An Roinn Sláinte
Department of Health

National Adult Palliative Care Policy

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Message from the Minister

Stephen Donnelly
Minister for Health

Palliative care is something we may all need at some point in our lives. Dying is a universal experience. The new National Adult Palliative Care Policy aims to support people on that difficult journey.

It does so by ensuring the best palliative care is available to everyone where and when they need it. Having access to all necessary supports (whether physical, spiritual, or psychosocial) provides reassurance and comfort – to the person, carer and family. Supporting people to live their best life while living with a life-limiting illness is at the core of this policy.

The first National Adult Palliative Care Policy adopted in 2001 (NACPC Report, 2001) demonstrated a government commitment to growing and sustaining services begun by voluntary and community organisations. Ireland was one of the first countries in the world to publish such a policy. Significant progress has been achieved in the intervening years. There is more access for people to palliative care services across the country. There is a greater awareness of palliative care by the public and other healthcare professionals. The development of children's palliative care services is also notable. The National Clinical Programme for Palliative Care was established in 2010 with a Model of Care for Palliative Care published in 2019. Sláintecare is committed to achieving universal palliative care.

The focus of the new policy is on the person and integrated palliative care. It strives for equitable and affordable access to palliative care services for all those who need it. It enables people to die at home where appropriate. In line with the objectives of Sláintecare, an integrated approach to palliative care will provide services at the lowest possible level of complexity – as close to the home of the person as possible. Many people will have the majority of palliative care needs met by their General Practice (GP) and community services. At the core of this policy is a focus on achieving integration across primary, acute, and social care services. In doing so, patients have better outcomes and a better service experience.

This policy was developed following extensive research and consultation with all key stakeholders. International evidence was examined. A public consultation was undertaken and an evaluation of implementation of the 2001 policy was also completed. The findings of this work informed priority areas for inclusion in the new policy.

The experience and expertise of key stakeholders who formed part of the steering group, chaired by Professor Karen Ryan, guided the development of the policy. This collaborative approach has resulted in a clear action oriented, outcome focused policy.

The policy includes 25 Recommendations with associated Strategic Actions. A high-level roadmap of Activities with associated timelines has been developed to progress delivery of universal palliative care. The expected improvements in palliative care will occur over the lifecycle of the policy.

I would like to acknowledge the contribution of the steering group, chaired most effectively by Professor Karen Ryan. Their expertise, commitment, and dedication to achieving the best outcome for people with a life-limiting illness is reflected in this comprehensive policy document.

Throughout this policy, we will support people to live as well as possible for as long as possible and then to have as 'good' a death as possible. I am confident that this new policy reflects our strong values of care and compassion. Delivery on this policy will continue to place Ireland as a world leader in quality palliative care services. I look forward to its implementation.

Foreword from the Chairperson

Professor Karen Ryan
Chairperson of the National Adult Palliative Care Policy Steering Group

UCD Clinical Professor and Consultant in Palliative Medicine, Mater Hospital, and St. Francis Hospice Dublin.

Palliative care is characterised by community. In times of serious illness and strain, people come together to provide care and support, and to journey alongside the individual with a life-limiting condition and their family.

As the author Kevin Toolis observes, *'To be truly human is to bear the burden of our own mortality and to strive, in grace, to help others carry theirs; sometimes lightly, sometimes courageously.'*[1]

Ireland has a proud palliative care history dating back to the 1870s with the establishment of Our Lady's Hospice in Dublin and St Patrick's Hospital in Cork. The publication of the Report of the National Advisory Committee on Palliative Care in 2001 was a seminal moment that marked government commitment to further developing services. That commitment was echoed and expanded in 2017 when the 'Houses of the Oireachtas Committee on the Future of Healthcare "Sláintecare" report', recommended that universal palliative care should be a core part of our healthcare system.

1. Kevin Toolis, *My Father's Wake: How the Irish Teach Us to Live, Love and Die* (London: Weidenfeld & Nicolson, 2018)

This policy builds on our internationally recognised achievements and harnesses the strength of collaboration to set a vision for the future, where high-quality palliative care may be accessed by all those in need without financial hardship. The vision is underpinned by a carefully considered implementation roadmap, in order to ensure that change is achieved in a timely and effective manner.

This document results from long months of work by the Department of Health, members of the Policy Steering Group and many others. I would like to acknowledge the extensive work undertaken by all, and to express my appreciation for the manner in which people gave so generously of their time, expertise and personal insights. Great benefit was derived from the preparatory work involving evidence review, evaluation and national consultation. Dialogue with stakeholders and the input of a cross-departmental group were valuable sources of knowledge and critical appraisal.

There is an ageless wisdom in the Irish saying, *'Ar scáth a chéile a mhaireann na daoine.'* People need each other, and we live in each other's shadows. Palliative care recognises this by affirming and enabling life, while bringing comfort in times of grief. To borrow the words of Professor Tony O'Brien in his foreword to the first national palliative care policy, *'As a society, perhaps the most sensitive measurement of our maturity is the manner in which we care for those who are facing the ultimate challenge - the loss of life.'* This second national palliative care policy aims to ensure that we create space for leaning into our shared humanity, continue traditions of meitheal and community building, and maintain unwavering focus on ensuring world-class palliative care is available and accessible to all in need.

Executive Summary

Palliative care provides care for people who have been diagnosed with a life-limiting illness, from the time of diagnosis through death and bereavement.

People who are dying often report worry about getting access to good care and support, as well as the cost of care. Knowing that the right care and supports are available can provide comfort at such a difficult time.

Palliative care focuses on improving the quality of life for both the person with a life-limiting illness and that of their family. It involves:

- Treatment of pain, and other symptoms.
- Easing of suffering.
- Including patients, families, and carers in planning care needs.
- Providing social, spiritual and bereavement supports.

The benefits of palliative care are known to include:

- Increased patient and service provider satisfaction.
- Improved symptom control.
- Greater ability to discuss and honour a person's choice about where they die.
- Fewer and less intensive hospital admissions towards the end-of-life.
- Less anxiety and depression.
- Less caregiver distress.[2]

As Ireland's population continues to grow, so too does the number of older people. Most of the people who die in Ireland each year are aged over 65 years. Studies have shown that eight out of ten people who die each year would benefit from palliative care. They also show that for every person dying with palliative care needs, twelve others are living with palliative care needs.[3] Separately, a survey by the Irish Hospice Foundation (IHF) published in 2021, showed that people prefer to stay and be cared for in their own home.[4] Despite this, hospitals remain the most common place where people die.[5]

2. Mark T. Hughes and Thomas J. Smith, "The growth of palliative care in the United States," Annual review of public health 35, no. 1 (March 2014): 459–475, https://doi.org/10.1146/annurev-publhealth-032013-182406

3. Peter May et al., "Population-based palliative care planning in Ireland: how many people will live and die with serious illness to 2046?," HRB Open Research 2, no. 35 (January 2020): 1-24, https://doi.org/10.12688/hrbopenres.12975.2

4. Irish Hospice Foundation, "Time to Reflect National Survey Findings," Hospicefoundation.ie, March 18, 2022, https://hospicefoundation.ie/bereavement-news/time-to-reflect-national-survey-findings/.

5. Soraya Matthews et al., Review of Dying and Death in Ireland: What Do We Routinely Measure, How Can We Improve? (Dublin: Irish Hospice Foundation, 2021), https://hospicefoundation.ie/wp-content/uploads/2021/11/Dying-and-Death-in-Ireland-what-do-we-routinely-measure-how-can-we-improve-2021.pdf.

Fulfilling the 2020 Programme for Government commitment and considering developments in palliative care, along with the health reform programme as set out in Sláintecare, the Department of Health has developed a new policy to provide adult palliative care with person-centred care in mind. This policy considers both the needs of the person with a serious illness and that of their carer. The policy is in line with the aims of Sláintecare to provide equal access to high-quality palliative care for all those who need it, whilst making sure they do not face financial hardship as a result of their illness.

The new policy builds on the 2001 Report of the National Advisory Committee on Palliative Care (NACPC Report).[6] A review of implementation of the NACPC Report[7] recognised that significant progress has been made so far, especially in:

- Setting up specialist palliative care services.
- Creating strong links between the voluntary and public sector in palliative care.
- Creating more awareness of palliative care as an important healthcare service.
- Establishing the principles and ethos of palliative care in Ireland.

However, more needs to be done. The 2024 policy is focused on:

- Improving services and supports for patients, families, and carers.
- Ensuring equal access to palliative care services for all those who need it no matter where they live.
- Enabling people to die at home where appropriate.
- Further developing technology to facilitate care.
- Improving education and training in palliative care for all healthcare professionals.
- Developing links between services to make it easier for children to move from children's to adult palliative care services.
- Changing management and oversight structures in palliative care to promote safety and accountability.
- Better planning and management of palliative care through applied research.
- Strengthening All-Ireland collaboration in support of a shared vision of universal palliative care.

The policy makes 25 recommendations. Supporting the patient, family and carers is at the heart of this policy. Actions with timelines have been identified to deliver each recommendation. This will ensure progress in delivering the policy can be measured. It will also make sure that the goal of providing the right care, at the right time, in the right place and by the right people is achieved.

This policy offers an opportunity to develop the governance, coordination, and delivery of palliative care services in line with existing and emerging structures such as the HSE Health Regions, as well as programmes such as the Enhanced Community Care (ECC) Programme, National Cancer Programme, and Traveller Health Programme. People will be supported to access care more easily through strengthened integrated ways of working.

6. Department of Health and Children, "Report of the National Advisory Committee on Palliative Care" (Dublin, June 10, 2001), 1-157, https://assets.gov.ie/9240/1a34b770c7ee43afbf1c69a81c4391e2.pdf.

7. Peter May et al., "Population-based palliative care planning in Ireland: how many people will live and die with serious illness to 2046?," HRB Open Research 2, no. 35 (January 2020): 1-24, https://doi.org/10.12688/hrbopenres.12975.2

Introduction

Palliative care is an interdisciplinary approach that improves quality of life for people with a life-limiting illness and those important to them through a focus on expert pain and symptom management, improved communication and goals-of-care discussions, and the provision of psychosocial, spiritual and bereavement support.

Ireland has a long tradition of palliative care provision that continues to influence service delivery today. Services originated in the voluntary sector during the late 19th century with the establishment of St. Patrick's Hospital in Cork and Our Lady's Hospice in Dublin. In 1995, Ireland became the second country in Europe to recognise palliative medicine as a medical speciality and the period since then has been characterised by growth and expansion.

In 2001, Ireland became the first country in the world to publish a national policy on palliative care. The Report of the National Advisory Committee on Palliative Care (NACPC Report) marked government commitment to growing and sustaining services begun by communities and voluntary organisations. Subsequently, a number of key developments led to the publication of this policy as set out in **Figure 1**.

The National Clinical Programme for Palliative Care was established in 2010 with the aim of ensuring that people with life-limiting conditions and their families can easily access a level of palliative care service that is appropriate to their needs. A Model of Care for Palliative Care[8] was published in 2019.

Cross-party government commitment to development of palliative care services was affirmed in 2017 when the 'Houses of the Oireachtas Committee on the Future of Healthcare "Sláintecare" Report'[9], recommended universal palliative care should be provided as part of universal healthcare in Ireland.

