Child Health Partnership

A STRATEGY FOR CHILDREN'S PALLIATIVE AND END-OF-LIFE CARE 2016-26

Progress Report – June 2021

Introduction

A Strategy for Children's Palliative and End of Life Care was published in 2016. Partners such as the NI Children's Hospice (NICH) and staff from children's services within Trusts have been working collectively for many years to help improve outcomes for children with palliative care needs. However, a concerted effort to deliver against the 23 objectives as set out within the Strategy was not practicable until funding was made available to assist with a number of priorities in 2018/19. Transformation funding allowed a number of palliative care projects to be supported across the health and social care (HSC) system.

Within the paediatric palliative care work, Transformation funding was made available to appoint a paediatric and end of life nurse (PALLS nurse) who is employed by the NICH and works between the hospice and Royal Belfast Hospital for Sick Children / Royal Jubilee Maternity Hospital (RBHSC/RJMH). Other funds were made available to support 1 programmed activity per week for paediatric palliative care clinical leads in each Trust as well as a Regional Paediatric Palliative Care Consultant. A Child Health Partnership (CHP) Senior Programme Manager was also appointed from the Transformation funds and this manager leads on the co-ordination of the implementation of the Strategy.

Therefore, whilst the Strategy was published in 2016 and individuals worked hard to improve outcomes for the relevant children and young people in the intervening years, substantive work to help progress the various objectives within the Strategy did not formally commence until 2019. From that point on a Paediatric Palliative Care Network (PPCN) was formally convened. The PPCN is made up of key clinical staff, commissioners and managers from across the DoH, HSC and NICH. A review of membership will be undertaken 2021/22.

Added to the above issues, the ongoing pandemic has impacted on many areas of work within the HSC, including on the needs of children and young people.

The remainder of this report has looked at the list of objectives and recorded progress against each, as well as outlining plans for future work to help ensure the successful achievement of all objectives.

Objective 1

Parents and children will be provided with information on their child's condition and the care and support options available to them in a clear, open and timely manner to ensure they are fully involved in decision-making. In the case of a pre-birth diagnosis, information and advice on perinatal hospice and palliative care, and support for parents, are to be provided.

Comment & Progress

Substantial work has been done to progress this objective. The appointment of lead clinicians in each Trust has allowed for improved coordination and consistency of approach. Enhanced communication between the Tertiary Centre paediatric palliative clinical lead, the PALLS nurse at NICH, the NICH and the various clinical leads at each Trust has advanced this objective. Furthermore, the PPCN allows also for quarterly discussions of areas of work and, issues that could be improved and identifies areas for potential improvement and proposes solutions. This open, transparent discussion enables staff to highlight areas of improvement in this and other objectives that are linked to the strategy.

During the pandemic, NICH and various clinical leads in the PPCN looked specifically at the issue of perinatal diagnosis. A substantive process of engagement was carried out and this resulted in the completion of a perinatal pathway to be used in these circumstances. . This draft pathway is complete and is awaiting approval to be implemented in Trusts. When this has been completed this will have a significant impact on ensuring this objective is fully realised.

Objective 2

Appropriate arrangements should be put in place for families across all HSC Trust areas to receive planned and emergency short breaks within their own home and in other appropriate settings, provided by skilled staff to meet the assessed needs (social, emotional, psychological and spiritual) of both the child and their family, as resources permit. Consideration will be given to the provision of planned or emergency short breaks for those children who, for social reasons, currently can only be accommodated in hospital.

Comment & Progress

Arrangements are in place across all Trusts for all families, as appropriate, to receive planned and emergency short breaks, if needed, across NI. It is crucial that access to short breaks is equitable across the region. With the pandemic, the availability of these breaks, or indeed the desire to avail of them, has reduced. This is due to a number of factors, for example re-profiling of services within Trusts to respond effectively to the pandemic through to families not wishing to avail of breaks as they wish to self-isolate rather than putting their child at potential risk of exposure to COVID-19.

A review of emergency and short break provision is planned in the near future and it is anticipated that this will lead to a new service specification for emergency and planned short breaks for relevant families in NI. A needs assessment and prevalence study is currently underway across NI to get comprehensive data on numbers involved and also the main needs of relevant families/children & young people. This study has drawn on the expertise of clinical teams across all Trusts, NICH and also families who use this service.

