Children in Scotland

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A Children in Scotland Evaluation of the Diana Children's Nurse Service

Final Report

November 2017

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Acknowledgements

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Contents

Executive summary

Recent years have witnessed an increased understanding of the extent of the palliative care needs of babies, children and young people[1], and increased recognition of the need to respond to them strategically at a national policy level.

Since 2014 three **Diana Children's Nurses** (DCNs) have been employed by Children's Hospices Across Scotland (CHAS) to build capacity in palliative care services for children. Their three key objectives are:

- To provide strategic and professional regional nursing leadership in the development and delivery of a multi-professional seamless service which integrates children's palliative care across all sectors, and within the core value, vision and purpose of CHAS
- To lead and support the development of a care workforce with the necessary knowledge, skills and expertise to deliver improvements in the care of children with palliative care needs and their families, through collaboration with education providers
- To support the implementation of the Strategic Framework for Action on Palliative and End of Life Care and its ten commitments, the CHAS Plan and other relevant policies which impact on children with palliative care needs by supporting the care workforce in their practical implementation.

This report presents the findings from a DCN service evaluation that took place between December 2015 and October 2017. The evaluation combined repeated qualitative interviews with DCNs, CHAS staff, frontline staff and policymakers with case studies and quantitative monitoring evidence.

The DCN service comprises three different areas of work:

- Direct work with families to support the palliative care needs of children
- Workforce capacity building to develop the knowledge, skills and experience of public sector and voluntary sector staff to address the palliative care needs of children
- Strategic influencing and leadership to steer policy and practice change at organisational, health board and national levels.

Each of these areas of work is important in terms of increasing support for children, and how they affect and interact with each other.

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[1] Henceforth shortened to children, with the understanding that this term includes babies and young people, too.

In terms of **direct work**, support had been provided to a total of 239 individuals (parents and children) between April 2015 and March 2017. The number increased year on year, with 97 in 2015/16 and 142 in 2016/17. The types of direct work DCNs had undertaken was varied and complex, but included increasing access to specialist support, including CHAS, empowering families to make choices about care and end of life, and providing emotional support.

In the three case studies, families talked about the impact of the DCN service. They described regaining a sense of control in desperate circumstances, making positive memories with their children, and receiving valuable emotional support. Evidence would also suggest that DCNs had been successful in terms of supporting some families to achieve their preferred place of care. However, hospital was still the commonest place of death, particularly for babies. This indicates that work may still be required to enable greater choice within and out with hospital settings.

In terms of **staff capacity building**, interview participants identified that the DCNs had a role to play in terms of the following areas:

- Increasing staff understanding of palliative care
- Encouraging and facilitating holistic approaches to supporting families
- Liaison and relationship building between services to ensure joined up working, particularly between CHAS and the NHS
- Widening use of ACPs and the Children and Young People Acute Deterioration Management (CYPADM) form.

DCNs delivered staff capacity building through staff training, online learning resources, liaising between services to encourage joint working, working alongside staff to 'role model' good practice with families, and providing advice and guidance. A further crucial function of the DCNs' work was to provide emotional support to NHS staff through distressing circumstances, including end of life care.

Between April 2015 and March 2017 the DCNs recorded that they delivered a total of 91 training sessions (36 in 2015/16 and 55 in 2016/17). Based on the 69 sessions where data was available, a total of 2,029 participants were recorded as taking part. This included a range of professionals from medical, nursing, allied health professional and community backgrounds, as well as students from universities across Scotland. Evaluations from training sessions showed notable increases in participant scores from pre to post-training across all learning outcomes.

In terms of **strategic influencing**, the DCNs have managed to achieve significant advances, including co-chairing the Scottish Children and Young People's Palliative Care Network (SCYPPCN), contributing to the universal Anticipatory Care Planning (ACP) document and supporting the development of national guidance as part of the perinatal pathway. These developments have occurred within the context of other important national policy drivers, such as the Strategic Framework for Action on Palliative and End of Life Care, and the Children in Scotland Requiring Palliative Care (ChiSP) study.

All of these activities have contributed towards the three key objectives of the DCN service. From the evidence obtained in the evaluation, we conclude that the DCNs have demonstrated leadership in palliative care for children at national and local levels and this has resulted in positive change for families, for staff and for the system as a whole. However, this change has not been universal, either geographically, professionally or by specialism, and there are still significant gaps in care.

The impact of the DCN service has been limited by a number of challenges and barriers:

- Balancing priorities between the three core aspects of work
- Having sufficient capacity to respond to the needs of families and services (both within the DCN service, CHAS and wider NHS and community settings)
- Different specialisms in the three regions have made it difficult to develop a consistent offer across the whole of the country
- Pockets of staff resistance to change or buy in, particularly among some consultant colleagues
- Geographical challenges
- Ensuring equity of access, particularly in terms of 24-hour care
- Overcoming barriers between the voluntary and statutory sectors.

In terms of recommendations for the future, the evaluation suggests that:

- Capacity should be increased to enable DCN specialisms to roll out across the whole country, and address some of the logistical challenges of working in the North of Scotland
- In order to build capacity within the system as a whole, there should be a continued emphasis on building the palliative care skills, knowledge and expertise of NHS and community staff. A more detailed analysis of where current strengths and weaknesses lie within the system, and where priorities for future training are, will help target approaches and resources accordingly
- Discussions should be held with NHS Education Scotland, Royal Colleges, Scottish Government and others to explore how the emotional support needs of NHS staff working in palliative care settings can be better addressed
- The DCN service should continue its emphasis on strategic influencing to improve palliative care standards across Scotland. This should continue to be informed by priorities, gaps and issues identified regionally
- Over time, as capacity, skills and guidance are embedded elsewhere in overall systems of care, there may be a possibility of less emphasis on direct work with families. However, it is recognised that direct clinical work informs care, encourages rapport and develops mutual trust and understanding. We recommend that CHAS review the role of direct work within the service, and to agree the appropriate balance of direct work to other activities going forward
- The DCNs and their supporting team should explore how the experiences of families, and children and young people who have used the service can be captured and shared.

1. Background

1.1 | What we know about palliative care in Scotland

Life-shortening conditions have been defined as those 'for which there is no reasonable hope of cure and from which people will ultimately die prematurely'[2]. The definition often includes life-threatening conditions, where curative treatment may be feasible but can fail.

In 2015 the University of York published the Children in Scotland requiring Palliative Care (ChiSP) study, which investigated the numbers of children and young people with life-shortening conditions in Scotland, and provided evidence about their, and their families' psychosocial support needs. It revealed an increase in the prevalence of children and young people (aged 0-25 years) with a life-shortening condition in Scotland from 2003/4 and 2013/14. Specifically, it found that:

- The absolute numbers of children and young people with a life-shortening condition have risen from 12,039 (2009/10) to 15,404 (2013/14). Of these, the absolute numbers of children and young people with a life-shortening condition in hospital have risen from 4,334 (2003/4) to 6,661 (2013/14)
- 2,201 children and young people were unstable/deteriorating or dying during 2013/14
- The average number of deaths in Scotland each year in children and young people with a life-shortening condition was 195
- Prevalence decreased by age group with the highest prevalence in the under 1 age group
- Overall 73.0 % of deaths were in hospital, 5.6% hospice and 21.4% home. Variation by age was seen with 90.2% of the under 1 age group dying in hospital.

The ChiSP Study makes a series of recommendations and concludes that more children and young people with life-shorting conditions in Scotland should have access to palliative care. Given the growing numbers of children and young people with palliative care needs, this requires interventions beyond those which specialist services alone can provide.

1.2. | Policy context

Living and Dying Well: a national action plan for palliative care and end of life care in Scotland, published in 2008, was notably deficient in addressing the specific palliative care needs of children[3]. As a consequence of this gap, a Framework for the Delivery of Palliative Care for Children and Young People in Scotland was published in 2012 by the Scottish Children and Young People's Palliative Care Executive Group (SCYPPEx)[4]. This set out five outcomes and eleven key objectives to ensure recognised pathways for palliative care within and between health boards for every child and young person with a life-shortening condition. It aligned palliative care to Getting it Right for Every Child, Scotland's national approach to improving outcomes and supporting the wellbeing of children and young people[5].

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[2] http://www.york.ac.uk/inst/spru/research/pdf/chisp.pdf
[3] http://www.gov.scot/resource/doc/239823/0066155.pdf
[4] http://www.gov.scot/Resource/0040/00408254.pdf
[5] http://www.gov.scot/Topics/People/Young-People/gettingitright

The most recent Strategic Framework for Action on Palliative and End of Life Care 2016 to 2021[6] outlines key actions and commitments by the Scottish Government to ensure that services are able to respond to the palliative care and end of life care needs of individuals.

Commitment 4 of the strategy makes specific reference to promoting the development of holistic palliative care for the 0-25 age group, marking the first time that they have been specifically referenced within national palliative care strategy. It is particularly significant that the strategy includes the under one year age group, where the highest prevalence of children with palliative care needs can be found.

In 2016 the Scottish Government further emphasised its commitment to children's palliative care through the announcement of increased investment of £30 million funding over five years awarded to CHAS.

1.3 | About the Diana Children's Nurses Service

In 1998, following the death of Diana, Princess of Wales, the Prime Minister announced that the Government would set up the Diana, Princess of Wales Memorial Fund, to commemorate her life and work. Over subsequent years the fund has supported a range of children's nursing positions across the UK, and since 2008 in Scotland these have been exclusively within the field of palliative care. Following a review in 2011, it was agreed that the Diana monies in Scotland would be used to create three full-time DCNs, employed and managed by CHAS, with an additional administrative support to help coordinate both their work across Scotland and the collection of data across their diverse work streams.

The three DCNs and their administrator have been in post since early 2014, with individual nurses located in the West, East and North of Scotland. The nurses have bases predominantly within the NHS but are employed and supported by CHAS.

The overarching aim of the DCN service is that *'Babies, Children and Young People in Scotland will have access to palliative care when and where they need it.'* To achieve this aim, the service has the following objectives:

- To provide strategic and professional regional nursing leadership in the development and delivery of a multi-professional seamless service which integrates children's palliative care across all sectors, and within the core value, vision and purpose of CHAS
- To lead and support the development of a care workforce with the necessary knowledge, skills and expertise to deliver improvements in the care of children with palliative care needs and their families, through collaboration with education providers
- To support the implementation of the Strategic Framework for Action on Palliative and End of Life Care and its ten commitments, the CHAS Plan (2011-2016) and other relevant policies which impact on children with palliative care needs by supporting the care workforce in their practical implementation.

