
Palliative Care Services

THREE YEAR
DEVELOPMENT
FRAMEWORK
(2017 – 2019)



HSE PRIMARY CARE DIVISION 2017



Building a
Better Health
Service

Seirbhís Sláinte
Níos Fearr
á Forbairt

Foreword from HSE National Director Primary Care

Palliative care is an active and total approach to care from the point of diagnosis through to death and beyond. It embraces the physical, emotional, social and spiritual elements of care and engages with patients and families as equal decision makers in that care.

As a country we are fortunate to have in place the National Advisory Committee Report on Palliative Care which, although published in 2001, continues to guide the development and provision of palliative care services in Ireland. The fact that the Report is still relevant today is testimony to the quality and vision of the document. However, the healthcare landscape has changed very significantly since then and whereas it is important to retain much of what the 2001 Report espoused it is also important to acknowledge that the needs of the population have also changed.

The aim of this Framework is to provide an improved and evolving quality palliative care service that meets the needs of individuals and their families in all care settings. Its ambition is to ensure a seamless care pathway across inpatient, homecare, nursing home, acute hospital and day care services.

One of the very widely acknowledged successes of palliative care has been the genuine partnership approach adopted across statutory and voluntary organisations. Without this cooperation it is very much doubtful that we would have achieved so much since 2001, and it is this continued approach that will help ensure that every individual, regardless of diagnosis or location, will have access to the type of service that they need. The HSE will fully engage with the Department of Health and our voluntary partners to progress the implementation of the Framework recommendations and to agree the way forward for palliative care.

I would like to sincerely thank Pat Quinlan the Chair of the Steering Group, Kevin O'Dwyer the Framework Project Manager and each member of the Steering Group for their work and dedication. I would also like to acknowledge all those who contributed to the development of the Framework during the consultation phase.

I endorse the publication of this Framework in the confidence that it remains true to the vision of the National Advisory Report on Palliative Care and that it will continue to progress the development of palliative care services in Ireland.

"You matter until the last moment of your life, and we will do all we can, not only to help you die peacefully, but to live until you die."

Dame Cicely Saunders, founder of the hospice movement.



JOHN HENNESSY

National Director Primary Care

Foreword from Chairperson of the Framework Steering Group

This Development Framework (2017 – 2019) was commissioned by the HSE. The objective of the Framework was to inform and direct the development of adult palliative care services, both generalist and specialist, in Ireland for the three-year period. In so doing, the focus of the Framework was to identify the gaps that exist in the current level of service provision and to present a set of recommendations and actions which over the duration of the Framework (and at times beyond) would seek to address these service issues / deficits, subject to available resources.

In order to achieve this objective a Steering Group, with representation from the key stakeholders in palliative care, both statutory and voluntary, was appointed, and assigned the task of overseeing the Project. In addition, a Project Manager was appointed to support the work of the Steering Group and this position was co-funded by the HSE and the Voluntary Hospices Group.

From the outset, the Steering Group fully endorsed the vision and principles, enshrined in the 2001 *Report of the National Advisory Committee on Palliative Care* (DoHC) (NACPC) which, as current government policy, continues to direct national palliative care strategic development. Indeed, many of the recommendations contained in the Framework are based on those set out in the original NACPC Report.

A key objective for the Steering Group was to seek to improve access to palliative care services across the country, particularly in those areas which for the last number of years have been identified as inpatient service 'blackspots'; there are clear recommendations contained in the Framework which, on implementation, will achieve this objective. The other areas addressed include improved palliative care service delivery in both community and acute hospital services, with a major focus being placed at all times on the delivery of quality person-centred, safe care for patients and their families. Worthy of note is that all of the above link back to the goals and objectives contained in the HSE's Corporate Plan, *Building a high quality health service for a healthier Ireland - Health Service Executive Corporate Plan 2015-2017* (2015).

The overall timeframe set for compiling this report was approximately seven months, and within this limited period, focused consultation took place with many key stakeholders, including service user representative bodies and representative organisations in palliative care, and an online survey tool was also used to gain feedback from healthcare staff and management. Feedback from all of these sources was fully considered in framing the final draft report.

The consensus within the Steering Group, was to recommend that the proper and comprehensive development of palliative care services should be planned out in a number of phases as follows:

Phase 1: The publication of a Three Year Development Framework covering the period 2017 - 2019.

Phase 2: An updated government policy based on the revision by the Department of Health of the 2001 NACPC Report, to take place in 2018 – 2019.

Phase 3: Commence the implementation of the recommendations contained in the new policy in 2020.

The Framework gives full cognisance to the context for planning palliative care service provision in Ireland in the years ahead, with due consideration being given to Ireland's ageing population, a growing demand for services, the need to improve access across the country, the full inclusion of patients with chronic illnesses, increasing cultural diversity, support for the move away from acute hospital-centric health service delivery to care delivery at/or close to home, and seeking to ensure optimum integration and efficiencies in all settings. A major aim of the Framework was to set out a series of recommendations which could address these issues over time.

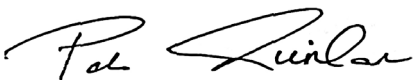
The economic case for investment in palliative care is well established, evidence-based and firmly grounded. It demonstrates that fully developed inpatient hospice services alongside properly resourced community services, can substantially reduce the level of acute admissions for patients with both malignant and non-malignant diseases, particularly in the last three months of life – in these instances the number of people being cared for at home significantly increases. This leads to cost savings within acute hospitals, as well as a reduction in inappropriate hospital admissions, a more appropriate care pathway, and an improved experience for patients and their families.

While the Framework proposes targeted investment to develop service provision over its timeframe and bring service levels to those recommended in the 2001 NACPC Report, there is no doubt that the return on such investment will greatly benefit patients and their families and ultimately the wider healthcare sector.

I would like to thank all of those who supported and contributed to this process during the various stages of consultation, which was very much appreciated.

I wish to also take this opportunity to thank my fellow members of the Steering Group for their hard work, professionalism and commitment given to this initiative. I am also very appreciative of the input and direct support received from, Dr Karen Ryan, HSE Clinical Lead, Palliative Care Programme and Sheilagh Reaper Reynolds, HSE National Lead for Palliative Care, who, within their respective roles greatly assisted in advancing this project.

A special word of acknowledgement and thanks to Kevin O Dwyer, Project Manager, whose input, expertise, resilience, commitment and overall contribution to the development of the Framework allowed so much to be achieved within what was a very tight timeframe.



PAT QUINLAN

Chairperson- Steering Group

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SECTION 1 Overview

1.1 INTRODUCTION

The National Director for Primary Care, who has overarching responsibility for palliative care within the HSE, requested a new Palliative Care Development Framework for the three years 2017 to 2019, and appointed a Steering Group to undertake the work. The terms of reference for the Steering Group are shown in Annex A and the membership of the Steering Group is listed in Annex B.

1.2 OBJECTIVE AND SCOPE OF THE FRAMEWORK

The objective of the Development Framework is to inform and direct the development of adult palliative care services in Ireland for the three year period from 2017-2019. It will build on existing policy and development documents, remaining true to the principles and vision described in the 2001 National Advisory Committee on Palliative Care (NACPC) Report¹ which was adopted as government policy, and directs national palliative care strategic development.

The focus of the Framework is on adult palliative care services and, while recognising that adult services do provide care for children and their families, it does not attempt to address the needs of children's palliative care. However, the Framework recognises that there will always be a need for ongoing interaction between adult and children's palliative care to ensure optimum synergy in policy development and service integration.

The HSE's 2009 Development Framework² dealt almost exclusively with specialist palliative care services; this Framework considers both generalist and specialist palliative care.

A focused review of the literature was carried out, in parallel with an initial consultation process with key stakeholders. A formal and wider consultation process followed, requesting feedback via an on-line survey on the main recommendations of the Framework. All feedback was analysed and systematically discussed by the Steering Group, and taken into account in the final draft of the Framework.

1.3 APPROACH

The initial approach adopted in the drafting of the Framework was to identify the gaps that exist in the current level of service provision, and to highlight what needs to happen over the lifetime of the Framework to progress or achieve the desired outcomes. From an early stage in the process, it became apparent to the Steering Group that it was not possible in the given timeframe to adequately research and analyse all the issues identified as requiring action, and therefore a three phase process was suggested by the Steering Group as follows:

Phase 1: Production of the Three Year Development Framework in which as many issues as possible would be identified and addressed within available resources over the period 2017 - 2019.

Phase 2: Development of new government policy based on a review of the NACPC Report for drafting in the period 2018 – 2019. This policy will guide and inform future palliative care strategic planning processes. Some preparatory work and the establishment of working groups as recommended in the Framework should commence in 2017. As this phase refers to policy revision it will be led by the Department of Health.

Phase 3: Commence the implementation of the recommendations contained in the new policy in 2020.

1.4 LAYOUT

The Development Framework is presented in five sections. Section One sets the context for the Framework; Section Two presents general considerations that apply to both generalist and specialist palliative care; Section Three covers generalist palliative care; Section Four looks at specialist palliative care; and Section Five summarises the recommendations made in the Framework.

1.5 DEFINITIONS, GLOSSARY

The World Health Organisation (WHO) definition of palliative care (2015), the levels of specialisation in palliative care, and the list of acronyms and abbreviations contained in the Framework, are listed in Annex C. The abbreviations and acronyms used are also explained when they first appear in the text.

Glossary of Terms

The definitions and terms used in this document are in accordance with the Glossary of Terms³ produced for the HSE by the National Clinical Programme for Palliative Care.

World Health Assembly

The Report of the 67th World Health Assembly⁴ addressed the strengthening of palliative care as a component of comprehensive care throughout the life course. The Assembly urged Member States (inter alia):

- To develop, strengthen and implement palliative care policies to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care;
- To ensure adequate domestic funding and allocation of human resources for palliative care initiatives, including education and training, and quality improvement initiatives;
- To provide basic support, including through multi-sectorial partnerships, to families, community volunteers and other individuals acting as caregivers, under the supervision of trained professionals, as appropriate;
- To aim to include palliative care as an integral component of the ongoing education and training offered to care providers, in accordance with their roles and responsibilities.

One of the key objectives of the Framework is to ensure compliance with this WHA Report, which will be achieved if and when the recommendations are implemented.

1.6 CONTEXT

Report of the National Advisory Committee on Palliative Care (2001)

Status of the NACPC Report

Palliative care services in Ireland have been guided for over sixteen years by the seminal 2001 NACPC Report. It is a visionary and comprehensive document that has served the sector well in ensuring that palliative care services in Ireland are planned and developed in a consistent and effective way to best meet the needs of patients and families. Most of its findings are as important and relevant today as they were in 2001, particularly its underpinning principles and broad model of care. However, there are also many aspects of the Report that are out of date due to changes in the healthcare environment, such as new healthcare structures, changes in policy and practice, new standards and regulations, funding issues, the establishment of the National Clinical Programmes, growth in demand, etc.

Progress Overview

Subsequent studies such as the 2006 Baseline Study⁵ and the 2007 HSE Audit⁶ showed that services had not developed uniformly across the country, and the full scale of development envisaged in the 2001 Report had not been realised. The HSE 2009 Development Framework² prioritised actions to address the most obvious gaps in service delivery, but its publication coincided with the economic downturn, and its implementation was inevitably delayed. Despite the adverse national economic circumstances, progress in opening new palliative care units and increasing resources in community services has been made, and plans are well-advanced to address many of the remaining priority actions in the lifetime of this new Framework.

Subsequent Developments

Since the publication of the 2001 NACPC Report, significant initiatives have taken place in the palliative care sector which greatly enhance its ability to develop, organise, improve and innovate. The creation of the HSE's National Clinical Programme for Palliative Care in 2010 to improve quality, facilitate equitable access and promote efficient use of resources, and the establishment of the All Ireland Institute for Hospice and Palliative Care (AIHPC) in the same year, with the potential to transform and promote palliative care education, research and practice, are exciting developments. They will contribute significantly to the quality of palliative care services in Ireland.

The publication in 2008 of Palliative Care for All⁷ and in 2011 of Primary Palliative Care in Ireland⁸ also contributed to the development of palliative care services; the first pointing the way for the integration of palliative care into disease management frameworks for a number of non-cancer conditions, and the second dealing with the challenges of delivering palliative care in primary care settings.

Structural changes have also occurred. The restructuring of the wider health services into hospital groups and community health organisations challenges the palliative care sector to ensure that the seamless integration of hospital, community and hospice palliative care services continues. The establishment of the HSE's Palliative Care Providers Network, a forum for voluntary and statutory service providers to discuss service issues, will help in this regard.

Model of Care

The broad model of care for all palliative care settings already exists, and is set out in the NACPC Report. A more detailed model of care is currently being developed by the National Clinical Programme for Palliative Care, which has already put in place some of the core elements required. In time, the model of care will fully describe best practice care provision for people with life-limiting conditions as they progress through the stages of advanced disease within the Irish health care system. As this Framework is equally grounded in the NACPC Report, there should be no conflict between its recommendations and the model of care that emerges.