The new policy builds on the 2001 Report of the National Advisory Committee on Palliative Care (NACPC Report). A review of the NACPC Report implementation recognised that significant progress has been made since its publication, especially in:

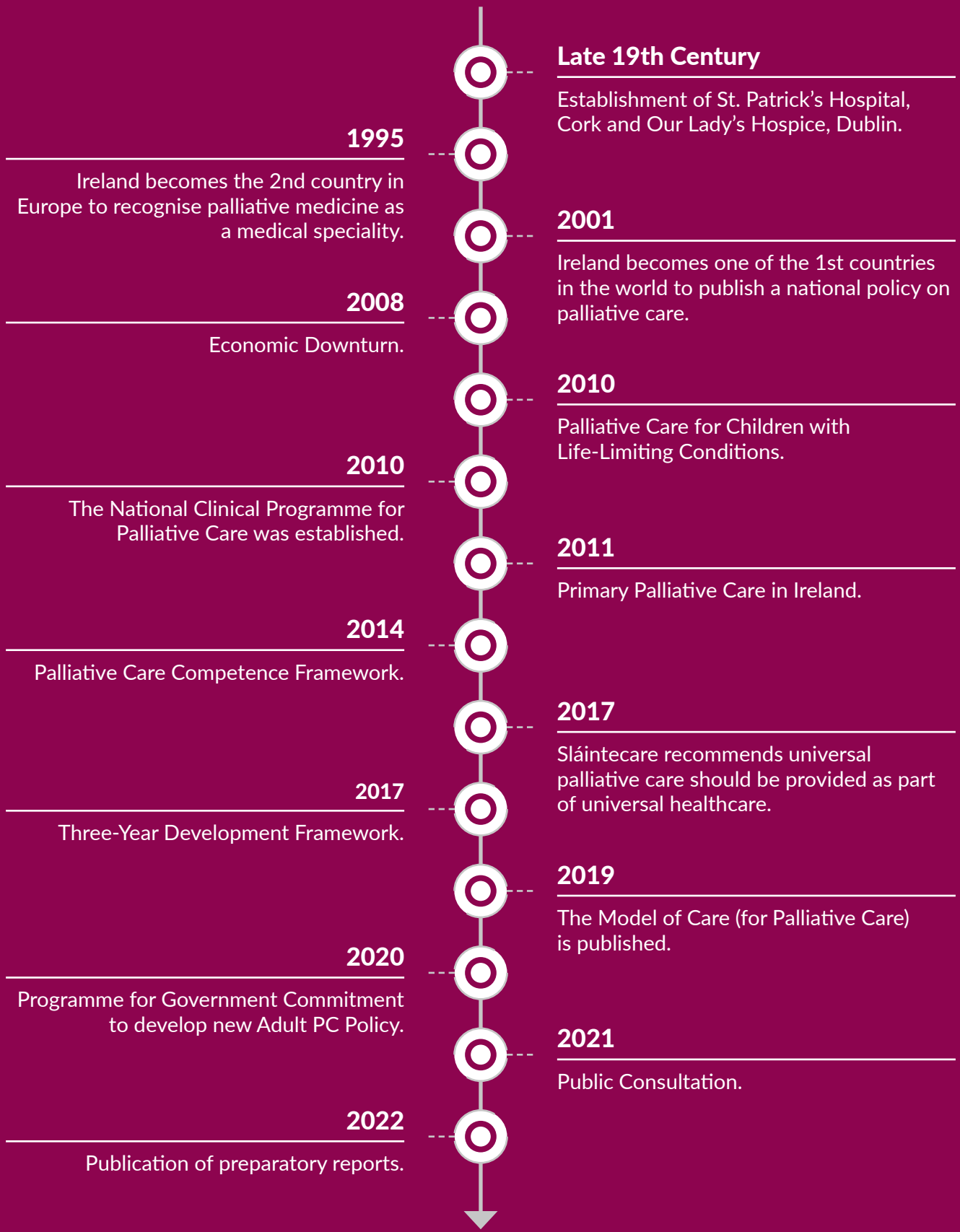
- Expansion of and access to specialist palliative care provision including Community Specialist Palliative Care Teams.
- Development of a Palliative Care Needs Assessment for Children (2005).[10]

8. National Clinical Programme for Palliative Care, "Adult Palliative Care Services, Model of Care for Ireland" (Dublin, April 25, 2019), 1-175, https://rcpi-live-cdn.s3.amazonaws.com/wp-content/uploads/2019/04/NCP-Palliative-Care-Model-of-Care-24.04.0219.pdf

9. Houses of the Oireachtas, "Committee on the Future of Healthcare Sláintecare Report" (Dublin, May 30, 2017), 1-192, https://data.oireachtas.ie/ie/oireachtas/committee/dail/32/committee_on_the_future_of_healthcare/reports/2017/2017-05-30_slaintecare-report_en.pdf

10. Department of Health and Children and Irish Hospice Foundation, "A Palliative Care Needs Assessment for Children" (Dublin, 2005), https://hospicefoundation.ie/wp-content/uploads/2021/01/A-Palliative-Care-Needs-Assessment-for-Children-2005.pdf.

Figure 1: Timeline of key developments leading to publication of National Adult Palliative Care Policy



- Establishment and activities of the National Clinical Programme for Palliative Care.
- Development of strong linkages between the voluntary and public sector in palliative care within the Republic, whilst developing collaborations with palliative care services in the Republic and Northern Ireland, and other international services.
- Increased knowledge, understanding and greater awareness of palliative care as an important healthcare service.

In the years following publication of the 2001 policy, there was a near doubling of the national palliative care budget amidst large economic growth. Notably, expenditure increased from €54 million in 2004 to €74m in 2011[11], evidencing the ongoing support for implementation of the 2001 policy. Increased levels of hospice and palliative care provision were evident. As a result, Ireland is a leader in palliative care, ranking high in international comparisons of palliative care development. In 2015, Ireland's palliative care services were ranked 4th in the world in the Quality of Death Index report produced by the Economist Intelligence Unit[12], indicating there is a relatively high provision of palliative care across the population.

Similarly, a recent study by Finkelstein EA, Bhadelia A, Goh C, et al. (2022)[13] ranked Ireland as second among 81 countries for end-of-life care, as determined by performance on a range of indicators focused on quality of care, quality of communication, and service affordability.

However, these new developments did not produce greater geographic equity and a number of key recommendations remained unaddressed. Whilst expenditure stabilised for a number of years, by 2020 it exceeded €100 million reaching a total of €133 million in 2022. Sustained government support for palliative care was reflected in a significant increase in the palliative care budget to over €155m in 2024.

While much has been achieved over the past 20 years, previous evaluations have also highlighted gaps in service provision. Only a modest proportion of people are able to die at home (22.5% in 2018), despite this being the preferred place of care for most (74%).[14]

Many people experience health issues in the last year of life which could be supported through the provision of appropriate palliative care services such as unmanaged pain and depression. Regional inequities in access to some services have also been identified.[15]

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11. Peter May et al., "Policy Analysis: Palliative Care in Ireland," *Health Policy* 115, no. 1 (March 2014): 68-74, https://doi.org/10.1016/j.healthpol.2013.07.016

12. The Economist Intelligence Unit, *The 2015 Quality of Death Index: Ranking of Palliative Care Across the World* (London: The Lien Foundation, 2015), https://maisonstraphael.org/wp-content/uploads/2016/02/The_Economist_Quality_of_Death_Index_October_2015_Part1.pdf

13. Eric A. Finkelstein et al., "Cross Country Comparison of Expert Assessments of the Quality of Death and Dying 2021," *Journal of Pain and Symptom Management* 63, no. 4 (April 2022): 419-429, https://doi.org/10.1016/j.jpainsymman.2021.12.015.

14. Matthews et al., *Review of Dying and Death in Ireland*, (2021).

15. Soraya Matthews et al., *Palliative and end-of-life care data in Ireland: establishing the state of the nation, mapping future direction: A report for the HSE National Lead for Palliative Care* (Dublin: Health Service Executive, 2023).

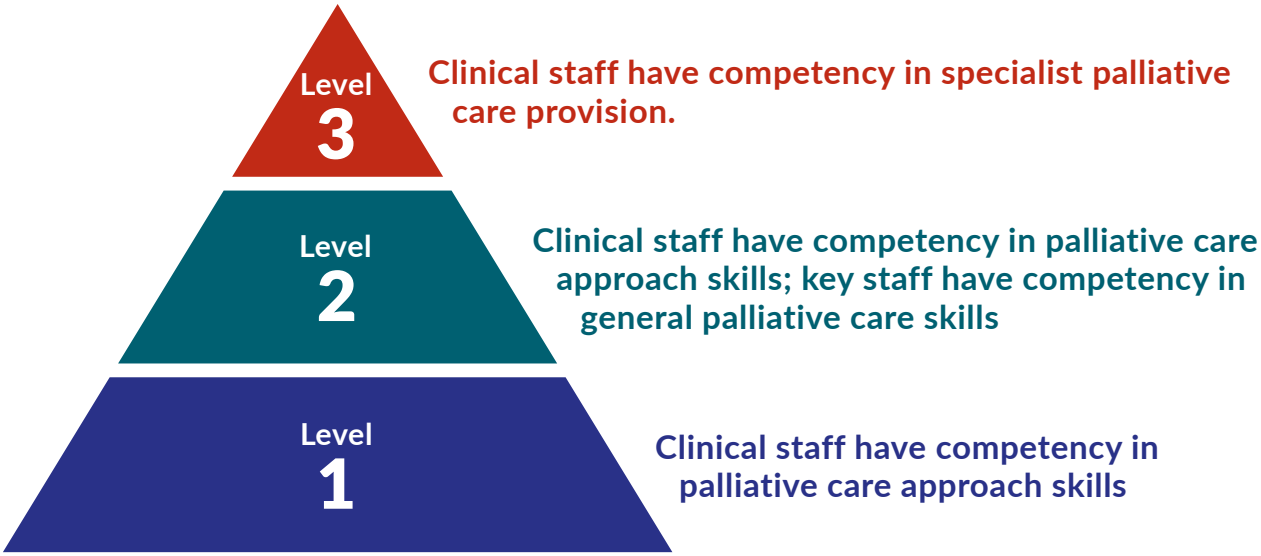
▸ Understanding palliative care

Palliative care is a crucial part of integrated, people-centred health services and a core component of universal healthcare.[16] Palliative care can be understood as both a set of principles that underpin an approach to care, and as a type of service that is provided. Many people still think of palliative care as care provided at the very last stage of life, around the time of death. However, the scope of palliative care has now broadened to providing palliative care at an earlier stage in the disease trajectory. In this model of integrated palliative care provision, palliative care is not dependent on prognosis and can be delivered at the same time as curative treatment.

Note on terminology

In Ireland, palliative care services are organised into specialist and general palliative care services that operate in partnership as part of an integrated network of providers. They are structured in three levels of ascending specialisation, each reflecting the palliative care expertise of the healthcare professionals providing care.

Figure 2: Integrated palliative care expertise & specialisation levels.



Throughout this policy document, the term 'palliative care' is used as an umbrella term for services providing a palliative care approach (Level 1 and 2) and/or specialist palliative care services (Level 3).

The term 'general palliative care' is used to refer to services provided by healthcare professionals who have 'palliative care approach' or 'general' palliative skills (Level 1 and 2). The role of general palliative care providers is fundamental to the provision of high-quality palliative care, and it is important to note that many palliative care needs can be appropriately and effectively met with the support of general palliative care providers only.

16. World Health Organisation, "Health in 2015: from MDGs, millennium development goals to SDGs, sustainable development goals" (978-92-4-156511-0, Geneva, November 30, 2015), 1-204, https://www.who.int/publications/i/item/9789241565110

The term 'specialist palliative care' is used to refer to services or people who provide specialist palliative care only.