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[6] http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/SFA

The objectives were refreshed in 2016 to align them with the Strategic Framework, and CHAS's own 2020 plan.

CHAS plan 2020

The CHAS plan 2020 concentrates on four key strategic themes: Reach, People, Growth and Influence. The development of the strategy has been influenced by The ChiSP Study. The following is a summary of CHAS's strategic themes

- **Reach:** transforming care to reach more children with palliative care
- **People:** attracting and retaining staff and volunteers to offer the highest standards of care
- **Growth:** Generate increased income through fundraising to help support infrastructure and make best use of resources
- **Influence:** research, advocacy and education will inform improvements in paediatric palliative care.

CHAS has developed a logic model to outline DCN activity to achieve stated aims and outcomes. This was developed as part of the initial funding agreements with the Scottish Government Chief Nursing Officers office. A copy of the refreshed logic model is presented in Appendix 1.

1.4 | About the evaluation

In 2015 Children in Scotland (CiS) was commissioned by CHAS to undertake an evaluation of the DCNs, to determine the extent to which the service has met its aims and objectives and to generate learning about the barriers and facilitators to improving palliative care for children in Scotland.

The evaluation approach was agreed jointly with CHAS and was designed to incorporate both a process and outcomes evaluation, and to provide evidence and feedback to support the DCN service on an ongoing basis.

The evaluation incorporated both qualitative and quantitative data collection methods to obtain evidence on views and experiences as well as reach and impact. The evaluation commenced in December 2015 and ran until October 2017. It consisted of the following stages:

Stage 1 Set up (Dec 2015 – Jan 2016)
Stage 2 Establishing the baseline (Jan 2016 – May 2016)
Stage 3 Outcome and process evaluation (June 2016 – October 2017)
Stage 4 Reporting (October 2017)

It is recognised that the evaluation commenced one year into a three-year cycle, and therefore the baseline established was not from when the DCNs commenced their new roles, but from when the evaluation started.

This final report presents the findings from Stages 1, 2 and 3 of the evaluation.

2. Methods

2.1 | Stage 1 Set up (December 2015 – January 2016)

The need for ethical approval was explored, and following advice from South East Scotland Research Ethics Service it was established that ethical approval was not required for this project. All approaches, tools and resources were developed in line with the Social Research Association Ethical Guidelines and informed consent was gained from all research participants[7].

2.2 | Stage 2 Establishing the baseline (January – May 2016)

In order to gauge the impact of the DCN service, it was necessary to establish a baseline for the work. This incorporated the following data collection methods;

- Inception meeting with senior CHAS managers to establish priorities for baseline data collection
- Evaluation workshop with three DCNs, three CHAS Regional Clinical Nurse Managers and CHAS Senior Managers to discuss collectively the aims and objectives of the service, how the identified work programme will meet these aims, and discuss the role evaluation will play within the service
- Qualitative interviews with three DCNs, three CHAS Senior Managers, three CHAS regional Clinical Nurse Managers and DCN service administrator to explore the barriers and facilitators to providing palliative care for children from the DCN service perspective
- Qualitative interviews with 14 frontline staff from across the three regions to explore the barriers and facilitators to providing palliative care for children from the palliative care service provider perspective. A list of frontline staff roles is available in Appendix 2
- Qualitative interviews with six policymakers (national and regional) to explore the barriers and facilitators to providing palliative care for children from a strategic perspective
- Analysis of DCN monitoring data with regards to service outcomes, service provision and staff training needs.

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[7] http://the-sra.org.uk/wp-content/uploads/ethics03.pdf

Qualitative interviews

In total 30 professionals at baseline were interviewed, from across the three regions and nationally. Fourteen (47%) of these were frontline staff, 10 (33%) CHAS staff, including the three DCNs, and six (20%) were national policymakers. Table 1 below presents an analysis of baseline interviews by role and region.

Region	Frontline Staff	Policy Makers	CHAS	TOTAL
East	3	0	2	5
North	6	0	2	8
West	5	0	2	7
National	0	6	4	10
Total	**14**	**6**	**10**	**30**

Table 1: Baseline Interviews by role and region

Evidence collected from qualitative interviews and the evaluation workshop was analysed thematically. Monitoring data was incorporated and the findings were presented in an interim report, published in May 2016.

2.3 | Stage 3 Outcome and Process evaluation (June 2016 – October 2017)

In order to discover whether the DCN service had progressed since baseline towards meeting its established aims and objectives, the following data collection activities were carried out:

- The development of three family case studies to illustrate the direct work of the DCNs with families. Each of the case studies focused on a complex case, where there had been significant involvement from the DCN service. Data collection activities involved interviews with a family, the DCN and a staff member who had been closely involved with the case
- Repeat qualitative interviews with three DCNs, three CHAS Senior Managers, three CHAS regional Clinical Nurse Managers and DCN service administrator
- Repeat qualitative interviews with 11 frontline staff from across the three regions
- Repeat qualitative interviews with five policymakers (national and regional)
- Analysis of DCN monitoring data with regards to service outcomes, service provision and staff training needs
- Final evaluation workshop with DCNs and DCN administrator, four Clinical Nurse Managers, Associate Nurse Directors and two CHAS Senior Managers.

Qualitative Interviews

In total 26 professionals at the repeat stage were interviewed, from across the three regions and nationally, with a small drop off of four (13%) from baseline. Table 2 below presents an analysis of repeat interviews by role and region.

Region	Frontline Staff	Policy Makers	CHAS	TOTAL
East	2	0	2	4
North	5	0	2	7
West	4	0	2	6
National	0	5	4	9
Total	**11**	**5**	**10**	**26**

Table 2: Repeat Interviews by role and region

2.4 | Analysis and reporting

Qualitative and quantitative evidence from stages 2 and 3 was analysed and has been aligned with the DCN service logic model to assess the extent to which progress has been made against key objectives, and identify where evidence gaps exists. Conclusions and recommendations have been drawn from the findings and are presented at the end of this report.

2.5 | Methodological limitations

The researchers recognise a number of limitations to the evaluation, which impact on the extent to which conclusions can be made about the overall impact of the DCN service.

Sample size and bias

Due to the scale of the evaluation, the researchers were only able to speak to a small sample of professionals, families and policymakers engaged with the DCN service. Efforts were made to ensure that stakeholders were interviewed from across the three regions, to give balance with national perspectives, however we recognise that many voices are absent from this evaluation, particularly from parents and families. It should also be recognised that there was some, predictable, drop off between stage 2 and stage 3 of the evaluation due to staff changes.

The study employed a purposive sampling design, and relied on the DCNs identifying frontline staff they had worked with. While the researchers then approached the staff directly, we recognise that this method may mean that more critical voices are absent from the evaluation.

Attribution

Given the complex nature of the DCN roles, and their role in influencing change at a strategic level, it is to an extent difficult to isolate the specific impact the DCNs have made, within the

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[6] http://thesra.org.uk/wp-content/uploads/ethics03.pdf

context of wider drivers, influencing factors, blocks and barriers. The case studies and monitoring data provide some evidence of direct impact on families and staff, however this is limited. The process evaluation describes many of the wider contextual factors at play, and this report endeavours to reach a conclusion about the DCN service's unique contribution to change.

Monitoring data quality

DCNs routinely record activity data in an evidence spreadsheet, developed by CHAS and with direct support from the DCN administrator. This should include all activity including direct work with families, staff training, and strategic influencing. It should also include numbers of participants and links to any evaluation forms or further reporting. All evidence is recorded according to key objective, and associated outcome (as listed in the logic model).

While this has provided useful data for illustrative purposes, and includes a wealth of descriptive information, in practice there have been a number of inconsistencies with evidence recording, making it difficult to draw overall conclusions about the extent and reach of DCN activity. These include the use of various formats for training evaluation forms, estimated participant numbers, and reliance on verbal feedback. Also, it is clear that there is some overlap between the outcomes listed under the three service objectives, meaning that similar activity may have been aligned to different outcomes on different occasions. Equally, on occasions the same activity fulfilled several of the outcomes at one time, but the recording mechanism limited input to a choice of just the one.

Timescales

As highlighted above, the evaluation commenced one year into a three year cycle, and therefore the baseline established was not from when the DCNs commenced their new roles, but from when the evaluation started. This may serve to under-record the impact the service has overall across the three years. It is recommended that future evaluations commence at the onset of any new development cycle.

3. Findings

In this section the findings from across the evaluation are presented. They are presented in terms of the Diana Children's Nurses service's role and function, perceptions of impact, and barriers and facilitators to progress.

3.1 | The Diana Children's Nurses service

As described earlier, the DCN service is informed and guided by the DCN Service logic model, as presented in Appendix 1. This links direct activities to the three overarching objectives of the service:

- To provide strategic and professional regional nursing leadership in the development and delivery of a multi-professional seamless service which integrates children's palliative care across all sectors, and within the core value, vision and purpose of CHAS
- To lead and support the development of a care workforce with the necessary knowledge, skills and expertise to deliver improvements in the care of children with palliative care needs and their families, through collaboration with education providers
- To support the implementation of the Strategic Framework for Action on Palliative and End of Life Care and its ten commitments, the CHAS Plan and other relevant policies which impact on children with palliative care needs by supporting the care workforce in their practical implementation.

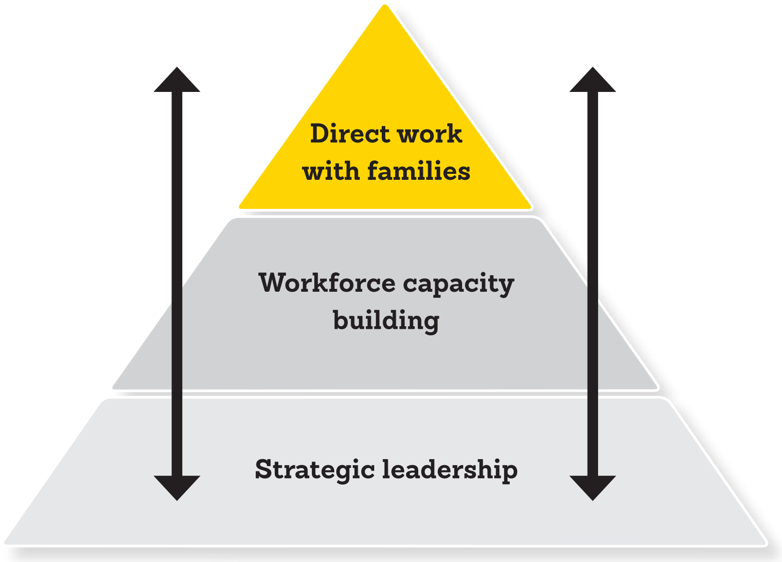
In the first evaluation workshop, the **DCN team** and **CHAS senior staff** discussed the logic model in depth to explore how the 37 different activity areas described in the logic model linked to the objectives, to understand their theory of change and to explore any gaps or inconsistencies.

