



Clinical governance and operational arrangements for supporting a model of care for children with life limiting conditions towards the end of life in the community in Ireland

FINAL REPORT AND RECOMMENDATIONS



Executive Summary

This document concludes the work of an Expert Advisory Group established by the Chief Clinical Officer of the HSE to set out an operational and governance framework for palliative care for children with life limiting conditions in the community. It sets out the current approach to care, limitations within the service and the proposed model for both operational and clinical governance.

This document builds on the model of care for children with life limiting conditions as previously set out in Chapter 39 of 'A National Model of Care for Paediatric Healthcare Services in Ireland', and does not seek to duplicate the document but should be supplementary to Chapter 39.

The Expert Advisory Group undertook to develop a number of scenarios and articulate pathways of care during the child's journey. The proposed model relies on an increased and reorganised workforce, as well as changes in practice. It is based on the triumvirate of primary care, local paediatric and adult community palliative care services, coordinated

by the Clinical Nurse Coordinator (CNC), working in a mutually supportive way to care for a child at home. A key enabler of the model is the remote support provided by consultants in paediatric palliative medicine and consultant paediatricians with an interest in palliative medicine.

The recommendations have been made with the knowledge that there are developing structures and policies under Sláintecare and the transformation of children's healthcare as part of the development of the model of care, recognising that as these evolve, different regions may need to prioritise these recommendations in different ways. The intention of this report is to strengthen governance arrangements and provide consistency. It should not disrupt existing arrangements and planned developments where these exceed the proposed model and recommendations.

A total of 14 recommendations have been developed divided across 4 themes:

Governance and professional practice

1. Each child with end of life needs, to have an identified core team of healthcare providers that includes a named paediatrician in the acute hospital closest to their home, palliative care provider, GP and aligned Clinical Nurse Coordinator. This core team is supported by a network of regional paediatricians with a special interest in palliative care for children or palliative care specialists.
2. Ensure paediatric palliative care is considered in the development of local governance frameworks.
3. Structured discharge protocols, including a requirement for an MDT meeting with defined outcomes, to be locally agreed.
4. Clear arrangements for communication channels between all the professionals involved in the care of children at end of life in the community.
5. The Association of Paediatric Palliative Medicine formulary to be used as the standard formulary in conjunction with clinical judgement.
6. Structured out-of-hours summaries to be used by GPs to communicate essential information.
7. Improve information sharing through continued advocacy for digital shared records.
8. Ensure that the children's outreach governance framework for children with life limiting conditions remain fit for purpose.

Strategic

9. The ongoing development of national, regional and local workforce provision aligned with national strategies under agreed governance models to support end of life care for children.
10. Re-establish regional committees to provide strategic direction and ensure integration of services at a local level in line with palliative care national policy recommendations.

Education and Training

11. Establish an education group to:
 - (a) agree a set of competences for primary care, paediatric and adult palliative care teams to enable safe and effective end of life care of children in the community, building on the Palliative Care Competence Framework (10),
 - (b) develop a comprehensive education and training plan to meet those competences further detail can be found in the complete recommendations.
12. Consideration should be given to incorporating curricular content and training in paediatrics within the adult palliative medicine higher specialist training programme.

Workforce

13. An implementation plan which enables additional workforce to be appointed within 3-5 years (further detail can be found in the complete recommendations).
14. Review resourcing available to Primary Care, including GPs, to provide palliative care to children with life limiting conditions.

Introduction

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 throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement⁽¹⁾.

Based on most recent epidemiological data from England⁽²⁾, it is estimated that there are 8,311 children (0-18 years of age) in Ireland with a life limiting condition. Of these, 19% (1,579 children) are thought to be either unstable (15%), deteriorating (2.2%) or dying in any one year⁽³⁾. They may have specialist palliative care needs at different stages during the illness trajectory. In 2019, 70 children who died in the community were supported by a CNC for Children with Life Limiting Conditions⁽⁴⁾.

In the past decade, a number of publications have described and made recommendations for children's palliative care. The main documents are:

- **Palliative Care for Children with Life-limiting Conditions, a National Policy**⁽⁵⁾,
- **National Model of Care for Paediatric Healthcare Services in Ireland including chapter 39 on paediatric palliative care**⁽⁶⁾, and,
- **National Model of Care for Adult Palliative Care Services**⁽⁷⁾.

In addition to this, three aspects of children's palliative care services were externally evaluated in 2016 and further recommendations were made⁽⁸⁾.

These publications, and the values they represent, form the backdrop to this report. The important principles of care described in the publications underpin this report but are not reiterated in detail here for the sake of brevity. They include:

- the holistic nature of palliative care,
- the centrality of the person involved, and those important to them,
- the breadth of expertise that specialist palliative care teams offer, and,
- the importance of a collaborative multidisciplinary multiagency approach to care.

Chapter 39 of 'A National Model of Care for Paediatric Healthcare Services in Ireland' stated that *"the link between paediatric and adult based palliative care services will be required to continue in the future and it is therefore suggested that the clinical governance of this service provision should be supported and further developed"*. This position remains unchanged and the development of clinical governance has become more pressing as concerns have emerged around the need for more clarity and consistency surrounding the arrangements for the care of children with life limiting conditions and their families, at home, especially towards the end of life.

In December 2019, at the request of the Chief Clinical Officer, an Expert Advisory Group was formed to address the following terms of reference:

1. Describe the clinical governance models and arrangements currently in operation between adult palliative care services and other services (including paediatrics and primary care) in the provision of care for children with life limiting conditions towards the end of life.
2. Make recommendations on adjustments that would strengthen the clinical governance model and operational arrangements within the Irish context reflecting need for training and/or resources as appropriate.

This paper reports the conclusions of the Expert Advisory Group, following consultation with a range of stakeholders. It is only part of the full spectrum of strategic, operational and clinical governance arrangements underpinning the care, treatment and support for children with life limiting conditions in all settings. It is one more step towards the necessary long term development set out in the national model of care. This document is not exhaustive in its identification of roles and responsibilities nor does it seek to supersede existing work arrangements between professionals where such relations serve the best interests of the child.

Appendix E details the process of consultation undertaken by the Expert Advisory Group.

Purpose and scope

The purpose of this document is to set out an operational and governance framework for palliative care for children with life limiting conditions in the community. It builds on the model of care for children with life limiting conditions as previously set out in Chapter 39 of 'A National Model of Care for Paediatric Healthcare Services in Ireland', and does not seek to duplicate the in-depth description of the model of care. This document should be regarded as supplementary to Chapter 39.

Clinical governance structures for the care of children within hospitals and hospices are determined by those organisational frameworks and are not replicated here.

This document focuses on what is required to ensure good governance for the care of the child with a life limiting condition in the community, especially towards the end of life. In this context, the term 'end of life' refers to the period when there is an expected prognosis of days to short weeks, and the focus is solely on palliation. Each Hospital Group defines the age cut-off for admission to paediatric services and this document refers to those who meet the age criteria (which may differ according to condition and location). It requires a certain level of investment in workforce and training, so a phased approach will be required. The ultimate aim must be to ensure that this is rolled out consistently and sustainably across the whole country.

Transformation of Children's Healthcare

The operational and governance framework in this document was developed in the context of broader transformations in children's healthcare.

Children's Health Ireland (CHI) is leading on the clinical and operational transformation of how children's healthcare will be delivered in the future including the centralisation of specific acute paediatric services into a national centre with support for a regional paediatric network⁽⁹⁾.