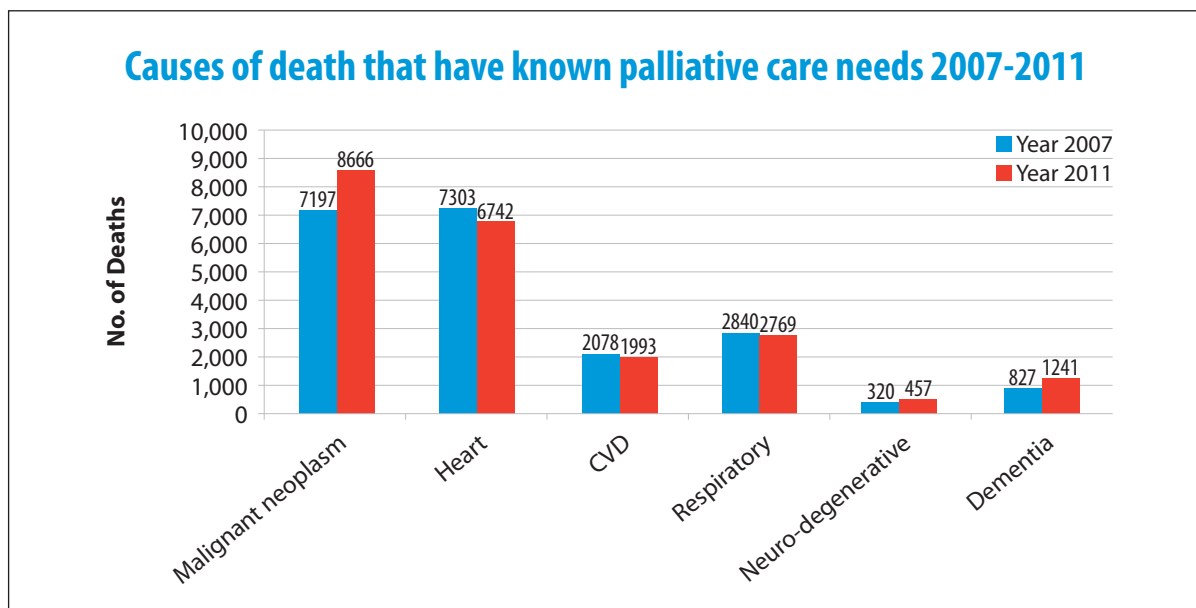
Epidemiology

The population of Ireland is projected to increase by 13.4% from 4.6 million in 2011 to 5.2 million in 2031, with the number of those over 65 years of age projected to increase by 86.3% from 532,000 in 2011 to 991,000 in 2031. The number of deaths of persons over 65 years of age is projected to increase by 28.6% from 28,000 to 36,000 in the same period.⁹

A study by Kane et al published in 2014¹⁰ estimated the potential population with generalist and/or specialist palliative care needs in Ireland. Some of the findings were:

- 80% of the 141,807 deaths during the period 2007 – 2011 were from conditions recognised as having associated palliative care needs, with approximately 30% from cancer and 50% from non-cancer conditions.
- There was an 18.6% increase in cancer deaths in 2011 versus 2007. The increase in cancer as a cause of death is likely to continue, given that the incidence of cancer diagnoses in Ireland is predicted to double by 2040.
- There was a 51.3% increase in dementia deaths in 2011 versus 2007. In Ireland, it is predicted that there will be a 63% increase in people living with dementia from 2006 to 2021.
- While it is recognised that diagnosis does not automatically infer a requirement for palliative care, Ireland would appear to have the most rapidly rising need for palliative care in Europe.

The study concluded that future palliative care policy decisions in Ireland must consider the rapidly aging Irish population with the accompanying increase in deaths from cancer, dementia, and neurodegenerative disease, with associated palliative care need, adding that new models of palliative care may be required to address this. The Framework endorses its conclusion that anticipated growth in demand must be addressed in any future strategic planning process.



Source: Kane, et al., 2015

Changing Practice

Many changes in practice have taken place since the 2001 Report was published, largely due to the recommendations in the Report itself. At the time, some specialist palliative care providers only offered their services to cancer patients, while in others the percentage of patients with non-malignant conditions was as low as 5%. By 2016 most services were fully operating to universal eligibility criteria, and admitting patients based on need rather than disease, with percentages for admissions of non-cancer patients as high as 45% for some community-based services and 31% for inpatient units. The prevalence of co-morbidities complicates the calculations, but the trend is still noteworthy.

Specialist Palliative Care in the Community	2010	2012	2014	2016
Cancer	83%	76%	72%	70%
Non-cancer	17%	24%	28%	30%
Specialist Palliative Care Inpatient Unit				
Cancer	93%	89%	88%	86%
Non-cancer	7%	11%	12%	14%

TABLE 1: Changing trends in cancer/non-cancer patterns of admission sourced from the

HSE Minimum Data Set

Another change occurred in discharge patterns. Traditionally discharge rates from specialist care services varied from unit to unit and in some cases were extremely low, but by 2016 services were operating universal discharge criteria, and the average discharge/transfer rate for inpatient units was 34%. The change indicates that more patients were enabled to live and die at, or closer to, home than previously. The figures belie the popular belief that hospices are essentially about dying and that admission to a hospice is the final stage of the journey. Whether due to better treatments, earlier intervention by specialist services, improved community services, enhanced integration between services, or a combination of these and other factors, it reflects a positive change in practice since 2001 of which there is little public awareness.

Economics

The Framework is written against a backdrop of intensive scrutiny of and greater accountability for the use of public funding. The rigorous financial discipline that followed the economic downturn brought about an increased focus on value for money and efficiency. Investment in palliative care programmes, as in any other area of the public services, can only be justified if it is seen to deliver improved patient outcomes and represents value for money. It is not the purpose of the Development Framework to make the economic case for investment in specialist palliative care, but there is already a growing body of evidence to suggest that it can benefit the healthcare system in terms of value for money, improved efficiency and improved patient outcomes.

The 2015 Report on the Economic Evaluation of Palliative Care in Ireland¹¹ indicates that where inpatient hospice services are available, the level of admissions with both malignant and non-malignant diseases to acute hospital beds is significantly lower in the last three months of life. This leads to savings within hospitals, as well as a reduction in inappropriate hospital admissions, a more appropriate trajectory of care, and an improved experience for patients and their families.

Any economic assessment of palliative care has to consider the impact of combined inpatient and community-based services, as one effect of the integrated service is to reduce hospital admissions of palliative care patients and to facilitate discharges from acute hospitals to the palliative care services. A focus on inpatient bed costs alone understates the economic value of specialist palliative care. A cost per patient based on total costs for inpatient and community-based services and the total number of patients engaged with both services better reflects the overall economic contribution of specialist palliative care. This of course attaches no economic value to the therapeutic and quality outcomes for patients and families.

General Challenges

Palliative care services, like the Irish health system in general, are facing other major challenges, which are listed in the Framework's Terms of Reference in Annex A.

Conclusion

This then is the context in which the Three Year Development Framework (2017 – 2019) is grounded. It offers a practical, strategic approach for developing the sector that acknowledges the challenges and opportunities presented. It recognises the limits of what was possible in the time available to the Steering Group, and of what can reasonably be expected to be achieved in the next three years. It makes recommendations on further steps to be taken to prepare for the future development of palliative care services in Ireland.

RECOMMENDATION 1:

In light of the various changes and developments that have occurred since 2001, this Framework recommends that the NACPC Report be revised (not replaced), and that this work commence in early 2018 to be completed in 2019. It further recommends that the implementation of the recommendations contained in the revised policy commence in 2020. In the interim, the underpinning principles and recommended staffing norms outlined in the NACPC Report should continue to guide national policy and strategy.

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SECTION 2 Underpinning principles and considerations – alignment with the HSE Corporate Plan

The Health Service Executive Corporate Plan 2015-2017¹ outlines the organisation's vision, mission, values and goals, and sets out what it wants to achieve and how it will organise and deliver services over the period of the plan. It establishes five corporate goals to guide service planning and delivery. The Three Year Framework is structured around the corporate goals, and looks at developing palliative care services in that context.

HSE Corporate Goal 1

Promote health and wellbeing as part of everything we do so that people will be healthier.

2.1 HEALTH PROMOTING PALLIATIVE CARE

Health promotion, as defined by the WHO Ottawa Charter, and palliative care share a focus on holistic care and ensuring quality of life for individuals and their families; however, health promotion places a strong emphasis on areas outside of service provision such as policy change and community engagement. Serious illness, death, dying, loss and grief are universal experiences. Health promoting palliative care approaches these experiences by taking a population-based health approach to change the ways in which: (a) people consider their own death; (b) communities care for people and their families as they encounter death; (c) healthcare service providers meet the needs of people facing the end of life; (d) palliative care services reach out to share their expertise in death, dying, loss and care; and (e) national policy and plans are developed and understood.² Such an approach emphasises the need to work in partnership with communities to stimulate community change and develop community led supports.³



Action Point: All specialist palliative care providers should develop a programme of health promoting palliative care activity within their local communities to raise public awareness and change the culture around death and dying in Ireland with a view to reducing inequity, fear and stigma, supporting communities in providing care, and enabling difficult end of life conversations and advance care planning.

2.2 REHABILITATION IN PALLIATIVE CARE

The overall goal of palliative care is to achieve the best quality of life for patients and their families, by helping patients live as actively as possible, and a focus on rehabilitation is entirely compatible with that goal. The body of evidence over the last fifteen years supports the concept of supportive and palliative rehabilitation in both malignant and non-malignant conditions. Rehabilitative palliative care is an interdisciplinary approach in which all members of the team, including nurses, doctors, psychosocial practitioners and allied health professionals, work collaboratively with the patient, their relatives and carers to support them to achieve their personal goals and priorities. Rehabilitative palliative care aims to optimise people's functioning and wellbeing, and to enable them to live as independently as possible, with choice and autonomy, within the

limits of advancing illness. It is an approach that empowers people to adapt to their new state of being with dignity, and provides an active support system to help them anticipate and cope constructively with losses resulting from deteriorating health.⁴



Action Point: All palliative care services should ensure that rehabilitative palliative care is an intrinsic part of their model and culture of care.

2.3 BEREAVEMENT

Bereavement support is an essential part of palliative care. However bereavement care does not rest with a single provider or service – it is comprised of informal support in families, in schools, in work and social organisations, as well as in both generalist and specialist health and social care services. A population health approach is well suited to bereavement – with individual needs being met from community and family supports right through to professional specialist bereavement supports. National guidance and standards for bereavement care at all levels of provision, based on national and local coordinated networks of voluntary and statutory providers, is required



Action Point: Each specialist palliative care inpatient unit should provide a comprehensive bereavement care service, with an identified bereavement coordinator.

Recent research⁵ shows that the prevalence of those at high risk of mental ill health following bereavement is 6.4%, with another 35.2% requiring some degree of formal bereavement support. Nearly 60% of bereaved people required support through general information about grief, including how to access services and well-informed social networks. These findings are consistent with National Institute for Clinical Excellence (NICE) guidance⁶ (See Figures 1 and 2).

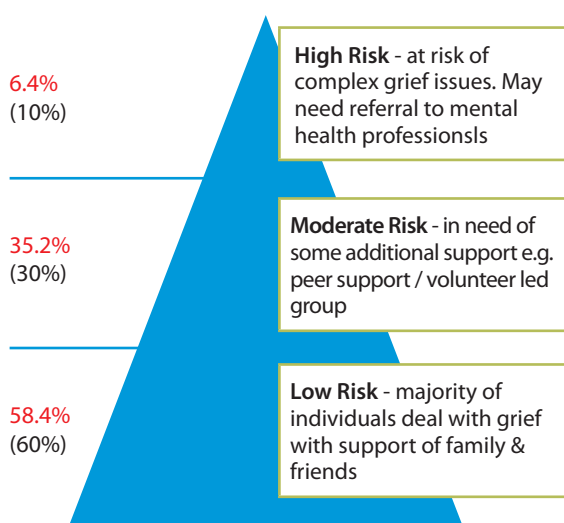


FIGURE 1: Public Health Model: Predicted (in brackets) and actual proportions for the three risk groups

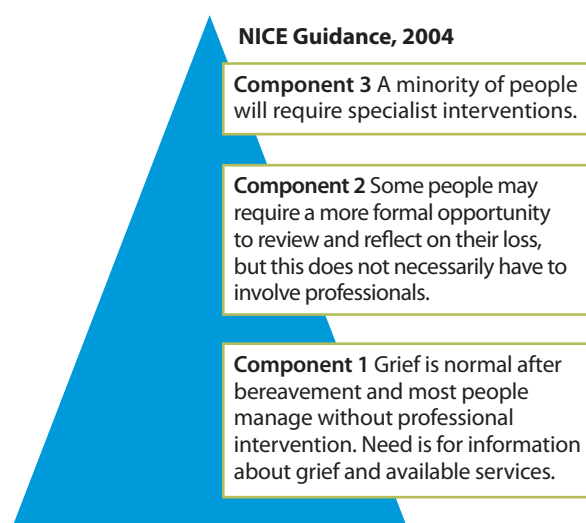



FIGURE 2: NICE Guidance on three levels of bereavement care

Planning for bereavement support in general, and in specialist palliative care, should take these findings into account, and work to deliver bereavement care through strong connections with community and non-health social care services.

Bereavement care is an aspect of all health professionals' responsibility but will need to be resourced and supported. The Palliative Care Competence Framework clarifies that some level of bereavement care competence should be acquired and demonstrated by all health care staff in primary, secondary and tertiary settings.

Bereavement services should be particularly attentive to the needs of children and adolescents, whose way of understanding, expressing and coping with grief may be quite different to that of adults, (NACPC, 2001). The Irish Childhood Bereavement Network has been in existence for five years and aims to promote best care for bereaved children through a multifaceted model. This model should be considered by each palliative care service as part of their bereavement referral pathways.

 **Action Point:** The HSE, in conjunction with other agencies, should initiate a process aimed at developing and implementing national guidance for bereavement care at all levels of provision, based on a population needs approach. The guidance should explicitly look to develop national and local coordinated networks, and standards for bereavement care, with a reach beyond palliative care services.


HSE Corporate Goal 2

Provide fair, equitable and timely access to quality, safe health services that people need.

2.4 ACCESS

One of the principles of palliative care in the NACPC Report is that specialist palliative care services should be available to all patients in need, wherever they are and whatever their disease. Although a new 15-bed specialist inpatient unit (IPU) is due to open in Kerry in 2017 there are still areas of the country without an IPU, most notably in the Midlands, the South East, and the North East. Other areas do not have the recommended bed complement and/or the recommended staffing levels. In addressing these deficits, the Framework builds on the progress achieved to date and the projects currently in the pipeline, some of which are at an advanced stage. There are plans in place, outlined later in this document, to ensure that by 2021, there will be equitable access to specialist inpatient palliative care services throughout the country.

Full access to palliative care services for patients with non-malignant disease is now the norm in the sector, with service providers accepting referrals based on need rather than condition. While the work of embedding palliative care in the disease trajectory for non-cancer conditions must continue, attention should now extend to the needs of vulnerable populations.

 **Action Point:** Services need to consider how best to extend care to vulnerable populations, such as those with intellectual disabilities, those with psychiatric illness, homeless people, ethnic minorities, and prisoners.

There are difficulties in some parts of the country in accessing community palliative care services in the evening and at weekends, and in accessing specialist advice out-of-hours. These are addressed in paragraph 3.1.

2.5 QUALITY AND SAFETY

“Every specialist palliative care service should have an explicit commitment to quality improvement”

NACPC Report, 2001

Performance Indicators and Outcome Measures

The NACPC Report recommended that suitable performance indicators and outcome measures should be identified at national level and utilised in specialist palliative care services in order to evaluate and maintain quality standards. Subsequent to that, the 2006 International Expert Advisory Committee Report suggested Benchmarks for Best Practice,⁷ possible outcome-focused performance indicators for specialist palliative care, adding to a growing body of work in the field. The Framework acknowledges the work that has been ongoing since then, and encourages this work to continue, particularly in the development of outcome indicators.

National Quality and Safety Standards

The national quality agenda was greatly advanced with the publication of two key documents by the Health Information and Quality Authority (HIQA) in 2009⁸ and in 2012.⁹ This Framework considers that the standards contained in these documents provide adequate benchmarks for the sector for the lifetime of the Framework, and additional standards specific to palliative care are not required.

