Children's Key Worker Service Evaluation Project
RESEARCH TEAM

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ACKNOWLEDGMENTS

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Special thanks also to the CLIC Sargent project management team (Jeanette Hawkins, Simon Morgan-Jones, Megan Hutchins and Michelle Wilson) for their insights, help and support throughout the project.

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I’m delighted to have been asked to write the foreword to this excellent project report.

In 2005 the National Institute for Health and Clinical Excellence (NICE) published service guidance on ‘Improving Outcomes in Children and Young People with Cancer’. The manual set out a care pathway, and a model of service organisation which remain the primary source for both commissioners and providers of care in a complex and changing health care environment.

The need for continuity and coordination of care was identified in this guidance, and the key worker approach was highlighted as an effective way to achieve this outcome. This resulted in a recommendation that ‘a key worker should be identified for each child or young person and their family to coordinate services and assess their support needs’. The guidance document acknowledged a ‘paucity of evidence’ to support that recommendation.

Following the publication of the NICE guidance, and in recognition of the complexity of cancer service provision for children and young people, an Implementation Advisory Group was set up at the Department of Health in England. This brought together the providers and commissioners of services, alongside service users (parents and carers), researchers and third sector partners. This was a fruitful and productive collaboration. CLIC Sargent was represented on this group; Professor Faith Gibson was a member, and I was there as part of the original NICE Guidance Development Group.

It was in part to inform the deliberations of this advisory group that CLIC Sargent embarked on their consultation work with children and families which resulted in the report More than my illness: delivering quality care for children with cancer (CLIC Sargent 2009). That document identified the role of the key worker as fundamental to the proposed model of care, and was followed by the project described in this report, focussing on the role of the nurse specialist key worker.

CLIC Sargent is to be commended on building into this project a comprehensive evaluation of the role, with a focus on demonstrating the achievement of clear patient and family centred outcomes. The project team entrusted with this evaluation, and led by Professor Gibson, is composed of some of the most respected researchers currently working in the field in the UK.

The project team has worked alongside the key workers involved in the project to identify the core functions of the role: knowledge and expertise; coordination of care; being the main point of contact for families and professionals, and communication. They propose a model which captures local variations in services whilst recognising those core functions. The report provides much needed evidence of the positive ways in which the role impacts on the experience of the child and family, and the factors which influence the achievement of the outcomes which matter most to them.

Rachel Hollis  RGN, RSCN, MHSc, FRCN

Lead Nurse for Children’s Cancer
Leeds Teaching Hospitals NHS Trust
FOREWORD

It’s a privilege to introduce this inclusive service evaluation, showing our understanding of the key worker model of care and the impact for children with cancer and their families.

When we look back on the CLIC Sargent Key Worker Project, I think it will stand as an exemplar of how to deliver a project with improving outcomes for service users at its core, contributing to the UK evidence base for specialist nursing, and demonstrating how to work in true collaboration and partnership between the NHS, university researchers and the charity sector, across health, social care and education.

I was working as Lead Cancer Nurse at Birmingham Children’s Hospital, with over 20 years of children’s cancer nursing experience, when the NICE (2005) Improving outcomes guidance for children and young people with cancer was published, recommending ‘key workers’. At first glance we considered whether our outreach nurse specialists were already delivering this model of care. But we had questions about whether we were delivering all that was described consistently, holistically, across hospital and community, as effectively as possible and with clear pathways of communication.

Discussion with others across the UK showed that we were not all approaching things in the same way. We didn’t know whether the differences were necessary, or whether some models were more effective than others. The CLIC Sargent Key Worker Project offered a rare opportunity to work together across UK principal treatment centres on delivering something in a joined up way, sharing best practice and unpicking challenges collectively along the route. What we really wanted to know, given that some aspects of delivering the key worker model is difficult and time consuming, is “does it make a difference to children and their families?” I worked for a period of time as a key worker and began to believe that this model of care had the potential to be a golden thread pulling together all the strings in the complex environment of children’s cancer care. Parents need a professional companion to walk with them and untangle the threads which work their way into knots between cancer centre and shared care, hospital and home, treatment and school, illness and normality, professionals and family.

The evaluators at London South Bank University, led by the eminent Professor Faith Gibson, offer in this report an insight into the daily work of specialist nurses using the key worker model of care. We are told the story of what this looks like when it’s working well, and what makes the delivery of the role more challenging, using qualitative and quantitative data. Importantly, we are told this story from a range of perspectives; from the key workers themselves, parents, children and the health, social care and education professionals they work with, both in hospital and in the community giving an honest 360° view. The report concludes with useful points for key workers, families, MDTs, managers and commissioners. This is a tribute to the profession of nursing and the efforts of all who took part.

Jeanette Hawkins RGN RSCN DPSN MSc

CLIC Sargent Assistant Director and Nursing Lead
EXECUTIVE SUMMARY

Background

The key worker is defined by NICE (2005) guidance as, ‘A person who, with the patient’s consent and agreement, takes a role in coordinating the patient’s care and promoting continuity, ensuring the patient knows who to access for information and advice’ (p 200). Responding to findings in the More than my illness (2009) report, the CLIC Sargent specialist nurse key worker role was aiming to provide holistic care to meet the individual needs of the child and family and facilitate safe care as close to home as possible. They may not deliver every aspect of care personally but will ensure someone is responsible for all elements of care needed. The underpinning report described them as a navigator, an enabler and a coordinator.

Across the United Kingdom (UK), there were 21 posts working with children and young people with cancer and their families as part of the CLIC Sargent Key Worker Project. Their roles are diverse, responding to local need, and developed as the role became more firmly embedded within their individual care settings. There is little information available about different patterns of provision and the determinants for success along with a paucity of evidence to indicate the requirements for service provision to achieve a well-coordinated transition or continuity of care for children and young people with cancer.

The evaluation of the nurse specialist key worker role aimed to:

- Evidence whether there is an improvement in patient and family experience as a result of nursing key worker support
- Evidence whether children and their families have improved emotional wellbeing as a result of nursing key worker support
- Evidence whether children are better able to participate in education, employment and training as a result of nursing key worker support
- Evidence whether children and their families are better able to spend more time safely at home during treatment as a result of nursing key worker support
- Identify obstacles to providing care closer to home that may or may not be overcome by the key worker role alone
- Identify the costs and benefits of this new service model
- Evidence whether best practice and learning have been adopted by other practitioners within local teams.

Methods

The project spanned 18 principal treatment centres in England, Scotland and Wales. A mixed methods approach was undertaken to provide in depth details of experiences and illustrate how the key worker role has been developed. Data collection was face to face and at a distance using questionnaires, interviews and group work. Annual reports from the key workers, job descriptions, other documentation and data collected each quarter on the role by CLIC Sargent (e.g. caseload numbers, contacts with stakeholders) were also included in the analysis.
In total, 19 specialist nurse key workers, three nurse educators involved in the development of a key worker education resource, 95 parents, 85 stakeholders (individuals the key worker was involved with through their role with families such as community nurses, social workers) and 10 children (six children from an advisory group took part in a group discussion activity) contributed to the study. Evaluation data were collected between March 2011 and March 2015. Key workers were interviewed at two points in time and some took part in a focus group (n=12). Parents from all the sites completed a questionnaire and 23 also took part in an individual interview. Four children took part in an interview (n=4). Bereaved parents only took part in an individual interview and were not asked to complete questionnaires (n=8). Stakeholders from all the sites filled in a questionnaire.

The uniqueness of each case, particular context, issues and story were the focus of this study (Stake 2000). Incorporating a multiple case study approach (Yin 2003) each key worker was defined as a case with the other participants (parents, children, young people, and stakeholders) being linked to them and their practice. The framework approach (Ritchie & Spencer 1994) was used to analyse the interview transcripts and descriptive statistics were reported for quantitative data.

**Findings**

The presentation of findings is organised in three main sections:

I) An overview of the models of care and how the role was developed in the 18 principal treatment centres (PTC).

II) Realistic evaluation of the models - two scenarios are described:

a. When it works - when the key working service has the capacity to deliver improved outcomes and influence a positive experience for families and professionals.

b. When it is challenging - when there are factors that make it challenging for professionals to deliver the role in such a way that it is effective and impacts on families’ experiences.

III) A comprehensive overall model of key working is introduced, showing examples from practice of what contributes to improved families’ experiences.

**Models of care**

The key worker was, in the majority of cases, a specialist nurse experienced in Haematology/Oncology and attached to a principal treatment centre. Key workers’ caseload composition varied in the number of families they supported as well as the types of diagnoses of children in their care.

Parents, children, key workers and stakeholders (health, social care and educational professionals) shared their views about the core responsibilities and roles of a specialist nurse key worker, these included: coordination of care (being the main point of contact in the hospital); knowledge and expertise (information sharing and explaining; training); ability
to establish relationships (with families and different professionals involved in the child’s care). These featured despite the variation in the way the role was developed across trusts.

Key workers developed their role within a continuum of in-reach and outreach work. Four main models of care were identified: 1) outreach (visiting families at home), 2) inreach with home visits (key workers who were based in the hospital and who do home visits occasionally), 3) inreach (based mainly in the hospital) and 4) palliative care (reflecting how the key worker role changes in this phase). The models also vary in key workers’ involvement in direct clinical care. Key workers were all involved in care coordination, but not all were involved in the direct delivery of clinical care.

**Realistic evaluation – When it works**

Specialist nurse key workers were the main link in the principal treatment centre for professionals as well as families. There was a clear pathway for both families and professionals, enabling key workers to streamline the communication process not only between families and professionals but also between professionals. Key workers liaised with a range of professionals based in education, social services, community teams and other relevant local organisations and voluntary agencies. The role of key workers in liaising with other professionals such as community nurses and with teachers was highly valued by families.

Perceived advantages for parents and children of having a key worker were centred on: having one person to contact about any concerns; someone who was in charge of coordinating services and making sure their needs were met. When in place, there was greater consistency and continuity of care and thus parental stress was alleviated. The key worker helped the family understand the diagnosis, navigate services, continue to support the family and assess their needs using a holistic approach; thus they got to know the family very well. The key worker was the family’s main point of contact and their approachable nature meant that they were the professional that a parent went to with concerns - parents felt they could ask them anything.

The impact of the key worker role on families’ experiences is embedded in the relationship they establish with each family. This relationship was one of trust and was built up over time. Parents appreciated having the key worker throughout their journey and although during some phases they might not be as involved, they were still the families’ point of contact; the professional who knows what they have been through, who knows the family and their child. Being able to easily contact the key worker also ensured patients stayed home safely.

In general, key workers perceived their role as having a positive effect on the work of other professionals: this view was shared by the stakeholders responding in the questionnaire. They noted that key workers were able to access appropriate support for families and refer to appropriate services. Stakeholders stated that key workers’ knowledge and expertise and coordination of care were linked with a high standard of care.

**Realistic evaluation – When it is challenging**

The key workers were asked whether they experienced any constraints or problems in their role. The main challenges in fulfilling their role were: time, caseload size, geographical area covered and staffing numbers. The key workers wanted to provide an equitable service to the families on their caseload but sometimes had to focus on the families most
in need (e.g. children at the start of treatment, or during end of life care). The inequality of local services also presented a challenge to care coordination for some teams.

**Key worker person-centred care in a challenging environment**

Key workers developed their role within contexts where there was a lack of resources, pressure of large caseloads and size of geographical areas covered, different levels of competency and staff numbers in the community added to the challenges of care coordination and consequently of care closer to home. Nevertheless, throughout the development of their roles, key workers developed and described examples of good practice of working with families and stakeholders; of information and care pathways leading to quality improvement, of policy development and consolidation of role definitions, among others. These examples serve to illustrate in this report how the key workers’ knowledge, coordination of care and relationship with families and professionals worked well in practice.

**Conclusion**

In conclusion, supported by the evidence collected, key working effectiveness is built on three pillars: knowledge, coordination and relationship: when these pillars are in place, a better quality family experience can be assured.
BACKGROUND

In 2008, CLIC Sargent asked children and young people with cancer, and their families, what they needed outside of hospital. They also considered previous consultations and worked closely with a range of health professionals including nurses, doctors, social workers and teachers. As a result of this wide and varied consultation exercise, CLIC Sargent published two reports. The first report, *More than my illness: delivering quality care for children with cancer* (CLIC Sargent, 2009) focused upon the needs of children aged 0 to 18 years and their families. The second, *More than my illness: delivering quality care for young people with cancer* (CLIC Sargent, 2010), made recommendations on how best to provide care and support to young people aged 16 to 24 years with cancer and their families.