Their aim is to deliver integrated primary, secondary and tertiary care to children, young people and their families, as part of an effective clinical care network. The benefits of specialist care are combined with those of a more local service in the most effective, efficient and child-friendly way. One of the guiding principles underpinning the new national Model of Care for Paediatric Healthcare Services is that clinically appropriate care and treatment should be delivered as close to the child's home as possible. This child-centred, family-focused approach to healthcare delivery will be supported by the following:

- **Paediatricians will be supported by outreach tertiary clinics in the regional centres. This will provide tertiary care closer to the child or young person's home, and will enhance shared care through the development of professional relationships between regional and specialist paediatricians.**
- **General Paediatrics play a central role in children's health services in Ireland. This national model of care requires a correct balance of general paediatricians and paediatric subspecialists and, for the most part, all children and young people should be firstly referred to a general paediatrician. The development of specialist services depends on excellent 'gatekeeping' by general paediatricians. The vast majority of children in Ireland are healthy, and acute illness can be managed in local primary care and the interface between primary care and secondary care is critical.**

This document aims to align with these developments and the broader Sláintecare agenda insofar as possible. The workforce enhancements are recommended on the basis of the footprint of the 6 new regional health regions being implemented under Sláintecare.

Current approach to care

A significant proportion of children with life limiting conditions have complex needs from early childhood and so will already be receiving support in keeping with these additional needs. Other children whose life limiting illness interrupts a previously normal childhood may not be linked to such services, and the introduction of holistic care occurs rapidly. In both cases, support will vary according to the stage of the child's development, illness, health and care needs and the support available in their locality. In order to provide a comprehensive palliative care service there is a need for close collaboration between the child's general practitioner, consultant paediatrician, palliative care services, nursing services, therapists and the voluntary sector. The children's hospitals and paediatric units around the country are pivotal to the ongoing care of children with life-limiting conditions. In addition, a child with a life limiting condition will usually be referred to a CNC for Children with Life Limiting Conditions at the time that the child is known to be deteriorating.

The role of CNC was recommended and described in the 2010 National Policy (5). The primary focus of these nurses is to facilitate the smooth transition of a child with palliative care needs from hospital to the community. Their aim is to co-ordinate care and to support families and health care professionals in their role of providing care for the child with end-of-life needs at home. The role of the CNC is underpinned by a governance framework.

The CNC, along with other health professionals in a child's care, become particularly important when their condition becomes unstable and/or when they are dying. At this time their physical, psychological and social needs may change or increase. They and their family may have a preference for care and treatment at home.

Children who are receiving care at home may be under the governance and care of a specialist consultant, or paediatrician in a hospital, in partnership with the child's GP. Due to the relatively small numbers of patients involved, Ireland does not have specialist paediatric palliative care teams available regionally. Therefore community specialist palliative care teams (adult services) usually provide the end of life care at a local level, in partnership with the child's existing paediatric and primary care teams. The level of input varies across the country. The CNC has a pivotal role

in accessing and coordinating these services alongside the other longer term supports the child has been accessing. Voluntary services play an important role in providing the care available.

Care for the child at home is documented in their 'My Story' folder, which is held by the child's parents and holds key information relating to the child, clinical practice guidelines and specific care directives from the child's multidisciplinary team.

If needed, the specialist paediatric palliative care team based in CHI provide remote support to community specialist palliative care, general paediatric and primary care colleagues. This team comprises a consultant paediatrician with a special interest in paediatric palliative medicine, consultants in adult palliative medicine and CNSs in paediatric palliative care.

The role of the CNS (Clinical Nurse Specialist) in paediatric palliative care is hospital based and is part of the specialist paediatric palliative care service. The role is both advisory & consultancy around symptom management. The role provides information and support for families in both hospital and home. Support is also provided for colleagues particularly in the provision of education. The CNS provides support and advice regarding the transfer of a child from hospital to home and liaises directly with the adult palliative care CNS and community teams as and when required.

A common goal exists to enable an environment where hospital, community and primary healthcare providers are supported to provide a palliative care approach as part of their normal service provision. As noted in Ireland's Palliative Care Model of Care, *'palliative care services enable patients to avoid inappropriate acute hospitalisation and remain safely and adequately cared for at home; lead to better patient and family satisfaction, and significantly reduce prolonged grief and post-traumatic stress disorder among bereaved family members; and lower costs by delivering care that is aligned to patient and family needs, and that enables avoidance of unnecessary hospitalisations, diagnostic and treatment interventions, and inappropriate intensive and emergency department care'* (7).

Limitations to the current arrangements

The relative rarity of end of life care in childhood and subsequent lack of familiarity of most professionals with the management of a child's palliative care needs makes the provision of multidisciplinary care outside of a hospital setting more challenging. Currently there is no standardisation of clinical governance or operational practice, including information sharing, across the country; most structures have evolved over the years.

The current configuration of end of life care in the community relies on the GP providing a key role in the care of the child in partnership with specialist palliative care teams and the child's existing paediatric and primary care teams. Support for the child and family out of hours may be limited. A number of individual healthcare practitioners and/or teams may be involved at any one time and this can cause confusion about who is leading the care and/or has overall responsibility for decision-making. CNCs play a pivotal role in coordinating the provision of services, however their capacity is limited as they are generally lone workers with limited cover for leave and provide service over a large geographical area on a 9am to 5pm, Monday to Friday basis.

The national Model of Care for Adult Palliative Care Services (7) acknowledges that adult community palliative care services have an important role to play in supporting the care of children at home. However, some of these teams have concerns that providing care to children is outside their scope of practice. Similarly, general paediatric and primary care teams are not likely to care for enough children to gain specialist skills in paediatric palliative care. While many of the professionals involved in the care of children at end of life are very skilled and knowledgeable, there is no consistent education or training requirement in paediatric palliative care. Acquiring and maintaining competency is difficult (10), so it is rare that any of these teams would be able to take on medical responsibility for the care of a child with paediatric palliative care needs in isolation. This means there is a need for professionals and teams to work together through shared responsibility.

The specialist paediatric palliative care team located in CHI Dublin provide advisory and supportive capacity at a national level, to those providing care to children at end of life at home.

However, this support is currently delivered 24/7 via telephone support on a grace and favour basis and is therefore not sustainable in the long term.

Nationally, access to palliative care and supporting services varies according to age, geographic location and diagnosis. The factors influencing variation in access include:

- **access to GPs and other healthcare professionals providing a palliative care approach and with the necessary and up to date skill set;**
- **reluctance of professionals to provide care in the absence of clarity regarding clinical governance;**
- **variability in funding and access to home care packages;**
- **lone workers covering large and/or remote geographical areas;**
- **fragile arrangements for holiday cover for some professionals;**
- **limited responsiveness of out-of-hours provision;**
- **lack of specific provision for paediatric services in the service arrangements for palliative care services delivered by Section 39 funded agencies; and**
- **variability of specialist palliative care provision for adults, including limited out of hours care in some geographic areas.**

It is essential that service providers work together to optimise the child's quality of life but, under the current circumstances, it is difficult to ensure robust clinical governance to underpin operational delivery of a community based service that meets the needs of the child and their family and is consistently delivered across the country.

See Appendix B for further blocks and mitigation to addressing these challenges.

Proposed model of clinical governance

The proposed model builds on that described within the Paediatric Model of Care (6) but recommends modifications. It relies on the triumvirate of primary care, local paediatric and adult community palliative care services, coordinated by the CNC, working in a mutually supportive way to care for a child at home. A key enabler of the model is the remote support provided by consultants in paediatric palliative medicine and consultant paediatricians with an interest in palliative medicine.

Each child with end of life needs, to have an identified core team of healthcare providers that includes a named paediatrician in the acute hospital closest to their home, palliative care provider, GP and aligned Clinical Nurse Coordinator. This core team is supported by a network of regional paediatricians with a special interest in palliative care for children or palliative care specialists

The proposed model relies on increased and reorganised workforce, as well as changes in practice. Some of the workforce additions are described here to provide context to the practice enhancements that follow. The full suite of recommendations is included at the end of the report.

