circulation and respiratory signs and symptoms; and digestive system/abdomen signs and symptoms).

## **Complex Conditions**

The second phase of the analysis was to investigate the outcome measures for conditions with long lengths of stay, defined by us as complex conditions. As discussed above, this is a sub-analysis of the data by the following conditions:

- Admissions of children with an underlying Q code
  - Congenital malformations, deformations and chromosomal abnormalities
- Admissions of children with an underlying G code
  - Diseases of the nervous system
- Admissions of children with an underlying code in E70-E90
  - Metabolic disorders

## **Site A1**

### **Bed days for complex conditions**

Figure 14 shows the monthly number of bed days for children with complex conditions, expressed per 100,000 of all children, along with the regression lines, pre- and post- the introduction of CCN (April 2008). It also shows the national data and the national regression line. The overall trend in the national rate for these conditions, with the regression model, shows a monthly rise in the number of bed days per 100,000 of 0.76 per month

(95% CI: -0.48, 1.04), which was statistically significant ( $p < 0.001$ ). The number of bed days per 100,000 in Site A1 was higher than the national rate throughout the study period.

**Figure 14: Site A1 bed days by month (per 100,000): Complex Conditions**

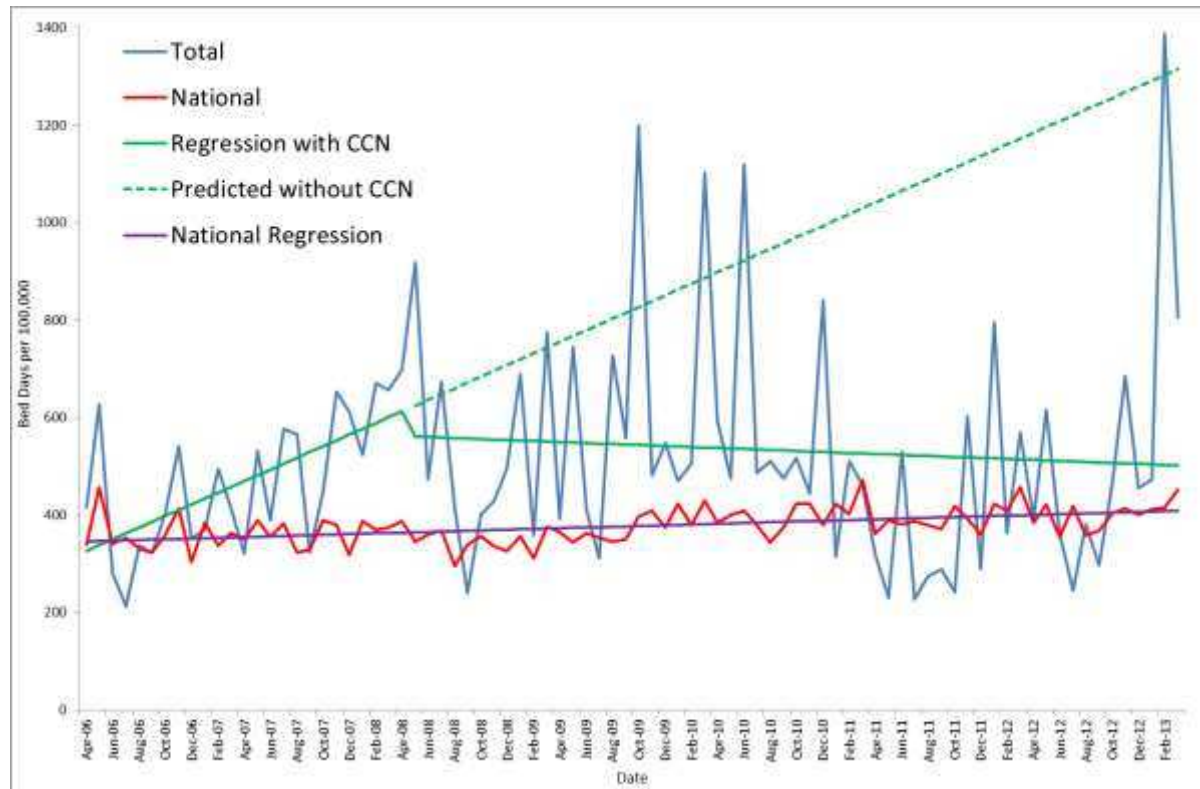


Table S12 shows the parameter estimates from the linear segmented regression models.

At the start of the analysis period in April 2006, there were 314.932 bed days per 100,000. Prior to the introduction of CCN in February 2008 there was an annual rise of 11.92 (95% CI: 0.07, 23.77) in the number of bed days per 100,000 per month ( $p=0.052$ ). There was a fall immediately after the intervention of 50.40 (95% CI: -250.93, 150.14), but this was not statistically significant ( $p=0.624$ ). After the intervention, it is estimated that the magnitude of the underlying trend was decreased by 12.94 (95% CI: -25.23, -0.65,  $p<0.001$ ), hence this demonstrates there was a statistically



significant difference between pre-intervention and post-intervention slopes. Following the introduction of CCN there was a decrease of 1.02 per month (11.916 -12.938).

Table S12 also shows the sub-group analysis. Due to the need to suppress data to preserve anonymity, day of admission and day of discharge were grouped as Monday – Thursday and Friday to Sunday and deprivation as ‘most deprived’ and ‘other’. Ethnicity was not analysed at all, for the same reason. There were some statistically significant findings within remaining sub-groups. Statistically significant differences (reductions) between pre- and post- intervention slopes were found for children aged 2 weeks to one year, paediatric admissions (so described), children from the most deprived areas, Monday to Thursday admissions and discharges, and elective admissions.

### **Length of stay**

Figure 15 shows the monthly average length of stay for the chosen complex conditions, along with the regression lines pre and post the introduction of CCN (April 2008). It also shows the national data and the national regression line. The overall trend in the national rate is flat, with the regression giving a small monthly fall in the length of stay of 0.003 days per month (95% CI: -0.004,- 0.002), which was statistically significant ( $p < 0.0012$ ). The average length of stay was similar to the national rate throughout the study period.

### **Figure 15: Site A1 length of stay by month: Complex Conditions**

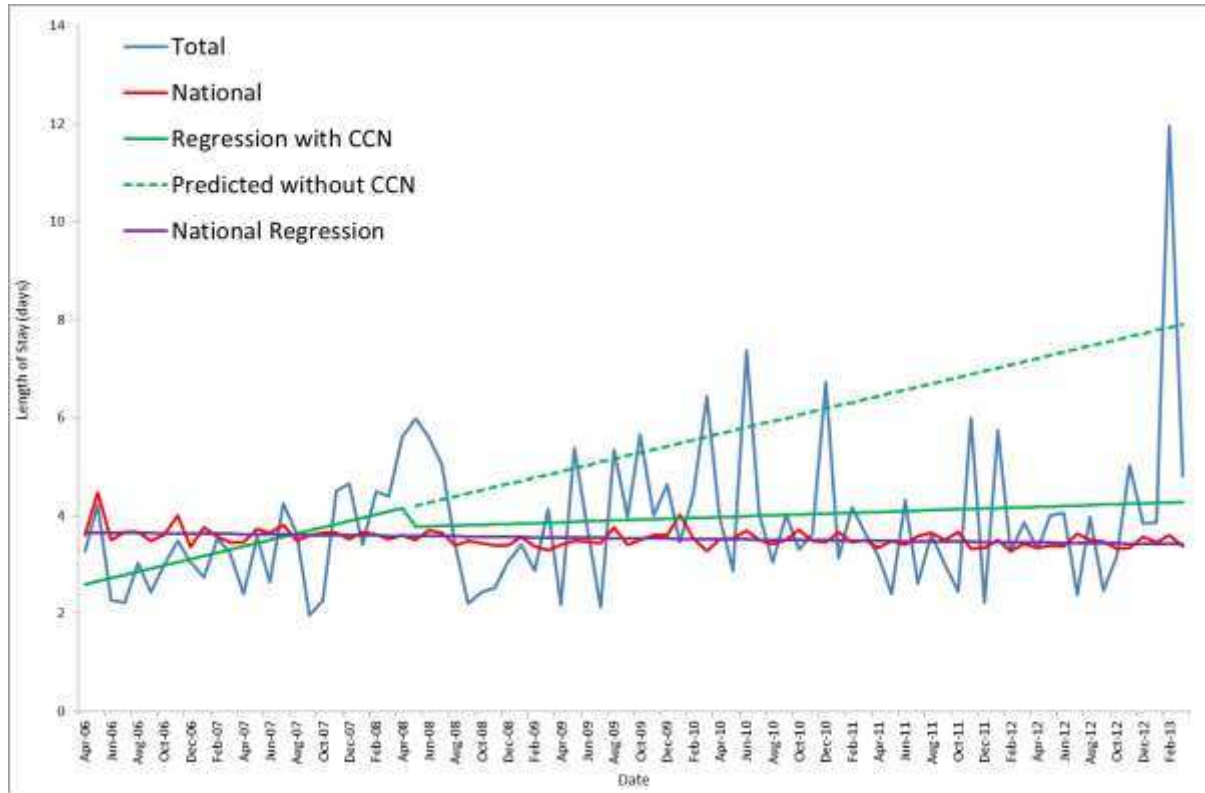


Table S13 shows the parameter estimates from the linear segmented regression models.

At the start of the analysis period in April 2006, the average LOS was 2.54 days. Prior to the introduction of CCN in April 2008 there was an annual rise of 0.064 (95% CI: -0.01, 0.14) in LOS per month ( $p=0.112$ ). There was no statistically significant change immediately after the intervention (-0.381, 95% CI: -0.171, 0.94,  $p=0.575$ ). After the intervention, it is estimated that the magnitude of the underlying trend was decreased by 0.056 (95%

CI: -0.136, 0.024,  $p=0.184$ ), but there was no overall statistically significant difference between pre-intervention and post-intervention slopes. Overall, after the introduction of CCN there was a small increase of 0.008 per month (0.064 -0.056).

Table S13 also shows the sub-group analysis.

There was one statistically significant difference (reduction) between pre- and post-intervention slopes, for children aged between 2 weeks and one year of -0.013 bed days (0.096 + (-0.109)).

## **Site A2**

### **Bed days for complex conditions**

Figure 16 shows the monthly number of bed days per 100,000 children, along with the regression lines pre- and post- the introduction of CCN (February 2008). It also shows the national data and the national regression line. The number of bed days per 100,000 was similar to the national rate throughout the study period.

**Figure 16: Site A2 bed days by month (per 100,000): Complex Conditions**

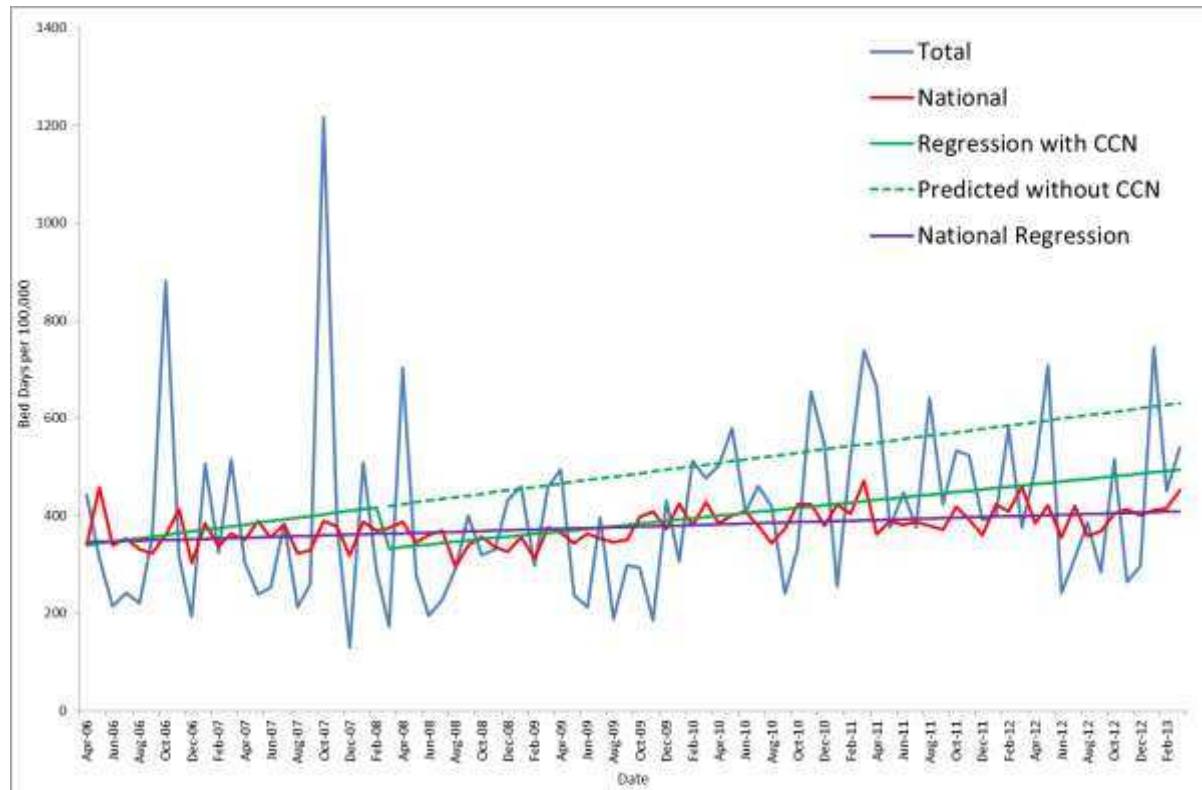


Table S14 shows the parameter estimates from the linear segmented regression models.

In the overall model, the Durban Watson statistic was 2.070, which is close to 2 indicating no serious autocorrelation.

At the start of the analysis period in April 2006, there were 336.30 bed days per month per 100,000. Prior to the introduction of CCN in February 2008 there was an annual rise of 3.51 (95% CI: -7.28, 14.29) in the number of bed days per 100,000 per month ( $p=0.526$ ). There was a fall of 86.59 (95%

CI: -251.18, 78.01) immediately after the intervention, but this was not statistically significant ( $p=0.306$ ). After the intervention, the magnitude of the underlying trend was decreased by 0.82 (95% CI: -11.89, 10.25,  $p=0.885$ ), thus there was no statistically significant difference between pre-intervention and post-intervention slopes. Overall, following the introduction of CCN there was an increase of 2.69 per month (3.506 -0.818).

Table S14 also shows the sub-group analysis. There were no statistically significant findings within sub-groups, except in relation to weekend admissions which showed a statistically significant reduction immediately after introduction of CCN (-10.06,  $p=0.041$ ) but this was not sustained over time.

### **Length of stay**

Figure 17 shows the monthly average length of stay for children with complex conditions, along with the regression lines pre and post the introduction of CCN (February 2008). It also shows the national data and the national regression line. The average length of stay was similar to the national rate throughout the study.

Table S15 shows the parameter estimates from the linear segmented regression models.

At the start of the analysis period in April 2006, the average LOS was 3.18 days. Prior to the introduction of CCN in February 2008 there was an annual rise of 0.02 (95% CI: -0.06, 0.10) in LOS per month. There was fall of 0.11 (95% CI: -1.34, 1.12) immediately after the intervention, but this was not statistically significant ( $p=0.863$ ). After the intervention, the magnitude of the underlying trend decreased by 0.018 (95% CI: -0.100, 0.064,  $p=0.668$ ), thus there was no statistically significant difference between pre-intervention and post-intervention slopes. Overall, following the introduction of CCN there was an increase of 0.002 per month in average LOS.

**Figure 17: Site A2 average length of stay by month: Complex Conditions**

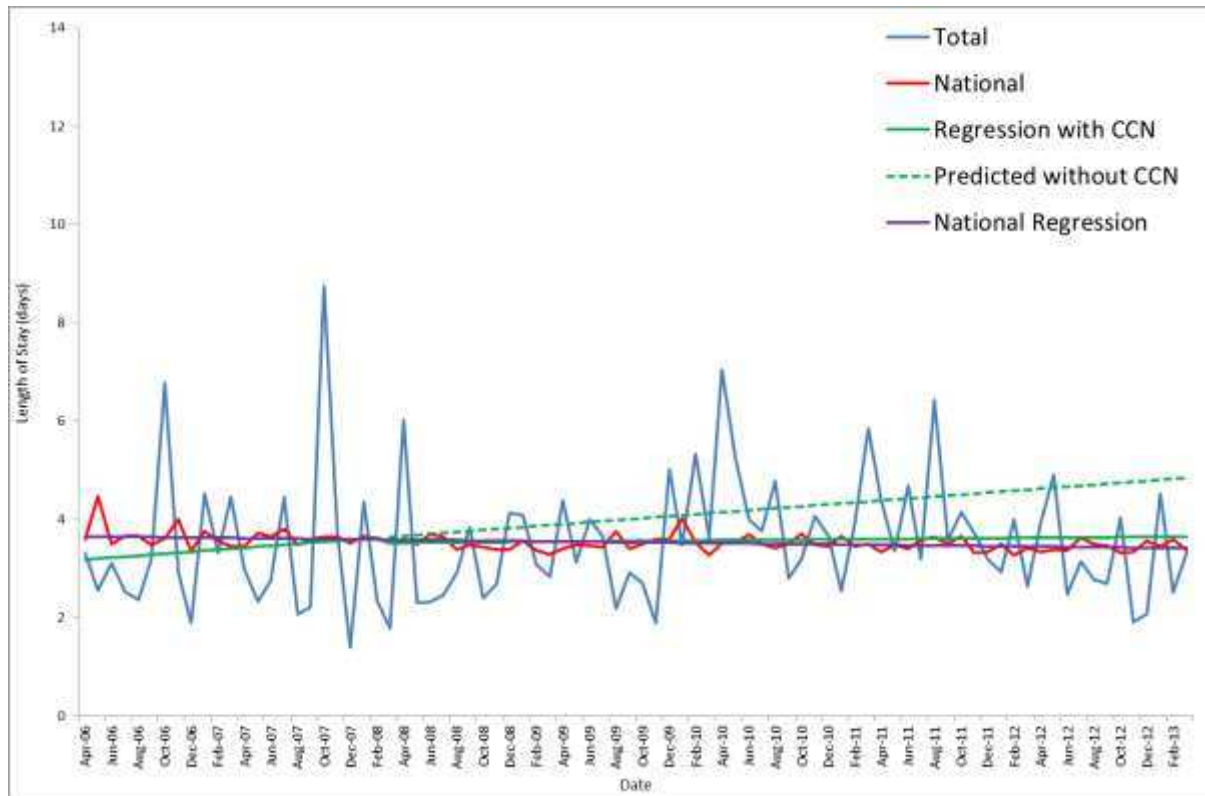


Table S15 also shows the sub-group analysis. There were no statistically significant findings within sub-groups.

## **Site B**

### **Bed days for complex conditions**

Figure 18 shows the monthly number of bed days per 100,000, along with the regression lines pre and post the introduction of CCN (October 2011). It also shows the national data and the national regression line. The number of bed days per 100,000 in Site B was higher than the national rate throughout the study period.

**Figure 18: Site B bed days by month (per 100,000): Complex Conditions**

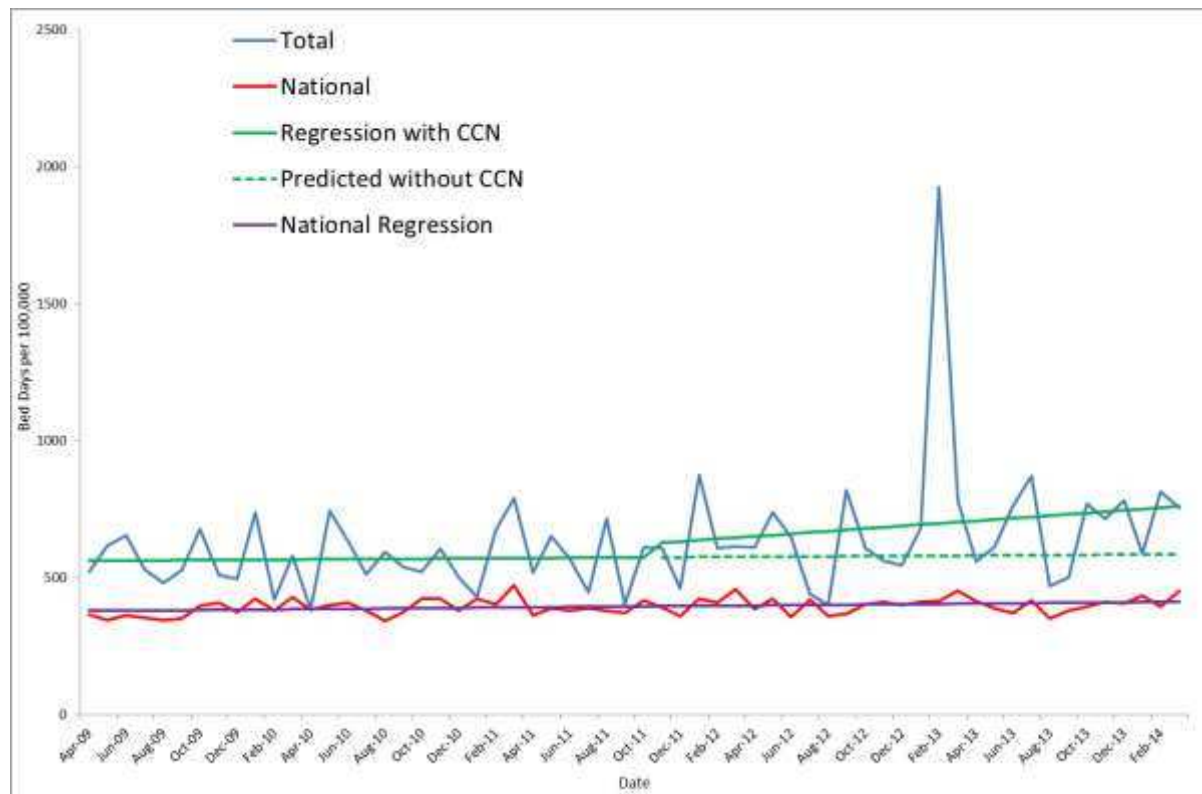


Table S16 shows the parameter estimates from the linear segmented regression models. At the start of the analysis period in April 2009, there were 561 bed days per 100,000. Prior to the introduction of CCN there was an annual rise of 0.41 (95% CI: -7.63, 8.45) in the number of bed days per 100,000 per month ( $p=0.920$ ). There was a rise of 48.76 (95% CI: -158.62, 256.15) immediately after the intervention, but this was not statistically significant ( $p=0.647$ ). After the intervention, the underlying trend increased by 4.34 (95% CI: -7.65, 16.32,  $p=0.481$ ), showing no statistically



significant difference between pre-intervention and post-intervention slopes. Overall, following the introduction of CCN there was an increase of 4.75 per month ( $0.41 + 4.34$ ).

Table S16 also shows the sub-group analysis. There were no statistically significant findings within sub-groups, except in relation to the least deprived group when there was a statistically significant difference in the pre- and post-intervention slopes.

### Length of stay

Figure 19 shows the monthly average length of stay, along with the regression lines pre and post the introduction of CCN (October 2011). It also shows the national data and the national regression line. The average length of stay was similar to the national rate throughout the study period.

**Figure 19: Site B length of stay by month: Complex Conditions**

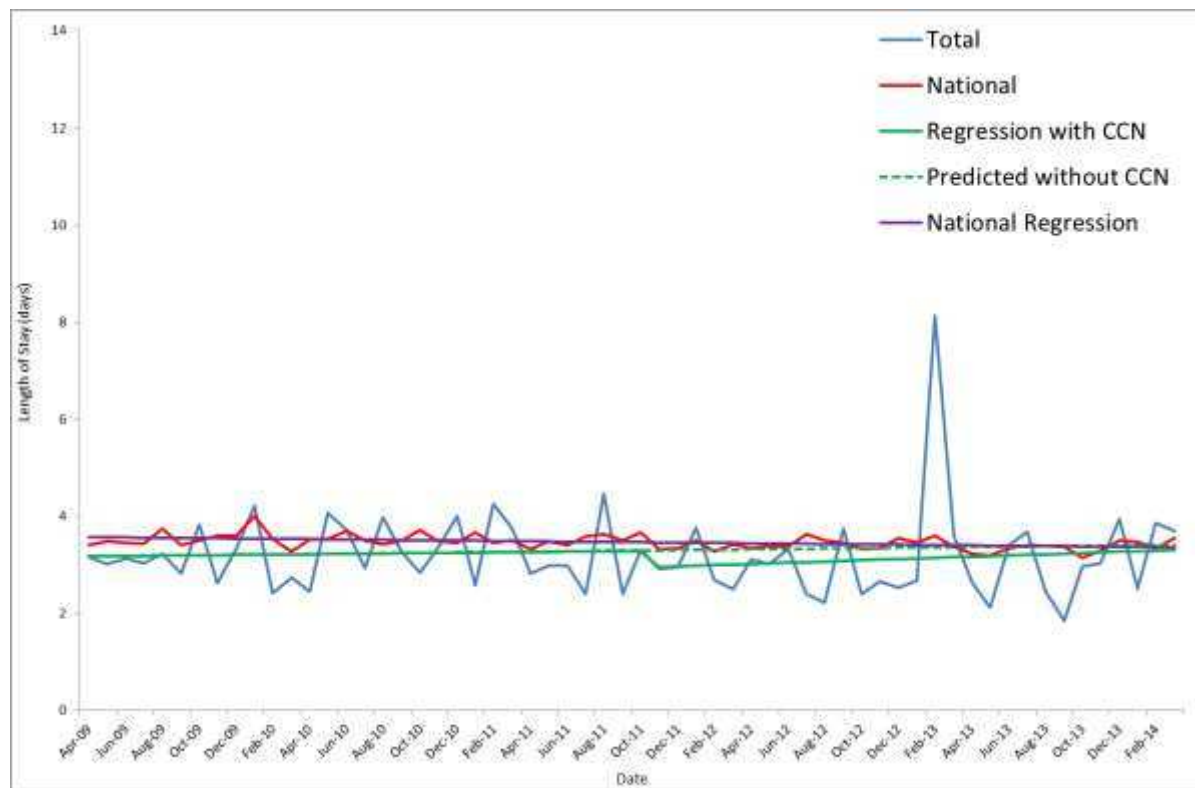


Table S17 shows the parameter estimates from the linear segmented regression models for LOS. At the start of the analysis period in April 2009, the average LOS was 3.174 days. Prior to the introduction of CCN in October 2011 there was an annual rise of 0.004 (95% CI: -0.032, 0.039) in length of stay per month ( $p=0.842$ ). There was no statistically significant change immediately after the intervention (-0.340, 95% ci: -1.254, 0.575,  $p=0.470$ ). After the intervention, it is estimated that the magnitude of the underlying trend was increased by 0.009 (95% CI: -0.044, 0.062,  $p=0.743$ ), showing no statistically significant difference between pre-intervention and post-intervention slopes. Overall, following the introduction of CCN there was an increase of 0.013 per month (0.004 + 0.009).

Table S17 also shows the sub-group analysis. There were no statistically significant findings within sub-groups.

#### **Site D: Acute hospital admission avoidance for children with complex conditions**

##### **Rate of admissions per 100,000 children with complex conditions**

Analysis for this site was undertaken on G codes only – diseases of the nervous system - as described above. There was no sub-group analysis due to suppression of data in order to preserve anonymity.

Figure 20 shows the rate of admission per 100,000, along with the regression lines pre- and post- the introduction of CCN (March 2008). It also shows the national data and the national regression line. The overall trend in the national data shows an increasing admission rate of 0.07 per month (95% CI: 0.06, 0.07) over the whole study period, which was statistically significant ( $p<0.001$ ). The rate of admissions per 100,000 was higher in Site D than the national rate until 2011. From 2011, there was a dip in the rate of admissions per 100,000, with lower rates than the national rates, which might suggest possible discontinuity in the data.