Once completed, the Health and Social Care Board (HSCB) will draw up a specification based on the needs assessment to help inform future service provision.

Objective 3

All clinical staff are to be made aware that the medical lead for Children’s Palliative Care within each Trust should be the initial contact for all children with palliative care needs.

Comment & Progress

The PPCN and each clinical lead have been carrying out significant engagement with relevant colleagues across their Trusts to raise awareness of the role of the clinical lead and to increase the visibility of paediatric palliative care issues. The clinical lead at the RBHSC has been engaging in a similar role with tertiary specialist colleagues. Coupled with this, the PPCN has been developing means to ensure that similar governance arrangements are in place in each Trust. This area has seen significant improvements but will continue to be developed.

Objective 4

At the point of recognition of a potentially life-limiting condition, specialists will work closely with the family/carers to carry out an initial multi-disciplinary assessment of the child's and family's needs as close to the family home as possible, including the identification of a keyworker. Each keyworker will plan and co-ordinate services for palliative care and support, and ensure continuity of care for the child and their family.

Comment & Progress

The appointment of the paediatric lead clinician in each Trust has helped progress this objective and led to enhanced co-ordination of care. However, it is important that there is a degree of fluidity across Trusts and each clinical lead has a slightly different scope and delivery plan. The creation of the PPCN and the close working between clinicians in the Tertiary centre and in District General Hospitals has ensured closer working between specialists and those involved in the local delivery of care.

The level of involvement of a keyworker has some variation between health trusts and between patient groups. Future developments will focus on improving recognition within this group of patients and developing a consistent approach to having a keyworker for co-ordinating palliative care needs.

Objective 5

Within a regionally agreed time from diagnosis of a potentially life-limiting condition, all children should have their and their family's needs assessed, and the recommendations of that assessment implemented without delay. The holistic assessment should evaluate physical needs such as equipment, housing adaptations, and financial assistance, but also consider the emotional, psychological, social and spiritual needs for care and support. These needs are to be regularly and at least annually reviewed by a multi-disciplinary team.

Comment & Progress

Paediatric Palliative Care provides a holistic approach to care for children with life-limiting conditions. At present, the holistic assessment is often performed by skilled and experienced teams who are not classed as 'palliative care teams'. We see future developments focusing on establishing 'Paediatric Palliative Care teams' within each Trust who can work more clearly towards this objective in a consistent way from Trust to Trust.

With the creation of the PPCN and with clinical and nursing leads from each Trust now having the opportunity to work collaboratively in a formal way, the region will be able to agree and progress the optimal way to achieve this objective.

Objective 6

Family members/carers will be invited to participate in at least one multi-disciplinary team review annually.

<u>Comment & Progress</u>

At present, there is not a consistent approach to this objective. Many Trusts will have multi-disciplinary teams in place to review children with life limiting conditions on a regular basis. The teams are often not thought of as formal 'palliative care teams' but do provide holistic input.

The PPCN will consider collectively how best to achieve this objective consistently across Northern Ireland.

Objective 7

Each child should have access to 24/7 multi-disciplinary community services and direct access to 24/7 crisis and specialist palliative care advice and end-of-life services, including access to medicines for symptom relief.

<u>Comment & Progress</u>

24/7 access to palliative care advice and end of life services is available to children across NI. However, much of this is done on an informal basis by clinicians, Children's Community Nurses and staff from the NICH. Whilst staff work tirelessly to meet the needs of each child, the PPCN recognises that the absence of a formalised commissioned regionally agreed approach is not ideal.

The PPCN aims to address this matter in 2021/22. A workshop to assess the various approaches that currently exist as well as assessing best practice from other areas will be conducted in the coming months. It is the intention for the PPCN to bring these lessons together into one regionally agreed approach for adoption across the HSC.

Objective 8

All units, including neonatal, should have clear, agreed care pathways for managing children and supporting their families in the last days of life. It is expected that this will form part of the remit of the new Regional Network for Children's Palliative Care.

