# Transforming community health services for children and young people who are ill: a quasi-experimental evaluation

Gemma Spiers,<sup>1</sup>\* Victoria Allgar,<sup>2,3</sup> Gerry Richardson,<sup>4</sup> Kate Thurland,<sup>5</sup> Sebastian Hinde,<sup>4</sup> Yvonne Birks,<sup>1</sup> Kate Gridley,<sup>1</sup> Helen Duncan,<sup>5</sup> Susan Clarke,<sup>1</sup> Linda Cusworth<sup>1</sup> and Gillian Parker<sup>1</sup>

<sup>1</sup>Social Policy Research Unit, University of York, York, UK <sup>2</sup>Department of Health Sciences, University of York, York, UK <sup>3</sup>Hull York Medical School, University of York, York, UK <sup>4</sup>Centre for Health Economics, University of York, York, UK <sup>5</sup>Public Health England, York, UK

\*Corresponding author

Declared competing interests of authors: none

Published September 2016 DOI: 10.3310/hsdr04250

# **Scientific summary**

**Transforming health services for children and young people** Health Services and Delivery Research 2016; Vol. 4: No. 25 DOI: 10.3310/hsdr04250

NIHR Journals Library www.journalslibrary.nihr.ac.uk

# **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. While 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 that there is a need for evidence about these outcomes.

## Aims

The aims of this research were to (1) test whether or not introducing or expanding CCN services affects acute hospital admission for common childhood illness, and bed-days and length of stay (LOS) for all paediatric conditions (including a subset for complex conditions); (2) examine the costs of delivering and using these services; and (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.

There were three main studies:

- 1. an interrupted time series (ITS) analysis of Hospital Episode Statistics (HES) to examine acute admissions for common childhood illnesses, and bed-days and LOS for all paediatric conditions (including a subset of complex conditions), using between 60 and 84 time points
- 2. a cost–consequence analysis, drawing on 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 on in-depth interviews.

We also carried out a process evaluation with 41 commissioners, managers and practitioners across the case sites, drawing on longitudinal in-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 multiethnicity (based on Index of Multiple Deprivation quintiles) 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 team's introduction seemed to affect this rate immediately and significantly and continued to do so for around 3 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 multiethnicity 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, in which 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 the use of accident and emergency (A&E) departments. 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 paediatric observation and assessment unit (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. Although 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 LOS.

<sup>©</sup> Queen's Printer and Controller of HMSO 2016. This work was produced by Spiers *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

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 the 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 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. Furthermore, given the different type and costs of the four services included in this part of the work, it is difficult to meaningfully synthesise the findings.

Individually, the paediatric nurse practitioner team that targeted admissions of children with very complex conditions (site D) was the service in which 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- 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; nor 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 who would otherwise have attended hospital outpatient 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 or not better value is achieved for continuing care expenditure from this model of CCN team compared with

other ways of delivering continuing care (e.g. 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 that are 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, when taking place across multiple providers, a mechanism to oversee changes (e.g. 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 in which 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 care 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–consequence analyses.

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.

## Funding

Funding for this study was provided by the Health Services and Delivery Research programme of the National Institute for Health Research.

<sup>©</sup> Queen's Printer and Controller of HMSO 2016. This work was produced by Spiers *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

# **Health Services and Delivery Research**

ISSN 2050-4349 (Print)

ISSN 2050-4357 (Online)

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: nihredit@southampton.ac.uk

The full HS&DR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hsdr. Print-on-demand copies can be purchased from the report pages of the NIHR Journals Library website: www.journalslibrary.nihr.ac.uk

#### Criteria for inclusion in the Health Services and Delivery Research journal

Reports are published in *Health Services and Delivery Research* (HS&DR) if (1) they have resulted from work for the HS&DR programme or programmes which preceded the HS&DR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

#### **HS&DR** programme

The Health Services and Delivery Research (HS&DR) programme, part of the National Institute for Health Research (NIHR), was established to fund a broad range of research. It combines the strengths and contributions of two previous NIHR research programmes: the Health Services Research (HSR) programme and the Service Delivery and Organisation (SDO) programme, which were merged in January 2012.

The HS&DR programme aims to produce rigorous and relevant evidence on the quality, access and organisation of health services including costs and outcomes, as well as research on implementation. The programme will enhance the strategic focus on research that matters to the NHS and is keen to support ambitious evaluative research to improve health services.

For more information about the HS&DR programme please visit the website: http://www.nets.nihr.ac.uk/programmes/hsdr

#### This report

The research reported in this issue of the journal was funded by the HS&DR programme or one of its preceding programmes as project number 11/1015/12. The contractual start date was in June 2012. The final report began editorial review in August 2015 and was accepted for publication in February 2016. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health.

© Queen's Printer and Controller of HMSO 2016. This work was produced by Spiers *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).

# Health Services and Delivery Research Editor-in-Chief

Professor Jo Rycroft-Malone Professor of Health Services and Implementation Research, Bangor University, UK

## **NIHR Journals Library Editor-in-Chief**

Professor Tom Walley Director, NIHR Evaluation, Trials and Studies and Director of the EME Programme, UK

# **NIHR Journals Library Editors**

**Professor Ken Stein** Chair of HTA Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

Professor Andree Le May Chair of NIHR Journals Library Editorial Group (EME, HS&DR, PGfAR, PHR journals)

Dr Martin Ashton-Key Consultant in Public Health Medicine/Consultant Advisor, NETSCC, UK

**Professor Matthias Beck** Chair in Public Sector Management and Subject Leader (Management Group), Queen's University Management School, Queen's University Belfast, UK

**Professor Aileen Clarke** Professor of Public Health and Health Services Research, Warwick Medical School, University of Warwick, UK

Dr Tessa Crilly Director, Crystal Blue Consulting Ltd, UK

Dr Eugenia Cronin Senior Scientific Advisor, Wessex Institute, UK

Ms Tara Lamont Scientific Advisor, NETSCC, UK

**Professor Elaine McColl** Director, Newcastle Clinical Trials Unit, Institute of Health and Society, Newcastle University, UK

Professor William McGuire Professor of Child Health, Hull York Medical School, University of York, UK

**Professor Geoffrey Meads** Professor of Health Sciences Research, Health and Wellbeing Research and Development Group, University of Winchester, UK

Professor John Norrie Health Services Research Unit, University of Aberdeen, UK

Professor John Powell Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK

**Professor James Raftery** Professor of Health Technology Assessment, Wessex Institute, Faculty of Medicine, University of Southampton, UK

Dr Rob Riemsma Reviews Manager, Kleijnen Systematic Reviews Ltd, UK

Professor Helen Roberts Professor of Child Health Research, UCL Institute of Child Health, UK

Professor Jonathan Ross Professor of Sexual Health and HIV, University Hospital Birmingham, UK

**Professor Helen Snooks** Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

**Professor Jim Thornton** Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

**Professor Martin Underwood** Director, Warwick Clinical Trials Unit, Warwick Medical School, University of Warwick, UK

Please visit the website for a list of members of the NIHR Journals Library Board: www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: nihredit@southampton.ac.uk