Both of these reports echoed recommendations made in the Improving Outcome Guidance for Children and Young People with Cancer (National Institute for Health and Clinical Excellence [NICE], 2005) that cancer services for children and young people should have processes in place to ensure effective coordination between professionals involved in the care of children and young people. Care should be integrated and coordinated throughout the patient’s cancer journey: in primary, secondary and tertiary care settings, across statutory and voluntary sectors, and across health and social care settings. The key worker role has been identified to provide this service and meet this recommendation. The key worker is defined by NICE (2005) guidance as, ‘A person who, with the patient’s consent and agreement, takes a role in coordinating the patient’s care and promoting continuity, ensuring the patient knows who to access for information and advice’ (p 200).

Across the United Kingdom (UK), during the project there were 19 specialist nurse key workers and three educators working with children with cancer and their families, funded by CLIC Sargent, to enable time to participate in the service evaluation. Their roles are known to be diverse, responding more often to local need, and developing as the role becomes more firmly embedded within their individual care settings. Facilitating and making holistic care closer to home a reality is the expressed aim of *More than my illness*. The aim of the project described within this report was to evaluate the enhanced key worker service model, to see if the aims of the NICE Guidance and the CLIC Sargent *More than my illness* report could be established in a cost effective way, by working in partnership with the NHS with CLIC Sargent project support (Figure 1).

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1 The evaluation reported here was developed simultaneously with the evaluation of the CLIC Sargent Teenage and Young Adult (TYA) Service Development Evaluation Project.
We began with a structure-process-outcomes framework, to provide a solid foundation in which to think and evaluate quality in relation to the key worker role. Over time this was enhanced and described as a case study, using mixed methods and realistic evaluation, to describe context, mechanism and outcomes, to best illuminate ways of working that impact on quality of care. What follows is a journey, we have travelled this with key workers and have taken every opportunity to share early learning and manage any limitations emerging during data collection through ongoing dialogue with the funders. We present here case study research, drawing on multiple sources of data, from a range of informants, and present models of delivery to be considered by readers, to be tested, refined and evaluated by others to ensure care is integrated and coordinated to support families along their cancer journey.
INTRODUCTION

An average of 1,574 children per year in the UK were diagnosed with cancer between 2009-2011, and of these approximately 252 died. 82% of children in Great Britain survived their childhood cancer for five years or more between 2006-2010. These statistics from Cancer Research UK (www.cancerresearchuk.org/cancer-info/cancerstats/childhoodcancer/) evidence the potential for a cancer diagnosis to have a huge impact on children, young people and their families. Families face the challenge of the disease itself, its symptoms, therapies and side effects of treatment. Besides the complexities of treatment, families have to deal with many issues, including ongoing and sometimes unresolved uncertainty and the need for support of different types and at different time points: for example, transition and home visit support (including training and coordinated care planning); practical support (to ensure access to services); information, emotional, financial and employment support and support for the whole family (CLIC Sargent, 2009).

Such complexity of need demands a coordinated approach to service provision that offers the best experience to families and improves outcomes, and, importantly, does not increase the pressure and confusion that children and young people, and their families, can feel when interacting with so many different practitioners (CLIC Sargent, 2009). The National Institute for Health and Clinical Excellence's Improving Outcomes for Children and Young People with Cancer guidance (NICE, 2005) recommends that cancer services for children and young people should have processes in place to ensure effective coordination between professionals involved in the care of children and young people. Effective multiagency working and key working with families have been described in many publications to meet this need (see reference list).

Policy and research from the field of disabilities have demonstrated that families caring for a disabled child benefited from having a multi-agency 'key' worker (Greco and Sloper, 2004; Liabo et al., 2001). Aiming high for disabled children states that a key worker is crucial in improving the overall quality of life of families with disabled children, reducing parental stress and enabling families to make better use of other services (Department for Education and Skills, 2007). Studies have shown that key working contributes to enhanced communication and information sharing between professionals and agencies and families and this has resulted in families feeling more informed and ensured easy access to relevant, high quality, and coordinated care (Carter and Thomas, 2011; Sloper et al, 2005; Greco et al, 2006; Mukherjee et al, 1999; Tait and Dejnega, 2001). Consistent with this the National Service Framework for Children, Young People and Maternity Services (Standard 8) notes that studies of key workers ‘consistently report positive effects on relationships with services, fewer unmet needs and greater family wellbeing’ (p.28). Moreover, it is also acknowledged that worries and concerns (apprehension) about transition can be greatly reduced when there is a clearly identified key worker in place (designate) for young people to identify with and to take forward the coordinated planning of care within adult services (Together for Short Lives, 2015).
Important hospital-based service developments for children and young people with cancer are already underway as a result of the recommendations made in the NICE Improving Outcomes for Children and Young People with Cancer guidance published in 2005; however there is still a long way to go to ensure that the planning and delivery of care for children and young people with cancer fully addresses all of their needs (CLIC Sargent, 2009 and 2010). The enhanced model of care described here, illustrates benefits as well as challenges in delivering consistent coordination of care that maximises patient and family experience.

**Person-centred care**

Person-centred care aims to ensure a person is an equal partner in their health care: the individual and the health system benefit because the individual experiences greater satisfaction with their care and the health system is more cost-effective (Royal College of Nursing [RCN]: www.rcn.org.uk/development/practice/cpd_online_learning/dignity_in_health_care/person-centred_care.)

The principles of person-centred care include:

- Treating people as individuals;
- Respecting their rights as a person;
- Building mutual trust and understanding;
- Developing therapeutic relationships.

McCormack and McCance (2006) describe care processes, and pre-requisites of person-centred care that leads to better outcomes: satisfaction with care, involvement with care, feelings of wellbeing and creating a therapeutic culture. Although described from work involving older people, we present it here as a framework in which we might understand the key worker role, its various nuances that influence the delivery of care that is truly person and family centred.

**Evaluation aims**

CLIC Sargent’s *More than my illness* project funded 21 key worker posts, of which 19 had a caseload and three were educator posts supporting the roles in Scotland. The key workers supported children and young people with cancer (0-18 years) at 18 principal treatment centres across the United Kingdom. These appointments followed a successful corporate partnership and fundraising campaign with TESCO in 2010. The roles appointed to are diverse, responding to local need, and are continuing to develop as roles become more firmly embedded within their individual care settings. There is little information available about different patterns of care provision and the determinants for success along with a paucity of evidence to indicate the requirements for service provision to achieve a well-coordinated transition or continuity of care for children and young people with cancer.
The evaluation of the nurse specialist key worker role aimed to:

- Evidence whether there is an improvement in patient and family experience as a result of nursing key worker support
- Evidence whether children and their families have improved emotional wellbeing as a result of nursing key worker support
- Evidence whether children are better able to participate in education, employment and training as a result of nursing key worker support
- Evidence whether children and their families are better able to spend more time safely at home during treatment as a result of nursing key worker support
- Identify obstacles to providing care closer to home that may or may not be overcome by the key worker role alone
- Identify the costs and benefits of this new service model
- Evidence whether best practice and learning have been adopted by other practitioners within local teams.
METHODOLOGY

Participatory research methodologies were used to encourage and facilitate involvement and engagement with participants across the geographical settings where key workers were based. A mixed methods approach was undertaken to provide in depth details of experiences and illustrate how the key worker role has been developed. Data collection was face to face and at a distance using questionnaires, interviews and facilitated group work.

The topics explored in questionnaires and interviews with key workers, stakeholders and families were informed by Greco et al’s (2005) evaluation of key worker services for children with disabilities and Carter et al’s (2010) evaluation of the WellChild Children’s Nurse programme. All questionnaires, interview schedules and data collection methods were piloted before use. By seeking the views and perspectives of the key workers, the families, people and professionals they work with, this study effectively adopted a 360° feedback approach: a similar approach has been used elsewhere (Carter et al., 2010).

The general aim of this study was to evaluate the impact of the CLIC Sargent Children’s Specialist Key Worker. The research incorporated what Stake (1995) refers to as an ‘intrinsic’ case study design where, in this instance, the key worker role was the primary focus. Case studies are advocated when a phenomenon of which little is known but which involves consideration of multiple dimensions and perspectives, is the focus of inquiry (Strauss and Corbin 1998, Yin 2003). Case study research takes a holistic approach (i.e. it considers the case within its context) and is characterised by a convergence of diverse sources of data, which appears to provide a means of considering the multiple elements likely to shape and influence the key workers’ role (Stake 2000). They are acknowledged as being particularly appropriate for an in depth study of bounded (that is, tightly defined) units of analysis about which a great deal can be learned from a few examples (Patton 2002). To understand and reveal complexities of the case, multiple sources of data that centre on the key workers’ role was collected. The uniqueness of each case, particular context, issues and story are the focus of this study (Stake 2000). In this study each key worker is defined as a case with the other participants (parents, children, young people, and stakeholders) being linked to them and their practice.

Recruitment and consent

All key workers had an agreed role in the evaluation process. First, all key workers were interviewed. In this first interview we mapped how many families’ key workers worked with, and the stakeholders (e.g. General Practitioners (GPs), teachers, community nurses) they linked with most often. Following this mapping, families received a questionnaire package, as did stakeholders. The recruitment strategy is represented in Figure 2.
FIGURE 2: Overview of the recruitment strategy

Bereaved families were also recruited, but for an interview, through a personalised letter. To be comprehensive in our evaluation, to best illuminate the complexity of the role, we considered the views of these families, to understand more about what their needs are and how they are best met through the role. Measures were put in place to protect families in bereavement.

Method overview

The project spans the 18 principal treatment centres. Specialities included: neuro-oncology, radiotherapy, and leukaemia. Nurses were employed by the NHS and all developments in the role were in partnership with NHS and local arrangements. CLIC Sargent offered project management support and contributed to role development through the delivery of a support package; study days, newsletter, facilitated networking through email circulations, contract meetings with a template (available on request) that enabled sharing good practice, identifying challenges and items to be covered in future study days. Contract meetings were used as a time for reflection on developments and an opportunity to consider potential solutions and agree local action plans. Later in the project CLIC Sargent was able to share local data dashboards against a median across the UK to help trusts benchmark how they were progressing in the role. There were annually updated operational plans with objectives, milestones and timeframes, action logs, Gantt charts and contract meetings with London South Bank University (LSBU) which all supported the overall delivery of the project. For further information regarding the development of key working in other specialities please contact CLIC Sargent.
In total, 19 nurse specialist key workers, and three nurse specialists involved in the development of an education resource, 95 parents, 85 stakeholders and 10 children contributed to the study. Evaluation data were collected between March 2011 and March 2015. As shown in Figure 3, key workers were interviewed at two points in time and some took part in a focus group (n=12). Key workers also collected data regarding their caseload and the support given to families and patients [patient's demographic data (e.g. age, gender); stage of treatment; assessments, education and meetings (e.g. patient focused meetings); contact with professionals within (e.g. social worker) and outside (e.g. GP) the hospital; number of home visits attended and arranged; how many times the care was delivered in specific settings (e.g. school); discharge planning (e.g. if the key worker was involved with discharge planning)]; this data were collected between 2011 and 2015. Parents from all sites filled in a questionnaire and out of the 95 who completed these, 23 took part in an individual interview. Four children took part in interviews (n=4) and six participated as part of an advisory group (n=6). Eight bereaved parents (n=8) participated. Stakeholders from all the sites completed a questionnaire.