An important consideration is how the standards are being used. One of the resources produced by the National Clinical Programme for Palliative Care, *Towards Excellence in Palliative Care – Quality Assessment and Improvement Workbooks*,¹⁰ is a practical guide to assessing specialist palliative care services against the 2012 HIQA Standards, and supports services to prioritise actions for ongoing quality improvement. With a licensing requirement imminent, the entire sector needs to engage whole-heartedly with the process of quality improvement.


The National Palliative Care QA+I Enablement Committee was established in 2016. The aim of the committee is to provide leadership and to support services in their implementation of the HIQA National Standards for Better Safer Healthcare. It is a partnership approach by and between services and is a most welcome addition to the sector.



Action Point: *Towards Excellence in Palliative Care – Quality Assessment and Improvement Workbooks* should be used by all specialist palliative care providers, regardless of where they see themselves in their quality improvement journey, or if they have already achieved external accreditation.

Clinical Effectiveness

Two National Clinical Guidelines on palliative care have been published by the National Council for Clinical Effectiveness - Guideline Number 9 *Pharmacological Management of Cancer Pain in Adults*¹¹ and Guideline Number 10 *Management of Constipation in Adult Patients receiving Palliative Care*¹². A further guideline on the care of the dying adult has been prioritised to proceed to development. These guidelines are in addition to guidelines on a number of specific cancers either published or in development. The HSE is committed to the implementation of the Guidelines.

 **Action Point:** The NCEC Guidelines should be implemented by all specialist palliative care providers. As part of its monitoring and audit function on quality and patient safety the HSE should develop appropriate KPIs.

Governance for Quality and Safety

“We are all responsible, and together we can create a safer health care system”

Report of the Quality and Safety Clinical Governance Development Initiative (2014)

The foreword to *The Report of the Quality and Safety Clinical Governance Development Initiative* (2014)¹³ stated the HSE’s intention that all health service providers place quality and safety at the top of every agenda. All providers of specialist palliative care should conduct an audit of their current accountability arrangements for quality and patient safety to determine that they have documented arrangements in place for monitoring quality and patient safety; that processes and systems are in place to ensure that quality and patient safety is a priority for senior managers; and that their Board, CEO and senior management team are fully informed of all key areas of quality and patient safety in their organisation.


**HSE
Corporate
Goal 3**

Foster a culture that is honest, compassionate, transparent and accountable.

2.6 PERSON-CENTRED CARE

The palliative care approach positions the person and their family at the centre of decision-making. This approach is in keeping with the commitment in the Corporate Plan¹ to listen with respect, kindness, consideration and empathy to patients, service users and carers when planning and delivering services.

Organisations can only fully embrace this commitment if they develop cultures that are person-centred and can demonstrate how they value the views and lived experiences of all persons who provide and use their services. There is mounting evidence to suggest that there is a strong connection between staff wellbeing and the degree to which care is person-centred, positively associated with a good practice environment, and patient outcomes.¹⁴ The HSE’s National Programme to Develop Culture of Person-centredness commenced in February 2017. The aim of the programme is to implement a 3-year practice development programme to develop facilitators to lead culture development in person-centredness across the HSE. The programme is co-facilitated by HSE staff and Queen Margaret University, Edinburgh. Within Palliative Care, an initiative using the same approach is underway to implement palliative care needs assessment within a number of older persons residential services.

 **Action Point:** Organisations providing palliative care should embrace these initiatives and extend their person-centred philosophy to encompass staff as well as patients and families.

2.7 GOVERNANCE

New Healthcare Structures

Specialist palliative care is well-placed to adapt successfully to the new healthcare structures. Because it is delivered across all settings in an integrated and comprehensive programme, it has long-established links with acute and community services, which will help it to forge the necessary governance arrangements within community and hospital structures. Within these structures, the hub and satellite model recommended in the NACPC Report is still relevant, and should continue to be the basis for the development of specialist palliative care services.

As the HSE evolves, there is the potential for the coordination, monitoring and development of palliative care services to become more challenging. A properly staffed and resourced palliative care function at corporate level should be re-established to meet these new challenges. One of its core responsibilities will be to manage the relationships between the sector, the diverse functions within the HSE, external agencies such as the Department of Health and HIQA, and the voluntary organisations active in the sector. Part of its role will also be to ensure that the goals in HSE Corporate Plans regarding integration, service delivery and outcomes, and the use of resources, as they impact palliative care are fully met. This corporate office, in partnership with the Clinical Care Programme will also play a critical role in progressing the recommendations and identifying priority action points in this Framework, as well as future strategic planning processes.

The NACPC Report recommended consultative and development committees for the exchange of information and ideas on all matters pertaining to palliative care. The corporate function should be tasked with identifying an appropriate replacement structure for the consultative and development committees that can provide similar functions in the new health structures.

RECOMMENDATION 2:

It is recommended that a properly resourced palliative care corporate function be re-established to coordinate, monitor and develop palliative care services in emerging healthcare structures. This function will also ensure the equitable rollout of planned developments as well as integration between community and hospital structures and voluntary providers. The corporate function should also ensure that an appropriate replacement for the NACPC consultative and development committees is put in place.

Corporate Governance


All service providers should have the highest standards of corporate and financial governance in line with legislative requirements, service agreements, the HSE accountability framework, and best practice, irrespective of size or type of service. The relatively small size of some specialist palliative care services, especially community-based services, can present particular governance challenges for them.



Action Point: New specialist palliative care inpatient units and existing local community specialist palliative care services should formally engage to develop shared governance structures, to ensure integrated care of patients and families, to meet the requirements of regulatory compliance, and to prepare for a commissioning funding model.

Governance Structures for Nursing

In a small number of specialist palliative care providers, nursing staff do not report to a director or assistant director of nursing for professional leadership and clinical accountability. An agreed nursing governance structure that provides consistency on professional nursing structures, professional leadership, strategic planning and development within specialist palliative care is needed. It should be implemented in all organisations and settings to ensure strong governance and clear leadership, along with accountability for quality and safety.


 **Action Point:** It is recommended that the HSE develop and implement an agreed nursing governance structure for all specialist palliative care provider organisations, particularly where clarity on professional reporting relationships is currently absent.

2.8 VOLUNTEERS

“Volunteers are an integral part of the specialist palliative care service, whether they are working directly with patients and their families, or giving other essential support, such as raising money”

NACPC Report 2001

Volunteers are a huge resource in specialist palliative care services, with the number in some hospices matching or exceeding the number of paid staff. Their roles are many and varied, and their contribution to their local service is enormous. It is impossible to put an economic value on their input, because they bring a dimension to the supported organisation in terms of enthusiasm, commitment and vitality, not to mention their life skills and community links, which is immeasurable.

 **Action Point:** The appropriate supports for volunteers must be put in place in each specialist palliative care organisation. This should include the post of volunteer coordinator as recommended in the NACPC Report, with responsibility for the recruitment, training and placement of volunteers.

2.9 LEADERSHIP

The NACCP Report recognised the Specialist Inpatient Unit as being the “hub of the specialist palliative care services within each designated area” and identified the full spectrum of service provision within specialist palliative care, illustrated below:

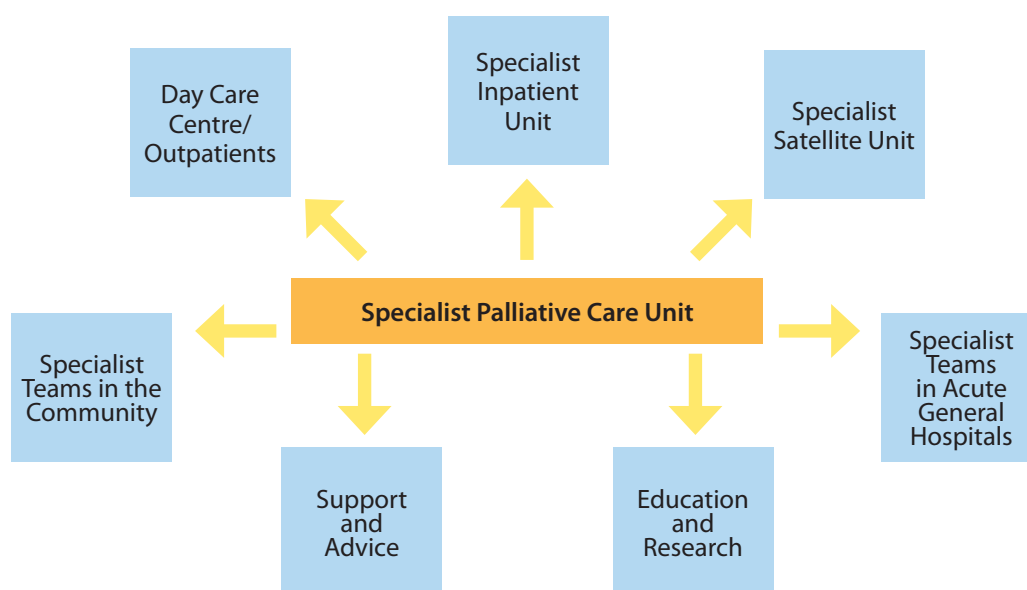


FIGURE 3: From the Report of the National Advisory Committee on Palliative Care

In all of the above it is recognised that the specialist unit acts as a key resource for other health professionals in the area, by providing support and advice when needed, as well as providing facilities for research and education in palliative care.

The Framework recognises the key leadership role that specialist palliative care providers can play in the overall delivery of palliative care in Ireland.

HSE Corporate Goal 4

Engage, develop and value our workforce to deliver the best possible care and services to the people who depend on them.

2.10 PALLIATIVE CARE EDUCATION

Education is a core component of specialist palliative care. The importance of disseminating the principles of palliative care is central to the philosophy of empowering not only other health care professionals but also the patient, family and carers.

NACPC Report 2001

The World Health Assembly took into account “that the avoidable suffering of treatable symptoms is perpetuated by the lack of knowledge of palliative care”. It highlighted “the need for continuing education and adequate training for all hospital and community-based health care providers and other care-givers, including non-governmental organisations and family members”, and urged Member States “to aim to include palliative care as an integral component of the ongoing education and training offered to care providers, in accordance with their roles and responsibilities”.¹⁵

The need for palliative care education is well-documented. The HSE Palliative Care Competence Framework,¹⁶ along with other recently published reports, clearly describes the training, education and skills required to provide highly functioning services across the three levels of palliative care described in Annex C. The *Report of the Palliative Care Community Learning Project*¹⁷ identified and evaluated the needs for palliative care education in the community; the *All Ireland Institute for Hospice and Palliative Care (AIHPC) Education Needs Analysis Report*¹⁸ documented 25 topics as priority needs and made recommendations on how to address them; the *Report on the First National Palliative Care Support Beds Review*¹⁹ highlighted needs in Model 1 and 2 hospitals; and the 2015 Evaluation Panel Report on the National Cancer Strategy 2006²⁰ commented on the importance of education for non-specialist palliative care providers. The All-Ireland Palliative Care Education Network, with membership drawn from over fifty organisations engaged in palliative care education published a position statement in 2015²¹ in relation to palliative care education both for health and social care professionals and for the wider public, including users and carers.

There are many organisations involved in the provision of palliative care education. The Palliative Hub designed by the AIHPC provides a gateway to relevant palliative care information as well as the Learning Platform, which gives access to online and blended palliative care education. The AIHPC also maintains the all-Ireland Palliative Care Education Database (in collaboration with the IHF, the IAPC and Qualifax). Nevertheless, the AIHPC Needs Analysis¹⁸ suggested that, despite the wide range of courses and programmes available, current education provision may not be fully addressing the needs of health and social care professionals.



Action Point: The palliative care corporate function, in conjunction with the National Clinical Programme and the AIHPC, should develop a palliative care education strategy to ensure that competency-based palliative care education and training is planned and delivered in an integrated, collaborative, cost-effective and comprehensive way that meets the needs of service providers, staff and public alike. The AIHPC, given its mission and vision, and the level of engagement it has within the sector, should be the appropriate vehicle to lead on such a project.

2.11 PALLIATIVE CARE RESEARCH

The findings from the 2013 AIHPC's systematic review of palliative care research on the island of Ireland clearly demonstrated that palliative care research had increased, particularly over the previous five years. The findings also indicated a diverse range of research activity, ranging from death and dying, symptom assessment, bereavement and communication to complementary and alternative approaches and a focus on different groups and populations. This diversity is indicative of the different disciplines involved in palliative care research.

The All Ireland Palliative Care Research Network (PCRN) was established by the AIHPC in 2012. It aims to build research capacity and to foster a strategic approach to internationally-competitive research. The Network has been supported through funding provided by the AIHPC, the Health Research Board in Ireland and the Research Office of the Public Health Agency in Northern Ireland, with over €5 million attracted to palliative care research since its establishment. In 2017/18 the PCRN aims to model the translation of research output in practice settings and policy making arenas. The PCRN embraces an interdisciplinary approach to research, bringing together clinicians, social scientists and policy analysts, building around two thematic research areas of social justice and measurement and evaluation. The PCRN is committed to user and carer engagement and involvement in palliative care research.



Action Point: The PCRN should become a primary coordinating centre for palliative care research in Ireland, and be utilised to maximise existing resources, leverage expertise and capability, and further build the research community in order to produce excellent, internationally-competitive research.

2.12 WORKFORCE DEVELOPMENT

It is recognised that in order to deliver a better experience for patients and families, health and social care staff need to be highly skilled and motivated individuals. The components of effective workforce development that can help and support developing higher order skills and build motivation are:

- A performance management and development system to facilitate review and competence framework-based development planning;
- An education and training system to ensure individual and organisation needs are assessed and provided;
- A supervision and support system to help identify and support the impact of the emotional and psychological challenges of working in the area of palliative care;
- Competence framework based recruitment, induction and orientation processes;
- Personnel feedback systems to facilitate constructive input from staff;
- Communications systems to ensure that staff are kept informed of strategic developments that may impact their working environment or role requirements.



Action Point: Specialist palliative care providers may need to review how comprehensive and effective their current workforce planning / development systems are. The HSE has well-developed systems in place that should be made available to the voluntary sector. The AllHPC too is well placed to support the sector in introducing or developing many aspects of workforce development.

**HSE
Corporate
Goal 5**

Manage resources in a way that delivers best health outcomes, improves people's experience of using the service, and demonstrates value for money.

2.13 INTEGRATION

Within current HSE structures Palliative Care is located in the Primary Care Division, and requires operational working arrangements across Divisions, Community Health Organisations (CHO) and Hospital Groups. Within CHOs integration also needs to be achieved between primary care services, general practice, community pharmacy, and mental health, social care and health and wellbeing services .

