EVALUATION OF THE CHILDREN'S PALLIATIVE CARE PROGRAMME (CPCP)

A jointly funded programme of work arising from *Palliative Care for Children with Life-limiting Conditions - A National Policy*

SUMMARY REPORT

Dr Joanne Jordan GEN Research &
Deirdre Fullerton Insights Health and Social Research

September 2016

An Roinn Sláinte agus Leanaí
DEPARTMENT OF HEALTH AND CHILDREN

Feidhmeannacht na Seirbhíse Sláinte
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The Irish Hospice Foundation
Striving for the best care at end of life for all

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FOREWORDS

Palliative care for children and young people with life-limiting conditions is an active and total approach to care from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on the enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and are though death and bereavement. (ACT and Royal College of Paediatrics and Child Health, 2001)

I welcome the publication of this report as it demonstrates the significant progress made on the implementation of key recommendations contained in *Palliative Care for Children with Life-limiting Conditions in Ireland – A National Policy* (Department of Health 2009). The national policy was developed to ensure that children with life-limiting conditions and their families would have access to the type and support and services they need during the most difficult time of their lives.

The focus of this evaluation was on the development of a specialist Consultant Paediatric service, an Outreach Nursing service and a comprehensive education programme delivered to healthcare staff. The evidence strongly confirms the success of these initiatives in for example improving the communication, co-ordination and the overall quality of care provided. The report also highlights the impact these three developments have had on almost all of the 19 recommendations contained in the national policy report.

I would like to thank the Chairs and members of the National Development Committee under whose direction these developments happened. I would also like to thank the evaluation team, Dr. Joanne Jordan and Deirdre Fullerton, whose dedication and commitment deserves particular mention – the sensitivity of their approach is evidenced by the depth and richness of the feedback received from the parents they engaged with. The evaluators were ably assisted by the project Steering Group who provided expertise, guidance and oversight of the research. My appreciation is also due to the Consultant, the Children's Outreach Nurses and the education Programme Co-ordinator in Children's Centre for Nursing Education in Our Lady's Children's Hospital Crumlin. I acknowledge and commend all our partners working in the sector and in particular the Irish Hospice Foundation whose very significant financial contribution ensured that these developments became a reality.

This report would not have been possible without the willingness of parents, staff and partners to give of their time and energy to participate in the evaluation – your views will help identify the things we need to improve on and will help shape the future of children's palliative care in Ireland.

The dedication and commitment of the research team is deserving of mention – the sensitivity of their approach is evidenced by the depth and richness of feedback from the parents they engaged with.

John Hennessy
National Director
Primary Care
HSE

The news that your child will most likely die in infancy or childhood can be overwhelming and parents often find themselves isolated and at a loss.

The mission of the Irish Hospice Foundation is to strive for the best care at end of life, for all. Supporting the development of palliative care services for children with life-limiting conditions has been and continues to be a cornerstone of the work of the Irish Hospice Foundation since its inception. The recommendations contained in the Department of Health 2009 policy were built on a needs assessment, funded by the Irish Hospice Foundation, strongly reflecting the views of families and health care providers on what was needed to ensure children and their families would have access to co-ordinated quality services.

The Irish Hospice Foundation (IHF) is delighted to be associated with this programme and its evaluation, particularly with the positive outcomes for parents described in the report. It was heartening to read the appreciative comments from so many parents on how the new services have made a difference to the lives of their children and their families. It is evident from the comments and feedback how things have greatly improved and now parents feel more supported in their role as primary carer for their child. The experience of other health service providers using this service is that it is of high quality with strong impacts being achieved.

However, we need to acknowledge that there are parts of the country where parents are still waiting for these services or areas where the existing services are overstretched. We also need to acknowledge that hands-on nursing care for children at home, respite and bereavement services are far from adequate. The key objectives of the 2009 policy remain valid we need to move to the next phase of development in children's palliative care and identify clear development priorities for the coming years.

I would like to commend the HSE for our strong partnership which has developed over the last number of years, and especially for pushing ahead at a time when resources were extremely limited and for their continuing commitment to this programme of work.

My sincere thanks go to the many parents who participated so willingly in the evaluation and who generously shared their experiences.

The charity sector is going through a challenging period at the moment but this report provides a clear indication of what can be achieved when charitable funds are used to seed fund and enable strong national policy. This work could not have happened without the support and generosity of the Irish public and in particular Early Childhood Ireland, who donated the proceeds from their Pyjama Day to this programme for four years.

We welcome the opportunity to continue our work with the HSE and other partners on this programme to ensure the needs of children and families are addressed and met.

Sharon Foley
CEO
Irish Hospice Foundation

FUNDING

This report was commissioned by the Irish Hospice Foundation (IHF), Department of Health (DoH), and Health Service Executive (HSE).

ACKNOWLEDGEMENTS

The authors wish to convey their sincere gratitude to those who participated in this study, including: the parents who gave so generously of their time to share their experiences in interviews and in the survey; the service providers from the acute and community sectors who participated in surveys and who volunteered their time for interviews; and the Children's Outreach Nurses and Consultant Paediatrician with Special Interest in Paediatric Palliative Medicine for the multitude of ways in which they participated throughout the evaluation. Our thanks also to the Project Officer, Palliative Care HSE (Stephen Toft) who provided information from the Minimum Data Set and to the Children with Life-limiting Conditions Programme Coordinator, Our Lady's Children's Hospital Crumlin (Cecilia McGarry) for sharing the evaluation of the Level A & B education and training programmes. We are particularly grateful for the support provided by Sheilagh Reaper Reynolds who was a constant source of guidance, information, practical help and encouragement. The research was directed and supported by a Steering Group, chaired by Dr Máirín Boland, who provided invaluable expertise and guidance through research initiation, development, research ethics committee application, review and completion and our sincere thanks go to them. Our thanks also to Dr Ronan Glynn and Dr Fiona Cianci who provided support to the Steering Group during the course of the research.

The views expressed in this report are those of the authors and do not necessarily reflect the views or policies of the funders.

MEMBERSHIP OF STEERING GROUP

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Ms Sharon Foley	CEO, Irish Hospice Foundation
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Dr Claire Quinn	Lecturer, NUI Galway
Ms Sheilagh Reaper Reynolds	National Lead for Palliative Care, HSE

ABBREVIATIONS USED IN THE REPORT

ACT	Association for Children with Life-Threatening or Terminal Conditions (now Together for Short Lives)
A&E	Accident and Emergency
ADON	Assistant Director of Nursing
APC	Adult Palliative Care
CCNE	Centre of Children's Nurse Education, Our Lady's Children's Hospital Crumlin
CHO	Community Health Organisation
CLLC	Children with Life Limiting Conditions
CME	Continuing Medical Education
CNS	Clinical Nurse Specialist
CON	Children's Outreach Nurse
CPCP	Children's Palliative Care Programme
CPCT	Adult Community Palliative Care Team
CPD	Continuing Professional Development
CPE	Continuing Professional Education
DOH	Department of Health
DOHC	Department of Health and Children
DNAR	Do Not Attempt Resuscitation
EAPC	European Association of Palliative Care
ED	Emergency Department
HCP	Health Care Professional
HSE	Health Service Executive
IAPC	Irish Association of Palliative Care
IHF	Irish Hospice Foundation
LLCs	Life Limiting Conditions
MDS	Minimum Data Set
MDT	Multi-Disciplinary Team
NDC	National Development Committee for Children's Palliative Care
NUIG	National University of Ireland, Galway
OLCHC	Our Lady's Children's Hospital, Crumlin
Consultant PPPM	Consultant Paediatrician with Special Interest in Paediatric Palliative Medicine
PCT	Palliative Care Team
SpR	Specialist Registrar

TERMINOLOGY USED IN THE REPORT

Advance Care Plan	A document that records the advance wishes of a child or young person and/or those with parental responsibility for them.
Child	Person up to the age of 18 years.
Children's/paediatric palliative care	An active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond.
Life Limiting Conditions (LLCs)	Life limiting conditions are those for which there is no reasonable hope of cure and from which children or young people will die. For the purposes of this report, the term 'life-limiting' will encompass life-limiting, life-shortening and life-threatening conditions.
Parent / Carer	For the purposes of this report, the term 'parent' will encompass all immediate / primary carers.
Palliative Care	Focuses on managing pain and other distressing symptoms, providing psychological, social and spiritual support to patients, and supporting those close to the patient. It can be provided at any stage in the progression of a patient's illness, not only in the last days of life when the focus of treatment has generally moved from trying to actively manage disease and prevent deterioration to managing the patient's symptoms and keeping them comfortable.
Service Provider	A person or organisation whose formal role is to provide a social, health or educational service to private citizens or to the general public. The particular service provided may be funded privately or publicly.

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EXECUTIVE SUMMARY

Background

A comprehensive needs assessment completed in 2005 identified that children's palliative care services needed to be strengthened (Dept of Health/Irish Hospice Foundation). In 2009 the Department of Health published *Palliative Care for Children with Life-limiting Conditions – A National Policy*. The policy was a universally agreed vision for improving children's palliative care in Ireland. The document included 19 recommendations (further subdivided into 31 individual recommendations) to be implemented on a phased basis. The first phase of implementation included the provision of education and training for staff, the appointment of a Consultant Paediatrician with special interest in Paediatric Palliative Medicine (Consultant PPPM), and the establishment of a national network of (initially) eight children's outreach nurses based in key locations around Ireland. These priorities were put in place over the next three years under a partnership agreement between the HSE and the Irish Hospice Foundation. The Foundation agreed to provide almost 85% of the start-up costs on the understanding that the initiatives would become main-stream funded within three to five years.

This report considers these three priority initiatives which, for ease of description, are called the Children's Palliative Care Programme (CPCP).

The CPCP forms only a part of the full spectrum of children's palliative care services which are provided in paediatric units, in particular the tertiary hospitals, in the community and through voluntary/charitable organisations. While this evaluation focuses on the impact of the CPCP it needs to be acknowledged that in the course of the research some parents may, at times, have found it difficult to differentiate between specific services, for example, between the role of the Consultant and the specialist team in Our Lady's Children's Hospital in Crumlin.

Aims

The aims of the evaluation were

- To evaluate the inputs, outputs, progress and, where possible, outcomes of the CPCP
- To review the extent to which the programme is operating as a national service in terms of coverage and coordination
- To assess the contribution of the CPCP towards the implementation of Palliative Care for Children with Life-limiting Conditions in Ireland–A National Policy (DOHC 2009)

Methodology

The evaluation consisted of three phases over a two year period. Phase One included a literature review, development of research design/tools, ethical approval and stakeholder consultation. Phase Two, a process evaluation, comprised a survey of service providers as well as stakeholder interviews and focus groups. The final summative evaluation phase consisted of an E-survey of service providers and parents; interviews and/or focus groups with parents, service providers, service managers, stakeholders, and the training provider; and a secondary analysis of feedback from training participants.