**Figure 20: Site D G-Code rate of admissions by month (per 100,000)**

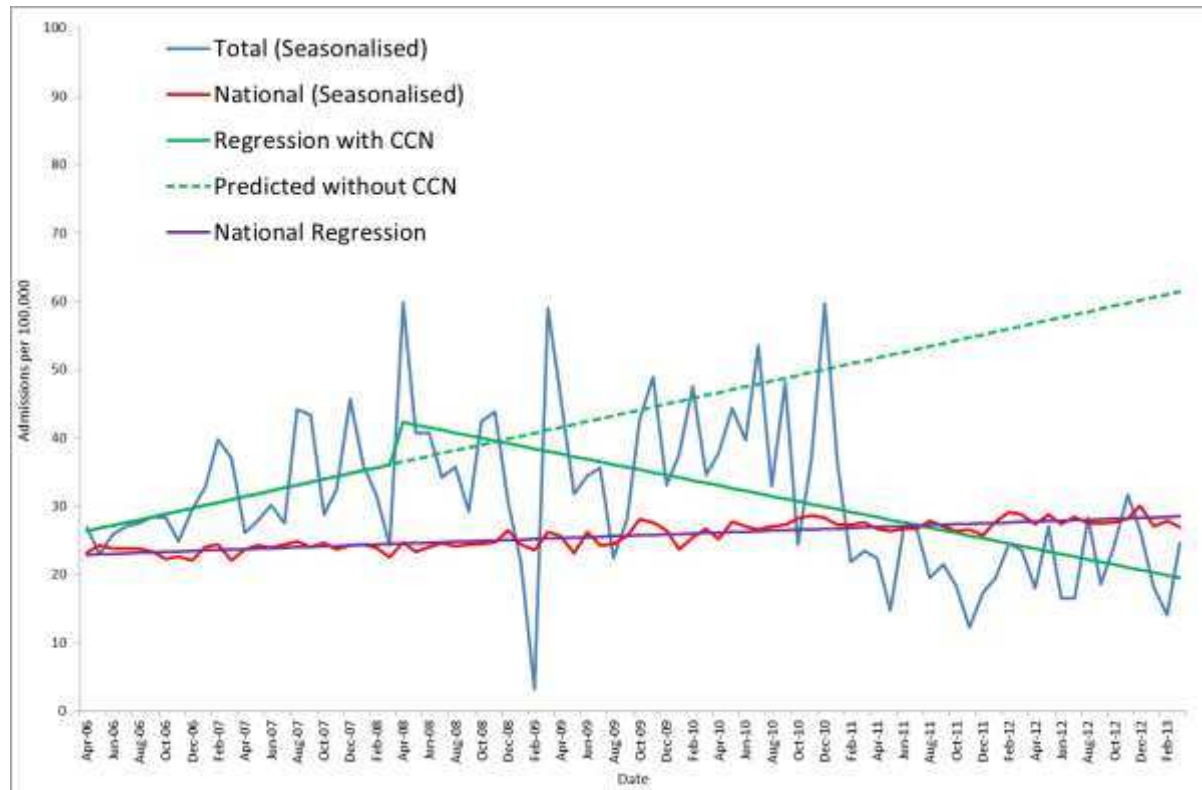
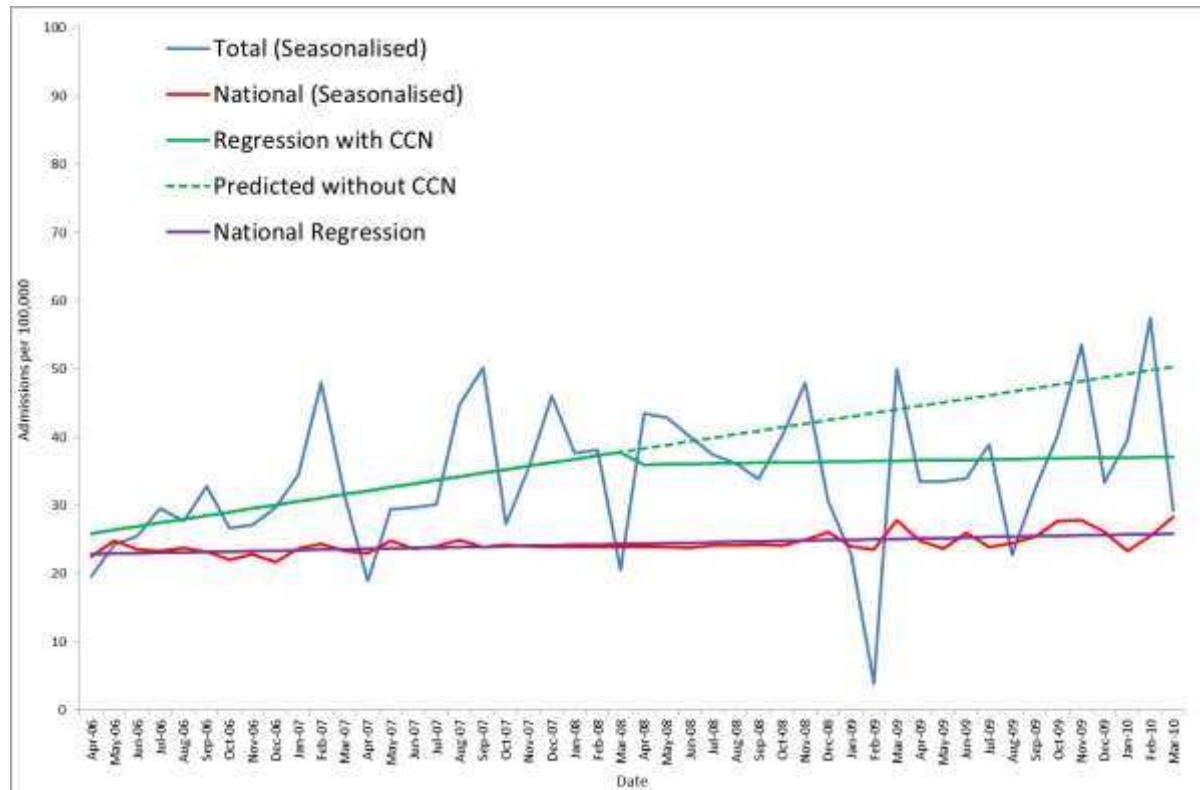


Table S18 shows the parameter estimates from the linear segmented regression models. At the start of the analysis period in April 2006, there were 25.91 admissions per 100,000. Prior to the introduction of CCN in March 2008 there was an annual rise of 0.42 (95% CI: -0.13, 0.97) in the rate of admissions per 100,000 per month, but this was not statistically significant ( $p=0.135$ ). There was no statistically significant change in the rate of admissions immediately after the intervention (6.61, 95% CI: -2.24, 15.45,  $p=0.147$ ). After the intervention, the magnitude of the underlying trend decreased by 0.81 (95% CI: -1.38, -0.24,  $p=0.006$ ), showing a statistically significant difference between pre-intervention and post-intervention slopes. Overall, following the introduction of CCN there was a decrease of 0.39 admissions per 100,000 per month (0.423 -0.809).



As discussed above, there was a fall in the rate of admissions in 2011 suggesting some possible discontinuity in the data. We therefore, re-ran the analysis using only data up to two years post intervention (April 2008 – March 2010).

**Figure 21: Site D G-Code rate of admissions (per 100,000) – two years post-intervention only**



As before, the overall trend in the national rate shows an increasing admission rate of 0.06 per month (95% CI: 0.04, 0.07) over the reduced time period, which was statistically significant ( $p < 0.001$ ). Table 17 shows the parameter estimates from the linear segmented regression models. At the start of the analysis period in April 2006, there were 25.41 admissions per 100,000. Prior to the introduction of CCN in March 2008 there was an annual rise

of 0.52 (95% CI: -0.04, 1.08) in the rate of admissions per 100,000 per month, but this was not statistically significant (p=0.077). There was no statistically significant change in the rate of admissions immediately after the intervention (-1.90, 95% CI: -12.93, 9.13, p=0.738). After the intervention, the magnitude of the underlying trend was decreased by 0.47 (95% CI: -1.27, 0.33, p=0.254), showing no statistically significant difference between pre-intervention and post-intervention slopes. Overall, following the introduction of CCN there was an increase of 0.05 per month in admissions of children with complex conditions (0.52-0.47).

No sub-group analysis was undertaken because of the need to suppress data, due to the relatively small number of admissions for G-Codes.

**Table 17: Site D G-Code rate of admissions (per 100,000) – two years post-intervention only**

		<b>Coefficient</b>	<b>SE</b>	<b>Beta</b>	<b>t-statistic</b>	<b>p-value</b>
<b>Total</b>	DW=1.973					
	Intercept	25.405	4.102		6.193	<0.001
	Baseline Trend	0.519	0.287	0.723	1.809	0.077
	Level change after CCN	-1.897	5.628	-0.095	-0.337	0.738
	Trend after CCN	-0.470	0.406	-0.375	-1.157	0.254

## Summary of main findings

### Non-elective admissions

1. The overall trend in the national rate shows an increasing non-elective admission rate of 0.49 per month (95% CI: 0.30, 0.68) over the whole period of analysis, which was a statistically significant increase (p<0.001).

2. Site A1, which is a generic CCN team (community based) had an admission rate that was higher than the national rate. The analysis shows a statistically significant fall in admissions immediately after CCN, but no statistically significant change in the slopes pre-CCN team vs post CCN team. The admission rate was increasing monthly pre-CCN and post-CCN. However, the abrupt fall in admissions post-CCN suggests that CCN may have had an impact with an estimated 399 fewer admissions in the two years post-CCN than predicted without CCN.
3. Site A2 was a generic CCN team (hospital based) and had an admission rate that was higher than the national rate. The analysis shows no statistically significant changes, although the rate of admissions was falling slightly prior to CCN, with a slight increase immediately after CCN, and a slight rise post CCN. This suggests that CCN had no impact on the rate of non-elective hospital admissions.

### **Bed days**

1. The overall trend in bed days per 100,000 nationally shows a flat rate, with the regression giving a small monthly fall in the number of bed days per 100,000 of 0.20 per month (95% CI: -1.00, 0.60), which was not statistically significant increase ( $p=0.623$ ).
2. In Site A1 the rate of bed days per 100,000 was increasing prior to CCN, with an annual rise of 10.49 (95% CI: -0.33, 21.31) in the number of bed days per 100,000 per month (not statistically significant). There was a fall of 22.98 (95% CI: -160.18, 206.15) immediately after the intervention, but this was also not statistically significant. Following the introduction of CCN there was a decrease of 2.85 bed days per month, but this was not a statistically significant change. In the two year timeframe post CCN, using the regression lines, this change in slope represents 1548 fewer bed days than that predicted without CCN. Hence, although not statistically significant, there does seem to be some effect of CCN on bed days.
3. Site A2 which was a generic CCN team (hospital based) shows no statistically significant changes, although there was an increase in admission rates. The rate of bed days per 100,000 was rising prior to CCN (10.62, 95% CI: -3.33, 24.57), and although there was an increase immediately post CCN (58.20, 95% CI: -271.15, 154.75), there was a slower monthly increase post CCN (2.57 per month). Hence, although not statistically significant, there does seem to be some effect of CCN on the rate of bed days per 100,000. In the two year timeframe post CCN, using the regression lines, this represents 1864 fewer bed days than that predicted without CCN.



## LOS

1. The overall trend in LOS nationally shows a flat rate, with the regression giving a small monthly fall in the length of stay of 0.0028 days per month (95% CI: -0.0023, -0.0012), which was a statistically significant fall ( $p < 0.001$ ).
2. In Site A1 there were no statistically significant changes in slope or immediately after CCN. While the LOS were similar to those seen nationally, by the end of the period the LOS had fallen to below the national average.
3. In Site A2, the LOS was lower than the national rate, with no statistically significant changes in slope or immediately after CCN and no net change over the whole study period.

## Complex care

### Bed days

- In Site A1, prior to the introduction of CCN in February 2008 there was a significant annual rise in the number of bed days per 100,000 per month ( $p = 0.052$ ) for children with complex conditions. In Site A2 the trends were similar but with a smaller, non-significant, annual rise. In Site A1 there was a fall immediately after the introduction of CCN but this was not statistically significant ( $p = 0.624$ ), and this was mirrored in Site A2. In Site A1, there was a statistically significant difference between pre-intervention and post-intervention slope, with a decrease of 1.022 per month post CCN. There was no statistically significant change in Site A2; indeed following the introduction of CCN there was an increase.
- Site B showed no statistically significant changes. Similar trends were observed to those in Sites A1 and A2, however, with an increase in LOS pre-CCN, a slight fall immediately after CCN, and lower LOS post CCN than was predicted with the regression without CCN.
- Site D was analysed only on the rate of admissions per 100,000 for children with Group G conditions. The analysis revealed a statistically significant change in slope, with lower admission rates than would have been predicted without CCN. This was mainly due to a fall in the admission rate in 2011, three years after the intervention date. It is not clear whether or not this reflects some discontinuity in the data or a real effect.

## Summary

The ITS approach has several advantages. The approach is easy to do and provides powerful, easy-to-understand results. ITS controls for secular trends in the data and therefore reduces bias that might be present in a simple 2-time-period model (that is, simple pre–post measurement and analysis). ITS does not require adjustment for individual-level characteristics.<sup>63</sup>

There are important threats to validity in ITS analyses. The most serious of these is history,<sup>60</sup> thus our ITS analysis is only valid to the extent that the introduction of CCN was the only thing that changed in the selected sites. Other changes that could have affected the outcome variable are commonly referred to as competing interventions. Some of these were outlined in Chapter 2 and we will return to them in Chapter 8.

Another threat to validity in ITS is changes in instrumentation or the ability to measure the outcome of interest. In this study, data prior to April 2006 was excluded due to the introduction of payments at this point associated with hospital admissions. For the complex conditions, suppression of the HES data was required where there were fewer than six admissions in a particular month. The effect of this may be to the rate of admissions or increase the number of bed days, due to a smaller base size.

Selection bias is another threat to validity, particularly if the composition of the intervention group changes at the same time as the policy/program me.<sup>60</sup> However, the composition of the population under study did not change across the pre- and post CCN periods.

Although ITS has many strengths, there are important statistical limitations to be aware of. First, estimating the level and slope parameters requires a minimum of eight observations before and after the policy/program implementation in order to have sufficient power to estimate the regression coefficients.<sup>59</sup> In this analysis data was extracted 24 months prior to CCN and at least 24 months post-CCN.

The regression analysis models presented in this report make full use of data available at the time of data extraction to maximise statistical power and for consistency across the analyses. Post-intervention data was collected to March 2013 (March 2014 for Site B), which is up to five years post-

intervention. The longer post-intervention data may have influenced the post-intervention slope estimates, as it may be influenced by longer term trends possibly diluting the shorter term effects. This can be seen to some extent in Site A1 (Figure 4), when the admission rate increased approximately three years post-intervention, resulting in a larger rise per month (post-intervention slope) than would have been the case if only two-year post intervention data was used. This was also seen in Site D (Figure 20) where the admission rate fell approximately three years post-intervention. The regression showed a decrease of 0.39 admissions per 100,000 per month (post-intervention slope). When re-analysing this data using only two-years post intervention data (Figure 21), the regression showed an increase of 0.05 per month in admissions per 100,000 per month (post-intervention slope). This should be taken into account when interpreting these findings.

Another limitation is the identification of a suitable control population. In some cases, it is possible to use a non-equivalent control group.<sup>60</sup> ITS may still be conducted on the intervention group; however, the strength of inference is weaker in the absence of the counterfactual outcome. In this study, the national rates were used as a comparator and two control sites were used to compare the trends found in the main analysis.

Finally, ITS cannot be used to make inferences about individual-level outcomes when the series is a set of population rates.<sup>59</sup> In our analysis, it would not be appropriate to conclude that any individual child would have a greater or lesser likelihood of an admission after implementation of the CCN and we have not done so. In order to make person-level inferences, an investigator would need to construct a time series of within-person measurements<sup>59</sup> (for example, an individual's admission rate or length of stay measured over time with an interruption demarcating an intervention intended to increase admission or length of stay).

## **Chapter 7      Exploring the costs and consequences of CCN services**

### **Key messages:**

- i.      Reductions in costs due to reductions in bed days and numbers of admissions were found, but these were outweighed by the cost of the teams. However, this analysis did not account for the wider impact the CCN teams may have had.
- ii.     An additional cost analysis using parental questionnaires, reporting NHS resource use was conducted for site A. This suggests that when a wider definition of the impact of the CCN team is considered, a cost saving may be realised. However, this result is highly uncertain given the small number of questionnaires completed.
- iii.    Questionnaire data also indicated a high level of satisfaction with the level of care provided by the CCN teams. However, there was insufficient evidence to comment on the impact of the CCN teams on health outcomes.

### **Introduction**

Chapter 6 considered the impact of the four CCN teams on the rate of admissions, number of bed days and length of stay in the populations of interest. In this chapter, we quantify the cost implications of these changes in NHS activity, contrasting them with the cost to the NHS of providing the CCN teams. This chapter also explores other elements of resource use which might be affected by the CCN teams, and the impact on health outcomes and wider social values.

The primary aim of this analysis was to use evidence collected throughout the project to assess whether the introduction of CCN teams was likely to provide value for money compared with current service provision. Evidence from both the ITS analysis and questionnaires completed by the CCN teams and parents of children being cared for was used. The primary analysis considers whether the introduction of a CCN team results in net cost

savings to the NHS, that is, the additional costs to the NHS of engaging a CCN team are outweighed by the cost saving as a result of reductions in the resource use elsewhere in the NHS. However, change in admissions is also considered in this chapter.

Initially, the chapter considers the impact of the CCN team on bed days alone, and considers how any cost saving from a reduction in bed days compared to the additional cost to the NHS of having a CCN team in place. Bed days have been selected as the primary analysis for their higher level of granularity over admissions, being able to account for changes in length of stay not just number of admissions.

As in the rest of the report, separate analyses are presented for each case site.

## **Methods**

### **Overview**

The methodological approach taken to considering the impacts on costs and consequences of the CCN team is presented in this section. The cost implications are considered in two parts throughout: the cost to the NHS of having a CCN team in place in the different sites (item 1 below), and the cost implications as a result of a change in the resource use within the NHS (item 2).

We address these topics in the following order:

1. The cost to the NHS of having a CCN team in place
2. The cost implications as a result of a change in the resource use within the NHS
  - a. The cost implications of a change in bed days
  - b. The cost implications of a change in non-elective admissions for common conditions
  - c. The cost implications from wider resource use changes
  - d. The cost implications to parents and wider society
3. The health and well-being consequences

- a. MHFI questionnaires
- b. Threshold analysis.

The primary analysis takes the perspective of the NHS and Personal Social Services (PSS), with all costs being discounted at a rate of 3.5% per annum, to ensure consistency with best evaluative practice as outlined by the National Institute for Health and Care Excellence (NICE) methods guide.<sup>66</sup> As outlined in Table 12 (Chapter 6), the CCN teams have a different set of defining caseloads, and, as such, the analytical approach needed to be tailored to each team. Table 18 below presents an overview of the types of analysis relevant to each of the sites. Note that Site C is not included here as it was included in Chapter 6 as a control site only.

**Table 18: Analyses conducted in this chapter, by site**

<b>Site</b>	<b>A1</b>	<b>A2</b>	<b>B</b>	<b>D</b>
<b>Caseload</b>	Acute, chronic, complex, palliative	Acute, chronic, complex, palliative	Complex conditions (mostly neurological)	Complex conditions (neurological only)
<b>Resource use analyses</b>				
<b>2a. The cost implications of a change in bed days (preferred analysis)</b>	Yes, analysis considering all children	Yes, analysis considering all children	Yes, analysis considering only complex conditions	No, team only targets admissions
<b>2b. The cost implications of a change in admissions</b>	Yes, analysis considering all children	Yes, analysis considering all children	No	Yes, analysis considering only complex conditions
<b>2c. The cost implications from wider resource use changes</b>	Yes, analysis considering only complex conditions	No, no data was collected for this site	No, insufficient data was collected for this site	No, insufficient data was collected for this site
<b>2d. The cost implications to parents and wider society</b>	Yes, analysis considering only complex conditions	No, no data was collected for this site	No, insufficient data was collected for this site	No, insufficient data was collected for this site

**Part 1: The cost to the NHS of having a CCN team in place**

We used a ‘bottom up’ approach to ensure differences in the CCN teams were reflected in the cost estimate.

To achieve this, each CCN team completed three questionnaires. A sample of these questionnaires can be found in Appendix 4. Multiple questionnaires were completed to account for changes in the team over the analytical period, typically as a response to changes in caseload.

This analysis utilises the staffing whole time equivalent (WTE) and estimates of the distance travelled by the CCN team to attend patients to derive an average cost of the CCN team per annum, estimated over the entire analysis period. Details of the WTE was collected for all members of the team. Distance travelled was reported as total miles travelled by the team. All fields covered the period of the past week to ensure accuracy of reporting. The estimates across the three questionnaires were averaged to provide a mean team structure per annum across the analysis period.

Additional details of the methods and unit costs applied to derive the cost of the CCN teams can be found in Appendix 3 (Methods applied in Chapter 7).

## **Part 2: The cost implications as a result of a change in resource use within the NHS**

This section considers how these observed changes from Chapter 6 can be transformed into a total cost (saved or incurred) over the analysis. The primary analysis presented focuses on bed days. This section additionally considers if the cost implications of considering change in admissions, rather than bed days, would affect any conclusions drawn from the bed day analysis. Finally, there is a limited analysis of questionnaires completed by parents of children with complex conditions cared for by the CCN teams to ascertain if meaningful conclusions can be drawn as to the impact of the CCN teams on a wider definition of resource use in the NHS and out of pocket costs to the parents themselves.

The pros and cons of the two approaches (use of the ITS analyses from Chapter 6 versus information from the parent questionnaires) are presented in Table 19 below. The table shows that each approach has strengths and weaknesses, and neither would be expected to show the full picture around resource use. While the parent questionnaire considered a much wider definition of the resource use affected by the CCN teams, the limitations in the scale and scope of the questionnaires collected has led us to present the ITS analysis as the primary source, with bed days selected for the reasons given above.



**Table 19: The pros and cons of the use of the ITS results versus the parent questionnaires**

Pros	Cons
<b>Use of the ITS analysis from Chapter 6</b>	
Data extracted from HES	Assumes (all) impact on bed days/admissions related to CCN teams
Available for each site, where relevant to caseload	Requires assumptions about nature of impact (that is, what regression structure) as discussed in Chapter 6
Consistent approach to statistical analysis presented in Chapter 6	Assumes impact of CCN team is limited to general bed day/admissions No out of pocket costs to parents
<b>Use of the parent questionnaires</b>	
Covers multiple areas of resource use	Potential errors and missing data in memory and bias of parents
Directly observes the impact of the CCN team in relevant group	Not all CCN team caseloads are necessarily complex care children
Includes out of pocket costs to parents	Not all parents and sites fully represented

In order to compare the cost of having a CCN team in place (discussed in Part 1) and the change in resource use it is necessary to convert the rates of bed days and admissions per 100,000 population reported in Chapter 6 to absolute estimates over the full analysis period. To do this the rates are adjusted by the size of the paediatric population in each of the four sites. The population sizes were drawn from the latest ONS estimates.<sup>67</sup>

### **The cost implications of a change in bed days**

As presented in Chapter 6, the introduction of a CCN team in three of the four sites (Site D excluded as the team targets only admissions) can be assessed by evaluating changes in total bed days in the affected population. Chapter 6 presented estimates of the change in total paediatric bed days as a result of the introduction of a CCN for specified periods of analysis. We then apply unit costs to the bed days that were saved, or additionally occurred. This approach allows for an estimation of the impact of the introduction of the CCN team that comes from an observed change in bed days.

This analysis uses the regression estimates presented in Chapter 6 to estimate the difference in bed days between the periods before and after introduction of the CCN teams. Uncertainty in the ITS regressions is incorporated in our model.<sup>68</sup> This approach allows the uncertainty in the underlying ITS regressions to be incorporated in the estimate of total cost.

The cost per bed day applied to the predicted change in total bed days is drawn from NHS reference costs.<sup>69</sup> These represent the average unit costs to the NHS of providing a range of secondary healthcare to NHS patients. Further details of the methods and unit costs applied to derive the cost of the CCN teams can be found in Appendix 3 (Methods applied in Chapter 7).

Once the estimated unit cost is applied to the change in bed days the estimate is adjusted to the size of the at risk population, that is, the size of the paediatric population covered by the CCN team in that site. This provides a final estimate of the total cost of a change in bed days over the analysis period.

### **The cost implications of a change in admissions**

As discussed earlier in this chapter, there are two important reasons also for considering the impact CCN teams had on admissions rather than bed days.

The approach taken to the evaluation of admissions is methodologically identical to that presented above, with unit costs being applied to the ITS analysis findings to provide an estimate of the cost implications of the CCN team over the period of interest. As with the bed days analysis, this can then be compared to the cost to the NHS of having a CCN team in place to determine the net cost effect to the NHS.

As with bed days, a different unit cost must be applied to the CCN teams with a broad caseload (Sites A1 and A2) than to those that focus solely on children with complex care needs (Sites B and D). It is also important to recall that for all sites, in contrast to the bed day analysis which considered all

bed days (elective and non-elective), the admissions analysis only considers non-elective admissions for common conditions. The unit cost per admission categories have been selected to reflect this different in analytical definition, considering only the non-elective categories.

Details of the unit costs applied to derive the cost of the CCN teams can be found in Appendix 3 (Methods applied in Chapter 7).

### **The cost implications from wider resource use changes**

The bed days and admissions analyses consider only the impact of the CCN team on single areas of NHS activity. The analysis presented in this subsection considers a wider range of NHS interactions.

Questionnaires about resource use were administered by the researcher to all recruited parents following interview. For those taking part in two interviews six months apart, two questionnaires were administered - one at each interview. The first questionnaire (Time 1) asked about resource use in the six months prior to referral to the CCN team (that is, 'before') and the second (Time 2) about resource use in the preceding six months since the first interview. For those taking part in just one interview (the established team users – see Chapter 5), one resource use questionnaire was administered about resource use in the preceding six months. The full questionnaire can be seen in Appendix 4 (parent cost questionnaire(s)). A total of 32 questionnaires were completed. Table 20 provides a breakdown of questionnaire completion.

**Table 20: Breakdown of questionnaire completion**

Family Resource Use Questionnaires			
Site	Time 1 questionnaire completed only	Time 2 questionnaire completed only (Established users – single data collection point)	Time 1 and 2 questionnaires completed
<b>A</b>	3 <sup>a</sup>	12	2
<b>B</b>	0	4	5
<b>D</b>	1 <sup>b</sup>	4	1
<b>Total</b>	4	20	8

<sup>a</sup> In two cases, the participant withdrew from the study at round 2 and so no Time 2 questionnaire was completed. In one case the Time 2 cost questionnaire was not administered for ethical reasons that we cannot disclose for confidentiality purposes. Thus, despite two interviews, only a Time 1 questionnaire for the six months prior to referral was completed.

<sup>b</sup> In this case, the participant withdrew from the study at round 2 and so no Time 2 questionnaire was completed.

Unit costs can be applied to all of the categories of NHS interactions reported. This approach allows for a difference-in-difference analysis by comparing the level of NHS activity before allocation to the CCN team and after, when the CCN team is providing care for the child. Questionnaires were collected from parents in Sites A1, B and D, as A2 did not take part in this part of the study.

Details of the assumptions, methods and unit costs applied to derive the cost of the CCN teams can be found in Appendix 3 (Methods applied in Chapter 7).

The change in cost across the two periods is then averaged across the sample population for each site to give the expected change in per child cost to the NHS (not including the cost of the CCN team itself) as a result of the introduction of a CCN team in that area. This expected cost is then multiplied by the number of complex care children the CCN team has in its caseload to give a total cost impact of the CCN team on wider NHS interactions in that area.

### **The cost implications to parents and wider society**

The questionnaires completed by parents of children with complex care needs also included questions considering the direct costs to the parents of caring for the child. This covered any specific costs incurred to, for example, adapt their home or buy specialist equipment, and the loss of time of paid employment to care for their child. The questions were included in both the Time 1 and 2 questionnaires to consider the impact of allocation to a team on the wider costs to society. While these costs will represent only one part of the wider social cost, both to the wider set of carers of the children and other public bodies, such as education, and none of the consequences, they will arguably represent the largest area of direct cost influenced by a CCN team and the most readily quantified.

### **Bringing the costs together**

The two elements of the cost estimation - the cost to the NHS of having a CCN team in place in each site, and the cost implications resulting from a change in resource use within the NHS - are brought together through an economic model. The model considers the monthly costs for both parts (and across the different approaches) for the full period of analysis, where the period of analysis was defined in Chapter 6. The costs are all discounted at a rate of 3.5% per year to ensure consistency with best evaluative practice as outlined by the National Institute for Health and Care Excellence (NICE) methods guide.<sup>66</sup> Results are reported as a per annum basis, averaged across the analytical period to allow for clear interpretation.

The uncertainty present within all of the costing estimates, drawn from the range of Monte Carlo simulations reported above, is estimated through probabilistic sensitivity analysis (PSA).<sup>68</sup> This uncertainty is expressed for each combination of cost scenarios as a probability that the net impact of

the CCN team is cost saving to the NHS, that is, the probability that the cost of having a CCN team in place is outweighed by the cost saving from reduced NHS interactions.

The different approaches to estimating the cost implications as a result of a change in the resource use within the NHS (part 2 above) are combined with the direct cost of the CCN team (part 1) in a number of scenarios. As noted above, not all scenarios are relevant to all sites due to different caseloads and levels of engagement in this project. The scenarios constructed are:

- Preferred analysis: the cost of the CCN team coupled with bed days
- Scenario 1: the cost of the CCN team coupled with admissions
- Scenario 2: the cost of the CCN team coupled with parent questionnaires on NHS interaction
- Scenario 3: the cost of the CCN team coupled with parent questionnaires on NHS interaction and costs to the parents.

### **Part 3: The health and well-being consequences**

An important additional consideration, beyond the net cost of the CCN team to the NHS, is the impact of the team on the health and well-being of the children being cared for and their parents. To consider the impact of the CCN teams on these factors two approaches are considered: firstly the use of a series of questionnaires conducted during the evaluation, and secondly a threshold type analysis considering the impact the CCN teams would have to have on population health to be considered a cost-effective allocation of NHS resources.

#### **Medical Home Family Index (MHFI) questionnaires**

An additional set of questionnaires was completed by parents, representing an adapted version of the MHFI, which sought to capture families' experience of using services for children with special health care needs (see Appendix 4g).

These questionnaires were completed at the first and second interviews with the research team. The MHFI questionnaires were completed based on current levels of satisfaction rather than the preceding six month period. As allocation to a CCN team had already occurred it is not possible to do a before and after analysis. Therefore the results must be carefully interpreted, as will be discussed further below.

The full questionnaire gives us a good understanding of the level of satisfaction felt by the parents towards the CCN team, and allows a detailed audit of what is driving this level of satisfaction. However, this chapter will focus on the final question of the MHFI (see Appendix 4g) which asks how satisfied parents are with the care provided by the CCN team, on a scale of 1 to 5. The results of this question are averaged across all responses in that site for the questionnaires completed at interview one and two. This allows not only an estimation of the level of satisfaction but also an estimation of how this has changed over the period of analysis.

### **Threshold analysis**

An alternative method to the evaluation of the impact of the CCN teams on wider health and well-being is to conduct a threshold analysis of the scale of impact the CCN teams would have to have on population health to be considered a cost-effective allocation of NHS resources. This analysis considers the total number of quality adjusted life years (QALYs) that would have to be gained as a result of the CCN team for the total costs (estimated from parts 1 and 2) to be worthwhile. The analysis uses a NICE style approach, which considers any new intervention which results in a cost per additional QALY gained of less than £20,000 to be cost-effective. A hypothetical QALY gain per child cared for by the CCN team will be estimated.

### **Results**

As in the ITS analysis, the results of the analyses are presented separately for each of the sites.

## **Site A1**

The wide scope of the CCN team, reflected in their relatively broad caseload, coupled with the engagement of the site in the questionnaires, allows for results to be presented across all four of the cost scenarios, in addition to both evaluative investigations of the health and well-being consequences of the CCN team in that area.