It became evident from these discussions that the DCN service was conceptualised internally in terms of three different areas of work:

- Direct work with families to support the palliative care needs of children
- Workforce capacity building to build the knowledge, skills and experience of public and voluntary sector staff to address the palliative care needs of children
- Strategic influencing and leadership to influence policy and practice change at organisational, health board and national levels.

Each of these activities support and inform the other, so that demonstrating good practice with families influences other frontline staff working with DCNs, and building relationships with staff influences decision-making, for example (see diagram 1).

Diagram 1: DCN areas of work



Interviews with **frontline staff** and **policymakers** at baseline about the role of DCNs corroborated the views and opinions of the DCNs and CHAS staff, highlighting the same three activities as being crucial to the role. These have remained consistent throughout the life of the evaluation, although at times different activities have been given more or less priority – a theme this report will return to later in this section.

These activities map on to the logic model to an extent, although the model has never included specific reference to the direct work by DCNs to support children and families, even though this has been a consistent feature of the work from the outset. It was recognised at the first evaluation workshop that direct work was absent from the logic model, and the fact that to an extent this limits the opportunity to explore and incorporate the outcomes of direct work to achieving the overall aim of the service.

Nevertheless, since it is such an important aspect of the work of the DCNs, it is included in the evaluation and attributed outcomes of direct work to aspects of the logic model where possible.

The following sections describe each activity area in more detail, identifying the learning across each.

3.2 | Direct work with families

The DCN service provides specialist clinical input and direct support to children with palliative care needs and their families. The DCN activity data provides evidence of 48 instances in 2015/16 and 105 instances in 2016/17 where DCNs worked to ensure that children receive enhanced palliative care. In terms of individuals supported, monitoring data indicates that 97 individuals (parents and children) were directly supported by DCNs in 2015/16 and 142 in 2016/17, an increase of 46.3%.

While there is not specific reference to direct family work in the DCN logic model, it clearly contributes to DCN service objectives, particularly Objective One, 'To provide strategic and professional regional nursing leadership in the development and delivery of a multi-professional seamless service which integrates children's palliative care across all sectors, and within the core value, vision and purpose of CHAS'.

3.2.1 | The purpose of direct work

Participants in the baseline interview recognised that the palliative care needs of children were diverse, and based on a range of factors including age and condition. It was felt that needs went beyond medical care and also incorporated a range of practical and emotional support needs. Participants also highlighted that it was not just children who had palliative care needs, but also their parents and wider families. This was particularly important with regards to making choices about end of life, and also in terms of their emotional wellbeing.

The needs of families in relation to palliative care can be summarised as follows:

- **Holistic support** (clinical, practical, emotional, social and spiritual)
- **Parental support** (emotional and bereavement support and practical support)
- **Support with decision making and planning** (parents, children and young people).

Participants in the first evaluation workshop suggested that holistic support required that families should receive palliative care from a range of providers including the voluntary sector, NHS and schools. This includes incorporating preventative approaches where appropriate and a strong emphasis on quality of life.

Supporting choice for families was highlighted by 18 of the baseline interview participants as a priority. It was felt that families needed to be informed and "aware of all options" in order to make confident choices about how to proceed with their child's care. Informing families about the choices available needed to take place at a time and a pace that suited them.

It was suggested that enabling choice in the home setting proved to be challenging. One DCN felt that traditionally professionals have viewed hospitals as the preferred place of death: "….the temptation is to keep the clinical management of a child… within a hospital team". Three participants highlighted lack of capacity, as well as inadequate 24-hour service provision within the community setting, as factors that impacted choice within the home setting. Another individual echoed this by saying that care needed to be "appropriate and realistic" for families. A nurse commented: "if the family say we want to have end of life care provided at home, we should be working to facilitate that".

Priorities identified at baseline for the DCNs in relation to choice were as follows:

- Helping families to be aware of the options available to them
- Working with community teams, to help them support end of life at home and facilitate compassionate extubations
- Supporting transfers to the home and hospice setting.

3.2.2 | Case studies

To better understand the complex and wide ranging aspects of the DCNs direct work with families, three case studies were developed as part of the evaluation. One was selected from each of the three regions where the DCNs are based. They were produced through in-depth discussions with parents, DCNs and other staff working with the families. In total nine interviews were undertaken, with ten participants (one interview involved two parents).

The case studies describe three significant areas of direct work relating to the priority areas identified above: support with decision-making and planning, holistic support and emotional support for parents and families. There is some overlap between these three areas, but for the purposes of understanding the range of direct work undertaken by the DCNs, findings are presented separately according to these three themes.

Case Study One: Support with decision-making and planning

Supporting families to develop Anticipatory Care Plans (ACPs) was recognised by the DCNs as being an important aspect of their work with families. Extending the use of ACPs features within their logic model, as part of ensuring that more children die in their preferred place of care. Going through the process of anticipatory care planning was viewed as an important mechanism for working through difficult decisions, and one that was ultimately empowering for families, as was illustrated in Case Study One.

Case Study One

The DCN first became involved with the family when the child was four months old. When the baby was born he experienced a number of breathing and feeding problems, and had been transferred to another hospital for further investigations and genetic testing. The parents received the news that their baby had a life-shortening metabolic condition and were presented with a very negative outlook on their child's future.

The DCN was initially introduced to the family immediately after their return home to provide emotional support to the family and take them through the process of preparing the Anticipatory Care Plan (ACP) and outline decisions on resuscitation. She helped the family to freely express their emotions about what they wanted in terms of aspects of their child's care:

"*We would never have said this to a doctor, the fact that we almost wanted him to just fade away and die rather than have this horrible life of being in pain.*"
(Interview with Mother)

Other staff involved recognised that giving parents the time and space to express themselves was important:

"*Sometimes it's probably about just giving them time, you know time actually with the parents... it can permit the parents to open up, to actually appreciate the strength and also the fears that they have.*"
(Interview with Frontline Staff)

The ACP process involved focusing on how the parents wanted their child to be cared for, the goals that they wanted to achieve together, as well as discussing end of life wishes.

The DCN tailored her approach with the family and went at the pace of the family. Initially, she reflected that some of the thoughts the family had expressed at previous meetings, and about how they wanted their child to be cared for. Writing the ACP helped to give the family back a sense of control over a particularly difficult situation. The DCN was able to present the family with realistic options and to discuss their fears and concerns:

"*I think for me the best bit [about the DCN service] was discussing the end of life plan, giving us options... and discussing the deepest darkest parts of death and what might happen and finding out what we can do when he does die.*"
(Interview with Mother)

Discussing end of life and recording it on the ACP form allowed the family to focus on enjoying their time with their child.

"*So that changed us into a very positive frame of mind and these are the things we now want to achieve. Whereas we didn't see us leaving the house.*"
(Interview with Father)

One of the goals the family wanted to achieve was to be able to go hillwalking with their child. The family was enabled to do this because of the support they received from the DCN, the CHAS activities team and the lead consultant.

In interviews, the DCNs recognised that it would be possible, and indeed desirable, for other NHS staff to undertake Anticipatory Care Planning, and indeed upskilling staff in ACPs and supporting their roll out is part of the DCN job (a theme this report will return to later on). This will be essential if all families with children with palliative care needs are to have access to this process.

However, it would appear that presently DCNs are often best placed to do this work with families, as they have the experience, time and confidence to do this sensitively, compassionately, and realistically. As they indicated, knowing what may and may not be possible for families requires some degree of expertise and knowledge of palliative care needs and types of support and help available.

Case Study Two: Facilitating access to holistic support

Enabling families to access specialist and holistic support they otherwise might not be aware of, was another key area of direct work identified by DCNs, families and frontline staff. Often this was supporting access to CHAS services, such as respite care or CHAS at Home. In 2015/16 37 referrals were made by DCNs to CHAS and in 2016/17 this had increased to 62. It is not clear whether any of these referrals would have happened without DCNs intervention, and it is possible that some of them may have. However, in interview, DCNs, families and frontline staff recognised the DCNs' important role in facilitating access to other services, and liaising between the two:

"Although we've got the hospital and you've got CHAS, the DCN seems to fill this gap in the middle of bridging the two." (Interview with Mother, Case Study One)

Case Study Two

The family first met the DCN in the Paediatric Intensive Care Unit (PICU). At that point, their child had been in intensive care for over six months after initially being transferred from one city hospital to another due to cardiac difficulties.

The DCN's involvement came as a result of a discussion with the lead consultant. The consultant wanted to give the family the opportunity to take their child for a walk outside the hospital and for the child *"to feel the sunshine, daylight."* (Interview with DCN). However, the DCN was also aware that the family needed to spend some quality time together.

"So what I felt their needs were, were for the three of them to be able to have time out of hospital together to be a family because they were just living this horribly disjointed life." (Interview with DCN)

As a result the DCN suggested that the family could take advantage of a short planned break at Robin House Children's Hospice.

The DCN played a significant role in acting as the main point of contact between the hospital unit and Robin House. Prior to the visit, she ensured that staff at Robin House received training on the child's ventilator. She also helped coordinate the transportation from the hospital to Robin House.

From the hospital perspective she liaised with the pharmacy, dieticians, medical and nursing staff and occupational therapists. She also prepared the care plan with the family. The DCN also provided checklists for hospital staff in advance of the transfer.

"This idea (visiting Robin House) seemed a daunting challenge, yet made seamlessly efficient by the input and direct contact of the DCN."
(Interview with Frontline Staff)

The family had a positive experience visiting Robin House and were able to enjoy quality family time together. During their two visits to Robin House the parents were able to take their child on walks, take him to the hydrotherapy pool and visit the Sealife centre. Visiting Robin House allowed the mother and father to feel like parents again:

"Feeling like [he] was our own… it felt like that when she (DCN) gave us that opportunity because although we were in intensive care and he is our child, you didn't feel like it sometimes because you always have to ask to do things like change his nappy."
(Interview with Mother)

The family was also able to use Robin House to help smooth the transition process back home from the PICU to their local hospital:

"It can be a wee bit daunting for staff in the [local hospital] to accept the transfer of a child who's been in intensive care for months and months… [however] they could see that actually this wee boy had spent the weekend in Robin House, he was waving at him through the VC."
(Interview with DCN)

The meeting helped the family to feel more relaxed in anticipation of their transfer back home as they could ask any questions and alleviate any fears.