Findings

The CPCP had four anticipated outcomes and the collective evidence confirmed that the new services are widely understood to be adding significant value to service provision for children with life-limiting conditions and their families.

Outcome 1: Improved quality of life for children and their families

The feedback from parents and service providers indicates that the introduction of the CPCP improved the quality of life for children and parents in a wide range of ways including facilitating home-hospital-home transition, securing resources and equipment for children at home, providing expert advice and support in symptom management, and helping parents in their role as primary carers in the home setting.

Parents identified ongoing support needs which included access to high quality and consistent nursing hours, availability of respite, and improved access to equipment and supplies.

Outcome 2: Improved co-ordination of services to children with life-limiting conditions so they can be cared for in the home setting as far as possible.

The valuable co-ordinating role of the Children's Outreach Nurses was a recurring theme. Having one 'go-to' person with the relevant experience was consistently described by parents and service providers as greatly easing their burden of care and improving continuity of care. The consultant service was also seen as helping to co-ordinate services, particularly in the run-up to discharge from hospital. Also of critical importance were the supports required to get children home, which was articulated as a key desire in the 2005 needs assessment. The CPCP has enabled this to happen and the view is that there is now a considerably higher level of co-ordination and supports available.

Both parents and service providers acknowledged that the overall effectiveness of the nursing service is very much dependent on the existence and accessibility of wider health and social care services.

Outcome 3: An improved children's palliative care sector with increased education on children's palliative care and appropriate engagement of the Children's Outreach Nurses in the provision of education / training.

The CPCP education programmes were viewed as providing important training on the needs of children with life-limiting conditions for generalist staff throughout the country. The involvement of the nurses and the consultant in delivering the courses was viewed as valuable in terms of their expertise and raising awareness of the CPCP service and of the importance of children's palliative care more generally.

A small number of respondents highlighted barriers to attending training, which included staff shortages, reduced training budgets and the time required to attend.

Outcome 4: Increased awareness of children's palliative care and of the new service in both the public arena and health sector.

Both the Nurses and the Consultant were viewed as playing an important role in improving awareness of children's palliative care. Continued opportunities in education and training for community and acute sector (both statutory and voluntary) staff, including the continuing involvement of CPCP personnel, were viewed to be central to further increasing awareness.

During Phases Two and Three of the research, participants provided feedback on challenges to the effective delivery of the CPCP and also suggested areas for improvement and development. These included the geographical spread of services and high population density resulting in excessive workloads and the need for additional staff; better structured clinical supervision for the staff involved; improved information systems and administration support; clearer role delineation; the shortage of paediatric nurses in the community; access to out-of-hours support for parents; the lack of access to respite care; poorly developed bereavement support; limited access to therapy services; and challenges in transitioning from paediatric to adult services;

The evaluation also considered the impact the CPCP has had on the implementation of national policy. Of the 19 policy recommendations the CPCP has had a direct impact on the implementation of 12 recommendations and has contributed to the implementation of six others.

Recommendations

The report includes a set of 20 recommendations. Six recommendations are resource dependent including additional staff resources, ongoing funding of the education programme, and improved respite and bereavement care. Seven are structural/ organisational in nature and include strengthening and maximising the future role of the CPCP, further integration of services, and a review and reconfiguration of the National Development Committee for Children's Palliative Care. Two recommendations are administrative consisting of the provision of administrative support and making the best use of communication tools. The remaining five are on governance, training needs and progressing the development of the next phase of children's palliative care, including priority setting.

Conclusion

This research has shown that the three key elements of the CPCP have been welcomed by parents, front line services and stakeholders. The initiatives have improved the level and quality of care being provided to children with life-limiting conditions and their families. The education component has also been widely accepted by the full range of healthcare staff who provide care for this cohort of children and their families. The CPCP has also had a very positive impact on the implementation of national policy. The report identifies challenges and areas for improvement and draws on the collective evidence gathered to provide a series of recommendations which will enable the setting of key priorities for the future.

This document is a summary of the full Evaluation Report which is available from Sheilagh.reaper-reynolds@hse.ie

SECTION ONE

Introduction and background

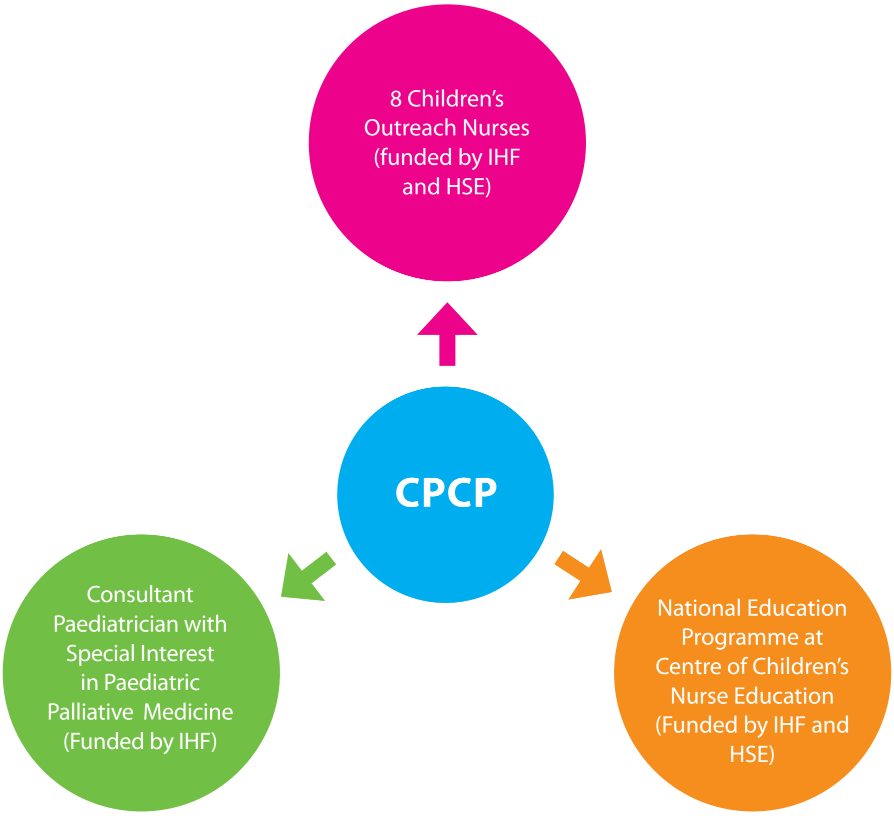
SECTION ONE INTRODUCTION AND BACKGROUND

In 2001, the National Advisory Committee on Palliative Care report highlighted the need for a review of paediatric palliative care services in Ireland. Subsequently, a national children's palliative care needs assessment, *A Palliative Care Needs Assessment for Children*, was undertaken in partnership with the IHF and DOHC, and published in September 2005 (DOHC 2005). Arising from the report, the DOHC established a children's palliative care committee to develop a policy for children's palliative care for the future. Its report, *Palliative Care for Children with Life-Limiting Conditions in Ireland, A National Policy*, was published in 2009 (DOHC 2009). The NDC for Children's Palliative Care was subsequently established by the HSE with a remit to implement the recommendations of national policy.

Based on the report's recommendations, a programme of work, called the *Children's Palliative Care Programme* (CPCP), was established jointly by the HSE and the IHF. In short, the programme includes the:

- appointment of a Consultant Paediatrician with a Special Interest in Paediatric Palliative Medicine (Consultant PPPM)
- appointment of eight Children's Outreach Nurses (CONs)
- development of a national education programme (Level A and Level B), based in OLCHC, to provide basic and intermediate levels of education in paediatric palliative care (Figure 1).

Figure 1: New services introduced as part of the CPCP



The CPCP aims to add value to existing services so that children with LLCs can be cared for as far as possible in the home setting. The programme has four initial expected outcomes, set out in Box 1 below.

BOX 1: The four anticipated outcomes of the CPCP

CPCP anticipated outcomes
1. Improved quality of life for children with LLC and their families.
2. Improved co-ordination of services to children with LLCS so they can be cared for in the home setting as far as possible.
3. An improved children's palliative care sector as a whole with increased education on children's palliative care and appropriate engagement of the CONs in the provision of education / training.
4. Increased awareness of children's palliative care and of the new service in both the public arena and health sector.

This summary report presents key findings from the full report[1] on the final summative evaluation of the CPCP.

1.1 Key messages from the international literature

Life-limiting conditions in a child "*are those for which there is no reasonable hope of cure and from which children or young people will die*" (Together for Short Lives 2013). There are over 300 conditions that are described as life-limiting, which can be grouped according to four categories (known as the ACT categories) that outline the types of illness trajectory which will require children's palliative care provision (Table 1).

Table 1: Together for Short Lives Categories of LLCs (ACT categories)	
Category 1	LLCs for which curative treatment may be feasible but can fail. Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. *Examples: cancer, irreversible organ failures of heart, liver, kidney.*
Category 2	Conditions were premature death is inevitable. There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. *Examples: cystic fibrosis, Duchenne muscular dystrophy.*
Category 3	Progressive conditions without curative treatment options. Treatment is exclusively palliative and may commonly extend over many years. *Examples: Batten disease, mucopolysaccharidoses.*
Category 4	Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death. *Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event or episode.*

Children and young people (hereafter, children) diagnosed with a LLC share the prognosis of a shortened life-expectancy (Hain et al 2011). Most children diagnosed with a LLC will spend some time is hospital (Hain et al 2011), but with advances in portable medical technologies and improved the long-term management of children with LLCs, the preferred location of care is now the home, where children are cared for by their parents (JN Research 2013).

In 2013, the findings from the first in-depth English regional needs assessment of children with LLCs and their families, *The Big Study* (Hunt et al 2013) were published. Although the study highlighted examples of excellent care and some very positive feedback from families, many unmet needs were identified. Families highlighted

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[1] A copy of the full report is available by emailing Sheilagh.Reaper-Reynolds@hse.ie

the beneficial role of a named contact person, who contributed greatly to their coordination. Whilst some parents commented very positively on children's hospice services, respite and end-of-life care were routinely described as inadequate. Collaboration between services was often felt to be fragmented, and although some examples of well-coordinated community care were identified, a perceived lack of multi-disciplinary and multi-agency working with service users was seen as a pivotal failing.

The findings of *The Big Study* are consistent with the wider international and national evidence (Courtney 2014; Craig et al 2007; Fraser et al 2015; Helen & Douglas House 2011; JN Research 2013; Nicholl 2007, 2008), which collectively highlight current limitations in the availability and delivery of palliative care services for children with LLCs. These include:

- inequity in availability and quality of care provision (geographically, and by diagnosis)
- deficits in agreed (common) assessment process, pathways and best practice
- lack of coordinated provision across public, voluntary and private sectors
- lack of consistency in the availability and role of 'key workers'
- a need for enhanced community-based care, including 'out of hours' access
- families having to 'fight' for essential services
- limited patient choice concerning the place of care, including at end-of-life
- inadequate respite provision
- a need for families to travel long distances for essential services
- a need for better management of the transition between children's and adult services.