▸ Palliative care need and impact

The new policy takes account of the projected increase in both Ireland's older population and the corresponding increase in the number of people with life-limiting conditions requiring palliative care. Population need for palliative care in Ireland is among the highest in the world and projected to rise sharply over the next 25 years. For every person over the age of 55 in the last year of life, there are approximately 12 living in the earlier stages of an illness indicating palliative care needs.[17] This means that by 2046, there will be 40,355 people over 55 years of age in the final year of life experiencing palliative care needs, and 548,105 people who are living with a condition associated with palliative care needs. As life expectancy increases, people will also be living longer with more complex needs. Whilst palliative care is often associated with cancer, the importance of these services for people with other diagnoses such as neurological conditions and cardiovascular and respiratory diseases is also being increasingly recognised. People may also require palliative care for a longer period, or at different times or stages of their illness. Palliative care services in Ireland will need to adapt in order to address these needs and meet future demand.

People approaching end-of-life account disproportionately for healthcare budget expenditure. It has been calculated that the <1% of people who die each year in Ireland account for around 8% of healthcare spending; although the true ratio is sensitive to recent rapid increases in both inflation and public health spending, and the fact that estimates likely undervalue total spend by using public service unit costs only.[18] The large majority of these last-year-of-life costs are attributable to older people with a diagnosis associated with palliative care need: €69,013 per person on average, or €1.8 billion total. Despite this, care near the end-of-life is often fragmented and not aligned with peoples' preferences. Overall, this suggests a significant proportion of people are receiving expensive care that yields poor value.[19]

Multiple studies have shown that palliative care can change care trajectories, leading to improved quality of care, better outcomes for people with a life-limiting illness and their families, and reduced costs for the healthcare system. These benefits include:

- Enabling people to avoid acute hospitalisation and remain safely and adequately cared for in the community.[20]
- Increasing patient and family satisfaction with care[21] and reducing prolonged grief among bereaved loved ones.[22]

17. May et al., "Population-based palliative care planning in Ireland, (2020).
18. May et al., "Population-based palliative care planning in Ireland, (2020).
19. Matthews et al., Palliative and end-of-life care data in Ireland, (2023).
20. Barbara Gomes et al., "Effectiveness and Cost-Effectiveness of Home Palliative Care Services for Adults with Advanced Illness and Their Caregivers," Cochrane Database of Systematic Reviews 2013, no. 6 (June 2013): 1-232, https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD007760.pub2/full
21. Samar M. Aoun et al., "Winners and Losers in Palliative Care Service Delivery: Time for a Public Health Approach to Palliative and End of Life Care," Healthcare 9, no. 12 (November 2021): 1615, https://doi.org/10.3390/healthcare9121615
22. Samar M. Aoun et al., "The Impact of Supporting Family Caregivers Before Bereavement on Outcomes After Bereavement: Adequacy of End-of-Life Support and Achievement of Preferred Place of Death," Journal of Pain and Symptom Management 55, no. 2 (February 2018): 368-378, https://doi.org/10.1016/j.jpainsymman.2017.09.023

- Reducing costs by providing care that aligns with peoples' needs and preferences; and reducing unnecessary hospitalisations, diagnostic and treatment interventions, and inappropriate intensive and emergency department care.[23]

▸ Development of this policy

To assess the current state of palliative care provision in Ireland and provide a foundation for this new policy, the Department of Health commissioned a programme of work between 2020 and 2022 including:

1. An international evidence brief summarising national palliative care policies in high-income countries.[24]
2. An independent evaluation of implementation of the existing national palliative care policy (2001 NACPC report).
3. A public consultation process resulting in a published report.[25]

International Evidence Brief – PC policies in high income countries

The evidence brief addressed the question of what approaches have been taken in Australia, New Zealand, Scotland, and the Netherlands to national policy for adult palliative care. A key finding from analysis was that equitable access to palliative care on a national scale is critically dependent on community-based service delivery and that supports need to be provided to enable such service development.

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

The purpose of this evaluation was to assess progress achieved in the implementation of the recommendations of the NACPC Report and make recommendations on future priorities. The approach taken encompassed an analysis of available data on palliative care service provision, stakeholder interviews and a review of international developments, innovation, and best practice. The report found that substantial progress has been achieved in strengthening the delivery of palliative care across all levels and settings. Key developments included improved access to palliative care services, increased awareness of palliative care and strong collaboration across the public and voluntary sectors. However, many of the recommendations made in the NACPC Report are not fully implemented and services have not developed uniformly across the country. Substantial changes within the Irish health and social care system and the palliative care sector since 2001 also mean that key areas require further attention. Core recommendations included: expanding general palliative care capacity; addressing regional variation in service provision and access; undertaking strategic workforce planning; improving health information systems; and strengthening governance and systems.

23. Samantha Smith et al., "Evidence on the cost and cost-effectiveness of palliative care: a literature review," Palliative Medicine 28, no. 2 (February 2014): 130 -150, https://doi.org/10.1177/0269216313493466

24. Camille Coyle et al., National policies for adult palliative care in four countries: An evidence brief (Dublin: Health Research Board, 2021), https://www.gov.ie/pdf/?file=https://assets.gov.ie/217580/ecc3e190-b8d1-401f-8ff4-f7d1cfc0123b.pdf#page=null

25. All Ireland Institute of Hospice and Palliative Care, Report on the Department of Health's Public Consultation for the Palliative Care Policy for Adults (Dublin: AIIHPC, 2021), https://www.gov.ie/pdf/?file=https://assets.gov.ie/219446/2b36c272-dba5-4704-9fa3-bc30273c9c3f.pdf#page=null

Public consultation

A public consultation process was launched by the Minister for Health in September 2021. The consultation utilised a questionnaire to obtain the views of those who work in the field of palliative care, interested organisations, and members of the public on a number of key issues related to palliative care in Ireland. The public submissions recognised that palliative care service provision in Ireland has moved from strength to strength. Several areas emerged as priorities for future development by both individuals and organisations. These included: ensuring equitable access to services; investment in staff and infrastructure across all settings; increasing education and training opportunities for healthcare professionals; and the need to improve metrics used to measure and monitor palliative care provision.

In May 2022, the Minister for Health established a steering group chaired by Professor Karen Ryan. The purpose was to provide expert guidance and advice to the Department in the development of a new adult palliative care policy, setting out a vision and implementation plan for delivery of palliative care and end-of-life care in Ireland. Membership of the steering group is set out in Appendix 4.

Guiding principles

The guiding principles set out in the Report of the NACPC (summarised in Appendix 1) remain relevant today and form the foundation on which this policy has been developed.

Vision and way forward

This policy's vision is that everyone who needs palliative care is able to easily access person-centred and effective services, irrespective of financial status.

▸ Sláintecare

The Report of the Committee on the Future of Health, Sláintecare Report recognises that thanks to modern medicine, people are living longer with serious, chronic, and complex illnesses. It draws attention to the urgent need for system reform and the development of integrated, person-centred systems of care that are oriented towards primary and community care. Crucially, it sets out a high-level policy roadmap to address these issues and deliver universal healthcare that includes palliative care.

3 Three key dimensions of Sláintecare: **access, quality**, and **affordability**.

8 Eight fundamental principles: **patient is paramount; timely access; prevention and public health; free at the point of delivery; workforce; public money and interest; engagement;** and **accountability**.

Published in 2017, Sláintecare policy direction has been reaffirmed in the Sláintecare Action Plan 2019[26], the Sláintecare Implementation Strategy and Action Plan 2021- 2023[27], the HSE Corporate Plan 2021-2024[28], and the Department of Health's Statement of Strategy 2021-2023.[29]

While the delivery of universal palliative care is a core goal of Sláintecare, the principles of Sláintecare have themselves in turn shaped the Adult Palliative Care Services Model of Care for Ireland and the development of this policy.

▸ Sláintecare implementation and the development of the HSE Health Regions

Progress has been made against all of the Sláintecare principles since publication of the Sláintecare Report. A recent, key advance has been the establishment of the HSE Health Regions. The Health Regions are regarded as vital to the achievement of healthcare reform.

26. Department of Health, "Sláintecare Action Plan 2019" (Dublin, March 13, 2019), 1-58, https://www.gov.ie/pdf/?file=https://assets.gov.ie/9379/05384619bb2240c18c294b60578117e1.pdf#page=null

27. Department of Health, "Sláintecare Implementation Strategy and Action Plan 2021-2023" (Dublin, May 11, 2021), 1-76, https://www.gov.ie/pdf/?file=https://assets.gov.ie/134746/9b3b6ae9-2d64-4f87-8748-cda27d3193f3.pdf#page=null

28. Health Service Executive, "HSE Corporate Plan 2021-24" (978-1-78602-166-3, Dublin, February, 2021), 1-30, https://www.hse.ie/eng/services/publications/corporate/hse-corporate-plan-2021-24.pdf

29. Department of Health, "Department of Health Statement of Strategy 2021-2023" (Dublin, March 4, 2021), 1-48, https://www.gov.ie/pdf/?file=https://assets.gov.ie/125397/10ca01a6-78c7-4d0e-ad66-ce1457fdc2cc.pdf#page=null

In particular, the implementation of the six new Health Regions will contribute to the delivery of person-centred health and social care services that are informed by the needs of the people and communities in each of the regions. Health Regions will enable the alignment of community and acute services and enable population-based resource allocation and governance to better provide integrated care. National standards of care will be balanced with local decision-making with the purpose of improving population health and wellbeing. Implementation of the HSE Health Regions will ensure that services are planned around local needs, people are well-informed and supported when accessing services, and resources are fairly allocated and accounted for.

The Enhanced Community Care (ECC) Programme is a key component of the Sláintecare Implementation Strategy and Action Plan. The ECC programme is investing €240 million into community health services to support the provision of care at a local level and support the transition from hospitals to the community. This policy offers opportunity to develop the governance, coordination, and delivery of palliative care services in line with these emerging structures and programmes. In this way, governance and coordination between local, regional, and national levels will be improved, critical mass and capability will be ensured, and integrated ways of working strengthened.

▸ An all-island vision of universal palliative care

The vision of universal palliative care is shared across the island of Ireland. A tradition of cross-border collaboration and knowledge sharing in palliative care policy and practice has been valued and strongly supported by stakeholders, as evidenced by the establishment of the All-Ireland Institute of Hospice and Palliative Care. This policy provides impetus for further dialogue and engagement.

▸ The way forward

The achievement of universal palliative care will require a whole systems approach to developing capability and capacity to care for people with a life-limiting illness. Multifaceted actions will need to be undertaken across all of the health system components: service delivery, workforce, health information systems, medicines and technologies, leadership, and governance. Some of the actions will have immediate impact; others will need a longer-term shift in approach and mind-set before their effect is seen.

Regardless of any action's scale and scope, governance and implementation planning are necessary foundations for success. National and international experience points to the benefits of considering implementation planning as part of the policy development process. Other factors needed for implementation success are resourcing, the capacity to monitor and learn from mistakes, leadership, communication, and buy-in. The Terms of Reference of this policy were developed to support these considerations. A resourcing and implementation roadmap have been developed to support delivery of this policy for the next 7 years.

▸ The structure of this policy

Echoing the Sláintecare commitment of 'right care, in the right time and place, provided by the right people,' the goal of universal palliative care will be achieved by focusing on the following four strategic objectives:

1. The design and implementation of services to provide the 'right care' in the form of safe, effective, and person-centred palliative care.
2. The development of organisational structures and processes to provide services in the 'right time and right place' so that palliative care is available and accessible to all when and where needed.
3. The development of a workforce that is appropriately resourced and skilled, supported and valued so that the 'right people' provide palliative care.
4. The strengthening of clinical leadership and accountability, culture, coalition building, intelligent use of information, and research, innovation, and quality improvement capability to ensure that 'good governance' is in place.