Currently there are 2.2 whole-time-equivalent (WTE) consultants who provide out-of-hours paediatric palliative medicine telephone advice for the whole country on a grace and favour basis, as well as a clinical workload in CHI Dublin. One of the recommendations of this report is that this workforce should be increased to 5 WTE over time to enable sustainable national 24 hour on-call advisory provision by consultants in paediatric palliative medicine. This will also enable them to take on a workforce development role, especially in training and development of others.

Supplementary to the appointment of additional consultants in paediatric palliative medicine, the appointment of consultant paediatricians with an interest in palliative medicine is recommended. These consultants will provide a regional point of contact to GPs, paediatricians and consultants in palliative medicine, with specialist knowledge and adult dedicated working time for clinical and strategic leadership for the region. The recommendation is that they have 0.4 WTE of their role dedicated to paediatric palliative care. It is recommended that in each Sláintecare region there is at least one consultant in paediatric

palliative medicine or consultant paediatrician with an interest in palliative medicine. Cross-cover arrangements for leave will be required within or across regions, or with CHI Dublin. These paediatric roles will work closely with general and community paediatricians (where available) to support the needs of children with complex care needs in community settings.

Please refer to Appendix A of this document for a full description of the roles described above.

Consultants in paediatric palliative medicine, in general, are consultant paediatricians who have undertaken specialist recognised training in paediatric palliative medicine and whose role is focused solely within palliative medicine. There are currently 2.2 WTE doctors who are filling this role nationally, based in CHI Dublin. By contrast, consultant paediatricians with an interest in palliative care, are doctors who may have undertaken recognised training in paediatric palliative care, but whose roles are not wholly focused within palliative medicine. This report recommends that 0.4 WTE of their role be thus focused. There is currently no specific post like this in the country, although there are a small number of doctors who are known to be educated and experienced in this field and who, if allocated protected 0.4 WTE, could undertake this role.

The CNC role is seen as pivotal to supporting and providing coordination for the proposed model. It is recommended that there is an increase in CNC WTE from the current 16 funded posts to 22, to achieve equitable geographical coverage and cross-cover arrangements.

There is strong international evidence that an integrated health and social care system delivers better outcomes for patients and clients, provides a better environment for staff, and is more efficient. Fundamental to the HSE's Transformation Programme is the development of health and personal social services that reflect this global trend towards greater integration within and between acute and community service. Service integration provides well-organised services that are seamlessly connected, so that people who need access to more than one service can move easily through the entire care system.

The model aligns with the aspiration of CHI to create a virtual hospital model to support the paediatric model of care locally, regionally and at home.

A number of case studies are included in Appendix C as illustration of the range of issues and approaches that may occur.

It is important to note that in some areas, for some children, the standard of provision (and governance thereof) goes beyond what is proposed below, and the extent and quality of team-working between the professionals and services involved, are excellent.

This should be celebrated and encouraged. There is no suggestion that this should be diminished in any way, but it is necessary to set out a robust minimum standard that needs to be in place to ensure equity, regardless of age, geographical location or diagnosis, and to enable sustainability over the long term.

The Expert Advisory Group undertook to develop a number of scenarios and articulate the pathways during the child's journey.

Care for a child at home who is relatively stable

When a child with a life limiting condition is at home and is relatively stable, their GP and primary care team continue to provide family centred medical care, strongly supported by their named paediatrician and the paediatric team. The child may be known to the CNC in that area. Voluntary sector and contracted providers may be involved in assisting with hands-on care. This reflects the current arrangements and should remain the foundation.

Where the child is at home and gradually deteriorating but not yet in the last weeks to days of life, they may benefit from a referral to specialist palliative care services for an assessment and to develop a planned holistic approach to their care. It is recognised that the earlier a child with life limiting condition whose health is beginning to deteriorate is referred to palliative care, the better their outcomes and the outcomes for their family members. This can occur alongside potentially curative treatments.

Increased availability of consultants in paediatric palliative medicine at a national level and consultant paediatricians with an interest in palliative care at a regional level, as recommended by this report, will provide additional support, advice and knowledge to GPs, paediatricians and consultants in adult palliative medicine who are making this assessment of the child. Similarly, increased availability of CNCs will allow CNCs to play a strong coordination role in every case. The assessment should inform the holistic approach to be taken by all professionals involved in the care of

the child and should be documented as clearly as possible and kept up to date.

The CNC plays a key role in liaising with the family and supporting the coordination of the various roles and responsibilities involved. They will often facilitate joint home visits to reduce the 'stranger effect' when new team members are being introduced to the child and family.

In delivering holistic, family centred care to the child, the GP is supported by the child's named paediatrician (for advice related to paediatric issues, e.g. feeding, management of underlying condition, care and treatment approaches) and the child's named consultant in adult palliative medicine (for advice related to palliative care issues, e.g. symptom management and other palliative approaches, holistic care, support for child and family, expert communication). They may seek further advice from the paediatrician with an interest in palliative medicine or consultant in paediatric palliative medicine. Furthermore, the community palliative care team and other members of the primary care team may be involved. Voluntary sector and contracted providers often assist with hands-on care.

In Appendix A, there are further descriptors of the key responsibilities of each clinician which distinguishes their key contributions and responsibilities in the context of looking after a child dying at home.

End of life care for a child who is at home

The care of a child with a life limiting condition, who is at home, may focus more on palliation as they begin to deteriorate, and it is recognised that the child now has an expected prognosis of days to short weeks. A multidisciplinary team meeting should be triggered by the GP, CNC, paediatrician, palliative care team or whoever recognises that the child's condition is deteriorating. This may involve the child being brought to the paediatric unit for reassessment or a home visit may take place including the GP and/or paediatrician, CNC and a member of the community specialist palliative care team. It is recognised that all professionals may not be available to be physically or virtually present for these meetings, however it is advised that their services should be represented as much as

possible and pre and post meeting communication should include all parties.

The outcome of the multi-disciplinary meeting is a detailed care plan for the day-to-day clinical management, out-of-hours, escalation and advance care needs of the child, with details of who needs to be involved when, including any other relevant information. This is written by the child's paediatrician and agreed by all parties. The consultants in paediatric palliative medicine and regional consultant paediatricians with an interest in palliative medicine can provide additional advice and support. Voluntary sector and contracted providers may be involved in assisting with hands-on care.

Discharge home from hospital for end of life care at home

When a child is discharged from hospital to die at home, the multi-disciplinary meeting described above should ideally take place prior to discharge including the discharging professionals and the triumvirate of primary care, local paediatric and adult community palliative care services who will support the end of life care for the child at home. Pre-discharge planning greatly supports the provision of care at home. This is described in the flowcharts below.

Where a child is discharged home with an expected prognosis of days to short weeks and a sole focus on palliation, the GP normally provides the first point of contact and assesses the child

as required. They will ideally have attended the pre-discharge multidisciplinary meeting and have received a detailed care plan from the discharging paediatrician.

The model recommends that if a child is being discharged from a national tertiary centre, they are referred to a named consultant paediatrician, based in their local paediatric unit. However, it is recognised that there may be circumstances where the paediatric team from the discharging hospital may undertake the role described as 'local' or 'regional' in this model. For example, if the child has a rare condition and their specialist paediatrician delivers a service locally.

Prior to discharge for end of life care at home

The pre-discharge algorithm set out below describes what should normally happen prior to discharge. There are times when this needs to be expedited. There are also times when unpredictable events happen that disrupt plans already made or when discharge home simply cannot happen. For example when discharge home needs to happen so quickly that planning time is not available or when, despite careful planning and every effort being made to meet the preferences of the child and family, it is not possible or safe to manage the end of life care for the child at home. It is important that healthcare professionals are able to discuss these limitations and challenges with the child and family and are supported to do so.

The Clinical Programme for Palliative Care Rapid Discharge Guidance is applicable to paediatric palliative care: www.hse.ie/eng/about/who/cspd/ncps/palliative-care/resources/rapid-discharge-guidance/.