### **The cost to the NHS of having a CCN team in place**

The results of the questionnaires completed by the Site A1 team are reported in Table S21 in Supplementary document. The estimated total annual cost to the NHS of the team over the analysis period is £1,224,269, with most of this cost being made up of the cost of the band 5 and 6 community nurses. As noted previously, it is the discounted value (£1,111,049) that is used in the evaluative model, as this value calculates the net present value of all future costs over the analytical period.

### **The cost implications of a change in bed days**

Over the analysis period (April 2008 to March 2013) an estimated 9,634 bed days were saved in Site A1 as a result of the CCN team, at an estimated cost per bed day of £330 each as reported in the Methods section. This gives an estimated undiscounted total cost saved of £3,179,220 across the analysis period (59 months). Therefore the annual estimated cost saving is £646,628. When discounting and uncertainty are incorporated into this estimate the annual estimate cost saving here becomes £578,272: this is the value that will be used in the combined analysis reported below.

### **The cost implications of a change in admissions**

Over the analysis period an estimated 154 admissions were saved in the full population at an average cost per admission of £2,020. This gives an estimated, undiscounted total cost saved of £311,080 over the full analysis period, and an annual cost saving of £63,271. When discounting and uncertainty are included the annual cost saving is £99,116.



### **The cost implications from wider resource use changes**

In total, 19 NHS resource use questionnaires were completed by parents in Site A1, five covering the period before allocation to a CCN team and 14 after. Table S22 in Supplementary document reports the results of the analysis of the questionnaires, considering the cost implications to the NHS.

On average the children with complex conditions cost the NHS £9,160 more in the six months before allocation to the CCN team than the six months after. When adjusted for the number of children with complex care needs on Site A1's caseload (140) this gives a total annual cost saving of £2,564,800 (£2,278,287 when discounted over the full analysis period). However, it is important to highlight the very low number of questionnaires completed and the very high level of variation in resource use within the sample.

### **The cost implications to parents and wider society**

Finally, the resource use questionnaires completed were also used to inform an estimate of the impact of allocation to a CCN team on out of pocket costs (direct costs and lost employment) to the parents. Table S23 in Supplementary document reports the results of this analysis.

On average, allocation to a CCN team resulted in parents being £585 better off. As with the resource use questionnaires, these data were highly variable. Adjusting this cost reduction by the size of the population in this site suggests that, on average, each year parents covered by the Site A1 team save a total of £163,800 of out of pocket costs (£197,466 when discounting and uncertainty is included).

### **Total cost implications**

Table 21 below reports both parts of the cost analysis across the primary analysis and the three additional analyses. All costs are presented as an average cost across the full analysis period for Site A1 (59 months) taking into account all uncertainty. As such, the costs presented in the table may differ from the direct calculations made earlier in this section. In addition, the table presents estimates of the probability of the CCN team being cost saving given each of the scenarios in isolation. This provides a representation of the level of uncertainty underlying the mean estimates provided above and in Table 21.

**Table 21: Combined cost analyses across all scenarios, Site A1**

<b>Evaluative scenario</b>	<b>Direct cost of the CCN team</b>	<b>Cost saving (NHS/parents)</b>	<b>Expected total cost saving</b>	<b>Probability team being cost saving</b>
<b>Preferred analysis – bed days (points 1 and 2a)</b>	£1,111,049	£578,272	-£532,777	26%
<b>Scenario 1 – admissions (points 1 and 2b)</b>	£1,111,049	£99,116	-£1,011,933	9%
<b>Scenario 2 – parent questionnaires (points 1 and 2c)</b>	£1,111,049	£2,278,287	£1,167,236	49%
<b>Scenario 3 – parent questionnaires (points 1 and 2c and 2d)</b>	£1,111,049	£2,475,752	£1,364,702	53%

The table shows a number of important findings for Site A1. Firstly, there is a very large level of uncertainty in the estimates of annual cost saving, with estimates ranging from £99,115 to £2,475,752. This variation is indicative of the failure of a single measure such as admissions to demonstrate the full impact of the CCN team, as well as the significant limitations in the data available to demonstrate the impact of the teams, both from HES and the questionnaires. Secondly, while the results of Scenario 2 and 3 may initially appear the most appealing and representative of the full impact of the CCN team, the high expected annual total cost saving is not reflected in a high probability of the teams being cost saving (shown in the final column). This is as a direct result of the very large level of variation and small sample size in the parent completed questionnaires used to inform these scenarios. Figure 22 below gives a graphical representation of this uncertainty in Scenario 2. Each point in the figure represents a single realisation of the uncertainty from the 1,000 draws from the Monte Carlo simulations, that is, given the uncertainty in the data each point is a realisation of what the true cost results could be. While many of these observations represent extreme cases, it highlights the important limitation in Scenarios 2 and 3 and indicates why we chose to use the ITS analyses from Chapter 6 as the preferred analysis rather than the broader, but hugely uncertain, parent questionnaires.

**Figure 22: Graphical representation of the uncertainty in Scenario 2, Site A1**



### **The health and well-being consequences**

MHFI questionnaires were completed by a number of parents covered by the Site A1 team. The results of the satisfaction score provided by the parents are provided in Table S24 in Supplementary document, where the satisfaction score was on a scale of 1 to 5.

The results show that the level of satisfaction among the patents who completed the questionnaire is high, with a relatively low level of variation (as shown by the standard deviations).

In addition, the results for the cost analysis can be used to conduct a threshold analysis on the required impact of the CCN teams on population health (measured by QALYs) for the service to be considered cost-effective under typical health technology assessment assumptions. For this exploratory analysis we use only the primary costs analysis (that is, bed days saved) and assume that significant health gains are made only in the 140 children with

complex care needs on the caseload. We use a cost-effectiveness threshold of £30,000 per QALY, the higher threshold at which NICE considers new treatments to be cost-effective. Finally, we assume that all of the gains made in population health come from improvements in health related quality of life (the Q in QALY), and none in improvements in mortality.

The primary cost analysis suggested that the CCN team had a net cost impact on the NHS of £532,777 per annum. From this we can estimate the required number of QALYs that would have to be saved each year in the population of children with complex care. This is the net cost to the NHS divided by the threshold value, (that is, £532,777/£30,000), and equals as 17.76 QALYs. Given the 140 complex care children on the team's caseload, this gives a required QALY saved per year per child of 0.13.

## **Site A2**

While the Site A2 CCN team has a broad caseload matching Site A1 they did not participate in the parent questionnaire section of this project. Therefore, the cost analysis of this team is limited to the preferred analysis and scenario 1.

### **The cost to the NHS of having a CCN team in place**

The results of the questionnaires completed by the team are reported in Table S25 in Supplementary document. The estimated total annual cost to the NHS of the team over the analysis period is £816,496, with most of this cost being made up by the band 6 community nurses. Miles travelled were completed for only one of the questionnaires; this was assumed to be unchanged across the remaining two questionnaires.

As noted previously it is the discounted value (£698,042) that is used in the evaluative model, as this value calculates the net present value of all future costs over the analytical period.

### **The cost implications of a change in bed days**

Over the analysis period (February 2008 to March 2013) an estimated 8,969 bed days were saved as a result of the CCN team, at an estimated cost per bed day of £330 each as reported in the Methods section. This gives an estimated undiscounted total cost saved of £2,959,879 across the analysis period (61 months). Therefore the annual estimated cost saving is £582,653. When discounting and uncertainty are incorporated into this estimate the annual estimated cost saving here becomes £501,030; this is the value that will be used in the combined analysis reported below.

### **The cost implications of a change in admissions**

Over the analysis period an estimated 1,273 more admissions occurred across the population, at an average cost per admission of £2,020 (that is, after the CCN team was introduced admissions increased). This gives an estimated, undiscounted total additional cost of £2,571,460 over the full analysis period, and an annual additional cost of £506,192. When discounting and uncertainty are included the annual additional cost is £356,603. Note that incorporating discounting into the estimate of additional cost here has a relatively large effect due to the largest number of additional admissions occurring at the end of the analysis period in this case.

The increase in admissions seen, in contrast to the fall in total bed days, again shows the failings of admissions to show the same level of effect as bed days, the more granular measure.

### **Total cost implications**

Table 22 below reports both parts of the cost analysis across the primary analysis and the additional analysis. All costs are presented as average costs across the full analysis period of 61 months taking into account all uncertainty. As such, the costs presented in the table may differ from the direct calculations made earlier in this section. In addition, the table presents estimates of the probability of the CCN team being cost saving, given each of the scenarios in isolation. This provides a representation of the level of uncertainty underlying the mean estimates provided above and in Table 22.

### **Table 22: Combined cost analyses across all scenarios: Site A2**

<b>Evaluative scenario</b>	<b>Direct cost of the CCN team</b>	<b>Cost saving (NHS)</b>	<b>Expected total cost saving</b>	<b>Probability team being cost saving</b>
<b>Preferred analysis – bed days (points 1 and 2a)</b>	£698,042	£501,030	-£197,012	35%
<b>Scenario 1 – admissions (points 1 and 2b)</b>	£698,042	-£356,603	-£1,054,646	9%

The table shows a number of important findings. First, as the bed days and admissions scenarios present different directions of effect of the CCN team (the former showing a reduction in bed days, the latter showing an increase in admissions), the cost savings also have different signs. As a result the overall findings of the two scenarios are very different, with a total annual expected cost difference of £857,633. While these two scenarios are clearly not directly comparable, due to the lack of sensitivity of admissions to show the full impact of the CCN teams, they highlight the challenges of analysis. As expected, the probability of the CCN teams being associated with a cost saving to the NHS is low (9%), while the preferred bed day analysis finds that in 35% of the Monte Carlo draws the team is cost saving.

### **The health and well-being consequences**

The analysis of the health and well-being consequences of the Site A2 CCN team is much more limited as this site did not take part in the MHFI questionnaires completed by the parents. As such it is not possible to comment on the change in levels of satisfaction with the care provided by the team over the period.

As with Site A1, we can comment on the required annual gains in QALYs for the CCN team to be cost-effective under traditional cost-effectiveness thresholds. This approach gives a required QALYs per year of 6.57 across the population. Unfortunately, without the questionnaires we do not have an estimate of the number of children with complex conditions on the team's caseload.



## **Site B**

As noted in Table 18, the Site B CCN team has a more restrictive caseload than Sites A1 and A2, covering only children with complex conditions (mostly neurological). As a result, and as discussed earlier in this chapter, the analysis conducted is limited, to the preferred analysis (bed days) considering only bed days related to complex conditions. While Site B did return a number of parent questionnaires (detailed further below) these were too few to conduct the full cost analysis.

### **The cost to the NHS of having a CCN team in place**

The results of the questionnaires completed by the Site B team are reported in Table S26 in Supplementary document. The estimated total annual cost to the NHS of the team over the analysis period is £986,419, with most of this cost being made up by the band 3 clinical support workers, the number of whom increased significantly over the analysis period as the caseloads increased. As noted previously, it is the discounted value (£865,120) that is used in the evaluative model, as this value calculates the net present value of all future costs over the analytical period.

### **The cost implications of a change in bed days**

Over the analysis period (October 2011 to April 2014) an estimated additional 3,634 bed days for children with complex conditions occurred in Site B following the expansion of the CCN team, at an estimated cost per bed day of £417 each as reported in the Methods section (this is the cost per bed day for a complex case). This gives an estimated undiscounted total additional cost of £1,515,378 across the analysis period (30 months). Therefore the annual estimated additional cost is £606,151. When discounting and uncertainty are incorporated into this estimate the annual estimate additional cost here becomes £539,817, this is the value that will be used in the combined analysis reported below.

### **The cost implications from wider resource use changes**

In total, 10 NHS resource use questionnaires were completed by parents in, five covering the period before allocation to a CCN team and five after. Table S27 in Supplementary document reports the results of the analysis of the questionnaires, considering the cost implications to the NHS.



On average, the children with complex conditions cost the NHS £42,028 more in the six months before allocation to the CCN team than the six months after. However, the very low number of questionnaires completed, coupled with the large variation in the sampled population, is highly likely to violate the assumptions outlined in the Methods section as necessary to extrapolate these findings out to the full caseload of the CCN team. As it would be misleading to use these findings to conduct the full costing analysis, in the light of such uncertainty, no further results are presented for this cost scenario.

### **The cost implications to parents and wider society**

Finally, the resource use questionnaires completed were used to inform an estimate of the impact of allocation to a CCN team on out of pocket costs (direct costs and lost employment) to the parents. Table S28 in Supplementary document reports the results of this analysis.

On average, allocation to a CCN team resulted in parents being £1,267 better off. However, as with the results from these questionnaires outlined in the previous section, it was decided that the assumptions necessary to extrapolate these values to the full population would not hold, and no further analysis was conducted.

### **Total cost implications**

Due to the complex care specific nature of the Site B CCN team and the limited number of questionnaires returned by parents, only the preferred cost analysis was possible. These results are outlined in Table 23 below. All costs are presented as average costs across the full analysis period for Site B (20 months) taking into account all uncertainty. As such, the costs presented in the table may differ from the direct calculations made earlier in this section. In addition, the table presents estimates of the probability of the CCN team being cost saving given each of the scenarios in isolation. This provides a representation of the level of uncertainty underlying the mean estimates provided above and in Table 23.

**Table 23: Combined cost analyses across all scenarios: Site B**

<b>Evaluative scenario</b>	<b>Direct cost of the CCN team</b>	<b>Cost saving (NHS)</b>	<b>Expected total cost saving</b>	<b>Probability team being cost saving</b>
<b>Preferred analysis – bed days (points 1 and 2a)</b>	£865,120	-£539,817	-£1,404,937	4%

The table shows that the direct cost of the CCN team as well as the negative cost saving (driven by an increase in bed days after the initiation of the CCN team) combine to give an expected total cost to the NHS of £1,404,937 per year. This is associated with a very low probability of being cost saving of four per cent.

While it has not been possible to use any other sources of data to improve this cost estimate, it is likely that there may be a significant cost saving coming from the wider set of NHS interactions. This issue is covered further in the discussion section of this chapter.

### **The health and well-being consequences**

A number of parents completed MHFI questionnaires considering their level of satisfaction with the level of care provided by the CCN teams. The results of these are presented in Table S29 in Supplementary document.

As with the cost questionnaires, the small number of completed questionnaires necessitates careful interpretation and extrapolation of these results. However, Table S29 gives a slightly different picture than was seen in Site A1 (and in Site D presented next), with mean satisfaction a little lower on average and falling between the interviews. There is also a slightly larger level of spread (shown by the standard deviation) than in the other sites. This result does not suggest a lower level of care being provided by the Site B team and care must be taken in comparing the sites in this way.

Second, a threshold analysis of the gains in QALYs needed for the team to be cost-effective at the given level of cost was conducted. This analysis gives a required QALY gain of 0.24 per child per year across the 195 children with complex care needs on the Site B caseload.

## **Site D**

As noted in Table 18 the Site D CCN team had a more restrictive caseload than Sites A1, A2 and B, covering only children with complex neurological conditions. As a result, and as discussed earlier in this chapter, the analyses conducted are limited. Specifically the analysis is limited to Scenario 1, considering only admissions related to complex conditions. While Site D did return a number of parent questionnaires (detailed further below), as with Site B, these were deemed too few to conduct the full cost analysis.

### **The cost to the NHS of having a CCN team in place**

The results of the questionnaires completed by the Site D team are reported in Table S30 in Supplementary document. The estimated total annual cost to the NHS of the team over the analysis period is £250,135, made up only of three band 8 nurses and the distance they travelled. It is the discounted value (£229,727) that is used in the evaluative model, as this value calculates the net present value of all future costs over the analytical period.

### **The cost implications of a change in admissions**

Over the analysis period an estimated 836 admissions of children with complex conditions were saved across the population, at an average cost per admission of £1,471 (this is the admission cost for complex conditions). This gives an estimated, undiscounted total cost saved of £1,229,756 over the full analysis period, and an annual cost saved of £250,120. When discounting and uncertainty are included the annual cost saved is £215,954.

### **The cost implications from wider resource use changes**

In total, five NHS resource use questionnaires were completed by parents, two covering the period before allocation to a CCN team and three after. Table S31 in Supplementary document reports the results of the analysis of the questionnaires, considering the cost implications to the NHS.

On average, the children with complex conditions in Site D cost the NHS £5,981 less in the six months before allocation to the CCN team than the six months after. However, as with the Site B questionnaires it would be misleading to use these findings to conduct the full costing analysis. In addition to

the low numbers of questionnaires, the result is largely driven by a single child having an estimated post allocation cost of £65,111 due to extremely high use of the NHS over the period covered by the questionnaire. As such no further results are presented for this cost scenario.

### **The cost implications to parents and wider society**

Finally, the resource use questionnaires completed were used to inform an estimate of the impact of allocation to a CCN team on out of pocket costs (direct costs and lost employment) to the parents. Table S32 in Supplementary document report the results of this analysis.

On average, allocation to a CCN team resulted in parents being £2,500 better off. However, as with the results from these questionnaires outlined in the previous section, it was decided that the assumptions necessary to extrapolate these values to the full population would not hold, and no further analysis was conducted.

### **Total cost implications**

Due to the complex care specific nature of the Site D CCN team and the limited number of questionnaires returned by parents only the scenario 1 cost analysis was possible. These results are outlined in Table 24 below. All costs are presented as an average across the full analysis period (59 months) taking into account all uncertainty. As such, the costs presented in the table may differ from the direct calculations made earlier in this section. In addition, the table presents estimates of the probability of the CCN team being cost saving given each of the scenarios in isolation. This provides a representation of the level of uncertainty underlying the mean estimates provided above and in Table 24.

**Table 24: Combined cost analyses across all scenarios: Site D**

<b>Evaluative scenario</b>	<b>Direct cost of the CCN team</b>	<b>Cost saving (NHS)</b>	<b>Expected total cost saving</b>	<b>Probability team being cost saving</b>

<b>Scenario 1 – admissions (points 1 and 2b)</b>	£229,727	£215,954	-£13,772	38%
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The table shows that the expected net cost to the NHS of the team is relatively small (£13,772) per year, with a correspondingly high probability of being cost saving of 38%.

### **The health and well-being consequences**

As with Site B, only a small number of parents completed MHFI questionnaires about their level of satisfaction with the level of care provided by the CCN teams. The results of these are presented in Table S33 in Supplementary document.

As with the cost questionnaires, the small number of completed questionnaires necessitates careful interpretation and extrapolation of these results. However, a high level of satisfaction was reported with the level of care provided. This level was maintained over time and associated with a small level of variability.

Second, a threshold analysis of the gains in QALYs needed for the team to be cost-effective at the given level of cost was conducted. Using the scenario 1 analysis (admissions) a required QALY gain of 0.008 per child per year across the children with complex care needs was calculated.

### **Summary**

This chapter has shown that, given estimates of the direct cost of the CCN teams and the ITS analyses presented in Chapter 6, we would not expect the introduction of a CCN team in any of these sites to be associated with a cost saving. All of the primary analyses (considering the bed day impact) and scenario 1 analyses (considering admissions), showed that the reduction in costs due to reductions in bed days and numbers of admissions (with the

exception of admissions in A2 and bed days in Site B which increased after the CCN team were introduced) were outweighed by the cost of the teams. However, limited information about the wider impact of the CCN teams' introduction on factors such as the rate of bed closure or impact on the wider health community affects the robustness of this finding.

In addition to the use of the ITS results from Chapter 6, this chapter also utilised data from a number of parental questionnaires considering the level of NHS resource use by their children (all with complex care needs), in an attempt to incorporate the changes to wider NHS resource use. A full analysis of these questionnaires was completed only for Site A1 (due to Site A2 not participating and small numbers of responses from the other sites). The analysis conducted for Site A1 (scenarios that included cost implications from wider resource use changes, and to parents and wider society) suggested that the CCN team might have had a net cost saving effect to the NHS over the analysis period (with an expected annual cost saving of £1,167,236). However, this result was found to be highly uncertain, given the small and variable nature of the questionnaires completed.

Finally, of a limited number of MHFI questionnaires completed by parents across three of the sites (excluding Site A2) a series of threshold analyses were used to consider the observed level of satisfaction with the care provided and the estimated per patient QALY changes needed for the CCN teams to be considered cost-effective. The MHFI questionnaires suggested an overall high level of satisfaction with the level of care, which remained high throughout the analysis period for Sites A1 and D, but not for Site B. The threshold analyses found the required QALY gains per complex care child per year required varied from 0.008 in Site D to 0.24 in Site B. As with the cost analysis this does not, however, suggest the Site D team is the most effective and Site B the least, and should be considered on a site specific basis.

## **Chapter 8      Discussion and synthesis of findings**

This project was a quasi-experimental evaluation, involving both quantitative and qualitative data, which addressed the following research questions:

1. Does redesigning children's health care services and introducing children's community nursing (CCN) teams affect acute hospital admission rates for common childhood illnesses and length of stay for all conditions?
2. What changes in the quality of care do families caring for children with complex health care needs experience when CCN teams are introduced?
3. What benefits and challenges do commissioners and providers experience, as the new services are planned, implemented and established?
4. What are the costs and outcomes of the new services compared to those achieved by alternative service configurations?

In this chapter we bring together the findings from the mixed methods, case study design we used to address these questions, first on a case-by-case basis, and then across the cases (sites). This allows us, first, to address the research questions and to explore any links between processes and outcomes in the individual sites. We then explore whether there are any common links between the sites and, in doing this, link our findings into the existing literature on organisational change.

First, however, we outline the strengths and limitations of our work.

### **Strengths and limitations**

#### **The study as a whole**

The main strength of our work is its contribution to a very small evidence base on the key policy imperative of delivering care 'closer to home'.

Transforming Community Services<sup>4</sup> encouraged commissioners 'to develop services so that children with support from family members can choose to



be cared for at home at all stages of their illness or disability' (p.13) and suggested that this would deliver 'high impact' change. Community health services in general and those for children in particular are under-researched; the substantial challenges that Transforming Community Services outlined reflect this.

Our work constitutes the first formal evaluation of CCN services using quasi-experimental methods and has generated new knowledge about impact, quality, outcomes, activity and achievements in CCN services. It was also innovative in its design, using a formal quasi-experimental design with embedded longitudinal qualitative elements, allowing it to explore which changes work, for whom, and in what contexts.

As predicted in our proposal, our work took place during a period of radical change in health service commissioning and delivery. Because of this, we included an element in the project to explore how new commissioning arrangements affected service redesign that was already happening and that which was planned. This has given us insight into the challenges faced by those attempting to bring about 'high impact' change in community services and to maintain the impact of those already introduced, at a time of restructuring at higher levels in the organisation.

A further strength of our work was the regular input provided by our project advisory group. This allowed us to ground our work in the realities of the NHS context. For example, they provided helpful insight into how HES data are coded in day-to-day practice, as well as guiding us in our choice of disease groups and variable splits for the ITS analysis.

The main limitations of our work mirror, to some degree, its strengths. Before submitting our proposal we had identified three areas of the country that had already introduced CCN services (Sites A1 and A2) or were well on with planning their introduction or development (Sites B and C). By the end of the project, one Site (C) had abandoned its plans altogether, despite the considerable time, effort and resources that had already gone into planning, and another (B) had not implemented the acute admission avoidance service that would have partnered its CCN services for children with complex conditions. As a result we had to recruit a new site (D) that had implemented a service some time previously, and could carry out only a more restricted range of analyses on Sites B, C and D. These changes allowed us the insight into the challenges of developing community health services that we

outlined above, and we adapted our research plans to reflect the changes. However, only in Site A1 were we able to carry out all the work and analyses that we had originally planned.

Given this limitation, future researchers might consider only evaluating services that are already contracted, rather than those that are still in development. However, this may make it more difficult for researchers to respond to the timing of NIHR commissioned calls for research. Researchers cannot control the fact that the NHS environment in which services are developed changes frequently but can develop research strategies to help deal with such change. For example, we added a supplementary research question about the impact of changing commissioning arrangements and this proved helpful in understanding service development.

### **The qualitative elements**

As described in Chapter 5, we struggled to recruit newly referred parents to our study. On reflection, this was perhaps an ambitious approach, both because it is a small population from which to draw and also because of the challenges parents face during this difficult period soon after onset or diagnosis. As a result, we were unable to carry out the longitudinal element to the full extent we intended. Instead, we also drew upon established users, of which there were far more who were ready and able to participate, and carried out a single point of data collection to examine their experience of care and change retrospectively. This amendment to the longitudinal approach is a limitation, but was necessary in order to generate sufficient qualitative material to allow meaningful analysis of the data. We thus undertook a ‘true’ longitudinal analysis on two data collection points with just under half of the sample, but were still able to draw meaningful accounts of change from those where we undertook one retrospective interview.

A strength of the study was the process evaluation of how the services were planned and implemented. We were able to build a detailed picture illuminating the complexity of this process for some, and the relative simplicity of it for others. Although we experienced attrition in some staff taking part, we were still able to attain sufficient information about service change.

As noted earlier, we were unable to undertake observations as planned. This presents a further, although minor, limitation to the qualitative work. Had we been successful in undertaking these observations, this may have added a descriptive layer to our understanding of the process of developing CCN services.

### **Interrupted time series analysis of impact on acute hospital activity**

The statistical strengths and limitations of the ITS analysis as an approach in quasi-experimental evaluation are discussed in detail in Chapter 7. Here we discuss the more general issues related to the use of HES data for our work.

The main strengths of HES data are both their specificity and their potential universality. The data are gathered at a local level and therefore should provide a clear log of local activity in hospital settings that would be difficult to generate cost-effectively in any other way. At the same time, because data collection uses the same framework in all service sites, the data can be aggregated to provide national pictures of activity. This allowed us to see how our chosen case sites differed from or were similar to what was going on in England as a whole over the periods we selected for analysis. In both local and national applications, the long-running nature of the data collection opens up opportunities for longitudinal analysis and therefore, potentially, the ability to track change in activity alongside change in policy and practice.

In reality, however, our experience was that HES data needed to be used and interpreted with care. First, we found unexpected discontinuities in runs of data. In some cases we could propose credible explanations for these (for example, the introduction of payment by results) and take this into account by analysing only data from after the introduction of this change. In other cases we struggled to identify possible causes (for example, the spikes in acute activity in Site D, see p.104) and therefore needed to interpret the data cautiously. Secondly, the smaller the group in question, the more cautious we need to be. HES use requires suppression of data when numbers are small, and small numbers, by definition, introduce added uncertainty into results. This was particularly the case for Site D where the analysis was based on a single disease category group. Thirdly, service commissioners and managers interviewed in the qualitative elements of the work often told us that standards of HES data collection were not as high as they might have

wished, particularly in relation to diagnostic categories for children, whose symptoms may be more vague than in adults, making a secure diagnosis difficult, even after investigation.

Overall, however, we believe that ITS analysis of HES data of the sort we carried out is a powerful addition to the quasi-experimental tool kit in service delivery and organisational research, where fully experimental evaluation is unethical and/or impractical. However, it is important that analysis of this sort is based on a very thorough understanding both of the underlying structure of the data over time and of the quality of collection at local levels.

### **The costs and consequences study**

In this element of our work, we used the analysis of the HES data to examine the cost implications of introducing or expanding CCN services, by looking at changes in NHS activity, as measured in this instance by bed days, and wider resource use. We also looked at parents' satisfaction with CCN services. There were some inevitable limitations with this part of our work, over and above those outlined above in relation to using HES data.

The CCN teams themselves provided good information about the costs of running the teams, which we used in the health economics modelling. However, this modelling did not take into account any disinvestment in acute services, which we know happened in Site A and which might have been expected in other areas planning to move services into the community. Thus, our comparison of the costs of CCN teams with the costs of hospital activity does not consider any such disinvestment. Second, the small number of questionnaires completed by parents about resource use and the very high level of variation in the data within them limited the extent to which we could draw conclusions about cost implications for wider resource use and costs to society.

Third, because of the design of the study, resource use questionnaires were limited to parents of children with complex needs. Although these children form a core component of CCN team caseloads, they are not the only children served by generic CCN teams (for example, Sites A1 and A2).

Therefore, any conclusions made are limited to this population only. Together, these issues underline the importance of treating the conclusions of the cost study with caution.

Finally, the additional analysis utilising parental questionnaires highlights that a broader estimate of costs beyond simple measures of bed days and admissions may be required to define fully the NHS activities influenced by CCN services. However, the complex nature of the range of services provided in a hospital and community setting makes any attempt to disaggregate all interactions with the NHS into constituent parts challenging.

These challenges in constructing a robust study represent significant limitations to the cost-consequence analyses. Two main limitations of this type have been identified: reliance on provider questionnaires to inform cost of the team rather than the true cost of setting up and maintaining a team, and the use of average rather than marginal costs to represent change in bed days and admissions. First, the cost-consequence analyses utilise questionnaires completed by the providers to estimate an average cost for each site. While this approach will accurately reflect the WTE of the teams when sampled, it is potentially biased if the sampled periods do not represent a true reflection of the average. Further, this approach is likely to overlook broader costs of maintaining a CCN team and is unable to reflect potentially high, upfront costs of implementing a team. Secondly, the unit cost estimates of bed days and admissions saved as a result of the CCN teams are based on average costs estimates produced for the NHS. The use of an average, rather than a marginal, cost implies that the cost savings estimated as a result of reduced hospital activity are overestimates of the true cost. The scale of this overestimate is impossible to estimate given existing data. However, as none of the sites was found to be associated with a cost-saving, this limitation does not affect the conclusions of the analysis. Further research is needed on the marginal cost of displaced bed days and hospital admissions before a robust estimate of the cost impact of CCN teams can be assessed.

## **Site-by-site synthesis of findings**

### **Site A**

These two sites had introduced (Site A1) or expanded (Site A2) CCN services as part of a major redesign of children's services across a large health and social care community.

## Site A1

Site A1, which took part in all elements of our project, introduced a new, community-based, CCN service that met a wide range of needs from acute admission avoidance to long-term support for children with very complex needs. The team operated in an area of substantial deprivation and, before the introduction of the CCN service, had a non-elective admission rate for common childhood conditions (the ‘top 12’ on which we based our analysis) that was substantially higher than the national rate and that was growing at a much higher rate than was the case nationally.