The 2014 HSE Report on Community Healthcare Organisations²² recommended a service delivery structure, using nationally agreed standardised models of care, based on primary care networks of around 50,000 people with an average of five primary care teams of 7,000 – 10,000 in each network ‘with the primary objective of enabling and supporting integrated care within community services and between them and hospital services’.

Developing integrated care within a CHO is a challenging task. The inclusion of hospital groups and a vibrant voluntary sector makes it considerably more difficult – and palliative care involves all three service delivery strands. Nevertheless, some work has already been done through the National Clinical Programme and, as the CHO Report noted, ‘Crucially organisational integration is not necessarily required. The key requirement is clinical and service level integration.’ It stated that ‘... integrated care means looking at processes and outcomes of care rather than at structural and organisation issues. Achieving integrated care means that services must be planned and delivered with the patient’s needs and wishes as the organising principle’.

The CHO Report suggests that a step-by-step approach should be adopted with the initial focus on the ‘development of standardised models of care. These will need to incorporate clear business and clinical processes, care pathways and internal and external outcome measures’ and ‘...linking resources provided to outcomes delivered and with an appropriate suite of key performance indicators and other measures’.

As expected the CHO Report focuses on arrangements within that system, while an earlier report²¹ examined acute hospital issues. Both reports emphasise consultation as essential and refer to external agencies, including voluntary organisations – this is particularly important within palliative care, given that a significant level of palliative care services are delivered by voluntary organisations.



Action Point: The corporate palliative care function should be given the responsibility, authority and resources to ensure that the necessary service integration takes place.

2.14 FUNDING

Revenue Funding

The NACPC Report recommended that adequate and equitable statutory funding should be made available to meet the core running costs of all specialist palliative care services; that the distribution of funding should be through service plans and service agreements; and that there should be a separate ring-fenced budget for specialist palliative care services.

Currently the sector relies heavily on fundraising and donations to maintain services. In 2016 the provision of statutory funding to voluntary service providers ranged from 45% to 93%. In contrast, the new hospices being planned will be 100% statutory funded.

This Framework endorses the recommendation that core revenue costs, including pay and non-pay, should be statutory funded, and sees an incremental move in that direction as necessary preparation for the introduction of new commissioning / funding models. The challenge in reaching agreement on what constitutes core costs, in the absence of specific recommendations on administrative and support staffing levels in the NACPC Report and with the mix of stand-alone and co-located inpatient units, is recognised but urgent action on easing the fundraising burden of many voluntary providers is needed. Any eventual consensus should be informed by the NACPC Report, the prospective funding study by Prof. Charles Normand (which is part of the current work stream of the National Clinical Programme), the emerging model of care, and the experience of service providers.

RECOMMENDATION 3:

The corporate palliative care function, in collaboration with the HSE's Clinical Care Programme and the Palliative Care Providers Network, should establish a short life working group to define by the end Q1 2018 what constitutes a core specialist palliative care service, including both pay and non-pay costs, with a view to having all core costs statutory funded by 2021.

The night nursing service provided and funded by the Irish Cancer Society (ICS) for cancer patients and by the Irish Hospice Foundation for non-cancer patients cost the organisations €2.4 million and €0.7million respectively in 2016, with a possible 20% rise anticipated in the IHF costs in the coming years. This service, which has been externally evaluated,²⁴ should be regarded as part of the core generalist services, and should receive at least 50% of its funding from the state. The Framework notes that discussions between the HSE, the ICS and the IHF on how that might be achieved and over what timeframe are underway.



Action Point: It is recommended that steps be taken over the life of the Framework to progress on a phased basis the provision of 50% statutory funding for the Night Nursing Service currently funded by the ICS and the IHF.

Capital Funding

Capital funding for palliative care infrastructure should in ideal circumstances be provided by the State, but over the years local fundraising groups have provided the full cost of, or made significant contributions to, capital development projects. They continue to do so in order to advance local projects that might otherwise be delayed because of pressures on national capital budgets. Such partnerships mean that scarce revenue funding can be leveraged resulting in more services projects delivered. They also have the added benefit of ensuring ongoing support for local services. The HSE should continue to work with local groups to encourage strategic investment and support for capital projects that are included in national palliative care development plans. However, where local contributors cannot be identified efforts should be made to have these projects included on the HSE capital development plan.

Funding Allocation

The current model of funding services i.e. through annual service plans and service agreements should continue until such time as newer funding models have been consulted on and agreed. Specialist palliative care should be considered for inclusion in the early roll out of the commissioning model of funding.




Action Point: The HSE's Palliative Care Provider Network should prepare recommendations on how the commissioning model of funding might work best for all stakeholders.

2.15 WORKFORCE PLANNING


Specialist palliative care services have generally been successful in attracting and retaining qualified staff, and have managed to avoid the worst of the recruitment difficulties currently being experienced in the wider health services. It is essential that the sector takes the necessary steps to ensure that situation continues.

These can include providing career pathways for all disciplines, good workforce development processes, clear role definition, opportunities for education and research, and good working conditions, but the overall objective should be to enhance the work experience of all staff and empower them to achieve their full potential and be the best they can be. This will in turn enhance the quality of service provision and improve patient experience.

 **Action Point:** The National Clinical Programme for Palliative Care, in conjunction with the Office of Nursing and Midwifery Services Development, should action the following workforce planning initiatives :

- The role of the clinical nurse specialist should be further described and fully developed in specialist palliative care, and supported through professional development and links with academia, so that the full remit of the role can be developed;
- The role of the advanced nurse practitioner should be planned, progressed and implemented;
- The current range and numbers of nurse medicinal prescribers should be determined with a view to expansion as appropriate.

Medical workforce planning needs to reflect the key leadership role of consultants within the multidisciplinary team; the contribution of their specialist knowledge and skills to achieving best outcomes and experiences for patients and families; a move to 7-day service provision; a meaningful expansion of consultant presence in the community; the establishment of cancer care centres; and international developments. This Framework supports the case for additional consultants, and notes the proposals in this matter in the report of the RCPI Palliative Medicine Clinical Advisory Group, but recognises that the HSE's National Doctors Training and Planning Unit is the appropriate forum for advancing it.

 **Action Point:** Pending the outcome of ongoing current deliberations, the staffing levels of consultants should be brought up to the levels proposed in the Hanley Report²⁵

The NACPC recommended one physiotherapist, one occupational therapist and one social worker for every ten inpatient unit beds, and for services in the community recommended the same level of staffing for every 125,000 population. The report also recommended each unit should have two chaplains, a pharmacist, and one session of speech and language therapy and one session of dietetics per week. The appropriateness and acceptability of these recommendations needs to be reviewed. Social workers for example are witnessing an increasing complexity in family composition, issues of vulnerable persons, addiction, mental health, and financial distress. They are also providing a considerable amount of bereavement support, particularly for young families and for children. Additional resources, including psychologists, may be justified.

Specialist palliative care addresses spiritual pain as well as physical and psychosocial pain, and the chaplain was recognised as an important member of the multi-disciplinary team in the NACPC Report. The role and staffing levels of chaplains/pastoral care workers across the health services at large is being examined by a national group, and palliative care should be included in that work, with representation from the palliative care sector on the group. Any development of the role of the chaplain/pastoral care worker in palliative care should await the outcome of that exercise. The Steering Group heard many well-argued proposals for staffing levels in these and other disciplines in excess of those recommended in the NACPC Report, (which were identified as minimum recommendations at the time).



Action Point: Staffing levels should be best considered as part of the recommended revision of the NACPC Report. In the meantime, staffing deficits should be discussed at local management level within the respective CHO, hospital and Division.

Cases for change to the NACPC Report should be advanced through the National Clinical Programme for Palliative Care and the National Lead within the Primary Care Division in collaboration with the appropriate clinical disciplines in the sector, linking with the Department of Health Workforce Planning Group and with the HSE's National Doctors Training and Planning Unit.

It is essential for all disciplines that the third level education sector at undergraduate and post graduate pre-registration level ensure that curricula are designed to ensure that health and social care professionals have core competencies in palliative care as outlined in the HSE Palliative Care Competence Framework¹⁶.

2.16 KNOWLEDGE AND INFORMATION (ICT)

“The HSE is taking the opportunity to reform the way in which healthcare is provided to the whole country. At the centre of this reform is the absolute need to increase the capability and capacity to build knowledge and provide access to information that supports the provision of healthcare for public, patients and clinicians alike”

Knowledge and Information Strategy, Delivering the Benefits of eHealth in Ireland, HSE 2015

Over the three years of this Framework and beyond, there are ambitious plans to transform the use of information technology within the health services. The HSE's Knowledge and Information Strategy,²⁷ if provided with the necessary investment, will see the roll out of electronic health records based on a single consistent identifier for each patient, practitioner and location. Users will have access to the full local record and core national record at the point of care delivery. The benefits will include:

- The real-time recording of data as the patient is seen, the sharing of patient information, more clinician time spent with the patient, greater ability for patients to participate in their own care, and better quality of care and patient safety;
- Information management, reporting and analysis which will enhance timely, reliable information and decision making support for patients, clinicians and management at both patient and healthcare system levels. This will facilitate better care, efficient service and financial planning, and clinical and financial audit.



Action Point: The opportunities presented by the new developments, which will accommodate electronic prescribing and other point of care technologies, should be embraced by the palliative care sector, and it should articulate its desire to be included and involved in relevant initiatives, such as the MOCIS (Medical Oncology Clinical Information System), from the outset.

2.17 THE NATIONAL CLINICAL PROGRAMME FOR PALLIATIVE CARE

It is clear that the establishment of the National Clinical Programme for Palliative Care has made a significant contribution to the development and improvement of the sector while also implementing the HSE's five corporate goals. The Programme has been responsible for the development of seminal core guidelines, frameworks and quality improvement initiatives and it is expected will have completed the Model of Care by the end of 2017. The significance of the Programme is further evidenced by the number of references to it throughout this Framework and by the number of recommended actions to be undertaken by the Programme.

RECOMMENDATION 4:

The National Clinical Programme for Palliative Care should be properly resourced, supported and sustained to continue its work in integrating palliative care across the HSE's Divisions, pursuing the quality agenda and ensuring the best use of resources.

2.18 RECENT LEGISLATIVE AND STRATEGIC DEVELOPMENTS

Advanced Healthcare Directives

The Assisted Decision-Making (Capacity) Act is expected to come into effect in late 2017/early 2018. Part 8 of the Act provides a framework for advance healthcare directives. An advanced healthcare directive is a statement made by a person with capacity setting out his/her will and preferences regarding treatment decisions that may arise in the future in the event that s/he lacks the capacity to provide consent to or to refuse those treatments. Under the Act a person can make a legally-binding refusal of treatment (up to and including life-sustaining treatment) in his/her advance healthcare directive. The Act also introduces a mechanism through which an adult with capacity may nominate a legal representative to be involved in the healthcare decision-making process on his or her behalf if he or she was to subsequently lose capacity. A person may also request that certain treatments be provided. This request is not legally binding; however, it must be taken into account in any decision-making process about the treatment. A Code of Practice will be produced to outline how the legislation will operate on a day-to-day basis, as well as providing examples of best practice for designated healthcare representatives, healthcare professionals and others dealing with people who have made advance healthcare directives

National Cancer Strategy 2017 – 2026²⁸

The new strategy, published in 2017, describes cancer services for the coming decade. In its section on palliative care it mentions the need for co-ordinated and integrated care based on need rather than prognosis. It also highlights the fundamental role of generalist palliative care services in the provision of quality care and the need for training. The strategy contains two recommendations for adult palliative care services - the adequate staffing of cancer centres, including psycho-oncologists, and the training of oncology staff to ensure competence in the standard identification and assessment of need.

Oireachtas Committee on the Future of Healthcare - Sláintecare Report²⁹

This cross party report was published in 2017. It recommends that palliative care should be expanded and included in universal health care provision. It further recommends that services should be resourced to provide this within the first five years of the plan.

Department of Health Statement of Strategy 2016-2019³⁰

The Statement sets out a range of actions to improve the health services under five main strategic objectives and reflects the commitments in the Programme for a Partnership Government. With regard to palliative care the actions include to update the NACPC Report; to work with non-governmental organisations to improve information and awareness; to open further hospices and encourage the development of homecare where there are no hospices.

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SECTION 3 Generalist Palliative Care

3.1 PRIMARY PALLIATIVE CARE

Context

The majority of generalist palliative care is delivered in primary care or acute hospital settings. The NACPC Report noted that not all patients with advanced disease require the services of the specialist palliative care team. It emphasised that clinical responsibility for the patient should remain with the General Practitioner (GP) and that the GP along with the primary care team are the main providers of palliative care in the community. The GP should involve the specialist palliative care team as and when required; their role is to act as a resource and to provide support and education to primary care health professionals. For this model to work, it is important that specialist palliative care resources avoid becoming involved in clinical activity not provided for in their advisory role, but this is ultimately dependent on primary care teams being adequately resourced.

The 2001 Primary Care Strategy¹ reorganised the delivery of primary care, and proposed the establishment of primary care teams and networks. It recognised that primary care teams had the potential to deliver much of the care currently delivered by specialist services, but that the realisation of that potential would require better integration between secondary and primary care services.

A recent initiative is the phased introduction of Community Intervention Teams. These teams have a key role in supporting the transition of palliative care patients from hospital to home, preventing admission to hospital, and providing support in complex cases where prognosis is short.

Community nursing services are currently provided at levels 1, 2 and 3 to cater for the complexity of palliative care patient and family needs. The NACPC Report described a shared model of care without clearly defining it. Research undertaken in two areas suggests differences in the integration and delivery of shared care between public health nursing services and specialist palliative care services.



Action Point: In the interests of progressing the collaboration and integration of nursing services in the community, an agreed understanding of the roles and duties of public health nursing and specialist palliative care is needed. The National Clinical Programme for Palliative Care and the corporate palliative care function should lead this work and promote an agreed model on a national basis.

Primary Palliative Care Programme

The Irish Hospice Foundation (IHF), in partnership with the Irish College of General Practitioners (ICGP) and the HSE, established the Primary Palliative Care Programme, in order to identify initiatives that would support primary care teams to care for patients in the community. A report with prioritised and longer term recommendations was published in 2011² and a progress report followed in 2014.³ Many of the recommendations have been advanced by various initiatives of the National Clinical Programme for Palliative Care, the All Ireland Institute for Hospice and Palliative Care (AIHPC), and the Irish Association of Palliative Care (IAPC), but the following recommendations of the Programme Report remain to be addressed:

- **Specialist Palliative Care Community Services.** The Programme reiterated a NACPC Report recommendation that specialist palliative care nurses should provide a seven-day service to patients in the community. That ambition has not yet been fully realised, and should remain one of the key priorities for the development of community specialist palliative care services. There have been calls too for a longer working day, but a needs analysis and resource implications study is necessary to support such a recommendation.