**FIGURE 3:** Summary of participant numbers and data sources

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<th>KEY WORKERS</th>
<th>PARENTS</th>
<th>STAKEHOLDERS</th>
<th>CHILDREN</th>
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<td>• Interview 1 n=23</td>
<td>• Questionnaires n=95</td>
<td>• Questionnaires n=85</td>
<td>• Interviews n=4</td>
</tr>
<tr>
<td>• Interview 2 n=19</td>
<td>• Interviews n=31</td>
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<td>• Drawings</td>
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<tr>
<td>• 1 Focus Group n=12</td>
<td>• 8 - bereaved parents</td>
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<td>• CLIC Sargent Children</td>
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<tr>
<td>• Annual Reports</td>
<td></td>
<td></td>
<td>and Young People’s</td>
</tr>
<tr>
<td>• Other documents</td>
<td></td>
<td></td>
<td>Advisory Group n= 6</td>
</tr>
</tbody>
</table>

**Questionnaires**

Validated questionnaires were used as well as investigator lead questionnaires (Table 1). The *More than my illness* questionnaire package was reviewed by parents prior to use. Time to complete the package was approximately 45 minutes, which has been rated by patients and families in other studies as being acceptable (Gibson et al, 2010).

**Table 1. More than my illness Questionnaire Package for Parents**

| Parental needs | A 21-item scale of parental needs was used. This scale has been used in previous research (Quine and Pahl, 1989; Sloper and Turner, 1992; Beresford 1995) and comprises items covering needs common to parents, such as ‘spending more time with my partner’, ‘having more time with my other children’ and ‘help getting my child to sleep better’. Items are rated on a three-point scale, of ‘Getting enough help’, ‘Need help’ or ‘Help not needed’. |

3 We had planned to use the 27-item Needs Assessment of Family Caregivers-Cancer (NAFC-C); however, after review it was decided to remove this questionnaire from the final version.
| **Aspects of key working** | A twelve-item scale was used measuring how much the family’s key worker performed various aspects of the key worker role. Items in the scale are based on research about a key worker role (Mukherjee et al., 1999). Examples of items are: emotional support, information about your child’s condition, information about services, advice, identifying the needs of all family members and addressing the needs of all family members. Two items were added to the original scale – ‘signposting you to other services’ and ‘other’. Respondents rated the items as ‘Not at all’, ‘Some’ or ‘Very much’, according to how much support they received from their key workers regarding each item. |
| **Impact of key worker on quality of life** | A seven-item scale was used to measure the effects of having a key worker on parental Quality of Life (QoL). This scale had been used in previous research (Mukherjee et al., 1999) and incorporated items such as ‘My physical health or wellbeing (for example, sleep, rest, exercise)’, ‘My emotional/mental health (for example, stress, anxiety, depression)’ ‘Time to myself (for example, work, studies, interests)’, ‘My relationships’, and ‘My financial or material circumstances (for example, income, housing)’. Participants identified if the key worker had an impact on these areas of their lives over the past six months. |
| **Stress** | One item measured how the contacts with the key worker service affected the amount of stress experienced by parents was used, rated from ‘considerably reduced my stress’ to ‘considerably increased my stress’. |
| **Contacts with the service** | Parents were asked to identify the frequency of contact and if they would like more, the same or less contact and who initiated the contact (the key worker or the parent). |
| **Professionals signposted by the key worker** | A list of professionals is presented with three options for each professional listed: I/my child have seen; signposted by the key worker and both. |
| **Parents empowerment** | Three questions to measure the key worker role in empowering parents. Participants rated each question from 1 (Never) to 4 (Always). |
| **Key worker coordination & communication** | Seven questions measuring how often the parent was confused or unsure about roles, as well as waiting for appointments and information sharing between professionals. Respondents rated the items from 1 (Never) to 5 (Always). |
| **Measure of processes of care** | An anglicised version (McConachie and Logan, 2003) of the Measure for Processes of Care (MPOC, King et al, 1995) was used. The MPOC is defined as a means to assess family-centred behaviours of professionals in services for disabled children and is a self-report measure of parents’ perceptions of the extent to which specific behaviours of care professionals occur. Respondents were asked to rate each item on a four-point scale from one (Never) to 4 (Always), or as ‘not applicable’. For the purposes of this study, the four questions specific to children with disability were removed (total 51-item scale). |
Methodology | Children’s Key Worker Service Evaluation Project

<table>
<thead>
<tr>
<th>Key worker role specific tasks</th>
<th>15 tasks included in the description of the key worker role were listed and participants were asked if in the last six months the key worker had performed any of the tasks using one of the three options to answer “yes”, “no” and “n/a”</th>
</tr>
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<tbody>
<tr>
<td>Satisfaction with the key worker service</td>
<td>One item measured how satisfied the respondent was with the key worker service. The question was ‘Overall, how satisfied are you with the key worker service you receive?’ The question was rated on a four-point scale from ‘Very satisfied’ to ‘Not at all satisfied’</td>
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</table>

The questionnaire for stakeholders using a 5-point scale, 1 (Never) to 5 (Always) explored: perceptions of key worker services; frequency and nature of contact with key workers; the way in which the key worker role has affected families’ relationships with the stakeholder’s service; views on advantages and limitations of key working, not only for children and families but for the stakeholder and service they provide; knowledge about the key worker service; suggestions for service development; if best practice and learning has been adopted by other practitioners within local terms.

**Interviews**

Two semi-structured interviews and one focus group were conducted with key workers. The first interview was conducted, either face-to-face or over the telephone. In this initial interview, other professionals and services the key worker works with were captured and mapped out: stakeholders were identified. This interview involved an in depth exploration of the key workers’ role, their caseload where relevant, and the context of their practice. The second interview aimed to build up information on the key workers’ developing role. Interview questions varied between key workers to reflect the different focus of the roles as well as to examine the role in relation to different time points in the child or young person’s cancer journey. The interview schedule set out a list of questions and possible prompts to guide interviewers but was used flexibly in order to respond to the issues raised during the interview. The focus group (held in one of the key workers annual meetings) aimed to bring key workers together to consider their roles and competencies, what works well, what has been achieved and what is more difficult. The nominal group technique was used to generate group ideas and consensus (Gibson and Soanes, 2000).

In order to gain a more in depth understanding of families’ experience of the key worker services, the positive aspects of the service and the areas for improvement, the interview topic guide included questions on: the parent’s understanding of the key worker role; views on their key worker service; information on their contacts with the key worker; changes in the key worker role over the course of the child/young person’s cancer journey; the coordination of services; the quality and availability of services in the area; the key worker’s relationship with the child and family; advantages and disadvantages of the service; information about the key worker’s relationship with the child’s school or nursery; possible improvements to the service. Similar topics were covered in the child’s interview.

Children and young people took part in an individual face to face interview. Participatory techniques were used to enable dialogue about abstract aspects of children and young people’s care experiences (Christensen and James, 2000; Laybourn et al., 2001). The use
of the different participatory techniques helped to establish a comfortable relationship
to ameliorate where possible, the child-researcher power differential effect (Backett and
Alexander, 1991; Coyne, 1998; Kortesluoma et al., 2003). We incorporated these techniques
into the interviews with children and young people. We used sorting cards and diamond
ranking exercises which are a visual representation of ideas designed to work with children of
different ages with varied literacy skills. Children were also asked to respond either ‘yes’ or
‘no’ to ten statements, developed to measure key aspects of service quality which were found
previously to be important to young people (Mitchell and Sloper, 2001, 2003): one change
was made, the words ‘the staff’ in the original version were replaced with ‘my key worker’.

Data analysis
Analysis is a process undertaken to ‘give meaning to first impressions, as well as to final
compilations’ (Stake 2000 p71). The core elements of our analysis were the qualitative
data, ‘words’ generated from interviews, workshops and documentary data. Quantitative
data, ‘numbers’ were used as supplementary, to best illustrate contextual factors.
Descriptive statistics are used to report those aspects of the data amenable to this
approach. Due to the number of cases inferential statistics are not appropriate and will not
be used during the reporting of data. The use of a mixed methods approach has some
advantages (Mason, 2006). One of the areas of strength of qualitative evaluations is the
presentation of a holistic analysis of many contextual factors affecting the performance
of the programme, hence the inclusion of qualitative and quantitative data. Data are
presented here as cases/narratives to best explore the similarities and differences in roles.

The Framework approach was used to analyse the interview transcripts (interviews were
transcribed verbatim). This method was developed by the National Centre for Social
Research and involved five key stages that are closely interlinked (Ritchie & Spencer
1994): familiarisation - immersion in the data and development of an overview of the
main ideas in the data; identifying a thematic framework - organisation of the recurring
ideas into groups of similar ideas or themes; indexing - the draft of the theoretical
framework developed in the previous phase is applied back to the transcripts of
raw data to explore the ‘fit’ (Ritchie et al, 2003); charting - after the data have been
indexed according to the theoretical framework, the data are summarised into thematic
charts; mapping and interpretation - the descriptive summaries in the charts become
incorporated into explanatory accounts that clarify the data (Spencer et al. 2003).

Ethical considerations
This project was approved by a NHS Research Ethics Committee (Reference: 12/
WM/0365) as well as by each of the trust’s Research and Development (R&D)
departments. The principles outlined by the National Research Ethics Service for
informing participants and gaining consent underpinned the recruitment and consent
process (National Research Ethics Service, 2011). This included ensuring confidentiality
and anonymity. Informed consent was sought from all participants at the outset (all
participant information sheets, invitation letters and consent and assent forms are
listed in the Appendix List; this list also includes where the documents can be found).
The eight principles of the Data Protection Act (1998) were also adhered to.
RESULTS

The presentation of findings is organised in three main sections (each section is structured around specific subsections). First, we will present an overview of the models of care of how the role was developed in the 18 principal treatment centres (PTC). Secondly, the models are presented, using a realistic evaluation process (Pawson and Tilley, 1997) and description of the context, mechanism and outcome with a focus on two scenarios – when it works and when it is challenging. Finally, a comprehensive overall model of key working will be introduced. Relevant data sources are drawn upon to best illuminate findings, weaving together qualitative and quantitative data to support the findings.

In terms of presentation, the words of the participants are displayed in italics followed by the identification of the participant (key worker, parent, child, or stakeholder), the interview number (key workers had two interviews; ‘a’ indicates the first interview or ‘b’ the second interview) and the page number for each data set for ease of reference. Key workers’ performance data were collected on a quarterly basis; hence descriptive data will be presented with reference to the different quarters. Descriptive data from questionnaires will be presented with reference to one questionnaire filled in by parents or stakeholders.

I. Models of care

The specialist nurse key worker role has a set of roles and responsibilities identified in the job descriptions, contracts and CLIC Sargent Specialist Nurse Key Worker Handbook, these include: assessment and care planning, coordination of service delivery, providing specialist cancer support and advocating and empowering the family and the child. The analysis of key workers, parents, children and stakeholders’ perspectives about the core roles and responsibilities of a key worker show the impact of these in practice (this will be discussed in detail in the section – Realistic evaluation of the key worker role); but we will focus now on the concept of the key worker, overall roles and responsibilities in order to set the scene for what follows.

The key worker role

The key worker was, in the majority of cases, a specialist nurse experienced in haematology/oncology (only three out of the 21 key workers interviewed had less than 10 years of experience working in the field) and were attached to a PTC. Only a few were new to a coordinating role. The key workers’ professional background is described as: paediatric oncology outreach nurse specialist (n=14); clinical nurse specialist/specialist practioner (n=4) and other (n=3).

Key workers’ caseload composition varied in the number of families supported (the median caseload varied between 39 and 51 patients; there were however key workers with double this number of patients) as well as the diagnosis covered (five key workers only covered either children with a brain/spinal tumour or leukaemia; 14 key workers worked with a range of diagnoses; and two key workers only worked with families during the radiotherapy phase). Key workers supported children aged 0 to 16 years old and some also supported an older age group of 16 and over (Figure 4); with regards to gender, there was a balanced distribution, but with more boys than girls (throughout the data collected in the quarters, the percentage of female and male varied between 51.5% female and 48.5% male and 59.2% female and 40.8% male).
When asked what best described a good key worker, a set of attributes were highlighted by key workers. On the one hand, attributes were needed for the coordination of care (instrumental) and on the other, attributes were needed for building a relationship/partnership with families (interpersonal) (Figure 5).