After the introduction of the CCN service, there was a large and significant drop in non-elective admissions for common conditions, and particularly for boys aged between one and four years of age. There was also evidence of a reduction in Sunday admissions and discharges and for two specific groups of conditions – intestinal infectious diseases, and general signs and symptoms. However, this effect seemed to be diluted over time so that, two to three years after the CCN service started, non-elective admissions reached again the level that would have been expected if no service had been introduced, and then continued to rise throughout the rest of the period covered in our analysis. Over the full period of analysis, then, the health economics work estimated that 154 admissions for common conditions had been avoided, with an annual cost saving of £99,116. This contrasts with the estimated 399 admissions avoided in the first two years of operation of the team.

The changes in admission rates were reflected in bed days for all conditions. Again, this site had been operating at rates well above the national before the service was introduced, but experienced a reduction after the service started. The underlying trend of bed days fell after the service started and continued to fall throughout the period of analysis, bringing it much closer to the national average. None of these changes in bed days was large enough to reach statistical significance, but they did have cost implications. The health economics analysis estimated a saving of just under 10,000 bed days over the five years between the introduction of the CCN team and the end of our analysis period, at a potential cost saving of £578,272 per year.

Despite the very large differences from national rates in admissions and bed days, average length of stay for all conditions in Site A1 was actually close to the national average both before and after the introduction of CCN services. There was thus less potential for change. Despite this, and despite a

small rise in length of stay immediately after the service started, there was a small but sustained reduction in length of stay over time such that, at the end of the period of analysis, it was below the national average. Again, however, the changes were not large enough to reach statistical significance. Length of stay was not used in the health economics analysis.

Site A1 also met the needs of children with complex conditions and here, again, the number of bed days was substantially higher than the national average before the service was introduced. There was a large fall in bed days for children with complex conditions immediately after the CCN service started but this did not reach statistical significance. However, over time, the reduction continued and was large enough to reach statistical significance. This element of saving of NHS resources was not costed separately, however, it is likely that the cost of a bed day for a child with a complex condition is considerably higher on average for that of all children on average.

Average length of stay for children with complex conditions was close to the national average, both before the introduction of the CCN team and after. There was a small reduction in length of stay after the team was introduced which was maintained, but neither change was large enough to reach statistical significance.

The direct annual cost of the CCN team in Site A1 was calculated as £1,111,049 and, as we saw above, the cost savings to the NHS only from the reduction in bed days was calculated as £578,272 a year. This cost saving calculation did not take into account any savings generated by disinvestment in other provision, any possible impact of all the other types of work that the team did (for example, running long-term conditions clinics), or the differential cost of the significant reduction of bed days for children with complex conditions.

The qualitative work with staff highlighted some challenges around embedding and maintaining visibility of the team to primary care, and dealing with a large complex caseload. The first had been addressed through team innovations, such as creating a dedicated post for primary care liaison and a complex needs coordinator. Other challenges, such as being asked by commissioners to demonstrate impact and value, persisted somewhat, with the team wanting to find ways of measuring quality based outcomes. Qualitative work with families suggests that various aspects of the service contributed

to a positive experience, which itself was shaped by whether or not they felt supported by the team. As we saw in Chapter 5, parents' accounts suggested the team played a more intensive role to begin with, gradually decreasing input as parents become more empowered and the team's role became one of 'maintenance'. Different service features were important at different points because of this decreasing trajectory of input. Despite the tapering role of the team, assessments of quality were still high, and this seemed to be linked with the confidence parents had accrued in their earlier use of the team and the fact that they knew they could contact the team any time if needed for advice, reassurance and support.

### **Site A2**

Site A2 had a small CCN team that was developed significantly as part of the area-wide change in children's services and at the same time as the CCN team was introduced in Site A1. In contrast to Site A1, the service was based in a hospital setting, although it worked in the community and also met a wide range of needs from admission avoidance to support for children with long-term, complex needs. As explained in Chapter 1, this site did not take part in the qualitative elements of the project so we present here only findings from the ITS analysis and health economics.

The rate of admission for children with common conditions was higher than the national average before the CCN team was developed and although there was a slight fall afterwards, this was not maintained. Indeed, over the whole period of analysis, the rate increased, leading to an estimate of a higher number of admissions than would have been expected if nothing had changed. The health economics work estimated that an extra 1273 admissions for common conditions occurred over the five-year period of analysis, at an average annual increased cost of £356,603.

The number of bed days for all conditions was slightly higher than the national picture in Site A2 before the CCN team was developed, and was increasing by 10% per year. After the expanded team was introduced there was a small drop in bed days that was not statistically significant. However, this reduction was maintained over time, meaning that the rate of growth was much slower than would have been expected if the team had not been in place. The health economics work estimated that over five years, almost 9000 bed days had been saved, resulting in an overall cost saving of £501,030 per year.



As in Site A1, length of stay in Site 2 was not very different from the national average – indeed it was somewhat lower than the national average. There was a small but not significant rise in length of stay after the team was developed, but over the longer term there was no increase or reduction. Length of stay was not used in the health economics analysis.

Site A2 also supported children with complex conditions, and bed days for this group of children was close to the national average. There was a reduction in bed days immediately after the expanded team was in place and this was maintained over time, such that the rate remained below what would have been expected if no change had taken place. However, neither change was large enough to reach statistical significance. This is in some contrast to Site A1. Length of stay for these children was also close to the national average in Site A2 before the team was developed. As with bed days, there was a small reduction in length of stay after the enlarged CCN team was put into place and this reduction was maintained over time. However, neither change was large enough to reach statistical significance.

The direct annual cost of the CCN team in Site A2 was calculated as £698,042 and, as we saw above, the cost saving to the NHS from the reduction in bed days for common conditions was calculated as £501,030 a year. This cost saving calculation did not take into account any savings generated by disinvestment in other provision or any possible impact of all the other types of work that the team did, including the differential cost of the reduction in bed days for children with complex conditions. This team did, however, see an increase in acute admissions for non-elective common conditions, which could change the balance of the health economic appraisal of this model of CCN provision.

There was no qualitative work with this team, although we did gather information about the team from the commissioner and service manager, as described in Chapter 2. This information indicated that the main focus of the Site A2 team was acute admission avoidance rather than support for children with complex conditions, although it did also provide some input for these children.

## **Site B**

Site B was selected for our study because, well before we submitted our proposal, plans were being developed to introduce a CCN team that would target acute admissions and length of stay for all children. This service would complement an already existing CCN service for children with complex

needs that was also planned to expand its remit in order to meet the needs of children with continuing care packages. In the end, the acute home care team was not introduced and our work therefore focussed on the complex care team and the impact of the changes it had undergone. However, ITS analysis of admissions for common conditions, using a dummy intervention point the same as that in Site A1, allowed us to explore what happened when a planned change targeting acute activity did not actually take place. The health economics work, however, was confined to the impact of changed services on children with complex conditions.

Site B was an area of high deprivation but with only slightly higher non-elective admission rates for common conditions than the national average. Admissions were falling slightly before the dummy intervention point but rose substantially (although not statistically significantly) after and this rise was maintained over the analysis period. Significant increases were seen for children aged between one and four years, for weekend admissions, and for specific conditions – infective enteritis and colitis, circulation and respiratory signs and symptoms, and signs and symptoms of the digestive system/abdomen. These increases mirror some of the decreases seen in Site A1.

For complex conditions, the number of bed days was higher than the national average before the expansion of the CCN team, and remained so throughout the analysis period. There was a slight rise in bed days for complex conditions immediately after the expansion, and this continued throughout, meaning that bed days were at a higher level than would have been expected if no change had occurred. However, none of the changes was large enough to reach statistical significance.

The annual cost of the Site B team for children with complex conditions was £865,120, and the cost of the observed increase in bed days for children with such conditions was £606,151 per year.

The qualitative work highlighted the challenges of expanding existing teams, particularly in terms of clarity and understanding, but these appeared to be short lived for the Site B team. Thus, their expansion appeared to become embedded in a relatively short period of time. Processes for getting care packages in place were seen to have become more efficient, and as a result, were believed by the team to be enabling earlier discharges. However, due

to problems accessing patient level data, the commissioner could not confirm any reduction in length of stay. Our ITS analysis would suggest otherwise, though it is important to note that the categories of complex conditions used may reflect a wider population than that served by the team. From the perspectives of families using the complex care team, there were consistent messages that it served an important support function, but assessments of quality were closely tied to whether certain aspects of the service were adequately delivered. These included getting allocated hours of care, having a key worker, and continuity of staffing.

## Site C

We chose this site for the project because, when we wrote the proposal, it was at an advanced stage of planning for standardising and enhancing its CCN provision across a complex network of historical PCTs that had been amalgamated into a single PCT. This amalgamation had left gaps in services across the area, and created substantial geographical differences in access to CCN services. The planned changes were part of a wider strategy to reconfigure other community-based children's services. This area was very different from Sites A and B, both in terms of its rural/urban mix and its relative affluence.

Although we recruited this site at this advanced stage of planning, by the end of the project the changes had not taken place; indeed, it would be fair to say that they had been abandoned, despite the considerable investment of time and resources that had gone into planning for them. We were thus limited in which aspects of the project we could pursue in this site. We carried out the qualitative elements with service commissioners and providers and used the ITS analysis to explore what happens to acute activity when planned changes do not materialise. We did not explore any aspect of provision for children with complex conditions.

As in Site B, we used a dummy intervention point that was the same as the actual intervention point in Site A1 for the ITS analysis.

The rate of non-elective admissions for common conditions in Site C was similar to that found nationally, but there was a statistically significant month to month increase in this rate before the dummy intervention date. The analysis then showed an abrupt, though not statistically significant, reduction in rate that was sustained during the period of analysis. Further analysis of the data, including sub-group analysis, suggested that there were considerable discontinuities in the data, suggesting change in the ways in which HES data were recorded in Site C, before and after the mock intervention point. Indeed, a former commissioner in this site confirmed that coding of POAU attendances at one trust in Site C had been changed at some point to be counted as inpatient admissions. Other work elsewhere highlights this as a problem nationally.<sup>70</sup>

The number of bed days was slightly lower in Site C than the national average but was increasing slightly before the dummy intervention date. As with admissions, there was a substantial (though not significant) decrease in bed days after the dummy intervention date. This reduction was not sustained, and over the whole period of analysis, the number of bed days increased, although not to such an extent as to reach statistical significance.

Average length of stay in Site C was below the national average before the dummy intervention point and was reducing significantly, and remained below the national average throughout the period of analysis. However, after the dummy intervention point, there was an increase in average length of stay that was maintained through the period of analysis. This increase over time was statistically significant.

The longitudinal qualitative work with commissioners and managers in this site highlighted the process of attempting service change and the challenges associated this, especially when taking place in the context of organisational flux (that is, the NHS reforms). The absence of dedicated finance for the intended change required competing providers to audit, review and negotiate resources and services. This was a lengthy process, which itself was not aided by changed leadership at the commissioning level, brought about by the changes in commissioning arrangements. Thus, despite the best efforts of managers and some commissioners, who between them had extensive expertise in CCN development, other contextual factors ultimately thwarted plans to reconfigure their services as planned.

## **Site D**

As described in earlier chapters, Site D was recruited to the project at a relatively late stage, to compensate for the loss of data caused by the abandoned change in Site C. This team of paediatric nurse practitioners ran in parallel with a wider range of services in the area that delivered generic CCN care. The specific focus of the new Site D team that we researched was to complement the existing provision by supporting children with complex neurological needs who were frequent users of acute hospital care. Given the tight focus of the team, we confined our ITS and health economics analysis to children in the relevant disease group in HES (code G) and to non-elective admissions only.

Site D was an area of high deprivation and its non-elective admission rates for the group in question was higher than the national rate and growing, until half-way through our analysis period (July 2011), when the data showed a substantial reduction. Overall, while there was no immediate reduction in non-elective admissions for the G code children, there was a sustained and significant decrease across the period of analysis, bringing the rate below the national average by the end of the period.

Given the large swings in the HES data, we suspected some discontinuity in the data and therefore reran the analysis, restricting it to the two years before and two years after introduction of the team. This analysis still showed a reduction in the underlying trend of non-elective admissions but, over this shorter period and without the effect of the potential discontinuity, this trend was no longer statistically significant.

This reduction in admissions tallies with what we learnt about this site in the qualitative study; that its intention was to reduce acute admissions for children with complex neurological conditions, and that such intentions were achieved from the perspectives of the limited number of parents we interviewed in this site.

Over the whole period of analysis, the health economics work estimated a saving of 994 admissions for children with complex conditions, which translated into an estimated annual saving of £215, 954.

The estimated annual cost to the NHS of the team in Site D was £229,727 and the estimated cost saving of the reduction in bed days was £215,954. This analysis did not include any changes in bed days or length of stay.

Even though the ITS analysis suggests this area was successful in reducing acute admissions for the target group, the qualitative work with staff indicates there were still challenges being faced in practice in achieving their intended outcome. The main challenge was maintaining visibility to the acute trust since they had moved their service base into the community. This was thought to affect consultant referrals to the team.

Whilst we were able to interview only a small number of parents from this site, messages were consistent about the team helping them to assess the need for acute admission and in some cases avoid it. Overall satisfaction with the service was also high, which was linked to its ability to respond quickly and assess and prescribe in home and school, which were settings seen as more accessible than primary care and A&E; the nurses' clinical familiarity with the child; and the option for parents of contacting the team for advice when needed.

## Integration of findings

We now move on to bring together the findings across the case sites to address the four research questions posed in our proposal.

1. Does redesigning children's health care services and introducing children's community nursing (CCN) teams affect acute hospital admission rates for common childhood illnesses and length of stay for all conditions?

As explained in Chapter 8, bed days per 10,000 children is a more granular, and therefore more sensitive, indicator of impact on acute activity. Thus, although we had not originally planned to, we used bed days for the health economics work. However, one team (Site D) was specifically intended to reduce acute admissions so this remained the main outcome measure for this site.

Across the sites, we saw a mixed picture of change in all three possible indicators of activity. However, it is possible to develop a narrative that helps to bring these different patterns together and that may allow us to think about a theory of change for the introduction of CCN teams. First, in making this first step towards developing a theory of change, we draw together the evidence on acute activity for all children.

Site A1 was a large, community-based CCN team working in an area of highest deprivation and multi-ethnicity and which, before the team was introduced, had non-elective admission rates for common childhood illnesses that were substantially higher than the national average, and which were growing rapidly. The introduction of the team appeared to affect this rate immediately and continued to do so until for around three years. We do not know conclusively what caused the effect to wane, but possible factors identified during our work include later organisational change in children's urgent care in the locality, and issue with team visibility, which may have affected referral to the team. The reduction in admissions was accompanied by a reduction in bed days for all children, which had also been substantially higher than the national average before the team was in place.



Site A2 was part of the same redesign of children's services as Site A1; it was in the second to highest deprivation group but had a lower rate of multi-ethnicity than Site A1. Its non-elective admission rates were also substantially higher than the national rates and growing rapidly before the team was introduced. Unlike Site A1, however, Site A2 saw no reduction in admission rates – indeed, they increased over the study period – but did see a sustained reduction in bed days over time. What could explain these differences?

There are three factors to consider.

First, the A1 team took parent self-referrals, whilst the A2 team did not. We do not know the exact rate of self-referrals for team A1, but we were told by practitioners in this site that they tended to have a number for conditions such as chronic constipation, eczema, and asthma, where word of mouth (for example, at school playgrounds) led some parents to contact the team directly. The option of self-referral increases accessibility to the team, some of which may be replacing use of A&E. This may help to explain some of the lowered rate of admissions in this site.

Second, the A1 team was community (clinic) based, whereas the A2 team was hospital based. We wondered if this might explain these differences to some extent; given its base, did the A2 team have a predisposition to triage children to short-term admission, which might explain both the increase in admissions and the reduction in bed days in this site? The commissioner and manager in this site both said that the team's priority was admission avoidance, and they had developed referral pathways from consultants and advanced paediatric nurse practitioners in A&E to the CCN team. This would suggest no particular predisposition to triage children to short-term admission. However, if children were referred first from A&E to the POAU prior to referral to the CCN team, and if POAU attendances are coded as admissions, this could explain the increased rate of admissions and the lowered bed-days.

Third, our qualitative work with parents in Site A1 highlighted the role of the team in empowering parents to care for their child, and the role the team played in assisting with acute episodes of illness. Whilst this work focused on those with complex conditions, it is not improbable that this philosophy extended across the wider caseload of those with less complex conditions. Thus, it is possible that an empowering role helps to change help-seeking behaviours for episodes of acute illness. Not only is this something that we saw in our earlier work on CCN teams,<sup>9</sup> but past work

has repeatedly demonstrated the importance of empowerment (e.g. through provision of information, training) for parents dealing with acutely ill children.<sup>17, 28, 29, 71</sup> However, there is no evidence such parent empowerment reduces acute admissions for children with acute illness.

Without the in-depth qualitative work with practitioners, which we were unable to undertake in Site A2, we are not able to put any further flesh onto these possibilities.

We explored changes in our three indicators of acute activity in Site C and acute admissions only in Site B, both of which had been unable to implement elements of planned change. This was to provide a degree of control for our findings in Sites A1 and A2. Despite its high levels of deprivation, Site B had admission rates close to the national average at the start of the analysis period, which were falling slightly. This fall was not sustained and admissions increased over time. Site C was different from all the other case sites in that it had low levels of deprivation and also had admission rates for common conditions similar to those found nationally. The HES data for Site C were difficult to interpret, with a suggestion that there had been significant changes in the way HES data were recorded during the period of analysis, which showed falls in admissions and bed-days but increases in average length of stay.

Overall, then, it may be that when rates of admission for common conditions are much higher than the national average there is more scope for admissions to fall, thus making it more likely that the ITS would identify an effect. However, it is also possible that the model of CCN team also has an impact; the more community-based and parent-facing (as in Site A1), the more scope there is for reducing both admissions and bed days.

Turning now to children with complex conditions, there was evidence of significant impact in both Site A1 (on bed days) and Site D (on non-elective acute admission, the main outcome for this site). In both cases, rates before implementation of the CCN service had been substantially above national rates. By contrast, Site A2, which had a level of bed days close to the national average, showed a smaller level of reduction. Without the qualitative insight in Site A2, it is difficult to elucidate the reasons for this difference. We do know, however, that Site A1 acted not only to empower parents of children with complex conditions to feel confident about caring for their children at home, but also played a key role

in care management in the early days after diagnosis or discharge from hospital. This may explain the reduction in bed days for complex conditions in this site. It may also be that the population of children with complex conditions in Site A1 was always larger than that in Site A2 and there may thus have been more scope for a reduction in bed days, but we are not able to confirm this in the absence of any national statistics on children with complex conditions.

Site B showed a slight increase in bed days over the period of analysis, despite already having a rate higher than the national average.

Again, then, it seems that the original level of activity may be important in whether or not an effect is possible. However, these findings again suggest that the model of CCN service is important. The teams in both Site A1 and Site A2 were ‘integrated’, in the sense that their work to avoid acute admission for all children was of a piece with their work to support children with complex conditions. Site D, was very different, but was highly targeted on a specific group of children and on a single outcome (avoiding acute admission for children with complex neurological conditions). By contrast, Site B had not developed much from its origins as a respite service, even when it had taken on responsibility for children with continuing care packages. The inability of the area to deliver the planned CCN service that would focus on acute admission may have meant that the Site B team had no opportunity to develop the more active work with parents of children with complex conditions that we saw was an important part of the work of the Site A1 team.

As noted in the introductory chapter, evidence about the impact of CCN services in secondary care is tentative.<sup>9,33</sup> Our work here adds to this evidence by highlighting the potential for either a generic or highly focused acute avoidance model to reduce admissions. However, given the limitations outlined above, this is a cautious and tentative conclusion. Although our work adds to the limited work on impact of CCN services on secondary care, there remains no firm evidence about this.

2. What are the costs and outcomes of the new services compared to those achieved by alternative service reconfigurations?

Chapter 7 gives a full account of how we examined the costs and consequences of the introduction or development of CCN teams in our case sites and we have summarised some of this material above.

Given the type of health economics analysis that was possible based on the ITS findings and the inclusion of other costs only for children with complex conditions whose parents took part in the qualitative work, it is difficult to be secure about any of the individual findings. Further, given the very different type and costs of the four services included in this part of the work, it is difficult to synthesise the findings in any meaningful way. Individually, it seems that Site D had the service where costs most closely matched savings. This was a highly targeted service with only one main outcome and the small numbers involved in the ITS analysis mean that there is greater potential variability around the outcome. Given this, however, the overall conclusion is that this service has a relatively high probability of being cost saving. Parents valued the service, too.

For the Site A1 and A2 teams, the health economics verdict remains unclear. We were not able to assess the impact of the disinvestment that had taken place in the acute sector before the teams were introduced, neither were we able to assign value to benefits or costs that might arise from all the other work that these teams did. For example, both sites ran a number of long-term condition clinics in the community to provide care for children that would otherwise have attended hospital out-patient clinics.

Site B is unusual, both in terms of our case sites and in terms of CCN services more generally. The high proportion of children funded via continuing care packages means that an analysis based on bed days is slightly out of kilter with the aims of the team. The question that should, perhaps, be asked about this team's activities is whether better value is achieved for continuing care expenditure from this model of CCN team compared with other ways of delivering continuing care (for example, via spot purchasing of services). The team was established because spot purchasing had been problematic in the past, so that perhaps provides part of the answer.

This is the first attempt, to our knowledge, to examine the costs and consequences of a range of different types of CCN team, meeting diverse types of needs. There is clearly much still to be done.

3. What changes in the quality of care do families caring for children with complex health care needs experience when CCN teams are introduced?

The three services used by parents we interviewed (Sites A1, B and D) identified different trajectories of service use, reflecting provision for different types of needs, for a very similar group of children - those with complex conditions. A decreasing trajectory of ‘hands on’ input was seen where the team played an empowering role, spanning clinical and care coordination, and gradually stepped back as the responsibility of care shifted to parents and/or other services were set up and in place (A1). A constant trajectory was seen where input reflected a designated allocation of hours for a continuing care package, with less evidence of parents being encouraged to increase their confidence and input (Site B). Finally, we saw an episodic trajectory, where input fluctuated in response to acute episodes of illness (Site D, and to some extent in Site A1). These patterns of service use have not previously been identified in evaluations of CCN services. Whilst the role of nurses in empowering parents has been repeatedly demonstrated in other studies,<sup>9, 16, 17, 20</sup> its association with a decreasing trajectory of service use is less apparent in current evidence around CCN services, and has implications for practice (see chapter 9).

Where CCN service provision and use decreases over time (as typically seen in Site A1), change is evident in what aspects of provision are important to families for feeling supported over time, but this is not the case for ‘constant’ or episodic trajectories. Also, changes in the perceived quality of care do not necessarily follow these trajectories. Despite decreasing or episodic use of teams in Site A and D, assessments of quality were overall positive. Despite the intended regular shift-like pattern of service input in Site B, assessments of quality were closely tied to service processes such as staffing continuity. Thus, input does not need to be resource intensive to result in positive experiences of care quality. What appeared to be the critical service feature in positive accounts was having the team as a potential back-stop – someone to call on, if needed. This probably reflects the anxieties parents have when caring for acutely ill children, whether or not associated with the additional demands associated with caring for children with more complex conditions.<sup>16, 27-29, 35, 36, 40</sup> It is also consistent with findings from other studies of community and tele-health interventions, where telephone access to health professionals is a way of seeking reassurance in times of uncertainty.<sup>72-74</sup>

4. What benefits and challenges do commissioners and providers experience, as the new services are planned, implemented and established?

In Chapters 3 and 4 we synthesised the material from across our case sites in relation to the experience of planning and implementing (or not) the planned changes to CCN services. In this chapter, we examine this material against the factors that other research has shown may help or hinder service change.

Leadership and the ability of leaders to articulate and communicate a vision for and the goals and purpose of change to all stakeholders are seen as key factors in the success of service redesign.<sup>45</sup> In Site A, in a very large programme of service redesign that went well beyond the introduction of CCN teams, a multi-disciplinary network led all aspects of the change programme and, crucially, helped to ensure that professionals in the NHS gave their support to it. This included those that might be considered particularly powerful in times of change – doctors, who are seen to be at the top of the NHS hierarchy.<sup>75</sup> In Site B, by contrast, there was clear leadership for a much smaller change (introduction of a CCN team targeting acute admissions) at commissioner and provider level. However, the medical directorate at the acute trust opposed plans for a CCN team to take on acute care for ambulatory-sensitive conditions. By contrast, a neurology consultant supported the bids for funding for the expansion of the complex care team in this site and this was felt to have been crucial in their success. In Site C, where nothing changed despite very advanced plans, there was clear leadership and a vision for the future of children’s services across the existing health and social care community, but this was disrupted at a crucial stage by wider NHS restructuring.

Thus, while committed leadership is undoubtedly important, both individual stakeholders<sup>43, 45, 47</sup> and wider change can scupper even the best planned and most advanced strategies. Even in Site A, we became aware that there had been some loss of focus, over time, on the key objectives of the system-wide service redesign, as individuals moved on, other policy preoccupations came to the fore, and nationally-led restructuring created competition between providers. Others have argued that change needs a stable environment<sup>43, 44</sup> and our work serves to reinforce this, and to highlight the wasted resources that continued restructuring might lead to.

Dedicated funding for change is another factor identified in earlier work as crucial to the success of change.<sup>43</sup> This was in place in Site A (both teams) and Site D where change was successfully implemented, was applied for successfully when the complex care team in Site B was expanded, but was not available in Site C. The planned changes in Site C required review and reallocation of existing resources and, in an environment where competition between trusts had come to the fore, this became increasingly difficult to achieve.

This last point links to others' suggestions that the timing and pacing of change can also be important for their sustainability.<sup>45</sup> We saw evidence of this both in relation to wider policy and to the scheduling of implementation. In the case of Site C, the planned implementation of change came just too late in terms of wider NHS restructuring. In Site A, by contrast, the European Working Time Directive and anxieties about the sustainability of existing services provided a fertile ground for planting the seeds of change. Site A also paced its programme carefully - ensuring that public and service support was largely in place before change began - and, once it did, setting up the CCN teams before reducing inpatient beds and recruiting to the teams over time, so as not to destabilise acute services.

## Chapter 9      Conclusions

In this report, we have presented findings from a project that has attempted to examine the impact of reconfiguring CCN services on experienced quality of care, hospital activity and costs. As discussed in the previous chapter, our headline findings are:

- Different models of CCN provision may have differential impact on acute activity and on costs, both for common childhood conditions that lead to non-elective admission, bed days for all children and for complex conditions.
- Our analysis of costs was inevitably limited, but provided the basis for future development of health economics approaches to assessing the value to the NHS of care closer to home.
- There were varying degrees of success when introducing CCN services in line with national policy, with evidence of facilitating factors and resistances to change. Once implemented, services can struggle with problems of visibility.
- There is no commonly agreed way of assessing quality-based outcomes of CCN services and this can be a barrier to demonstrating value to commissioners.
- *It is important to parents that they feel 'held' by a service, even if not actively using it. Knowing the CCN team was a telephone call away for advice and reassurance if needed, along with 'check-ins', appeared to contribute to parents feeling supported and secure in managing their ill child at home.*
- Maintaining perceived quality of care is still possible, even if level of contact with the team declines or fluctuates, when teams work in partnership with families to increase their confidence in caring for their child.

We use this final chapter to consider the implications of these findings for health care practice and present recommendations for future research.



## **Implications for health care practice**

At the stage of understanding we have now reached, the strongest message for health care provision is that large, generic CCN teams that work in an integrated way for all children with common childhood conditions and those with complex conditions, may be most likely to have ‘high value’ impact<sup>4</sup> on acute activity for both groups. Parent empowerment, through intensive early-stage involvement, regular training and the availability of telephone contact for support and reassurance, may be a process that underlines this impact on acute activity. Highly targeted admission avoidance services for children with complex conditions may also have such impact, with highly skilled nurses able to offer a fast and responsive alternative to primary and secondary care. Overall, the potential for impact seems greatest for children with complex conditions and, for all children, when acute activity is above the national average. Services that serve predominantly to provide continuing care, without access to other service elements that target admission rates by working in partnership with families, may be less likely to have ‘high value’ impact.

Various factors influenced the development and planning of CCN services, with some areas successfully introducing services as planned, whilst others struggled to get them in place, facing resistances from other stakeholders and commissioners. For those that did achieve the change intended, challenges to visibility, balancing caseload demands and demonstrating value to commissioners continued to test the teams. Two key implications emerge from this.

First, despite repeated national policy emphasis on moving care into community settings, and the recent reiteration of this in the Five Year Forward Plan<sup>76</sup> resistances in practice and commissioning seem to be undermining moves that would achieve this. Care closer to home policy is rooted in efforts to improve care quality and make efficient use of secondary care, yet our findings raise questions about the extent to which it is possible to achieve these fully within children’s health services. Improved understanding among some commissioners and professionals about the objectives of care closer to home policy for children and young people – which is not just about saving money but also about providing the care that is most appropriate to the youngest members of the population - might help.

Second, even where services are implemented as planned, difficulties establishing and maintaining visibility have immediate implications for service take up by others, and longer-term implications for wasted resources if the services are not used fully. When teams are established, initial and continued ‘marketing’ of their services to other professionals would help to maintain referrals and understanding.

For children with complex health needs, different types of nursing and health needs can be met with different models of CCN input. Not only do these different models appear to meet different sets of needs, but it was evident that a constant level of input was not necessary to maintain positive experiences of care, as long as certain service features were available at the times when parents needed them to manage their child’s care. This has implications for designing and delivering services, in terms of what could be offered to best support families and when.