Prior to Discharge

Decision to discharge home agreed with the child, family, child's paediatrician, GP, CNC, community palliative care team and other key members of the team

Referral made and decision communicated by child's paediatrician with:

- Child's GP
- Named consultant paediatrician (consultant-to-consultant referral, if not previously known)
- Named consultant in adult palliative medicine (consultant-to-consultant referral unless previously known)
- Regional consultant paediatrician with an interest in palliative care
- CNC

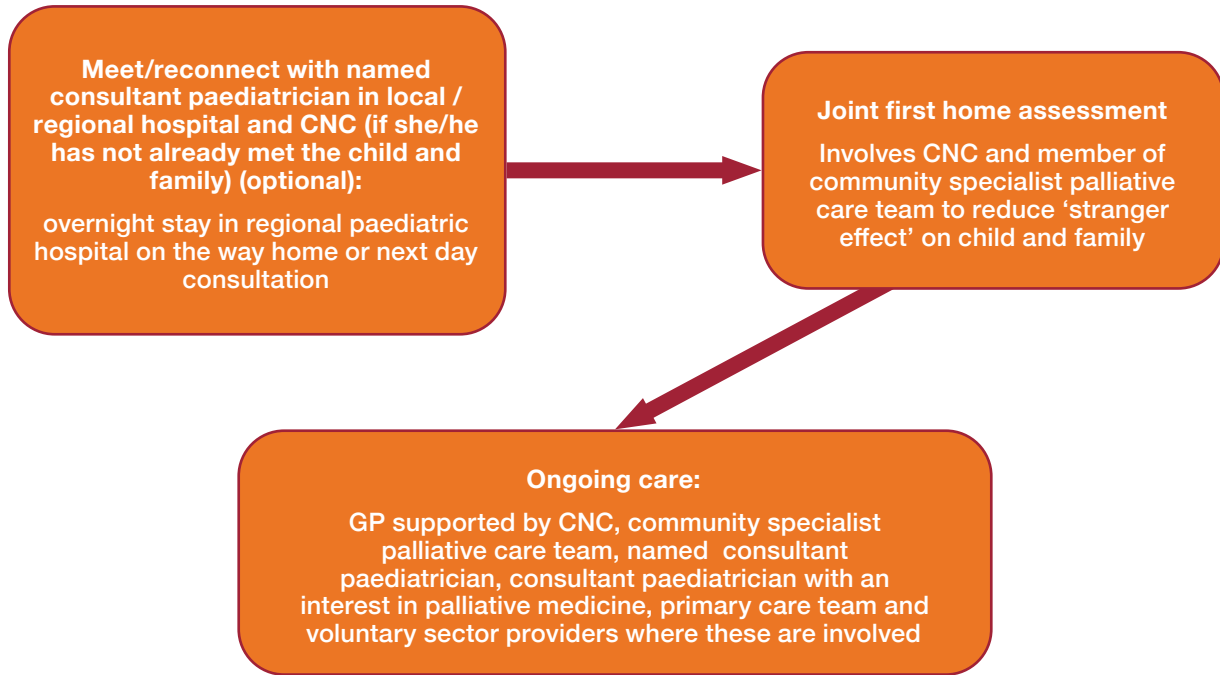
Multidisciplinary Team meeting, led by paediatrician (or representative) and coordinated by CNC:

- To ensure an individualised and coordinated plan of care for the child
- Involves discharging and receiving paediatric teams, GP, primary care, community specialist palliative care team and other supportive services who are to be involved
- Involves child and family – depending on wishes and circumstances

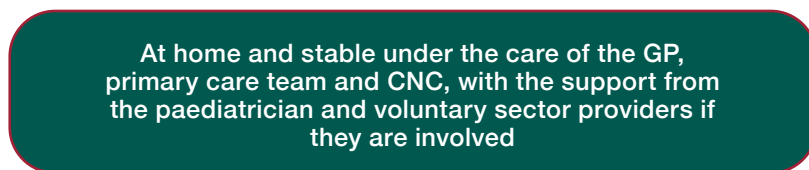
Outcomes and outputs of MDT meeting includes:

- Written information provided by the child's paediatrician:
 - Detailed care plan for day to day clinical management, out-of-hours plan, escalation plan and advance care plan, who needs to be involved when - agreed by all parties.
 - o Name and contact details of the GP & CNC
 - o Name and contact details of a named consultant paediatrician and consultant in adult palliative medicine – agreeing to provide shared care and support the GP, and ensure that on-call cover is accessible
 - o Name and contact details of consultant in paediatric palliative medicine involved, especially if child's underlying condition will affect symptom management or delivery of symptom control
 - o Agreement about arrangements for writing, dispensing and administering medication, including syringe driver if required
 - o Name and contact detail of regional consultant paediatrician with an interest in palliative medicine (may be the same person as the consultant in paediatric palliative medicine, depending on the region)
- Offer of overnight stay or consultation at regional hospital to connect with named regional consultant paediatrician
- Structured written handover in the child's My Story folder
- As levels of service, availability and out of hours cover varies, each local service may wish to produce a patient information (or service user) leaflet for the child and their family which can support informed decision making.

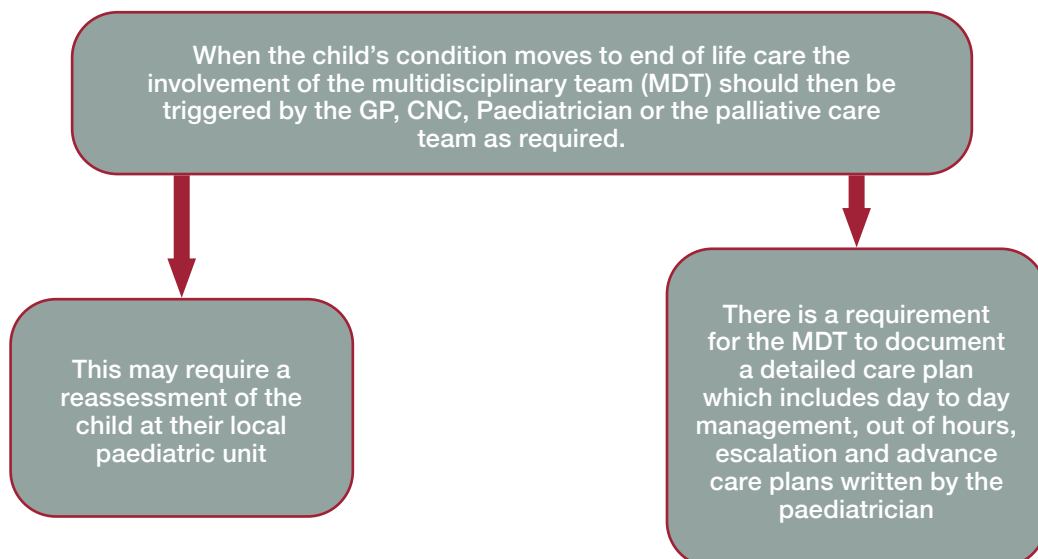
On Discharge



At Home and Stable



At Home and at End of Life



Palliative care for neonatal infants

The care of women whose babies have been diagnosed with a life limiting condition, including the care of her infant prior to, during and after delivery while in the maternity unit, is described in the pathway guide published by the National Implementation Group for the HSE Standards for Bereavement Care following Pregnancy Loss and Perinatal Death⁽¹¹⁾.