**FIGURE 5: Characteristics of a ‘good’ key worker**

**Instrumental characteristics:**
- Organised
- Good time management
- Willing to seek advice from others
- Able to signpost
- Understands treatment process and able to reflect on it with families
- Experienced
- Knows organisation
- Understands community working

**Interpersonal characteristics:**
- Friendly, nice
- Good communicator
- Approachable
- Empathetic
- Supportive
- Compassionate
- ‘Able to say no, that they can’t do everything’
- An advocate for the family
- Has sense of humour

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4 Key workers submitted quarterly caseload data represented as Q1, Q2 etc. Rapid increase in patient numbers in 2011/2012 demonstrates new post-holders joining the project, followed by a decline in 2014/15 as some completed three years in the project.
Consistent with the core roles and responsibilities, stakeholders’ views of the advantages of the key role included:

- **(1) Knowledge/expertise**
- **(2) Communication within and between teams**
- **(3) Support for families**
- **(4) Single point of contact for families and professionals**
- **(5) Coordination and continuity of care**
- **(6) Care closer to home**
- **(7) Improved quality of care**

Perceived advantages for parents and children of having a key worker were centred on having one person to contact about any concerns, having someone who was in charge of coordinating services and making sure their needs were met. Where this was in place, there was greater consistency and continuity of care and thus stress was alleviated. The key worker was a professional with expertise who was also approachable - someone parents could ask anything of and who would help them understand information about their child’s condition; hence, key workers provided better information to families, quicker referral to other services and access to appropriate services, and reduced misunderstandings and duplication. The importance of the key worker building a relationship of trust with families and working in partnership with families was emphasised and it was felt that this decreased parents’ feelings of isolation and increased their confidence to care for their child.

In general, key workers perceived their role as having positive effects on the work of other professionals. They noted that key workers were able to access appropriate support for families and refer to appropriate services, they arranged meetings and took responsibility for contacting people, they facilitated contacts and understanding between professionals, they undertook work on issues that were not within the specific expertise or remit of other professionals, and by being proactive they could anticipate future needs of families and provide information for management so that forward planning was facilitated. These views were shared by stakeholders, as shown in Figure 6.
Despite specialist nurse key workers overall positive perception of the key worker role, the attitude towards the ‘title’ was less positive. For most of them, the introduction of the key worker title did not reflect a new role as many elements that were specified within the remit of the key worker role - both clinical work and emotional support - were considered to already be integral elements of the existing nurse specialist remit. The new title was also viewed as being potentially confusing for families. Professionals believed that the title ‘specialist nurse’ was more informative; hence, some did not use the title in their interaction with families, believing families or children would know them by their name or as a specialist nurse. Although some key workers might use the title and have leaflets and letters identifying themselves as key workers, families still thought of them as a specialist nurse.

Key worker, parents, children and stakeholders shared the view on the core responsibilities and roles of a key worker; the role was however developed in different models of care.

**Inreach-outreach continuum**

The in depth exploration of the role, key workers’ caseload, and the context of their practice contributed to the identification of the differences and similarities between roles and four models of care were identified, with reference to some supporting statements (Figure 7).
Key workers developed their role within a continuum of inreach and outreach work as represented in models 1, 2 and 3. Some key workers were paediatric oncology outreach nurse specialists (referred to as POONS) before the role of the key worker was funded, as key workers they continued to support families in the community and doing home visits (model 1); whereas other key workers were mainly based in the hospital with a greater inreach focus (model 3). Model 2 represents key workers who were involved in coordination of care, based in the hospital and who did home visits occasionally; for example, they might do a home visit when the child goes home or they might be involved in school visits. As shown in Figure 8, key workers were involved in delivering and/or organising home visits.

The importance of the key worker building a relationship of trust with families and working in partnership with them was emphasised. It was felt that this decreased parents’ feelings of isolation and increased their confidence to care for their child.
The fourth model included the palliative care phase and this phase is represented as a separate model due to the changes in the role that occur during this phase (e.g. some key workers who were mainly hospital based, had a greater involvement at home during the palliative and/or end of life care phase). Not all key workers were involved in the palliative phase and the number of patients varied across trusts (the overall numbers are shown in Figure 9).

The models also vary in key workers involvement in direct clinical care. Key workers were involved in care coordination, but not all were involved in the direct delivery of care. Nurses in the ward, or community nurses, were more often involved in delivery of direct care. Nevertheless, as discussed in the key workers’ focus group and shown in the graph (Figure 10), other health professionals might be involved in the technical delivery of treatments, but key workers continued to be involved and to have an important role in the provision of information, practical and emotional support and specialist advice.

“That’s what I do primarily if they’re going to you and they’re going back into therapy, I would talk about what that means in response to their questions, so it’s not just about coordinating or hands on clinical care. It’s about educating, I would say.” (Key Worker, Focus Group, p3)
“Good clinical care (...) it’s subtle, using all of your expertise, all of your knowledge and skills in every single interaction that you have with the family. So, you may not be going out putting up chemo but you’re certainly still doing clinical care.” (Key Worker, Focus Group, p4/5)

Across all the different models of care, key workers contacted their patients frequently as shown in the graph below.

**FIGURE 10: Number of times care was delivered in the specific settings**

The overall description of the professionals funded as key workers, their caseload and the way the service had been developed (inreach–outreach approach) is the basis for the understanding of the context and mechanisms described in the next section: Realistic evaluation of the key worker role.

**II. Realistic evaluation of the key worker role**

Policy and research have supported the value of the key worker role; hence it was anticipated that these funded key worker roles would have impact on specific outcomes, as shown in Figure 11. In order to understand the impact of the role, however it is necessary to identify the context and mechanisms involved in the outcomes and the challenges to outcomes’ achievement. The impact of the nurse specialist key worker will focus on four main outcomes: (1) improvement in patient and family experience; (2) improved emotional wellbeing; (3) enabling families to spend more time at home and thus receive care closer to home; (4) children and young people are better able to participate in their own education. In addition, a fifth outcome is considered: (5) best practice and learning is adopted by local teams.
Context-Mechanism-Outcome: Case 1 - when it works

The model of care adopted was influenced by the resources available in the community and in the principal treatment centre. In this section, we will describe the context and mechanisms that contributed to the positive impact of the role on the outcomes presented in Figure 11.

The work developed by the specialist nurse key worker had expertise and experience at its core and was valued by key workers, parents, children and stakeholders. Stakeholders stated that one of main advantages of the key worker role was their knowledge and expertise, this was an asset for the teams and families; and this knowledge and expertise was linked with a higher standard of care.

Specialist nurse key workers were the main link in the principal treatment centre for families and professionals; hence there was a clear pathway for both families and professionals, enabling key workers to streamline the communication process between families and professionals and between professionals. Internal and external stakeholders emphasised that the key worker had an important role in the communication within and between teams and hospitals and being the main point of contact for professionals and families. As shown in Figure 12, 86.9% of stakeholders agreed with the statement that the key worker improved coordination of care and 81.9% agreed with the statement that the key worker simplified the contacts between services. Stakeholders also acknowledged that the key worker improved information sharing with professionals (78.6%) and families (83.3%) and improved the families’ overall experience (81%).
Key workers gave several examples of how their knowledge of local teams, of the expertise and the resources that were available, and of the family helped them influence care planning and coordination of care:

“A first point of contact, and, actually, because we’ve all got nursing backgrounds, then we understand a) the treatment process, and we understand the organisation (…) being able to talk to somebody who understood the complexities of a hospital, basically, and, actually, there are so many members of the team. You don’t want to have to keep on going round the houses to try and get to the people you want to, kind of, speak to.” (Key Worker 3a, p10)

The availability of local hospitals and community teams with expertise in cancer care in the area covered by the key worker facilitated the coordination of care closer to home. Key workers had the responsibility of finding out what was available and establishing links with the teams and professionals. In all the PTCs, the majority of key workers coordinated care and collaborated with professionals on behalf of families. These included education, social services and other relevant local organisations and voluntary agencies. Many examples were provided of key workers liaising with schools and providing information about services available in the community. Internal and external stakeholders acknowledged that the key worker was frequently responsible for making contact with members of the community multi-disciplinary team [MDT] (64.8% always and 28.2% frequently) and ensuring the sharing of appropriate information across agencies and key people involved in the delivery of care (57.7% always and 35.2% frequently) as well as being the single point of contact for relevant services involved (43.7% always and 42.3% frequently) (Figure 13).
Factors underlying successful collaboration and coordination included: building on an existing base of good collaboration between services; good communication, keeping all professionals in different services informed about the role, and being clear about each other’s role. Some key workers described how the role fostered a coordinated service. Through information sharing on specific cases they came to appreciate more about the working contexts of other professionals, including the constraints that they worked under (e.g. community teams’ staff levels and caseloads). Links with community teams and the continuity of care was facilitated by joint home visits with the community teams. In these joint home visits, the nurse specialist key worker was able to introduce the role of the community teams to the families and clarify how both were going to support the family and how this support was going to work. There was a clear definition of roles for all involved – families and professionals.

“(…) what we would try to do is do a home visit with the community nurse, quite early on in the treatment, to discuss the treatment. To meet the family and to say to the family, ‘So-and-so will be visiting you once a week to flush your line.’ So they build up that relationship.” (Key Worker 6b, p13)

Care closer to home was facilitated through delivery or coordination of clinical care at home, care planning and education of parents and health professionals. The two graphs (Figures 14 and 15) show that the key workers contacted different professionals inside and outside the hospital. There is a high involvement of the social worker compared with other professionals within the hospital; the number of contacts shows that key workers and social workers work closely to support the families’ different needs. Outside the hospital, the number of contacts with the community nurse highlights how care closer to home was coordinated by the key worker. As mentioned before, the key worker might not be involved in the direct delivery of care, but was responsible for setting up the support in the community for families.
Key workers’ holistic approach to assessment of families’ needs was central to the support given to families and the coordination and care planning. A holistic approach was formalised in a structured form - the Holistic Needs Assessment (HNA). This document included patient, carer, and professionals involved in the patient’s care contact details; a section on assessment information and preferences - general health; physical needs; social and occupational needs; work and finance; family and close relationships; social and recreational; psychological wellbeing; spiritual wellbeing; and then an action plan. As a result, this document enabled the key worker to know the family and identify their needs and plan the care and support accordingly. The HNA was used by most key workers (Figure 16), though some used it in a more informal way (e.g. not going through the form with the family, but asking the questions and filling in the form later), others did introduce the form and use it as an aid to open up the discussion with the family about their needs; this also helped the family and key worker clarify the role and manage families’ expectations.
Results | Children’s Key Worker Service Evaluation Project

FIGURE 16: Percentage of cases with complete assessment

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<th>Q1</th>
<th>Q2</th>
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- Percentage with a complete assessment (HNA or another tool) of those due
- Percentage with a complete HNA (of any kind) of those due
- Percentage with a complete CLIC Sargent HNA of those due

Education and training was developed in a formal way with the involvement of the key workers in study days, training sessions within the hospital and in the community. Their expertise (e.g. on treatment protocols; holistic approach to families’ needs) was also shared in an informal way in the multidisciplinary team meetings and with families in the hospital, at home or over the phone. Key workers stated that having someone who monitors, gives expert advice and support enabled families to stay home safely. It also contributed to families’ empowerment and trust in the service. Stakeholders emphasised key workers were an approachable and expert source of support for families; facilitated care closer to home and reduced visits to the hospital; hence viewed the role as an excellent asset to maintain and improve quality of care (Figure 17).

FIGURE 17: Stakeholders’ perspectives of key worker’s involvement in sharing knowledge with other professionals

- Acting as an expert resource for local teams within shared care
- Maintaining a resource of current educational material relevant to caring for children with cancer
- Sharing evidence based knowledge with other professionals

Key workers shared the perception that the role was viewed positively by other professionals they linked with both within the hospital and outside the hospital. For some, there was some initial work done with the teams on what the key worker role was and what to expect from the key worker role. This facilitated the work between different professionals and the key worker.

Overall, the coordination of care and care closer to home was perceived as saving the organisation and families’ resources (e.g. reducing admissions that could be prevented).
Contact with families

Key workers and families were matched either on diagnosis type or geographical area, and, although families did not have a choice of who their key worker was, this was not described as a problem. Parents did, however, recognise that the relationship established was so important that if they did not get along with the key worker that it would be challenging for them if there were no other option.

Key workers would often meet the family on the ward and were sometimes present at the initial diagnosis conversation. The first meeting with the families was focused on introducing the role (a few key workers had leaflets with this information) and supporting the family.