<u>Comment & Progress</u>

The various clinicians across all Trusts together with colleagues from the NICH, have drafted a wide range of relevant pathways to assist with children and support families in the last days of life for their child. These include Advanced Care Plans and Rapid Discharge Plans amongst others. A number of pathways are currently in draft format and will require approval in 2021/22.

As noted at Objective 1, a substantive process of engagement was carried out on perinatal pathways and this resulted in the completion of a perinatal pathway that also includes this objective as one of its areas. This draft pathway is complete and is awaiting approval for *implementation within Trusts. When this has been completed this will have a significant impact on ensuring this objective is fully realised.*

Objective 9

Every child with palliative care needs should have an agreed, comprehensive transition/discharge plan involving the hospital, community services and the family, as set out in the Integrated Care Pathway for Children with Complex Physical Healthcare Needs. In respects of a transition plan, this should be agreed six months prior to the planned transition, if not before.

Comment & Progress

Clinicians from across services and Trusts work closely on robust discharge plans for children within their care. Such plans involve key staff from across disciplines and will include discussions between the tertiary centre and district general staff as well as relevant community or hospice staff, where relevant. These plans are comprehensive and reflect best practice. The work of the PPCN has helped improve this objective as the Network allows for clinicians to outline areas that have worked well and areas that required further improvement. The PPCN will continue to examine means to improve this area and will review this objective.

Transition care from children's to adult care is a more complex and problematic issue. Increasingly and very welcomed, due to advances in care many more children with palliative care needs are now living longer lives and are living into early adulthood. However, this brings about some distinct challenges. Transitional care is experienced in many aspects of paediatric care and not just paediatric palliative care. At the time that the HSC appointed lead paediatric palliative care clinicians in each Trust, attempts were made to appoint transitional care clinical leads for palliative care. Unfortunately, this was not successful.

The PPCN and wider Child Health Partnership will continue to examine means to improve transitional care arrangements across the full spectrum of paediatric services and this will also consider paediatric palliative care transitions.

Objective 10

A regional protocol should be developed to facilitate rapid discharge and transfer from hospital to home, hospice or any other chosen setting, to facilitate choice in relation to the child's place of death.

Comment & Progress

As outlined at Objective 8, a draft Rapid Discharge Plan has been drafted and is available for use across all Trusts. Advanced Care Plans have also been agreed between partners on the PPCN. Partners within the PPCN, from the Tertiary site at RBHSC, clinicians at District General Hospitals, Community Children's Nurses and professionals from within the NICH, including the PALLS nurse, work closely together to facilitate the needs of a child or the child's family in relation to the child's chosen place of death.

The clinical aspect of the work of the PPCN, and also education sessions run through Project Echo, allow for professionals to discuss how each case is handled and highlights potential *lessons for the PPCN and others in future cases. The PPCN will continue to review this objective and others and highlight best practice where it can.*

Objective 11

All young people who transition to adult health and social care services will transfer to the most appropriate service, based on assessed need. They will receive care that is age and developmentally appropriate. If their multi-disciplinary team agrees that the young person is close to the end of their lives, they may decide to continue their care within children's services.

Comment & Progress

As was outlined at Objective 9, transition from care within child health to adult care is complex and problematic. Increasingly and very welcomed, due to advances in care many more children with palliative care needs are now living longer lives and are living into early adulthood. However, this brings about some distinct challenges.

Transitional care issues are witnessed in many aspects of paediatric care and not just experienced in paediatric palliative care. At the time that the HSC appointed lead paediatric palliative care clinicians in each Trust, attempts were made to appoint transitional care clinical leads for palliative care. Unfortunately, this was not successful.

As stated above the PPCN will continue to assess how best to improve transitional care. This is an issue that is relevant across the full spectrum of care and will also be considered by the wider Child Health Partnership.

Objective 12

The relevant professionals should communicate in a clear and honest manner with each child and their family so that they understand their condition, care and treatment options, and the implications of the various options. This will ensure they are informed and can contribute to the development of an appropriate and flexible end-of-life plan when required. Where appropriate, the possibility of organ donation should be discussed sensitively with the family and young person for inclusion in the end-of-life plan. The plan should be developed at an appropriate time, and be supported by an experienced professional, for example, the child's keyworker, who has knowledge of both the child and family.