On reflection, the mother felt the best part of the DCN service was to help provide the family with options, as she was previously unaware that the hospice could be used in this way:

"For us it was just showing us that there were options to get out for a bit…"
(Interview with Mother)

It is apparent from Case Study Two that the DCN gave the family options that may not have been available to them otherwise, and made complex medical transitions between hospitals and services easier. Knowledge and relationships with both services was clearly helpful in this instance.

Case Study Three: Providing emotional support

The emotional impact of having a child with a life-shortening condition cannot be underestimated, and is something that the DCNs are very cognisant of. Monitoring data does not indicate which cases the DCNs provided emotional support to families in, but, based on how they describe their role and the needs of the families they support, it would be reasonable to conclude that this would be a very high percentage, if not all of them.

In all three of our case studies, emotional support was provided by the DCNs to families. However this third case study illustrates how this worked for one family at a very difficult time.

Case Study Three

The DCN first came into contact with the family after being approached by a consultant. The full term baby had been transported from the local hospital to the neonatal unit in a major hospital after initially experiencing breathing difficulties. The transport doctor involved in stabilising and transporting the baby approached the nursing and medical team to suggest that the DCN should immediately become involved with this family, as a source of family support.

From the onset, the DCN was able to support the family's individual emotional needs as well as their needs as a couple. This was felt to be of particular importance for the father, who did not have the midwife team support provided to the mother:

"The baby had a superhero team, I had my midwife team and he (father) felt that the DCN was his team."
(Interview with Mother)

The DCN also played an important role by explaining the situation to wider members of the family, helping to ease the pressure for the parents and allowing them to focus their attention on their baby.

"After we had spoken to the consultant they asked if I would explain what was happening to their parents because they didn't feel able to do that."
(Interview with DCN)

As the baby's condition began to deteriorate the DCN helped the family to enjoy the limited time they had with their baby through memory making experiences and activities. With support from the DCN, the family was able to hold their baby for the first time, experience feeding him and use inkpads to create footprint pictures. The hospital staff captured these memories through videos and photographs:

"I think that was the trigger for them to be his parents as well in a way because he was covered in all this machinery... So there were very little areas that they felt they could touch, but by getting them to do the footprints they were actually physically touching that part and I think that was a big thing for them at that point." (Interview with DCN)

The baby's condition severely deteriorated leading to difficult decisions for the family. The DCN, the transfer doctor and the neonatal nurse were present for the end of life care of the baby. With the help of the DCN and the hospital staff present the family were able to create more positive memories and enjoy being parents by having some of the experiences with their child that up until that point they couldn't experience:

"Thursday was the most horrendous day, but it was also the best day. That's the day we got to give him a bath, that's the day we got to dress him, that's the day that we got to hold him and take all these pictures." (Interview with Mother)

For the family, memory making and the DCN's input were some of the biggest sources of support during this difficult time.

"I think it must be awful to go through that experience and not have someone like the DCN." (Interview with Mother)

The family has received ongoing support and communication from the DCN who has been able to refer both parents to CHAS for individual bereavement counselling.

It is clear from this case study that families with a child who is reaching the end of life require significant emotional support. Professionals, such as DCNs, can help families make positive memories that support them through this difficult time.

3.2.3 | Perceived impact of direct work

Even in the baseline interviews the impact of the DCNs through their direct work with families was already being recognised. In terms of their direct work with children and families it was felt that the DCN service had helped families to make informed choices about the care of their children, and had enabled these choices to be realised. This included helping children to die in their preferred place and achieving "compassionate extubations".

The emotional support provided by the DCNs to families was also thought to have had a positive impact in terms of helping families to cope at a very difficult time;

"It is clear that it is very valued to have somebody in that role to speak to, to talk through things."
(Frontline Staff Interview)

Finally it was suggested that the DCN service had helped to facilitate families' access to other relevant services such as bereavement support.

At the repeat interview, a number of participants felt that they had noticed an increase in the **numbers of referrals to CHAS** as a direct result of the involvement of the DCN service.

"The last year between the three DCNs we've had about 12 more referrals to CHAS at Home... there's been about 50-odd from the DCNs to the hospices, but of that we've taken on 12 and that's been an increase in a year, it's been really good."
(Clinical Nurse Manager)

Monitoring data indicates that overall referrals to CHAS have slightly increased between 2015 and 2017, from 149 in 2015/16 to 152 in 2016/17. However, the proportion of referrals from DCNs has increased to a greater extent, from 37 (24.8% of all CHAS referrals) in 2015/16 to 62 (40.8% of all CHAS referrals) in 2016/17. Whether any of these families would have been referred to CHAS through other routes if the DCN service had not been involved is unclear.

In terms of the **nature and type of referrals**, it was suggested by interview participants that the DCNs have been increasingly able to attract referrals from specialities that they had not been able to previously. One example highlighted by two participants was children with renal problems. In addition, CHAS interviewees indicated that they were starting to receive antenatal referrals and continuing to receive higher numbers of neonatal referrals.

Monitoring evidence gives examples of antenatal and neonatal referrals:

"Met with a couple who are pregnant with a baby with a significant life-limiting condition. I discussed an antenatal ACP with them which both were keen to start. Liaison commenced with the Robin House team to ensure key worker be identified and ACP discussion and development take place."
(Monitoring notes)

It is difficult to gauge from the monitoring data however whether antenatal and neonatal referral figures have increased year on year.

Finally, in terms of supporting children to die in a **preferred place of care**, the evidence spreadsheet contains 28 examples of work undertaken in 2015/16 to ensure that an increased number of children die in their preferred place of care and in 2016/17 this had increased to 40. This included the following:

- Writing and supporting the development of rapid transfer checklists / emergency discharge planning
- Supporting Anticipatory Care Planning on individual and strategic levels
- Referrals to CHAS services, including CHAS at Home support
- Raising awareness of compassionate extubations amongst professionals and supporting them to take place.

CHAS referral information indicates that of 35 CHAS referrals where the child had died in 2016/17, 27 (77.1%) were in hospital, 5 (14.5%) in a CHAS Hospice (Robin or Rachel House) and 3 (8.6%) at home. It is unclear what the preference of families was in any of these cases, but it would appear that hospital is still by far the most common place of death, even for families that have been receiving support from the DCNs and CHAS.

3.2.4 | Barriers and facilitators

Through the case studies, baseline and repeat interviews, a number of barriers and facilitators to direct work with families were identified.

In Case Study Three, the transport doctor felt that **early referral**, as had happened in this case, brought many benefits for families. Being referred at an earlier stage meant that the DCN was able to develop a relationship with the family, which was important when they faced difficult stages in their child's journey. It was felt that, as the DCN's reputation developed, earlier referral was becoming more common:

"I think that more and more the DCN is being involved at earlier stages, which is great to see... because she can build up a rapport with the family before you get to critical decision making processes."
(Interview with Frontline Staff)

Another important facilitator to direct work with families was **positive relationships**, between DCNs and CHAS and between DCNs and NHS staff. One participant suggested that the close relationship between CHAS staff and the DCN service was *"improving our referral system"* (CHAS Clinical Nurse Manager). Others attributed positive change to combined efforts of both the DCN service and additional NHS posts specifically dedicated to children's palliative care.

In terms of barriers, these included some nervousness among staff to raise the suggestion of palliative care with families for fear of distressing them, and reluctance on the part of some families to accept that they were at a point where palliative care would be beneficial. In part this could be attributed to ongoing misconceptions about palliative care being solely about end of life care, and DCNs described how in some instances they were able to overcome initial fears:

"A lot of times it's the parents, they're just like 'no, no, I'm not wanting anything to do with the hospice.'"
(CHAS Clinical Nurse Manger)

Another key barrier to direct support identified in the repeat interviews and final evaluation workshop was capacity to respond to palliative care needs – this was highlighted both in terms of DCN capacity, CHAS capacity and wider NHS capacity. Certainly, monitoring data points to a sizable increase in the DCNs' direct work with families over the course of the evaluation, with inevitable consequences for capacity to undertake other work.

Direct work with families: summary of key findings

- The number of individuals DCNs support directly has increased by 46.3% from 97 individuals (parents and children) in 2015/16 to 142 in 2016/17
- DCNs support families with a range of areas including choices over care, access to holistic and specialist services and emotional support
- Families and frontline staff welcome and value the support given to them with DCNs, and recognise its impact on making informed decisions, creating positive memories and feeling supported
- Capacity and lack of understanding about palliative care continue to be barriers to direct support work.

3.3 | Staff capacity building

Objective Two of the DCN service is 'to lead and support the development of a care workforce with the necessary knowledge, skills and expertise to deliver improvements in the care of children with palliative care needs and their families, through collaboration with education providers'. In this section we explore the ways in which DCNs have worked to achieve this objective through staff capacity building.

3.3.1 | The needs of staff and services at baseline

During the baseline interviews we explored participants' views on how well-equipped the current system was to support the palliative care needs of children. Key points raised were as follows:

- Provision was inconsistent across the country
- Provision was inconsistent according to specialism (e.g. neonatal)
- Awareness of what palliative care consists of varied.

For many of the participants, inconsistency across the system was a significant issue. One of the DCNs indicated that this was particularly the case for babies:

"Neonates [neonatology] kind of differs from other areas. It's quite unique in that it is almost playing catch up with other areas, it is a very new introduction."

There was the recognition that good palliative care was being delivered by some professionals: *"I think there are pockets of areas where it works well. You'll find some families that things seem to work really well for them."* (CHAS Senior Manager) However, a policymaker suggested that the existence of a "postcode lottery" had resulted in children and their families being unable to access the *"right type of palliative care expertise"*.

One of the DCNs suggested that *"many professionals are delivering palliative care to babies, children and young people at some level but don't necessarily recognise it"*. It was therefore suggested that professionals needed greater understanding that palliative care was "core" to their role. For example, it was not felt to be fully understood that palliative care was not limited to end of life care, but also encompassed care delivered to children with complex and exceptional health care needs, and could take place over a long period of time.

As a CHAS Senior Manager expressed: *"I think there is still a lot of education required with staff at understanding what palliative care really is… there is still a delay in referring to palliative care services."*

During the baseline interviews, frontline staff expressed different levels of confidence around palliative care. Eight of the frontline staff indicated that they felt equipped, to some extent to deal with the palliative care needs of children. Responses ranged from "very well equipped" to "I feel okay". Three frontline staff expressed that they were not well equipped. One nurse manager highlighted the need for more knowledge around the medications used to control pain management. A further two suggested they would benefit from greater awareness.