“‘I [key worker] am your one link. I will be the person that makes sure that everybody knows what’s going on and if you have a question, if you don’t know which of these various different specialists to go to, you come to me and I will sort that out.’ For me, that was really important, because, you know, we’d gone from having a very fit, healthy [child] to suddenly having somebody who needed help from a whole host of different medical professionals.” (Parent 22, p6)

As described in this quote, the key worker supported parents in the navigation of services involved in the child’s care. Parents’ questionnaires also showed that, for most parents, the key worker accomplished the following aspects of the role: coordination of care, speaking on behalf of the family, advice, information about the child’s condition and help/support in a crises were rated by more than 50% of parents as ‘very much’. There was less agreement towards ‘Identify the needs of all the family members’; 33.7% said ‘some’ and 29.2% said ‘not at all’ (Figure 18).

**FIGURE 18: How much the key worker fulfilled aspects of the role**
The provision of contact details and the way this message was communicated legitimised contact. In addition to the face-to-face contact either in the hospital or at home, families used phone calls, text and email to contact their key worker. Key workers were seen as approachable and emphasised in their communication with parents that they could ask them anything; as a consequence parents felt confident in asking questions and in contacting the key worker. There were additional advantages to being able to contact such an approachable professional, namely the key worker’s expertise, the emotional and practical support given and the continuity and consistency of care.

“You’re kind of this person in the middle who’s with the family, who tries to coordinate a whole lot of other stuff that kind of goes along with the diagnosis of cancer (…) Lots of professionals get involved, and for families that can be very confusing, and they don’t know quite who is doing what where. To have one person that they feel they can contact.” (Key Worker 8a, p3)

“There’s someone to ask your silly questions to, and that there’s somebody who, like you, knows everything that’s going on.” (Parent 22, p12)

“I see them as an empathetic ear as well.” (Parent 10, p5)

Consistent with the interviews, parents’ questionnaires show that, for the majority of the needs listed, they were getting enough advice. ‘Learning the best way to look after my child’ (50.5%) and ‘having someone to talk about my child with’ (51.6%) were the areas in which the majority of parents said they had received enough advice, followed by ‘help planning my child’s schooling’ (42.9%) and ‘help getting the information needed’ (40.7%). The main areas where advice is needed were: help with planning the child’s future (38.6%). Although ‘having someone who will show us which services are available to us’ was mentioned by a third of parents as something they needed advice on (33.3%); 44.4% of parents found they had enough advice (Figure 19).

**FIGURE 19: Parental needs**

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<thead>
<tr>
<th>Need</th>
<th>Getting enough advice</th>
<th>Need advice</th>
<th>Advice not needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help with transport problems</td>
<td>9.9</td>
<td>7.7</td>
<td>82.4</td>
</tr>
<tr>
<td>Someone to look after my child, I can go to work</td>
<td>5.6</td>
<td>12.2</td>
<td>82.2</td>
</tr>
<tr>
<td>Help with my child during the school holidays</td>
<td>6.6</td>
<td>13.2</td>
<td>80.2</td>
</tr>
<tr>
<td>Help with the housework</td>
<td>4.4</td>
<td>10.0</td>
<td>85.6</td>
</tr>
<tr>
<td>Having more time with my other children</td>
<td>9.2</td>
<td>18.4</td>
<td>72.4</td>
</tr>
<tr>
<td>Spending more time with my partner</td>
<td>5.6</td>
<td>14.4</td>
<td>80.0</td>
</tr>
<tr>
<td>Getting a break from caring for my child</td>
<td>10.0</td>
<td>12.2</td>
<td>77.8</td>
</tr>
<tr>
<td>More time to spend with my child (e.g. to play, relax)</td>
<td>15.6</td>
<td>10.0</td>
<td>74.4</td>
</tr>
<tr>
<td>Having more money in order to care for my child</td>
<td>32.2</td>
<td>20.0</td>
<td>47.8</td>
</tr>
<tr>
<td>Help obtaining aids and equipment for my child</td>
<td>32.2</td>
<td>10.3</td>
<td>57.5</td>
</tr>
<tr>
<td>Help getting my child to sleep better</td>
<td>18.7</td>
<td>13.2</td>
<td>68.1</td>
</tr>
<tr>
<td>Help with managing my child’s behaviour</td>
<td>28.9</td>
<td>17.8</td>
<td>53.3</td>
</tr>
<tr>
<td>Help with the day to day care of my child</td>
<td>30.3</td>
<td>10.1</td>
<td>59.6</td>
</tr>
<tr>
<td>Help planning my child’s schooling</td>
<td>42.9</td>
<td>25.3</td>
<td>31.9</td>
</tr>
<tr>
<td>Help getting the information we need</td>
<td>40.7</td>
<td>24.2</td>
<td>35.2</td>
</tr>
<tr>
<td>Help with planning for my child’s future</td>
<td>31.8</td>
<td>38.6</td>
<td>29.5</td>
</tr>
<tr>
<td>Meeting other parents of children with cancer</td>
<td>30.0</td>
<td>18.9</td>
<td>51.1</td>
</tr>
<tr>
<td>Someone who will show us which services are available</td>
<td>44.4</td>
<td>33.3</td>
<td>22.2</td>
</tr>
<tr>
<td>Having someone to talk about my child with</td>
<td>51.6</td>
<td>20.9</td>
<td>27.5</td>
</tr>
<tr>
<td>Learning the best ways of helping my child</td>
<td>50.5</td>
<td>24.2</td>
<td>25.3</td>
</tr>
</tbody>
</table>
Being able to contact their key worker also ensured patients stayed home safely. Parents would seek advice when unsure if they should bring their child to hospital; with their expertise, key workers were able to advise parents, monitor any changes and develop a plan of action.

‘I think just knowing that you’ve always got that one person there that no matter when it is, you can contact them. If you’re really worried about something, especially in the early days, there’s a lot of things that’s you don’t fully understand, but you know that at any point you can just ask that question. They make you feel that comfortable that you don’t worry about having to ask.’ (Parent 8, p11)

Key workers supported parents understanding the information shared with regards to diagnosis, treatment plans, protocols and who was involved in their child’s care; they also played an important role in the child’s understanding of their condition and information shared. In addition to the description of their journey, children discussed at length how the key worker supported them in understanding the information shared.

“[the key worker] was there to just discuss things with that you wouldn’t normally get the information off the doctor straight. They could explain the information that the doctor gave to you or they could just explain other details that you’d not fully understood to you.” (Child 4, p2)

“Sometimes when [the key workers] were there and doctors were there as well and doctor would say some huge words, I used to ask [the key worker] ‘What does that mean?’ (…) they’ll just explain it to me and, that’s it.” (Child 3, p30)

“Some of them [doctors] were cool (…) but the others just did their job and left. They would, like, give you bad news and they’d leave you (…) [‘cool doctors’ also gave bad news], but they were nice about it and they stayed. They talked about it.” (Child 2, p18)

Understanding the information was important to children as it made them feel less worried and scared, as described below:

“’My keyworker makes my life easier (…) [key worker] explain things to make me feel less worried, less scared.’” (Child 1, p27)

“If I have any questions I don’t have to worry, I could just ask [the key worker].” (Child 3, p26)

“If you sit there and say it all in language that only a doctor would understand, it confuses and worries more than it would do if you were to break it down into more simple, normal language that we’ll be able to understand clearly. So if you want to know what’s happening, you’re safe in your knowledge that you actually understand what’s happening and it’s not what your interpretation of what they’ve said is. Make it clear and easy to see what’s happening.” (Child 4, p15)
This drawing is also a testament of the importance of information for children about, in this case, the side effects of the treatment (Figure 20).

**FIGURE 20:** Child’s drawing of what is important for children

Cancer journey – from hospital to home

Support and contact with families was intense at diagnosis. This is one of the phases key workers and families highlighted as crucial in the support given and received; at diagnosis families had to deal with the information and the emotional turmoil of receiving the diagnosis. Key workers were present at diagnosis, if they were not present then, they met the family shortly after that meeting and discussed with the family the information shared about the diagnosis, treatment and helped the family understand the information shared (e.g. explaining the medical terminology) and treatment plan. Families often had many questions and appreciated the opportunity to ask questions of someone with expertise in cancer care. Families also valued the time the key worker had to listen to them, not being rushed.

“To be fair I think that, for me, sometimes listening to what the doctors were saying went a little bit over the top of my head but when [key worker] sat down and explained it, it seemed a lot clearer (...) was also very good at explaining things to the [child].” (Parent 8, p3)

In the initial meeting(s), sometimes the conversation would focus only on parent’s information and emotional needs, but it was also an opportunity for a first approach to identify their needs and set up support structures. It was at this point that most social workers were involved in supporting the families. Understanding the information was only a part of
the complexity involved in the families’ experience, service navigation was another level of complexity, which added to their experience. Navigating services was more or less complex depending on the child’s diagnosis; hence practical support given by the key worker in contacting and informing the parent who to contact was highlighted in particular by parents of children with more complex needs, such as when their child had a brain tumour. Children interviewed shared the view of the importance of having a key worker:

“I thought it was a brilliant thing to have because it just kept some easy to access links to what we were going through because [the key worker] knew what we needed to do in certain situations. [The key worker] was always there to sort out any worries or questions we had for her. [The key worker] was just really useful and really nice.” (Child 4, p16)

In line with this, parents’ questionnaires show that for most parents having a key worker reduced their stress levels (55.8%) and the service had an impact on parent’s peace of mind (69.7%), followed by emotional/mental health (48.7%) (Table 2 and 3).

**TABLE 2: Impact on parent’s quality of life**

<table>
<thead>
<tr>
<th></th>
<th>Physical health or wellbeing</th>
<th>Emotional/mental health</th>
<th>Time to myself</th>
<th>Relationships</th>
<th>Financial circumstances</th>
<th>Feeling of control</th>
<th>Peace of mind</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15.8%</td>
<td>48.7%</td>
<td>10.5%</td>
<td>7.9%</td>
<td>25%</td>
<td>18.4%</td>
<td>69.7%</td>
</tr>
<tr>
<td>No</td>
<td>84.2%</td>
<td>51.3%</td>
<td>89.5%</td>
<td>92.1%</td>
<td>75%</td>
<td>81.6%</td>
<td>30.3%</td>
</tr>
</tbody>
</table>

**TABLE 3: Impact on parent’s stress levels**

<table>
<thead>
<tr>
<th></th>
<th>Considerably reduced my stress</th>
<th>Somewhat reduced my stress</th>
<th>Not had any effect on my stress</th>
<th>Somewhat increased my stress</th>
<th>Considerably increased my stress</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>12.6%</td>
<td>43.2%</td>
<td>20.0%</td>
<td>10.5%</td>
<td>3.2%</td>
</tr>
</tbody>
</table>

Following the initial phase of the diagnosis, the treatment phase was as different as the different protocols and diagnosis supported by the key worker; but what they all had in common was the need for continuity and consistency of care at the transition points: from hospital to home; from PTC to local hospital; between teams/professionals.

Despite the desire to go home, parents have to deal with the fear of not being able to give all the care the child needs at home; there are confidence issues involved as well. So being able to go home with support was highly valued by parents.

“I think the most important time is when you start that process of leaving hospital (...) it’s quite a big transition (...) While you have somebody in the ward, just looking after your every need and then you’re at home and you’re having to do it all, so that was a really important time that [kw name] would come (...) and sit and listen, that would, I say, was highly important, in terms of just being at home and trying to transition from hospital to home (...)” (Parent 3, p4)
The way the key worker manages and informs the parent about the transition back home and the support parents will receive, in particular if community teams are involved, is crucial to parents’ confidence in the new professionals involved along with parents’ perception of consistency and continuity of care. From a key worker perspective, the transition may also be facilitated with a follow-up call when the patient is discharged plus trying to catch up with the family when they are next in for a clinic appointment. Seeing the family when they are in the hospital is an opportunity to identify and address any needs they may have. Home visits were also seen as a mechanism that facilitates transition back home, in particular in the first weeks after diagnosis.

Parents valued having a main point of contact, having professionals who were knowledgeable and approachable, but also that key workers were proactive in the support given. So, for example, as this key worker describes below, it is important to contact families at transition points where their needs might change and support is needed.