## **Recommendations for future research**

- The evidence suggests a generic CCN model and a highly targeted nurse practitioner model may have scope to affect positively both experienced quality of care and acute activity, but as the evidence comes from just two (very different) sites, we cannot generalise widely from this. The next important research step would be to extend evaluation across multiple sites with similar models of CCN provision.
- This research focused on quality, secondary care and costs outcomes. The qualitative work with parents showed the key role of the generic CCN team in managing the child's clinical care and nursing needs (for example, delivering IV treatment at home, managing assistive technology, such as feeding tubes), and of the nurse practitioner team in assessing and prescribing for acute illness. Further work could examine the clinical outcomes of these specific aspects of CCN provision. Such evidence could also feed into a fuller picture of cost-effectiveness.
- Further work could examine the effect of variables relating to the CCN service on outcomes achieved. For example, do factors such as the number of parental contacts with the CCN team, fluctuations in team size and skill mix, duration of episodic and total CCN team involvement, or whether families have a named nurse affect outcomes? Some of these were raised by our project advisory group, but the current project was not designed to examine them.
- The findings from staff indicate the importance of demonstrating quality-based outcomes. Further research could explore and establish the best ways to measure quality based outcomes of CCN services, and how these can be used to support the development of these services as well as future cost-effectiveness research.
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- As part of this work we translated the MHI (now the CCN development tool) and MHFI. Further work is needed to develop the MHFI (see Appendix 4) and examine its validity and utility in English health care settings. Further work could also evaluate the use of the CCN development tool in practice and might contribute to identifying appropriate quality measures for services, as in the previous paragraph.
- The outcomes measured as part of the cost consequence analysis were not those typically used in decision-making. Further work exploring the feasibility of generating outcomes, such as QALYs for CCN services would enhance the usefulness of such analysis.

- The qualitative work with parents and staff suggests that CCNs play a role in enabling school attendance. Future research could examine impact of CCN support on educational outcomes for children and young people with complex conditions.
- An issue highlighted by our work was inconsistency in HES coding of short stay ward attendances, and the potential for this to ‘skew’ inpatient admissions data. Further work could seek to understand the extent of this variation in coding practice and the implications for service planning decisions.
- Issues regarding the emotional resilience of staff who spend long periods caring for children in the home were raised by staff in Site B. Further work to examine the most effective ways of supporting the well-being of staff working closely with families in relative isolation in home settings would help to provide evidence for those grappling with this issue.

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### Data sharing

None of our qualitative data can be shared, as we did not consent participants to use of their data by others. The HES data we used is publicly available through Public Health England, and we have no ownership of this.

### Contributions of authors

**Gemma Spiers** (Research Fellow, Social Policy Research Unit (SPRU)), co-developed the original proposal and study design, managed the project, led on the qualitative studies, collected and analysed data for the qualitative studies, collected data for the costs studies, contributed to the translation of the CCN development tool and MHFI, and drafted Chapters 1, 2, 3, 4, 5 and co-wrote Chapters 8 and 9.

**Dr Victoria Allgar** (Senior Statistician, Health Sciences/Hull York Medical School (HYMS)), co-developed the original proposal and study design, led the development of and undertook the ITS analysis, drafted Chapter 6, contributed to data to the health economics work, and approved the final report.

**Dr Gerry Richardson** (Senior Research Fellow, Centre for Health Economics (CHE)), co-developed the original proposal and study design, developed the materials for the cost study, contributed to the development of the ITS analysis, supervised the analysis for the cost studies, drafted Chapter 7 and approved the final report.

**Kate Thurland** (Head of Health Intelligence, Public Health England (PHE)), contributed to the development of the ITS analysis, undertook extraction of HES data for the ITS analysis, co-developed the analytical toolkit, and contributed to the methods section of Chapter 6 and associated appendices.

**Sebastian Hinde** (Research Fellow, Centre for Health Economics (CHE)), undertook the analysis for the costs study, drafted Chapter 7 and associated appendices, and approved the final report.

**Professor Yvonne Birks** (Professor of Health and Social Care, Social Policy Research Unit (SPRU)), co-developed the original proposal and study design, contributed to the development of the ITS analysis and the analysis of the qualitative studies, drafted elements of Chapter 3, 4, 5 and 9, and approved the final report.

**Kate Gridley** (Research Fellow, Social Policy Research Unit (SPRU)), co-developed the original proposal and study design, and advised on methods and analysis for the qualitative study with staff and contributed to Chapters 3 and 4.

**Dr Helen Duncan** (Programme Director, Public Health England (PHE)), co-developed the original proposal and study design, contributed to the development of the ITS analysis and co-developed the analytical toolkit.

**Susan Clarke** (Research Fellow, Social Policy Research Unit (SPRU)), collected and charted data for the qualitative study with parents.

**Dr Linda Cusworth** (Research Fellow, Social Policy Research Unit (SPRU)), undertook some of the early analysis for the ITS analysis for Site A.

**Professor Gillian Parker** (Professor of Social Policy Research, Social Policy Research Unit (SPRU)), (Principal Investigator) developed the original proposal and study design, took overall responsibility for the project, contributed to the development of the ITS analysis, contributed to the translation of the CCN development tool and MHFI, advised on methods and analysis for all study components, co-wrote Chapters 8 and 9 and edited the final report.

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# Appendices

## Appendices

### Appendix 1 Additional table from Chapter 3

**Table 25: Summary of recruitment and attrition of commissioning and management staff across waves**

Site	Wave 1 interviews	Wave 2 Interviews				Wave 3 Interviews			
	# Participating	# Participating from wave 1	# Attrition from wave 1	# New individuals taking part	Total # of wave 2 interviews	# Participating from wave 2	# Attrition from wave 3	# New individuals taking part	Total # of wave 3 interviews
A	3	0	3	1	1	1	0	0	1
B	2	1	1	0	1	0	2 (one from wave 2, one from wave 1)	2	2
C	4	2	1 (+1 not approached as not relevant)	2	4	1	2 (+1 not approached as not relevant)	0	1
D	3								
Total	12	3	5	3	6	2	4	2	4

## Appendix 2

### Chapter 6 - Data extraction plan for Hospital Episodes Statistics

#### Methods

##### Identification of the main reasons for emergency admissions of children

Hospital Episode Statistics (HES) were used to initially identify the top twelve reasons for emergency admissions of children aged 14 days to 15 years inclusive for each site, in the 24 months prior to the intervention date. Each record contains a primary diagnosis which is classified using the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10). These were presented in clinical code blocks (which are placed in the hierarchy between ICD chapter and ICD code) in order to group similar conditions together and provide a more meaningful analysis. Neonates aged under 14 days were excluded as they are admitted in large numbers for reasons which are not in the scope of CCNs, for example infant feeding problems. Children admitted for mental health reasons (primary diagnosis in ICD-10 chapter V: Mental and behavioural disorders) were also excluded as the care of these children is best managed by specialist mental health services and a CCN team should have little impact on the admission of these children.

The sites selected were defined by primary care trust (PCT) boundaries, which captured the population served by the CCNs in the analysis. Until March 2013, PCTs were the commissioning organisation for the population in their area, and so analysis by commissioning boundary is the most meaningful in terms of assessing outcomes and impacts of services. As of April 2013, PCTs were abolished and GP-led clinical commissioning groups (CCGs) were established.

##### 1. Data extraction for emergency admission analysis

Once the 'top twelve' PCT-specific reasons for admission had been established, a detailed extract was run to allow admission rates to be calculated for 24 months pre-intervention date and 24 months post-intervention, in order for the interrupted time series (ITS) analysis to be carried out. This was restricted to finished admissions where the primary diagnosis was one of the PCT's 'top twelve', the child was aged between 14 days and 15 years and the admission method indicates an emergency admission via A&E, a general practitioner, an outpatient clinic or various other means. Data were also extracted using the same filters but with no restriction on PCT, to allow the same analysis to be carried out at a national level in order to provide a comparator.

Numbers of admissions were then sorted into financial year and month, and split by the following characteristics of the patient or their admission to hospital:

- Gender
- Age (on admission), grouped into the following categories:
  - 2 weeks to under 1 year
  - 1 year to 4 years



- 5 years to 11 years
- 12 years to 15 years
- Day of week the patient was admitted
- Day of week of discharge
- Medical specialty under which the patient was treated
- Diagnosis (grouped by code block as previously described)
- Ethnicity
- Deprivation: the Indices of Multiple Deprivation (IMD) average score (based on the patient's postcode) was assigned to a national quintile, as a measure of the deprivation of the area in which they live. Patients who live in areas within quintile 1 are in the most deprived areas.

Other ways of breaking down the data, such as by time of admission, were included in the project protocol but were not possible due to the relevant fields not being captured in the data.

Crude admission rates were calculated per 100,000 children, using mid-year population estimates for primary care organisations (revised following the 2011 Census) from the Office for National Statistics. The mid-year population estimate was used to calculate rates for each month in the same financial year; for example the mid-2008 population estimates were used as the denominator for all twelve monthly admission rates shown from April 2008 to March 2009.

For some of the characteristic splits listed above, the rates calculated were based on a specific subset of the population figures.

- Gender-specific rates were per 100,000 population aged under 16 years of that gender
- Age-specific rates were per 100,000 population of relevant age. As population estimates are available only by year of age, total population aged less than one year was used as the denominator for the rates of admission for infants aged 2 weeks to under one year.

## 2. Data extraction for length of stay analysis

A similar detailed extract was run to allow lengths of stay following admission to be calculated for 24 months pre-intervention date and 24 months post-intervention, for further ITS analysis. This was restricted to both elective (planned, booked or from waiting list) and emergency admissions. Although admissions for reasons of mental health were excluded, there were no further restrictions on reason for admission. Planned day cases were also excluded, which is usual practice when calculating lengths of stay. Similar to the elective admission extraction, data were also extracted using the same filters, but with no restriction on PCT, to allow the same analysis to be carried out at a national level.

Total bed days were then sorted into financial year and month, and split by the following characteristics of the patient or their admission to hospital:

- Gender
- Age (on admission), grouped as previously described

- Day of week the patient was admitted
- Day of week of discharge
- Specialty under which the patient was treated
- Diagnosis, grouped by whether the primary diagnosis is in the PCT's 'top twelve' or not, and then by diagnosis code block
- Ethnicity
- Deprivation, as previously described
- Elective or emergency admission

Two measures were calculated to consider length of stay.

- Total bed days per 100,000 children, using mid-year population estimates for primary care organisations from the Office for National Statistics as previously described.
- Average length of stay following admission. These values were calculated by dividing the total bed-days in the month by the number of discharges in that month, to provide a value in days indicative of the average length of stay.

As previously described, the calculated rates for gender and age were based on the relevant population estimate subsets.

#### Data quality issues

The following table summarises each field's likely data quality, and indicates whether methods of defining and recording the field are likely to have changed over the period considered. For the dataset and years included, it is considered that the overall data quality is good, although any conclusions based on diagnosis or specialty should be interpreted with caution.

**Table 26: Data quality in relation to each field**

<b>Field</b>	<b>Data Quality</b>	<b>Change over time due to local admission practices or data recording changes?</b>
Gender	Good	No
Age on admission	Good	No
Day of week of admission or discharge	100%	No
Specialty	Fair	Possible
Primary diagnosis code block	Good	Some known issues, other issues likely
Ethnicity	Fair	Unlikely
Lower super output area (for calculation of deprivation quintile)	Good	Possible, unlikely
Method of admission (elective or emergency)	100%	Unlikely

## Chapter 6 - Syntax for ITS analysis

FOR EACH VARIABLE AND ITS CORRESPONDING NATIONAL FIGURE.

\*LOOK AT TIME PLOTS.

\*CHECK PACF AND ACF PLOTS.

\*ADJUST FOR SEASONALITY IF NECESSARY.

\*PLOT ORIGINAL AGAINST SEASONAL.

\*PLOT ADJUSTED AND NATIONAL.

\*RUN OLS REGRESSION.

\*LOOK AT TIME PLOTS.

GRAPH

/SCATTERPLOT(BIVAR)=timeperiod WITH TOTAL BY Phase

/MISSING=LISTWISE.

TS PLOT VARIABLES=TOTAL NATIONAL

/ID=DATE\_

/NOLOG

/MARK PHASE.

\*ADJUST DATA TO ACCOUNT FOR SEASONALITY.

\* Seasonal Decomposition.

TSET PRINT=BRIEF NEWVAR=ALL MXNEWVAR=8.

SEASON

/VARIABLES=TOTAL NATIONAL

/MODEL=MULTIPLICATIVE

/MA=EQUAL.

\*CHECK PACF AND ACF PLOTS

ACF VARIABLES=TOTAL SAS\_1

/NOLOG

/MXAUTO 16

/SERROR=IND

/PACF.

\*EXAMINE SEASONALITY PLOTS.

TSPLOT VARIABLES=TOTAL SAS\_1

/ID=DATE\_

/NOLOG

/MARK PHASE.

TSPLOT VARIABLES=NATIONAL SAS\_2

/ID=DATE\_

/NOLOG

/MARK PHASE.

TSPLOT VARIABLES=SAS\_1 SAS\_2

/ID=DATE\_

/NOLOG

/MARK PHASE.

\*RUN REGRESSION.

\*SAS\_1.

REGRESSION

/MISSING LISTWISE

/STATISTICS COEFF OUTS R ANOVA

/CRITERIA=PIN(.05) POUT(.10)

/NOORIGIN

/DEPENDENT SAS\_1

/METHOD=ENTER timeperiod Phase slope

/SCATTERPLOT=(\*ZPRED ,\*ZRESID)

/RESIDUALS DURBIN HISTOGRAM(ZRESID)

/CASEWISE PLOT(ZRESID) OUTLIERS(2.5)

/SAVE PRED.

\*compute predicted line, if CCN had not been introduced.

COMPUTE pre\_2 = 498.239 + (-0.249\*timeperiod).

EXECUTE.

\*run regression on national data, to illustrate national trend.

\*SAS\_2.

REGRESSION

```
/MISSING LISTWISE
/STATISTICS COEFF OUTS R ANOVA
/CRITERIA=PIN(.05) POUT(.10)
/NOORIGIN
/DEPENDENT SAS_2
/METHOD=ENTER timeperiod
/SCATTERPLOT=(*ZPRED ,*ZRESID)
/RESIDUALS DURBIN HISTOGRAM(ZRESID)
/CASEWISE PLOT(ZRESID) OUTLIERS(2.5)
/SAVE PRED.
```

\*delete variables not needed, and rename and label ones to keep.

delete variables ERR\_1 SAF\_1 STC\_1 ERR\_2 SAF\_2 STC\_2.

rename variable (sas\_1 sas\_2 pre\_1 pre\_2 pre\_3 = total\_seas national\_seas total\_with total\_without national\_pred).

variable labels total\_seas 'Total rate (seasonalised)'

/national\_seas 'National rate (seasonalised)'

/total\_with 'Total rate - prediction with CCN'

/total\_without 'Total rate - prediction without CCN'

/national\_pred 'National rate - best fit'.

\*plot time series, with 3 predicted lines.

TSPLLOT VARIABLES=total\_seas total\_with total\_without national\_pred

/ID=DATE\_

/NOLOG

/MARK PHASE.

## Appendix 3

### Methods applied in Chapter 7

#### 1. The cost to the NHS of having a CCN team in place

A definition of missing data was constructed a-priori, to include any field where no value was entered by the team (that is, not '0' or 'N/A') AND a value of zero was inconsistent with what was known about the team from interviews and previous questionnaires. Missing data was recorded in only one questionnaire in the miles travelled field; this value was inputted using mean substitution as no reason could be discovered why this value would be expected to deviate from the mean derived from the other questionnaires.

Once a mean team structure across the analysis period had been defined, a unit cost was assigned to each of the variables fields (four nurse band fields, miles travelled, and 'other' team member field). The 'other' team member field was costed on a case by case basis as the definition of the team member was case specific. The unit costs applied and sources are provided in Table 27 below. The unit cost estimates of the cost to the NHS of employing each of the team members incorporates both the wage and non-wage costs (as defined by PSSRU, <sup>77</sup>) to incorporate the wider costs to the NHS of their employment, these costs are combined in the unit cost values presented in Table 27. All values in Table 27 are drawn from PSSRU <sup>77</sup>. The assumptions made to derive the unit costs are provided in the table; no qualification costs are assumed throughout, consistent with PSSRU's base-case estimates.

**Table 27: Unit cost estimates applied to CCN team cost questionnaires**

Questionnaire field	Unit cost	Assumptions
Nurse band 5	£58,682 per annum	Qualified nurse band 5, non-wage costs back-calculated from band 6
Nurse band 6	£66,252 per annum	Qualified nurse band 6
Nurse band 7	£74,196 per annum	Qualified nurse band 7, non-wage costs back-calculated from band 6
Nurse band 8	£82,972 per annum	Qualified nurse band 8a, non-wage costs back-calculated from band 6
‘Other’ – band 3	£32,736 per annum	Clinical support worker nursing band 3, non-wage costs back-calculated from band 6
‘Other’ – band 4	£51,306 per annum	Qualified nurse band 4, non-wage costs back-calculated from band 6
Miles travelled	67p per mile	Cost per mile for first 3,500

To account for the change in team structure over the analysis period, and to additionally incorporate changes to the team not observed in the questionnaires collected, uncertainty analysis was applied to the cost estimates. This was conducted through the fitting of site specific normal distributions to each of the fields of the team questionnaires.

### **2a. The cost implications of a change in bed days**

The ITS analysis presented in Chapter 6 gives us an estimate of the total number of bed days with and without the CCN team. However, it cannot tell us specifically what type of bed days were averted as a result of the CCN team. The cost associated with different types of stay varies dramatically. To account for being unable to know the type of bed days saved, we apply a range of possible bed day costs using Monte Carlo simulations. This approach repeatedly samples from a distribution fitted to the full range of unit costs available from the NHS Reference Costs (which are weighted by their frequency such that those with the highest frequency are most likely to be sampled) and thus allows us to fully characterize this underlying uncertainty. In all cases, a gamma distribution was chosen from which the Monte Carlo simulation would draw as it is positively skewed and bound by 0, making it a fair representation of the typical distribution of costs.

In both Sites A1 and A2 the population considered can be said to be all children admitted to hospital, as the CCN teams have a broad caseload of ‘acute, chronic, complex, palliative’ care and as such the ITS analysis considered all elective and non-elective paediatric admissions. However, Site D’s caseload is more restrictive (complex conditions) (mostly neurological)). As such, the unit cost per bed days assigned to the changes seen in the ITS analysis must reflect these differences.

As a result the source of NHS Reference Costs used to inform the analysis, the unit costs differ in Sites A1 and A2 compared to Site B. Both Sites A1 and A2 draw from all reference costs with a duration of one day for all reference categories specifying paediatric of 18 years and under. It is important to note that while the CCN teams will not affect the incidence of many of the categories of care, for example, critical care, a reduction in total bed days may come from any of the categories as children may be discharged earlier given that a CCN team (specifically one with a broad remit, such as Sites A1 and A2) are available to provide care. Given this approach the average cost per bed day in these areas is estimate to be £330 (SD-150).

In contrast, for Site B, whose caseload is limited to complex care conditions, to be consistent with the approach taken in the ITS analysis, only categories that closely matched the definition of complex care made in Chapter 6 were sampled from. These reference cost categories were congenital conditions (major or other), cerebral degenerations or miscellaneous disorders of the nervous system, nervous system disorders, and metabolic disorders. Categories were no longer limited to those specified as paediatric or under-18 as these complex conditions are not distinguished by age in the NHS Reference Costs. The resultant cost per bed day estimate is £417 (sd-274). The similarity of the mean cost per bed day with the full population used in Sites A1 and A2 (£87 different) suggests that while the complex care patients may have longer stays the daily cost is relatively similar. However, the significant difference in SD demonstrates the greater variation in the daily cost for complex care patients.

## **2b. The cost implications of a change in admissions**

The mean unit cost per admission applied to Sites A1 and A2 is £2,020 (SD-2,622), and for Sites B and D £1,471 (SD-812). While it is perhaps surprising that the cost per admission from the NHS Reference Costs is greater for the all category group than the complex condition definition, this is likely to be a reflection of a greater number of admissions per child with complex conditions, and a lower threshold of admission than a child without complex conditions. However, it is impossible given existing data to tease out the drivers behind this result.



## **2c. The cost implications from wider resource use changes**

This approach to estimating the cost implications to the NHS requires a number of core assumptions to be useful to inform the cost implications to the NHS of engaging a CCN team in each of the sites. First, as only children with complex care needs are included in this part of the analyses it requires the assumption that there is no impact of the CCN team on all non-complex care need children cared for by the CCN team (only relevant to Site A1 who have a wider caseload). While this assumption appears extreme it is expected that the CCN team has the greatest impact in the complex care cases, and as such the analysis will encompass the majority of the impact of the team on NHS interactions.

Second, as with any difference-in-difference type analysis, including the ITS analysis presented in Chapter 6, the use of the parent completed questionnaires assumes that there was no underlying change in the illness or level of medical need of the child during the analysis period and that the level of care provided by the NHS (excluding the CCN team) was unchanged throughout. This assumption is necessary as it allows for the introduction of the CCN team to be the only factor changing, and thus any change in NHS interactions can be attributed to their introduction. While on a case by case basis this assumption is unlikely to hold, due to the relapse remitting nature of many complex conditions, when considered across the group sampled from it can be expected to hold.

Third, as not all parents of children with complex care needs covered by the CCN teams completed questionnaires, the assumption must be made that those who did are representative of those who did not. This assumption is necessary due to the lack of data from the full population of complex care patients, and might bias the result as it is possible that parents with more unwell children were not able to complete the questionnaires due to the excessive time requirements of caring for their children.

Finally, the use of such questionnaires assumes that parents' memory and understanding of which specialists their children are seeing is perfect. While it is likely that some NHS interactions were forgotten over the six month period requested, or incorrect categories reported, this error is expected to be small. In addition, it was considered that if parents were aware of the role of the questionnaires and were keen to keep a CCN team in their area they might intentionally bias the results by over reporting the impact of the CCN team on the level of care required from elsewhere in the NHS. However, this bias was deemed unlikely and no methods were available to measure it or adjust for it.

The range of categories collected by the questionnaires and the unit costs applied are presented in Table 28 below, alongside the source of the estimates. These unit costs were applied to the two period questionnaires and the costs summed for each, to give a total cost of NHS interactions per child with complex care needs per six months, both before and after allocation to a CCN team.

**Table 28: Unit cost categories in parent questionnaire cost analysis**

Category	Unit Cost	Source and assumptions
<b>Hospital interactions</b>		
Overnight stays in hospital	£417	Cost per bed day for complex care children, taken from analysis 2a
Outpatient appointments	£132	NHS Reference costs 2012-13 Procedures in Outpatients
A&E attendance	£115	NHS Reference costs 2012-13 Accident and Emergency Services
Day case surgery	£693	NHS Reference costs 2012-13 Day Cases
Other day case treatments	£132	Assumed same unit cost as ‘outpatient appointments’
<b>Other NHS/PSS interactions</b>		
General Practitioner	£45	PSSRU 2013 estimate based on 11.7 minute consultation
Practice Nurse	£11	PSSRU 2013 estimated 15.5 minute duration of contact
Occupational Therapist	£112	NHS reference cost 2012-2013 child one to one
Speech and Language Therapist	£88	NHS reference cost 2012-2013 child one to one
Physiotherapist	£80	NHS reference cost 2012-2013 child one to one
Clinical or Child Psychologist	£191	NHS reference cost 2012-2013 outpatient
Children’s Social Worker	£55	PSSRU 2013 social worker (children), assume full hour per patient
Child Development Officer	£55	Assume same unit cost as ‘Children’s Social Worker’
Health Visitor	£50	NHS reference cost 2012-2013 outpatient Face-to-Face, One to One

As with previous analyses, the uncertainty associated with the questionnaires is incorporated into the analytical model by using Monte Carlo simulations, drawn from a given distribution. Due to the low number of questionnaires completed, and the relatively large number of categories, the

distribution of costs was fitted to the total cost estimate per child rather than at a category by category level. This approach may reduce the level of uncertainty in the analysis but was necessitated by the low number of questionnaires which could easily be biased by a single outlier. All unit costs were assumed to be fixed. The Gamma distribution was used as the distribution to draw from, consistent with the approach in the previous section.

In several cases, parents completed questionnaires only after allocation to CCN teams, and as such a before questionnaire is not available. It is assumed that in these cases the children are no different from those who completed both a before and after, and as such can still be used to inform the average cost of a complex care child after CCN team allocation.

Where no response was given to a field in the questionnaire it was assumed that the child did not experience any of that type of interaction with the NHS. No further missing data was reported.

#### **2d. The cost implications to parents and wider society**

All the assumptions made in the previous section (2c) around the use of this questionnaire data are required here, that is, representativeness of the sample, perfect memory of parents, no underlying change in illness or care and no impact of CCN team on non-complex care children.

As with previous analyses presented, this analysis compared the costs to the parents (direct and lost employment) before allocation of their child to a CCN team, with those after. To estimate the lost income as a result of being unable to work due to caring for their child we assumed the average national income per week (£478) and the average number of hours worked per week (32.1) from the ONS <sup>78</sup>, a five day working week was assumed. As with previous analyses the total cost to the parents before and after was averaged across all parents in the site and uncertainty incorporated through Monte Carlo sampling of a gamma distribution fitted to the total cost to the parents.

## **Appendix 4 Research instruments**

## Appendix 4      Research Instruments

### 4a                      Sample information sheet



## Transforming Children’s Community Services (TraCCS) Study

### Information about the Research for NHS Organisational Staff

You are being invited to take part in a research study (the ‘TraCCS’ Study) being conducted by researchers at the Social Policy Research Unit (SPRU) at the University of York. This study is funded by the Department of Health (DH) and has been approved by [name of trust R&D office] and [name of REC]. Before you decide whether or not you would like to take part in the study, please read this leaflet, which provides information about the research and what taking part will involve.

#### What is the purpose of the study?

The aim of this study is to understand the impact of introducing or expanding Children’s Community Nursing Teams. We are doing this by studying three teams in England that are being, or have recently been, reconfigured. One of the teams is the [team name]. As part of this research, we would like to speak with senior NHS staff who are involved with developing children’s services in [area name].

#### Why have I been contacted?

You have been contacted as you have been identified as someone who plays a key role in developing children’s services in this area. You may be a Commissioner, a Senior Manager in the Provider Trust, or a General Practitioner. We are inviting you to take part in this study, so that we can learn from your experiences of developing Children’s Community Nursing Teams.

#### What does taking part in the research involve?

If you decide to take part in the research, we will interview you to find out a) how Children’s Community Nursing Teams in your area have been developed, b) what you have learnt from this, and c) how changing commissioning arrangements have impacted on the reconfiguration of local services for ill children. As we are tracking the development of the [name of team] and the service context in which it operates, we would like to interview you approximately every six months during the project (up to five times in total).

**What does each interview involve?**

Interviews will be conducted via telephone, and will take between 45 to 60 minutes. We would like to record the interview with your permission, but if you prefer not to be recorded, we will take notes.

**If I choose to take part in this study, will my participation be kept confidential?**

Your involvement in the study will be kept confidential. All data collected will be stored securely in accordance with the 1998 Data Protection Act and University of York Ordinances. We will anonymise the information you provide and use it to help write our report and other project outputs (for example, journal articles), but you will not be named in any of the project outputs.

**What are the benefits of me taking part in this research?**

The information you provide will be invaluable in helping us learn about developing and implementing Children's Community Nursing Teams, and in the context of changing NHS structures. There is a lack of evidence about how to develop Children's Community Nursing Teams, and thus the information you provide will be helpful to other health communities who are developing similar teams.

**Will taking part in an interview affect my employment?**

No, taking part in the research will not affect your employment in any way. Similarly, if you decide not to take part your employment will not be affected in any way.

**Do I have to take part?**

No, you do not have to take part in this research. If you choose not to take part in the research, please indicate this decision on the enclosed response form and return it to us in the prepaid envelope. Once we have received your form we will not contact you again about taking part in an interview.

**I would like to take part. What should I do?**

Please indicate your decision by completing the enclosed response form, and providing us with your contact details. You can then return the form to us in the prepaid envelope. When we receive this, we will contact you to answer any questions you have, and arrange a time and date for the first interview. After this, we will contact you again at approximately six monthly intervals to arrange up to five further interviews.

If you do decide to take part, you are still free to withdraw at any time, and you do not have to give a reason.

**Thank you for taking the time to read this leaflet. If you have any questions, please do not hesitate to contact [name], the Researcher, using the details below:**

☒ SPRU  
University of York  
Heslington  
York  
YO10 5DD

**Please retain this leaflet for your information.**

**4b Sample consent form**

## Transforming Children's Community Services (TraCCS) Study

### Consent Form: Interview 1

Please tick each box if you agree with statement.

1. I confirm that I have read and understood the information sheet dated [date and version] for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary, and that I am free to withdraw at any time.
3. I understand that the information I provide will be kept confidential and used only for research purposes.
4. I agree to allow the interview to be digitally recorded (you can decline to have your interview recorded but can still take part in the study).
5. I agree to take part in the above study.

---

**Name of Participant**


---

**Date**


---

**Signature of Participant**


---

**Name of Researcher**


---

**Date**


---

**Signature of Researcher**

**Copies: 1 for Participant, 1 for Researcher**

## 4c Topic guides for interviews and focus groups with staff, parents and children

### Transforming Children's Community Services (TraCCS) Study

#### Topic Guide for Organisational Staff involved in Local Service Redesign: Interview 1

##### Introduction and consent process

- Introduce yourself and study
- Interview expected to last up to 1 hour
- Explain participants rights
- Answer questions
- Ensure consent form signed.

*The interview will explore the following topics:*

##### Background

- Professional role of participant

##### Service changes

- Background/drivers to recent service redesign
- Service design prior to reconfiguration
- Key changes
  - Redesigned care pathways in local area for ill children (acute, life-threatening, life-limiting)

##### Processes – what is being done as part of service reconfiguration

###### Developing and reconfiguring local services for ill children: knowing about local health needs and planning services accordingly

- Use and usefulness of information about local health needs to plan services
  - Information gaps, population targeting
- Collection and use of outcomes data to monitor effectiveness
- Role of primary care in service reconfiguration.
- Public consultations about changes

###### Developing and reconfiguring local services for ill children: implementing new services and approaches

- How new approach/service reconfiguration ensures services quality and contribute to positive outcomes



- Variability, efficiency, productivity
- Expected and achieved cost savings compared to previous service design.

#### **Developing and reconfiguring local services for ill children: access and availability**

- How equitable access to Children's Community Nursing services is ensured in service development/reconfiguration
  - Methods for monitoring this
- Impact of introducing/expanding local Children's Community Nursing team on primary care
  - Pathways, referrals.