Frontline staff also indicated that they lacked emotional support, particularly organisationally, when it came to dealing with the loss of a child. One nurse suggested that the impact on staff can "get a bit forgotten about".

It was acknowledged that there was an appetite amongst staff to receive information and support. One of the DCNs stated that, nursing staff were "open" to receiving enhanced support and advice. Another recognised "willingness" from staff to gain a greater "understanding" and made changes to their practice.

Interview participants identified the following areas where DCNs had a role to play in terms of training, knowledge and skills development:

- Increasing staff understanding of palliative care
- Encouraging and facilitating holistic approaches to supporting families
- Liaison and relationship-building between services to ensure joined up working, particularly between CHAS and NHS
- Widening use of ACPs and the Children and Young People Acute Deterioration Management (CYPADM) form.

DCNs undertake staff capacity building in a number of ways. This includes staff training, liaising between services to encourage joint working, working alongside staff to 'role-model' good practice with families, and providing advice and guidance. A further crucial, but to an extent unplanned function of the DCNs work is to provide emotional support to NHS staff through distressing circumstances experienced by the families they were working with.

The report will explore each of these areas in more depth below.

3.3.2 | Staff training

In 2016/17 DCNs indicated that they delivered 55 training sessions, compared with 36 in 2015/16. This presents a considerable increase of 52.7% on training course delivery from one year to the next.

The focus of these training sessions remained consistent over the two years, with the most common learning outcomes listed being as follows:

- Definitions and categories of children's palliative care
- Role of Diana Children's Nurse
- Anticipatory Care Planning / Children and Young Persons Acute Deterioration Management (CYPADM) forms
- CHAS services.

These learning outcomes link directly with indicators in the logic model (2.1 and 2.2) and some of the priority areas identified at baseline.

Some pre and post-training evaluation data was collected from participants of training courses, and data collection has become more routine with time. In 2015/16 evaluation data was available from 11 of the 36 courses (30.6%), and in 2016/17 this had increased to 36 of the 55 courses (65.5%).

Table 3 below summarises the evaluation data across the two years.

Training sessions	2015/16[8]	2016/17[9]
Number of training sessions recorded	36	55
Number of participants recorded	1023	1006
Average number of participants	54[10]	20
Range of participant numbers in training	1-260	1-240
Average baseline score (across all learning outcomes) based on 10 point scale	4.4	4.3
Average post training score (across all learning outcomes) based on 10 point scale	8.2	7.8
Average change in training score	3.8	3.5

Table 3: Training evaluation data

While we recognise that this data is incomplete, it does serve to illustrate that staff learning regularly improves as a direct result of participation in DCN training events, and in areas directly related to the DCN logic model indicators and objectives. On average participants arrived with lower to medium levels of knowledge and understanding about the learning outcome areas and departed with medium to high levels of understanding.

The professional backgrounds of participants who were undergoing training is not individually recorded, but from the evidence available in the monitoring spreadsheet we have concluded that this includes:

- Community children's nurses
- Consultants and medical staff
- Health visitors
- Neonatal support workers
- Nursery nurses
- Paediatric nursing teams
- Physiotherapy teams
- Play therapists / play support workers
- Students (nursing, health visiting, midwifery).

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[8] Participant figures available for 19 out of 36 training sessions (52.7%) and evaluation data available for 11 courses (30.6%)

[9] Participant figures available for 50 out of 55 training sessions (90.9%) and evaluation data available from 36 courses (65.5%)

[10] Numbers of participants in 2015/6 have been affected by a couple of large scale sessions

Qualitative evidence from the baseline and repeat interviews also corroborates the training evaluation data findings.

At the repeat interview stage frontline staff recognised an increased understanding of palliative care in themselves and peers and greater likelihood of identifying and responding to palliative care needs:

"Hugely improved awareness of the situation. And it is now becoming much more identified in the issues round about these children, and there's much more willingness in the clinicians to take on some of the roles associated with it."
(Frontline Staff)

Another consultant talked about the growing awareness amongst staff of the palliative care needs of children with "evolving complex medical conditions". Additionally, one of the DCNs highlighted the creation of new teams with the specific remit of children with complex and palliative needs.

Extending Reach

A number of staff recognised the role the DCNs were continuing to play by extending the reach of education and training to staff and students. For example the DCN in the North of Scotland was delivering sessions to 1st and 3rd year undergraduate nurses at Robert Gordon University and the DCN in the East of Scotland was approached to provide training to students at Edinburgh Napier University (supporting logic model 2.2.2). In addition, the DCNs were working in collaboration with other practitioners to reach more groups. A consultant discussed how he was working with the DCN in the North of Scotland to develop and deliver joint training sessions reaching a range of staff:

"We're going to be involved in postgraduate medical teaching as well as for paediatric registrars, as well as other teaching or education roles which are, I'd say multi-agency."
(Frontline Staff)

Additionally, the DCN in the East of Scotland discussed how she had worked with the Simpsons Memory Box Appeal (SiMBA) to deliver a minimum of four collaborative training days per year, designed for midwives and neonatal staff. The DCN explained that the collaborative work has allowed her to reach a wider group of staff out with her DCN geographical area. One policy maker suggested that she would like to see the DCNs involved in providing formal accredited training through colleges and universities.

Two of the DCNs and one of the CHAS Clinical Managers also talked about the role the DCNs have played in extending their reach through NHS Education for Scotland. For example, the DCNs have been able to reach a range of practitioners through the delivery of children's palliative care presentations via the Remote and Rural Health Education Alliance. The network reaches: GPs, district nurses, public health nurses and those working in the community field in remote and rural areas. This has given the DCN in the North of Scotland the opportunity to provide training to an increased number of practitioners within the community setting.

"I'm constantly so impressed at how much they manage to be involved in because of the remote and rural stuff, they're doing teaching that is filmed and then put onto a website so that people in the remote and rural areas can see it."
(CHAS Clinical Nurse Manager)

In addition, the DCNs have also obtained the editing role for the NHS Education Scotland's Managed Knowledge Network for the Babies, Children and Young People's Palliative Care Community of Practice. The DCN who has taken a lead role in updating the site described it as an electronic platform of resources and information accessible for all, and which is monitored, edited and updated monthly.

With a small team, and with limited capacity, employing creative methods, such as online learning opportunities make considerable sense.

However, while undoubtedly reach has been extended and progress made with specific groups of staff, including nurses and allied health professionals, it was not felt that change had been achieved across all professionals, with medical teams highlighted as one group where progress was still required. One CHAS Senior Manager recognised that it is still "challenging to say absolutely".

3.3.3 | Liaison between professionals and services

Palliative care can be a complex matter, involving many different professionals, medical equipment and a range of areas of expertise. Good co-ordination is therefore vital, particularly to ensure that the needs and priorities of the family do not get lost in practical arrangements.

There was a general consensus amongst frontline staff interviewed at baseline, for case studies and repeat interview stage that the DCNs had helped make the delivery of palliative care more cohesive by acting as a link between different services.

The DCNs were recognised for their role in informing professionals about and advocating for families' wishes and preferences:

"I think often she's very good at bringing issues to the surface, either perhaps things that the parents have been thinking of and dwelling on and allowing them to bring that to the attention of the medical staff."
(Interview with Frontline Staff, Case Study One)

In Case Study One the DCN has been involved in multi-disciplinary team meetings (MDT) to discuss the child's needs and care plan. Her role has allowed her to liaise directly with different members of staff between MDTs to relay the families' thoughts.

"I think sometimes waiting for MDTs and getting the whole team together is really difficult sometimes and I have the capacity therefore to meet one or two of them at a time."
(Interview with DCN, Case Study One)

A number of the participants at the repeat interview stage mentioned progress in terms of partnership working and the joining up of services. This was discussed at a national, regional and at a hospital level.

Recent collaborative efforts to establish a hospital based palliative care service for children within the Royal Hospital for Children, Glasgow, was highlighted as a good example of joint working. The DCN in the West of Scotland explained that she had worked jointly with other staff members to advocate for the creation of a palliative care service within the hospital:

"We're actively working together to develop and to evidence the need for a service within the hospital so we have a hospital based palliative care service."
(DCN)

As a result of their efforts, a sub-group had been created which included clinicians, hospital management and CHAS to discuss how they could work together to progress the service. One of the CHAS Senior Managers suggested that in the past these conversations would not have happened within the hospital. The DCN suggested that as a result of efforts a clinical nurse specialist role could be created for children's palliative care.

The DCN role was perceived by both frontline staff and policymakers as a link or liaison role. One of the DCNs said she had witnessed changes (in one health board) where a range of professionals were now communicating directly rather than going through her (which they had done previously).

The DCNs also continued to strengthen the relationship between CHAS, the NHS and the community. There was also discussion around how the DCN service is working more effectively with internal teams within CHAS. One of the clinical nurse managers discussed how they were working more closely with the DCNs regarding referrals. For example they highlighted that the DCNs were able to help identify children that were likely to require CHAS services in the future.

It was acknowledged by some of the participants that the DCNs were much more embedded within their roles at repeat interviews than they had been the year previously. A consultant suggested that the role of one of the DCNs was much more 'established' within the hospital. All three of the DCNs recognised that relationships had been strengthened after working together on particular cases:

"Once you have worked with them (and the family) they see the benefit of that and they will introduce you earlier."
(DCN)

Another DCN expressed that she noticed a significant difference since last year and now felt that there was more "trust" and that staff were more "open" to work with her due to past experiences. Another DCN felt that staff were more receptive as a result of training:

"I think I'm seeing some slow changes amongst the medics. And that has come from an interest in the delivering on some education and training to the specialist trainees both in neo-nates [neonatology] and paediatrics."
(Diana Children's Nurse)

3.3.4 | Advice, guidance and role modelling

Having a known and supportive expert to whom you could turn for specialist advice and support was identified by frontline staff as an important factor in increasing confidence and improving practice around palliative care; this included anticipatory care planning. Indeed, DCNs were described by some of the frontline staff as a "driving force" for rolling out ACP.

Participants at repeat interview stage indicated that they had seen an increased focus on Anticipatory Care planning and the Children and Young People Acute Deterioration Management (CYPADM) for children. In particular, frontline staff members were recognised as having a greater awareness of the ACP form, resulting in increased usage of ACPs. In the Highlands a system had been developed for identifying children who have an ACP.