“(…) making contact with families when it comes to the time of reassessment, disease reassessment because obviously that’s a time where there’s a lot of anxiety, a lot of worry about what these tests and investigations are going to show.” (Key Worker 9b, p11)

For parents, the consistency of support throughout the journey was highly valued.

“It’s great to have somebody from start to finish… follow you through the process.” (Parent 3, p14)

As highlighted in the parent’s quote, parents appreciated having the key worker throughout their journey and although at some phases they might not be as involved in the direct delivery of care, they are still the families’ point of contact; the professional who knows what they have been through, who knows the family and the patient.

School

Care closer to home aimed to enable the child to be safely at home, closer to family and friends, with access to education. Going home is an important point in their journey as they are able to reconnect with friends and family, be in a familiar context and it was also linked to a feeling of getting back to normal.

“It felt good that I was out of hospital (…) Because basically you’re just in a room, you’re trapped (…) You can’t leave the ward (…) The feeling that you’ve got your own bed, you’re comfy. You are back to your home.” (Child 1, p17)

“Really nice. I saw all my siblings (…) When I got home I had Wi-Fi and stuff so I could go on and talk to them and play games. It’d be really cool.” (Child 2, p10)

“I like home because I saw everyone and I got to play Xbox with my mates and talk to them. I like school because I saw all my mates. It was fun to, like, do stuff again, get back to normal.” (Child 2, p19)

The child’s journey back to their routine was reinforced with their return to school. The key worker had an important role in this transition; they worked with the child to plan and support their transition. Key workers were involved either directly in school visits and meetings with head teachers, child’s peers, or through
the coordination of the link between health professionals and the school. In addition, some key workers also delivered care in the school (Figure 21).

**FIGURE 21: Number of times care delivered and contacts with professionals in the school context**

A relevant element of support in the transition back to school was the contacts the key worker had with the school before the child was ready to go back, ensuring that all the equipment and support were in place, that the staff in the school felt confident in supporting the child and that a plan was agreed between the school and parent on how the child would attend school, how this could evolve and what they could expect (this was negotiated with the parent, the child and the school).

“[key worker] went into my school, and in the Year assembly (...) I stood up front with [key worker] and they asked me all sorts of questions then [key worker] answered some and if I felt alright I would answer some.” (Child 3, p19)

“When we were looking at me going back, she discussed with me what I wanted her to go and say to the teachers (...)I just said tell them what they need to know, just do what she needs to do with them because I trust her with people at school.” (Child 4, p4)

*It’s like a relationship, a trust*

“It’s like a relationship, a trust, and that’s what we’ve got with the key worker.” (Bereaved parent 2, p18)

We start this section with a quote from a bereaved parent because this quote captures the essence of the role and its impact on families’ experiences. The key worker meets the family at diagnosis; they support the family and assess their needs using a holistic approach, so they get to know the family very well. They are also the family’s main point of contact and the professional the parent goes to with questions and concerns. Nonetheless this is a description of tasks that fails to cover the mechanism behind the impact of the key worker role. Their impact on families’ experiences was also grounded in the relationship established with the family. This relationship was characterised by parents as similar to family, similar to friends, but much more than that because it was a professional relationship.
‘You have one person who knows you.’ (Parent 28, p23)

The relationship with the key worker was built gradually and children described how the key worker was available, approachable and supportive.

“[key worker] would come and see us most days and come to speak to me about how it was going and everything (...) and check everything was fine.” (Child 4, p1)

“They just checked up on me, really. Called my mum about a hundred times, so they were thinking of me.” (Child 3, p9)

“[key worker] knew how to help, like, how to, the right stuff to do for me, like to improve my balance and stability and all that. [key worker] knew how to help my Mum as well (...) Coping. I mean, like, we’re coping with the fact that I actually have cancer (...) [key worker] talked to her a lot.” (Child 3, p25)

The Measure of Processes of Care (MPOC) measures respondents’ perceptions of whether they feel that they received coordinated, enabling and responsive services. Families rated from 1 (never) to 4 (always) the quality of care they had received over the past six months. Respectful and supportive care: care in which parents are treated with respect as individuals, equals and experts about their child was rated ‘always’ by the highest percentage of parents (78.6%). Enabling partnership: reflecting parents’ involvement in the care process, particularly in decision-making was rated ‘always’ by 57.5% of parents. Providing general information: activities that meet parents’ general information needs was rated ‘always’ by 41% of parents; 31.3% rated ‘often’; 19.3% rated ‘sometimes’ and 8.4% rated ‘never’. Responds to individual needs includes aspects of goal planning together, consistency and response to change and was rated ‘always’ by 65.1% of parents. Good communication with the family includes complex communications and information exchange and was rated ‘always’ by 51.8% of parents; however, this was the factor more parents rated ‘sometimes’ (15.7%) and ‘never’ (12%) compared with the other factors (Figure 22).

FIGURE 22: Process of care domains - parents’ perspective
Context-Mechanism-Outcome: Case 2 - when it’s challenging

Key workers were all asked whether they experienced any constraints or problems in their role. The main challenges in fulfilling the key worker role were: time, caseload size, geographical area covered and staffing numbers. The inequality of local services was also a challenge in care coordination. This was linked to a number of factors, some of which varied between areas.

“I suppose time is a huge issue, just timeliness, as well, because the information is only relevant for the time that it is there, and so, sort of, you can’t be in all places at the same time.” (Key Worker 5a, p20-1)

‘I know [key worker] is in demand, and therefore, I feel I don’t want to waste her time, although she’s absolutely lovely and she’s very good with her time, I know she’s with demand.’ (Parent 13, p16)

Time is an important resource, but what it meant in practice was that practical/clinical aspects of the role had to be prioritised, leaving less time to provide emotional support for families; it also made the service potentially not equitable, with a focus on newly diagnosed patients and/or those with complex needs, while those on treatment still have needs and might ‘miss out’. Likewise, increase in caseload and/or large caseload (as a consequence of staff maternity leave, retirement, lack of cover) lead to pressures on the key worker and service delivery. Although the median number of patients was between 39 to 51 cases, some key workers had double the number of patients and as shown the graph (Figure 23) there was a consistent increase in new patients, this was in larger number for some key worker; so there was an increasing pressure on key worker’s caseload. For some diagnoses there is an end to treatment and after a period of time the child is not active on the caseload, and the worker’s caseload will stabilise. However, for other diagnoses, especially brain tumours, the child or family may need support far into the future so these caseloads are continuing to grow beyond the life of the project.

FIGURE 23: Key workers’ median number of patients across quarters

Coordination of care was a central element of the key worker role; there was however some concern towards the danger of the role becoming too administrative-focused, with little time for seeing patients face-to-face.
In some areas it was challenging for key workers to accomplish all the elements of their role, such as home visits, due to the resources available and constant demands on time. For example, covering a large geographical area, thus requiring significant time spent on travelling to see families at home, and/or a large caseload, meant the key workers were not able to do home visits. This was also an obstacle to build up relationships with local teams and knowing what was available. For others the diversity of what was available in the community meant they had to adapt to the lack of resources in some of the areas covered (lack of resources in some places were a consequence of NHS reduction in local services). Sometimes the services were not very local to families or there was limited capacity and reduction in the services available or even a lack of availability of services.

Challenges mentioned by key workers setting up home tuition were: time consuming, funding issues, varied approach between schools, and the removal of home schooling in some areas due to cut-backs. Also challenging was supporting young people seeking employment after treatment, schools not accommodating the child’s needs or appreciating need for support in school.

There were aspects of the role that were challenging due to resources and practices in the PTC. Discharge planning issues identified reflect how the role can be undermined if there is not communication between professionals and the key worker, namely delays in discharge caused by lack of forward thinking, care not set up at home/equipment needed or colleagues discharging patients without ensuring care is set up at home; a key worker only informed of a patient being discharged on the day of discharge (and then having to set everything up for home care).

The development of the key worker role, on some occasions, was undermined by other professionals. For example, key workers reported the lack of support as challenging in the development of their role, in particular when they aimed to coordinate care.

“I think some of the teams feel that some people feel that the key worker does everything and they do feel that, since the phrase ‘key worker’ has come into play, that other professionals see the key worker as the dumping ground where they dump everything on the key worker.” (Key Worker 2b, p12)

As shown, stakeholders identified some factors that do not facilitate the coordination of care and the work between different professionals and teams. These include: having separate documentation; lack of awareness and appreciation of the roles and responsibilities of others between services and potential overlap of the roles and duplication of services (Figure 24).
It was also discussed if the relationship between the key workers and families could lead to families becoming too dependent; however families and key workers describe the opposite. It is important to manage families’ expectations (in what the key worker can and cannot do):

“There are challenges around families expecting information there and then (...) They think if they’re assertive with us, that we’ll get them what they want, and often we can’t, just because we can’t produce something the next day, because there isn’t the space.” (Key Worker 18a, p17)

Key workers’ support impacted on parent’s confidence and as described in the previous section parents felt more confident going home because they had their key worker’s support. Although key workers supported parents’ empowerment. 29% of parents said that the key worker did not act as an advocate and help them develop their self-advocacy skills, 19.2% said the key worker did not help them to know about how to access the services and 18.6% did not feel they were supported to increasingly take on coordination of their child’s care (Table 4).

**TABLE 4: Empowerment of parents**

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helped you know about and how to access the services</td>
<td>19.2</td>
<td>28.2</td>
<td>24.4</td>
<td>28.2</td>
</tr>
<tr>
<td>Acted as an advocate and helped you to develop your self-advocacy skills</td>
<td>29.0</td>
<td>23.2</td>
<td>17.4</td>
<td>30.4</td>
</tr>
<tr>
<td>Supported and enabled you where possible to increasingly take on coordination of your child’s care</td>
<td>18.6</td>
<td>25.7</td>
<td>27.1</td>
<td>28.6</td>
</tr>
</tbody>
</table>

**FIGURE 24: Stakeholders’ perspectives of work between professionals**

- Services have separate documentation
  - Don’t Know
  - Agree
  - Neutral
  - Disagree

- Poor working relationships between services
  - Don’t Know
  - Agree
  - Neutral
  - Disagree

- Lack of trust and confidence in the abilities of other agencies between services
  - Don’t Know
  - Agree
  - Neutral
  - Disagree

- Lack of awareness and appreciation of the roles and responsibilities of others between services
  - Don’t Know
  - Agree
  - Neutral
  - Disagree

- Poor communication between the key worker and other services
  - Don’t Know
  - Agree
  - Neutral
  - Disagree

- Contributed to an overlapping of roles and duplication of services
  - Don’t Know
  - Agree
  - Neutral
  - Disagree
Even though the key worker was the main point of contact for the family, they could not be the only point of contact. Key workers expressed their concerns with the plans to cover the key worker role when they were absent. This challenge was recognised by key workers and stakeholders. In some trusts, though, a team approach to key working was put in place to tackle this challenge.

**When it’s challenging for families**

Parents interviewed reported in the majority of cases positive experiences; there were however a few parents who had a less positive experience. For one of the parents the lack of communication and information throughout their family’s experience meant the parent had to ‘chase around’ to find information and had to coordinate a lot without help (e.g. school, appointments). Information was not shared which meant the parent did not know at times what to expect. Additionally, there was a lack of support with transition back to school. This parent’s experience is reported as ‘stressful’ and the final stage as “Once you get to the end of treatment, I personally felt quite dumped by the system.” (Parent 20, p20).

One of the parents reports a stressful experience before a key worker was involved with their case, clearly stating the difference in families experience before and after the key worker involvement.

In one of the interviews it was also acknowledged by children how the lack of the key worker support can also impact on their experience, namely the experience of having a professional with time to discuss their concerns. So this quote is in contrast with the advantages stated that the key worker has an important role in supporting the family understanding the information and address their concerns/needs.  

“I didn't really talk to the doctors or nurses about it [worries/concerns] (…) I didn’t really like the doctors, not because they were nasty, because they always brought bad news. So, I didn't really to talk to them, and they were always busy and stuff (…) The nurses were nice but they had other stuff to do. So, I couldn't really talk to them.” (Child 2, p9)

**End of treatment and follow up**

The graph (Figure 25) shows that the majority of cases on the key worker caseload are patients on treatment, but there are patients at end of treatment and follow-up (early and long term) also receiving support.