Action Point: A short life working group should be established to explore the need for out-of-hours (OoH) specialist palliative care community services and the resource implications involved.

- **OoH Specialist Advice.** The Programme also echoed the NACPC call for 24-hour access to specialist advice. Variations exist around the country in how this advice is provided, and guidance is needed on what might represent best practice.



Action Point: The National Clinical Programme for Palliative Care and palliative care corporate function should map current practice regarding 24-hour availability of specialist advice, and make recommendations on an appropriate delivery model.

- **OoH Handover.** The Programme identified a need for a palliative care summary for communication with OoH services. A pilot study of a summary form is underway, and the Framework supports the initiative, with a recommendation that the National Clinical Programme for Palliative Care should be consulted on the information to be communicated. Efforts to devise an electronic version of the form that is compatible with GP software systems should be fully supported by the HSE.
- **Timely Access to Community Resources.** The 2001 NACPC Report made specific recommendations regarding access for palliative care patients to the provision of a ring-fenced bank of equipment / aids / appliances for palliative care patients. The Primary Palliative Care Programme Report confirmed that problems in these areas continue.



Action Point: Palliative care patients in the community should be given priority when requests for services and equipment are made on their behalf, similar to the manner in which medical cards are fast-tracked for specialist palliative care patients.

- **Psychosocial Support for Patients and Families.** The need for psychosocial support for some patients and families was identified. Where risk assessments indicate a need for level 2 or level 3 support, and such support is not readily available within community services; specialist palliative care services operating in the community should provide the required support. The community teams need to be adequately resourced to do so.

3.2 PALLIATIVE CARE SUPPORT (INTERMEDIATE CARE, LEVEL 2) BEDS

Context

The 2001 NACPC Report introduced the concept of palliative care support beds as a means of providing an intermediate level of inpatient palliative care for patients in a local environment, typically in designated centres for older people. Since then, palliative care support beds have developed in an ad hoc manner in response to local needs, opportunity and initiatives, with the result that there are inconsistent levels of provision, administration and care standards across the country. The access issue is illustrated by way of example in Figure 4, which shows the number of palliative care support beds as well as the number of beds per 100,000 of population per CHO. Recent information provided by the Social Care Division suggests that the overall number of support beds has fallen in recent years.

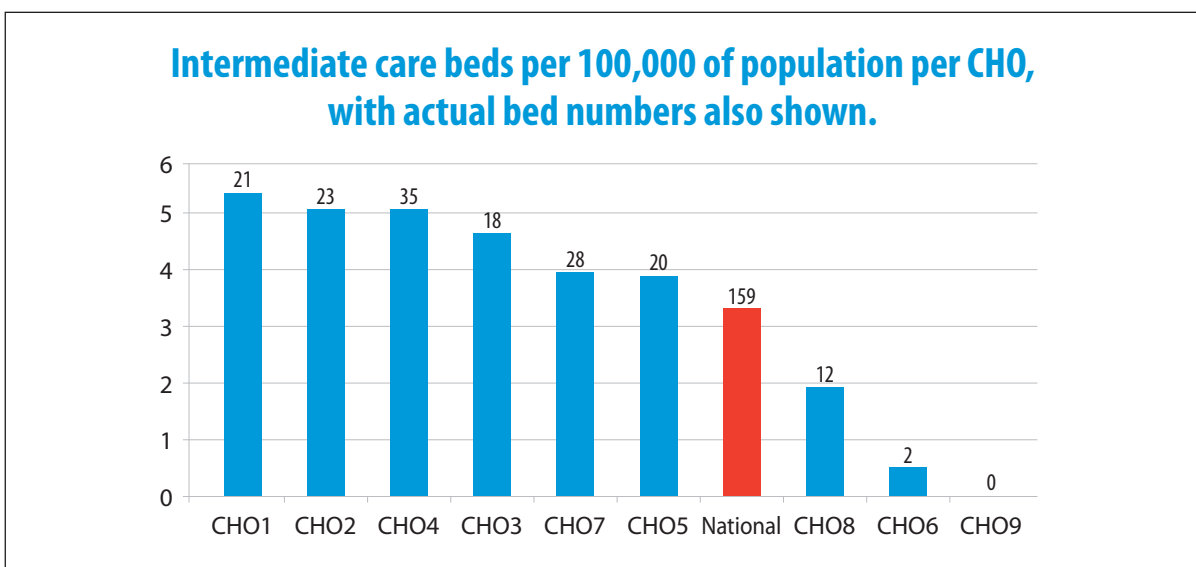


FIGURE 4: Number of Palliative Care Support Beds per 100,000 of population per CHO. (Compiled from CSO population data 2016 & HSE data on Support Beds, August 2017)

The organisation and function of palliative care support beds was reviewed in 2014 by the National Clinical Programme for Palliative Care, and the ensuing Report⁴ contained a number of recommendations on the model of care, integration with specialist palliative care services, evaluation, audit, education and training, access, and metrics. The Framework fully endorses all of the recommendations contained in this review.

Development of Palliative Care Support Beds

The benefits of palliative care support beds, particularly in terms of the experience of patients and families, need to be audited, but there is sufficient anecdotal evidence available in the parts of the country with well-developed services to justify the expansion of this service




Action Point: The National Clinical Programme for Palliative Care and corporate palliative care lead on the implementation of the *Report of the First National Palliative Care Support Bed Review*. Furthermore, the Programme should convene a short life working group to examine the demand for and usage of existing palliative care support beds, and to recommend an appropriate level of provision nationally by mid-2019.

3.3 ACUTE HOSPITALS

Generalist Palliative Care. It is important to recognise that the provision of palliative care is the responsibility of the whole healthcare system and not just specialist palliative care services. The term ‘generalist palliative care providers’ refers to all those services, health and social care providers who utilise a ‘palliative care approach’ or possess ‘general’ palliative care skills. Their role is fundamental to the provision of high quality care for people with life limiting illnesses, and the needs of many patients can be appropriately and effectively met with the support of generalist palliative care providers. All hospital healthcare staff will encounter and care for patients with palliative care needs, and should be trained in the palliative care approach.

However, should a patient experience unstable symptoms or develop complex problems as a consequence of their illness, then input from the hospital-based specialist palliative care services should be sought and provided. The Role Delineation Framework for Adult Palliative Care Services⁵ points out that quality palliative care provision is best realised when generalist and specialist palliative care providers collaborate together to meet the needs of patients. This ensures that complexity of need does not automatically dictate the setting of care.


 **Action Point:** It is recommended that all hospital healthcare staff be trained in the palliative care approach, and that structures that encourage and facilitate improved integration between generalist and specialist palliative care providers working in acute and community settings be established and supported in all CHOs / Hospital Groups.

Changing Culture in Acute Hospitals on Dying, Death and Bereavement

Dying, death and bereavement are a core part of the work of an acute hospital. Understandably acute hospitals place a strong emphasis on curative treatments with often a lesser focus on palliative, end of life and bereavement care. However, with 43% of all deaths occurring in hospitals a greater focus needs to be placed on these vital aspects of care.⁶ The Hospice Friendly Hospitals (HfH) Programme is an evaluated initiative of the IHF^{7, 8} which in partnership with the HSE seeks to ensure that these become central to the everyday business of hospitals.

As part of its work, HfH developed Quality Standards for End-of-Life Care in Hospitals.⁹ A core principle of these standards is the need to ensure access to palliative care according to patient needs.

To facilitate and promote change at the hospital level, the majority of hospitals have established End-of-Life Care Committees chaired by a senior member of the management team, with representation from specialist palliative care. These committees developed quality improvement plans aimed at improving quality standards. Presently, each hospital group is also moving towards supporting these committees with in-hospital or group end of life coordinators. The mainstreaming of the HfH Programme by the HSE is enabling the IHF to reduce its involvement. The Framework endorses the HfH philosophy and approach, and encourages the specialist palliative care teams in the acute hospitals to work closely with it.

 **Action Point:** It is recommended that at both individual and group hospital level, the HfH Programme be adopted and supported with adequate coordination and strong linkage with the specialist palliative care services. In tandem with this, the IHF, in consultation with the National Clinical Programme for Palliative Care, should continue its work on developing a set of appropriate metrics aimed at evaluating the outcomes and effectiveness of this programme.

3.4 CARERS

The 2012 National Carers' Strategy¹⁰ envisioned that carers would be recognised and respected as key care partners, supported to maintain their own health and well-being and to care with confidence. It recognised that assisting carers is one of the most effective ways of helping those in receipt of care, and acknowledged that the transition to life, once the need for caring has ended, can be difficult for some carers.

Carers' needs fall into two categories, support to enable them to care for their relative, and support to care for themselves.¹¹ Feedback from the Voices4Care Network, an AllHPC initiative to involve service users, carers and the wider community in the work of the AllHPC, suggests that caring for their relative includes access to better information on their condition and prognosis; more opportunities to ask questions of health professionals; more home help hours; quicker access to equipment and community therapists (similar to the medical cards model); more information on supports and services available to them, (including financial advice and faster access to applications for the carer's allowance); training; and a single point of contact. Access to respite care (both outside and in the home), and emotional and social support, are concerns carers have in terms of looking after themselves. Social support extends to support from the local community, and a need for a public awareness campaign to develop community support was identified.

The Framework Steering Group recognised the significant role and needs of carers, but time constraints did not allow for any conclusions on how best to assess individual needs or the resource implications. These issues should be considered more fully during the revision of the NACPC Report, and in the next Strategic Plan.

Specialist palliative care providers have traditionally regarded the family as the unit of care, and recognise their role in responding to the needs of carers, and acting as advocates on their behalf. Meeting the needs of carers will increase the workload of the specialist team working in the community, and nursing and social work staffing levels should reflect that reality.



Action Point: An awareness of the needs of carers should be embedded in specialist palliative care culture, with a view to ensuring that those needs are identified and met.

3.5 HEALTH PROMOTING PALLIATIVE CARE IN ACTION

Public Awareness

The 2001 NACPC Report recommended that the concept of palliative care should be promoted in the wider community and among non-healthcare professionals. A number of initiatives to increase public awareness of issues around death and dying have taken place in Ireland in recent years, including the Forum on End of Life, the IHF's Think Ahead Programme, and the AllHPC's Public Awareness Campaigns; never the less taboos remain widespread in Irish society around the subject. Carers have reported the isolation that can be experienced when caring for a relative at home, and the inability of neighbours and friends to express their support.



Action Point: The HSE should actively support initiatives to raise public awareness and to change the culture around death and dying. Any new initiatives should build on the work done to date.

Compassionate Communities

Specialist palliative care services have a responsibility to share their expertise and knowledge to strengthen the coping capacity of communities, groups, families and individuals, far beyond the scope of their services. The Compassionate Communities Project is an initiative developed through Milford Care Centre in Limerick to address these issues and embrace the theory of health promoting palliative care. The Project seeks to support people to think a little differently about death, to encourage people to plan ahead, talk with others and offer practical support within the community to those facing the end of life. This low-budget project was evaluated^{12,13} and was found to have had a positive impact.



Action Point: The Compassionate Communities Project should be considered as a potential national model.

The Compassionate City Charter

The Compassionate City Charter¹⁴ represents a commitment by a city to embrace a view of health and wellbeing that embraces community empathy, directly supporting its inhabitants to address the negative health impacts of social inequality and marginalisation attributable to dying, death and loss.

Compassionate Cities publicly seek to enlist all the major sectors of a community to help reduce the negative social, psychological and medical impact of serious illness, care-giving, and bereavement. Compassionate Cities are communities that publicly encourage, facilitate, support and celebrate care for one another during life's most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail ageing and dementia, grief and bereavement, and the trials and burdens of long-term care.

The Compassionate City Charter can contribute to meeting the health promoting palliative care challenge, and deserves careful consideration and support.

References

1. Dept. of Health & Children (2001), *Primary Care – A New Direction*.
2. IHF, ICGP & HSE (2011), *Primary Palliative Care in Ireland*.
3. IHF (2014), *Primary Palliative Care Programme Report on Progress February 2012-March 2014*.
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6. IHF (2013), *The strategic importance of palliative care within the Irish health service – Perspectives on future service delivery*, Perspectives Series No. 1.
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12. Brereton, M. (2012), *Report on the evaluation of Milford Care Centre's Compassionate Communities Project*, Milford Care Centre.
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SECTION 4 Specialist Palliative Care

4.1 OVERVIEW OF THE PROVISION OF SPECIALIST PALLIATIVE CARE IN IRELAND

The HSE’s Five Year Development Framework covering the years 2009 – 2013¹ identified significant gaps in the provision of specialist palliative care services nationally, and made 43 recommendations on how the priority needs should be addressed. Some progress has been achieved since 2009, most notably the opening of a new 44 bed unit at Marymount Cork (20 additional beds); a new 24 bed unit by St Francis Hospice in Blanchardstown, North West Dublin; an additional 6 beds at Galway Hospice and the opening of a new 15 bed unit in Kerry due to happen in 2017. However available data confirm that regional variations still exist in access to specialist palliative care in inpatient units, day care services, acute hospitals, and community-based services, both in infrastructure and staffing levels. Some new development projects rectifying the infrastructural deficits are at an advanced stage, and will be delivered during the lifetime of this Framework.

The current level of service provision in Ireland is described in Annex D.

4.2 INPATIENT UNITS

Bed Numbers. The number of specialist palliative care beds available in Ireland is planned to increase significantly during the period 2017-2021. This will be a considerable achievement, but requires commitment to all the projects currently in the pipeline, particularly those in Tullamore, Drogheda, and Cavan, which are not as far advanced as other projects. These areas were identified as black spots in the 2006 Baseline Study,² and it is vital that concrete plans for these new inpatient units are progressed urgently.

Table 2A shows the proposed inpatient unit developments prioritised in the 2009-2013 Development Framework which will be progressed during the lifetime of this Framework - all are subject to having capital in place along with statutory revenue funding becoming available in the respective years. Table 2B shows the proposed extensions or redevelopments of existing inpatient units to be progressed in the same period. The capital costs of many projects are attracting generous support from local fundraising groups, and although projects should not be delayed because local capital contributors have not been identified a pragmatic approach will need to be taken in these instances. Once Waterford IPU has been established the proposal to open a 12 bed satellite unit in the grounds of St. Luke’s General Hospital, Kilkenny will be revisited.