This collective evidence also points to a number of components of care that seem to make a strong contribution to (perceived) effectiveness of services provided to children with LLCs. These include:

- being able to care for a child at home, including at the end-of-life
- having access to flexible respite care, whether in a family's own home or another setting
- access to a key worker / care co-ordinator who is able to help families navigate the system and secure access to relevant services and resources in a timely manner
- well-coordinated community care, in which different services and sectors (are seen to) communicate and collaborate with one another
- well-coordinated and timely transitions between hospital, hospice and home.

1.2 Prevalence of life-limiting conditions in children in Ireland

In Ireland, in 2014 there were 396 deaths in those aged under 20 years old, from which 346 were due to non-accidental causes (CSO 2014). Official statistics do not record cause of death according to the ACT categories. Notably, deaths in the first year of life constituted nearly two thirds of deaths in children (62%, 248/396).

Current national policy, planning of services and allocation of resources is based on data from the 2005 needs assessment (DOHC 2005). In the assessment, the then estimated UK prevalence rate of 12:10,000 per child population was applied to the Irish census data for 2001, to estimate the number of children living with a life-limiting condition in Ireland at 1,369. At the time, this was known to be an underestimation. Since then a new prevalence estimate has been made, using more up-to-date and robust data from the UK in combination with the 2011 Irish census data (Ling et al 2014). Using a prevalence rate of 32:10,000 per child population, it is now estimated that there are 3,840 children in Ireland living with a life-limiting condition. This is almost 3 times the estimate currently used in the national policy, and being used to inform the development, planning and funding of children's palliative care. Ling et al (2014) argue that the new estimated prevalence indicates the need to revisit the 2009 national policy. The need for such a review is supported by the NDC, which was established to oversee the implementation of the recommendations arising out of the 2009 national policy document. Certainly, the significantly increased estimated prevalence needs to be taken into consideration by policy makers, planners and providers in any decision-making concerning future service development.

1.3 Children's Palliative Care

Palliative care for children with LLCs has been defined as *"an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement"* (Together for Short Lives 2013). Children's palliative care is therefore provided to a child and family not just in the dying stages, but in the weeks, months and years before a child's death.

Children's palliative care involves a multitude of professional and other care-givers, working in a wide range of different services and organisations in health, social care, education and the voluntary sectors, all of whom require specific training and expertise to deal with the unique set of needs of children and their families (Hunt et al 2013). Co-ordinated, collaborative working across these services and organisations is essential to meet the holistic needs of the child and family (Craig et al 2007). As parents typically become their child's primary carer, often over prolonged periods of time, it is extremely important that they receive the care and support they need, including access to in and out of home respite (Skone et al 2015).

Over the recent past children's palliative care has been developing as a sub-speciality, reflected in the increasing policy focus across the UK and Ireland on driving up the quality of services providing care to children and support to their families (see, for example: Dept. of Health 2008; DOHC 2009; Scottish Government 2012).

As outlined in the introduction, children's palliative care in Ireland over the past seven years has been underpinned by policy set out in *Palliative Care for Children with Life-Limiting Conditions in Ireland, A National Policy* (2009). Current service provision in Ireland can include a range of services. Care is usually led or initiated by hospital based paediatric departments, working alongside community adult palliative care teams (or "home care" teams). As there is an absence of dedicated specialist community paediatric palliative care teams, health care professionals working within existing home care teams often provide end-of-life care to children and families within the community setting. The GP acts as the primary health care provider for all children in the community and, depending on the child's condition, care may also involve: public health nursing, disability services, dietetics, psychology, occupational therapy, physiotherapy and speech therapy, social work, home care packages and specialist or mainstream educational services.

Notably, the standard of paediatric palliative care knowledge and professional expertise possessed by providers working in any of these services can vary. Historically, the voluntary sector in Ireland has played a significant role in the provision of children's palliative care. This role includes: home nursing, respite and liaison services (the Jack and Jill Foundation); respite and hospice services including an evolving hospice at home service (LauraLynn Children's Hospice); night nursing to enable children to be cared for and to die at home (Irish Cancer Society and the IHF); and numerous locally based charities which provide valuable hardship funds and other supports.

SECTION TWO

The evaluation of the CPCP

SECTION TWO THE EVALUATION OF THE CPCP

In 2014 the DOHC, HSE and IHF commissioned an independent evaluation of the CPCP. The three aims of the overall evaluation were:

1. To evaluate the inputs, outputs, progress and where possible outcomes of the CPCP
2. To review the extent to which the programme is operating as a national service in terms of coverage and coordination
3. To assess the contribution of the CPCP towards the implementation of the *Palliative Care for Children with Life-limiting Conditions in Ireland–A National Policy* (DOHC 2009).

This report presents, in summary, the final summative evaluation of the CPCP.[2] The evaluation involved:

1. describing the services delivered as part of the CPCP
2. exploring the process of delivering the three services
3. evaluating the perceived impact of the programme
4. assessing the contribution of the CPCP towards the implementation of national policy as in *Palliative Care for Children with Life-limiting Conditions in Ireland – A National Policy* (DOHC 2009).

The paper concludes by drawing on the collective evidence to make a series of recommendations for the development of the CPCP.

2.1 Outline of overall evaluation design

This section presents a brief overview of the evaluation design and conduct. Full details are presented in the full report. The evaluation was conducted over 24 months and involved three distinct phases. It employed a mixed methods design, involving self-completion surveys (online and postal), and interviews (individual and focus group) to capture the range of views and experiences of different stakeholders (parents, service providers, funders and policy makers). Box 2 provides an overview of activities undertaken during the first two phases of the research.

BOX 2: Summary of Phase 1 and Phase 2 activities

Phase One: Familiarisation with the CPCP	Phase Two: Process Evaluation
Review of national and international research literature Review of relevant evaluation designs and instruments Application for research ethical approval for fieldwork to be conducted in Phase 2 and Phase 3 Consultation with key informants and key stakeholders (n=19 interviews) Development of Logic Model	Survey of service providers N=112 (n=80 with experience of the CON & Consultant PPPM services) Interviews or focus groups with N=49 key stakeholders: • CPCP personnel • ADON managers and Champion Consultants • Funders (IHF, DOH) and members of the NDC • Service providers in children's palliative care (statutory and voluntary sector providers)

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[2] The findings from an earlier process evaluation, including the Logic Model (LM) for the CPCP, are presented in a separate report, Evaluation of the CPCP, Interim Report, March 2015.

Phase Three, which commenced in September 2015, sought to capture progress on all four anticipated outcomes of the programme. Box 3 provides summary information on the activities and reach of Phase 3.

BOX 3: Summary of Phase 3 activities

Phase 3: Summative Evaluation

- E-survey of CONs (n=8) and Consultant PPPM team at OLCHC (n=3)
- E-survey of service providers (Phase 2: n=112; Phase 3: n=44)
- E-Survey of parents (n=49) (22 parents bereaved; 27 parents currently caring for living children)
- Interviews / focus groups with service providers (n=20)
- Interviews with the CON ADONs and Champion Consultants (n=9)
- Interviews with CPCP key stakeholders (n=3)
- Interviews with Level A & Level B education programme training providers (n=1)
- Secondary analysis of Level A and Level B education programme participant feedback
- Interviews with parents (n=12) (5 face-to face; 7 telephone) (10 parents bereaved; 2 parents of living children)

Prior to fieldwork with parents and service providers the study secured research ethics approval.[3] As the evaluation addressed a particularly sensitive issue, an extensive range of measures were adopted to minimize and alleviate any distress caused to parents. The preservation of confidentiality and anonymity were paramount and was observed at all times.

2.2 Limitations of the evaluation

Four limitations of the evaluation are acknowledged. Firstly, participants self-selected to complete the questionnaire. Second, the Phase 2 service provider e-survey was dependent on particular individuals, namely service managers, 'cascading' it to colleagues. Third, consultation with children and young people was beyond the scope of the evaluation. Finally, the focus of the evaluation was the initiatives funded through this particular programme of work. However, it must be acknowledged that the Consultant PPPM is supported by two part-time Consultants in Palliative Medicine and three x 0.5 WTE CNSs and it may have been difficult for parents to make a distinction between specific aspects of the service and the service as a whole.

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[3] Research ethics approval for Phase 2 fieldwork with service providers was granted by the Irish College of General Practitioners (ICGP) on the 26th August 2014. Approval for Phase 3 (fieldwork with parents and service providers) was granted by the ICGP on the 17th November 2014 and by the Children's University Hospital, Temple Street, Dublin on the 1st April 2015.

SECTION THREE

Evaluation findings

SECTION THREE EVALUATION FINDINGS

In this summary report we present the key findings from the evaluation which are split into five sections:

1. description of each of the CPCP services
2. the CPCP: the CONs and Consultant PPPM's views and experiences of delivering the services
3. the CPCP: service providers' and parents' perceptions of the services
4. the CPCP: stakeholders' perceptions of the services
5. the CPCP's contribution to progressing the recommendations of the national policy.

3.1 Description of the CPCP

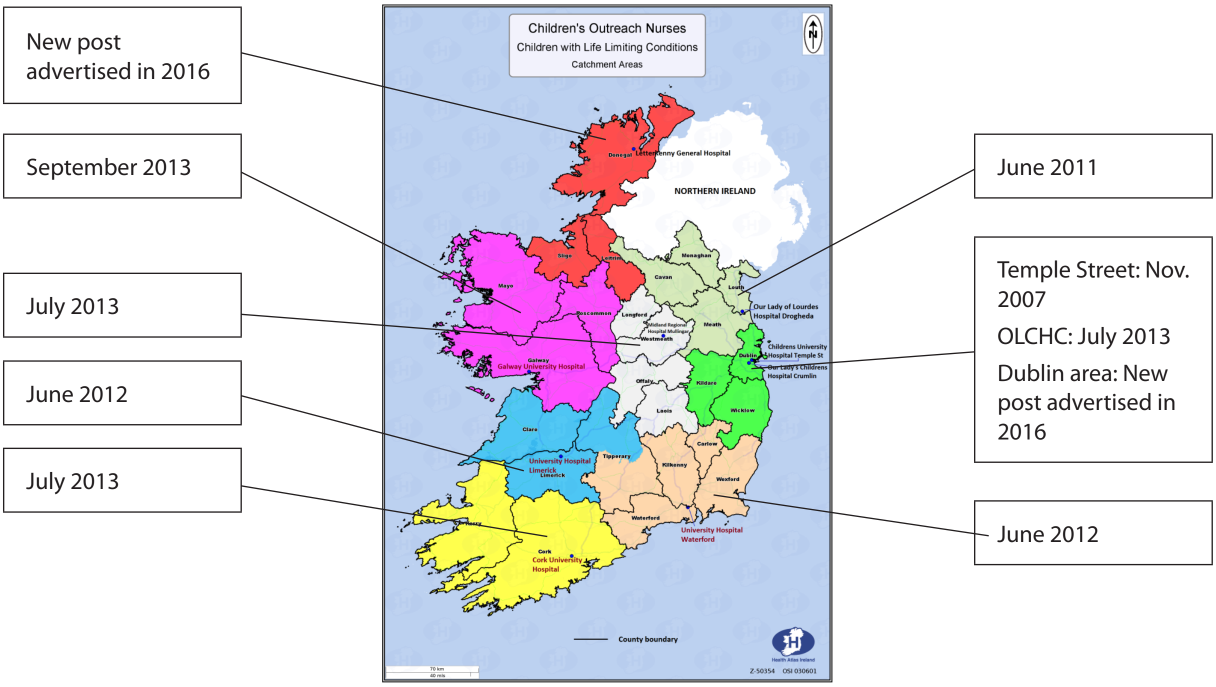
The CPCP is funded jointly by the IHF, and the HSE, with funding guaranteed for up to five years by the IHF. It was implemented in a phased process over the period 2011-2013, overseen by the NDC (see Fig 1 above). Since 2014, the funding of the Consultant PPPM and the existing 8 CONs is gradually being assumed by the HSE.