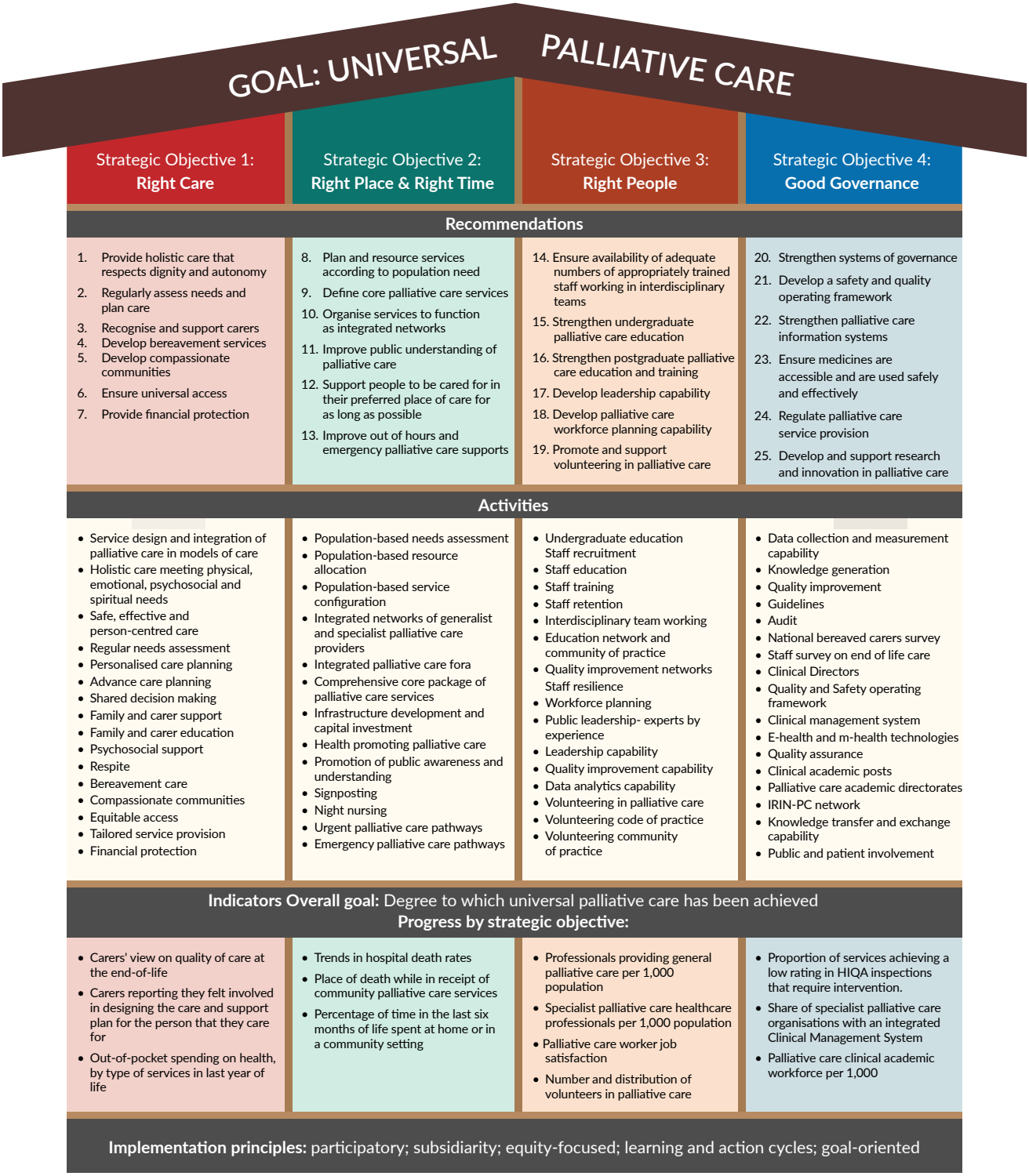
These strategic objectives are considered in turn over the next four chapters of this policy. A series of recommendations are provided in each chapter to guide action and achieve the relevant strategic objective. There are 25 recommendations in total – seven associated with the 'right care' objective, and six with each of the others.

Each recommendation has an accompanying Strategic Action. The Strategic Action is comprised of a set of Activities that are key to operationalisation of the Action.

Given the complex nature of healthcare and the multiple interdependencies that exist between components of the healthcare system, it is not surprising that in some cases, Activities primarily associated with one Action can also be important to the achievement of others. An example of this is the development of a Palliative Care Clinical Management System – while this is key to developing knowledge generation and management capability (Action 22, 'good governance'), it also is an enabler of integrated care planning (Action 2, 'right care'). Rather than duplicating activities across multiple actions, a logic model is provided in the appendices which demonstrates interdependent relationships between recommendations, activities, and impact.

Figure 3 (overleaf) provides a diagrammatic representation of this policy's content and summarises the policy's overall goal, strategic objectives, recommendations, activities, and indicators.

Figure 3: Palliative care policy overview.[30]



30. This is an adaptation of an original work "WHO global strategy on integrated people-centred health services-An Overview. WHO global strategy on integrated people-centred health services 2016-2026. Executive Summary. Placing people and communities at the centre of health services" Geneva: World Health Organization (WHO); [2015]. Licence: CC BY-NC-SA 3.0 IGO". This adaptation was not created by WHO. WHO is not responsible for the content or accuracy of this adaptation. The original edition shall be the binding and authentic edition". https://interprofessional.global/wp-content/uploads/2019/11/WHO-2015-Global-strategy-on-integrated-people-centredhealth-services-2016-2026.pdf WHO/HIS/SDS/2015.20

Goal - To Deliver

1 Right Care

Recommendations

1. Provide holistic care that respects dignity and autonomy
2. Regularly assess needs and plan care
3. Recognise and support carers
4. Develop bereavement services
5. Develop compassionate communities
6. Ensure universal access
7. Provide financial protection

Activities

- Service design and integration of palliative care in models of care
- Holistic care meeting physical, emotional, psychosocial and spiritual needs
- Safe, effective and person-centred care
- Regular needs assessment
- Personalised care planning
- Advance care planning
- Shared decision making
- Family and carer support
- Family and carer education
- Psychosocial support
- Respite
- Bereavement care
- Compassionate communities
- Equitable access
- Tailored service provision
- Financial protection

Indicators

Overall goal: Degree to which universal palliative care has been achieved

Progress by Strategic Objective

- Carers' view on quality of care at the end-of-life
- Carers reporting they felt involved in designing the care and support plan for the person that they care for
- Out-of-pocket spending on health, by type of services in last year of life

Implementation principles: participatory; subsidiarity; equity-focused; learning and action cycles; goal-oriented

Universal Palliative Care

2 Right Place and Right Time

Recommendations

8. Plan and resource services according to population need
9. Define core palliative care services
10. Organise services to function as integrated networks
11. Improve public understanding of palliative care
12. Support people to be cared for in their preferred place of care for as long as possible
13. Improve out of hours and emergency palliative care supports

Activities

- Population-based needs assessment
- Population-based resource allocation
- Population-based service configuration
- Integrated networks of generalist and specialist palliative care providers
- Integrated palliative care fora
- Comprehensive core package of palliative care services
- Infrastructure development and capital investment
- Health promoting palliative care
- Promotion of public awareness and understanding
- Signposting
- Night nursing
- Urgent palliative care pathways
- Emergency palliative care pathways

Indicators

Overall goal: Degree to which universal palliative care has been achieved

Progress by Strategic Objective

- Trends in hospital death rates
- Place of death while in receipt of community palliative care services
- Percentage of time in the last six months of life spent at home or in a community setting

Implementation principles: participatory; subsidiarity; equity-focused; learning and action cycles; goal-oriented

Goal - To Deliver

3 Right People

Recommendations

14. Ensure availability of adequate numbers of appropriately trained staff working in interdisciplinary teams
15. Strengthen undergraduate palliative care education
16. Strengthen postgraduate palliative care education and training
17. Develop leadership capability
18. Develop palliative care workforce planning capability
19. Promote and support volunteering in palliative care

Activities

- Undergraduate education
- Staff recruitment
- Staff education
- Staff training
- Staff retention
- Interdisciplinary team working
- Education network and community of practice
- Quality improvement networks
- Staff resilience
- Workforce planning
- Public leadership - experts by experience
- Leadership capability
- Quality improvement capability
- Data analytics capability
- Volunteering in palliative care
- Volunteering code of practice
- Volunteering community of practice

Indicators

Overall goal: Degree to which universal palliative care has been achieved

Progress by Strategic Objective

- Professionals providing general palliative care per 1,000 population
- Specialist palliative care healthcare professionals per 1,000 population
- Palliative care worker job satisfaction
- Number and distribution of volunteers in palliative care

Implementation principles: participatory; subsidiarity; equity-focused; learning and action cycles; goal-oriented.

Universal Palliative Care

4 Good Governance

Recommendations

20. Strengthen systems of governance
21. Develop a safety and quality operating framework
22. Strengthen palliative care information systems
23. Ensure medicines are accessible and are used safely and effectively
24. Regulate palliative care service provision
25. Develop and support research and innovation in palliative care

Activities

- Data collection and measurement capability
- Knowledge generation
- Quality improvement
- Guidelines
- Audit
- National bereaved carers survey
- Staff survey on end of life care
- Clinical Directors
- Quality and Safety operating framework
- Clinical management system
- E-health and m-health technologies
- Quality assurance
- Clinical academic posts
- Palliative care academic directorates
- IRIN-PC network
- Knowledge transfer and exchange capability
- Public and patient involvement

Indicators

Overall goal: Degree to which universal palliative care has been achieved

Progress by Strategic Objective

- Proportion of services achieving a low rating in HIQA inspections that require intervention
- Share of specialist palliative care organisations with an integrated Clinical Management System
- Palliative care clinical academic workforce per 1,000

Implementation principles: participatory; subsidiarity; equity-focused; learning and action cycles; goal-oriented.

Strategic Objective 1. Right Care

Sláintecare describes 'right care' as being care that is safe, effective, and person-centred.

In the context of palliative care, 'right care' may additionally be understood as care that focuses on the prevention and relief of physical, psychosocial, or spiritual suffering associated with a life-limiting or life-threatening illness.

This care does not only focus on the person with a serious illness - it also extends support to families to help them cope with their family member's illness and their own experience of grief, loss, and bereavement. Importantly, 'right care' in palliative care recognises that communities have a role to play in mobilising around people-led approaches to compassionate citizenship and supporting care provision.

In order to ensure that this conceptualisation of 'right care' meets our core goal of universal palliative care, we must also ensure that palliative care is accessible across all settings based on need and without risk of financial hardship.

To achieve this, we will ensure that:

1. Care focused on quality of life for all days of life

Every person with a life-limiting or life-threatening condition will receive care that respects their dignity and autonomy and meets their physical, psychosocial, and spiritual palliative care needs.

2. Person centred care, decision-making and care planning

Health care professionals will offer people who are receiving palliative care regular opportunities to understand and consider their illness. Comprehensive assessment of need will lead to the co-development of individualised care plans. People will be helped to engage in advance care planning, where desired.

3. Support and engagement of family and carers

Family and those important to the person with a life-limiting condition will be supported to maintain their own well-being. Carers will be recognised as partners by healthcare professionals. They will be supported to care with confidence while participating as fully as possible in economic and social life.

4. Extension of care into bereavement

The ongoing development of bereavement services will be supported. Bereavement support will be available in all settings where specialist palliative care is provided.

5. Development of compassionate communities

Communities will be empowered to be ready and able to help people in their journey through illness, death, and bereavement.

6. Ensuring universal access

High-quality services will be universally accessible across all settings based on need. Palliative care services will respond to the health inequalities faced by some groups, which require tailored interventions taking into account the social determinants of health to ensure equity in access, experience, and outcomes.