**FIGURE 25: Patients on treatment/end of treatment and follow up**

![Graph showing patients on treatment/end of treatment and follow up](image-url)
Overall, both parents and key workers recognised the challenges in the support available after the treatment phase. This was a particular issue for patients with a brain tumour who after treatment have on-going needs. It was challenging to ensure on-going support/assessment for children with disabilities after treatment. For other parents, the lack of support is also described from an emotional perspective. Feelings of abandonment after end of treatment were shared in the interviews and comments section of the questionnaire.

“Initially (after diagnosis) it was horrendous, but you haven’t got time to think about it, because you’re living day to day with appointment to appointment, that’s how you live for quite a while….but almost now you feel, I don’t know what the word is really, you almost feel, sort of, dumped…I think you probably need support now more so than you did then (…) and I think it probably affects us more now than it did then.” (Parent 5, p10)

“It would be an amazing thing to have an end of treatment key worker. As in, part of the same team, but somebody who specialises in end of treatment.” (Parent 3, p5)

“(…) there isn’t that same level of support when you move into the chronic phase, I think. That would be the only gap, I would say.” (Parent 3, p14)

“I think that because it’s such a big event, a life-changing event, we as a family, sort of, thought well, we want to get on with our own life but you feel bereaved because you’ve come away from something else. I think that they need to come to you rather than you go to them, you know, and maybe, sort of, call or arrange a home visit, in our comfort zone rather than in a clinical place.” (Parent 12, p10)

Patients diagnosed with brain tumours presented a set of needs that were more complex compared with other patient groups supported by key workers; hence the role of the key worker in coordinating the support given to families was more intense. For example, there was a consistently large number of individual education plans discussed and actioned for the brain tumours patient group, compared with the solid tumours and leukaemia patient group (Figure 26).

**FIGURE 26: Number of individual education plans discussed and actioned by patient group**
Support for siblings

Sibling support was mentioned by parents when reflecting back on their experience; having a child diagnosed with cancer is very intense for the whole family, but parents mentioned that support for siblings was missing. They were able to identify this need when they have passed the most intense phase of diagnosis and treatment; hence key workers may want to consider discussing this topic a little further down the treatment timeline and signpost families to sibling support.

“Hindsight, now, I think my children should have got instant support, emotionally, from the beginning’ – realised later how it was affecting them emotionally, problems at school, behaviour, ‘I think we waited until the symptoms came to light, whereas I think at the beginning, I didn’t know that my other (...) children would suffer as well, emotionally. I think, in future, I would have said, not just the child who’s ill, but the parents and siblings need emotional support as well.” (Parent 13, p17)

“Sibling support, I would say, was awful, absolutely awful.” (Parent 3, p15)

Nevertheless, some key workers mentioned they offer sibling support; in some places there is psychological support available for siblings; in other trusts the social workers organise siblings’ days. This is one aspect of support that varies across trusts and it is an example of how the context and resources available impact on what is available for key workers to signpost families, and thus impacting on families’ experiences.

Context-Mechanism-Outcome: palliative care

Some key workers took the lead in the coordination of palliative care, for example arranging palliative care planning meetings and liaising/meeting with the GP as necessary. A formal re-assessment of the family’s needs often took place at this stage key workers were responsible for organising the resources that enabled parents and children to have their care at the place of their choice.

“Well, I’d call it knitting. I would call it making sure that the five or six elements that we needed, they were knitted together, they were coordinated.” (Bereaved parent 4, p8)

“Certainly for the patients needing palliative care we’re very much in the driving seat in terms of assessment of patients’ needs both from a medical, psychological and emotional perspective, looking at drug interventions and the whole coordination of their care linking in with general practitioners and local services, children’s hospices.” (Key Worker 9b, p5)

Parents’ choice of the place of care was supported by the key worker as shown in the graph (Figure 27). The key worker discussed with parents the options for end of life care, what they could expect and would support parents in their choice, e.g. contacting the hospice, organising a visit before the parents decided; meeting with the different professionals involved in this phase.

“If they had the palliation at home, it would very much be working alongside the nurses in the community that were actually delivering the hands-on care. It would be liaison with general practitioners and a lot of community staff that are involved in providing the care. If they chose to have their palliative period in the hospital, it would again be that coordinating role of
making sure that everything was set up so that they were in the right place, where they wanted to be. Then it was having discussions about what might happen, talking about symptoms, what might happen at end of life, what might happen afterwards.” (Key Worker 2b, p2)

FIGURE 27: Number of palliative care cases and contacts

The role of the key worker sometimes changed during palliative care, as they offered increased support to families. For example, some key workers who did not undertake home visits for children on treatment would visit children at home who were receiving end of life care. In some cases these visits were daily. Phone contact with these families also increased, again this was often daily and some key workers also offered a 24 hour on call service for patients who were palliative.

Key workers’ expertise and delivery of clinical care at home supported parents’ feelings of security. Having a key worker facilitated health professionals and parents to get to know one another and become emotionally close; continuity of care was highly valued by parents. Positive relationships with the key workers and open and honest communication supported and reassured parents throughout this phase.

“They held our hand and led us through the whole process (...) and you are supported every single step of the way.” (Bereaved parent 1, p19)

“Their honesty. Trusting them, and knowing that whatever they told me would be the right thing (...) because obviously, when your child is ill, all you really want is reassurance.” (Bereaved parent 5, p16)

The relationship between the key worker and the family was vital to the support given to and received by parents and enabled individualised support.

“The key worker quite understood us as a family (...) it’s such a personal time and it’s such an intense time.” (Bereaved parent 6, p11)

“Eventually you have to be able to not hold yourself together (...) and actually have the conversations you need have (...) with somebody actually knows where you’re from. Knows how you live, where you live. I think you need some kind of bond.” (Bereaved parent 4, p7)
Support in the palliative phase had its own challenges including: lack of out of hours palliative care available in the community; setting up complex palliative care packages at home is time consuming and resource intensive (caseloads need to be managed so this is taken into consideration); increase in nursing needs/24 hour support provided; providing effective bereavement support for families, variation in support available for bereaved families.

Scotland Educators Project

In tandem with the key worker role evaluation, in Scotland, there was an additional initiative that focused on education. The Key Worker Education Project was led by CLIC Sargent funded nurses; based in Edinburgh, Glasgow and Aberdeen and ran from June 2012 to October 2014. During this period, the project team were tasked with developing an educational resource package which could be utilised by all staff within primary care, community children’s nurses, shared care centres and other local services who may be involved in caring for a child or young person with cancer and their family. Better education for professionals outside the PTC should improve and enhance the overall and local support offered to children and young people with cancer, enabling key workers in Scotland to organise more care closer to home.

A scoping exercise was conducted in the first year of the project to identify the need for such a resource, its content and how training should be delivered, evaluated and sustained. This involved data collection (using questionnaires) with: children, young people, parents and professionals involved in caring for children and young people with cancer (including MDT members, teachers, GPs). Information collected from the questionnaires was fed back to various professional groups to give the opportunity to add anything that had been missed.

Communication was highlighted as an area for improvement by families and professionals. Regular and ongoing contact between all healthcare professionals and a named person was viewed as imperative. Families wanted regular follow up/contact by a named person, the wider MDT to be kept up-to-date and a key worker for each child. Other suggestions to improve care for families included: improved preparation for end of treatment and GP/community staff being included from diagnosis to aid transition back at end of treatment.

Questionnaire responses from professionals indicated that the majority would appreciate an education package. Suggestions regarding the content of the education package were grouped into four main categories: background information (e.g. treatments and their side effects), practicalities of care (e.g. caring for a Hickman line/portacath), psychosocial issues (e.g. how to tell siblings, body image) and education for professionals (what is available and how to access it).

The second year of the project involved: delivery of training, development of the education resource package and roll-out of the package. One of the project co-ordinators describes the benefits of the package and how it might be used in practice: “What we envisage is that when we go out, as a POONS, to meet a community nurse for the first time, you could not only give her or him the information sheets that they would need to know, that they would find useful to know about that whatever it was for that child. Also you could signpost them to the education package online, that they could go, at their leisure, and peruse through. When the key worker or the POONS is phoning the GP quite quickly and initially to get everybody communicating, most GPs you speak to have never seen a
child with cancer, or they’ve seen one or two, and they feel disempowered and don’t have much knowledge. So, part of what we’ve done in the education package is to try to really address that, that they can very quickly feel empowered.” (Key Worker 22a, page 7)

Outputs from the project:

- The education resource package – available through the Managed Service Network (MSN) for Children and Young People in Scotland website
- A family held treatment record – designed to improve communication between professionals and centres
- Standard letter for GPs/Health Visitors - to be personalised by the POONS and sent to the child/young person’s GP/Health Visitor shortly after diagnosis
- Further information about this project and the findings is available from the final report: CLIC Sargent Key Worker Education Project June 2012 – October 2014 Evaluation Report (available from www.clicsargent.org.uk/content/key-worker-education-project-evaluation-report.)
III. Key worker person-centred care in a challenging environment

**CONTEXT**
Other professionals know who the key worker is for a specific case and what to expect from a key worker

**Nurse specialist key worker with experience and expertise**
- Key worker shares information about the role with different stakeholders
- Stakeholders support the key worker role
- Caseload
- Geographical area covered

**MECHANISM**
- Relationship established between the key worker and the family
- Key worker contacts the family regularly face to face when family is in clinic/hospital or phone call to check how the family is doing
- Key workers give their contact details to the family and reinforce that the family can contact them
- Key workers contact the family according to their preferences – families’ preferences are different and can change
- Information/expertise
  - Going through the information with parents after the meetings
  - Parent teaching
  - Staff training
  - Information pathway
- Coordination
  - Being main point of contact
  - Key worker role – team approach
  - Key worker knows what is available in the community; knows local teams
  - Key worker explains when and why the role is transferred

**OUTCOME**
- Improvement in patient and family experience
- Families spend more time at home and patients have care closer to home
- Best practice and learning is adopted by local teams
- Improved emotional wellbeing
- Children/young people are better able to participate in education
In the previous section, we described the development of the key worker role and the facilitators and challenges to key working. The main challenges were identified in the environment. The challenging environment included the lack of resources available within and outside the hospital. The pressure of large caseloads and geographical areas covered; staffing levels and competency of different teams add to the challenges of the coordination of care and accomplishment of one of the outcomes of the service: safe care closer to home.

Within this challenging environment, key workers throughout the 18 PTC developed their services, their role, the support to families and professionals and identified what needs to be changed and improved. In this section, the focus will be on these examples of good practice to accomplish the outcomes outlined in the diagram opposite.

All the key workers interviewed shared examples of how their role influenced practice and some were involved directly in developing the key worker service and policy within their trusts. For example, one key worker worked on a project involving numerous elements aimed at defining and developing the key worker role and improving patient care. They were tasked with developing an operational policy for the key worker role. Discussions and a survey within the MDT took place to agree: the role and functions of the key worker role, when transition to another key worker within the PTC/to a local key worker is indicated, the process to support transition and referral and discharge criteria. An audit of patient notes revealed gaps in the recording of the named key worker, the key worker then worked with the MDT co-ordinator to ensure the key worker is discussed and documented. The notes audit also identified the need to develop core information packs for families and to amend how this is documented in patients’ notes. An information pathway had previously been developed, this was reviewed and the key worker updated written and web-based information given to families.

Other key workers described similar projects focusing on the definition and implementation of the key worker role. This involved reviewing existing local policies around key working and working with families and MDTs to improve clarity of the role, coming to a consensus locally about what is involved in the key worker role and how it works in practice.

Key working was facilitated when the policy clearly defined who the key worker was and what the role covered. There was then the need to share with different professionals within and outside the hospital what they could expect from the role and what the role did not cover (managing expectations was essential to the work between different professionals). The key worker was not someone that would do everything or do what other professionals did not want to do. As described previously, the key worker role is at its best when the professionals involved in the child’s care acknowledged the responsibilities and competencies of the key worker. This might involve in the beginning, sessions or meetings where the key worker shares examples of the work developed with the families and different professionals involved in the child’s care.