The programme aims to add value to existing services so that children with LLCs can be cared for as far as possible in the home setting.

3.1.1 The CON service

The CON service currently consists of 8 regionally based CONs who operate throughout most of the country.[4] The CONs were appointed on a phased basis over 2011-2013. Two further appointments have been agreed, with both posts to be funded by the HSE. Figure 2 outlines the regional basis of the current and new posts.

Figure 2: Map of the CON service showing location, region of cover and start date for current and new posts



New post advertised in 2016

September 2013

July 2013

June 2012

July 2013

June 2011

Temple Street: Nov. 2007

OLCHC: July 2013

Dublin area: New post advertised in 2016

June 2012

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[4] A Children's Outreach Nurse was already in place in OLCH prior to the CPCP.

A sub-group of the NDC drafted the *Education and Governance Framework* which guides the work and development of the CON service. A summary of the role and responsibilities of the CONs is outlined in Box 4.

BOX 4: Summary of roles and responsibilities of the CONs

Role and responsibilities of the CONs

1. To plan, implement, deliver and evaluate care for a caseload of children with life-limiting conditions and their families, in collaboration with local healthcare professionals/carers. This role will apply to both acute and community care settings.
2. To facilitate education and training for health and social care professionals in collaboration with relevant stakeholders.
3. To support the collection of data in relation to children with life-limiting conditions.
4. To act as an informed resource and link person for children and family carers and for health and social care professionals involved in the care of children with life-limiting conditions.
5. To link with PHN, Disability Services, Community Children Link Nurses, Adult Specialist Palliative Care Teams and Voluntary organisations. The nurses are also supported by the Children's Palliative Care Clinical Governance and Development Network which was established to ensure best practice, standardisation and coherence within the CON service.

Each CON is based in the paediatric unit within a regional hospital. They are directly supervised by an Assistant Director of Nursing (ADON). Each CON also links with a local 'Champion' Paediatrician (typically known as a 'Champion Consultant'). The Consultant PPPM acts as a further resource and support.

The CON service is a delivered on a weekday basis, with no weekend or evening cover. Currently, there is no formal holiday or sick cover. By September 2015, a total of 478 referrals had been made to the Children's Outreach Nurses since the inception of the service. In December 2015, the CON service was providing support to 267 children and their families. In the same year an average of 33 children were being supported by each CON each month. Table 2 provides a summary of the CON service caseload for 2015.

Table 2: Profile of CON service caseload for 2015

Metric	CON service 2015	
	n	(%)
New cases Total	73	(100)
Number of cases discharged (Total)	**70**	**(100)**
Cases discharged because of death	60	(85.7)
*Cases discharged (other reasons)**	10	(14.3)
Age of new cases (years) (Total)	**73**	**(100)**
Age 5 or under	45	(61.7)
Age 6-9	9	(12.3)
Age 10+	19	(26.0)
ACT category of new cases (Total)	**73**	**(100)**
Category 1	20	(27.4)
Category 2	1	(1.3)
Category 3	19	(26.0)
Category 4	33	(45.2)
Place of death (Total)	**60**	**(100)**
Acute hospital	28	(46.5)
Children's hospice	1	(1.5)
Family home	31	(52)

* Reasons for discharge include: change of diagnosis / improvement; moved out of region; had a transplant; aged over 18

Further analysis of the trends in the average number of children supported by the CON service over the 3 year period 2014-2016 indicates sustained growth. For example, in 2014 the CON service provided support to an average of 214 children each month; in 2015 it was 252; and from January to May in 2016, the average was 279.

3.1.2 The Consultant PPPM service

The Consultant PPPM was appointed in 2011 to lead the specialist paediatric palliative care team already in place at OLCHC. The post was originally funded by the IHF as part of the development of new services under the CPCP; at the time of writing the funding of the post is being taken over by the HSE. The Consultant PPPM is supported by two part-time Consultants in (adult) palliative care and three 0.5 WTE CNSs. Although the Consultant PPPM works as part of this team, only the Consultant post is funded by the IHF (as part of the CPCP). A summary of the roles and responsibilities of the Consultant PPPM is outlined in Box 5.

BOX 5: Role and responsibilities of the Consultant PPPM

Role and responsibilities of the Consultant PPPM	
Clinical care	1. Be responsible for the development of a comprehensive interdisciplinary palliative care service at OLCHC and ultimately at the new paediatric hospital. 2. Provide an advisory service and clinical support to paediatricians and teams responsible for the care of children with LLCs at OLCHC. 3. Provide an advisory service and clinical support to neonatology teams at Coombe Hospital caring for neonates with life-limiting conditions. 4. Act as a further resource and support to the Children's Outreach Nurses.
Research and development	1. Assist in the development and delivery of paediatric palliative care training programmes for healthcare professionals. 2. Develop and lead a research agenda for children's palliative care.
Service development	1. Provide clinical leadership for future development and professional recognition of children's palliative care in Ireland, in hospital and community settings. 2. Be involved in decisions relating to, and the development of, an integrated children's palliative care service.

The Consultant PPPM service is delivered during the working week (Monday to Friday). Unofficial weekend and out of hours support via telephone is offered by the Consultant PPPM and the two part-time adult palliative medicine consultants, who work as part of the team based at OLCHC, on a 'grace and favour' basis.

Table 3: Profile of Consultant PPPM service caseload for 2015

Metric	Consultant PPPM service for 2015
Total number of cases in 2015	220
Total number of cases discharged	76
Cases discharged because of death	67
Cases discharged (other reasons)	9

During 2015, a total of 220 children have received care from the OLCHC team. During this year the service discharged 76 cases (of which 67 were due to death and 9 for other reasons) (Table 3). Analysis in the average monthly number of cases supported by the Consultant PPPM service indicates sustained growth. In 2014, the service provided support to an average of 117 children each month; in 2015 it was 120, and indications are that in 2016 from January to May the average was 145. In 2010, prior to the appointment of the Consultant PPPM, a total of 33 children were referred to the service; in 2014 the number had more than doubled (n=88). Based on the figures for 2015 (n=115), the rate of increase in referrals appears to be maintaining this upward trend.

3.1.3 The Education Programme

The third element of the CPCP is the education programme delivered by the Centre for Children's Nurse Education (CCNE) at OLCHC. This intermediate level education programme delivers two national courses: Level A (one day) and Level B (7 day). At the time of writing this is the only education programme on the care of children with life limiting conditions which is available nationally.[5]

In addition to the Level A and Level B courses, the CCNE also delivers a modified version of the Irish Hospice Foundation funded one day 'Final Journeys' programme to staff at OLCHC, as part of the Hospice Friendly Initiative. Tables 4a to 4c provide an overview of each of the education programmes.

Table 4a: Summary of the Level A education programmes

Programme	Description
Level A	• A one day programme, targeted at nursing staff and allied healthcare professionals who provide care for children LLCs and their families • Aimed at providing an introduction to the principles and practices of a palliative care approach for children with LLCs and their families • Offers NMBI Post Registration Category 1 • Co-ordinated by the CCNE and facilitated by the CONs and members of the OLCHC multi-disciplinary team, supported by the local Centre for Nurse and Midwifery Education • The programme is delivered in each of the CON geographic areas

Table 4b: Summary of the Level B education programmes

Programme	Description
Level B	• Seven day course (delivered over three weeks with 42 classroom contact hours) targeted at nurses and midwives who provide care for children with LLCs and their families • Aims to provide participants with opportunities to acquire knowledge to provide supportive palliative care for children with LLCs and their families • Aligned with the Palliative Care Competency Framework[1],and is accredited through UCD • Offers NMBI Post Registration Category 1 approval with 5 credits at Level 8 of the NQAI framework • Co-ordinated by the CCNE, delivered by nurse tutors, clinical nurse facilitators, clinical nurse specialists, medical staff and members of the multi-disciplinary team, including the Consultant PPPM • Until 2016 the Level B programme was delivered in Dublin; in 2016, as part of a pilot, the June programme was delivered in Limerick

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[5] A new Level 9 MSc/Post Graduate Diploma specifically dedicated to children's palliative/complex care will commence in NUIG in Sept 2016.

[1] https://www.hse.ie/eng/about/Who/clinical/natclinprog/palliativecareprogramme/Resources/competencyframework.pdf

Since its inception, a total of 998 participants have completed the Level A course. Some participants attend this course in their own time (i.e. without study leave). To date, 120 staff have attended the seven day Level B course.

Table 4c: Summary of the Final Journeys Programme and the Consultant PPPM education role

Programme	Description
Final Journeys	• A one day adaptation of the adult focused Hospice Friendly Hospital programme available to all staff working in OLCHC • Designed to enhance the quality of the interactions between children at end-of-life, their families and hospital staff • Delivered using a range of methods, including group work, discussion, scenarios, role play and facilitator presentation
Consultant PPPM role in education and training	• The Specialist Registrar (SpR) training in Adult Palliative Medicine • Bedside teaching and grand rounds within OLCHC and The Coombe Women & Infants University Hospital • Contributing to Level A, Level B, and Final Journey courses • Undergraduate teaching of final year medical students • Multidisciplinary meetings and clinical meetings • Presentations at local and international conferences, masterclasses and workshops, and as part of postgraduate courses at two universities

To date, the OLCHC adaptation of the Irish Hospice funded Final Journeys programme has been attended by medical social workers, physiotherapists and occupational therapists, and administration staff. The experience of the course co-ordinator is that it is difficult to get doctors to attend, although the content of the course would be very relevant to their practice.