7. Financial protection

Palliative care services will be accessible across all settings without risk of financial hardship.

Why are the 'right care' recommendations important and how will they be actioned?

▸ Care focusing on quality of life for all days of life (Recommendation 1)

Cicely Saunders stated, 'You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully but also to live until you die.' Although Ireland has a strong history of palliative care provision, we know that people still experience serious health-related suffering and that palliative care services are not uniformly integrated across the healthcare system. Addressing these gaps will require changes in how health services are designed and delivered.

In Ireland, the HSE National Clinical Programmes and Integrated Care Programmes are the primary reference points for clinical leadership and population-based clinical design. The Clinical Programmes develop models of care to provide broad definition for the way health services should be organised and delivered in order to optimise health system performance.

Recommendation 1 activities affirm the importance of the Clinical Programmes in defining best practice care and services for people with a life-limiting or life-threatening illness and their families. The National Clinical Programme for Palliative Care (NCPPC) and other relevant Clinical Programmes are mandated to further develop their Models of Care to respond to priority areas of need identified by this policy.

A range of activities are required to achieve Recommendation 1. Appropriate resourcing of the NCPPC is recommended, together with the promotion of interdisciplinary leadership in service design and implementation. As palliative care moves upstream in the disease trajectory, the importance of rehabilitative care in the optimisation of quality of life is increasingly recognised. Rehabilitative palliative care enables people with a life-limiting illness to live as independently as possible, with choice and autonomy within the limits of advancing illness. Activities to develop and scale best practice and provide functional and psychological supports to maintain the well-being of people with a life-limiting illness are described.

While this policy focuses on the provision of adult palliative care services, the role of adult palliative care services extends to two key areas

in the care of children with a life-limiting illness. Firstly, adult palliative care services support the end-of-life care of children in the home setting and this policy affirms that role. The Report on the 'Clinical governance and operational arrangements for supporting a model of care for children with life-limiting conditions towards the end-of-life in the community in Ireland'[31] describes a model of integrated care provision where community specialist palliative care, general paediatric, paediatric palliative care, GP, and primary care teams collaborate to provide care. Ongoing implementation of this report will be supported, while activities focused on training and workforce planning will ensure that adequate numbers of appropriately trained staff are available to provide care. Secondly, adult palliative care services are important partners in the process of supporting the transition of adolescents from children's to adult services. An activity that is focused on appropriate design and implementation of transition services will ensure that best outcomes are achieved during this important time period.

▸ Person-centred care and care planning (Recommendation 2).

Person-centred care is a way of thinking and doing things that sees the people receiving palliative care as equal partners in planning, developing, and monitoring care to make sure it meets their needs. It supports people to develop the knowledge, skills, and confidence they need to more effectively manage and make informed decisions about their own care. Crucially, it ensures that people are always treated with dignity, compassion, and respect.

A palliative care needs assessment is the first necessary step to recognising and responding to need. Unfortunately, assessment of palliative care need is still often not undertaken in a systematic or holistic way. As a result, distressing symptoms and concerns can go unrecognised. Research has highlighted that distress is best managed if recognised and addressed in a timely manner, and if prompt referrals are made to specialist palliative care for those who need it.[32] Activities related to Recommendation 2 focus on the development and implementation of communications and needs assessment training and documentation in order to address current deficits in practice. Acknowledging that individuals are often not adequately involved in decision-making, activities also support the implementation of the Assisted Decision-Making (Capacity) Act (2015).[33]

Optimal palliative care practice is proactive. While care plans should always address current symptoms, they should also try and pre-empt foreseeable future problems whenever possible. Engagement with anticipatory and advance care planning can help to avoid unnecessary crises and unwanted hospital admissions. Additional activities under this recommendation consider the importance of advance care planning and ensure palliative care services will offer adults with life-limiting or life-threatening conditions regular opportunities to make timely, realistic, and practical plans for their future. Consideration is also given to scaling the learning from successful programmes of care planning.

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31. Samantha Smith et al., "Evidence on the cost anHealth Service Executive, "Clinical governance and operational arrangements for supporting a model of care for children with life-limiting conditions towards the end of life in the community in Ireland" (Dublin, December, 2020), 1-30, https://www.hse.ie/eng/services/publications/children/operational-and-governance-framework-for-children-with-life-limiting-conditions.pdf

32. Gomes et al., "Effectiveness and Cost-Effectiveness of Home Palliative Care Services for Adults".

33. Assisted Decision-Making (Capacity) Act, 2015, (Ireland). https://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html

▸ Family and carers (Recommendation 3)

Family and other informal carers play vital roles in the provision of palliative care. While caregiving can be a rewarding experience, caregiving responsibilities may also affect carers' physical and mental health. Carers may experience financial hardship due to direct and indirect costs, including out-of-pocket expenditure and reduced income due to time invested in providing care. Recommendation 3 recognises the enormous contribution family and carers make as partners in care and the need to adequately support and empower them in this role. Recommendation 4 considers bereavement support for family and carers, while Recommendation 7 focuses on financial protection.

A range of activities relating to each of these areas must be undertaken to help carers maintain well-being, participate as fully as possible in economic and social life, and provide care with confidence. Specific activities associated with Recommendation 3 relate to carrying out a review of respite and short-break provision in order to inform service delivery, and on the development of evidence-based training and online resources to address carers' information needs.

▸ Bereavement (Recommendation 4)

Loss, grief, and bereavement are an intrinsic part of life. For most people, although associated with distress, grief takes the form of a healthy and adaptive response to loss. However, some require additional supports, and a minority are at risk of developing complications or difficulties in their grieving. The National Clinical Programme Model of Care (2019)[34] describes a tiered pathway of bereavement supports where different levels of need require different levels of intervention.

The four levels of need are universal grief needs, organised support needs, professional counselling needs and complex grief needs. A range of services across Primary Care, Specialist Palliative Care and Specialist Mental Health Services should be in place to respond to identified need. This does not mean that every hospital, community, specialist palliative care organisation and primary care organisation should provide a full range of bereavement supports services. Rather, it means that a population-based and needs-based approach to service provision should be adopted and services providing different levels of bereavement support should work in collaboration across defined catchment areas. The move to the HSE Health Regions will provide opportunity to consider planning and resource allocation further for both general and specialist palliative care services. It will promote coordination and integration of services across settings.

The Model of Care recommends that specialist palliative care services should, at a minimum, have capability to provide:

- Pre-death services to meet high levels of distress.
- Post-death services to meet universal grief, low complexity, and intermediate care needs.

Two activities are central to ensuring specialist palliative care services have adequate capacity to achieve this recommendation. The first focuses on mapping demand and resources required to provide bereavement care; the second addresses identified deficits in workforce and infrastructure.

34. National Clinical Programme for Palliative Care, "Adult Palliative Care Services, Model of Care for Ireland" (2019)

▸ Compassionate communities (Recommendation 5)

For as long as societies have experienced serious illness, grief and death, communities have provided help and care to those affected. The compassionate communities movement[35], similar to its policy cousin in the WHO Healthy Cities movement[36], emerges from a global public health agenda. It offers a social model of health that enlists support from all sectors of society to prevent or relieve potential harm associated with living with dying, caregiving, grief, and loss. Furthermore, the social model recognises that health is not merely the prevention of harm but also the promotion, enhancement, and the maintenance of health and wellbeing.[37] Although serious illness and death may be times of challenge and sadness, they may also be times of meaning and growth.[38] The integration of a public health-oriented dimension into palliative care as described in Recommendation 7 recognises the invaluable contribution that civic engagement can make to meeting the needs of those with a life-limiting or life-threatening illness and their families.

In line with a community development approach, the compassionate communities approach gives guidance on where implementation should be focused, but it does not specify how implementation should take place – instead, actions emerge that are tailored to local community context. In this way, local government and community organisations act as change agents across settings such as schools, workplaces, and hospices. Compassionate communities recognise that healthcare organisations do not bear sole responsibility for palliative care provision – rather palliative care is 'everyone's responsibility.' Activities associated with this recommendation aim to support communities to develop their capacity by mobilising available resources, scaling up exemplar models of community action and building regional partnerships between specialist palliative care services and local citizens.

▸ Ensuring universal access and addressing palliative care inequities (Recommendation 6)

Recommendation 6 centres on the concept of 'universality' – that is everyone who needs palliative care services should be able to access them. Services must be physically accessible, financially affordable, and acceptable to patients if universal palliative care coverage is to be achieved. Increasingly, it is recognised that there are specific population groups that experience inequitable access to, or experience with, palliative care. To date, efforts to address these inequities have generally been localised rather than achieving national implementation or impact. As a result, Recommendation 6 focuses system-level attention on the need to reduce palliative care disparities among racial, ethnic, geographic, socioeconomic, and other groups. In the journey towards universal palliative care, it is essential that no person is left behind.

A number of activities are required to support achievement of this recommendation. Given that advancement of health equity requires high-quality information to guide service development, a focus on strengthening existing methods of data collection and analysis is essential. In addition, attention

35. Allan Kellehear, "Compassionate communities: end-of-life care as everyone's responsibility," QJM: An International Journal of Medicine 106, no. 12 (December 2013): 1071-1075, https://doi.org/10.1093/qjmed/hct200

36. Agis D. Tsouros, "The WHO Healthy Cities Project: state of the art and future plans," Health Promotion International 10, no. 2 (June 1995): 133–141, https://doi.org/10.1093/heapro/10.2.133

37. Michael Marmot and Richard Wilkinson, Social determinants of health (Oxford: Oxford University Press, 2005)

38. Allan Kellehear, "Grief and loss: past, present and future," The Medical Journal of Australia 177, no. 4 (September 2022): 176-177, https://doi.org/10.5694/j.1326-5377.2002.tb04726.x

must be directed to service design so that the special needs of particular populations are recognised and responded to in the Model of Care for Palliative Care services.[39] A number of other recommendations contain activities that will support universal access to palliative care. For example, the reform of organisational functions and structures proposed in Recommendation 8 will support regional equity in resource allocation. The development of a research infrastructure established with the aim of addressing policy-related questions (such as how best to implement population-based planning in palliative care) is proposed in Recommendation 25.

▸ Financial protection (Recommendation 7)

Ensuring financial protection from healthcare spending is a core dimension of universal healthcare. This is linked to the belief that accessing necessary health services should not come at the expense of non-health aspects of a household's well-being, including financial security, or spending on other essential items. Financial protection is achieved when direct payments made to obtain public health services do not expose people to financial hardship.

Affordability of services for those with a serious illness remains an issue. Although many services, medicines and technologies are publicly available or financed, research has shown that out-of-pocket payments that remain can be high. These payments can contribute to financial hardship for households and also create barriers to accessing appropriate and timely healthcare. Recommendation 7 affirms that palliative care services should be available across all settings without risk of financial hardship.

The accompanying Strategic Action (7) considers how to promote universal protection against financial risk and includes activities to expand eligibility and ensure adequate coverage to publicly funded palliative care services. Recognising current deficiencies in our measurement capability, an evidence review will be conducted that examines international practice for measuring financial hardship among people with life-limiting conditions at a population-level and provide an options appraisal for collecting relevant data in Ireland.

The accompanying Strategic Action (7) considers how to promote universal protection against financial risk and includes activities to expand eligibility and ensure adequate coverage to publicly funded palliative care services.

39. National Clinical Programme for Palliative Care, "Adult Palliative Care Services Model of Care for Ireland" (2019)

Table 1: 'Right Care' recommendations and associated core strategic actions.