Comment & Progress

Clinicians from across Trusts would carry out this function as part of their duties but the situation has been aided by the creation of the PPCN and appointment of lead paediatric clinicians in each Trust. These developments have facilitated two areas in particular in relation to this.

The appointment of a lead paediatric clinician in each Trust acts as a single point of contact for dissemination of best practice and expertise to relevant clinicians throughout the Trust. A key role of each paediatric palliative care lead is education and training. These lead clinicians disseminate key learning on a number of areas, including communicating in an open and honest manner with families and children.

The creation of a formal PPCN has also improved outcomes within this objective as the Network has outlined the ability for collective learning and highlighting areas of best practice and potential areas of improvement regarding communication to families and children in an open and clear manner.

Moving forward, this objective will be kept under review by the PPCN to ensure that best practice is shared widely throughout the region.

Objective 13

A range of bereavement support should be available in a timely manner to meet the specific needs of families who have experienced the death of a child. Every family should be offered practical advice about their availability by a professional who is already known to them.

Objective 13 (a)

The new Regional Network for Children's Palliative Care will review the current provision of bereavement services provided to parents in the circumstances of a pre-birth diagnosis of a potentially life limiting condition, and make recommendations to the Department on further improving the delivery of services including the role of perinatal hospice care.

Comment & Progress

Bereavement support is available for families in Northern Ireland and there are Bereavement Coordinators in each Trust; however, their focus is on adults. During the 2020/21 a process has commenced to review current paediatric bereavement guidelines under the auspices of the PPCN. Colleagues in NICH are leading on the scoping exercise and will consult widely.

Once completed, the scoping report and recommendations will be brought to the PPCN for further discussion and agreement on next steps.

Objective 14

A new Regional Network for Children's Palliative Care should be established as a subgroup within the Paediatric Managed Clinical Network proposed in the Paediatric Community and Hospital Based Strategy. This subgroup should have a wide remit, including the delivery of standards of care (including routine and emergency stock levels), the development of care pathways, research, improved co-ordination of care, improved communication with families and carers, influencing commissioning, and governance.

Comment & Progress

As outlined in the introduction, the Strategy was published in 2016 and individuals worked hard to improve outcomes for the relevant children and young people in the intervening years. However, substantive work to help progress the various objectives within the Strategy did not formally commence until 2019. From that point on a Paediatric Palliative Care Network (PPCN) was formally convened. The PPCN is made up of key clinicians, planners, commissioners and managers from across the DoH, HSC and NICH. The membership is open to others and will seek further membership in 2021/22.

The PPCN role is evolving but it primarily offers leadership for paediatric palliative care work in NI and oversees the delivery of key aspects of the Paediatric Palliative Care Strategy. It also acts as a means to share information and best practice on clinical issues amongst members of the network.

The PPCN has also opened closer working relations with colleagues in GB and in the ROI. It is anticipated that these enhanced links will highlight areas for closer working ties and best practice that will ultimately improve outcomes for children and young people in NI.

Objective 15

A minimum dataset and information system to support children's palliative care services should be developed.

Comment & Progress

During the period 2020/21, the HSCB/PHA and PPCN commenced an approach to gather more robust quantitative and qualitative data regarding the prevalence of children and young people living with palliative care conditions in NI. This process is gathering data from individual clinicians in Trusts, as well as data available from sources centrally that are held at DoH and HSCB. The project lead will assess all the relevant data to ensure that a minimum dataset is available for use by the PPCN and regional bodies when considering services moving forward.

Objective 16

Clear accountability arrangements, with a single regional commissioning lead, for commissioning children's palliative care should be put in place, which will also address the needs of children with very complex palliative care needs.

Comment & Progress

The creation of a formal PPCN has made significant improvements on this objective as there are clearer lines of reporting and information as a result of the PPCN. However, it must be noted that there are significant developments occurring within regional commissioning structures and this will include how children's services are commissioned. It will be crucial that the issues highlighted by the PPCN and other areas are included in future considerations on how the entirety of children's services are planned for and commissioned. The PPCN and wider Child Health Partnership will be a crucial partner in these discussions.