3.2 The CPCP: the CONs and Consultant PPPM's views and experiences of delivering the services

During the course of the different phases of the evaluation, all personnel delivering the three CPCP services were interviewed. At the end of the evaluation, all of the CONs and the Consultant PPPM also completed an anonymised online survey to present their reflections of delivering the two services.

3.2.1 The views and experiences of the CONs

This section presents a summary of the key messages from the interviews and survey with the CONs. The data is grouped according to what is working well (i.e. enablers of service delivery), challenges to the services (i.e. barriers to service delivery) and what is required to further improve the services. Tables 5a and 5b summarise the key messages.

Table 5a: CONs reflections on service delivery	
	CONs' reflections
Service delivery enablers	• Peer support • Support from ADON and Champion Consultant • Cooperation and support of fellow healthcare professionals • Supportive paediatrician and health professionals • Support from National Lead for Palliative Care • Clinical Governance and Development Network • CPD days • Practical support such as email access on phone, parking facilities in hospital • Clinical supervision • The relationships with families
Barriers to the delivery of the service	• Increasing demand on the service • Evolving service – still some grey areas • Large geographic areas with time spent travelling from family to family • Inequity in service (areas without a CON and high density areas - additional posts are planned) • Working across counties and / or hospital boundaries • Sharing information – no common network – data protection o No flagging system to alert CON child has been admitted to hospital or child has died over a weekend • No national co-ordinator • Gaps in, or lack of availability of, essential services for families e.g. nursing hours, paediatric nurses to provide nursing support, respite care, access to equipment and supplies • Inequitable provision of bereavement services for families depending on geography

The opportunity for continuing professional development, shared learning from peer support days, and continued work on implementation of best practice were highlighted as important enablers for the delivery of the service. The CONs valued the strong support of the paediatric medical and nursing teams, from whom a clear appreciation of the service was evident in stakeholder interviews.

As a consultant, I have huge confidence in the CON, which is very reassuring in terms of the care of these children and their families. Coordination of information between all services involved, I feel, has streamlined the care of the child.

While support from colleagues in the acute and community services was considered central to the success of the service, it was felt that further promotion of the service at national level would assist with the integration of the service at a local-level, particularly with regard to some of the 'off-base' hospitals and community services.

As might be expected, the positive experience of delivering the service and working with families (and colleagues) was valued by the CONs and understood to be a key factor in the success of the service. A recurrent theme was the importance of providing a 'child-centred' service, combined with building positive relationships with families to provide more holistic care. Providing outpatient appointments that helped prevent subsequent hospital admission, securing advice on medications, and co-ordinating community services were all viewed as making a profound difference for families.

Throughout the interviews the CONs described a number of barriers to the effective discharge of the service. A recurrent theme focused on deficits and geographical variation in some services, which often limit the effectiveness of the CON's coordinator role and provision of support to families. Examples included limitations in the availability of care packages, skilled paediatric nurses to provide home nursing and respite care, and equipment and other essential supplies. All such issues were echoed in interviews with parents.

A lack of ideal care was particularly felt in relation to bereavement support for families. Whilst the CONs provide some bereavement support, the frequency of contact with the family is often limited. The group highlighted the inadequacy of bereavement and counselling services in many areas, along with the barriers families often experience in accessing such services (e.g. long distances to travel and waiting lists).

In addition to describing the benefits derived from the existing governance and operational structures underpinning the CON service, the CONs suggested a number of potential enhancements (Table 5b).

Table 5b: CONs' recommendations for improvements to the CON service

	CONs' reflections

Recommendations for improvements to the CON service	• A more defined induction programme and a specific needs based education programme for the CONs
	• Structured approach to supervision
	• Financial support for attending conferences/ relevant courses
	• Administrative / practical support (e.g. secretarial support, email access on phone/parking facilities)
	• Enhanced National Clinical Governance and Development Network
	• Appointment of a national coordinator
	  o to focus on service development
	  o to develop guidelines and standards
	  o protocols for national engagement with other service providers
	• Appointment of additional CONs
	  o to improve access for families
	  o to reduce the work burden and to provide out of hours cover
	• Further support at national level to promote the service as a resource
	  o more information about the service from national level to community based groups
	  o further collaboration with the voluntary sector
	  o further support and buy-in from medical/ nursing staff in the acute hospital setting

There was a strong consensus amongst the CONs on the need for a national co-ordinator[6] to provide structured support and guidance for the entire service. The co-ordinator was considered to play a crucial role in the representation, coordination and planning of the service operationally and strategically, both nationally and locally. The CONs also recommended increased engagement and support from the National Clinical Governance and Development Network as essential to the future development of the service, a consideration shared by one of the Champion Consultants.

'It's important that the Champions are involved at some level in service planning and development and that they are in fairly regular contact with the overall paediatric service.'

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[6] In 2015, a national co-ordinator was appointed on a 0.5WTE basis, who was in post for a short time before taking up another post.

The need for a structured approach to the facilitation of a nationally agreed framework for individual clinical supervision was stressed. Following an initial period of funding by the IHF, the importance of facilitating individual supervision sessions for the CONs had not been recognised in most regions.

As the name would suggest, the role of the outreach nurse requires a robust infra-structure to support effective working. In this regard, the CONs highlighted the importance of additional practical resources such as improved information systems and administrative support to help with the discharge of the role and to maximise the time available for children and their families.

Throughout the interviews it was evident that CONs provide care and support to large numbers of children. In doing so, they described routinely working beyond their designated hours, as well as being available to respond to unplanned crisis situations. The evident increase in service demand and the inequity of service provision in areas of high density and geographic spread was considered a clear indication of the urgent need for an increase in CON numbers, a need that was further endorsed by the ADON/Champion Consultant group which described a '*hugely busy'* CON service with an '*excessive workload'* that evidently needed to be addressed.

Over the course of the evaluation, the CONs described a number of pilot initiatives currently being undertaken by individual CONs or by the CON service as a whole, in collaboration with other agencies. These were considered to have made an important contribution to improving the palliative care offered to children with LLCs and their families. Table 6, below, presents a summary of some of this work.

Table 6: Examples of pilot initiatives

'Our Story' Folder	The 'Our Story' parent held folder, a national initiative developed by the IAPC Children's Palliative Special Interest Group[7] acts as a communication tool between the parent and different service providers. It holds key information relating to the child, clinical practice guidelines and specific care directives from the child's multidisciplinary team, including Advance Care Plans. Parents are encouraged to bring the folder to outpatient appointments and hospital admissions. This initiative, finically supported by the HSE, IAPC, Jack & Jill, LauraLynn and the IHF is implemented by the CONs, Jack & Jill and LauraLynn and its use is due to be audited later in 2017.
'My Story' parent-held care plan	The CON group commenced a pilot of the use of a newly developed 'My Story' parent-led care plan which is being used successfully in the many areas of the country where there is not yet an agreed system for HSE care plans for children in the home. This plan is also kept in the child's 'Our Story' folder.
Information sharing in local hospital	In one hospital the CON created a folder on an IT network drive to hold information on all children linked with the CON, including information on advance care planning. This folder can be viewed by healthcare professionals within the hospital, which is particularly helpful when a critically ill child with a LLC attends the Emergency Department.
Collaborative work with National Ambulance Service (NAS)	Collaborative work between the CONs and the NAS has led to the development of a Hospital-Ambulance services communication pathway, and a document that outlines the appropriate treatment measures agreed for the child – this is named an Ambulance Care Directive (ACD). The child's home address and alternative places of care are flagged on the NAS central computer system, thus providing crews with advance notification that an ACD is in place. The ACD has been piloted and evaluated in the North East and South East regions and a national adoption of the system is proposed.

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[7] The Our Story is a collaborative partnership between the CONs, Our Lady's Children's Hospital Crumlin, LauraLynn, and the Jack and Jill Foundation, with support from the Irish Hospice Foundation and IAPC.

The 'Our Story' folder is an example of collaborative work between the voluntary and statutory services that has helped to improve communication between families and services. The folder, along with the introduction of the 'My Story' care plan and the communication pathway with the NAS, were all considered capable of making an important contribution to the timely sharing of information between services, continuity of children's care and, very importantly, a reduction in the burden of repeated conversations for parents regarding their child's health care needs.

In many regions the CONs work collaboratively with their local hospital End of Life Committees and have developed advance care discussion documents and bereavement support literature. Their active involvement in the organisation of hospital based memorial services and bereavement support was praised by parents during interviews.

3.2.2 The views and experiences of the Consultant PPPM

In general, the views of the Consultant PPPM concerning the enablers and barriers to the delivery of the service echo those of the CONs (Table 7 provides a summary of the team's views on the added value of the post and suggestions for improvements). The Consultant PPPM perceived the new post as providing children with LLCs with improved access to paediatric palliative care in three main ways. Firstly, within OLCHC, through the direct provision of care. Secondly, in other paediatric hospital and community settings, through the provision of support and advice to colleagues working across Ireland. Finally, helping to organise care when children are being discharged back home, as they are well positioned to liaise with community sector colleagues to implement the transition.

We are able to do the links with community and suggest that going home is a possibility where people [paediatric teams] might be a bit nervous about even thinking of going home or not knowing who to talk to in the community…

All such work can be seen to have significantly improved equity of care as it means that all children, irrespective of where they live or are being cared for, have access to an expert paediatric palliative care input.

The role was understood as increasingly embedded within existing service provision within OLCHC, working closely with colleagues from a wide range of paediatric specialities including, for example, cardiology, gastrointestinal medicine and neurology. In this context, the expert contribution of the Consultant PPPM in the symptom management of children was particularly valued by colleagues (as evidenced by their feedback in the surveys undertaken in Phase 2 and Phase 3). Since the appointment of the Consultant PPPM and day-to-day presence on the wards, at meetings etc., the visibility of the palliative care team based at OLCHC has increased significantly. This enhanced visibility is reflected in the ongoing increased referrals to the service.

As stated above, a core component of the Consultant PPPM role involves the provision of advice and guidance to colleagues working elsewhere. Much of this advice is provided over the phone. Although the provision of telephone support to colleagues was considered to be a positive and much needed service development, a governance concern was raised within the OLCHC team relating to a degree of clinical vulnerability caused by not having actual sight of the children about whom advice is being provided.

Table 7: Consultant PPPM and OLCHC team's reflections on service delivery	
OLCHC team's reflections	
Perceived added value of the Consultant PPPM post to children with LLCs	• Improved access to palliative care for children with LLCs • Improved organisation of services and improved quality of care • Paediatrician with specialist training available for advice o Availability on site at OLCHC to review referrals as needed o Availability to attend MDT meetings within OLCHC: therefore, increased referrals to the service • Increased awareness of paediatric palliative care among paediatricians through lectures and education • Increased availability of palliative care support for the paediatricians and also community adult palliative care teams • Availability for the perinatal service at The Coombe • Recognition within the hospital, medical/nursing/paramedical population of specialist palliative care • Involvement in education and training in paediatric palliative care
Suggested improvements to the service	• Appointing at least one but possibly two more consultants • Appointing more CNS in palliative medicine • More secretarial and support staff

Although a majority of the work of the Consultant PPPM and the OLCHC team is directly clinical, they make an important contribution to aiding advance care planning. Typically, the Consultant will be asked to help facilitate discussions being undertaken with parents.