UNIT	NO. OF BEDS	PROPOSED OPENING
Kerry Developed with Kerry Hospice Foundation	15	2017 – Q4
Mayo Developed with Mayo Roscommon Hospice Group	14	2019
Waterford Developed with Waterford Hospice Movement	20	2019
Wicklow Developed with Wicklow Hospice Foundation	15	2019
Drogheda Developed with local philanthropy	30	2020/2021
Cavan Developed with St Christopher’s Hospice	16	2020/21
Tullamore	15	2020/21

TABLE 2A: Proposed new inpatient unit developments as recommended in the HSE 2009-2013 Development Framework with indicative schedule of opening.

UNIT	DEVELOPMENT	NUMBER OF BEDS		OPENING PLANNED
		Existing Total	New Total	
Our Lady's Hospice & Care Centre (Harold's Cross, Dublin)	Redevelopment to all single rooms	36	36	2016/2017
St. Brigid's (Kildare)	Redevelopment to all single rooms	7	13	Q1 2018
Milford Care Centre (Limerick)	Redevelopment to all single rooms	30	30	2017
St. Francis' Hospice (Raheny, Dublin)	Redevelopment to all single rooms	19	20	Phase 1: 2021 Phase 2: 2023
Galway Hospice	Relocation to a new site	18	26	2021
North West Hospice (Sligo)	Redevelopment to all single rooms	8	12	2020/2021

TABLE 2B: Proposed redevelopments of existing inpatient units

RECOMMENDATION 5:

The capital projects in Tables 2A and 2B should proceed as planned and be completed in accordance with the timeframes identified. Tight deadlines should be identified at the early stages of the process for each of the stages required for capital developments, to ensure all projects are completed within the timeframe. The estimated revenue costs associated with the new hospice developments in Table 2A will be in the region of €25 million.

Single Room Accommodation

There is a growing international trend in favour of 100% single room accommodation in all acute settings, a view emphasised in the Report of the International Expert Advisory Group⁴ for specialist palliative care inpatient units in particular. This Framework notes the decision to provide all single rooms in the new developments listed in Tables 2A and 2B above, and fully endorses that decision. It also notes the plans outlined in Table 2B for the conversion of some of the existing inpatient units to single room configuration, and recommends that the remaining units should be converted over time. It will be essential to ensure that any new builds and the reconfiguration of existing units are in compliance with Health Information and Quality Authority (HIQA) standards.

The staffing implications of 100% single rooms have been examined in the literature, with conflicting results. The situation should be monitored closely as the move to single rooms accelerates, and the impact on staffing levels should be examined in the context of the update of the NACPC Report.

RECOMMENDATION 6:

Existing specialist inpatient units should develop plans to move to all single room patient accommodation in order to ensure the privacy and dignity of each person and to be in compliance with HIQA standards. In preparing for this change, the HSE's Palliative Care Providers Network will need to monitor and evaluate the impact of single room accommodation on staffing levels and make recommendations as appropriate.

IPU Staffing Levels

The most recent HSE figures available indicate a variation in staffing levels and staff mix across the country, and also show deficits compared to the NACPC recommendations. The NACPC Report also recommended that specialist palliative care services should have an appropriate level of administrative, secretarial and general support staff, without specifying actual numbers. The Voluntary Hospices Group (VHG) has indicated the skill mix and numbers needed under these three categories, as well as typical non-pay costs which need to be considered into the funding base for inpatient units.

Pending agreement on what constitutes core costs, (see paragraph 2.14), all existing inpatient units should be brought up to appropriate staffing levels using the recommendations in the NACPC Report as a guideline. An initial review of the staffing levels this would require an estimated investment of approximately €2 million over the lifetime of this Framework; however, a thorough analysis of existing posts needs to be undertaken as it may be possible to re-configure a significant number of posts (See Annex E, for a breakdown of costs).

A detailed case for additional consultant posts is being prepared by the consultant group and will be considered in line with the Model of Care and negotiated through existing HSE mechanisms. Pending the outcome of such deliberations, the staffing levels of consultants, who play key roles in all specialist care settings, should be brought up to the levels proposed in the Hanley Report³ over the life of the Framework. This would require 20 new posts at a cost of between €3.5m - €4.2m.

RECOMMENDATION 7A:

The clinical staffing levels in all existing inpatient units should be brought up to the levels recommended in the NACPC Report, and the number of consultants in palliative medicine should be brought up to the level recommended in the Hanley Report.

4.3 DAY CARE SERVICES

The provision of specialist palliative care day care services is limited to locations where inpatient units currently exist or are planned. There are noted variations in the model of care offered (social and/or medical), and the number of hours or days which a service is available for. The Clinical Programme's emerging model of care will incorporate the provision of day care and it should be further considered in the context of the update of the NACPC Report.



Action Point: The National Clinical Programme for Palliative Care should establish a short life working group to examine the appropriate model of care and the demand for specialist palliative day care services, and to make its recommendations within twelve months of its establishment.

4.4 COMMUNITY-BASED SERVICES

Staffing Levels

Annex D details specialist palliative care staffing requirements as described by the NACPC. Annex F captures the current level of staff working in the community by CHO (Community Health Organisation) in 2016 and while many areas are well resourced in nursing terms, the multidisciplinary mix envisaged in the NACPC Report is largely absent from all teams. The deficits in recommended staffing levels are captured in Annex F. The Framework recommends that the deficits in all disciplines be addressed over the lifetime of the Framework. It is acknowledged that nursing deficits have been significantly addressed; however, further work is required in this area including the use of evidence based methodologies such as those used in the Taskforce on Staffing and Skill Mix for Nursing. It is estimated that eliminating the WTE deficits in physiotherapy, occupational therapy and social work will cost approximately €6.5m.

RECOMMENDATION 7B:

It is recommended that the staffing levels of specialist palliative care services in the community are brought up to the NACPC recommended levels over the lifetime of this Framework.

Extended Service

It should be noted that the NACPC Report did not specify the staffing requirements for 7-day or out-of-hours services. This will need to be considered at a future date as patients can deteriorate quite rapidly and may require hospital admission due to the lack of access to specialist medical and/or nursing care.

The issue of extending specialist palliative care in the community to provide a seven-day service has been addressed in paragraph 3.1.

4.5 ACUTE HOSPITALS

Staffing Issues

The designation of hospitals as Model 1, 2, 3 or 4 hospitals, the centralisation of cancer services in larger centres, and developments in the U.K. suggest that the 2001 NACPC Report recommendations on staffing levels for acute hospitals need to be re-visited. Some differentiation between Model 3 and Model 4 hospitals may be warranted, with somewhat higher staffing levels in the latter. The staffing levels suggested in the U.K.'s National Institute for Health and Care Excellence (NICE) guidance for cancer centres⁵ is significantly higher than the NACPC recommendations, (see Table 3 for comparison), while higher levels again are emerging in the commissioning guidance in the U.K.⁶ The needs of Model 1 and Model 2 hospitals should be met by the specialist palliative care teams in the community – this may have implications for the staffing of these teams and should be considered as part of workforce planning developments.

The appropriate specialist palliative care staffing levels for Model 3 and Model 4 hospitals should be considered in the context of the earlier recommendation regarding workforce planning (Paragraph 2.15). This work should take into account weekend cover requirements, the impact of the size of different cancer centres, work load, linkages with the specialist palliative care inpatient unit, the need for other disciplines such as psychology and speech and language therapy, and any other relevant issues.

	NACPC REPORT		NICE GUIDANCE	
	Model 3	Model 4	Model 3	Model 4
Consultant	Population-based	Population-based	Population-based	1.5
NCHD	Population-based	Population-based	Population-based	1.0
CNS	1 per 150 beds	1 per 150 beds	2.0 – 3.0	5.0
Physiotherapist	No recommendation	No recommendation	2.5 sessions/week	5 sessions/week
Occupational Therapist	No recommendation	No recommendation	2.5 sessions/week	5 sessions/week
Dietician	No recommendation	No recommendation	2.5 sessions/week	5 sessions/week
Pharmacist	No recommendation	No recommendation	1 session/week	2.5 sessions/week
Chaplain	No recommendation	No recommendation	1 session/week	2.5 sessions/week
Social Worker	1	1	-	-
Secretary	1	1	-	-

TABLE 3: Comparison of NACPC Recommended Staffing Levels in Acute Hospitals and NICE Guidelines

In the meantime, the staffing levels recommended in the NACPC Report should be implemented. The deficits in recommended staffing levels will cost approximately €2.6m. (See Annex G) The requirement of additional consultant posts has been addressed in paragraphs 2.15 and 4.2.

RECOMMENDATION 7C:

Specialist palliative care staffing levels in Model 3 and 4 acute hospitals should be brought up to the NACPC Report recommended levels over the life of this Framework

4.6 OTHER CONSIDERATIONS

Integration of Palliative Care in Acute Hospitals

The NACPC Report recommended that palliative care should be integrated into patient care at an early stage in the disease trajectory, an approach endorsed in the 2014 Final Evaluation Panel Report of National Cancer Strategy 2006,⁷ which found that palliative care often appeared to be provided to patients only in the last few weeks of life, contrary to international best practice. There is every reason to assume that a similar situation exists in relation to other life-limiting diseases, despite the growing acceptance by specialists in all disciplines of the benefits of palliative care for patients with non-malignant conditions.

There is a need to transform the model of care for all life-limiting conditions and ensure actions are taken to achieve an effective interface between palliative care and specialist care, from as early as the initial life-limiting diagnosis. This could be achieved by involving palliative health care professionals in multi-disciplinary teams and establishing joint clinics as recommended in the NACPC, and reiterated in the Final Evaluation Panel Report. It is essential that a culture that values the role of palliative care alongside the delivery of other treatments is fostered.



Action Point: It is recommended that models of care for all life-limiting conditions include provision for the delivery of palliative care alongside other treatments.

Fast-tracking Admissions and Discharges

It is inappropriate to have palliative care patients wait for admission to an acute hospital, or to need to seek admission through hospital emergency departments. A system for fast-tracking the admission of such patients is required. Equally, discharge should be arranged if and as soon as a person's condition allows, either to their home, community hospital or nursing home (with appropriate liaison with community services), or to the local specialist palliative care inpatient unit. The patient's choice regarding place of care, compatible with their condition, should be facilitated to the greatest extent possible.



Action Point: This Framework recommends the use of the *Rapid Discharge Guidance for People Who Wish to Die at Home* produced by the National Clinical Programme for Palliative Care⁸ where discharge from the acute hospital is chosen.

References

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SECTION 5 Recommendations

The recommendations listed below are an amalgamation of individual recommendations and actions contained within Sections 1 – 4 of the Framework. The order does not indicate priority but rather where the recommendation appears in the document, as shown by the page number.

RECOMMENDATION 1 (Page 11): In light of the various changes and developments that have occurred since 2001, this Framework recommends that the NACPC Report be revised (not replaced), and that this work commence in early 2018 to be completed in 2019. It further recommends that the implementation of the recommendations contained in the revised policy commence in 2020. In the interim, the underpinning principles and recommended staffing norms outlined in the NACPC Report should continue to guide national policy and strategy.

RECOMMENDATION 2 (Page 17): A properly resourced palliative care corporate function be re-established to coordinate, monitor and develop palliative care services in emerging healthcare structures. This function will also ensure the equitable rollout of planned developments as well as integration between community and hospital structures and voluntary providers. The corporate function should also ensure that an appropriate replacement for the NACPC consultative and development committees is put in place. A key role of the function will be to address the following recommendations and action points, either directly or through collaboration, commissioning or delegation:

- Revision of the NACPC Report, and future strategic planning (Recommendation 1);
- Definition of core costs in all specialist palliative care settings (Recommendation 3);
- Collaboration with the National Clinical Programme for Palliative Care on its actions (Recommendation 4)
- Progression and completion of the recommended capital programme (Recommendation 5);
- Phased and balanced implementation of the NACPC staffing levels (Recommendation 6) ;
- *Towards Excellence in Palliative Care – Quality Assessment and Improvement Workbooks* should be used by all specialist palliative care providers, regardless of where they see themselves in their quality improvement journey, or if they have already achieved external accreditation (Page 15);
- Identification of an appropriate replacement structure for the consultative and development committees at CHO level. (Page 17);
- Development of shared governance structures between new specialist palliative care inpatient units and existing local community specialist palliative care services (Page 17);
- The corporate palliative care function should be given the responsibility, authority and resources to lead the process and ensure that the necessary integration takes place (Page 22);
- Movement on a phased basis to 50% statutory funding of the night nursing service currently funded by the Irish Cancer Society and the Irish Hospice Foundation (Page 23);
- The HSE's Palliative Care Provider Network should prepare recommendations on how the commissioning model of funding might work best for all stakeholders (Page 23);
- Pending the outcome of ongoing current deliberations, the staffing levels of consultants should be brought up to the levels proposed in the Hanley Report (Page 24);
- Availability of 7 day service provision and access to Out of Hours services needs to be considered. (Page 29)

- Palliative care patients in the community should be given priority when requests for services and equipment are made on their behalf, similar to the manner in which medical cards are fast-tracked for specialist palliative care patients (Page 29).
- This Framework recommends the use of the *Rapid Discharge Guidance for People Who Wish to Die at Home* produced by the National Clinical Programme for Palliative Care where discharge from the acute hospital is chosen (Page 39).

RECOMMENDATION 3 (Page 23): The corporate palliative care function, in collaboration with the HSE's Clinical Care Programme and the Palliative Care Providers Network, should establish a short life working group to define by the end Q1 2018 what constitutes a core specialist palliative care service, including both pay and non-pay costs, with a view to having all core costs statutory funded by 2021.

RECOMMENDATION 4 (Page 26): The National Clinical Programme for Palliative Care should be properly resourced, supported and sustained to continue its work in integrating palliative care across the HSE's Divisions, pursuing the quality agenda and ensuring the best use of resources. The National Clinical Programme will have a key role in addressing the following action points in the Framework:

- The NCEC Guidelines should be implemented by all specialist palliative care providers. As part of its monitoring and audit function on quality and patient safety the HSE should develop appropriate KPIs (Page 16);
- Developing and implementing an agreed nursing governance structure for all specialist palliative care provider organisations and in all settings where clarity on nursing reporting relationships is currently absent (Page 18);
- Linking with the Department of Health Workforce Planning Group and with the HSE's National Doctors Training and Planning Unit on staffing requirements in specialist palliative care (Page 24).
- Mapping current practice regarding 24-hour availability of specialist advice, and recommending an appropriate delivery model (Page 29);
- An agreed understanding of the roles and duties of public health nursing and specialist palliative care is needed (Page 28).
- Developing the palliative care support beds network (Page 30);
- Ensuring that all hospital healthcare staff are trained in the palliative care approach (Page 31);
- The HfH programme should be adopted and supported and metrics developed to evaluate effectiveness (Page 31);
- Establishing a short life working group to examine the appropriate model of care and demand for specialist palliative day care services (Page 37);
- Ensuring provision for the delivery of palliative care alongside other treatments in models of care for all life-limiting conditions (Page 39);
- Collaborating with the corporate palliative care function on its tasks (Recommendation 2).