Recommendation 1. Every person with a life-limiting or life-threatening condition will receive care that respects their dignity and autonomy and meets their physical, psychosocial, and spiritual palliative care needs.		
Strategic action		
1. Ensure that the National Clinical Programme for Palliative Care (NCPPC) and other care programmes continue to develop dynamic models of care that inform the process of implementing and monitoring palliative care service provision. The further development of Models of Care will respond to priority areas of need identified by this policy.		
Activities	**Responsibility**	**Timeframe Commence before end:**
1.1 Appoint a Clinical Lead, GP Lead, Nursing Lead, Health and Social Care Professional Lead, Programme Support Manager and Grade V administrator to the NCPPC. Provide budget and expertise to support data collection and evaluation capability.	HSE	**2024**
1.2 Develop, evaluate and scale models of rehabilitative palliative care provision.	HSE	**2028**
1.3 Conduct a review of palliative care support bed provision; use findings to inform service planning and provision.	HSE	**2024**
1.4 Design and implement funded pilots to test, demonstrate, and evaluate models for the integration of mental health and palliative care services.	HSE	**2026**
1.5 Implement the National Cancer Control Programme Psycho-oncology Model of Care[40] in all settings where palliative care is provided.	National Cancer Control Programme	**2026**
1.6 Fully implement and embed in practice the recommendations of the report on 'Clinical governance and operational arrangements for supporting a model of care for children with life-limiting conditions towards the end of life in the community in Ireland.'	HSE	**2024**
1.7 Design and implement models of transition from children's to adult palliative care services.	HSE	**2025**
1.8 Develop prescribing guidance to support services providing palliative care to children.	HSE	**2025**

40. National Cancer Control Programme, "Hospital and Community-based Psychosocial Care for patients with cancer and their families: A Model of Care for Psycho-Oncology" (ISBN: 978-1-78602-165-6, Dublin, September, 2020), 1-40, https://www.hse.ie/eng/services/list/5/cancer/profinfo/psycho-oncology-programme/model%20of%20care.pdf

1.9 Develop and implement simulation training for central line use and care for children and adults	HSE	**2026**
1.10 Include integrated assessment and response to population-based palliative care need in the design of all relevant Clinical and Integrated Care Programme Models of Care.	HSE	**2026**

Recommendation 2. Healthcare professionals will offer people who are receiving palliative care regular opportunities to understand and consider their illness. Comprehensive assessments of need will lead to the co-development of individualised care plans. People who wish to do so will be helped to engage in advance care planning.

Strategic action

2. Provide people receiving palliative care with regular opportunities to express their needs, wishes, feelings, beliefs, and values, and ensure this is reflected in the care, support, or treatment they receive.

Activities	Responsibility	Timeframe Commence before end:
2.1 Update the national interdisciplinary e-module on palliative care needs assessment	HSE	**2024**
2.2 Scope the utility and feasibility of implementing interRAI Palliative Care as a standardised assessment tool	HSE/ Department of Health	**2028**
2.3 Affirm that, as far as possible, all people have the right to play an active role in decisions that affect them and implement the Assisted Decision-Making (Capacity) Act (2015) in all settings where palliative care is provided.	HSE/Service Providers	**2024**
2.4 Promote the learning from models of anticipatory and advance care planning, and scale successful models of implementation.	HSE	**2027**
2.5 Produce and disseminate modules for communications training relating to the provision of palliative and end-of-life care.	HSE	**2025**

Recommendation 3. Family and those important to the person with a life-limiting condition will be supported to maintain their own well-being. Carers will be recognised as partners by healthcare professionals. They will be supported to care with confidence while participating as fully as possible in economic and social life.

Strategic action

3. Support the development of evidence-based training and support programmes for family caregivers supporting people with different care needs.

Activities	Responsibility	Timeframe Commence before end:
3.1 Conduct a review of the Palliative Care Hub; use findings to inform its future development and the development of evidence-based training and support programmes for family caregivers.	HSE	**2026**
3.2 Conduct a review of respite and short break provision for patients in receipt of specialist palliative care; use findings to inform service planning and provision.	HSE	**2026**

Recommendation 4. The ongoing development of bereavement services will be supported. Bereavement support will be accessible in all settings where palliative care is provided and will continue to be a core part of specialist palliative care provision.

Strategic action

4. Develop bereavement services in all settings where palliative care is provided in accordance with the Palliative Care Model of Care.

Activities	Responsibility	Timeframe Commence before end:
4.1 Undertake a comprehensive demand and capacity analysis of specialist palliative care bereavement services at regional and individual service level to identify productivity opportunities and specific capacity gaps, staff, and other infrastructure.	HSE	**2026**
4.2 Address deficits in staffing and infrastructure identified by the demand and capacity analysis so that specialist palliative care service providers have adequate and competent staff to provide bereavement services to meet the needs of those whose family member accessed specialist palliative care, regardless of location of provision of care.	HSE	**2027**

Recommendation 5. Communities will be empowered to be ready and able to help people in their journey through illness, death, and bereavement.		
Strategic action		
5. Support the development of compassionate communities.		
Activities	**Responsibility**	**Timeframe Commence before end:**
5.1 Engage across Government Departments and agencies with the aim of empowering local government to mobilise available resources to address local needs for palliative and end-of-life care.	Department of Health	**2026**
5.2 Identify, evaluate, and implement exemplar models of community action in palliative, end-of-life care, and bereavement through competitive applications to the Sláintecare Healthy Communities Programme.	Service Providers	**2025**
5.3 Implement community development programmes in Health Regions so that local citizens and specialist palliative care providers develop initiatives that build community action in palliative, end of life care and bereavement.	Service Providers	**2027**
Recommendation 6. High-quality services will be universally accessible across all settings based on need. Palliative care services will respond to the unique needs of different population groups to ensure equity in access, experience, and outcomes.		
Strategic action		
6. Support identification and analysis of palliative care inequities; design and implement models of service delivery to address difficulties in equitable access to care.		
Activities	**Responsibility**	**Timeframe Commence before end:**
6.1 Develop service design considerations for those with dementia as a module within the Model of Care.	HSE	**2025**
6.2 Develop Model of Care module on service design considerations for people with intellectual disabilities.	HSE	**2026**
6.3 Develop Model of Care module on service design considerations for Adolescent and Young Adult palliative care services.	HSE	**2026**

6.4	Further develop the HSE Minimum Dataset in Palliative Care to collect data relating to inequities in service provision and outcomes.	HSE	**2027**
6.5	Update Health Atlas to include data on palliative care services and providers.	HSE	**2024**
6.6	Develop and publish an Atlas of Variation for Palliative and End-of-Life Care to support identification and analysis of inequities in access to and outcomes of palliative care service provision.	HSE	**2024**

Recommendation 7. Palliative care will be accessible across all settings without risk of financial hardship.

Strategic action

7. Promote universal protection against financial risk for patients and families accessing palliative care services.

Activities		Responsibility	Timeframe Commence before end:
7.1	Expand eligibility on a phased basis to move towards universal palliative care, and support a shift to community-based, integrated care within all Health Regions in line with the commitments of the Sláintecare Implementation Strategy.	Department of Health	**2026**
7.2	Conduct an evidence review that examines international practice for measuring financial hardship among people with life-limiting conditions at a population-level and provides an options appraisal for collecting relevant data in Ireland.	Department of Health	**2025**
7.3	Continue to support healthcare delivery in the context of palliative care by providing reimbursement services to contractors for the provision of health services, including Centralisation of Discretionary Hardship Arrangements in Primary Care Reimbursement Service (PCRS).	Department of Health	**2025**

Strategic Objective 2. Right Place and Right Time

'Right place and right time' means people can access high-quality palliative care, where and when they need it.

Central to the vision of Sláintecare is a re-orientation of services so that care is provided in integrated ways as close to home as possible. The importance of ready access to reliable care at all times is also recognised, given that the onset or worsening of illness can happen at any hour of the day or night.

Moving from a historic over-reliance on hospital-based care towards care that is closer to home requires a dual focus on both patient-centred and population-planned care. While an individual's specific health needs and desired health outcomes are the driving forces behind patient-centred care, population-planned care looks beyond the traditional clinical setting to consider both the wider determinants of health and resourcing of the delivery system.

Time and place of provision of care assume particular importance in the context of palliative care. Research continues to show that many people who could benefit from palliative care do not receive such support, or access services very late in their illness trajectory.[39] It also confirms that many, though not all, wish to be cared for at home.[40] In order to deliver on the goal of 'right place and right time' we need to improve preparedness and connectedness at all levels – between individuals, teams, services, and systems. We need to develop a range of service delivery options that include alternatives to hospital emergency admission.

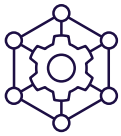
To achieve this, we will ensure that:

8. Population Planned Services

Palliative care services will be planned and adequately resourced according to population need. Specialist palliative care services will be organised along regional lines; there will be streamlining of multiple clinical and corporate governance lines, where appropriate.

9. Core Services

A framework to define core palliative care services will be developed and implemented, and all associated revenue costs, including pay and non-pay, will be statutorily funded.



10. Integrated Systems

Integrated regional networks of general and specialist palliative care service providers will support the ongoing development of system working and will help shape the system in which they operate.

11. Public Awareness

Information will be provided to help the public understand what palliative care is, and to know where and how to access services.

12. Preferred Place of Care

Supports will be provided to enable people to stay in their preferred place of care and communities for as long as possible and with as good quality of life as possible.

13. Out-Of-Hours Care

A whole systems approach will be taken to improve out-of-hours urgent and emergency palliative care provision.

Why are the 'right place and right time' recommendations important and how will they be actioned?

▸ Population-planned services (Recommendation 8)

The use of a population-based approach represents a significant shift in how healthcare is currently planned and delivered in Ireland. A population-based approach is underpinned by recognition of the social determinants of health such as education, income, housing, and local environment. It has particular relevance for addressing inequities in access, experience, and outcomes given that some population groups require tailored interventions to best meet their needs.

Recommendation 8 recognises the essential contribution that population-based planning will make towards achieving universal palliative care. The Report of the National Advisory Committee on Palliative Care (2001) used the former Health Board Areas as the basis for planning. We must now move to plan and provide services in line with the principles of Sláintecare. Acknowledging the formation of the six new HSE Health Regions, it is recommended that specialist palliative care services are configured to map to these structures and that multiple governance lines across organisations are streamlined as far as is possible and appropriate. As part of this process, consideration should also be given to the organisation of services so that an integrated network of general and specialist providers is formed at Health Region level.

Other key activities supporting the implementation of population-based planning are considered in further detail in the next chapters, 'Right people' and 'Good governance.' These include support for the development of high-quality data relating to palliative care need and service capacity as described in activities 18.1 and 25.2.

▸ Population-based funding (Recommendation 9)

Population-based funding is an important lever that enables population-based planning. It facilitates the adjustment of funding across populations according to variation in need and the cost of providing the necessary services and supports. Population-based funding also increases transparency in the distribution of resources.

In the context of palliative care, a population-based funding model will be a mechanism for promoting equity in health outcomes and access to services. Funding for palliative care services is currently distributed based on exsisting levels of service – that is, historic patterns of demand amongst those who have accessed care – rather than being guided by current or projected population need. This approach to funding can reinforce structural inequities as current utilisation patterns may not accurately reflect population need, particularly where there are cost barriers and long waits to access care. Additionally, some core palliative care services and infrastructure development projects are only partially funded by the public health system and are reliant on funding provided by communities.

Recommendation 9 highlights the need to develop a framework that defines and fully resources core palliative care services within the public health system. The framework will demonstrate best value for money and pursue areas of disinvestment, where appropriate. Activities will ensure this framework guides resource allocation across all settings and regions, including for services provided outside-of-hours and those responding to urgent and emergency needs. Public funding will also be provided to strengthen palliative care infrastructure and build required capacity.