Sometimes they [a child's consultant] refer specifically to an advance care planning discussion which may not be totally appropriate because they know the child best and I'm very happy to sit in with them but I don't think I should lead it if I don't know the family because it is a very difficult area…

The Consultant PPPM firmly supported the idea of advance care planning for children with LLCs and of the benefits it brings by providing explicit instruction concerning appropriate care. In this context, the Consultant highlighted the problems a lack of planning carries for professionals working in community and hospital settings who care for children in the palliative phase, especially ambulance crews and staff working in A&E who are called upon to provide emergency care.

In all of the above, a strong theme emerged concerning the contribution of the Consultant PPPM to supporting professional colleagues in the emotionally and clinically difficult task of providing paediatric palliative care. This was also evidenced in the feedback received from service providers in the Phase 2 and Phase 3 surveys. This support is delivered in a range of different ways, including the relatively straightforward provision of information and guidance, contributing to advance care planning and, more fundamentally, acting as a source of reassurance and confidence-building.

As described in Section 3.1.3, above, the Consultant PPPM has extensive involvement in education and training relating to children's palliative care. In addition, in terms of raising awareness of children's palliative care, the Consultant PPPM and the OLCHC team have been involved in the development of a range of documentation that is now routinely shared with different departments and specialties. This includes, for example, the Resuscitation Treatment Agreement Form, which was considered by the Consultant PPPM to not only be an extremely useful clinical tool, but also to have raised the profile of the OLCHC team within the hospital and beyond. Similarly, ongoing research and audit activity was understood to have widened appreciation of both the team and also of children's palliative care more generally.

It's an integral part of the job and it's so important in a fledging speciality like children's palliative care.

In addition to these roles, the Consultant PPPM also regularly undertakes de-briefing of colleagues who can telephone to simply talk through particularly difficult cases. The Consultant PPPM highlighted a lack of similar support and supervision in relation to the Consultant post, as well as the wider OLCHC palliative care team, and suggested that such supervision would be of immense value.

Increasing demand as well as the current absence of formal out-of-hours cover were understood to point to the need for a second Consultant PPPM to ensure that the current and anticipated workload can be managed effectively. The perceived need for additional staff was not limited to a second Consultant PPPM; a need for additional CNSs was also highlighted, again based on the current and anticipated OLCHC team workload.

3.3 The CPCP: perceptions of service providers and parents

Service providers' and parents' views and experiences of the new services were explored through self-completion questionnaires and during individual interviews (please see the full report for a more detailed description of the findings from the evaluation). Overall, the collective evidence from the data confirms that the new services introduced as part of the CPCP are perceived by both parents and service providers as adding significant value to current provision for children with life-limiting conditions and their families. Both the Consultant PPPM and CON service were viewed by many as having improved the quality of care available to children with LLCs. Indeed, both were regularly described as operating well beyond expectations.

The palliative care team in the hospital setting is extremely important. It is so important to have their expertise in the acute sudden death or compassionate withdrawal of care and also for the more long-term life limiting conditions where a child may live for years. They are instrumental in helping parents come to decisions with compassion and empathy. Their involvement in symptom management ensures the dignity of the child and limits unnecessary pain and suffering on the child and the family. (Service Provider)

[Name of CON] is fantastic at getting information/documentation etc from the hospital. If we are coming into the hospital the CON is great, she will have everything in place - A&E, ambulance etc. If I have any worries I could call on her and she will visit the house. Her efficiency and overall approach. You don't feel you are talking to someone who is doing a job - she comes across as someone who cares. (Parent)

The sections below provide a summary of the key findings from the feedback provided by service providers and parents.

3.3.1 Perceptions of service providers

Overall, there is consistent evidence that the CPCP programme is perceived to be moving towards achieving its anticipated outcomes. Given that the new services are primarily focused on providing child-centred care and improved transitions between hospital and home, participants in the Phase 2 survey perceived greater progress being made towards Outcome 1 (*Improved quality of care for children and their family*) and Outcome 2 (*Improved co-ordination of services for children with LLC so that they can be cared for in the home setting as far as possible*) than towards Outcome 3 (*An improved children's palliative care sector as a whole with increased education on children's palliative care and appropriate engagement of the CONs in the provision of education / training*) and Outcome 4 (*An increased awareness of children's palliative care and the new service in both the public arena and health sector*).

That said, in Phase 3, service providers commented on their enhanced awareness of paediatric palliative care, at least partly based on the increased opportunities for learning (e.g. from the Level A and B courses and from study days, conference presentations, master-classes, MDT meetings, ward rounds, and specialist rotations with the Consultant PPPM). In the Phase 3 survey, a majority of the service providers perceived some or a lot of progress as having been made towards all four outcomes, and provided examples of how the new services have contributed to an improved children's palliative care sector, including in terms of increased awareness of children's palliative care.

Over the three phases of the evaluation there was evidence of a growing appreciation of improvements in the quality of paediatric palliative care. The new nursing and consultant services were perceived by many to be fundamental to this process.

The management of children at the end of life has definitely improved with the introduction of these services. This applies in all cases whether or not the child is cared for at home or in hospital. (Service Provider)

Key messages from the Phase 2 and Phase 3 surveys indicate that service providers perceived:

- improved co-ordination of services for families – more seamless care and support
- improved communication between community and acute settings
- increased child and family focused care
- improved access to expert support (from the Consultant PPPM) for hospital medical teams and community palliative care teams on symptom control and management
- much valued advice and support from the CONs on care of the child
- increased awareness of the specialist services provided by the OLCHC team and the CONs.

However, respondents from both the acute and community sectors noted significant limitations in current health and social care provision, all of which were perceived to impact negatively on the (perceived) effectiveness of the CPCP services. For the CON service these included:

- the continued need for smoother transitions from hospital to community settings, and the need for better communication from hospitals after brief hospital visits
- the need for clear role delineation between the CON and other community based services (e.g. disability services or voluntary organisations providing nursing care)
- the shortage of paediatric nurses to provide nursing care in the home (this is a particular difficulty for older children who can no longer avail of Jack and Jill nursing hours)
- the lack of weekend and evening cover in the CON service
- the need for improved information technology and communication channels to facilitate timely and efficient information sharing
- the increasingly high caseload for both the CONs and Consultant PPPM, with risk of work overload.

It is important to note that many of the concerns related to resource issues rather than problems with the CPCP services themselves. These included:

- a need for a fairer system for allocation of services to families (taking geographic spread into consideration) and additional CONs to meet the increasing demand on the service

- reduced budgets which limited access to essential services (e.g. physiotherapy / occupational therapy)
- limited availability of respite care
- limited availability of bereavement support
- a need for improved access to care packages (e.g. reliable service, continuity of nursing care) and nurses with sufficient training in paediatric care.

Parents need supports, they need a fair system of structured use of resources and management there in with regard to e.g. Home nursing, access to services, support and counselling for child and family. We are at an impasse, we are able to identify what is wrong, but failing to address the problem. (Service Provider)

A number of service providers, although very appreciative of the funding from the IHF to kick-start the CPCP, stressed a need for the HSE to now fund both the Consultant PPPM and the CON posts as this would contribute to security of posts, and to the full integration of the new services into wider service provision. At the time of writing the HSE has indicated that all of the existing posts will be funded by the HSE from June 2016.

Overall, feedback from service providers confirms the new CPCP services as understood to be adding value to current provision for children with life-limiting conditions. In the Phase 3 survey, the appointment of the Consultant PPPM was viewed by many as an important addition to both paediatric and palliative medicine, resulting in increased awareness of the importance of paediatric palliative care.

3.3.2 Perceptions of parents

The fieldwork with parents during Phase 3 provided an important opportunity to learn about their views and experiences of the two new services. Many examples of well co-ordinated, child and family-centred care were provided. Collectively, parents confirmed how the CONs:

- helped with the smooth transition from hospital to home
- provided advice on, and reassurance concerning, the care of their child
- offered support and provided a listening ear
- fast tracked their child to the hospital ward without a need to attend A&E or brief the ambulance staff on the child
- communicated their child's needs to hospital staff
- provided practical advice and information on financial support e.g. medical cards, reduced/free car parking, reduced cost of meals in hospital etc.
- co-ordinated the services in the home
- prepared parents for end-of-life and advance planning (although some parents said they would have liked more direct conversations and preparation)
- offered sensitive care during and after the death of their child.

Some of the parents of the first referrals to the CON service described a number of weaknesses e.g. the referral to the CON service as too late to be helpful to the child and/or family, or the CON/hospital staff as slow to involve the OLCHC palliative care team. A small number viewed the CON service to be duplicating the role of other services, thereby adding to the burden of excessive numbers of carers coming into the home. That said, for a majority of parents, the CON service fulfilled an extremely important service co-ordination, care and support role. Feedback from parents with more recent experience of the services shows that as the CONs have gained experience in their role the service is seen as performing very positively, thereby significantly enhancing the quality of care delivered to their child.

Similar to the international research (described in section 1.1), and to feedback from service providers (described above), parents identified a number of gaps and limitations in current health and social care provision. These included:

- lack of appropriately trained paediatric nurses to provide consistent and reliable nursing care at home
- difficulty in accessing home based respite, particularly for children with complex health care needs who cannot avail of out of home respite
- variations in systems for accessing supplies and equipment e.g. in some areas supplies and equipment are delivered or available for collection locally, but in other areas parents have to drive long distances to collect supplies (sometimes with their child in the car)
- lack of support to care for other children e.g. during school runs etc.
- limited access to services including occupational therapy, physiotherapy etc.
- poorly co-ordinated and signposted transition from children's to adult services
- limited access to counselling and bereavement services
- lack of out of hours provision of the CON service (although many parents described how the CON worked well beyond their formal hours).

Parents need reliable, appropriately trained nurses or carers to relieve the pressure and responsibility. The wrong person caring for your child makes life harder not easier for parents (Parent)

There needs to be someone available to call in case of emergency / last minute admission/illness when own CON is on annual leave, in the evenings or on weekends and bank holidays. It's all well and good providing this service during 'office hours' but unfortunately my child's illness is full time 24/7. (Parent)

Preparation for end-of-life care emerged as a fundamental need for some parents. Whilst some described very good examples of clear guidance and support on advance planning, including advice on resuscitation from the Consultant PPPM and / or the CON, a small number felt there was still some reluctance among medical teams and, in some cases the CON, to approach the subject in a direct manner. This was a theme that also emerged in the interviews with medical staff. Related to this was the importance of smooth transitions from aggressive curative, to palliative care.