"I think there's more recognition about anticipatory care planning or planning for death and how that's done."
(Policymaker)

In addition to carrying out ACPs with families, the DCNs have played a key role in helping to train and support staff to undertake ACPs. In part this has been developed through role modelling good practice. The DCNs have also achieved this by running sessions to raise awareness of the ACP to different groups of staff. Groups of staff mentioned included: staff working in oncology, school nurses, health visitors and family nurse practitioners.

One member of frontline staff stated that they felt "empowered" to carry out an ACP after receiving training from one of the DCNs. Another said that the DCN role was helping to *"empower them (staff) to start the conversations"* with families (CHAS Clinical Nurse Manager).

This was viewed as a positive development because it ensured that there was *"continuity of care for a longer period of time."*
(Frontline Staff Interview)

Discussion focused specifically on a perceived increased usage of the anticipatory care plan at the antenatal stage.

"We're seeing more and more antenatal referrals, referrals before the baby is born and things are picked up."
(CHAS Senior Manager)

The DCN in the East of Scotland has worked closely with a consultant neonatologist to adapt the ACP form to make it appropriate for antenatal use. She has also been involved with supporting the other DCNs to work in this area. Highlighting that supporting other staff members is the only way to ensure the service is provided *"equally and nationally"* (DCN). However, one of the other DCNs noted that "*I can't replicate what she is doing because that is a full role in itself.*" (DCN)

The question of how all DCN specialisms can be rolled out equally across Scotland is one we will return to later.

3.3.5 | Emotional support

As well as providing families with emotional support, the DCNs have also been able to support staff emotionally, when they have had significant involvement with end of life situations. This emotional impact on staff of palliative care work was recognised by frontline staff and DCNs in the case studies, and it was clear that DCNs were viewed as invaluable in terms of their informal debriefing role:

"She's very good at almost doing like a debrief, sit down, let's have a chat about how things go... I think it's underestimated how traumatic medical and particularly nursing staff find the deaths of babies they've looked after."
(Interview with Frontline Staff, Case Study Three)

One member of staff suggested that her relationship involved a *"degree of peer support and clinical supervision."* (Frontline Staff repeat Interview) Emotional support for staff was particularly evident within the neonatal context. This was acknowledged by the DCN herself:

"Staff feel comfortable coming to share with me, recently clinically we've had a lot more staff feeling a bit nervous and anxious about delivering end of life care."
(DCN repeat interview)

However, while undoubtedly welcome and appreciated by frontline staff, it is questionable whether emotional support and debriefing for staff should form part of the DCN role. There is an argument that this type of intervention should form part of standard support and supervision systems within NHS services rather than falling to staff from external services, but it undoubtedly helps provide some of the support for colleagues, and so builds bridges which may help going forward in terms of subsequent joint working.

3.3.6 | Barriers and facilitators to capacity building

Through the baseline and repeat interviews and both evaluation workshops a number of barriers and facilitators to staff capacity building were identified, some of which have been described above.

It is clear that while training has increased in terms of the number of sessions offered, and a wide range of professionals are taking part, there are still some areas where there were felt to be gaps. Releasing staff for training continues to be a problem in some cases, in others it is getting beyond the "usual suspects" to those not already bought into the methods and approaches advocated by the DCNs. Reaching consultants and other medical staff, while not identified as such an issue at repeat interview stage as at baseline, was still considered to be a problem by DCNs.

At least four of the interviewees, primarily from CHAS, felt that early referral was an area that still required focus and development. In some cases, they felt that referrals received could have happened sooner than they did, thereby limiting the opportunities to provide support.

Delays in receiving referrals were attributed to a number of different factors including resistance from staff members and lack of information. However, a couple of participants also suggested that they had to be sensitive to the needs of parents, and parental resistance can sometimes result in delays.

One of the CHAS Senior Managers highlighted an uncertainty regarding whether emotional support and debriefing was within the remit of the role of the DCN. However, she recognised that there is a need within the system to support staff dealing with palliative care and bereavement and that the DCNs were well placed to provide this.

Staff capacity building: summary of key findings

- In 2016/17 DCNs delivered 55 training sessions, compared with 36 in 2015/16, an increase of 52.7% one year to the next. Average scores on learning outcomes before and after training increased markedly for participants
- Training reach was extended through collaborative working with NHS Education Scotland and others to create online learning resources
- Liaison work has proved effective within health boards and has improved relationships between NHS and CHAS services
- Trust and relationships grow with time and act as facilitator to further joint working however reaching those who were reluctant to engage or did not see palliative care as part of their role (particularly consultants) continues to be a barrier.

3.4 | Strategic leadership

The DCN service has as its third key objective 'to support the implementation of the Strategic Framework for Action on Palliative and End of Life Care and its ten commitments, CHAS Plan and other relevant policies which impact on children with palliative care needs by supporting the care workforce in their practical implementation'.

In recognition that knowledge, services, skills and capacity to deliver palliative care for children vary across Scotland, the DCNs have viewed strategic national influencing work as an increasingly important aspect of their role.

3.4.1 | The policy context at baseline

Recognition of the needs of children in the recently published ***Strategic Framework for Action on Palliative and End of Life Care***[11] (SFA Action on PEoLC) was signified as an important driver for change by a number of participants including: policymakers; CHAS Senior Managers and the DCNs. Prior to this, children had failed to be explicitly recognised in the previous strategy, ***Living and Dying Well***. A policymaker commented: "people who were involved in delivering care said that's not good enough and here's a framework, here's a policy to go alongside that." This resulted in the Scottish Children and Young People's Palliative Care Executive (SCYPPEx) producing a National Palliative Framework for Palliative Care for Children and Young People, published in 2012[12].

The recent framework (SFA Action of PEoLC), published in December 2015, was highlighted by one of the CHAS Senior Managers as being significant, not least because of the inclusion of "the word zero" (i.e. palliative care for 0-25 years) in recommendation 4 of this framework. It was emphasised that this was important because a significant number of children who die, with palliative care needs, are less than one year old.

One of the DCNs described the framework as a "tool for leverage". Another DCN suggested that the framework provided evidence for focusing on certain areas, for example promotion of ACPs. However, one policymaker emphasised that whilst the framework had been a positive development she was "under no illusion that there is a tremendous amount that still needs to be done". Another policymaker expressed that the policy context is not able to "guarantee" change and suggested that within the field of palliative care "we see quite slow change".

Two policymakers drew attention to the reviews of different health professional roles and services, which they perceived as relevant "policy drivers" in Scotland. Relevant services undergoing review included: CCN; health visitors; school nurses; district nurses and maternal and neonatal services. Both policymakers highlighted that the role and remit of these different services needed to be reconsidered to incorporate provision of palliative care. One policymaker emphasised that in order to "deliver services on the ground, at the coalface within the child's home school and nursery" the involvement of a children's community nurse is required.

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[11] http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/SFA
[12] http://www.gov.scot/Publications/2012/11/8118/2

Additional policy drivers highlighted by policymakers included: the *Children in Scotland Requiring Palliative Care: identifying numbers and needs (The ChiSP Study) 2015; Children and Young People Act Scotland 2014; Charter of the Rights of the Dying Child- Trieste Charter and the Health and Sport Committee report 'We need to talk about palliative care' 2015.*

Both frontline staff and policymakers suggested that the "national drivers" listed above had resulted in the creation of NHS posts specifically focused on the delivery of palliative care. Frontline staff highlighted that the newly created posts were able to lend support to the DCNs.

3.4.2 | The perceived role of DCN service to influence policy

There was an understanding by interview participants that being able to influence key decision-makers, both nationally and locally, should be a key focus of the DCN service, to ensure that palliative care was kept on the agenda. It was felt that part of this role involved continuing to raise both public and political awareness of palliative care in relation to children and the policies that exist. One CHAS Senior Manager commented: "*I think we have already started a process, we are speaking to lead politicians, civil servants and leaders within palliative care in Scotland.*"

Two DCNs/CHAS staff discussed the need for increased awareness in relation to transitions. Both highlighted that more young people are living with life-shortening conditions and are surviving into adulthood. One commented: "*transition to adult services needs to be high on the agenda*" and suggested that due to small numbers, palliative care for children and for adults had been viewed separately. A policymaker echoed this point and suggested that separation has created an "artificial barrier"; because adults' and children's palliative care services are viewed, planned and resourced separately.

Monitoring data provides a wealth of information about the number of strategic groups the DCNs sit on, the resources and guidance they have contributed to, and the expertise they have provided to national policy making. This was added to by the perspectives of interview subjects, particularly participating policymakers at repeat interview stage. Key achievements according to these sources are outlined below.

3.4.3 | Scottish Children and Young People's Palliative Care Network

A significant development identified by interviewees was the role of the DCN for the West of Scotland as Co-chair of the Scottish Children and Young People's Palliative Care Network (SCYPPCN). The DCN for the West of Scotland recognised that "*looking at things from a national perspective helps to make changes*". Within this role the DCN has been able to establish and chair a short life working group focused on producing national guidelines. The DCN in the West of Scotland is also working in partnership to develop standards and quality performance indicators so that there is equity across Scotland within the context of palliative care for an oncology diagnosis.

3.4.4. | Universal ACP Document

The national review of ACPs led by Healthcare Improvement Scotland was another important development discussed. It was explained that the review will result in a national ACP document for all age groups across Scotland. One of the DCNs explained that *"it's the one document for across Scotland unified and recognised by all health boards"* (DCN). It was highlighted that the first iteration of the national document did not have as much of a focus on children, resulting in the creation of a sub-group, through which all of the DCNs have been able to contribute. One of the DCNs emphasised that they had undertaken considerable work to 'advocate' for the recognition of children and young people's needs within the proposed documentation, as the document had previously been largely focused towards the adult population.

One member of frontline staff expressed concern regarding the universal document in case it was "less efficient and effective" than the documentation used in their present health board. However, the staff member did discuss the positive relationship she had with CHAS and the DCN, which has allowed her to feed into the review process.

3.4.5 | Perinatal Pathway

As well as feeding into the national review of ACPs, some of the interviewees discussed how the DCNs had played a leading role in the creation of guidance to support staff if parents want to take a baby or child home after death.

Guidelines were initially created after one of the DCNs identified a specific gap in this area. As a result, the DCN collaborated with a NHS Lothian Clinical Fellow and Police Scotland to create local guidelines. These guidelines were then shared with the Neonatal Managed Clinical Network group and have since been shared nationally with neonatal units throughout Scotland.