► Integrated systems (Recommendation 10)

Quality palliative care is best realised through strong integrated networks between general and specialist providers, where all healthcare professionals work together to meet the needs of all people. Research and experience provide clear evidence that when different parts of the healthcare system do not work together effectively, patients and their families are not able to access the right care, in the right place at the right time.

Palliative care has long recognised the value of integrated working and has a proven track record in this area. However, as the landscape of hospital, community and primary care grows and evolves, so too must palliative care. This means that palliative care services will need to develop new ways of working and forge new relationships, in order to continue to provide high-quality integrated care as described in Recommendation 10.

Achieving the benefits of integrated care requires strong system leadership and palliative care services should proactively contribute to the design and implementation of integrated care pathways and organisational change. Effective system leadership for the delivery of integrated palliative care must be distributed, operating at all levels, and involve people who both use and provide care. At a macro level, policy direction is provided by the Department of Health, and strategic direction by the HSE. At a meso level, leadership will be provided by Health Region infrastructure, while at point of care and delivery, relationships between professionals from different teams, care settings and sectors are key.

The development of Integrated Palliative Care Fora is proposed. A Forum will act as a locus for collaborative decision-making among organisations responsible for arranging and delivering health and care services in a locality or community. The Forum will present an important opportunity for the HSE, local government, health and social care providers, voluntary organisations, skills and education services, and people and communities who use services to corral local knowledge, make the most of existing services and lead the local agenda in the design and delivery of integrated palliative care. The intention is to support partners to build on existing arrangements, strengthen signposting and integration, and support the transition to working within Health Region structures.

In order for integrated care to become a reality, there must also be focused activity to address systemic barriers to integrated care relating to data infrastructure and information sharing.

▸ Awareness and understanding of palliative care (Recommendation 11)

Raising awareness and knowledge of palliative care is central to a population health approach that aims to empower decision-making, enhance self-efficacy and well-being, and strengthen community engagement and support. Information, outreach, and education are instrumental in helping the public understand what palliative care is, and where and how to access services. Given the breadth of the relevant audience and complexity of the topic, it is important to ensure that messages are tailored to the needs of different groups. With this in mind, a Communication and Awareness Plan for Palliative Care Health and Wellbeing in the Wider Community will be developed and implemented with the aim of reducing stigma and promoting well-being among people with palliative care needs, those important to them, informal and formal carers. As previously described, a review of the Palliative Care Hub will be conducted to guide the further development of its informational and training resources for patients and informal carers in collaboration with stakeholders. In particular, the review will consider how resources can better respond to people's health literacy needs. Education and training are also crucial in shaping the knowledge, attitudes and practices of healthcare professionals and relevant actions are considered further in the next chapter, 'Right People.'

▸ Preferred place of care (Recommendation 12)

Recommendation 12 draws attention to the importance of proactively engaging with and providing individuals and their families with supports to enable them to stay in their preferred place of care. Understanding and enabling choice whenever possible regarding place of care and place of death is core to palliative care practice. As previously described, a palliative care needs assessment is the first necessary step to recognising and responding to need. Assessment of need should then be followed by the development of a care plan that responds to physical, psychosocial, and spiritual concerns.

When home is chosen as the individual's preferred place of care, practical concerns commonly arise as part of the care planning process that are unique to this setting. In the main, these relate to ensuring ready access to appropriate care (considered in Recommendation 1), the provision of carer support (considered in

Recommendation 3), and the need to adapt or alter the home environment in order to maintain quality of life and maximise independence.

Research has demonstrated that currently individuals are incurring considerable out-of-pocket costs on equipment and/or home modifications despite the availability of a range of grants, schemes, and other financial supports. Palliative care providers should develop improved capability to signpost and connect patients and carers to available schemes and supports as considered within Recommendation 12 activities.

▸ Out-of-hours, urgent and emergency care (Recommendation 13)

Due to the serious nature of their underlying illness, people with palliative care needs are at a high risk of experiencing episodes of increased distress or deterioration. For some, hospital admission is clinically indicated and represents the best chance of stabilisation; for others, alternative urgent care response systems at or closer to home offer appropriate care better aligned with individual needs and wishes. A number of models of alternatives to hospital admission exist, such as GP home visiting, Community Intervention Team input, hospital outreach services and community palliative care provision. Other approaches, such as Same Day Emergency Care, enable senior clinicians to provide care at point of arrival to the hospital, removing delays and enabling same day discharge, if clinically appropriate. Currently, such services are not uniformly available. Moreover, hours of provision vary significantly which is of importance given that urgent care needs can arise at any time, including during out-of-hours periods.

It is essential that options should exist for people with a life-limiting or life-threatening illness to receive high-quality urgent care without hospital admission in all localities. When hospital admission is indicated, it is vital that rapid access pathways to hospital are in place that, where clinically appropriate, avoid the necessity of Emergency Department presentation.

Addressing recognised shortcomings in the current provision of urgent, emergency and out-of-hours palliative care will require a number of activities. Recognising the significant inconsistency between the different out-of-hours care offers available, a review and options appraisal of out-of-hours home-based palliative care provision will be carried out and the clear articulation of core and expanded hours of service will be considered as part of Recommendation 9's focus on definition of core services. Models of rapid response will be designed tested and scaled; expansion of funding for night support services will be provided and a review of service provision conducted.

Table 2: 'Right Place and Right Time' recommendations and associated core strategic actions.

Recommendation 8. Palliative care services will be planned and adequately resourced according to population need. They will be organised so that integrated networks of general and specialist providers are available and accessible across Health Regions.			
Strategic action			
8.	Organise service provision so that each Health Region has a population-planned network of adequately resourced, general and specialist palliative care service providers.		
Activities		**Responsibility**	**Timeframe Commence before end:**
8.1	Organise palliative care services into integrated networks of providers supporting the implementation of Health Region structures. Implement regional operating models that assure specialist palliative care service and clinical governance, organisational resilience and realise economies of scale and skill.	HSE	**2025**
8.2	Use data on population need and access to inform service planning, funding, delivery, and evaluation in line with the principles of Sláintecare.	Department of Health/HSE	**2026**
Recommendation 9. A Framework to define core palliative care services will be developed and implemented, and all associated revenue costs, including pay and non-pay, will be statutorily funded.			
Strategic action			
9.	Plan and distribute palliative care resources according to the nationally agreed Population-Based Resource Allocation (PBRA) funding model.		
Activities		**Responsibility**	**Timeframe Commence before end:**
9.1	Develop and implement a framework to define core palliative care services.	HSE	**2025**
9.2	Continue the programme to construct population-planned specialist palliative care units, with the delivery of new specialist palliative care units in CHOs 1 and 8 to meet population needs.	HSE	**2024**
9.3	Continue the programme of development of existing population-planned specialist palliative care units in order to meet demographic changes and population need.	HSE	**2024**

9.4 Ensure that investment in capital infrastructure for specialist palliative care services is considered for inclusion in the HSE's Capital Programme in accordance with existing HSE capital development processes for other healthcare services. Note that the responsibility for planning and delivery of specialist palliative care infrastructure projects will be led by the state and may be supported by funding from local organisations.	HSE	**2024**

Recommendation 10. Integrated networks of palliative care service providers will support the ongoing development of system working and will help shape the system in which they operate.

Strategic action

10. Support the provision of integrated care.

Activities	Responsibility	Timeframe Commence before end:
10.1 Develop a framework for the development of Integrated Palliative Care Fora.	HSE	**2025**
10.2 Establish learning sites for Integrated Palliative Care Fora and evaluate their utility.	HSE	**2026**
10.3 Develop essential enablers to the delivery of integrated palliative care including data collection and sharing capability and the implementation of shared systems such as summary care records, shared care records, electronic health records, anticipatory and advance care plans, and advance healthcare directives.	HSE	**2026**
10.4 All relevant Clinical and Integrated Care Programmes to consider and respond to population-based palliative care needs in the development of their Models of Care guided by Sláintecare principles and the WHO model of universal healthcare. The National Clinical Programme for Palliative Care (NCPPC) and other relevant programmes to collaborate to ensure that palliative care service design is co-ordinated across Programmes.	HSE	**2025**

Recommendation 11. Information will be provided to help the public understand what palliative care is, and to understand where and how to access services.

Strategic action

11. Promote public understanding of palliative care and help patients, the public and healthcare professionals understand the roles and responsibilities of different levels of palliative care service provision.

Activities	Responsibility	Timeframe Commence before end:
11.1 Develop and implement a Communication and Awareness Plan for Palliative Care Health and Wellbeing in the Wider Community.	HSE	**2026**

Recommendation 12. Supports will be provided to enable people to stay in their preferred place of care and communities for as long as possible and with as good quality of life as possible.

Strategic action

12. Enable people to stay in their preferred place of care as far as possible.

Activities	Responsibility	Timeframe Commence before end:
12.1 Proactively connect patients and carers to home modification and equipment schemes.	HSE/Service Providers	**2025**
12.2 Advance equitable access to night support services to support patients and carers at the end-of-life.	HSE/Service Providers	**2024**
12.3 Increase the statutory funding allocation to night support service providers to 50% of total costs of service provision.	HSE	**2025**
12.4 Conduct a comprehensive demand and capacity analysis of nursing for night care services to identify productivity opportunities and specific capacity gaps, staff, and other infrastructure.	HSE	**2024**

Recommendation 13. A whole systems approach will be taken to improve out-of-hours urgent and emergency palliative care provision.		
Strategic action		
13. Improve out-of-hours urgent and emergency palliative care provision.		
Activities	**Responsibility**	**Timeframe Commence before end:**
13.1 Conduct a review that examines the current arrangements that are in place for the provision of out-of-hours home-based palliative care and that provides an option appraisal of suitable arrangements for service provision.	HSE	**2025**
13.2 Promote synergistic working between the Pre-Hospital Emergency Care Council-registered practitioners, GP and primary care services, and specialist palliative care.	HSE	**2024**
13.3 Include out-of-hours service planning for patients with palliative care needs within population-based resource allocation models for palliative care.	HSE	**2026**
13.4 Design, test, and scale rapid/urgent response models of palliative care provision.	HSE	**2027**

Strategic Objective 3. Right People

The move towards integrated, person-centred care can only happen if the power of people – workforce, volunteers, and community – is harnessed through new ways of working, open approaches, and social innovation.

In order to ensure the achievement of universal palliative care, having the 'right people' means supporting the ongoing development of an appropriately resourced, accountable interdisciplinary workforce who are skilled in palliative care practice and who are supported and valued.

To achieve this, we will ensure that:

14. Staffing

Palliative care will be provided by interdisciplinary teams with the appropriate training, skill mix and expertise. Staff will be employed in adequate numbers and will be equitably distributed across settings and regions according to population-based needs.

15. Undergraduate Education

Education infrastructure and systems will be developed so that palliative care is integrated as a routine part of undergraduate healthcare professional education.

16. Postgraduate Education/ Continuing Professional Development

Education infrastructure and systems will be developed so that post-qualification education and training in palliative care is easily and equitably accessible to all health and social care professionals who provide care to people with life-limiting conditions and their families.

17. Leadership

Organisations and service providers will recognise, develop and support leadership capability.

18. Workforce Planning

Services providing palliative care will have improved ability to engage in workforce planning and will be able to identify current and forecast future requirements.

19. Volunteering

Volunteering in palliative care will be promoted and supported.

Why are the 'right people' recommendations important and how will they be actioned?

▸ Staffing (Recommendation 14)

The provision of high-quality palliative care services depends on having sufficient numbers of appropriately trained and motivated staff. This means having balanced networks of general and specialist palliative care providers working in integrated ways across the healthcare system.