When a newborn baby is known to have a life limiting condition, either diagnosed prior to delivery or shortly after, the care of the baby is undertaken and overseen by the neonatal services within the maternity unit. Nationally there are variations in the structure of the maternity services such that a baby may be under the care of a doctor specialising in their practice only in neonates or a doctors who also practices in general paediatrics. In the case of the latter, the neonatal doctor becomes the paediatrician. Where the neonatologists do not have

a remit in general paediatrics, local arrangements are made between neonatal and paediatric teams, following discharge from hospital, to ensure there is no gap in care during the transition time. Until the paediatrician assumes care, the neonatal team oversee the care and function as the de facto paediatrician. At the point of readiness for discharge home of a surviving infant with a life limiting condition, referral to the GP, CNC and other appropriate services, if not already made, are based on the needs of the infant and family. This may include the primary care team, community specialist palliative care team, and the voluntary sector. Engagement in the processes 'prior to discharge' and 'on arrival home' described above should take place to promote safe and considered transfer home. Every effort should be made for timely referrals acknowledging the very short timeframes that are sometimes inevitable.

Out of hours care for the child in the community

The GP, or in his/her absence the deputising GP, continues to provide medical care for the child during out of hours. The CNC will coordinate advance care planning and ensure that prior decisions and lines of communication are documented in the 'My Story' folder, a copy of which is emailed to the GP to ensure this information is known to him/her and communicated to the deputising services. This must be updated as necessary. The paediatric services and community palliative care services will also receive a copy of the 'My Story' folder and ensure appropriate on-call and out of hours information sharing arrangements are in place in their own service.

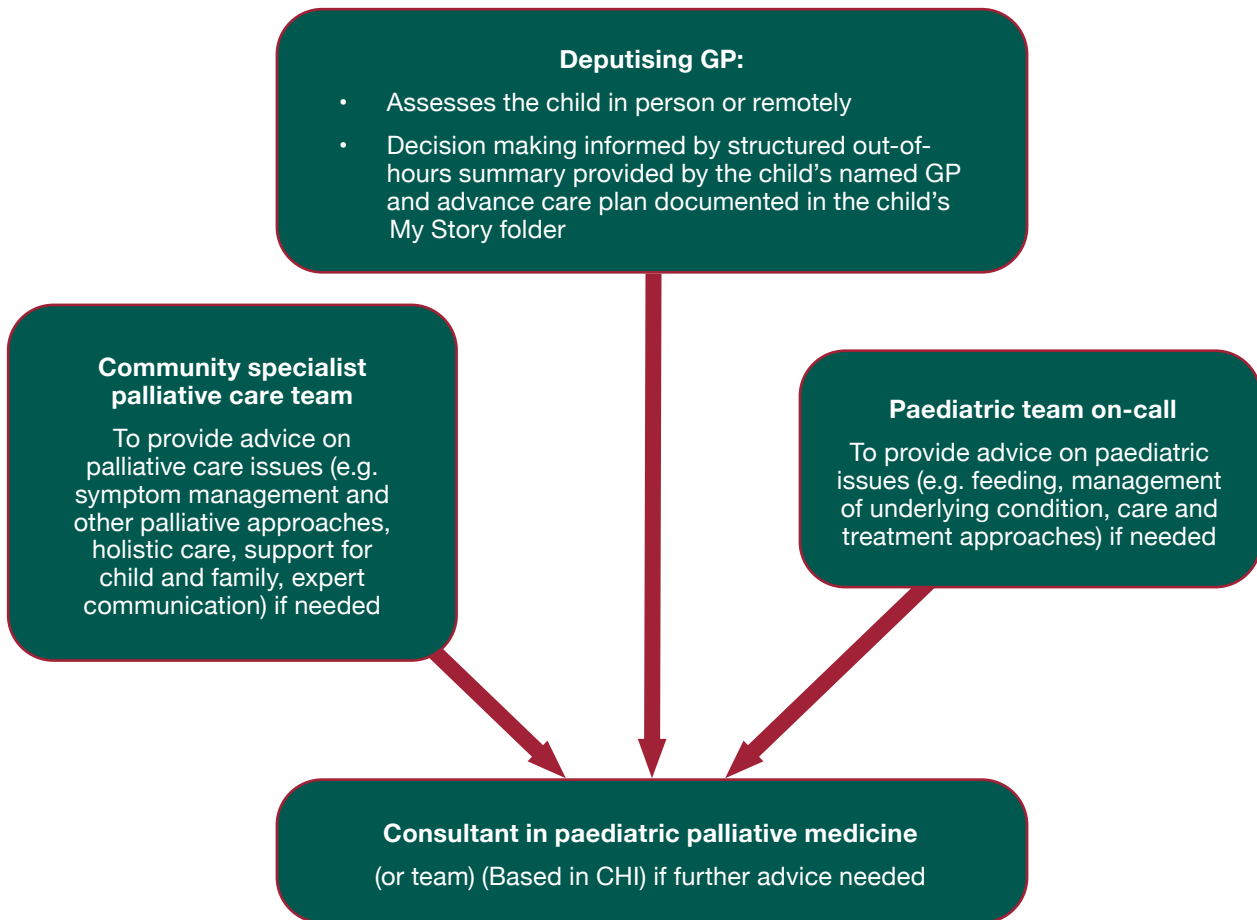
When a child is deteriorating or near end of life, their GP must ensure that up to date information about the child and their care needs is available to

deputising GP colleagues during out of hours. This will utilise existing processes such as the structured out-of-hours summary to the deputising services: hospicefoundation.ie/healthcare-programmes/primary-palliative-care/gp-out-of-hours-palliative-care-project/.

The summary for the deputising GP should include contact details for the consultant in adult palliative medicine and the consultant paediatrician on-call at the local hospital, so they can confer if required. Where any of these individuals require further advice, they will be able to call the consultant in paediatric palliative medicine for remote advice.

This information will help to support those making decisions out-of-hours, particularly where a situation has arisen that has not been anticipated.

Out of Hours



If the child no longer requires ongoing specialist palliative care

If the child's condition improves, the community specialist palliative care service may reduce the intensity of their involvement as would be their practice with any patient who no longer requires ongoing specialist palliative care input. The ongoing care and support of the child and family will revert to the process described under 'care for a child at home who is relatively stable' above. This would be agreed with the child's GP and paediatrician. The CNC and other members of the MDT involved will be informed. Plans for potential future involvement may be formulated and documented at this stage.

Recommendations

The scenarios above provide an outline of the practice and processes which can support optimum clinical decision making and care for a child with palliative care needs. The following recommendations are made by the Expert Advisory Group to support and enhance this practice over time.

In making the following recommendations, the Expert Advisory Group is cognisant of the developing structures and policies under Sláintecare and the transformation of children's healthcare under CHI. These recommendations are made in the context of current structures, recognising that as things develop they may evolve, however their underlying intention will remain unchanged. Different regions may need to prioritise these recommendations in different ways. The intention of this report is to strengthen governance arrangements and consistency, not to disrupt existing arrangements and planned developments.

Governance and professional practice

1. Each child with end of life needs, to have an identified core team of healthcare providers that includes a named paediatrician in the acute hospital closest to their home, palliative care provider, GP and aligned Clinical Nurse Coordinator. This core team is supported by a network of regional paediatricians with a special interest in palliative care for children or palliative care specialists.
2. Ensure paediatric palliative care is considered in the development of local governance frameworks.
3. Structured discharge protocols, including a requirement for an MDT meeting with defined outcomes, to be locally agreed.
4. Clear arrangements for communication channels between all the professionals involved in the care of children at end of life in the community, to be locally agreed, documented and widely known.
5. The Association of Paediatric Palliative Medicine formulary to be used as the standard formulary in conjunction with clinical judgement and advice from specialists in paediatric palliative medicine as required to support standardisation of prescribing practice by non-specialists in paediatric palliative care.
6. Structured out-of-hours summaries to be used by GPs to communicate essential information to GP deputising services and community specialist palliative care teams to enable rapid, effective out of hours decision-making.
7. Improve information sharing through continued advocacy for digital shared records that enables key information to be shared across organisational and geographical boundaries in real time.
8. With the growth in numbers of CNCs, ensure that the children's outreach governance framework for children with life limiting conditions is reviewed to remain fit for purpose.