RECOMMENDATION 5 (Page 35): The capital projects in Tables 2A and 2B should proceed as planned and be completed in accordance with the timeframes identified. Tight deadlines should be identified at the early stages of the process for each of the stages required for capital developments, to all projects are completed within the timeframe. The estimated revenue costs associated with the ensure new hospice developments in Table 2A will be in the region of €25 million.

RECOMMENDATION 6 (Page 36) Existing specialist inpatient units should develop plans to move to all single room patient accommodation in order to ensure the privacy and dignity of each person and to be in compliance with HIQA standards. In preparing for this change, the HSE's Palliative Care Providers Network will need to monitor and evaluate the impact of single room accommodation on staffing levels and make recommendations as appropriate.

RECOMMENDATIONS 7A,B,C (Page 36, 37 and 38): The staffing levels in all existing specialist palliative care inpatient units, community services and Model 3 and Model 4 acute hospitals should be brought up to the levels recommended in the NACPC Report, and the number of consultants in palliative medicine should be brought up to the level recommended in the Hanley Report, all within the lifetime of the Framework. This should occur in the context of evidence based methodologies and include the work currently being undertaken by the Department of Health Chief Nursing Office and the HSE's HR Division. This will ensure an integrated strategic planning approach to determine the most appropriate and efficient use of resources.

RECOMMENDATION 8: It was not possible within the given timeframe to adequately research and analyse all the issues identified as requiring action, therefore the following Action Points should be addressed as part of the revision of the NACPC Report and in the development of the Strategic Plan in 2019:

- Persuading all specialist palliative care providers to develop a programme of health promoting palliative care activity within their local communities (Page 12);
- Ensuring that all palliative care services have rehabilitative palliative care as an intrinsic part of their model and culture of care (Page 13);
- Developing and implementing national guidance for bereavement care, national and local coordinated bereavement networks, and standards for bereavement care (Page 14);
- Considering how best to extend care to vulnerable populations, such as those with intellectual disabilities, those with psychiatric illness, homeless people, the travelling community, ethnic minorities, and prisoners (Page 14);
- Promoting the person-centred culture approach, currently being developed by the HSE's Quality Improvement Division, among organisations providing palliative care (Page 16);
- Putting in place the appropriate supports for volunteers within each specialist palliative care organisation. This should include the post of volunteer coordinator as recommended in the NACPC Report, with responsibility for the recruitment, training and placement of volunteers (Page 18);
- Developing a palliative care education strategy (Page 20);
- Promoting the research agenda (Page 21);
- In conjunction with the Office of Nursing and Midwifery Services Development and in consideration of policy papers being developed by the Department of Health, describing and developing the role of the clinical nurse specialist and the advanced nurse practitioner in palliative care, and determining the current range and numbers of nurse medicinal prescribers with a view to expansion as appropriate (Page 24);
- Exploiting the potential of developments in information technology (Page 25);
- Developing an agreed model of nursing care for palliative care patients and their families in the community (Page 28);

- Exploring the need for out-of-hours specialist palliative care services and the resource implications (Page 29);
- Considering how to support carers, and the resource implications involved (Page 32);
- Raising public awareness and changing culture around death and dying (Page 32);

Estimated Revenue Costs

The revenue costs below are indicative of the estimated requirements. A full and detailed analysis will need to be undertaken, including the possible re-configuration of posts within services, and it is a realistic expectation that the total revenue requirement can be reduced.

PRIORITY	ESTIMATED COST €M
New IPU's / Hospices - Associated Revenue Costs	25.00
Eliminating Existing IPU Staffing Deficits	2.01
Eliminating Existing Community Nursing Deficits*	0.50
Eliminating Existing Community AHP and Social Work Deficits	5.20
Eliminating Existing Acute Hospital Deficits	2.41
Implementation of Hanley Report – Consultant Posts	4.17
50% Statutory Funding of Night Nursing Services currently provided through charitable fundraising	1.60
Total	41.06

TABLE 4: The revenue cost of implementing the Framework recommendations.

These costs do not include provisions made under the Lansdowne Road Agreement.

*Annex F shows a funding requirement of €1.5m for CNSs based on the staffing review carried out in early 2016; however due to ongoing recruitment it is estimated that this requirement will have been reduced to approximately €0.5m.

List of Annexes

Annex A	Steering Group Terms of Reference
Annex B	Steering Group Membership
Annex C	Definitions, Levels of Palliative Care Specialisation, Abbreviations & Acronyms
Annex D	National Overview of Current Service Provision
Annex E	NACPC Staff Recommendations with Actual and Deficits in Voluntary Specialist Palliative Care Inpatient Units (2016)
Annex F	NACPC Staff Recommendations with Actual and Deficits in Specialist Palliative Care Community Services (2016)
Annex G	NACPC Staff Recommendations with Actual and Deficits in Specialist Palliative Care Acute Services (2016)

Bibliography

ANNEX A

STEERING GROUP TERMS OF REFERENCE

Adult Palliative Care Services - Development Framework 2017 – 2019

Terms of Reference for Palliative Care Development Framework Steering Group

The development of a new strategic plan has been requested by the National Director for Primary Care, who has overarching responsibility for Palliative Care within the HSE. It is recognised that although the HSE and other stakeholders remain committed to meeting national strategy and policy recommendations, most of the relevant documents are now 7-16 years old and emerging approaches to palliative care need to be acknowledged and acted upon. The structures to support the development of services have also changed through the evolving Community Health Organisations and Hospital Groups.

1. CONTEXT FOR STRATEGIC PLAN FOR ADULT PALLIATIVE CARE SERVICES

The Irish Health System is facing 10 major challenges:

- an ageing population with increasing cultural diversity;
- growing demand for services;
- increasing duration and complexity of care required;
- increasing public expectation and strong demand for responsive, patient led and
- personalised health care;
- a move from predominantly hospital-centric health service delivery to delivery of care at /or
- close to home;
- an immediate requirement to progress the development of integrated chronic disease
- management and care delivery models;
- increasing emphasis on value based purchasing;
- developing dependency on ICT for successful general operations and clinical service
- delivery;
- introduction of licensing for all health delivery endeavours;
- Development of models of care;
- significant structural change to the health delivery model including:
 - development of 7 Hospital Groups
 - development of 9 Community Health Organisations
 - development of a new funding model, particularly concept of '*money follows the patient*' and '*universal health care*'
 - increasing co-dependency requirement between Voluntary Service Providers and the HSE to maintain and develop Palliative Care Services.

2. PURPOSE OF STRATEGIC PLAN

The purpose of the 2017 - 2019 Palliative Care Strategic Plan is to affect a purposeful response

to these challenges and ensure adult palliative care services deliver geographically needs based, evidence based, innovative, quality driven and person centred patient care.

The Strategy will build on previous strategies and guidance including:

- Report of the National Advisory Committee on Palliative Care **(DoH 2001)**
- Palliative Care Services - Five Year/Medium Term Development Framework **(HSE 2009)**
- Strengthening of Palliative Care as a component of comprehensive care throughout the life Course **(WHO 2014)**
- Towards Excellence in Palliative Care - Quality Assessment and Improvement Workbooks **(HSE 2014)**
- Palliative Care Competence Framework **(HSE 2014)**
- Palliative Care Needs Assessment Guidance **(HSE 2014)**
- Report of the First National Palliative Care Support Bed Review **(HSE 2014)**
- National Quality Standards for Residential Care Settings for Older People in Ireland - End of Life Care Requirements **(HIQA 2104)**

3. FRAMEWORK FOR DEVELOPMENT OF A STRATEGIC PLAN FOR ADULT PALLIATIVE CARE SERVICES

The Strategic Plan will provide 6 key directional themes and related critical success factors for progression.

(i) The patient, and their families / carers must remain at the centre of all Palliative Care service developments

Key critical success factors include:

- optimal access;
- integrated population centred care delivery;
- expansion of certain services particularly in the areas of non-malignant disease;
- appropriate and comprehensive management of presenting safety and risk issues.

(ii) Staff and organisational development

Key critical success factors include:

- development of Palliative Care Services Performance Management and Measurement System;
- development of a pan Palliative Care Learning and Development Strategy;
- effective recruitment;
- primacy of Clinical Leadership and Management;
- organisations that embrace excellence.

(iii) Information Communication Technology

Key critical success factors include:

- maximise all opportunities presented by ICT particularly in relation to:
- electronic patient record;
- electronic patient prescribing;
- full capacity to ensure clinical effectiveness / performance;
- full utilisation of point of care technologies.

(iv) Relationships

Key critical success factors include:

- further development of integration with Hospital Groups, Community Health Organisations and voluntary sector;
- development of locally integrated health delivery models;
- shaping and influencing the Health Reform Agenda in relation to palliative care services;
- further development of academic partnership arrangements particularly in relation to research and education.

(v) Financial Validation

Key critical success factors include:

- ensuring that Palliative Care Services remain appropriately funded for the designated portfolio of services;
- preparedness and readiness for introduction of new funding model.

(vi) Facilities

Key critical success factors include:

- progression of capital development priorities with particular emphasis on progression of specialist palliative care inpatient bed units and palliative care support beds.

4 STEERING GROUP TO DELIVER STRATEGIC PLAN

4.1 Membership

- Chair to be appointed by National Director for Primary Care
- Two CEOs from voluntary service providers
- National Clinical Lead Palliative Care
- HSE National Lead for Palliative Care
- Chair of Consultant Group
- Nominee of Irish Hospice Foundation

- Nominee of Irish Association for Palliative Care
- Nominee of All Ireland Institute for Hospice and Palliative Care
- Nursing Lead HSE Palliative Care Programme
- Patient / Service User
- Representation from
 - Community Nursing
 - Allied Health Professionals
 - Public Health Medicine
 - The Community Health Organisations
 - The Hospital Groups
 - The DoH
- Representation from HSE Divisions / Directorate as appropriate and when required

4.2 Reporting

The Steering group, through the Chair, will report to the National Director for Primary Care.

ANNEX B

STEERING GROUP MEMBERSHIP

Paddie Blaney	CEO, All Ireland Institute of Hospice and Palliative Care
Donal Buggy	Head of Services, Irish Cancer Society
Eileen Carruthers	Director of Nursing, Specialist Palliative Care, HSE
Brian Creedon	Chair, Irish Palliative Medicine Consultants Association
Niamh Finucane	Chair, Irish Association of Palliative Care
Sharon Foley	CEO, Irish Hospice Foundation
Anne Harris	Quality Improvement Division, HSE
Audrey Houlihan	CEO, Our Lady's Hospice and Care Services
Barry Murphy	Principal, Department of Health
Ger O'Callaghan	Chief Operations Officer, South/South West Hospital Group
Sean O'Healy*	CEO, Galway Hospice
Eileen O'Leary	Regional Support Manager, HSE
Lorna Peelo-Kilroe**	Palliative Care Nursing Lead, HSE
Pat Quinlan (Chair)	CEO, Milford Care Centre
Sheilagh Reaper-Reynolds	National Lead for Palliative Care, HSE
Deirdre Rowe Services	Occupational Therapy Manager, Our Lady's Hospice and Care Services
Karen Ryan	Clinical Lead, National Clinical Programme for Palliative Care, HSE
Aidan Ryan	Public Health Specialist, HSE

* Mary Nash replaced Sean O'Healy

** Margaret Codd replaced Lorna Peelo-Kilroe

ANNEX C

DEFINITIONS, LEVELS OF PALLIATIVE CARE SPECIALISATION & ABBREVIATIONS

1. THE WORLD HEALTH ORGANISATION (WHO) DEFINITION OF PALLIATIVE CARE (2015)

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance quality of life, and may also positively influence the course of the illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

2. LEVELS OF PALLIATIVE CARE SPECIALISATION

Palliative care provision is the responsibility of the whole healthcare system, and uses a team approach to planning and providing care tailored to meet the individual needs of the person and their family. Within the healthcare system there are three levels of palliative care provision, with increasing specialisation from level 1 to level 3:

Level 1: Provided in any location or setting by all healthcare professionals as part of their role and using a palliative care approach.

Level 2: Provided in any location, using a palliative care approach by healthcare professionals who have additional knowledge of palliative care principles and use this as part of their role.

Level 3: Provided by healthcare professionals who work solely in palliative care, and who have extensive knowledge and skills in this specialty.

3. ABBREVIATIONS AND ACRONYMS

The abbreviations and acronyms used in this document are listed in Appendix 1. They are also explained when first used in the text.

APPENDIX 1 to ANNEX C - ABBREVIATIONS AND ACRONYMS USED

AHP	Allied Health Professional
AIHPC	All Ireland Institute for Hospice and Palliative Care
CEO	Chief Executive Officer
CHO	Community Healthcare Organisation
CNM	Clinical Nurse Manager
CNS	Clinical Nurse Specialist
CSNAT	Carer Support Needs Assessment Tool
CSO	Central Statistics Office
GP	General Practitioner
HCA	Health Care Attendant
HfH	Hospice friendly Hospital
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
IAPC	Irish Association of Palliative Care
ICGP	Irish College of General Practitioners
ICS	Irish Cancer Society
ICT	Information Communication Technology
IHF	Irish Hospice Foundation
IPU	Specialist Palliative Care Inpatient Unit
MOCIS	Medical Oncology Clinical Information System
NACPC	National Advisory Committee on Palliative Care
NCHD	Non-consultant Hospital Doctor
NICE	National Institute for Clinical Excellence
OoH	Out of Hours
ONMSD	Office of the Nursing and Midwifery Services Director
PCRN	Palliative Care Research Network
RCPI	Royal College of Physicians of Ireland
RGN	Registered General Nurse
UHN	Unique Health Number
UK	United Kingdom
VHG	Voluntary Hospices Group
WHA	World Health Assembly
WHO	World Health Organisation

ANNEX D

NATIONAL OVERVIEW OF SERVICE PROVISION

1. GENERAL

The following paragraphs provide an overview of current service provision for inpatient units and community-based services by Community Health Organisation (CHO) utilising 2016 CSO data. It should be noted that the recruitment of CNSs in the community was ongoing at the time of data collection. Day care services and acute hospital services are not considered, as short life working groups will be examining these services.