#### **Developing and reconfiguring local services for ill children: care planning and case management**

- How care planning and case management has been built into service redesign
  - Methods for monitoring this
- Impact on and role of primary care.

#### **Developing and reconfiguring local services for ill children: effective health and care partnerships**

- Role and use of partnerships with relevant health and care organisations and service users, in developing/reconfiguring services.

#### **Developing and reconfiguring local services for ill children: information and technology**

- Role and use of IT systems in reconfigured Children's Community Nursing team
  - Integration of care across agencies/providers.

#### **Developing and reconfiguring local services for ill children: education and training**

- How is skill, knowledge and competence of practitioners ensured to deliver a consistent high quality Children's Community Nursing service
  - Recruitment and retention issues.

### **Barriers and facilitators to planning, contracting, monitoring and implementing Children's Community Nursing Team**

#### **Impact of changing commissioning arrangements on service redesign**

- Role of primary care/Clinical Commissioning Groups.
  - Who in CCG is leading on children's services

#### **[End of interview]**

- Feedback details
- Identification of other key people, relevant meetings, relevant documentation.

# Transforming Children's Community Services (TraCCS) Study

## Topic Guide for Organisational Staff involved in Local Service Redesign: Subsequent Interviews

### **Introduction and consent process:**

- Introduce yourself and study
- Interview expected to last up to 1 hour
- Explain participants rights
- Answer questions
- Ensure consent form signed.

*The interview will explore the following topics:*

### **Brief recap on preceding interview(s)**

**Where service development ongoing – progress, follow up on site specific issues from previous data collection**

**Where new/expanded service is implemented – outcomes, follow up on site specific issues from previous data collection**

### **Developing and reconfiguring local services for ill children: knowing about local health needs and planning services accordingly:**

- Progress in collection and use of outcomes data to monitor effectiveness.

### **Developing and reconfiguring local services for ill children: implementing new services and approaches:**

- Progress so far
- Expected and achieved cost savings compared to previous service design.

### **Developing and reconfiguring local services for ill children: access and availability:**

- Areas of success
- Areas of difficulty.

### **Developing and reconfiguring local services for ill children: care planning and case management:**

- Areas of success
- Areas of difficulty.

### **Developing and reconfiguring local services for ill children: effective health and care partnerships:**

- Areas of success
- Areas of difficulty.

**Developing and reconfiguring local services for ill children: information and technology:**

- Areas of success
- Areas of difficulty.

**Developing and reconfiguring local services for ill children: education and training:**

- Areas of success
- Areas of difficulty.

**Barriers and facilitators to planning, contracting, monitoring and implementing Children's Community Nursing Teams**

**Impact of changing commissioning arrangements on service redesign:**

- Role of primary care/Clinical Commissioning Groups.
  - Who in CCG is leading on children's services

**[End of interview]**

- Feedback details
- Identification of other key people, relevant meetings, relevant documentation.

## Transforming Children's Community Services (TraCCS) Study

### Topic Guide for Practitioners of the Children's Community Nursing Team: Interview/Focus Group 1

#### Introduction and consent process

- Introduce yourself and study
- Interview expected to last 1 hour
- Explain participants rights
- Answer questions
- Ensure consent form signed.

*The interview will explore the following topics:*

#### Background

- Professional role of participant.

#### Learning about the CCN team's practice: implementing new services and approaches

- What protocols have the team set to ensure service quality and positive outcomes for the child and family
- What has informed this intended practice
- How do the team expect this to work in practice
  - Benefits
  - Challenges.

#### Learning about the CCN team's practice: access and availability

- What protocols have the team set to ensure accessibility and availability of the team for families
- What are the pathways into the team, and how do these differ by need/group
  - GP, Hospital, Other
- Coverage/hours
- What has informed this intended practice
- How do the team expect this to work in practice
  - Benefits
  - Challenges.

#### Learning about the CCN team's practice: care planning and case management

- What protocols have the team set for care planning and case management
  - Anticipated caseload and caseload management
- What has informed this intended practice
- How do the team expect this to work in practice
  - Benefits
  - Challenges.

### **Learning about the CCN team's practice: effective health and care partnerships**

- What protocols have the team set to create effective health and care partnerships with:
  - Families (training etc)
  - Other professionals involved in the care of the child
- What has informed this intended practice
- How do the team expect this to work in practice
  - Benefits
  - Challenges.

### **Learning about the CCN team's practice: information and technology**

- What protocols have the team set to use technology and information in supporting the child and family at home? (e.g. texting, telephone support)
- What has informed this intended practice
- How do the team expect this to work in practice
  - Benefits
  - Challenges.

### **Learning about the CCN team's practice: education and training**

- What are the team's training needs and how will these be met
- Clinical governance issues
- Anticipated issues around recruitment and retention.

### **Reflecting on the introduction of the team/new component of the service**

- Overall expectations, anticipated benefits and drawbacks.

### **[End of interview]**

- Feedback details
- Identification of other key people, relevant meetings, relevant documentation.

## **Transforming Children's Community Services (TraCCS) Study**

### **Topic Guide for Practitioners of the Children's Community Nursing Team: Interview/Focus Group 2**

#### **Introduction and consent process**

- Introduce yourself and study
- Interview expected to last 1 hour
- Explain participants rights
- Answer questions
- Ensure consent form signed.

*The interview will explore the following topics:*

#### **Brief recap on interview 1**

#### **Learning about the CCN team's practice: implementing new services and approaches**

- How have the team's protocols for ensuring service quality and positive outcomes worked in practice so far
  - What is the learning from this
    - Challenges, benefits
  - Are any changes being made to protocols because of this learning? What changes, and why.

#### **Learning about the CCN team's practice: access and availability**

- How have the team's protocols for ensuring service accessibility and availability worked in practice so far
  - What is the learning from this
    - Challenges, benefits
  - Are any changes being made to these protocols because of this learning? What changes, and why.

#### **Learning about the CCN team's practice: care planning and case management**

- How have the team's protocols for care planning and case management worked in practice so far
  - What is the learning from this
    - Challenges, benefits
  - Are any changes being made to protocols because of this learning? What changes, and why.

#### **Learning about the CCN team's practice: effective health and care partnerships**

- How have the team's protocols for creating effective health and care partnerships worked in practice so far
  - What is the learning from this
    - Challenges, benefits
  - Are any changes being made to protocols because of this learning? What changes, and why.

#### **Learning about the CCN team's practice: information and technology**

- How have the team's protocols for using information and technology for supporting families at home worked in practice so far

- What is the learning from this
  - Challenges, benefits
- Are any changes being made to protocols because of this learning? What changes, and why.

**Learning about the CCN team's practice: education and training**

- How have the team's training needs changed if at all, and why, impact on practice
- Changes in clinical governance issues
- Changes in issues around recruitment and retention
  - What is the learning from these issues?
    - Challenges, benefits
  - Are any changes being made to the team's education and training? What changes, and why.

**Reflecting on the introduction of the team/new component of the service**

- Key points of learning
- What advice would you give to commissioners and managers who want to develop CCN provision.

**[End of interview]**

- Feedback details
- Identification of other key people, relevant meetings, relevant documentation.

## Transforming Children's Community Services (TraCCS) Study Topic Guide for Parents using the Children's Community Nursing Team: Interview 1

### Introduction and consent process

- Introduce yourself and study
- Interview expected to last 60- 90 minutes
- Explain participants rights
- Answer questions
- Ensure consent form signed
- Complete demographic form.

*The interview will explore the following topics:*

### Background

- Demographic form

### Experience of the CCN team: access and availability

- Parents' experiences of accessing the team at first use, early use
  - How/when/where accessed
    - Referral
    - Choice
  - Services used/support received for child's care prior to using the CCN team
  - What happened at first contact
  - Availability (e.g. when in the day used – day hours, evening, etc., views)
    - Outside of CCN teams hours – other services contacted
  - Telephone support
    - How and when is telephone support used (e.g. advice)

### Experience of the CCN team: care planning and case management

- Parents' experiences of the planning and management of their child's care, first use, early use
  - Role of CCN team, other services
  - Care plan
    - Who created care plan
    - Planned contact/visits
    - Unplanned contact/acute exacerbations
      - Who does parent contact/what services used (In and Out of GP hours)
  - Single contact/key worker

### Experience of the CCN team: effective health and care partnerships

- Parents' experiences of how CCN team works with themselves and others, first use, early use
  - Parent involvement in child's care in partnership with the team (e.g. training)
  - CCN team working with other agencies/services involved in the child's care
    - Hospital (e.g. discharge),
    - GP
    - Education/schools/teachers
    - Social care
    - Continuing healthcare

### Experience of the CCN team: information and technology



- Parents' experiences of the use of information and technology to support their child's care at home, first use, early use
  - What and how used
  - Texting with team staff
  - Tablet devices during CCN visits
  - Equipment used
    - Role of team coordinating equipment

#### **Experience of the CCN team: education and training**

- Parents' perceptions of the skills and training of the CCN team staff, first use, early use

#### **Experience of the CCN team: Implementing new services and approaches**

- Parents' experiences of the quality of the service they received, and achieving positive outcomes, first use, early use
  - Support
  - Relationships
  - Meeting needs

#### **Reflecting on the first use of the team**

- Overall views on how the quality of care and support provided by the team **compares** with other services used for the care of the child previously
  - Home/hospital
  - Being supported at home
- Expectations about using the team in future for child (link with any particular issues pertinent to parent)
- Overall views on helpful and unhelpful practice in first use/early of CCN team.

#### **Costs incurred by family (see template questions)**

##### **[End of interview]**

- Feedback details; MH Family Index; details about contact for arranging second interview.

## **Transforming Children’s Community Services (TraCCS) Study**

### **Topic Guide for Parents using the Children’s Community Nursing Team: Established parent users of team (1 interview)**

#### **Introduction and consent process**

- Introduce yourself and study
- Interview expected to last 60- 90 minutes
- Explain participants rights
- Answer questions
- Ensure consent form signed
- Complete demographic form.

*The interview will explore the following topics:*

#### **Background**

- Demographic form

#### **Experience of the CCN team: access and availability**

- Parents’ experiences of accessing the team
  - How/when/where accessed
    - Referral
    - Choice
  - Services used/support received for child’s care prior to using the CCN team
  - What happened at first contact
  - Availability (e.g. when in the day used – day hours, evening, etc., views)
    - Outside of CCN teams hours – other services contacted
  - Telephone support
    - How and when is telephone support used (e.g. advice)
  - How has parents’ experiences of accessing the team changed over duration of using the team
    - Views on this

#### **Experience of the CCN team: care planning and case management**

- Parents’ experiences of the planning and management of their child’s care
  - Role of CCN team, other services
  - Care plan
    - Who created care plan
    - Planned contact/visits
    - Unplanned contact/acute exacerbations
      - Who does parent contact/what services used (In and out of GP hours)
  - Single contact/key worker
  - How has parents’ experiences of the planning and management of their child’s care changed over duration of using the team
    - Views on this

#### **Experience of the CCN team: effective health and care partnerships**

- Parents’ experiences of how CCN team works with themselves and others
  - Parent involvement in child’s care in partnership with the team (e.g. training)

- CCN team working with other agencies/services involved in the child's care
  - Hospital (e.g. discharge),
  - GP
  - Education/schools/teachers
  - Social care
  - Continuing healthcare
- How has parents' experiences of how the team works with themselves and others for their child's care changed over duration of using the team
  - Views on this

### **Experience of the CCN team: information and technology**

- Parents' experiences of the use of information and technology to support their child's care at home
  - What and how used
  - Texting with team staff
  - Tablet devices during CCN visits
  - Equipment used
    - Role of team coordinating equipment
  - How has parents' experiences of the use of information and technology to support their child's care changed over duration of using the team
    - Views on this

### **Experience of the CCN team: education and training**

- Parents' perceptions of the skills and training of the CCN team staff
  - How has parents' perceptions of the CCN's skills and training changed over duration of using the team
    - Views on this

### **Experience of the CCN team: Implementing new services and approaches**

- Parents' experiences of the quality of the service they received, and achieving positive outcomes
  - Support
  - Relationships
  - Meeting needs
  - How has parents' experiences of service quality changed over duration of using the team
    - Views on this

### **Reflecting on overall use of the team**

- Overall views on how the quality of care and support provided by the team **compares** with other services used for the care of the child before and during use of the CCN team
  - Home/hospital
  - Being supported at home
- Overall views on how quality of care has changed (if at all) since first started using the team
- Expectations about using the team in future for child (link with any particular issues pertinent to parent)
- Overall views on helpful and unhelpful practice
- Suggestions for improvements, advice for other areas developing similar services

### **Costs incurred by family (see template questions)**

#### **[End of interview]**

- MH Family Index; give support leaflet; feedback details; enquire about child's possible participation.

## Transforming Children's Community Services (TraCCS) Study Topic Guide for Parents using the Children's Community Nursing Team: Interview 2

### Introduction and consent process

- Introduce yourself and study
- Interview expected to last 60 - 90 minutes
- Explain participants rights
- Answer questions
- Ensure consent form signed
- Complete demographic form.

*The interview will explore the following topics:*

### Background

- Number of times they have used the team since Interview 1
- Reasons for using the team since Interview 1.

### Experience of the CCN team: access and availability

- Parents' experiences of the team's access and availability
  - How/where accessed
    - Referral
    - Choice
  - Availability (e.g. when in the day used – day hours, evening, etc., views)
    - Outside of CCN teams hours – other services contacted
  - Telephone support
    - How and when is telephone support used (e.g. advice)
  - Use of other services in place of team
- How has this changed over the past 6 months

### Experience of the CCN team: care planning and case management

- Parents' experiences of the planning and management of their child's care
  - Role of CCN team, other services
  - Care plan
    - Planned contact/visits
    - Unplanned contact/acute exacerbations
      - Role of CCN team
      - Who does parent contact/what services used (In and Out of GP hours)
  - Single contact/key worker
- How has this changed over the past 6 months

### Experience of the CCN team: effective health and care partnerships

- Parents' experiences of how CCN team works with themselves and others
  - Parent involvement in child's care in partnership with the team (e.g. training)
  - CCN team working with other agencies/services involved in the child's care
    - Hospital (e.g. discharge),
    - GP
    - Education/schools/teachers
    - Social care

- Continuing healthcare
- How has this changed over the past 6 months

### **Experience of the CCN team: information and technology**

- Parents' experiences of the use of information and technology to support their child's care at home
  - What and how used
    - Texting
    - Equipment
- How has this changed over the past 6 months

### **Experience of the CCN team: education and training**

- Parents' perceptions of the skills and training of the CCN team staff
  - How has this changed over the past 6 months

### **Experience of the CCN team: implementing new services and approaches**

- Parents' experiences of the quality of the service they have received, and achieving positive outcomes
  - Support
  - Relationships
  - Meeting needs
- How has this changed over the past 6 months

### **Reflecting on using the team over the previous 6 months**

- Overall views on how the quality of care and support provided by the team **compares** with other services used for the care of the child;
  - How (and why) have these views changed since Interview 1
- Is there anything particularly helpful or unhelpful about the way the team supports you and your child at home
- What advice would you give to commissioners and managers about developing CCN teams.

### **Costs incurred by family (see template questions)**

#### **[End of interview]**

- Feedback details; MH Family Index; discuss possible participation of child/young person, and pass on relevant information.

# TraCCS Study

## Topic Guide for Children and Young People Using the Children's Community Nursing Team

**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 (for example, translators, 'Talking Mats') will be used as appropriate. For all interviews, parent's/carer's advice will be sought on how best to conduct the interview with their child.

### Introduction

- Introduce yourself
- Explain what the project is about and the importance of young people's views
- Explain that you will be talking to other children who use the same service as the interviewee
- Explain what you would like to talk about
- Show child some of the resources they can use during the interview (for example, coloured paper, pens, stickers, etc.)
- Emphasise that there are no right or wrong answers.

### Consent process

- Explain confidentiality, including when the researcher would have to break it
- Explain what will happen to the information collected and how the researcher will maintain confidentiality
- Emphasise that the 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 the child is happy to take part and ask the child to sign the consent form
- Ask permission to use the digital recorder and set it up with the child

- Discuss with the parent/carer and the child what the parent/carer is going to do during the interview.

#### **Warm up questions - a bit about you:**

- People the child lives with:
  - Ages of brothers and sisters
  - Pets
- Likes and dislikes.

#### **About the nurse who visits you at home:**

- Who comes to visit
- When first visited you
- Same/different person on different occasions
- What happens during visit
- What other people in family do when the nurse visits (mum/dad/brothers/sisters)
- How they felt about nurse visiting them at first
- How they feel about nurse visiting them now:
  - If changes in views, why
- Parts they like about the nurse visiting them
- Parts they don't like about the nurse visiting them
- Does the nurse visit you anywhere else:
  - School
  - Clinics.

#### **About other places you go to get help:**

- Hospital
- Clinics
- What is this like
- Which do you prefer - going to hospital/clinics or having a nurse visit you at home.

#### **Ideas for making services better:**

- When the nurse visits you at home, is there anything you would change to make it better.

#### **[End of interview]**

- Thank the child for taking part in the project
- Remind the child what you are going to do with recording and that you will send them a report
- Ask the 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).

## Transforming Children's Community Services (TraCCS) Study

### Demographic Form for Parents/Carers Taking Part in this Study

**Age (Parent/Carer):** \_\_\_\_\_

**Relationship to child:** \_\_\_\_\_

**Ethnicity (please tick):**

Asian	<input type="checkbox"/>	Black/Black British	<input type="checkbox"/>
Chinese	<input type="checkbox"/>		
Mixed	<input type="checkbox"/>	White British	<input type="checkbox"/>

White Other  (please specify below):  
\_\_\_\_\_

Any other ethnic background (please specify below):  
\_\_\_\_\_  
\_\_\_\_\_

Child's diagnosis (please state below):  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Are you in receipt of DLA for child?     Yes     No

(To be completed by the researcher at interview.)



***Longitudinal analysis of parent interview data****Data management*

Data was managed using an excel spreadsheet, with a participant by theme/category matrix display as per the Framework approach (Ritchie & Lewis, 2003). Where two interviews were conducted with a participant, each data point was allocated its own row in the spreadsheet. Figure 23 gives an example of this.

**Figure 23: Example of data management where there were two points of data collection**

	THEME/CHART 1		
Case	Sub-theme 1	Sub-theme 2	Sub-theme 3
Participant 1 TIME 1			
Participant 1 TIME 2			
Participant 2 TIME 1			
Participant 2 TIME 2			
Participant 3 TIME 1			
Participant 3 TIME 2			

*Developing the framework(s)*

The framework was developed based largely on a-priori themes and topics as set out by the topic guide. The framework was intended to be broad in scope, with further iterations later in the analysis intending to refine its focus. The chart was piloted by two researchers, and amendments made to improve fit. Data was then extracted onto the charts. The thematic framework used is presented in Table 29 below.

**Table 29: Thematic framework**

***Sheet 1 - Summaries***

1. Summary of early experiences of using the team
2. Summary of later experiences of using the team
3. Summary of change
  - a. Summary of change in use of CCN team (inc. change in child's needs)
  - b. Summary of change in views of care quality from CCN team
  - c. Summary of change in expectations about the CCN team
  - d. Other change
4. Summary of aspects of practice that work well/are helpful
5. Summary of aspects of practice that do not work well/could be improved/recommendations
6. Summary of aspects of practice that contribute to care quality (combination of 2 + 3)

***Sheet 2 – Pathway into the CCN service (Time 1 only)***

1. What support was parent receiving for child prior to referral to CCN team?

- a. Hospital
  - b. At home – no CCN support (e.g. used other services, such as GP)
  - c. At home – other CCN support
  - d. Other
  - e. Views about this support
2. Referral to CCN team
    - a. What led to referral
    - b. Who, when and how referred and what happened (inc. preparation, training, contact with CCN team whilst on the ward etc)
    - c. Knowledge of role of team
    - d. Views and expectations about referral and use of the team
    - e. Choice
  3. First visit
    - a. What happened and views
  4. Other

**Sheet 3 - Managing child's care at home**

1. Description of child's needs
2. Role of parent(s)
3. Views about own role in child's care
4. Role of the team
  - a. Clinical (acute and long-term management)
  - b. Care coordination
  - c. Other
5. Preferences about location of care

**Sheet 4 – access and availability (Time 1 and 2)**

1. Who contacts who (e.g. parent → team, team → parent)
2. Frequency of contact
3. Methods of contact used and preferred (e.g. telephone support)
4. Reasons for contact
5. Who does team contact outside team hours
6. Views of accessibility of team
7. How accessibility of team compares with accessibility of other services used for similar functions (e.g. GP)
8. (Time 2 only, or EA/B/D interviews) Summary of changes in parents access of team for child and views
9. Other

**Sheet 5 A – care planning and case management PLANNED (Time 1 and 2)**

1. Planned contacts and care
  - a. What planned contacts does the parent have with team?
  - b. Creation and use of care plan
  - c. Team's use of care plan/schedule (if applicable)
  - d. Views of care plan and team's use of care plan/schedule (if applicable)
2. Care coordination
  - a. Team's role in this
  - b. Views of team's role in coordinating care
  - c. Single point of contact/key worker in the CCN team

- d. Views on single point of contact/key worker in the CCN team (if applicable)
- 3. Continuity of staffing for care
  - a. Views on continuity of staffing for care
- 4. (Time 2 only, or EA/B/D interviews) Summary of changes in care planning and case management and views (PLANNED)

**Sheet 5 B – care planning and case management UNPLANNED (Time 1 and 2).**

- 1. Who does parent contact when child is acutely ill and why
  - i. CCN team
  - ii. GP
  - iii. A&E
  - iv. Other
- b. Role of CCN team in advising parents to manage acute illness
- c. Views on CCN team input for acute episodes
- d. Views on other service input (e.g. GP, A&E, walk-in centres) for acute episodes
- 2. (Time 2 only, or EA/B/D interviews) Summary of changes in care planning and case management and views (UNPLANNED)
- 3. Other

**Sheet 6 – partnerships (Time 1 and 2)**

- 1. Who else is involved with child's care
- 2. How does CCN team work with other services
- 3. Views on how CCN team works with other services
- 4. Distinguishing CCN team from other input
- 5. How team works with parent and family
- 6. Views on how team works with parent and family
- 7. (Time 2 only, or EA/B/D interviews) Summary of changes in partnership working between CCN team and others (inc. parent) and views
- 8. Other

**Sheet 7 – information and technology (Time 1 and 2)**

- 1. Technology used by the team
- 2. Views of technology used by the team
- 3. Child's equipment needs and team's role in this
- 4. Views on team's role in meeting child's equipment needs
- 5. (Time 2 only, or EA/B/D interviews) Summary of changes in I&T use and views
- 6. Other

**Sheet 8 – Skills and competencies of CCN team staff (Time 1 and 2)**

- 1. Type of staff in contact with in the team
  - a. Note if parent uncertain of staff type in contact with
- 2. Views on staff clinical competencies
- 3. Views on staff non-clinical competencies
- 4. (Time 2 only, or EA/B/D interviews) Summary of changes in parents' views of staff skills and competencies
- 5. Other

**Sheet 9 – Impact and outcomes (Time 1 and 2)**

- 1. Impact on and outcomes for (positive and negative)

- a. Parent
- b. Child
- c. Other family members
- d. Costs
- e. Employment
2. Ways in which team are meeting parents and child's needs
3. Outstanding needs, concerns
4. (Time 2 only, or EA/B/D interviews) Summary of any changes
5. Other

**Sheet 10 - overall views (Time 1 and 2)**

1. Overall views of the quality of the support received by the CCN team
2. Views about how CCN team support compares with other services used for child
  - a. Before CCN team referral (e.g. hospital, other CCN team)
  - b. During period of CCN team use (e.g. GP, other CCN team)
3. Suggestions, advice and improvements

*Data interrogation and analysis*

As per Lewis' (2007) and Holland *et al.*'s (2004) approach to longitudinal data, 2 analytical strategies were used:

1. **Narrative case analysis over time.** This strategy examines change by individual cases across data collection points in the study. Molloy *et al.*'s (2002) data interrogation questions were used to guide the examination of change through time for each case:
  - a. Has any change occurred?
  - b. What change has occurred?
  - c. How or through what mechanism has change occurred?
  - d. Why has change occurred?

Saldana (2003) also suggests examining the absence of change, by looking at what 'remains constant through time' in the data.

These questions were used to provide a summary of change in use of the service and experience of quality of care for each case. The summary was added to the charted data (see sheet 1 in table 1).

2. **Thematic analysis.** As per the Framework approach, thematic analysis was used. This analysis examined:
  - a) Pathways into the service
  - b) The ways in which the services were used
  - c) Experiences of care quality by looking at
    - a. Overarching views of care quality
    - b. Aspects of the service parents valued
    - c. Positive outcomes that parents felt were achieved as a result of using the service
    - d. Aspects of the service that could be improved and why

- d) Trajectories of change in service use
- e) If and how the valued aspects of the service changed over time (e.g. in how they were used by, or made available to, parents, at different times).
- f) If and how overarching views of quality of care changed over time, and if and how this was linked to changes in service use
- g) How quality of the care provided by the team compared to the quality of services used before and during CCN service use

Analysis strands A-F were undertaken by case site team, to understand how experiences differed by service model. Analysis strand G was undertaken across sites, because data was grouped into what service support parents were receiving before referral into the CCN team (hospital, other CCN support, no support). When also grouped by site, the numbers in each group/site were too small to undertake meaningful analysis.

The thematic analysis involved drawing upon the charted data in the framework (including the summaries), as well as creating sub-charts, as a means of further breaking down the data to identify patterns and themes.

For each strand of the thematic analysis, we built a thick description of the themes and issues, paying close attention to emerging typologies, diversity and deviant cases (e.g. see Green & Thorogood, 2009).

## ***Longitudinal analysis of staff interview and focus group data***

### *Data management*

Data was managed using an excel spreadsheet, with a participant by theme/category matrix display as per the Framework approach (Ritchie & Lewis, 2003). Where two or more interviews/focus groups were conducted with a participant/group, each data point was allocated its own row in the spreadsheet and ordered consecutively.

### *Developing the framework*

Two frameworks were developed – one for the NHS practitioner data (where there were two points of data collection), and one for the senior NHS staff involved in developing and commissioning the services data (where there were up to three points of data collection). Two separate frameworks were developed to reflect the different professional perspectives. For each dataset (practitioners and those involved in developing/commissioning services) one framework was developed to cover all sites. This enabled systematic comparison between, and thematic analysis across, all sites.

The framework themes were developed after the first round of data collection. This approach helped to focus the second round of data collection and ensured ease of comparisons between the two sets of data. However, framework sub-themes were broad and a spare column on each chart ('other') was used to chart material arising in the second and subsequent rounds of data collection that did not fit with the themes (Lewis, 2007). The framework was based on a-priori issues (see below the issues we wanted to understand) as well as emerging themes in the data. Table 30 below presents the thematic framework used for each dataset.

**Table 30: Thematic framework for manager and commissioner data**

#### **Manager and Commissioner Interview Data**

1. Service landscape before introduction/reconfiguration of CCN services
2. Planned changes (TIME 1 ONLY)
3. Drivers of CCN reconfiguration(s)
4. Outcomes & Benefits
  - 4.1. *Intended*
  - 4.2. *Achieved*
5. Process of reconfiguration
  - 5.1. *knowing about local health needs and planning services accordingly*
  - 5.2. *access and availability*
  - 5.3. *care planning and case management*
  - 5.4. *effective health and care partnerships*
  - 5.5. *information and technology*
  - 5.6. *education and training*
  - 5.7. *Other*
6. Progress

7. Challenges
8. Facilitators
9. Impact on primary care
  - 9.1. *Anticipated*
  - 9.2. *Actual*
10. Impact of changing commissioning arrangements on CCN service reconfigurations/development
11. Additional service context that may help to understand ITS analysis
12. Summary of issues arising from documents (where case is document, not participant)

**Practitioner Focus Group & Interview Data**

1. Description of CCN team's practice (TIME 1 ONLY)
2. Past changes and developments in CCN team (and reflections on how these have worked) (TIME 1 ONLY)
  - a. Access and accessibility
  - b. Care planning and case management
  - c. Health and care partnerships
  - d. Information and technology
  - e. Education and training
  - f. Implementing new services and approaches
  - g. Other
3. Key changes to provision, and expectations (TIME 1) and reflections (TIME 2)
  - a. Access and accessibility
  - b. Care planning and case management
  - c. Health and care partnerships
  - d. Information and technology
  - e. Education and training
  - f. Implementing new services and approaches
  - g. Other
4. Challenges experienced in developing/implementing new practice/team (TIME 1 AND 2)
  - a. Access and accessibility
  - b. Care planning and case management
  - c. Health and care partnerships
  - d. Information and technology
  - e. Education and training
  - f. Implementing new services and approaches
  - g. Other
5. Challenges 2 (TIME 1 AND 2)
  - a. Relating to introduction or expansion
  - b. Relating to every day practice
6. Factors facilitating development/implementation of CCN team (TIME 1 AND 2)
  - a. Practice level
  - b. Organisational level (e.g. commissioning)
  - c. Macro level structures
  - d. Other
7. Perceived benefits of the team (TIME 1 AND 2)

- a. To team's practice
- b. To other services
- c. To families
- d. Other
8. Primary care
  - a. Impact of primary care on the team (TIME 1 AND 2)
  - b. Impact of team on primary care (TIME 1 AND 2)
9. Advice to commissioners when developing CCN teams (TIME 1 AND 2)
10. Advice to other CCN teams when developing teams (TIME 1 AND 2)

Table 31 below presents an overview of the key issues we sought to understand, the analytical strategies employed, and notes about where strands of analysis merged.