The need for robust support after the death of a child was a recurrent theme within the accounts of parents who had experienced bereavement. Some parents described a need for counselling six months to one year after the death of their child, while others described the emptiness of the home. A small number considered that information about counselling or bereavement services and contact from the CON would be helpful after a period of time has elapsed.

Although many of the gaps and needs described by parents are outside of the immediate remit of the CPCP, all such issues were found to impact on the ability of the CONs to effectively discharge their role and responsibilities, and thus impacted on the perceived effectiveness of the service.

3.4 The CPCP: perceptions of key stakeholders

All of the key stakeholders interviewed were certain that the CPCP has significantly improved the care available to children with life-limiting conditions and their families. Collectively, the programme's achievements in, for example, reducing inequities in service provision across Ireland, as well as facilitating parental choice including in terms of the location of the child's care, were highlighted. More strategically, the CPCP was seen as having been instrumental in raising awareness of the importance of children's palliative care, as well as acting as a major impetus to the improvement of relevant health and social care services more generally.

Nonetheless, several areas in which the programme could be enhanced were identified; for the most part these overlapped strongly with those identified by other participants. Otherwise, key stakeholders highlighted more strategically oriented areas such as, for example, a need to develop a communications strategy supported by an explicit programme of work, and a need for the role and responsibilities of the CONs to be underpinned by a targeted programme of compulsory education and training. In terms of how this and other activity could be taken forward, some participants advocated for a reconfigured NDC, to advance the strategic identification of priorities for service development. The important role of the charitable sector in funding the CPCP was widely acknowledged. The fact that such initiatives are likely to continue to be reliant on charitable funding was seen by some as making it extremely important that effective partnership working is supported by explicit communication and branding agreements.

3.5 The CPCP's contribution to progressing the recommendations of the national policy

The third aim of the evaluation was, based on the evidence garnered during the course of the evaluation, to assess the CPCP's contribution to progressing the recommendations of the national policy for children's palliative care (DOHC 2009). The full report presents a detailed assessment. Box 6 presents a summary of progress on the recommendations specifically relevant to the CPCP.

BOX 6: Summary of the CPCP's contribution to progressing the national policy

National policy recommendation	The CPCP contribution to progress
National Policy Recommendation 1: *Children with imminent palliative care needs will be prioritised, especially those nearing the end-of-life.*	The appointment of the CONs and the Consultant PPPM helps to prioritise children with imminent palliative care needs.
National Policy Recommendation 2: *There should be clear assignment and documentation of responsibility within and between clinical teams involved in the care of the child with a life-limiting condition and their family.*	The Education and Governance Framework makes explicit the role and responsibilities of the CON, including the differentiation of their role from other clinical teams involved in the care of the children with LLCs. The National Clinical Governance and Development Network oversee the referral and care pathways and protocols guiding the work of the CON.
National Policy Recommendation 3: *A Consultant Paediatrician with a Special Interest in Paediatric Palliative Medicine should be appointed.*	Funding from IHF (commencing in 2010 for an initial period of 5 years) enabled the post of Consultant PPPM to be established and to subsequently become embedded within children's palliative care.
National Policy Recommendation 4: *A Children's Palliative Care Team should be established at the new National Paediatric Hospital.*	The appointment of the Consultant PPPM and the associated development of the palliative care team in OLCHC has progressed this recommendation.

National policy recommendation	The CPCP contribution to progress
National Policy Recommendation 5: *Regionally based Children's Outreach Nurses for children with life-limiting conditions should be appointed to facilitate service delivery and integration between hospital, community services and specialist palliative care.*	Funding provided by the IHF for an initial period of three years enabled five out of the current eight CON posts to be established. All eight posts are now funded by the HSE or are in the process of being so, and a further two additional CON posts are currently in the process of being appointed.
National Policy Recommendation 6: *Hospice at home teams should be developed by the HSE.*	Although Recommendation six lies outside the scope of the CPCP, the evidence of the evaluation confirms the important contribution made by the CON service in identifying available homecare services and in ensuring that these services are accessed by families and children in a timely manner.
National Policy Recommendation 7*:* *Parents should be actively involved in the decision-making and planning of location of care for their child.*	The CPCP has made an important contribution to helping to ensure that parents are actively involved in decision-making about the location of care for their child by (a) asking parents about their preferences concerning the care of their child; and (b) where possible, supporting their decisions.
National Policy Recommendation 8: *Hospitals should provide an appropriate environment for children with palliative care needs. This includes physical environment – facilities and ward space, and professional environment such as staff education and training.*	The CPCP has made an important contribution to enhancing the knowledge and skills of professionals involved in children's palliative care through the support of Level A and Level B programme. In addition, the appointment of the Consultant PPPM in OLCHC has offered opportunities for further staff education via master-classes and presentations, and formal training (e.g. the SpR rotation).
National Policy Recommendation 9*:* *The Consultant Paediatrician with a Special Interest in Paediatric Palliative Medicine [Consultant PPPM] and the team will act a resource providing support to maternity hospitals and neonatologists.*	The evidence of the evaluation confirms that the Consultant PPPM, with support from the children's palliative care team based at OLCHC, has acted as an extremely effective and much valued and respected source of support for those working within maternity and neonatology.
National Policy Recommendation 10*:* *A range of respite services should be developed for children with life-limiting conditions and palliative care needs.*	Although Recommendation 10 lies outside the scope of the CPCP, the evidence of the evaluation confirms the important contribution made by the CON service in identifying respite services where available and in ensuring that these services are accessed by families and children in a timely manner.
National Policy Recommendation 11: *Bereavement supports for children's palliative care should be developed relative to defined levels and encompass child, adult and family support.*	Although Recommendation 11 lies essentially outside the scope of the CPCP, the CON service is making an important contribution to improving bereavement services for parents of children on their caseloads who have died. This has been achieved in the face of a heavy clinical workload.

National policy recommendation	The CPCP contribution to progress
National Policy Recommendation 12: *In an effort to maintain normality, where possible the child's education should continue for as long as possible.*	The CON service makes an important contribution to enabling children with life-limiting conditions to continue their education for as long as possible by supporting and advising school staff in their care of the child.
National Policy Recommendation 13: *All relevant hospital and community staff should be facilitated to partake in education and training on children's palliative care.*	The CPCP has progressed this recommendation in the Level A and Level B training, which is available to all health care staff. Personnel from the two CPCP clinical services contribute to elements of the courses.
National Policy Recommendation 14: *All health care professionals working in palliative care should have the opportunity to engage in research.*	Recommendation 14 lies outside the scope of the CPCP. However, all personnel involved in the delivery of the CPCP are encouraged and actively supported to engage in research.
National Policy Recommendation 15: *Protocols and standards specifically in relation to palliative care for children should be developed and should be overseen by the National Development Committee on Children's Palliative Care.*	In so far as the National Clinical Governance and Development Network (a group established by the NDC), oversees the development of standards for the CON service, the CPCP has helped to advance Recommendation 15.
National Policy Recommendation 16: *A National Development Committee on children's palliative care should be established.*	All three compomnents of the CPCP are represented on the NDC.
National Policy Recommendation 17: *Data on children living with and dying from life-limiting conditions should be collected by the HSE.*	A Minimum Dataset (MDS) has been developed; this includes data returned by the CON and Consultant PPPM services.
National Policy Recommendation 18: *The HSE and the voluntary agencies should continue to develop closer working relationships around caring for children with life-limiting conditions.*	The CPCP has made an important contribution to the development of closer working relationships between the HSE and voluntary organisations. Accordingly, through their work in coordinating services for children and families, the CONs liaise and collaborate with a range of agencies, and a number of joint initiatives have been developed. In addition, several voluntary organisations participate in the NDC, including the IHF, Jack and Jill and LauraLynn. That said, challenges in shared understanding and discharge of respective roles and responsibilities on the ground were identified by the evaluation. In this context, the lessons to be learnt from experiences of joint working to date are of considerable value in suggesting mechanisms and processes to be developed to underpin more effective collaboration.

National policy recommendation	The CPCP contribution to progress
National Policy Recommendation 19: *The supply and demand for staff should be examined together with the existing and any additional training requirements which should be met by the education systems at undergraduate and postgraduate level.*	Recommendation 19 lies outside the scope of the CPCP. However, the NDC has advocated for a workforce plan to be developed. From September 2016, a Masters / Postgraduate Diploma in Health Sciences (Children's Palliative / Complex Care) will commence at NUIG / UCD.

Taken overall, the evidence arising from this evaluation demonstrates that the CPCP is playing a major role in ensuring that the national policy recommendations are being taken forward. In some cases, the CPCP directly underpins progress; in other cases, its contribution is indirect but no less important.

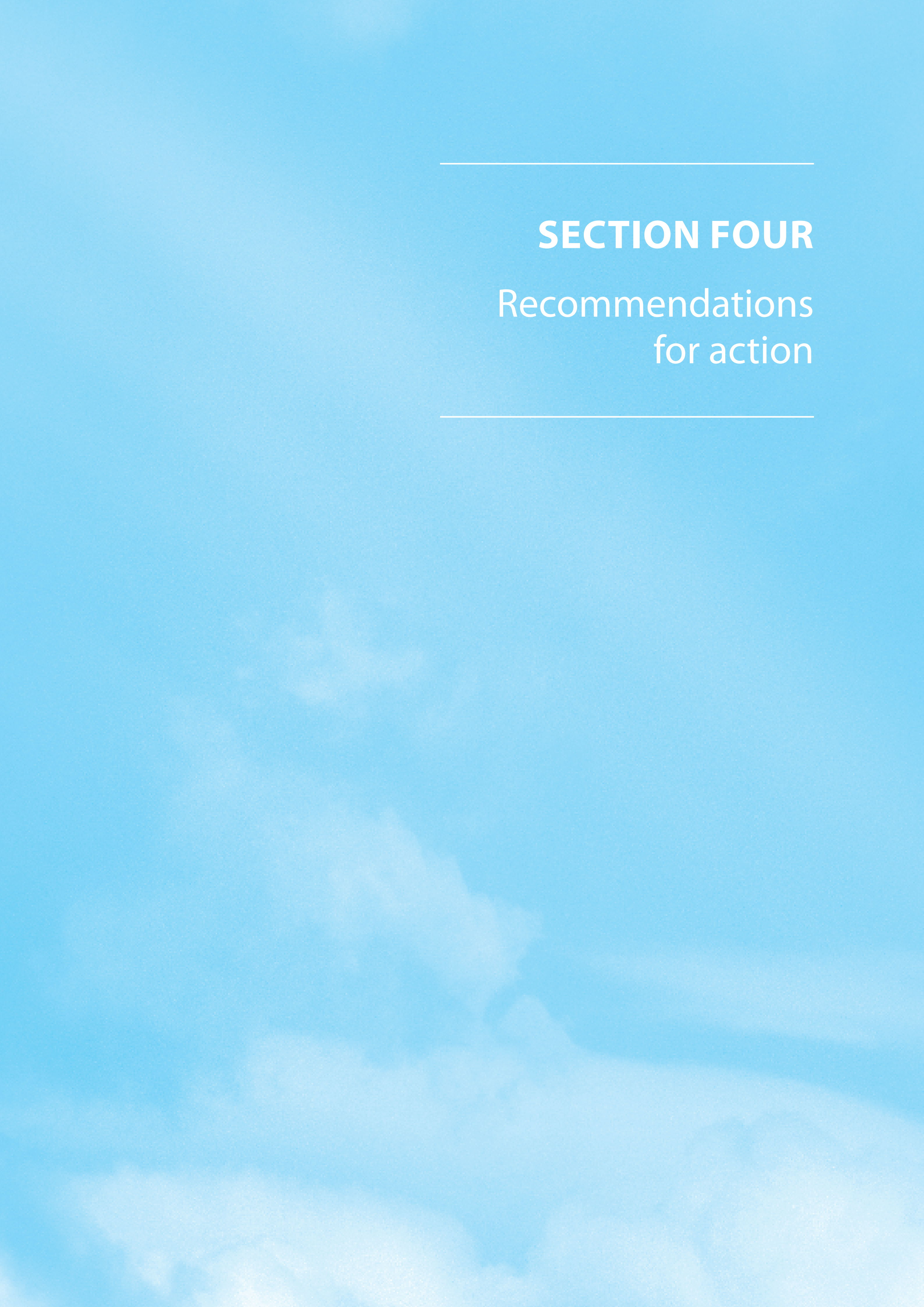
3.6 Summary of the Finding from Summative Evaluation of the CPCP