2 INPATIENT UNITS AND COMMUNITY-BASED SERVICES

CHO 1 (Cavan, Monaghan, Sligo, Leitrim, Donegal)

- **Inpatient Beds:** The population warrants 31-39 beds based on 8-10 bed per 100,000 recommended in the NACPC Report. Currently there are 8 beds in Donegal Hospice in Letterkenny. There are plans to increase the 8 beds in the North West Hospice in Sligo to a total of 12, . A 16 bed unit for Cavan/Monaghan is in the planning stage of development .
- **Community-based Services:** The population warrants 15.6 CNSs based on the 1 per 25,000 ratio recommended in the NACPC Report, and 3.1 each of physiotherapists, occupational therapists and social workers based on the 1 per 125,000 ratio recommendation. Currently there are 17.4 clinical nurse specialists (CNS) plus 1 clinical nurse manager (CNM), and no allied health professionals (AHP).

CHO 2 (Galway, Roscommon, Mayo)

- **Inpatient Beds:** The population warrants 36-45 beds based on 8-10 bed per 100,000 recommended in the NACPC Report. Currently there are 18 beds in Galway Hospice, with a plan to relocate to a new site and build a new 26 bed unit in 2020. A 14 bed unit is due to open in Mayo in 2018/19.
- **Community-based Services:** The population warrants 18.0 CNSs based on the 1 per 25,000 ratio recommended in the NACPC Report, and 3.6 each of physiotherapists, occupational therapists and social workers based on the 1 per 125,000 ratio recommendation. Currently there are 21.3 CNS plus 2.7 CNM, and 4.0 social workers.

CHO 3 (Clare, Limerick, North Tipperary)

- **Inpatient Beds:** The population warrants 31-38 beds based on 8-10 bed per 100,000 recommended in the NACPC Report. Currently there are 30 beds in Milford Hospice. The IPU unit is being re-developed in 2017 to provide, all single room accommodation.
- **Community-based Services:** The population warrants 15.0 CNSs based on the 1 per 25,000 ratio recommended in the NACPC Report, and 3.0 each of physiotherapists, occupational therapists and social workers based on the 1 per 125,000 ratio recommendation. Currently there are 16.8 CNS plus 6 registered general nurses (RGN), 2 physiotherapists, 2 occupational therapists and 2 social workers.

CHO 4 (Cork, Kerry)

- **Inpatient Beds:** The population of 690,575 warrants 55-69 beds based on 8-10 bed per 100,000 recommended in the NACPC Report. Currently there are 44 beds in Marymount, with a new 15 bed unit to open in Kerry in 2017.
- **Community-based Services:** The population warrants 27.6 CNSs based on the 1 per 25,000 ratio recommended in the NACPC Report, and 5.5 each of physiotherapists, occupational therapists and social workers based on the 1 per 125,000 ratio recommendation. Currently there are 22.36 CNS plus 1 CNM, and 1.75 social workers.

CHO 5 (South Tipperary, Waterford, Wexford, Carlow, Kilkenny)

- **Inpatient Beds:** The population of 510,333 warrants 40-51 beds based on 8-10 bed per 100,000 recommended in the NACPC Report. There is currently no inpatient unit in the area, with only 2 dedicated specialist palliative care beds available in Waterford Regional Hospital. Plans for a 20 bed unit in Waterford are well-advanced and due to come on stream in 2018/19. The possibility of an IPU in Carlow/Kilkenny will be explored at a later date
- **Community-based Services:** The population warrants 20.4 CNSs based on the 1 per 25,000 ratio recommended in the NACPC Report, and 4.0 each of physiotherapists, occupational therapists and social workers based on the 1 per 125,000 ratio recommendation. Currently there are 17.3 CNS, 3.4CNM, 3.4 RGN, and 2.5 occupational therapists.

CHO 6 (Wicklow, Dublin South East)

- **Inpatient Beds:** The population of 383,169 warrants 30-38 beds based on 8-10 bed per 100,000 recommended in the NACPC Report. Currently there are 12 beds in Blackrock Hospice, with plans for a 15 bed unit in Wicklow in 2018.
- **Community-based Services:** The population warrants 15.3 CNSs based on the 1 per 25,000 ratio recommended in the NACPC Report, and 3.1 each of physiotherapists, occupational therapists and social workers based on the 1 per 125,000 ratio recommendation. Currently there are 12.5 CNS plus 0.5 CNM, and 0.5 social worker.

CHO 7 (Kildare, West Wicklow, Dublin South, Dublin South West and Dublin West)

- **Inpatient Beds:** The population of 707,714 warrants 56-67- beds based on 8-10 bed per 100,000 recommended in the NACPC Report. Currently there are 7 beds in St. Brigid's Hospice with plans to open an additional 6 in 2017, and 36 beds in Our Lady's Hospice Harold's Cross
- **Community-based Services:** The population warrants 28.3 CNS based on the 1 per 25,000 ratio recommended in the NACPC Report, and 5.4 each of physiotherapists, occupational therapists and social workers based on the 1 per 125,000 ratio recommendation. Currently there are 20.57 CNS, 2 CNM, and 2.35 social workers.

CHO 8 (Laois, Offaly, Longford, Westmeath, Louth, Meath)

- **Inpatient Beds:** The population of 619,281 warrants 49-61 beds based on 8-10 bed per 100,000 recommended in the NACPC Report. There is no inpatient unit in the area at present, but there are plans for a 30-36 bed unit in Drogheda to open in 2020/21, and a 15 bed unit in the Midlands to open in 2020/21.
- **Community-based Services:** The population warrants 24.8 CNSs based on the 1 per 25,000 ratio recommended in the NACPC Report, and 5.0 each of physiotherapists, occupational therapists and social workers based on the 1 per 125,000 ratio recommendation. Currently there are 25.29 CNS, 4.1 CNM, 4.6 RGN, 3 Physiotherapists, 3.5 Occupational Therapists, and 7.2 Social Workers.

CHO 9 (Dublin North, Dublin North West, Dublin North Central)

- **Inpatient Beds:** The population of 621,405 warrants 50-62 beds based on 8-10 bed per 100,000 recommended in the NACPC Report. With the opening of the 24 bed unit in Blanchardstown in 2015, added to the 19 beds in St. Francis' Hospice, the area currently has 43 beds.
- **Community-based Services:** The population warrants 24.8 CNSs based on the 1 per 25,000 ratio recommended in the NACPC Report, and 5.0 each of physiotherapists, occupational therapists and social workers based on the 1 per 125,000 ratio recommended in the NACPC Report. Currently there are 17.5 CNS and 2.1 social workers.

ANNEX E

NACPC STAFF RECOMMENDATIONS, WITH ACTUAL AND DEFICITS, IN VOLUNTARY SPECIALIST PALLIATIVE CARE INPATIENT UNITS 2016

(EXCLUDING CONSULTANT DEFICITS)

	Our Lady's Hospice (48 beds)			Marymount Hospice (44)			St. Francis' Hospice (43)			Milford Hospice (30)			
	Rec.	Actual	Deficit	Rec.	Actual	Deficit	Rec.	Actual	Deficit	Rec.	Actual	Deficit	
CNM II	3	4	0	2	2	0	3	4	0	2	5	0	
CNMI	3	4	0	2	2	0	3	3	0	2	2	0	
RGN	45	41.5	3.5	42	40	2	40	45.39	0	28	30	0	
HCA	24	25	0	22	21	1	21.5	25.09	0	15	15.6	0	
Social Worker	4.8	3	1.8	4.4	3.6	0.8	4.3	1.8	2.5	3	2.4	0.6	
Physiotherapist	4.8	3.5	1.3	4.4	3.6	0.8	4.3	2	2.3	3	3.26	0	
Occupational Therapist	4.8	3.5	1.3	4.4	0	4.4	4.3	1.81	2.49	3	2.44	0.56	
Speech & Language Therapist	0.5	0	0.5	0.5	0	0.5	0.5	0	0.5	0.3	0.1	0.2	
Dietician	0.5	0	0.5	0.5	0	0.5	0.5	0	0.5	0.3	0.9	0	
Pharmacist	2	1.5	0.5	1	2.4	0	1	1.14	0	1	2	0	
Chaplain	3	1	2	2	2.4	0	2	1.27	0.73	2	2.55	0	
	Galway Hospice (18)			North West Hospice (8)			Total Deficits			Salary Incl. PRSI*			Cost €
CNM II	1	1	0	1	1	0	1	1	0	0	€65,997	0	
CNMI	3	3	0	1	1	0	1	1	0	0	€61,676	0	
RGN	18	18	0	7	11.6	0	7	11.6	0	5.5	€49,715	273,433	
HCA	8	11	0	4	5.6	0	4	5.6	0	1	€40,606	40,606	
Social Worker	1.8	2.0	0	0.8	2	0	0.8	2	0	5.9	€67,168	382,858	
Physiotherapist	1.8	1.3	0.5	0.8	0.5	0.3	0.8	0.5	0.3	5.4	€60,445	314,314	
Occupational Therapist	1.8	0.8	1.0	0.8	0.5	0.3	0.8	0.5	0.3	10.25	€60,445	607,472	
Speech & Language Therapist	0.1	0.0	0.1	0.1	0.1	0	0.1	0.1	0	1.8	€60,445	108,801	
Dietician	0.1	0	0.1	0.1	0.1	0	0.1	0.1	0	1.6	€60,445	96,712	
Pharmacist	1.0	1.0	0	0.6	0.6	0	0.6	0.6	0	0.5	€70,857	35,429	
Chaplain	1	1	0	1	1	0	1	1	0	2.73	€55,148	150,554	
Total								34.64				€2,010,179	

These costs do not include provisions made under the Lansdowne Road Agreement.

ANNEX F

NACPC STAFF RECOMMENDATIONS WITH ACTUAL AND DEFICITS IN SPECIALIST PALLIATIVE CARE COMMUNITY SERVICES (2016)

	CNS/RGN			CNM			Physiotherapist			Occupational Therapist			Social Workers		
	Rec.	Actual	Def.	Rec.	Actual	Def.	Rec.	Actual	Def.	Rec.	Actual	Def.	Rec.	Actual	Def.
CHO 1	15.6	17.4	0		1.0	0	3.2	0	3.2	3.2	0	3.2	3.2	0	3.12
CHO 2	18.0	21.3	0		2.7	0	3.6	0	3.6	3.6	0	3.6	3.6	4.0	0
CHO 3	15.0	22.8	0		0	0	3.0	2.0	1.0	3.0	2.0	1.0	3.0	2.0	1.0
CHO 4	27.6	22.36	5.24		1.0	0	5.5	0	5.5	5.5	0	5.5	5.5	1.75	3.55
CHO 5	20.0	20.7	0		3.4	0	4.0	0	4.0	4.0	2.5	1.5	4.0	0	4.0
CHO 6	15.3	12.5	2.8		0.5	0	3.1	0	3.1	3.1	0	3.1	3.1	0.5	2.6
CHO 7	28.3	20.57	7.73		2.0	0	5.4	0	5.4	5.4	0	5.4	5.4	2.35	3.05
CHO 8	24.7	29.89	0		4.1	0	5.0	3.0	2.0	5.0	3.5	1.5	5.0	7.2	0
CHO 9	24.8	17.5	7.3		Nil	0	5.0	0	5.0	5.0	0	5.0	5.0	2.1	2.9
Totals	189.3	185.02	23.1*		14.7	0	37.8	2.0	32.8	37.8	8	29.8	37.8	19.9	20.2

(Rec: Recommended; Def: Deficit)

*** Note – a significant number of the nursing deficits have been / are currently being addressed**

Cost of rectifying the deficits:

CNS	23.1 @ €65,997 = €1.5m
Physiotherapy	32.8 @ €60,445 = €2.0m
Occ. Therapy	29.8 @ €60,445 = €1.8m
Soc. Work	20.2 @ €67,168 = €1.4m
Total:	€6.7m

These costs do not include provisions made under the Lansdowne Road Agreement

ANNEX G

NACPC STAFF RECOMMENDATIONS WITH ACTUAL AND DEFICITS IN SPECIALIST PALLIATIVE CARE ACUTE SERVICES (2016)

(EXCLUDING CONSULTANT DEFICITS)

Hospital/Group	CNS			Social Worker			Clerical Officer		
	Rec.	Act.	Def.	Rec.	Act.	Def.	Rec.	Act.	Def.
South/South West									
CUH/CUMH	4.7	3	1.7	1	0	1	1	0	1
Waterford	2.9	0	2.9	1	0	1	1	1.5	0
Mercy	1.3	2	0	1	0	1	0.5	0.5	0
South Tipperary	1.1	1.65	0	1	0	1	0.5	0	0.5
Kerry General	1.5	1	0.5	1	1	0	1	1	0
SIVUH	0.8	2	0	1	0	1	0.5	0	0.5
Ireland East									
Mater	3.7	3	0.7	1	0.5	0.5	1	0.5	0.5
St. Vincent's UH	3.1	3	0.1	1	-	-	1	-	-
Kilkenny General	1.6	1.6	0	1	0	1	0.5	0.5	0
Wexford	1.4	1.5	0	1	0	1	0.5	0	0.5
Mullingar	1.2	1	0.2	1	0	1	0.5	0	0.5
Dublin Midlands									
St. James'	4.5	4	0.5	1	1	0	1	0.5	0.5
St. Luke's	1.1	2	0	1	0	1	0.5	0	0.5
Tallaght	3.1	2	1.1	1	0	1	1	0.5	0.5
Naas	1.2	1.95	0	1	0	1	0.5	0.2	0.3
Tullamore	1.4	1	0.4	1	0	1	0.5	1	0
Portlaoise	0.9	1	0	1	0	1	0.5	0	0.5
RCSI									
Beaumont	4.3	3	1.3	1	1	0	1	1	0
Connolly	1.3	1	0.3	1	1	0	0.5	-	-
Drogheda	2.7	0.8	1.9	1	1	0	0.5	0	0.5
Cavan	2.4	1	1.4	1	0	1	0.5	0	0.5
Saolta									
Galway	4.4	2	2.4	-	-	-	-	-	-
Letterkenny	2.3	1	1.3	1	0	1	0.5	0	0.5
Sligo	1.8	1.5	0.3	1	0	1	0.5	0	0.5
Mayo	1.9	1.8	0.1	1	-	-	0.5	-	-
University Limerick									
Limerick	2.4	3	0	1	0	1	0.5	0.1	0.4
Total Deficits			17.1			17.5			8.2

(Rec: Recommended, Act.: Actual, Def: Deficit)

Cost of rectifying the deficits:	CNSs	17.1 @ €65,997 = €1.13m
	Social Workers	17.5 @ €67,168 = €1.18m
	Clerical support	8.2 @ €33,300 = €0.27m
	Total	€2.58m

These costs do not include provisions made under the Lansdowne Road Agreement

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