Strategic

9. The ongoing development of national, regional and local workforce provision aligned with national strategies under agreed governance models to support end of life care for children.
10. Re-establish regional committees to provide strategic direction and ensure integration of services at a local level in line with palliative care national policy recommendations. These committees need to ensure that as part of a whole population approach to the development of specialist palliative care services, the needs of children and young people are taken into account.

Education and Training

11. Establish an education group to:
 - (a) agree a set of competences for primary care, paediatric and adult palliative care teams to enable safe and effective end of life care of children in the community, building on the Palliative Care Competence Framework.⁽¹⁰⁾
 - (b) develop a comprehensive education and training plan to meet those competences and fulfil the following:
 - i. Core palliative care skills for paediatric and primary care teams,
 - ii. Paediatric palliative care skills for adult palliative care teams and CNCs,
 - iii. Core palliative care skills for the paediatric home care and voluntary sector and contracted providers,
 - iv. Mechanisms for enabling rapid top-up training and mentorship whenever this is needed to care for a child at end of life.

12. Consideration should be given to incorporating specialist palliative medicine training in paediatric higher specialist training posts. The timeframe and numbers of posts to be considered.
13. Consideration should be given to incorporating curricular content and training in paediatrics within the adult palliative medicine higher specialist training programme.

Workforce

14. An implementation plan which enables additional workforce to be appointed within 3-5 years: (an expanded description of these roles are in **Appendix A** page 19)
 - a. CNC – 11.5 WTE currently in place. Funding is in place for a further 4.5 WTE and these should be appointed without delay. The posts need to be allocated so as to ensure at least two CNCs per region. Build towards 22 WTE to mitigate against current issues of lone working and patch operational resilience. Ensure consistency in role descriptions and supporting structures. Ensure CNC National Coordinator role (funding already in place) is successfully appointed. The CNCs Education and Governance Framework should be reviewed and amended to reflect developments in children's palliative care and emerging regional structures (see 7 above).
 - b. Consultant paediatricians with an interest in palliative medicine (level 2 - see Annex D for description) – appoint one for each region that does not have a consultant in paediatric palliative medicine. They should have 40% time allocated within job description for providing advice, consultation, direct care in some instances, clinical and strategic leadership for the region, and ideally, be able to provide advice and support in the community. Time and funding will need to be secured for the additional training they require to fulfil this role.
 - c. Consultants in paediatric palliative medicine (level 3 – see **Appendix D** for description) – there is a requirement to increase the current 2.2 WTE to 5 WTE in the country to enable them to provide 24 hour national on-call cover and an expanded role in workforce development, including the training and development of the level 2 regional consultant paediatricians, nursing and wider MDT workforce and others involved in delivering palliative care for children. They will provide the level 2 function for their region and may provide a mentoring function for another region outside their own. Consideration should be given to formal recognition of the existing 2.2 WTE as consultants in paediatric palliative medicine.
 - d. Review the need for additional CNSs in adult and paediatric palliative care as part of the wider nursing workforce development.
15. Review resourcing available to Primary Care, including GPs, to provide palliative care to children with life limiting conditions. This should include consideration of children's palliative care needs in discussions about the new GP contract.

Appendices

Appendix A

The following roles are required in every case where a child is discharged home to die. The descriptors under 'key role' set out the specific contribution of each clinician, as compared to another, in the clinical governance context of a child dying at home. The description is not meant to be comprehensive nor all-encompassing of all their skills, knowledge and expertise in the wider context. Nor does it describe the holistic nature of the care the child and family deserve, which is the responsibility of everybody involved.

Clinician/service	Key roles
GP	Plays a lead role in the care of the child in the community;
	Shares responsibility for clinical decision making along with named consultant paediatrician and consultant in adult palliative medicine;
	Understands family, environment and social context and current medical status;
	Holds complete set of records and communication;
	1st point of contact - assesses child (in and out of hours) as required before seeking advice from the child's paediatrician or consultant in adult palliative medicine as appropriate;
	Briefs colleagues and deputising GPs about the situation for out of hours and weekends, including providing structured written out-of-hours summary.
Consultant paediatrician	Shares responsibility for clinical decision making along with the child's GP and consultant in adult palliative medicine;
	Provides expertise and advice on paediatric issues, including the underlying condition, care and treatment approaches, feeding, etc.;
	Briefs paediatrician on-call for out of hours and weekends;
	Consults the named consultant in palliative medicine / local specialist palliative care inpatient unit for advice;
	Consults the paediatrician with an interest in palliative medicine or the consultant in paediatric palliative medicine for remote advice if required;
	Ensures that the GP holds the repository of all key information and decisions by making sure the GP is kept informed;
	NB: In some instances, e.g. in a young person at the transition stage, the local consultant 'paediatrician' may in fact be an adult physician.
Consultant in adult palliative medicine	Shares responsibility for clinical decision making along with the child's GP and named consultant paediatrician;
	Provides expertise and advice on aspects of end of life care which includes symptom management, holistic care, support for the child and family, expert communication and other palliative care approaches;
	Supports their community specialist CNS colleagues;
	Consults consultant paediatrician, consultant paediatrician with an interest in the palliative medicine or consultant in paediatric palliative medicine for advice if required;
	Ensures that information is shared with all relevant team members that are central to the child's care.

Clinical Nurse Coordinator for Children with Life-limiting Conditions (CNC)	Takes on named coordinator role for child and family;
	Coordinates involvement and communication of other clinicians and services to ensure the child and family's physical, emotional, practical and information needs are met with the minimum required disruption of their lives;
	Encourages the parent-held folder 'My Story' to be kept up to date;
	Wherever possible, be present to support if/when a new clinician or service is introduced to the child and family.
	Elements of the role described in this document as Clinical Nurse Coordinator for Children with Life Limiting Conditions are sometimes undertaken by other professionals such as Paediatric Link Nurse, or CNS in Paediatric Palliative Care depending on geographic availability and resourcing. Descriptions of the role undertaken by the CNC in this document are not intended to limit the input of other such professionals and should be read to include other roles, as appropriate.
Community specialist palliative care CNS	In consultation with their consultant lead, provides expertise and advice on palliative care based on experience of large numbers of adult patients and smaller number of paediatric patients, including care planning, holistic care and supporting families during this time;
	Sets up and maintains syringe drivers where there is no suitable alternative locally;
	Refers paediatric nursing issues to the CNC or paediatric palliative care CNS.
Consultant Paediatricians with an interest in palliative medicine (Level 2 – see terminology)	A key recommendation of this report is that those caring for children with life limiting conditions will have access to a consultant paediatrician with a an interest in palliative medicine based in their region (this function is provided by the consultant in paediatric palliative medicine instead, in the Sláintecare regions where this exists). It is expected that they will have had additional training and experience in palliative care, perhaps to diploma level, and to have some dedicated time for paediatric palliative medicine within their job description (0.4 WTE) to provide advice, consultation, direct care in some instances, and clinical and strategic leadership for the region. This includes engaging with their local specialist palliative care unit for relationship building and education.
	They will provide the first point of contact for paediatric palliative care advice and support for GPs, consultants in adult palliative medicine and named consultant paediatricians. In some situations, they may act as the named consultant paediatrician themselves. They will work closely with the CNC to ensure oversight for all dying children in their region. They are usually indirectly involved but may have met the child earlier.