Table 8, below, presents a summary of the evidence gleaned from each phase of the evaluation grouped by the CPCP anticipated outcome. As highlighted above, the collective evidence from this two year evaluation confirms that the new services introduced as part of the CPCP are widely understood to be adding significant value to current service provision for children with life-limiting conditions and their families.

Table 8: Summary of the collective evidence of the evaluation of the CPCP

Outcome	Commentary
Improved quality of life for children and their families.	The feedback from parents indicates that the introduction of the CON service has improved the quality of life of children and parents in a wide range of ways including, for example, facilitating the home-hospital-home transition, securing resources and equipment for children, and helping parents in their role as primary carers in the home setting. The Consultant PPPM was also considered to contribute to an improved quality of life by, for example, providing expert advice and support in symptom management. However, parents identified ongoing support needs important to their and their child's quality of life, which included access to high quality and consistent nursing hours, availability of respite, and improved access to equipment and supplies. Service providers also perceived the CON service and Consultant PPPM as improving the quality of life of children and their families in ways similar to those identified above. Some service providers perceived an overlap or duplication in role, considered to add to the burden of care for parents. Overall, the new services were perceived by both parents and service providers to add significant value to current service provision for children with life-limiting conditions and their families.

Table 8: Summary of the collective evidence of the evaluation of the CPCP	
Outcome	**Commentary**
Improved co-ordination of services to children with LLCs so they can be cared for in the home setting as far as possible.	One of the recurrent themes of the evaluation was the immensely valuable co-ordinating role of the CONs. The Consultant PPPM service was also seen as helping to co-ordinate services, particularly in the run-up to discharge from hospital. Both parents and service providers identified the co-ordinating role as one of the most important strengths of the new services. Having one 'go-to' person (a CON), with experience in paediatric nursing, complex care and of the health and social care system, was consistently described by parents as greatly easing their burden of care. The CONs were viewed by service providers as offering parents important practical support in accessing and co-ordinating services, especially during difficult periods. Both parents and service providers were keenly aware that all such support significantly enhanced the possibilities of a child being able to remain at home. Again, the Consultant PPPM service was also understood to play an important role in this regard, primarily through the provision of expert advice and support to community sector providers. However, both parents and service providers acknowledged that the overall effectiveness of the CON service is very much dependent on the health and social care services in place, and which they can access. A need for improved information sharing systems between the different sectors of care was also identified as a priority.
An improved children's palliative care sector with increased education on children's palliative care and appropriate engagement of the CONs in the provision of education / training.	The vast majority of service providers understood the three elements of the CPCP to have significantly improved children's palliative care. The Level A and Level B programmes were viewed as providing important training on the needs of children with LLCs. The involvement of the CONs in delivering the courses was viewed as valuable in both raising awareness of the CON service and of the importance of children's palliative care more generally. Similarly, the involvement of the Consultant PPPM in a wide range of education and training was understood to have advanced children's palliative care both clinically and in terms of its 'standing' as a discipline. The opportunity for SpRs to have a placement with the OLCHC team was viewed as important in raising relevant knowledge and skills of medical staff. A small number of survey respondents highlighted some barriers to attending training, which included staff shortages, reduced training budgets and the time required to attend.
Increased awareness of children's palliative care and of the new service in both the public arena and health sector.	Both the CONs and the Consultant PPPM were viewed as playing an important role in improving awareness of paediatric palliative care. Continued opportunities for education and training of community and acute sector (both statutory and voluntary) staff, including as this involved members of CPCP personnel, were viewed to be central to any strategy to further increasing awareness.



SECTION FOUR

Recommendations for action

SECTION FOUR RECOMMENDATIONS FOR ACTION

The collective body of evidence stemming from all aspects of the evaluation confirms the CPCP as having effectively progressed towards achievement of its four anticipated outcomes. For the most part, the recommendations detailed below therefore focus on refinements to the programme's design and processes of delivery in order to enhance what is already provided. More fundamentally, in order to ensure the ongoing effectiveness and sustainability of the CPCP over the long term, recommendations are made for additional resources, primarily in terms of new appointments to the two new services. Finally, based on the findings of the evaluation concerning gaps and inequities in the provision of health and social care services generally, recommendations are made concerning how these gaps and inequities could be addressed. The 20 recommendations are set out in Table 9, below.

Table 9: Summary of recommendations for policy and practice

Recommendation	Detail
1.	The HSE should **continue and strengthen the three services**: the CON, Consultant PPPM and education programme based at OLCHC.
2.	The HSE should make **additional CON appointments**. Attention should be given to strategic placement to ensure maximum effectiveness and efficiency, while taking into account population density and geography.
3.	Each Hospital Group / Community Health Organisation should be encouraged to **examine their provision of paediatric palliative care**. The potential role of the CONs, ADONs and Champion Consultants should be maximised in order to improve service integration and the overall development of children's palliative care.
4.	The Children's Palliative Care Clinical Governance and Development Network should examine the findings of this report with a view to developing **a series of educational, governance and operational recommendations** to guide the continued development and support of the CON service. These should address: *administrative support; clinical supervision; CPD planning, including in relation to the new Level 9 post-graduate course; the promotion of local and national service development initiatives to promote collaborative working across sectors and services; and strengthening paediatric palliative care services within each Hospital Group.*
5.	The development of **children's palliative care as a specialty** needs to be endorsed at a policy level, regional paediatric services for children with LLCs should be highlighted as a speciality paediatric service within each Hospital Group
6.	A fulltime **national co-ordinator** for Children's Palliative Care should be appointed as soon as possible. *In order to maximise the potential for the appointment of an individual with appropriate knowledge and expertise, as well as to ensure the effective discharge of the role, the appointment should be made on a full-time basis.* Careful consideration should be given to the core purpose of the role, and subsequent clarity of understanding achieved through an appropriate job description.
7.	Part of the role of the co-ordinator should be to work at a national level to ensure that the CON **service is fully integrated** with other services in the community, particularly within primary care and disability services.
8.	Each Hospital Group / HSE local management structure should provide each CON with **administrative support**.

Table 9: Summary of recommendations for policy and practice	
Recommendation	**Detail**
9.	The HSE should consider the appointment of a **second Consultant**. The post should be fully integrated with the original Consultant PPPM post, currently based in OLCHC. The issue of making clinical supervision available for the Consultants and the hospital based paediatric palliative care nurses working with them should be explored. As per national policy, both posts should relocate to the new children's hospital when opened.
10.	In order to **maximise efficient communication** with different service providers, consideration should be given by the HSE to identifying more effective ways for both the CON and Consultant PPPM to electronically share clinical information so as to ensure all key professionals receive timely information.
11.	The HSE should ensure the **continued funding of the Level A and Level B training courses** on caring for children with life-limiting conditions provided by the Centre of Children's Nurse Education in OLCH Crumlin.
12.	The HSE and Centre of Children's Nurse Education should consider how the current training could be most appropriately tailored to **meet the needs of community based adult palliative care teams and hospital based paediatric medical and nursing staff**. In this regard, consideration should be given to improving the 'reach' of training, for example by offering it through different media, locations and formats.
13.	The HSE should develop a programme of work to **strengthen understanding, and underpin effective integration,** of the CPCP in relation to HSE, non-HSE, and externally funded organisations. Communication should specifically acknowledge the role played by the charitable sector in enabling the establishment of CPCP services.
14.	A key area of work identified by this evaluation, and requiring immediate focus by the HSE, is the provision of adequate and needs based **respite services**. Current provision is failing to provide adequate care and support to children with LLCs and their families.
15.	The lack of available and standardised **bereavement care** has been identified by this evaluation. This area of care needs to be prioritised by the HSE as current service provision is failing to provide adequate support to families bereaved by the death of a child with a life-limiting condition.
16.	These recommendations should be brought to the attention of the Clinical Leads of the HSE's Paediatric and Neonatology Care Programmes with a view to **agreeing priorities for service development and ensuring that children's palliative care becomes fully integrated** into the ongoing work of the programme including the model of integrated care. This model must include the identification of necessary staffing levels and structures, embedded within wider workforce planning.
17.	The terms of reference and membership of the **National Development Committee should be reviewed** in order to ensure that it remains fit for purpose. The HSE should ensure a formal process of partnership working, involving key statutory and voluntary sector services, is in place in order to identify and implement service development priorities.
18.	This evaluation recommends a **review of the current revenue allocation** for children's palliative care and the possible identification of a discretely identified budget so as to meet the needs indicated by the re-estimated prevalence figure.

Table 9: Summary of recommendations for policy and practice

Recommendation	Detail
19.	The importance of continuing the momentum generated by this evaluation is emphasised. The HSE should develop an **action plan** for taking forward the learning from this evaluation by developing priorities for the next phase of the CPCP, and subsequent targeted dissemination and communication of these priorities to key stakeholders.
20.	The findings of this evaluation should be discussed by the DoH and HSE and used as evidence for the **development of priorities for policy and service development.** These priorities should reflect identified deficits including **bereavement services** for parents who have suffered the loss of a child; **respite care** (at home and out-of-home) for parents caring for a child with a life-limiting condition/complex care needs; proper provision for **end-of-life care**; access to appropriate **out-of-hours care**; the **transition from children's to adult services** for young people with a life-limiting conditions.

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