Reviewing and improving the patient’s journey/pathway were also focused upon and written policies were developed around this. For example, one key worker spoke about looking at what happens when a child/young person reaches late effects, palliative care or transition and ensuring these phases are all included in the policy developed. Another key worker had put a brain tumour pathway in place which helped the key worker to see where to focus their work and where delegation to others is appropriate. Sharing this pathway within the MDT helped
other professionals to understand what their roles and responsibilities are, thus improving how the MDT works with these patients and how the MDT can support the key worker.

Furthermore, the clarification of the role needs also to include when the role is transferred and how this process is formalised and in practice what does that mean for professionals and families. Again the competencies available in the community need to be considered and these plans need to be discussed with the professionals involved (as described in all the service development processes developed within the project, key workers involved different professionals through consultations in order to develop policies/practice).

Care closer to home is linked closely with the resources available in the community; the key worker can have a role in supporting the development of competencies within and outside the hospital, and thus supporting the improvement of the quality of care.

Key workers were also involved in sharing their knowledge and training other professionals. For example, one key worker’s role involved acting as an educator spreading understanding of brain tumours and their effects on children and young people. This key worker offered training for occupational therapists, physiotherapists and community nurses to talk about how to look after a child with a brain/spinal tumour in the community. The training also enabled the key worker to explain their role and find out more about community services to prevent duplication occurring and ensure the family’s needs were met.

The key workers’ expertise and knowledge is crucial and an important asset not only in professionals training, but also families’ support. Families trust and confidence in the service was facilitated by the key workers’ experience and expertise. The key worker was an expert that answered parents’ questions, prepared parents before they went home with their child; someone parents could contact when they had questions. Key workers’ expertise was also used in more formalised meetings. For example, as a result of feedback from a group of patients with a brain tumour and their families, one key worker had organised a neuro-oncology awareness day. All parents whose child had been diagnosed in the previous year were invited to this event. During the day professionals gave presentations about the ongoing effects of brain tumours (physical, psychological and cognitive), coping at home, how to access support, return to school and educational support and practical and financial support. Comments from parents on the feedback forms about this day showed it was highly valued:

“Excellent opportunity for informal discussions with staff. Well worth doing, very much worthwhile”.

“I found today very helpful with information and useful websites.”

Furthermore, key workers were involved in developing documentation to better support families and in some places there were whole teams using the Holistic Needs Assessment forms as a result of the work developed by one of the key workers (it was shown through practical examples how the HNA could be used and how useful it could be).

The relationship established with families and professionals was another central aspect of the role. The coordination of care was facilitated by key workers knowing what was available in the community and the local teams (this facilitated the communication and coordination of care). The relationship also allowed the families to feel confident at transition points when for example the care at home was mainly delivered by the community teams. Not all the
key workers were able to do joint home visits, it was however essential that the family was informed with regards to the transition and what was going to be transferred to other teams and why and what to expect from the PTC key worker. The relationship with the family was also facilitated by being able to see the family at home and this view was shared by both families and key workers. Being able to talk in the home environment facilitated the discussion of the families’ needs and also the relationship between the family and the key worker.

Although key workers are identified as a coordinating role, there were some suggestions that it should not be a heavily administrative role (e.g. making appointments). Where administrative support was available it was valued and freed the key worker to more contact with families and professionals; there were opinions this was a more cost effective way of using the key worker skills. Nevertheless, the administrative support needs to ensure the families’ trips to hospital are managed in a way that they are reduced to a minimum (e.g. not having to come to hospital for different appointments at different days when it is possible to book them in the same day).

Overall, experience and expertise, coordination and relationship were essential to an improved family experience, emotional wellbeing and care closer to home. Through the key workers experience and expertise they were able to coordinate care; support the family in understanding the information being shared; understand their child’s condition and how they could support their child. The family developed their trust in the key worker, due to their knowledge and the fact they were approachable. The relationship was built through this as well as the fact the key worker knew the family (the holistic approach to their needs created an opportunity for knowing the family); the care was individualised and parents reported not feeling as ‘just another case’.
DISCUSSION

The key worker role has been implemented in 18 principal treatment centres across England, Wales and Scotland. There are core shared characteristics as well as variety in the implementation and development of the role.

The key worker role was structured around four main functions: knowledge and expertise; coordination of care; being the main point of contact for families and professionals in the hospital/community; and communication.

Care coordination was facilitated by key workers’ experience and knowledge of how to navigate the system within their hospitals and experience of working with the community services (e.g. all key workers mentioned that they knew how professionals worked in local hospitals and in the community and the resources available). Albeit in practice it took different formats. Research showed that when care is well coordinated
patients will experience effective flow of information between clinicians throughout the course of their illness, with streamlined service provision in response to their physical, emotional and social needs (King et al. 2008; Young et al. 2011).

Having a main point of contact was perceived as an important aspect of the role. This concept echoes what Young et al. (2011) describe as continuity of care, in particular continuity within relationships. Families had someone who knew what was happening with the child and someone who had the knowledge to support them. Families preference for having someone known to them has been reported elsewhere (Dean 2006; Ling et al, 2013).

Care coordination and being the main point of contact meant also that key workers needed to know the families well - families’ needs assessment was a central aspect of the role. Families’ needs are often wide ranging and likely to change during treatment; hence key workers had a holistic and systematic approach in assessing and reassessing the families’ needs. Most key workers used an informal approach focused on the individual needs of each family, instead of going through a formal assessment form. Nevertheless, formal assessment forms were used as a guide and reminder of the different areas of families’ needs throughout the cancer journey.

One of the most important functions of the role was communication and information sharing with the families and between families and professionals. This supports the findings from Ling et al. (2013) research into the key worker role in adult cancer care. In both studies, specialist nurse key workers had a central role in the communication and interpretation of information to families.

The emphasis of the role upon patient holistic assessment, support, education, information and continuity of care within a multidisciplinary team framework was shared by all key workers; however the development of role in practice varied. Some key workers were mainly involved in outreach support, others had more occasional home visits and there was a group of key workers who were not involved in home visits. Key workers who were mainly hospital based set up support in the community and were available for telephone support. Home visits have been identified by health professionals and families in previous consultations as an important support factor in the transition from hospital to home.

Contextual factors influenced the development of the key worker role. Key worker’s involvement in care coordination and home visits was influenced by the resources available in the PTC, shared care hospitals and in the community, these included staff and caseload numbers. Time constraints hinder the implementation of the key worker role (Abbott et al. 2005, Greco et al. 2006). Coordination of care and family support are only be possible if key workers have time to fulfill all the aspects of their role as reported by Sloper et al. (2006) study of different services of key worker support.

The post-holders’ perspectives on the characteristics of a good key worker echoes the traditional nursing roles of providing holistic need’s led and psychosocial care (Leigh, 1998), but it also includes characteristics needed to coordinate care and consistent with the findings reported with key workers in adult cancer care (Ling et al. 2013), specialist nurses had a negative reaction to the label “key worker”, which reflects staff feeling that the label diluted their professional identity and did not capture their professional competence.
A mixed methods approach was undertaken to provide in depth details of experiences and how the key worker role has been set up and developed, perceived impact on family experience and service delivery. Data collection was face to face and at a distance using questionnaires, interviews and facilitated group work. When all combined using a case study approach data has enabled the voice of the key worker, other professionals, parents and some children to contribute to this final report.

In conclusion, supported by evidence collected, key working effectiveness is built on three pillars: knowledge, relationship and coordination: when these pillars are in place, a better-quality family experience can be assured.

Coordination, prominent in the NICE guidance (2005) definition of a key worker, that embraces signposting to information and advice, promoting continuity, described here as a ‘mechanism’, does not occur in isolation. The importance of context, expertise and experience, and the relationship established between the key worker and the family are essential elements that impact on outcome, for all family members:

“‘My key worker makes my life easier’ (…) [key worker] explain things to make me feel less worried, less scared.’” (Child 1, p27)

“‘I [key worker] am your one link. I will be the person that makes sure that everybody knows what’s going on and if you have a question, if you don’t know which of these various different specialists to go to, you come to me and I will sort that out.’ For me, that was really important……..” (Parent 22, p6)

Key workers were all involved in care coordination, but not all were involved in the direct delivery of clinical care. Key workers developed their role within a continuum of inreach and outreach work. Four main models of care have been described: 1) outreach (visiting families at home), 2) inreach with home visits (key workers who were based in the hospital and who do home visits occasionally), 3) inreach (based mainly in the hospital) and 4) palliative care (reflecting how the key worker role changes in this phase). Learning about what works well within these models, and what is more challenging to achieve, are messages for all readers to take away. But in concluding this report, we wanted to synthesise some of that learning, and direct these final messages to three specific groups of readers: key workers and parents, other professional groups and managers of cancer services, and finally policy makers.
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INDIVIDUAL LEVEL - FAMILIES AND SPECIALIST CHILDREN’S CANCER NURSES UNDERTAKING A KEY WORKER MODEL OF CARE

- A specialist children’s cancer nurse undertaking a key worker model of care is essential, supporting families from the time of diagnosis, through treatment, at the end of therapy and beyond
- Guidance through the journey for a survivor of childhood cancer, requires good, clear signposting, with information about re-accessing services: knowledge about their journey so far, support through transition and into follow-up care, will support a young person to make the right life and health choices
- More active, hands-on care and support will be required for those who require palliative care. This may require

SERVICE LEVEL - MDTs AND MANAGERS

- The specialist children’s cancer nurse undertaking a key worker model of care is an important member of the multi-disciplinary team, their ‘presence’ in the team is essential, where they are valued, and their role understood they are able to make a better contribution
- Good communication and systems, such as attending MDT team meetings, being notified when a new child has been admitted, enable early recognition of family need, allowing prompt referral and mobilisation of resources
- Holistic needs assessment, when undertaken and valued by the whole team, allows the key worker role to be more focussed, signposting families where a need is to be fulfilled
- Where a case-load allows, the key worker role can make more of an impact, a high case load leads to only the role of coordination being fulfilled, leaving families potentially unsupported in the care decisions they are making in the home
- The key worker is the family’s main point of contact, they are the professional the parent goes to with questions and concerns, but only where time to engage with a family was facilitated through a manageable caseload

POLICY LEVEL - COMMISSIONERS AND MANAGERS

- NHS services must be in place to meet the needs of families, from diagnosis and beyond. Services are required to remain responsive, informed by new treatment regimens and the associated care needs, so that staffing levels, and designation of roles, match family need
- NHS future policies and guidance must keep at their core person centred care if we are to ensure patient focused services are in place
- The key worker role works best when matched to family and service need, variations in model delivery should be welcomed and evaluated further to ensure the NHS and local trusts are informed when selecting and refining model of care
- Future cancer strategies must consider the key worker model for specialist children and young people’s cancer outreach nurses, and suggest approaches that endorse the need for these to be sustained, increased, and maximised where they are most needed: examples are provided within the body of this report
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Available on request:

- Health Professionals’ Invitation Letter
- Participant Information Sheet for Health Professionals
- Stakeholders’ Consent Form
- Key Workers’ Consent Form
- Parents’ Invitation Letter
- Participant Information Sheet for Parents
- Parents’ Consent Form
- Parents’ Consent for their child’s participation
- Younger Children Invitation Letter
- Participant Information Sheet for Younger Children
- Children’s Assent Form
- Younger Children Assent Activity
- Older Children Invitation Letter
- Participant Information Sheet for Older Children
- Older Children Assent Activity
- Young People’s Consent Form
- CLIC Sargent More than my illness questionnaire package for parents
- CLIC Sargent More than my illness interview topic guide for parents
- CLIC Sargent More than my illness interview topic guide for key workers
- CLIC Sargent More than my illness interview topic guide for children and young people
- CLIC Sargent More than my illness questionnaire for stakeholders

List of additional complementary publications

Contact CLIC Sargent for copies of additional related publications. This was a large study, key findings and supporting text are provided here, but similar to other case studies; not all of the rich data appears in a final report. Further interrogation of the data will result in future publications to aid dissemination and influence practice.

Dissemination to include:

- Four papers are scheduled: main data publication on the key worker project; perceptions of the key worker role; key worker role in palliative care, and neuro-oncology nursing.
- Presentations at conferences aimed at professional and lay audiences.
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The families featuring in the photographs cannot be assumed to be research participants. All participants were anonymised and are unknown to the CLIC Sargent project teams.

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