In addition, depending on the circumstances, some of the following may also be involved, as required:

Clinician/service	Key responsibility
Paediatric palliative care (PPC) CNS	Formally hand over coordinator role in the care of the dying child to the local CNC when the child is discharged home to die;
	PPC CNS may join the local CNC for a joint first assessment at home as part of the handover process;
	May provide mentorship and act as a point of contact and resource for advice for the CNC in specific situations where this has been agreed.
Other members of the primary care team (GP role described above)	Public health nursing, occupational therapists, physiotherapists, pharmacists and social workers may be involved in providing care and support in the community as part of the primary care team.
Nursing services provided under HSE contract or by voluntary sector and others	Hands on nursing care may be provided by private providers under HSE contract and/or by Jack and Jill Children’s Foundation, LauraLynn Ireland’s Children’s Hospice, and Irish Cancer Society/Irish Hospice Foundation Night Nursing Service.
Consultant in paediatric in palliative medicine (Level 3 – see terminology)	Provides specialist paediatric palliative medicine advice and support to GPs, consultants in adult palliative medicine, consultant paediatricians with an interest in palliative medicine, consultant paediatricians on call and nursing colleagues, on a 24 hour on-call basis.

Appendix B

Current risks/blocks and potential mitigation

Risk or block	Mitigation
Confusion over titles of paediatric palliative medicine roles and what these mean	Clarify by using terminology set out in Appendices A and D.
<p>Current variation in regional or local operational and governance arrangements.</p> <p>There is an ongoing risk in relation to the definition of the age of a child versus an adult in hospitals around the country. In at least two regions a 14 year old will be admitted to the adult wards and not have a local paediatrician.</p>	<p>The governance and operational model proposed is based on the new 6 regions being implemented under Sláintecare should enable similar expectations wherever the child is living. Explicit governance arrangements for paediatric palliative care to be included in service level arrangements.</p> <p>Explicit acknowledgement that different age criteria may be applied by different hospitals.</p>
Current variation in workforce across the country, leading to lone working and lack of cover for holiday and sickness	<p>Building workforce capacity in:</p> <ul style="list-style-type: none"> • additional CNCs • additional consultants in paediatric palliative medicine • additional consultant paediatricians with an interest palliative medicine. <p>National Coordinator for CNCs (role already funded) to standardise job descriptions and ensure coordination, training and education.</p>
Current variation in resourcing available to adult palliative care services, leading to a lack of out of hours cover for adults and children with palliative care needs.	Building workforce capacity and incorporate into long-term workforce planning.
Lack of succession planning to ensure sustainability of services	<p>Increase numbers of CNCs.</p> <p>Incorporate palliative medicine training within 2 of the paediatric higher specialist training posts to provide a pipeline for paediatricians with an interest in palliative medicine.</p>
Lack of recognition of significant needs and responsibilities involved for the GP and primary care teams in caring for a dying child in the community	<p>Proposed model makes it clear that the GP and primary care team are supported by the community specialist palliative care teams, the regional paediatric services and CNC. Keep GPs informed and offer remote MDT options for input and communication.</p> <p>Enhance the support provided to GPs through increased availability of CNCs and paediatricians with level 2 and level 3 expertise in paediatric palliative medicine.</p> <p>Review resourcing available to Primary Care, including GPs, to provide palliative care to children with life limiting conditions.</p>

Adult specialist care staff are unable to maintain their skills and have confidence in paediatric care, recognising that they are not involved frequently enough to maintain their skills	<p>Education group to work out the requirements and logistics to mitigate this.</p> <p>Enhance the support provided to adult specialist palliative care teams through increased availability of CNCs and paediatricians with level 2 and level 3 expertise in paediatric palliative medicine.</p>
CNCs able to maintain their skills and confidence in palliative care	Education group to work out the requirements and logistics to mitigate this.
Lack of clarity over who holds clinical responsibility and how to seek advice out of hours	Proposed model sets out the triumvirate of care and out of hours structures.
Reliance on grace and favour arrangements leads to unreliable provision and/or exposure of staff to inequity	Proposed model with increased and distributed workforce and agreed responsibilities.
Risk of not being able to ensure adequate levels of education and training where care is provided by voluntary sector and contracted providers	<p>Voluntary sector and contracted providers have systems for ensuring education and training is maintained for their staff.</p> <p>Local governance arrangements for all competences (beyond paediatric palliative care) needs to be established.</p>
Risk of not being able to provide comprehensive cover for hands-on care due to excessive reliance on voluntary sector and contracted providers	This needs to be part of long term workforce planning and contracts.

Appendix C

Katie

Katie is a 10 year old girl from Co. Laois, transferred up to CHI tertiary hospital in Dublin for admission due to a sudden onset of left sided weakness, needing further imaging and neuro-surgical review.

Imaging shows tumour, biopsy confirms malignancy with no surgical intervention, poor prognosis, estimated to be days to short weeks. Meeting held between family and Medical/Neurosurgical teams, along with Paediatric Palliative Medicine and Clinical Nurse Coordinator (CNC). Discussion around options and 3 locations of care: stay in tertiary centre, transfer back to closest paediatric unit, or go home. Parents advised that should they choose home as their preferred option, Katie would be transferred back to closest paediatric unit for approximately 24 hours to facilitate local service involvement. The family were also made aware of the limitations of home nursing support, but that the local CNC in Laois would liaise with them directly to give them more information about what may be available to them (Irish Cancer Society nurses, home care package hours, etc.) if they choose to go home.

Family are clear that their wish is to care for Katie at home, with their extended family for support. Following this meeting:

- Phone call made (consultant to consultant) to discuss and confirm acceptance and bed availability in the paediatric unit.
- MDT meeting called. As the local team were in Laois, teleconference facilities provided. The MDT involved:
 - Consultants from tertiary centre (admitting medical team, neurosurgical team, and palliative medicine), CNM and relevant CNS in Paediatric Palliative Care, and team from local paediatric unit (consultant, unit CNM, relevant CNS in Paediatric Palliative Care).
 - CNC from tertiary centre (or CNS in Paediatric Palliative Care) and CNC from Laois.
 - Members of Community Specialist Palliative Care Team from Laois.
- Transport via BUMBLEance arranged for the following day as bed available in Laois, and parents anxious to get home.
- Arrangements made locally for the regional consultant paediatrician and members of the community specialist palliative care team to meet the family together on the paediatric unit the following afternoon to discuss arrangements for care at home.
- Comprehensive discharge letter provided when leaving the tertiary centre and a transfer letter with current symptom management plan accompanied Katie to Laois.

Mia

Mia is 6 and from the West. She is admitted to her tertiary centre in Dublin for planned treatment for her metabolic haematological disorder. Unfortunately, it is evident on admission and assessment that she is less well and her disease is no longer amenable to treatment. Other organs are now demonstrating dysfunction. It is expected she will continue to deteriorate in the coming weeks. In view of her treatment not being undertaken, her treating paediatrician discusses the new findings and implications after the ward round. Her parents are understandably devastated and wish to be discharged immediately. Mia and her parents are advised of the plan to engage with the paediatric team at her nearest paediatric unit, to refer to the community specialist palliative care team (SPCT) and allied colleagues, and to undertake a teleconference prior to her transfer back to her nearest unit, prior to facilitating her discharge home. Her parents are made aware of the limitations of home nursing support, the role of the SPCT and paediatrician in symptom management, and that the local CNC will liaise with them directly to give them more information about what may be available to them (Irish Cancer Society nurses, home care package hours, etc.) when they are at home.

Mia's parents request that the treating team circumvent the plan to visit their local hospital and seek to leave the hospital within an hour. They express they do not wish to know their local paediatric team, having never attended the unit. They request urgent letters and prescriptions. They are given the opportunity to discuss their sense of urgency and are once again advised that a safe discharge is everyone's priority, and of the recommendation for transfer via their nearest paediatric unit particularly noting Mia's death is not expected in the immediate hours or days following. Parents share their disappointment and are angry, and intent on leaving the hospital to go home.

Teleconference is undertaken and documentation is shared securely via email. The hospital team take a 'safety pause' to reflect. Alternative routes of discharge are considered and explored, but the safest mode of discharge is still agreed to be via their nearest paediatric hospital.

Mia's treating paediatrician meets with the parents again. They remain frustrated at what they perceive to be time wasted. Their frustration and anger are acknowledged and they are asked if they wish to understand more about the treating team's reasons for the current discharge plan. They decline but agree to the transfer, noting that if that is the only way home they wish to 'get on with it.'