The DCN involved in writing the guidance expressed that before this guidance, it was not consistently clear whether a baby who had died could be taken home prior to their post mortem examination. By providing information to staff the DCN felt that staff members were able to offer choice to parents who wish to take their baby home:

"So that's big change in practice. Hopefully that will provide consistency for families. Consistency for staff... knowing what to do, knowing that it is an option for families."
(Diana Children's Nurse)

It was highlighted that following on from this work, a short life working group has been established, as part of the SCYPPCN work stream to look specifically at adapting the guidelines for the paediatric setting. This has resulted in a greater awareness amongst staff that parents have the option to take their child home after they have died.

The DCN co-chairing SCYPPCN played an instrumental role in helping to establish this group. The DCN stated that the guidelines should help to *"provide some equity across Scotland"* as there has been huge inequality across Scotland in relation to this.

In terms of other strategic changes, policymakers and other interviewees, highlighted the discussions surrounding the Scottish Children and Young People's Palliative Care Executive (SCYPPEx) potentially being developed into a National Managed Network focusing on palliative care for children. It was suggested that the DCNs have been able to inform this process.

3.4.6 | Barriers and facilitators to strategic influencing

Five of the interviewees highlighted the £30 million committed by the Scottish Government to support CHAS over the next five years as a tangible outcome of recent efforts to increase knowledge and awareness of children's palliative care, including the work of the DCNs. It was also viewed as something that would facilitate strategic developments in children's palliative care going forward:

"I think the reality of the investment of £30 million in children's palliative care through CHAS from the Scottish Government, so that's become a reality and it's making people think about and talk about children's palliative care in a way that it hasn't previously."
(Policymaker)

However, one policymaker noted that whilst the increase in funding for children's palliative care was a positive development, it coincides with a "*disinvestment in [other] services*". Many of the participants continued to highlight issues surrounding general NHS funding as a barrier to the delivery of good palliative care for children.

Strategic influencing: summary of key findings

- There has been an increased recognition of the palliative care needs of children within national policy in recent years
- However, there is an ongoing need to keep this high on the agenda and advocate for their specific interests and needs
- The DCNs have managed to influence change at a national level in terms of contributing to new national guidance and approaches
- New strategies, approaches and guidelines require adequate funding in order to ensure their effective implementation, of which the £30 million funding for CHAS is one important route.

4. Overarching themes

In the previous section the role and impact of the DCN service in three key areas were explored: direct work with families, staff capacity building and strategic leadership. As mentioned earlier, these three areas of work intertwine and inform each other. However, there are also tensions between them, in terms of where the DCNs best place their energies and limited time.

There are some other overarching factors that influence the direction and impact of the DCN service, which are explored in this section. All of these overarching factors have been areas for thought and debate throughout the course of the evaluation, from the first evaluation workshop onwards, although their nature and degree of challenge associated with them has varied over time.

4.1 | Balancing Priorities

There was recognition from the DCNs and the other participants that the DCNs face an ongoing challenge of trying to balance the different aspects of their role. One of the DCNs highlighted that her clinical work took priority, and she recognised that the increase in referrals had meant that it was more challenging to focus on other priorities. Another DCN felt she did not always have to be involved in all aspects of the clinical work but still felt it was a key aspect of her role.

For a couple of the participants the real strength of the role was the fact that the DCNs were involved both strategically and clinically:

"I'm really proud of what they do strategically but also clinically when they're there at the point of care with families, having honest conversations about very difficult situations and enabling families to understand that there is an option for them and that there might actually be a positive in all this heartache that they face."
(CHAS Senior Manager)

Going forward, balancing the priorities between the different aspects of their roles will depend on a number of factors including level of need and capacity within the wider system to respond, ideas of where change is required and the best mechanisms for achieving the desired change, and the particular skill set and strengths of the DCNs themselves.

4.2 | Specialism versus universalism

A key strength of the DCN service identified amongst evaluation participants was the skills and experience of the DCNs themselves, particularly in regard to specialisms such as neonatal palliative care. Frontline staff welcomed having someone with specialist knowledge to turn to and seek advice from, and this was viewed as adding considerable value, which further highlights the need for some direct clinical work. Participants also highlighted the support and specialist input provided by CHAS as a key strength of the service, both in terms of palliative care knowledge and expertise, but also in terms of facilitating access for families to CHAS services.

However, with one of the key goals of the service being to build awareness that palliative care was 'everyone's job', this relies on the ability to easily transfer skills, knowledge and experience to others. Resources and training activity undoubtedly support this, and findings from training and strategic influencing work suggest that they have begun to make a difference. However, evidence from the repeat interviews and final evaluation workshop did indicate that there was still a tendency in some areas to rely on the DCN for palliative care support, specifically because of their expertise. As one nurse manager described it, they provide the "gold standard".

Linked to this tension of specialism vs universalism was the ongoing reluctance on the part of some professionals to recognise that palliative care was part of their role. It should be acknowledged that this issue was raised much more often in baseline interviews than at repeat interview stage, but it still persisted in some quarters, particularly among some consultants.

One of the DCNs suggested that, for some staff, there continues to be a persisting misperception surrounding palliative care. As a result, this can have implications for the stage at which the DCN is invited to get involved with a family.

"I think people's understanding of what palliative care is remains the same. The majority of people think it's end of life care... and only introduce us when every other route has been explored."
(DCN)

To successfully persuade professionals that they can and should take on more palliative care responsibilities, to encourage colleagues to refer early, and to work sensitively with families to address their misgivings therefore all remain areas of ongoing work.

4.3 | Capacity to respond

In terms of key limitations, the small size of the team does limit the extent to which they were able to roll out improvements to palliative care across Scotland.

At least eight of the interviewees indicated that the reach and impact of the DCN service was limited due to the fact there were only three of them for the whole of Scotland. Some of the respondents suggested that if the team was bigger they might be able to make more of an impact. However, despite the limited number of DCNs it was recognised that they were still managing to achieve significant change. One of the policymakers expressed that the DCN team had actually surpassed expectations in terms of its reach:

"I think they have in many instances probably exceeded in terms of scale, given that they are only three individuals."
(Policymaker)

However, capacity issues were not unique to DCNs, and wider issues surrounding resource and staffing were identified as key barriers to the delivery of palliative care. A member of frontline staff working within the hospital setting indicated that they were often 'working at or above funded capacity'. Another member of frontline staff felt that there are not enough people on the ground to deliver adequate support. The DCN service was cited as a positive development because they were able to provide 'dedicated' support to families without competing pressures on the ward. Concern was also raised around missing roles within the NHS and the impact this was having on the delivery of palliative care.

Given these factors, the question of what constitutes adequate resource is difficult to answer. It would appear that additional DCN resource would have the potential to extend reach and impact, as would additional NHS resource. It certainly would not seem appropriate to argue for one over the other.

4.4 | Geography

As with capacity, geography has proven to be a challenge in some areas, particularly within the North. One member of frontline staff expressed that the region was challenging in terms of the size of the area, poor transport links and the small number of practitioners spread across it.

It was also suggested that that there can be a misperception about the distance between Inverness and Aberdeen. One of the policymakers felt the demands of travel would have implications on the DCN being able to follow matters up.

A member of frontline staff felt that if the DCN was based in Aberdeen she might be able to do more. The DCN covering the North of Scotland also identified that, whilst she was witnessing progress, *"being located away from Grampian is one of the negative features of this role"*. She emphasised that visibility and availability were essential elements in helping the DCN role to become embedded within the teams.

It must also be recognised that from the start, the three DCNs have focused on different aspects of palliative care, based on their individual expertise and local circumstances. Thus the East has seen more of a focus on neonatal support, for example, while the North has focused more on community support. While this has enabled the DCNs to build on their strengths, and test different approaches and models, it has meant that developing a broad, countrywide approach has been difficult. Going forward it may be advisable to bring in additional capacity and specialisms to 'fill the gaps'.

4.5 | Equity of access

Participants also expressed concerns around the delivery of palliative care being equitable for all children and their families. There was discussion around inequality due to lack of 24-hour service provision. A member of frontline staff recognised that when the DCN service is not available, families do not have the same opportunity to access an enhanced service. Another frontline staff member recognised that "you perceive inequality in what we can offer families" when children need to access services out of hours. Geography was also discussed in the context of equity.

One of the policymakers also suggested that it was difficult for the DCNs to facilitate consistency, as there are so many different clinical teams they have to work with that come in a variety of different forms. However, the DCNs suggested that efforts such as the creation of national guidelines for staff, to support families who wish to take a child home after their death, and a national ACP document would help provide greater equity across Scotland.

Voluntary sector vs statutory sector

Participants also discussed the benefits and drawbacks of coming from the voluntary sector but primarily working within the NHS. Participants expressed a variety of opinions. There was recognition by at least four of the DCNs/CHAS staff that the relationship with the NHS was in the main positive. One participant felt that having an NHS honorary contract had made things easier for the DCNs. However, another individual said that "it's not lending a lot of weight working within the NHS". All of the DCNs suggested that previous links and relationships with the NHS had helped them deliver aspects of their role.

Barriers between the voluntary and statutory sectors may also fall over time, as trust and understanding between the DCN service, NHS, CHAS and others build. Indeed there was some indication at repeat interview stage that this was already proving to be the case.

5. Conclusions

The aim of this report was to evaluate the extent to which the Diana Children's Nurse service has met its aims and objectives, and to generate learning about the barriers and facilitators to improving palliative care for children in Scotland.

The overarching aim of the DCN service is that '*Babies, Children and Young People in Scotland will have access to palliative care when and where they need it.*' To achieve this aim, the service has three objectives. We describe our conclusions against each of the three objectives in turn.

Objective One:

To provide strategic and professional regional nursing leadership in the development and delivery of a multi-professional seamless service which integrates children's palliative care across all sectors, and within the core value, vision and purpose of CHAS.

The DCN service has developed a regional approach to supporting the development of palliative care services for children, with DCNs based in the East, North and West of Scotland. In each of the three regions the DCNs have focused on delivering a combination of direct work with families, staff capacity building and strategic leadership, as described in this report. These have all had an impact on the families involved, on staff knowledge and skills and on local systems and structures.

However, the exact nature and form of the work has varied from region to region, depending on local circumstances and the skills and experience of the individual DCNs.

This set up has allowed for testing different approaches and responses across the country. In the East, for example, considerable expertise has developed in the area of neonatal support. In contrast, in the North, the emphasis on community engagement has allowed for wider partnerships to develop, including with schools. Cumulatively the DCN service should therefore have obtained useful knowledge about what works and what is required in different settings.