Objective 17

Regional medical leadership structures and processes should be developed by the proposed regional children's palliative care network.

Comment & Progress

The creation of a formal PPCN has made significant improvements on this objective as there are now explicit lines of leadership and channels of communication within Trusts and between Trusts on the issue of paediatric palliative care. The PPCN has highlighted how this can be *improved and the discussions with other paediatric palliative care networks in ROI and GB has also highlighted other examples of best practice and this is considered by the PPCN.*

The PPCN will continue to gauge progress on this and also highlight further potential improvements on leadership models in paediatric palliative care.

Objective 18

Each HSC Trust should appoint a lead Director for children's palliative care services (in both hospitals and the community), with appropriate knowledge and experience, accountable to the Board of their HSC Trust.

<u>Comment & Progress</u>

Through the leadership of the PPCN, each Trust has a nominated lead Director with responsibility for children's palliative care services.

Objective 19

All referrals for children who require palliative and end-of-life care should be co-ordinated by a medical lead within each Trust.

<u>Comment & Progress</u>

The clinical lead in each Trust has a key role in coordinating palliative care within their Trust and they work closely with relevant colleagues across their respective Trusts.

Objective 20

A dedicated regional consultant for children's palliative care should be appointed, with due consideration given to the need for cover arrangements and links with colleagues in Britain and Ireland.

<u>Comment & Progress</u>

A regional consultant for children's palliative care has been appointed and is working closely on establishing links in GB and also RoI.

Objective 21

Pre-registration and post-registration courses for key professional groups should include children's palliative care. A range of initiatives to ensure the highest possible level of competency for all staff involved in the provision of palliative care services should be developed.

<u>Comment & Progress</u>

At the present time there are formal educational opportunities within UK and ROI. These are available to medical and nursing staff to improve their post-registration knowledge and *qualifications. Future work should focus on making formal training in Paediatric Palliative Care more accessible at an undergraduate and postgraduate level within NI.*

Project Echo is currently being used as a means to extend knowledge and skills amongst relevant paediatric palliative care across NI. This allows for relevant staff to have a high range of skills and competency in the area. Clinical leads and other members of the PPCN participate in courses to raise their skills and clinical leads of the PPCN share knowledge and skills across relevant services.

Objective 22

Families and other carers, including teachers, should receive timely training and be supported to develop and maintain the necessary knowledge and skills to provide care for children with palliative care needs.

Comment & Progress

This is a crucial objective and the PPCN will ensure that this is included in future plans. There are resource issues related to this objective and that will be a factor in considerations.

Objective 23

The proposed Regional Network for Children’s Palliative Care will, in collaboration with Higher Education providers and the HSC Research and Development Department within the Public Health Agency, play a key role in driving forward and influencing the research agenda in this specialty.

Comment & Progress

This is a crucial objective and the PPCN will ensure that this is included in future working. Substantive discussions with the HSC Research & Development Department are required. During the 2020/21 period some discussions were held with academics from London as well as paediatric trainees to consider potential issues that would be relevant for research in paediatric palliative care.

Conclusion

The Strategy for Children’s Palliative and End of Life Care 2016 is a much welcome document that offers a major opportunity to improve outcomes for children and young people in Northern Ireland with palliative care needs.

The committed professionals working in paediatric palliative care have been successful in improving outcomes prior to the publication of the Strategy and continue to work to improve the outcomes for children and young people across NI.

The creation of a formal PPCN has also helped moved the agenda forward in the two years that it has been in place. Many of the objectives and outcomes listed above have witnessed significant improvements. However, much more is required including further support to deliver against these ambitious objectives.

To date, the projects and delivery of the Strategy have been supported by funding from Transformation funding which has been made available on a non-recurrent basis. Moving forward, the PPCN will continue to plan for progress against the 23 objectives within the Strategy and highlight areas of improvement. It would also welcome more certainty on future funding streams within this crucial area of delivery. The PPCN will also work with all key partners to improve outcomes for children and young people living with palliative care needs as well as their families.