**Table 31: Data interrogation and analysis**

Issues the analysis will provide an understanding of	Analytical strategies employed	AD HOC NOTE FROM ANALYSIS
The process of service reconfiguration, and the context in which it happens.	Narrative/descriptive analysis of the process of change within each case site over time.	
<p>(CONTEXTUAL MECHANISMS) The barriers and facilitators to planning, contracting, and monitoring and using CCN services, and:</p> <ol style="list-style-type: none"> <li>1. how these change over time</li> <li>2. the impact of these</li> <li>3. how commissioners and managers have responded to these,</li> <li>4. what we can learn from them.</li> </ol>	<p>Thematic analysis at stage 1, with further analysis from subsequent data collection stages feeding into existing themes or identifying new themes. Change will be examined using Molloy <i>et al.</i>'s (2002) data interrogation questions</p> <ol style="list-style-type: none"> <li>a) Has any change occurred?</li> <li>b) What change has occurred?</li> <li>c) How or through what mechanism has change occurred?</li> <li>d) Why has change occurred?</li> </ol> <p>As per Saldana (2003) we will look at what 'remains constant through time' in the data.</p>	<p>Analysis partly incorporates data on impact of changing commissioning arrangements.</p>
<p>Perceived impact of the redesign, over time, including impact on primary care.</p> <p><b>LINK WITH ACHIEVED OUTCOMES AND BENEFITS</b></p>	As above.	<p>Incorporated with analysis of benefits and outcomes</p>
<p>The influence of changed commissioning arrangements on the service redesign.</p> <p><b>LINK WITH BARRIERS AND FACILITATORS</b></p>	As above.	<p>Incorporated with analysis of barriers and facilitators</p>
<p>Key issues relating to outcomes, including:</p> <ol style="list-style-type: none"> <li>1. Intended outcomes of new services</li> <li>2. Achieved outcomes of new services</li> <li>3. Factors influencing outcomes</li> </ol> <p><b>LINK WITH BARRIERS AND FACILITATORS</b></p>	As above.	<p>Incorporated with analysis of benefits and impact</p>
Key issues relating to service quality.	As above.	<p>Incorporated with analysis of benefits.</p>
Anticipated and actual benefits of the reconfigured services.	As above.	<p>Incorporated with analysis of impact and outcomes.</p>
<p>- Any other emerging themes will also be drawn out.</p> <p>- Deviant cases will be sought to test and challenge emerging concepts and typologies (Green &amp; Thorogood, 2009).</p> <p><b>Comparisons</b></p> <p>- Data analysis will be overarching and by site to enable comparisons..</p>		

Translating and using the CCN development tool (formerly the MHI)

### **Purpose of the translating and using the MHI in the TraCCS project**

The MHI is a US developed service self-assessment tool designed to measure the extent to which services are achieving a 'medical home' for children with complex health care needs. The US concept of a medical home reflects the UK model of primary care, and has the ethos of family centred health care – an ethos reflected in NHS health care closer to home for children and young people who are ill. We intended to 'translate' and adapt the MHI so that it reflect CCN practice in the UK NHS context. We then wanted to explore with service managers whether it had any value for stimulating discussions around development of CCN services.

### **Process and summary of translation**

The process of translation took place over 9 stages:

1. The original MHI was presented to, and discussed with, commissioners and managers at the first TraCCS learning day.
2. A first attempt was made to translate the tool (Version 1). Details of changes are presented in the table below (first translation changes).
3. The tool was presented at the second TraCCS learning day, and feedback sought.
4. Further changes were made based on the feedback in stage 3. Details of changes are presented in the table below (further changes). These changes resulted in Version 2 of the tool, which included the removal of the quantification element, and the addition of short 'wall-chart' versions.
5. Version 2 was presented at a TraCCS Project Advisory Group meeting. Feedback was given, and recommendations made to change 'chronic condition management' to 'long-term condition management'.
6. Minor changes were made to the workbook to incorporate this feedback, resulting in Version 3.
7. Version 3 was presented and discussed at the third learning day. A recommendation was given to seek feedback from a contact at the Department of Health about the patient experience component.
8. Feedback was sought from this individual, and minor amendments made. These minor amendments included: a note to be included at the start of the tool about what 'family' refers to; revision of the cultural competence item to reflect UK discourse on diversity and equality; revision to domain one, item 4, level 4 to include a sentence saying the solutions and changes are demonstrated to CYP and their families.
9. This resulted in the finalised version of the tool (version 4), which is available in this appendix. A case site requested to pilot it.

### **Next steps**

The translation and adaption of this tool has been largely informed by the feedback from our NHS partners and Project Advisory Group representatives. The feedback we received suggested it could have value for

facilitate discussions around developing services. However, further work should fully evaluate the tool in practice.

The tool will be available on the Social Policy Research Unit website and free to use. We would encourage anyone using it to provide us with feedback, if possible.

First translation changes

<b>Translational change</b>	<b>Reason for change</b>
Primary care providers, office and practice changed to nurses, children's community nursing team (CCNT), or simply 'team'.	The services we are studying are children's community nursing teams.
<b>Language changes</b> <i>All language changes have been made to reflect the UK/NHS context. Changes by item/level are listed below.</i>	
<b>1.1., level 3:</b> 'mission' changed to 'aim'	Team 'aims' and 'objectives' are terms typically used in these teams rather than 'mission'.
<b>1.1., level 4:</b> 'parent/practice advisory group' changed to 'Patient & Public Involvement groups'	Patient & Public Involvement (PPI) groups are the recognised term for these kinds of groups in the NHS.
<b>1.2., level 1:</b> 'planned medical follow-up' changed to 'planned follow up'	We removed 'medical' from sentence as care provided CCNTs is largely recognised as nursing care rather than medical care.
<b>1.2., level 2:</b> The example is changed from 'call-in hours, phone triage for questions, or provider call back hours' to 'calling the team at designated times, phone triage for questions'	Change in wording reflects practice of CCNTs.
<b>1.2., level 4:</b> 'texting' has been added to the examples of communication preferences	Texting (via mobile/cell phone) is used between CCNTs and families.
<b>1.3., level 1:</b> 'medical' records has been changed to 'care' records	Records kept by the CCNT are not purely medical, but reflect wider aspects of the child's care.
<b>1.3., level 4:</b> 'staff locate space for families to read their child's record' has been changed to 'families hold their child's care record'	This more closely reflects the practice of CCNTs; families can hold copies of their child's care record.
<b>1.5., level 1 (now item 1.4 due to removal of an item):</b> 'health plan' is changed to 'commissioners/managers'	In the NHS, it is commissioners and/or service managers who (can) issue or request data collection on family feedback. 'health plan' is not a recognisable term in this context.
<b>1.7., level 2 (now item 1.6 due to removal of an item):</b> 'practice' changed to 'NHS trust'	It is the NHS trust (the organisation) who would support continuing education of staff.
<b>1.7., level 4 (now item 1.6 due to removal of an item):</b> 'family faculty' is changed to 'family experts'	'Family experts' is a term that would be better recognised in the NHS than 'family faculty'.
<b>2.2., level 1 (now item 2.1 due to removal of an item):</b> insertion of 'home' before 'visits'	The CCNT typically deliver care through visits to the family home.
<b>2.2., level 2 (now item 2.1 due to removal of an item):</b> 'non-acute' changed to 'planned'	'Planned' visits reflects language used in the NHS by CCNTs
<b>2.2., level 3 (now item 2.1 due to removal of an item):</b> 'practice back up/cross coverage providers' changed to 'other providers'	Other agencies in the UK public sector are generally referred to as 'providers'.
<b>2.3., level 2 (now item 2.2 due to removal</b>	

<b>of an item):</b> the example is changed to reflect language typically used in UK public sector (e.g. housing needs rather than needs for accommodation)	
<b>2.3., level 3 (now item 2.2 due to removal of an item):</b> 'external' providers changed to 'other providers'	'Other providers' more closely reflects language used in UK public sector
<b>2.6., level 4 (now item 2.4 due to removal of an item):</b> 'sponsors' changed to 'facilitates'	'Facilitates' more closely reflects what a CCNT would do in respect of this care activity.
<b>2.6., level 4 (now item 2.4 due to removal of an item):</b> 'state' removed	Not appropriate for UK context
<b>3.1.</b> Insertion of 'across agencies' in first sentence	This reflects that care coordination in the UK context is likely to be across different agencies/providers.
<b>3.2., level 1:</b> 'medical recommendations' changed to 'care recommendations'	A CCNT would make care recommendations but not medical recommendations.
<b>3.2., level 2:</b> 'treatment decisions' changed to 'care decisions'	A CCNT (with the family) would make care decisions, but not treatment decisions. Decisions about treatment would be made with the child's consultant, paediatrician, GP or other medical practitioner.
<b>3.2., level 3:</b> sentence reworded to reflect practice of CCNTs	
<b>3.3., level 2:</b> 'written information' changed to 'leaflets'	Written information is typically provided as a 'leaflet' in this context.
<b>3.3., level 3:</b> 'education' changed to 'information and advice'	Language more closely reflects that used in UK context.
<b>3.3., level 4:</b> as above	As above
<b>3.5., level 1:</b> 'insurance' removed	Not applicable to UK context
<b>3.5., level 1:</b> sentence changed from 'family intakes' to 'initial assessment'	This reflects the practice of CCNTs. There is no 'family visit intakes' in CCNT practice. Once a family is referred to the team, a member of the team will visit the family to undertake an initial assessment.
<b>3.5., level 2:</b> 'community and state' changed to 'local and national'	Reflects UK context
<b>3.5., level 3:</b> insurance options' removed	Not applicable to UK context
<b>3.5., level 3:</b> 'medical resources' changed to 'health resources'	A CCNT would be more likely to have knowledge of health rather than medical resources.
<b>3.6., level 1:</b> 'Parent support and Information Centers' changed to 'parent support groups'	Changed to reflect UK context
<b>3.6., level 2:</b> 'Parent to Parent groups' changed to 'parent groups'	Changed to reflect UK context.
<b>4.1., level 3:</b> 'state' removed	Not applicable to UK context
<b>4.1., level 4:</b> as above	As above
<b>4.2., level 2:</b> removed 'community' prior to	Another agency may not necessarily be

agency.	community based in the NHS context (e.g. a hospital).
<b>4.2., level 3:</b> as above	As above
<b>4.2., level 4:</b> 'sponsor' changed to 'facilitate'	Changed to reflect practice of CCNTs in UK context.
<b>5.1., level 1:</b> 'chart' changed to 'record', and 'payer sources' changed to 'commissioners'	Changed to reflect UK context
<b>5.1., level 2:</b> 'billing' removed	Not applicable to UK context
<b>5.1., level 3:</b> 'on the caseload' has been added	This reflects that the team's practice of data collection will pertain only to children on the team's caseload.
<b>5.2., level 2:</b> 'billing' removed	Not applicable to UK context
<b>5.2., level 3:</b> 'population' changed to 'caseload'	Data used by the team only pertains to those on the team's caseload and not the wider population of children with special healthcare needs.
<b>Other additions/changes</b>	
An answer option of 'In development' has been added.	As the teams trying out the UK version are developing their CCNTs, we have included this option to allow teams to document this.
Addition of a comments section after each domain	At the request of one of our NHS partners, this is to facilitate discussions of service development in relation to responses given in the domain items.
<b>1.4.</b> 'Office environment' item has been removed.	This item on office environment is incompatible with the practice of CCNTs as the teams mostly provide care in the family home or in school settings. The teams typically go to families to provide care, rather than families going to the team in a clinic.
<b>2.1.</b> 'Identification of children in the practice with special health care needs' has been removed.	Identification of this population is not within the remit of CCNTs. This is done by the NHS commissioners (at a strategic, rather than practice, level), through needs and population assessments. Thus, it is not the CCNT who identify families for care delivery; other practitioners and agencies refer families to the CCNT for care.
<b>2.5.1.</b> 'Supporting the transition to adulthood'. This item has been removed.	'Transition' from child to adult services is increasingly becoming a discreet aspect of service provision in the NHS. For the purposes of this study, and for the use of this tool in the development of CCNTs, it is unlikely to be applicable.

## Further changes made to tool after feedback from second learning day

Change	Reason for change (based on feedback from learning day 2)
<i>Structure and layout</i>	
Changed the layout from a table format to a workbook format with one item per page	<ol style="list-style-type: none"> <li>1. To enhance readability</li> <li>2. To enable larger font size</li> <li>3. Reading across makes it look like to complete all boxes</li> </ol>
Removal of answer options	<p>Current practice in the NHS involves a lot of self-assessment tools, which can be seen as punitive. Tick box/assessment tools can also inhibit the extent to which staff can think creatively about services. In order to use it as a service development tool, it would be better to remove the tick boxes.</p> <p>Consequently, we will no longer collect data using the MHI. We will discuss its use with our partners throughout the project to explore its value as a service development tool.</p>
Split introduction into 'Where this comes from' and 'how to use this workbook'.	Existing introduction was unclear. Revised introduction retains USMCHB funding acknowledgment and the original name of the tool.
Creation of shorter 'wall chart' versions of each domain	Some felt it was too long, but others thought it was an appropriate length. To compromise, we have created shorter, simpler version of each domain as wall charts. In each of these, the items have been abridged.
Addition of more space to make notes.	To underline the service development function.
<i>Language</i>	
Changed 'tool' to 'workbook'.	It was felt that 'tool' implies an assessment function. Changed to workbook to underline its service development function.
Change of title to reflect Children's Community Nursing rather than Medical Home Index.	Some felt keeping the term Medical Home Index was confusing as the translation is referring to a nurse-led service.
'Children with special health care needs' changed to 'children with complex health care needs'	<i>Children with complex health care needs</i> is a more common term used in the UK. To reduce the words in each item, we have stated at the start of the tool that it refers to this group of children, rather than stating this in each item.
Change care record to care plan.	CCN teams keep care plans but not care records.
Removal of examples in each item.	Some felt that the examples would encourage staff using the tool to focus solely on the examples due to time pressures. Removing examples would encourage staff to think more

	broadly.
Use of abbreviation list	To reduce wordiness of some items, abbreviations have been used and a list included at the start of the workbook.
<b>Simplification of language in some items.</b>	<b>Some felt the language was overcomplicated. To be able to use it, the language would need to be simplified.</b>  <b>We have simplified the language in the items list below, mostly to reduce wordiness and aid clarification. Where there are additional reasons, these are stated.</b>
<i>Domain 1</i>	
Item 2, level 1: removal of CCNT in second sentence	
Item 3, level 1: removal of CCNT. See above re use of <i>care plan</i> in place of <i>care record</i> .	
Item 3, level 4: restructure of sentence.	For clarification about families holding their care plan.
Item 4, level 1: 'practice' change to 'team'.	CCN services are usually referred to as team's rather than practices (which, in turn, are typically used to refer to General Practice surgeries in the UK).
Item 5, level 2: removal of 'through effort to obtain translators or to access information from outside sources'	
Item 5, level 4: Partial revision of sentence	
<i>Domain 2</i>	
Domain 2 – 'care continuity' changed to 'care planning'	Reflects how this would be termed in the UK context.
Item 1, level 2: removal of 'lab and medical'.	
Item 1, level 3: 'home, school and community concerns are addressed in this plan' changed to 'and addresses home, school and community concerns'.	
Item 1, level 4: removal of 'they include goals, services, interventions and referral contacts'.	
Item 2, level 2: removal of 'such as, specialists, schools and other community professionals who work with children with special health care needs'.	
Item 3, level 3: removal of 'family, the CCNT and specialists'.	
Item 3, level 4: removal of 'strong' and changed 'parents as partners' to 'parents'.	
<i>Domain 3</i>	
Item 2, level 4: 'contribute to a description of' changed to 'help describe'. 'this in the CCNT'	



removed.	
Item 3, level 3: removal of 'regarding having a child with special health care needs'	
Item 5, level 2: removal of 'the family seeks out additional information and may share back lessons learned.'	
<i>Domain 4</i>	
Item 1, level 2: revision of sentence.	
Item 1, level 4: removal of 'about population needs'.	
Item 2, level 3: changed 'that directly serve children with special health care needs' to 'directly involved with'.	
Item 2, level 4: removal of 'specialised home care, respite care recreation opportunities, or improving home/school/provider communication'.	
<i>Domain 5</i>	
Item 1: 'supports' changed to 'systems'.	Reflects terms more likely used in the UK.
Item 2: 'retrieval capacity' changed to 'use'.	
Item 2, level 4: removal of '(those producing and using data practice confidentiality).'	
<i>Domain 6</i>	
Item 1: removal of '(structures)'.	For clarity.
Item 1, level 3: removal of 'treatment for this population'.	
Item 1, level 4: QI removed from second sentence.	
Item 2: removal of '(processes)'.	For clarity.
Item 2, level 3: removal of 'for this population'.	
Item 2, level 4: 'needs of children on their caseload' added.	
<i>Other</i>	
<b>Verification from policy</b>	Some noted that it needs verification from policy to ensure it reflects the policy direction for children's community nursing.

## CCN development tool (formerly the Medical Home Index Pediatric)

THE UNIVERSITY *of York*



# The Children's Community Nursing Development Tool

CCN practice for children with long-term, complex health care needs

An adaptation of the Medical Home Index (Pediatric)

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## Where does this tool come from?

- The Medical Home Index (Pediatric) was developed by the Center for Medical Home Improvement in the USA (funded by the US Maternal and Child Health Bureau).
- Originally, it was a questionnaire designed to capture and quantify the activities of primary care practice for children and young people with chronic and complex health care needs.
- As part of the TraCCS project, we have adapted this questionnaire so that it is a development tool that reflects the organisation and delivery of Children's Community Nursing (CCN) services.
- We have developed this tool in partnership with NHS commissioners, managers and practitioners.

## How to use this tool

- This tool has **six** domains representing areas of service organisation and delivery of CCN teams.
- Each domain has a number of items describing aspects of practice.
- Each *item* contains **four levels** of practice.
- This tool can be used to facilitate discussions about what your *current* team practice looks like, and how you would *like* it to look. For each item across the six domains, you can choose which level best describes your current practice, and which level you want it to be.
- There are various ways to use the tool (e.g. within teams, as peer assessment across teams), and it is up to you how much of the tool is used at any one time. For example, you may choose to focus on one particular domain that is of particular interest to your current practice, and revisit the remainder of the tool at another time.
- There is space under each item, and each item level, to write notes, for example, about team development plans, or if you think the item is currently irrelevant to your team's practice. It may help to think about, and make a note of, current barriers you face as a team to achieving the different levels of practice.
- This workbook is about practice for children with long-term, complex health care needs only.

**Abbreviations:**

CCNT: Children's Community Nursing Team

PPI: Patient & Public Involvement

CC: Care coordinator

**Note about terminology**

Throughout this tool, we use the term 'family' to refer to: children and young people with complex health care needs using your service, their families (e.g. parents, siblings), and for those children and young people in care, their carers.

## DOMAIN 1: ORGANISATIONAL CAPACITY

### 1. The aims of the team

#### LEVEL 1

Nurses in the CCNT have individual ways of delivering care; their own education, experience and interests drive care quality.

#### LEVEL 2

Approaches to the care of children in the CCNT are child rather than family centred; the team's needs drive the implementation of care.

#### LEVEL 3

The CCNT uses a family-centred approach to care, they assess children and the needs of their families in accordance with its aims; feedback is solicited from families and influences the team's policies.

#### LEVEL 4

In addition to level 3, PPI groups are used to inform and develop family centred strategies, practices and policies; a written, visible mission statement reflects the CCNT's commitment to quality care for children and their families.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**

## DOMAIN 1: ORGANISATIONAL CAPACITY

### 2. Communication & Access

#### LEVEL 1

Communication between the family and the CCNT occurs as a result of family inquiry; contacts with the family are for test result delivery or planned follow up by the service.

#### LEVEL 2

In addition to level 1, standardised communication methods are identified to the family by the CCNT.

#### LEVEL 3

The CCNT and family communicate at agreed upon intervals and both agree on “best time and way to contact me”; individual needs prompt weekend or other special appointments.

#### LEVEL 4

In addition to level 3, the CCNT’s activities encourage individual requests for flexible access; access and communication preferences are documented in the care plan and used by other team staff.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**

## DOMAIN 1: ORGANISATIONAL CAPACITY

### 3. Access to care plan

#### LEVEL 1

A policy of access to care plans is not routinely discussed with families; plans are provided only upon request.

#### LEVEL 2

In addition to level 1, it is established among team staff that families can review their child's care plan (but this fact is not explicitly shared with families).

#### LEVEL 3

All families are informed that they have access to their child's care plan; staff facilitate access within 24-48 hours.

#### LEVEL 4

Families hold their child's care plan and staff make themselves available to answer questions. Team orientation and training materials include information about this.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**



## DOMAIN 1: ORGANISATIONAL CAPACITY

### 4. Family feedback and audit

#### LEVEL 1

Family feedback to the CCNT occurs through external mechanisms, such as, satisfaction surveys issued by commissioners /managers; this information is not always shared with team staff.

#### LEVEL 2

Feedback from families is elicited sporadically by individual CCNT staff or by a suggestion box; this feedback is shared informally with other providers and staff.

#### LEVEL 3

Feedback from families regarding their perception of care is gathered through systematic methods; there is a process for staff to review this feedback and to begin problem solving.

#### LEVEL 4

In addition to level 3, an advisory process is in place with families, which helps to identify needs and implement creative solutions; there are tangible supports to enable families to participate in these activities. Solutions and changes are demonstrated to families.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**

## DOMAIN 1: ORGANISATIONAL CAPACITY

### 5. Equality, diversity and inclusion

#### LEVEL 1

The CCNT attempts to overcome obstacles to diversity (e.g. communication needs) on a case by case basis when confronted with barriers to care.

#### LEVEL 2

In addition to level 1, resources and information are available for families of the most common diverse backgrounds and circumstances; others are assisted individually.

#### LEVEL 3

Materials are available and appropriate for a range of diverse backgrounds and circumstances; these materials are appropriate to the developmental level of the child/young adult.

#### LEVEL 4

In addition to level 3, family assessments include pertinent information about their diverse circumstances and needs to facilitate inclusion. This information is incorporated into care plans.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**

## DOMAIN 1: ORGANISATIONAL CAPACITY

### 6. Staff education

#### LEVEL 1

For all CCNT staff, an orientation to internal team practices, procedures and policies is provided.

#### LEVEL 2

In addition to level 1, the NHS trust supports (paid time, tuition support) continuing education for all CCNT staff in the care of children with complex health care needs.

#### LEVEL 3

In addition to level 2, educational information on community-based resources for children with complex health care needs, including condition specific resource information, is available for all staff.

#### LEVEL 4

In addition to level 3, families are integrated into CCNT staff orientations and educational opportunities as teachers or 'family experts'; support for families to take this role is provided.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**

## DOMAIN 2: LONG-TERM CONDITION MANAGEMENT

### 1. Care planning (Visits)

#### LEVEL 1

Home visits by the CCNT occur as a result of acute problems or well child schedules; the family determines follow up.

#### LEVEL 2

Planned visits occur with families to address long-term condition care; the CCNT determines appropriate visit intervals; follow up includes communication of tasks to staff and of test results to the family.

#### LEVEL 3

The CCNT and the family develop a care plan, which details visit schedules, communication strategies, and addresses home, school and community concerns. Other providers' practice is informed by this plan.

#### LEVEL 4

In addition to level 3, the CCNT uses condition protocols. A designated CC uses these tools and other standardised office procedures, which support children and families.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**

## DOMAIN 2: LONG-TERM CONDITION MANAGEMENT

### 2. Continuity of information and communication across settings

#### LEVEL 1

Communication among the CCNT, specialists, therapists and school happens as needs arise for children.

#### LEVEL 2

A CCN makes requests and/or responds to requests from agencies or schools on behalf of children; all communication is documented.

#### LEVEL 3

Systematic practice activities foster communication among the CCNT, family, other providers. These methods are documented and may include information exchange forms or ad hoc meetings with external providers.

#### LEVEL 4

In addition to level 3, a method is used to convene the family and key professionals on behalf of children; specific issues are brought to this group and they all share and use a written plan of care.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**

## DOMAIN 2: LONG-TERM CONDITION MANAGEMENT

### 3. Collaborative management between the CCNT and specialist medical

#### LEVEL 1

Specialty referrals occur in response to specific diagnostic and therapeutic needs; families are the main initiators of communication between specialists and their CCNT.

#### LEVEL 2

In addition to level 1, specialty referrals use phone, written and/or electronic communications; the CCNT waits for or relies upon the specialists to communicate back their recommendations.

#### LEVEL 3

The CCNT and family set goals for referrals and communicate these to specialists; together they clarify co-management roles, and determine how specialty feedback to the family and CCNT is expressed, used, and shared.

#### LEVEL 4

In addition to level 3, the family has the option of using the CCNT in a coordinating role; parents and the team manage the child's care using specialists for consultations and information (unless they prefer specialists to manage the majority of their child's care).

#### GAPS IN PRACTICE:

#### ACTIONS:

#### PERSON TO LEAD:

## DOMAIN 2: LONG-TERM CONDITION MANAGEMENT

### 4. Family support

#### LEVEL 1

Families are responsible for carrying out recommendations made to them by their CCN when they specifically ask for family support or help.

#### LEVEL 2

The CCNT responds to clinical needs; broader social and family needs are addressed and referrals to support services facilitated.

#### LEVEL 3

The CCNT actively takes into account the overall family impact when a child has a long-term condition by considering all family members in care; when families request it, staff will assist them to set up family support connections.

#### LEVEL 4

In addition to level 3, the CCNT facilitates family support activities; they have current knowledge of community support organisations and connect families to them.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**

## DOMAIN 2: LONG TERM CONDITION MANAGEMENT

### 5. Identifying and anticipating need

#### LEVEL 1

Presentation of children with acute problems determines how needs are addressed.

#### LEVEL 2

The CCNT identifies specific needs of children; follow-up tasks are arranged for, or are assigned to families and/or available staff.

#### LEVEL 3

The child, family, and the CCNT review current child health status and anticipated problems or needs; they create/revise action plans and allocate responsibilities at least 2 times per year or at individualised intervals.

#### LEVEL 4

In addition to level 3, the CCNT and families create a written plan of care that is monitored at every visit; the office CC is available to the child and family to implement, update and evaluate the care plan.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**



## DOMAIN 3: CARE COORDINATION

### 1. Care coordination/role definition

#### LEVEL 1

The family coordinates care across agencies without specific support; they integrate the CCNT's recommendations into their child's care.

#### LEVEL 2

A CCN or other team member engages in care coordination activities as needed; involvement with the family is variable.

#### LEVEL 3

Care coordination activities are based upon ongoing assessments of child and family needs; the CCNT partners with the family (and older child) to accomplish care coordination goals.

#### LEVEL 4

CCNT staff offer a set of care coordination activities, their level of involvement fluctuates according to family needs/wishes. A designated CC ensures the availability of these activities including written care plans with ongoing monitoring.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**

## DOMAIN 3: CARE COORDINATION

### 2. Family involvement

#### LEVEL 1

The CCNT makes care recommendations and defines care coordination needs, the family carries these out.

#### LEVEL 2

Families and children are regularly asked what care supports they need; care decisions are made jointly with the CCNT.

#### LEVEL 3

In addition to level 2, families and children are given the option of having a CC in the CCNT.

#### LEVEL 4

In addition to level 3, children and families help describe care coordination activities; a CC develops and implements these, which are then evaluated by families and designated supervisors.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**

## DOMAIN 3: CARE COORDINATION

### 3. Child & family education

#### LEVEL 1

Generic and specific reading materials and brochures are available from the CCNT upon request.

#### LEVEL 2

Basic relevant information is offered in one-on-one interactions with children and families; these encounters use supportive written leaflets with resource information.

#### LEVEL 3

General information and condition specific information, is offered by the CCNT in a standardized manner; information and advice anticipates potential issues and problems and refers families to other resources.

#### LEVEL 4

In addition to level 3, diverse materials and teaching methods are used to address individual learning styles and needs; information and advice is broad in scope and learning outcomes are examined.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**

## DOMAIN 3: CARE COORDINATION

### 4. Resource information and referrals

#### LEVEL 1

Information about resource needs is gathered during initial assessment; the CCNT addresses immediate family information and resource needs.

#### LEVEL 2

Using a listing of local and national resources, covering physical, developmental, social and financial needs, the CCNT responds to family information requests.

#### LEVEL 3

Significant team knowledge about family and health resources is available; assessment of family needs leads to supported use of resources and information to solve specific problems.

#### LEVEL 4

In addition to level 3, CCNT staff work with families to solve resource problems; a designated CC provides follow up, researches additional information, seeks and provides feedback and assists with the family to integrate new information into the care plan.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**

## DOMAIN 3: CARE COORDINATION

### 5. Advocacy

#### LEVEL 1

The CCN suggests that the family find support services and resources outside of the team when specific needs arise.

#### LEVEL 2

All families are routinely provided with basic information about parent groups, family support, and advocacy resources during scheduled home visits.

#### LEVEL 3

The team identifies resources to the family for support and advocacy, facilitates the connections and advocates on a family's behalf to solve specific problems.

#### LEVEL 4

In addition to level 3, the team advocates on behalf of children and their families as a population and helps to create opportunities for community forums, discussions or support groups which address specific concerns.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**

## DOMAIN 4: COMMUNITY OUTREACH

### 1. Community needs assessment

#### LEVEL 1

The CCNT's awareness of the population of children with complex health care needs in their community is directly related to the number of children for whom they provide care.

#### LEVEL 2

The CCNT make an informal assessment of the needs of children with complex health care needs in their community, based on known issues and personal observations.

#### LEVEL 3

In addition to level 2, the CCNT raise their own questions about children with nursing needs in their community; they seek pertinent data and information from families and local sources and use data to inform practice care activities.

#### LEVEL 4

In addition to level 3, at least one CCN participates in a community-based public health need assessment, integrates results into practice policies, and shares conclusions with relevant agencies.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**

## DOMAIN 4: COMMUNITY OUTREACH

### 2. Community outreach

#### LEVEL 1

When the family, school or another agency requests interactions with the CCNT on behalf of a child's community needs, the team responds, thereby establishing itself as a resource.

#### LEVEL 2

In addition to level 1, when another agency or school requests technical assistance or education from the CCNT a child, the team communicates, collaborates, and educates based upon availability and interest.

#### LEVEL 3

The CCNT initiates outreach to other agencies and schools that directly involved with the child; they advocate for improved community services and inter-organisational collaboration and communication.

#### LEVEL 4

In addition to level 3, the CCNT work with families to facilitate activities that raise community awareness of resource and support needs.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**

## DOMAIN 5: DATA MANAGEMENT

### 1. Electronic data systems

#### LEVEL 1

CCNs retrieve information/data by individual record review; electronic data are available and retrievable from commissioners only.