However, it has also meant that the palliative care system the DCNs have worked to develop does vary from region to region and consistent support across Scotland remains an issue within current capacity. To ensure comprehensive coverage across Scotland for all aspects of palliative care provided by the DCN service will require additional staffing.

Objective Two:

To lead and support the development of a care workforce with the necessary knowledge, skills and expertise to deliver improvements in the care of children with palliative care needs and their families, through collaboration with education providers.

The DCNs spend a considerable amount of time supporting staff around their palliative care knowledge, skills and expertise. This is undertaken through formal training and learning opportunities 'on the job', and working directly with frontline staff on individual cases. We found evidence to indicate that this work has had a positive impact on staff in terms of their knowledge and understanding of palliative care. The extent to which palliative care approaches have become embedded within NHS practice as a consequence of this input, is however unclear. The DCNs themselves have described how frontline staff members continue to regularly approach them and rely on them for their expertise.

This is no doubt welcome in terms of recognition of the DCNs' skills and trust in their abilities, and may mark a positive change from the start of the evaluation, when the DCNs described barriers between the voluntary and statutory sectors in more detail. It may also be responsible for the increased referrals for direct work with families the DCNs have received over the course of the evaluation – greater trust and recognition of what the DCNs can offer, resulting in increasing referrals from DCNs to CHAS services. These are all positive developments that should not be underestimated.

However, with 15,400 children having palliative care needs in Scotland, it is clear that the DCNs will only ever be able to provide direct support to a very small proportion of them, and it is likely that these will be from within the group of 2,200 who are seen as unstable or deteriorating. Therefore, it remains essential that improving skills and practice continue to be rolled out across the NHS – not just in terms of frontline staff using the DCN service as a bridge to specialist support, but in terms of the NHS taking on a greater palliative care role as part of mainstream provision. This will, of course, require adequate resourcing and prioritisation at a national level.

Objective Three:

To support the implementation of the Strategic Framework for Action on Palliative and End of Life Care and its ten commitments, the CHAS Plan and other relevant policies which impact on children with palliative care needs by supporting the care workforce in their practical implementation.

The last couple of years have witnessed greater recognition of the palliative care needs of children. This is very welcome, but there is still a considerable distance to travel to ensure that all children with palliative care needs get the support when and where they require it.

The DCNs have undoubtedly played a role in pushing this agenda forward and have contributed to the implementation of national policy through their role on national groups such as SCYPPCN. They have been able to identify gaps in current guidance (such as taking a baby home following a death) and work to fill them. They have also supported the development of universal approaches such as the universal ACP.

Clearly their influence sits alongside that of other professionals, policymakers and experts across Scotland. But their role, combining direct work with capacity building and strategic leadership gives them a unique position from which to view the strengths and weaknesses of the current system from multiple points of view.

6. Recommendations

Based on the findings from this evaluation, the recommendations are as follows:

For the Diana Children's Nurses (DCN) service

- In order to build capacity within the system as a whole, there should be a continued emphasis on building the palliative care skills, knowledge and expertise of NHS and community staff. A more detailed analysis of where current strengths and weaknesses lie within the system, and where priorities for future training are, will help target approaches and resources accordingly
- The DCN service should continue its emphasis on strategic influencing to improve palliative care standards across Scotland. This should continue to be informed by priorities, gaps and issues identified regionally
- Over time, as capacity, skills and guidance are embedded elsewhere in overall systems of care, there may be a possibility of less emphasis on direct work with families. However, it is recognised that direct clinical work in clinical cases informs care in particularly complex cases, and this both encourages rapport and develops mutual trust and understanding. We recommend that CHAS reflect on and review the role of direct work within the DCN service, to agree the appropriate balance of direct work to other activities going forward
- The DCNs and their supporting team should further explore how the experiences of families, and children and young people who have used the service can be captured and shared.

For Children's Hospices Across Scotland (CHAS)

- Capacity should be increased to enable DCN specialisms or nurses with similar skills to roll out across the whole country, and address some of the logistical challenges of working in the North of Scotland, and within other specialisms across the other areas of Scotland
- CHAS should support the DCNs to consider their future direction, in terms of where to target their future staff capacity building, what types of direct work they should prioritise, and what their national goals and priorities are.

For planners and decision makers

- It cannot be the role of the DCNs alone to build capacity for palliative care. Planners and decision-makers at local, regional and national levels should consider what is required to ensure the aims and outcomes of the Strategic Framework for Action on Palliative and End of Life Care are met, and plan accordingly
- Health boards and joint integrated boards should consider how the emotional support needs of NHS staff working in neonatal and paediatric palliative care settings can be better addressed. While we recognise the DCNs are valued for their support in this area, and bring knowledge and expertise to support this role, given their limited capacity, we conclude that further action is required at a decision-making level to explore how capacity can be built within statutory agencies. The experience of the DCN service should inform this.

Appendix 1 (Fold out)

Diana Children's Nurses (DCN) - A LOGIC Modelling Approach

Appendix 1: Diana Children's Nurses (DCN) - A LOGIC Modelling Approach

Babies, Children and Young People in Scotland will have access to palliative care when and where they need it

1 To provide strategic and professional regional nursing leadership in the development and delivery of a multi-professional seamless service which integrates children's palliative care across all sectors, and within the core value, vision and purpose of Children's Hospices Across Scotland (CHAS).		**2** To lead and support the development of a care workforce with the necessary knowledge, skills and expertise to deliver improvements in the care of babies, children and young people (BCYP) with palliative care needs and their families, through collaboration with education providers.		**3** To support the implementation of the Strategic Framework for Action on Palliative and End of Life Care and its ten commitments, CHAS Plan and other relevant policies which impact on BCYP with palliative care needs by supporting the care workforce in their practical implementation.		
1.1 BCYP receive enhanced palliative care; especially within the fields of neonatology, cancer services, intensive care and community	**1.2** Staff have increased confidence and skills in paediatric palliative care	**2.1** More staff have an understanding of a range of care settings, including; home, hospital, respite, school and hospice	**2.2** Staff across all care sectors are better educated about palliative care for BCYP	**3.1** Increased number of BCYP die in preferred place of care	**3.2** Policy makers have an increased understanding of the need for palliative care for BCYP in all care settings	**3.3** Key stakeholders and senior staff developing services have a better understanding of relevant national policies
1.1.1 An established baseline of palliative care services in Neonatal Units, Cancer, Paediatric Intensive Care and within the community **1.1.2** Frameworks / guidelines developed in line with national policy **1.1.3** Known bank of available services and resources across all care contexts (acute and community) **1.1.4** Know number of BCYP with palliative care needs	**1.2.1** Best practice guidelines and bodies of evidence produced and disseminated **1.2.2** Increased number of care staff involved in debriefs or clinical reflective meetings **1.2.3** An increased number of joint working activities between DCN and individual statutory practitioners for individualised care **1.2.4** Three education sessions delivered within each Regional Planning Group, region annually	**2.1.1** Working partnership between BCYP palliative care providers **2.1.2** NHS acute staff released to visit specialist paediatric palliative teams	**2.2.1** Established working relationships with Regional Practice Education Facilitator (PEF) **2.2.2** Educational sessions offered to support nursing students deliver Palliative Care **2.2.3** Increased knowledge and use of Anticipatory Care Plans and Children Young People Acute Deterioration Management forms	**3.1.1** Increased number of BCYP whom are referred to an appropriate palliative care service provider **3.1.2** Current resource database's of appropriate service providers **3.1.3** Successful interface with transition services **3.1.4** Increased knowledge and use of Anticipatory Care Plans and Children Young People Acute Deterioration Management forms **3.1.5** Clear referral pathways to palliative, end of life and bereavement services	**3.2.1** Out of Hours policy co-developed and implemented **3.2.2** Engagement plan co-developed and implemented **3.2.3** Relationships with Health Boards, Regional Strategic Planners and other Key Stakeholders are established.	**3.3.1** Contribute to research and audit reports with recommendations for change **3.3.2** Increased number of CHAS and other statutory organisation staff engaged in Quality Improvement activities
• Gap scoping exercises to define current service provisions • Awareness raising sessions regarding CHiSP report and promotion of its recommendations • Support the development of local paediatric palliative care groups within each area to interface with national groups • Signposting care staff / families to appropriate services • Contributing to bank of available services	• Promotion of debrief meetings at both clinical and emotional level. • Provide advice and guidance at the National / Local morbidity / mortality meetings • Undertake gap scoping exercise's for creating best practice evidence in BCYP palliative care • Promotion of palliative care multi-disciplinary team meetings • Clinical case work • Communications with care staff	• Establish collaborative working partnerships with CHAS, NHS, Marie Curie Cancer Care, et al to deliver end of life care • Promote staff development and recognition of work in different environments • Create DCN led workshops on the benefits of collaborative working	• Review training needs of staff delivering BCYP palliative care • Engage with NHS/NHS Education Scotland (NES) • Explore academic partnership working on palliative care courses • Plan palliative care awareness raising sessions • Facilitate collaborative working with each Health Board Practice Education Facilitator/ coordinator • Facilitate discussions surrounding ethical considerations and/or religious beliefs which may impact on the delivery of care • Promote the use of appropriate guidelines /frameworks, including ACP and CYPADM	• Map and engage with current palliative care providers • Contribute to the review and refining of referral processes between a variety of local/ national providers of palliative and bereavement care in each area • Awareness raising and promotion of relevant services and choices of care for professionals, BCYP and families • Gain awareness of local resources • Rapid discharge planning	• Contribute to the development and implementation of out of hours policy on service delivery for End of Life Care • Contribute to consultation documents • Cascade information from national regional policy • Support service re-evaluations to meet GIRFEC model, encouraging the development of lead professional roles • Regular meetings and communication with senior teams form health social care and education	• Develop a culture of continuous improvement amongst staff so that creativity, innovation and engagement are recognized and encouraged whilst ensuring children and families are absolutely central to service development • Encourage CHAS and other statutory organisation staff to participate in Quality Improvement, research and audit programs • Use of improvement methodologies, pilots and tests of change • Promote and facilitate a Quality Improvement /Research steering group/ Hubs in the regional planning areas (as NES)

Appendix 2

Frontline staff baseline interviews:

Job title
Charge Nurse Neonatal Unit
Community Children's Nurse Team Lead
Complex Needs Social Worker
Consultant Paediatric Anaesthetist
Consultant Paediatric Intensivist
Consultant Paediatrician
Cystic Fibrosis Nurse Specialist
Development Officer Additional Support Needs
Family Support Worker
Lead Nurse
Neonatal Consultant
Senior Charge Nurse
Team Leader Integrated Community Children's Nursing Service
Transport Doctor

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