Communication is expedited and Mia and her parents leave the hospital with a hard copy of their referral documentation forwarded to all teams including Mia's GP, the paediatric team in their nearest unit, the community specialist palliative care team, the CNC and public health nurse. Voluntary sector service referrals are completed remotely by the CNC and submitted with parents' expressed verbal consent. The time spent in the local paediatric unit is kept short and Mia's parents are able to take her home one day later.

David

David's parents were referred to palliative care following recognition during pregnancy that he had a cyanotic congenital cardiac abnormality for which no medical or surgical intervention was possible. It was considered that David had equal chances of dying in the hours after or surviving for days to short weeks. Multidisciplinary discussion took place at multiple stages regarding the obstetric management of David's mother and care for David in the perinatal time, resulting in a recommendation that he be delivered in a tertiary unit in order to facilitate early post-natal echo to confirm the antenatal findings as per his parents' expressed request. Subsequent discussions with the parents involved the neonatal team and foetal medicine midwives, to inform them of the supportive care which would be provided to David upon his birth. This plan was shared with them, and they were also informed of the possibility, but not promise, of short term survival. Prior to delivery, David's CNC was made aware of the case.

Following delivery, anticipatory prescribing was undertaken. David remained comfortable and was cared for, with his mother, on the gynaecological ward. His post-natal echo was consistent with the antenatal findings. His parents expressed a desire to spend some time in their home with him. His local CNC was advised of the delivery and when David's mother was deemed 'fit for discharge' home, the neonatal team and discharge co-ordinator liaised with the GP, PHN, regional consultant paediatrician and local community specialist palliative care team. With consent from parents, referrals were also made to a voluntary sector provider. Written advice regarding symptom management and anticipatory medications were provided from the discharging neonatal unit, to the parents, and the plans were shared with the above professionals. The parents were made aware of the limitations of home nursing support, and that the local CNC would liaise with them directly to give them more information about what may be available to them (Irish Cancer Society nurses, Jack and Jill, Laura Lynn, home care package hours, etc.) if they choose to go home and should David survive days into weeks.

Prior to discharge, agreement was reached via teleconference call organised by the child's Paediatrician, with regards to the following:

- Plan for GP review
- Referral to Community Palliative care Team in writing
- Out of hours contact numbers queries parents had
- Plan for verifying/pronouncing death and for issuing Notification of Death Certificate
- Plan for PHN/CNC / community palliative care team home visits (together where possible)
- Plan for engagement, with parents' permission, with the voluntary sector.
- Plan for paediatric review appointment

Acknowledging the anticipation of a short life (possibly hours to days) and taking his parents' strong preferences into account, transfer via nearest paediatric unit was omitted following multi-professional discussion and agreement.

Appendix D

Terminology for levels of care:

The Irish Report of the National Advisory Committee on Palliative Care recommended that palliative care services (largely providing care to adults) should be structured in three levels of ascending specialisation. We have adapted these for paediatrics aligning with the HSE published 'Palliative Care Competence Framework (2014) for members of the multi-professional team who provide care to both adults and children. These levels refer to the expertise of the health professionals delivering the palliative care services:

Level 1 – Palliative Care Approach

Palliative care principles should be practiced by all health care professionals. The palliative care approach should be a core skill of every clinician at hospital and community level. Many individuals with progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel. This would include all paediatricians and general practitioners, and primary and secondary care teams

Level 2 – General Palliative Care

At an intermediate level, a proportion of individuals and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care, perhaps to diploma level. Such intermediate level expertise may be available in hospital or community settings.

Health care professionals who wish to undertake additional training in palliative care should be supported in this regard by the hospital group or other employing authority. This would include some general practitioners, and some consultant paediatricians with a special interest in palliative medicine.

Level 3 – Specialist Palliative Care

Specialist palliative care services are those services whose core activity is limited to the provision of palliative care. These services are involved in the care of individuals with more complex and demanding care needs, and consequently, require a greater degree of training, staff and other resources. Specialist palliative care services, because of the nature of the needs they are designed to meet, are analogous to secondary or tertiary health care services. This would include consultants in adult palliative medicine and also consultant paediatricians in paediatric palliative medicine.

Source: Ryan K, Connolly M, Charnley K, Ainscough A, Crinion J, Hayden C, Keegan O, Larkin P, Lynch M, McEvoy D, McQuillan R, O'Donoghue L, O'Hanlon M, Reaper-Reynolds S, Regan J, Rowe D, Wynne M; Palliative Care Competence Framework Steering Group. (2014). Palliative Care Competence Framework. CHI Dublin: Health Service Executive

Appendix E

Clinical governance and operational arrangements for supporting a model of care for children with life limiting conditions who have palliative care needs in the community

Development of the framework

In November 2019 the need to review and enhance the governance arrangements for the Model of Care for paediatric palliative care was recognised. An Expert Group was convened by the Chief Clinical Officer of the HSE, focused on reviewing the clinical governance of care for children who are at end of life in the community, usually in their own home. The Expert Group was commissioned jointly by the National Clinical Advisor and Group Lead for Older Persons, Dr Siobhan Kennelly and National Clinical Advisor and Group Lead for Primary Care, Dr David Hanlon. An independent Chair, Professor Bee Wee, was appointed to the Expert Group. The expertise represented on the Expert Group included:

- Consultant in Paediatric Palliative Medicine
- Consultant in Palliative Medicine
- Clinical Nurse Coordinator for Children with Life Limiting Conditions
- Assistant Director of Nursing Palliative Care
- Paediatric Nurse Specialist
- Director of Public Health Nursing
- GP
- Education Specialist in Paediatric Palliative Care
- Consultant in Paediatrics

Terms of Reference

The Expert Group's Terms of Reference were as follows:

1. Describe the current clinical governance models and arrangements currently in operation between adult palliative care services and other services (including paediatric and primary care) in the provision of care for children with life limiting conditions towards the end of life.
2. Make recommendations on adjustments that would strengthen the clinical governance model and operational arrangements within the Irish context reflecting need for training and / or resource as appropriate.

Process

To achieve these Terms of Reference the Expert Group met on 5 occasions: December, January, February, March and August 2020. By the end of January 2020 the group had developed a consultation plan, including a framework 'discussion document'. Over the course of January, February and March the following groups were represented at focus group meetings to discuss and revise the framework:

- Consultants in Palliative Medicine
- Clinical Nurse Specialists in Palliative Medicine
- Clinical Nurse Coordinators for Children with Life Limiting Conditions
- Consultants in Paediatrics with special interest in palliative care
- Clinical Nurse Specialists in Paediatric Palliative Care
- Consultants in Paediatrics
- Consultants in Neonatology
- Community and Voluntary Groups providing paediatric palliative care services
- Children's Health Ireland
- GPs reviewed the discussion document and provided written feedback
- The views of Public Health Nurses, education specialists in paediatric palliative care, nurse link coordinators, and others were captured by representatives on the Expert Group.

It was not possible to capture the views of all interested parties and some views were contradictory. The Expert Group considered that the consultation process reached a critical mass to ensure that all views were heard, although given their sometimes competing nature, not all views could be reflected into the final recommended Framework. The outcome of the consultation was consolidated by the Expert Group into a Framework document.

A penultimate draft Framework document was circulated to the Expert Group, Clinical Advisory Group for Paediatrics, Clinical Advisory Group for Palliative Care, Children's Health Ireland and the Irish College of General Practitioners in July 2020. Based on feedback received, the document was revised and submitted as a recommendation to the National Clinical Advisors and Groups leads for Older Persons and Primary Care in August 2020.

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Breda Devitt	Administrator, Office of the Chief Clinical Officer, HSE

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Irish Hospice Foundation
Irish Cancer Society

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