#### LEVEL 2

Electronic recording of data is limited to scheduling; data are retrieved according to diagnostic code in relation to scheduling; these data are used to identify specific patient groupings.

#### LEVEL 3

An electronic data system includes identifiers and utilisation data about children on the caseload; these data are used for monitoring, tracking, and for indicating levels of care complexity.

#### LEVEL 4

In addition to level 3, an electronic data system is used to support the documentation of need, monitoring of clinical care, care plan and related coordination, and the determination of outcomes.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**



## DOMAIN 5: DATA MANAGEMENT

### 2. Data use

#### LEVEL 1

CCNs retrieve patient data from paper records in response to outside agency requirements.

#### LEVEL 2

The CCNT retrieves data from paper records and electronic scheduling for the support of significant team changes.

#### LEVEL 3

Data are retrieved from electronic records to identify and quantify the caseload and to track selected health indicators & outcomes.

#### LEVEL 4

In addition to the previous, electronic data are produced and used to drive practice improvements and to measure *quality* against benchmarks.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**

## DOMAIN 6: QUALITY IMPROVEMENT/CHANGE

### 1. Quality standards

#### LEVEL 1

Quality standards are imposed upon the CCNT by internal or external organisations.

#### LEVEL 2

In addition to level 2, an individual staff member participates on a committee for improving processes of care within the CCNT. This person communicates and promotes improvement goals to the whole team.

#### LEVEL 3

The CCNT has its own systematic quality improvement mechanism; regular team meetings are used for input and discussions on how to improve care and treatment.

#### LEVEL 4

In addition to level 3, the CCNT actively utilises quality improvement processes; staff and families are supported to participate in these activities; resulting quality standards are integrated into the operations of the CCNT.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**

## DOMAIN 6: QUALITY IMPROVEMENT/CHANGE

### 2. Quality activities

#### LEVEL 1

CCNs have completed courses or have had an adequate orientation to continuous quality improvement methods.

#### LEVEL 2

Commissioners identify gaps in the team and their practice, and set goals for improvements; team staff are identified to fix problems with limited participation in the process.

#### LEVEL 3

Periodic formal and informal quality improvement activities gather staff input about team improvement ideas and opportunities; efforts are made toward related changes and improvements.

#### LEVEL 4

In addition to level 3, the CCNT systematically learns about the needs of children on their caseload. The team and families design and implement team changes that address needs and gaps; they then study their outcomes and act accordingly.

**GAPS IN PRACTICE:**

**ACTIONS:**

**PERSON TO LEAD:**

**\*\*\*\*\* END OF TOOL \*\*\*\*\***

**This workbook was developed as part of the Transforming Children's Community Services research project. This project was funded by the National Institute for Health Research Health Services and Delivery Research programme (project number 11/1015/12). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NIHR HS&DR programme or the Department of Health.**

### Translating and trialling the Medical Home Family Index (MHFI)

The MHFI is a service tool developed in the states to assess use of the Medical Home (Cooley et al. 2003). As outlined in the protocol, there are similarities between the Medical Home and CCN teams as service models. Thus, we used this project as an opportunity to explore whether the MHFI could capture parents' experiences of using CCN teams. To do this, we:

1. 'Translated' the tool items to reflect CCN service delivery and English NHS context (changes summarised in the table below).
2. Pre-piloted the translated tool with a member of SPRU's Parent Consultation group who regularly uses a CCN team.
3. Made further changes based on this pre-piloting (see table below)
4. Administered the translated MHFI as part of data collection with parents after interview.
5. Used parent interview data to explore whether there were any aspects of their experience of using the CCN service that were not covered in the MHFI
6. Monitored participants' responses and written notes to identify potentially difficult to answer items.

This was not intended as a full validation exercise. Rather, we translated and trialled the MHFI as a 'pre-validation' exercise. The MHFI questionnaires (times 1 and 2) used as part of the data collection are at the end of this appendix. Some data from the MHFI was also used to inform the costs study.

### Using parent interview data to explore whether there are any aspects of experience not covered by the MHFI

The MHFI covered most of the issues parents discussed when recounting their experience of using the CCN services. However, five key issues/themes emerged from the data about using CCN services that are *not* covered explicitly by the MHFI. These are: *being able to access and use the team for advice when needed; assessing and prescribing for acute illness (mainly in relation to the nurse practitioner team); nursing care and treatment at home (e.g. tube care, IV treatment); training for parent and other family members; and, arranging the child's supplies*. However, it is possible that existing items on the questionnaire could be revised to incorporate most of these issues:

1. '*Being able to access and use the team for advice*' when needed could be incorporated into item 6 ('The CCN team listen to my concerns and questions'). Possible revision: *I am able to contact the CCN team to ask questions and advice, and to raise concerns, when needed*.
2. '*Assessing and prescribing for acute illness*' and '*nursing care and treatment at home*' could be made explicit as a subsection of item 1 ('The CCN team provides the support that my child needs when we need it'). Possible revision: *The CCN team provides the support that my child needs when we need it. This includes: nursing support for my child's ongoing needs (e.g. feeding tube care); dealing with my child's acute illness (e.g. assessing and prescribing)*.
3. '*Arranging the child's supplies*' could be added as a sub section of item 11 ('*My nurse, or someone else in the team, will:... e) Arrange my child's supplies*').

For the issue of training the parent and other family members in the child's care, a new item could be added. For example: *'The team provide training for myself and others (where applicable) in my child's care'*.

## Other changes to consider

### *Combining and removing items*

Our interviews with team staff showed they wished to collect data on quality outcomes, but that it was important to do this in a way that was quick and easy for both the parent and the nurse. One criticism of the MHFI in its current form is its length. It is important that any tool used to collect data imposes minimum burden on the parent completing it, and thus maximising response rates. With this in mind, it may be possible to reduce the length of the MHFI by removing, or combining items. For example, items 7-10 (including sub-items) amount to 9 questions about care plans. In our interviews with parents, care planning was discussed, but it was not necessarily one of the issues parents placed emphasis on as being particularly important. Also, not everyone we spoke to had a care plan, and for those that did, it wasn't always the CCN team that created it. Furthermore, items 10a-10c were problematic for some respondents, indicated by the missing data for these. Thus, it might make sense to reduce and amend the items on care planning in the MHFI to reflect these issues. Items 7-10 could be condensed into questions about: if the child has a care plan, if it is used by the team, if it is reviewed and updated.

Two other items to consider removing are items 21 and 22 in the time 2 questionnaire. These two items (*'I have seen changes made to the CCN service as a result of the my suggestions or those made by other families'* and *'The CCN team have conducted surveys of families' views or had discussions with families to see if they are satisfied with their children's care'*) were problematic in that some respondents did not answer them. Where answers were given, 29% (Q 21) and 19% (Q22) of respondents ticked 'not sure'. Finally, these kinds of issues did not emerge as having a particular importance to parents in the interviews. Another way of reducing length and burden is to select key items and use these in a short version of the questionnaire. Interview data suggest the key aspects of care that parents' value include: having the clinical nursing support in the community when needed, including nursing care for ongoing needs (e.g. maintaining feeding tubes) and acute needs; being able to contact the team for advice and support when needed; the team's coordination of the child's care across services, including secondary and primary care, education and social care; continuity of staffing; and, educating and training the parent and others (where applicable). The MHFI items that may best reflect these issues, and which could therefore constitute a 'short form' version of the questionnaire, are:

1. A revised version of item 1 (see above) to cover *having the clinical nursing support in the community when needed, including nursing care for ongoing needs (e.g. maintaining feeding tubes) and acute needs*
2. A revised version of item 6 (see above) to cover *being able to contact the team for advice and support when needed*
3. Item 11 to cover *the team's coordination of the child's care across services, including secondary and primary care, education and social care*
4. Item 2a to cover *continuity of staffing*
5. A new item about training the parent (see above)

### *Terminology of 'special health care needs'*

The MHFI uses the term children with special health care needs. We continued with the use of this term to reflect children with complex health needs. However, 'special health care needs' is not typically a term

used in the UK. 'Children with complex health needs' tends to be used. Thus, for purposes of consistency, the terminology in the questionnaire should be adapted.

#### *'Not applicable' options*

Some items contain 'not applicable' options. However, some respondents also wrote 'not applicable' next to other items, suggesting this answer option is required. Where an item is not applicable, this may simply reflect a particular aspect of service delivery that the team does not do, and which the parent does not expect them to do. In turn, this may be a reflection of the diversity of different models of CCN provision.

#### **Next steps**

Based on our trialling of the MHFI, we have identified a number of possible revisions that we believe may enhance its validity as an assessment tool for CCN services. Once these revisions are complete, a full validation exercise is required. This is beyond the scope of this project and was not part of protocol. Thus, we suggest it as future avenue of research.

Translations to the MHFI

Change	Explanation/Rationale
<b>Terminology</b>	
'PCP', 'the practice' and 'office staff' changed to the 'Children's Community Nursing (CCN) Team', 'My Children's Community Nurse', and 'members of the team'.	The services we are investigating are Children's Community Nursing (CCN) teams.
<b>Answer Format</b>	
Inclusion of 'not sure' option	This was included as parents who are new to the service at the Time 1 data collection may not be able to assess confidently their experience of the service at that time.
Replacement of Yes/No answer options with Never/Sometimes/Often/Always	After piloting the MHFI with a parent representative, we have changed the answer format for questions 13-23 from Yes/No to Never/Sometimes/Often/Always. The parent representative felt the latter would enable a more accurate response.
<b>Other</b>	
Use of two questionnaires	We will be using the MHFI twice with research participants. In the first data collection (Time 1), parents completing the MHFI will be new to the service, and will be unable to answer questions 21 and 22 (which require a longer period of service use). Thus, we have created two versions of the MHFI for use in our study. The first version, to be used with parents new to the service, omits questions 21 and 22. The second version, to be used with parents after they have been in the service for at least six months, will include questions 21 and 22.
General language adapted to reflect the practice and family use of CCN teams	The language of some questions has been adapted to reflect the practice of CCN teams and how families use them. The content of the question remains unchanged. For example, question 2 was changed from 'when I call the office' to 'when we come into contact with the team', as contact is often face to face.
Omission of Q24 and Q25	These have been removed to reduce duplication with the qualitative component of the study.
Inclusion of a satisfaction question (now Q24)	We have included a simple question asking the parent to rate their satisfaction with the CCN team. This will aid other parts of our study.
Inclusion of a question to assess whether the parent has a key worker for their child	Some of the activities described in the questions are also undertaken by a professional known in the English public sector as a 'key worker'. This individual is responsible for coordinating aspects of the child's care. Not every family has one. Sometimes the key worker is a member of a CCN team, and sometimes they are not. To better understand the answers parents give us on the questionnaire, we have included a question to establish whether they have a key worker who is <i>not</i> part of the CCN team. This issue was highlighted from our piloting of the questionnaire.



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## Medical Home Family index, Time 1 and 2

THE UNIVERSITY *of York*



**spru** | Social Policy  
Research Unit

# Medical Home Family Index UK Version

© Center for Medical Home Improvement 2001; adapted for use in England by Social Policy Research Unit, University of York

The Medical Home Family Index questionnaire was developed by the Center for Medical Home Improvement in the USA. Its purpose is to ask about families' experiences of using services for children with special health care needs. As part of the TraCCS Study, we have adapted this questionnaire. We want to know how useful the adapted questionnaire is for understanding families' experiences of using Children's Community Nursing (CCN) teams in England.

We are inviting you to complete this questionnaire about your experiences of using the [name of team] for your child's care.

Before continuing, please note the following:

- **Completion of this questionnaire is voluntary.**
- **If there are any questions that you do not want to answer, please leave them blank.**
- **All information you provide in this questionnaire will be confidential and used for research purposes only.**
- **By completing this questionnaire, the care you receive for your child will not be affected in any way.**

If you would like to complete the questionnaire, please sign below and then turn to **page 2** to begin.

Name: \_\_\_\_\_ Signature: \_\_\_\_\_

Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Contact ID:

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**Thank you for your help with this research.**

Contact ID:

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## Medical Home Family Index UK Version

Before you begin, please tell us if you have a **key worker** for your child? (please tick one)

Yes  No

If **yes**, is your key worker a member of the **[name of team]**? (please tick one)

Yes  No

Please tick one box on each line.		Never	Sometimes	Often	Always	Not Sure
1.	The children's community nursing (CCN) team provides the support that my child needs when we need it (including evenings, weekends and holidays).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	When we come into contact with the CCN team:					
	a) Staff know who we are;	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	b) Staff respect our needs and requests;	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	c) Staff remember any special needs or support that we have asked for;	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	d) We are asked if we have any new needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	The CCN communicates well (e.g. explaining terms clearly, helping us prepare for visits, email, or encouraging our questions):					
	a) With me;	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	b) With my child where applicable (tick here if not applicable _____).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	The CCN team ask for my knowledge and expertise as the parent or caregiver of a child with special health care needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Please tick one box on each line.		Never	Sometimes	Often	Always	Not Sure

Contact ID:

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5.	The CCN team asks how my child's condition affects our family (e.g. the impact on siblings, the time my child's care takes, lost sleep, extra expenses, etc.).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	The CCN team listen to my concerns and questions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	When the CCN team plan care for my child, these things happen: <b>a)</b> Writing down key information (e.g. recommendations, treatments, telephone numbers); <b>b)</b> Setting short-term goals (e.g. for the next three months); <b>c)</b> Setting long-term goals (e.g. for the next year or more); <b>d)</b> Checking to make sure the plan is put into action.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	The CCN team work jointly with our family to create a care plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	I receive a copy of my child's care plan with all updates and changes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	The CCN team: <b>a)</b> Use care plans they have created and deliver the care as planned; <b>b)</b> Use a care plan to help follow my child's progress; <b>c)</b> Review and update the care plan with me regularly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Please tick one box on each line.</b>		<b>Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>	<b>Not Sure</b>
11.	My Children's Community Nurse, or someone else in the CCN team, will: <b>a)</b> Help me with difficult referrals, and follow-up activities; <b>b)</b> Help to find needed services (e.g. transportation, durable equipment);	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Contact ID:

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	<p><b>c)</b> Make sure that the planning of care meets my child and my family's needs;</p> <p><b>d)</b> Help all people involved in my child's care to communicate with each other (with my consent).</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>12.</b>	<p>If I ask them to, the CCN team help me to:</p> <p><b>a)</b> Explain my child's needs to other health professionals;</p> <p><b>b)</b> Explain my child's needs to his/her school/nursery (tick here if not applicable _____).</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>13.</b>	Someone in the CCN team is available to review my child's medical record with me when or if I ask to see it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>14.</b>	Other members of the CCN team who are involved with my child's care know about his or her condition, history, and our concerns and priorities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>15.</b>	The CCN team have set-up or are able to direct me to other activities to support my family (e.g. support groups, parent skill building and activities, care skills)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>16.</b>	The CCN team help me to connect with family support organisations and other sources of information locally.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Please tick one box on each line.</b>		<b>Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>	<b>Not Sure</b>
<b>17.</b>	The CCN team show strong support for the rights and services important to children with special health care needs and their families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>18.</b>	The CCN team helps me find adult health care services for my child (tick here if not applicable _____).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Contact ID:

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<b>19.</b>	The CCN team organise and attend team meetings about my child's plan of care that include us and other agencies/staff when needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>20.</b>	The CCN team organise and attend events to talk about concerns and needs common to all children with special health care needs (CSHCN) and their families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>21.</b>	My experience of the CCN team is that they are committed to providing the quality of care and family support that we need.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>22.</b>	How satisfied are you with the care provided by the CCN team? Please rate your answer on a scale of 1 to 5 (please circle one) <i>(1 = not at all satisfied, 5 = very satisfied).</i>	<p>1 ————— 2 ————— 3 ————— 4 ————— 5</p>				

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# Medical Home Family Index UK Version

© Center for Medical Home Improvement 2001; adapted for use in England by Social Policy Research Unit, University of York

The Medical Home Family Index questionnaire was developed by the Center for Medical Home Improvement in the USA. Its purpose is to ask about families' experiences of using services for children with special health care needs. As part of the TraCCS Study, we have adapted this questionnaire. We want to know how useful the adapted questionnaire is for understanding families' experiences of using Children's Community Nursing (CCN) teams in England.

We are inviting you to complete this questionnaire about your experiences of using the [name of team] for your child's care.

Before continuing, please note the following:

- **Completion of this questionnaire is voluntary.**
- **If there are any questions that you do not want to answer, please leave them blank.**
- **All information you provide in this questionnaire will be confidential and used for research purposes only.**
- **By completing this questionnaire, the care you receive for your child will not be affected in any way.**

If you would like to complete the questionnaire, please sign below and then turn to **page 2** to begin.

Name: \_\_\_\_\_ Signature: \_\_\_\_\_

Date: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

**Thank you for your help with this research.**

## Medical Home Family Index UK Version

Before you begin, please tell us if you have a **key worker** for your child? (please tick one)

Yes  No

If **yes**, is your key worker a member of the [name of team]?

Yes  No

Please tick one box on each line.		Never	Sometimes	Often	Always	Not Sure
1.	The children's community nursing (CCN) team provides the support that my child needs when we need it (including evenings, weekends and holidays).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	When we come into contact with the CCN team:					
	a) Staff know who we are;	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	b) Staff respect our needs and requests;	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	c) Staff remember any special needs or support that we have asked for;	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	d) We are asked if we have any new needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	The CCN communicates well (e.g. explaining terms clearly, helping us prepare for visits, email, or encouraging our questions):					
	a) With me;	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	b) With my child where applicable (tick here if not applicable _____).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	The CCN team ask for my knowledge and expertise as the parent or caregiver of a child with special health care needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Please tick one box on each line.		Never	Sometimes	Often	Always	Not Sure



5.	The CCN team asks how my child's condition affects our family (e.g. the impact on siblings, the time my child's care takes, lost sleep, extra expenses, etc.).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	The CCN team listen to my concerns and questions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	When the CCN team plan care for my child, these things happen: <b>a)</b> Writing down key information (e.g. recommendations, treatments, telephone numbers); <b>b)</b> Setting short-term goals (e.g. for the next three months); <b>c)</b> Setting long-term goals (e.g. for the next year or more); <b>d)</b> Checking to make sure the plan is put into action.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	The CCN team work jointly with our family to create a care plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	I receive a copy of my child's care plan with all updates and changes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	The CCN team: <b>a)</b> Use care plans they have created and deliver the care as planned; <b>b)</b> Use a care plan to help follow my child's progress; <b>c)</b> Review and update the care plan with me regularly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Please tick one box on each line.		Never	Sometimes	Often	Always	Not Sure

<b>11.</b>	My Children's Community Nurse, or someone else in the CCN team, will: <b>a)</b> Help me with difficult referrals, and follow-up activities; <b>b)</b> Help to find needed services (e.g. transportation, durable equipment); <b>c)</b> Make sure that the planning of care meets my child and my family's needs; <b>d)</b> Help all people involved in my child's care to communicate with each other (with my consent).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>12.</b>	If I ask them to, the CCN team help me to: <b>a)</b> Explain my child's needs to other health professionals; <b>b)</b> Explain my child's needs to his/her school/nursery (tick here if not applicable _____).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>13.</b>	Someone in the CCN team is available to review my child's medical record with me when or if I ask to see it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>14.</b>	Other members of the CCN team who are involved with my child's care know about his or her condition, history, and our concerns and priorities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>15.</b>	The CCN team have set-up or are able to direct me to other activities to support my family (e.g. support groups, parent skill building and activities, care skills).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>16.</b>	The CCN team help me to connect with family support organisations and other sources of information locally.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Please tick one box on each line.</b>		<b>Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>	<b>Not Sure</b>

17.	The CCN team show strong support for the rights and services important to children with special health care needs and their families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18.	The CCN team helps me find adult health care services for my child (tick here if not applicable _____).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19.	The CCN team organise and attend team meetings about my child's plan of care that include us and other agencies/staff when needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20.	The CCN team organise and attend events to talk about concerns and needs common to all children with special health care needs (CSHCN) and their families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21.	I have seen changes made to the CCN service as a result of my suggestions or those made by other families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22.	The CCN team have conducted surveys of families' views or had discussions with families (in the last two years) to see if they are satisfied with their children's care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23.	My experience of the CCN team is that they are committed to providing the quality of care and family support that we need.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24.	How satisfied are you with the care provided by the CCN team? Please rate your answer on a scale of 1 to 5 (1 = <i>not at all satisfied</i> , 5 = <i>very satisfied</i> ).					

## Transforming Children's Community Services (TraCCS) Study

### Cost Questionnaire for Teams

Information for week beginning: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Site Code: \_\_\_\_\_

1. Please state the WTE for each band in your team in the table below:

Band	5	6	7	8	Other band(s)
WTE					

2. In the past week, how many **contacts** with families has the team had

\_\_\_\_\_

3. In the past week, please estimate how many hours have been spent on the activities listed, by staff band, in the table below:

Band	<i>Direct contact with family delivering care/intervention</i>	<i>Telephone support to family</i>	<i>Admin. tasks (e.g. referrals)</i>	<i>Travelling to and from family</i>	<i>Under supervision</i>	<i>Other (please specify)</i>
5						
6						
7						
8						

4. In the past week, approximately how many miles have the team accumulated in travelling to and from locations in which they deliver care? \_\_\_\_\_

5. Please estimate how many hours in total have been spent on training activities listed in the table below (by staff whilst employed as a member of the team)?

	<i>Undertaking training</i>	<i>Undertaking examinations</i>	<i>Being assessed or evaluated other than through examinations</i>
All bands			

**4i Resource use questionnaire for parents, Time 1 and 2**

**Transforming Children’s Community Services (TraCCS) Study**

**Cost questions for parent(s) interview**

*To be administered by the researcher at the end of the **FIRST** interview. This questionnaire refers to resource use in the **6 month period immediately before** parents are allocated a Children’s Community Nursing Team.*

**Your child’s use of hospital services:**

**1. Has your child had any overnight stays in hospital during the past 6 months?**

Yes  → If **yes**, please estimate the total number of nights:   
No

**2. Has your child had any outpatient appointments during the past 6 months?**

Yes  → If **yes**, please estimate the total number of attendances:   
No

**3. Has your child attended an Accident & Emergency department during the past 6 months?**

Yes  → If **yes**, please estimate the total number of attendances:   
No

**4. Has your child attended hospital for day case surgery during the past 6 months?**

Yes  → If **yes**, please estimate the total number of attendances:   
No

**5. Has your child attended hospital for other day case treatment during the past 6 months?**

Yes  → If **yes**, please estimate the total number of attendances:   
No

**Your child's use of services outside the hospital:**

6. Here is a list of other services your child may have been in contact with (use show card).

I will read each one out. Please tell me if your child has had contact with this service in the **past 6 months** and estimate the total number of contacts for each (please enter '0' if a particular service was not used):

General Practitioner	<input type="text"/>	<input type="text"/>	<input type="text"/>
Practice Nurse	<input type="text"/>	<input type="text"/>	<input type="text"/>
Occupational Therapist	<input type="text"/>	<input type="text"/>	<input type="text"/>
Speech and Language Therapist	<input type="text"/>	<input type="text"/>	<input type="text"/>
Physiotherapist	<input type="text"/>	<input type="text"/>	<input type="text"/>
Clinical or Child Psychologist	<input type="text"/>	<input type="text"/>	<input type="text"/>
Children's Social Worker	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child Development Officer	<input type="text"/>	<input type="text"/>	<input type="text"/>
Health Visitor	<input type="text"/>	<input type="text"/>	<input type="text"/>
Other (please specify below):	<input type="text"/>	<input type="text"/>	<input type="text"/>

**Use of day services:**

7. Has your child used any other services (e.g. home sitting, weekend clubs, home support) **during the past 6 months**? Please include any private or voluntary services:

Yes   
 No

If **yes**, please state (if possible) the approximate number of times you attended:

<input type="text"/>	<input type="text"/>
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8. Has your child used any respite services (e.g. overnight or day residential stays for child/family, activity holidays) **during the past 6 months**? Please include any private or voluntary services:

Yes   
 No

If **yes**, please state (*if possible*) the approximate number of times you attended:

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**Other costs you might have to pay:**

9. Have you or your partner made any other payments as a result of your child's condition: (*e.g. adaptations to your home or specialist equipment*)?

Yes   
No

If **yes**, approximately how much have you had to pay **during the last 6 months**?

£ 

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**Employment (parent being interviewed):**

10. a) Are you currently in paid work?

Yes  → If **yes**, go to Q11  
No

b) If **no**, over the **last 6 months**, were you in paid employment?

Yes  → If **yes**, go to Q11.  
No  → If **no**, go to Q13.

11. How many hours or days did/do you work on average per week?

--	--

 Hours/Days (*delete as appropriate*)

12. Have you taken any days off from work **over the preceding 6 months specifically to deal with your child's illness**?

Yes  → If **yes**, please estimate the number of days: 

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No

**Employment (Partner of parent being interviewed, if applicable):**

13. a) Is your partner currently in paid work?

Yes  → If **yes**, go to Q14.  
No

b) If **no**, over the **last 6 months**, was your partner in paid employment?

Yes  → If **yes**, go to Q14.  
No  → If **no**, go to end of cost questions.

14. How many hours or days did/do your partner work on average per week?

--	--

**Hours/Days** (*delete as appropriate*)

15. Has your partner taken any days off from work **over the preceding 6 months specifically to deal with your child's illness?**

Yes   
No

→ If **yes**, please estimate the number of days:

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**END OF COST QUESTIONS & INTERVIEW**



## Transforming Children’s Community Services (TraCCS) Study

### Cost questions for parent(s) interview

*To be administered by the researcher at the end of the **SECOND** interview. This questionnaire refers to resource use in the **previous 6 month period**.*

#### Your child’s use of hospital services:

1. Has your child had any overnight stays in hospital **during the past 6 months?**

Yes  → If **yes**, please estimate the total number of nights:   
 No

2. Has your child had any outpatient appointments **during the past 6 months?**

Yes  → If **yes**, please estimate the total number of attendances:   
 No

3. Has your child attended an Accident & Emergency department **during the past 6 months?**

Yes  → If **yes**, please estimate the total number of attendances:   
 No

4. Has your child attended hospital for day case surgery **during the past 6 months?**

Yes  → If **yes**, please estimate the total number of attendances:   
 No

5. Has your child attended hospital for other day case treatment **during the past 6 months?**

Yes  → If **yes**, please estimate the total number of attendances:   
 No

#### Your child’s use of services outside the hospital:

6. Here is a list of other services your child may have been in contact with *(use show card)*.

I will read each one out. Please tell me if your child has had contact with this service in the **past 6 months** and estimate the total number of contacts for each (please enter '0' if a particular service was not used):

General Practitioner	<input type="text"/>	<input type="text"/>	<input type="text"/>
Practice Nurse	<input type="text"/>	<input type="text"/>	<input type="text"/>
Occupational Therapist	<input type="text"/>	<input type="text"/>	<input type="text"/>
Speech and Language Therapist	<input type="text"/>	<input type="text"/>	<input type="text"/>
Physiotherapist	<input type="text"/>	<input type="text"/>	<input type="text"/>
Clinical or Child Psychologist	<input type="text"/>	<input type="text"/>	<input type="text"/>
Children's Social Worker	<input type="text"/>	<input type="text"/>	<input type="text"/>
Child Development Officer	<input type="text"/>	<input type="text"/>	<input type="text"/>
Health Visitor	<input type="text"/>	<input type="text"/>	<input type="text"/>
Other (please specify below):	<input type="text"/>	<input type="text"/>	<input type="text"/>

.....

**Use of day services:**

7. Has your child used any other services (e.g. home sitting, weekend clubs, home support) **during the past 6 months**? Please include any private or voluntary services:

Yes   
 No

If **yes**, please state (if possible) the approximate number of times you attended:

<input type="text"/>	<input type="text"/>
----------------------	----------------------

8. Has your child used any respite services (e.g. overnight or day residential stays for child/family, activity holidays) **during the past 6 months**? Please include any private or voluntary services:

Yes   
 No

If **yes**, please state (if possible) the approximate number of times you attended:

<input type="text"/>	<input type="text"/>
----------------------	----------------------

**Other costs you might have to pay:**

9. Have you or your partner made any other payments as a result of your child's condition: (e.g. adaptations to your home or specialist equipment)?

Yes

No

If **yes**, approximately how much have you had to pay **during the last 6 months**?

£ 

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**Employment (parent being interviewed):**

10. a) Are you currently in paid work?

Yes  → If **yes**, go to **Q11**.

No

b) If **no**, over the **last 6 months**, were you in paid employment?

Yes  → If **yes**, go to **Q11**.

No  → If **no**, go to **Q13**.

11. How many hours or days did/do you work on average per week?

--	--

**Hours/Days** (delete as appropriate)

12. Have you taken any days off from work **over the preceding 6 months specifically to deal with your child's illness**?

Yes  → If **yes**, please estimate the number of days: 

--	--

No

**Employment (partner of parent being interviewed, if applicable):**

13. a) Is your partner currently in paid work?

Yes  → If **yes**, go to **Q14**.

No

b) If **no**, over the **last 6 months**, was your partner in paid employment?

Yes  → If **yes**, go to **Q14**.

No  → If **no**, go to **Q16**.

14. How many hours or days did/do your partner work on average per week?

--	--

**Hours/Days** (delete as appropriate)

**15.** Has your partner taken any days off from work **over the preceding 6 months specifically to deal with your child's illness?**

Yes  → If **yes**, please estimate the number of days:    
No

**16.** Has the involvement of the CCN team changed the amount of time you spend **caring for your child's condition/health?** (*use show card*):

I have spent less time caring for my child

Has not had an effect

I have spent a little more time caring for my child

I have spent a lot more time caring for my child

→ If a change, follow-up with: Has that, in turn, had any impact on you or your family?

**17.** Has the involvement of the CCN team changed the amount of time you spend on **enjoyable activities with your child?** (*use show card*):

I have spent less time on enjoyable activities with my child

Has not had an effect

I have spent a little more time on enjoyable activities with my child

I have spent a lot more time on enjoyable activities with my child

→ If a change, follow-up with: Has that, in turn, had any impact on you or your family?

**END OF COST QUESTIONS & INTERVIEW**