Recognising that the structure of healthcare delivery in Ireland reflects past burden of disease and historical investment patterns, Sláintecare aims to further develop primary and community services. The commitment of the Sláintecare Reform Programme to addressing gaps in primary and community staffing is critical to the success of this policy given the essential role that general palliative care providers play in the care of people with life-limiting conditions, as emphasised by Activity 14.4. The importance of addressing specialist palliative care staffing gaps identified in the Adult Palliative Care Model of Care is, in turn, highlighted in Activity 14.1. Over a phased basis, these interventions and associated activities will ensure that interdisciplinary palliative care services are equitably distributed across regions.

The provision of high-quality care is not solely dependent on staff numbers; staff-mix, skill-mix, skill management, staff development and organisational context are all important factors to consider in the development of 'right people.' In order to deploy a fully efficient and effective workforce, attention must also be given to institutional environments that frame healthcare workers' educational preparation and professional regulation, and consideration must be given to the broad range of levers that can be mobilised at both organisational and system levels.[41]

The Palliative Care Competence Framework[42] will be updated to incorporate key workforce and service delivery developments and to include identification of pathways for career progression. Innovation in workforce deployment will be fostered through the funding of workforce pilots that are focused on improved ways of working. Issues relating to education, leadership and workforce planning are considered in the following recommendations.

41. Carl-Ardy Dubois and Debbie Singh, "From staff-mix to skill-mix and beyond: towards a systemic approach to health workforce management," *Human Resources for Health* 7, no.87 (December 2009): 1-19, https://doi.org/10.1186/1478-4491-7-87

42. Palliative Care Competence Framework Steering Group, "Palliative Care Competence Framework" (ISBN 978-1-906218-79-9, Dublin, August 1, 2014), 1-192, https://www.hse.ie/eng/about/who/cspd/ncps/palliative-care/resources/competence-framework/palliative-care-competence-framework-2411.pdf

► Undergraduate education (Recommendation 15)

Education is a key enabler for integrating palliative care within the health and social care system. Education helps healthcare professionals develop the skills, knowledge and confidence to identify and meet the care needs of people living with a life-limiting illness and those important to them. As population need for palliative care increases in Ireland, ensuring healthcare professionals have the appropriate palliative care competencies will be central to achieving universal access.

Ireland faces many of the same challenges incorporating palliative care into undergraduate education seen in other countries; these include crowded training programmes, limited resourcing, and underdeveloped palliative care leadership. As a result, a range of activities are required to support the delivery of undergraduate palliative care education. Among those, the development of academic leadership and capacity is regarded as key. Student placements in palliative care must be increased to provide practical learning opportunities and to ensure that identified competencies are achieved.

The further development of the Palliative Care Competence Framework and the Palliative Care Education Network will maximise the value of collaborative working and align programmes and outputs across the country. Statutory regulators of the health and social care professions have critical roles in setting standards of proficiency, approving and monitoring undergraduate education programmes and ensuring that the courses deliver learnings on palliative care, including placement experience. This work will receive ongoing support.

► Postgraduate education and continuing professional development (Recommendation 16)

Professional development is an essential component in building and maintaining competence and fitness to practice. It enables healthcare professionals to continually update and renew their skills and knowledge to match the changing complexity of healthcare needs.

Several activities are required to scale up and strengthen postgraduate palliative care education and training to achieve the ambition of Recommendation 16. As previously described in relation to undergraduate education, further development of education infrastructure and personnel is required. The Palliative Care, End of Life and Bereavement Education Database will be updated, maintained, and promoted as a resource for all healthcare professionals to identify and access relevant education and training programmes. Given the role that community palliative care teams have in the provision of care to children at the end-of-life, a review of postgraduate specialist training in palliative care will be conducted to better equip healthcare professionals to provide such care. Similarly, given the important role that GPs and primary care staff play in the provision of palliative care, educational materials and courses for GPs and primary care staff will be reviewed and further developed. The further development of a Palliative Care Education Network will also support bodies that provide Continuing Professional Development to work collaboratively to advance the delivery of interdisciplinary training, shared learning and understanding of individual roles and team working.

A number of statutory regulators have roles in setting standards, approving, and monitoring postgraduate education programmes, and their work with educators to deliver appropriate training at this level will be supported.

▸ Leadership (Recommendation 17)

It is essential that the HSE and service providers nurture cultures that ensure the delivery of continuously improving, high-quality, safe and person-centred healthcare. Leadership is the most influential factor in shaping organisational culture and so ensuring necessary leadership qualities and behaviours are developed in palliative care is crucial.[43]

Of equal importance to the development of professional leadership, is the recognition of the value of leadership provided by those with lived experience. People living with, or impacted by, a life-limiting or life-threatening illness must be empowered and actively engaged in service planning, design, and delivery. In particular, their experiences and expectations should guide activities for safety and quality improvement.

Activities associated with Recommendation 17 commit service providers to the active development of leadership capability and practice within their organisations. They also ensure the National Clinical Programme for Palliative Care and service providers further build and sustain active engagement with patients, carers, and the public.

▸ Workforce planning (Recommendation 18)

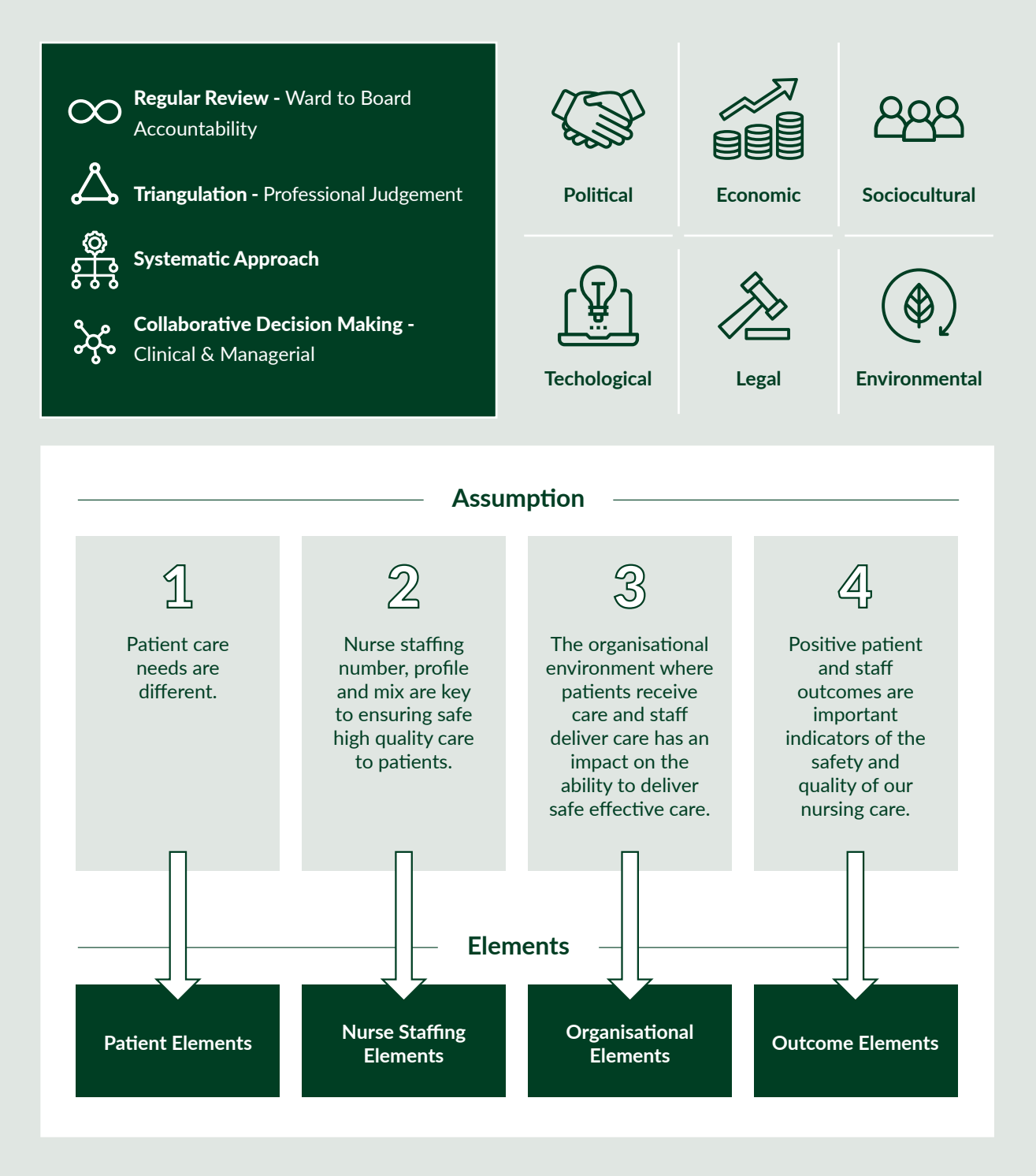
Workforce planning is essential for achieving the right balance between supply and demand for different types of healthcare professionals and how they are best distributed. Health workforce planning should be a dynamic process with regular evaluation and adjustment, where the starting point is always current and future population need.

The health sector in Ireland is facing significant challenges in the recruitment and retention of healthcare professionals, and these are expected to intensify. Traditional approaches to workforce planning tend to be specific to each profession, and typically use benchmarks or utilisation-based approaches to estimate the required workforce supply. However, as the healthcare system moves towards providing care in integrated ways, flexible, evidence-based approaches are needed that support service delivery and design.

A number of important programmes and initiatives are already underway that are developing and delivering on newer methodological approaches and this policy aims to support their development and expansion into palliative care through several actions. Building on work conducted in preparation of this policy, a sectoral register to track workforce capacity, distribution and flow in specialist palliative care services will be established. Specialist palliative care will have nurse staffing and skill mix determined by patient need, consistent with the Framework for Safe Nurse Staffing and Skill Mix. The National Doctors Training and Planning workforce model for palliative medicine will be updated and implemented. The feasibility of extending these frameworks to planning for specialist palliative care health and social care professional services will also be explored. In addition, workforce planning activities will consider the resources required to conduct activities related to quality, patient safety and knowledge generation.

43. Michael West et al., Leadership and leadership development in health (London: King's Fund, 2015), https://www.fmlm.ac.uk/sites/default/files/content/resources/attachments/Leadership%20in%20Health%20Care%20%20-%20A%20Summary%20of%20the%20Evidence%20Base_WEB.pdf

Figure 4: Framework for Safe Nurse Staffing and Skill Mix[44]



44. Department of Health, "Framework for Safe Nurse Staffing and Skill Mix in General and Specialist Medical and Surgical Care Settings in Adult Hospitals in Ireland: Final Report and Recommendations by the Taskforce on Staffing and Skill Mix for Nursing" (Dublin, April 15, 2018), 1-72, https://www.gov.ie/pdf/?file=https://assets.gov.ie/10011/e1a93e955329405694bb7b16aea50b98.pdf#page=null

▸ Volunteering (Recommendation 19)

Volunteers bring immeasurable benefits to the work of palliative care organisations in terms of enthusiasm, commitment, leadership, and community links. The valuable role that they play in palliative care is reflected in Recommendation 19. To ensure the dynamic and thriving culture is sustained and the full power of volunteering is harnessed, supports need to be further developed. These supports include the establishment of volunteer coordinator posts and the development of a Palliative Care Volunteer Coordinators Network. To ensure standardisation of best practice, clarity and protection for volunteers, a code of conduct for volunteers will be developed. To help bring new people to volunteering in palliative care, a public information and engagement programme will be rolled out and task-based and role-based opportunities will be made available to potential volunteers.

Table 3: 'Right People' recommendations and associated core strategic actions.

Recommendation 14. Palliative care will be provided by interdisciplinary teams with the appropriate training, skill mix and expertise. Staff will be employed in adequate numbers and will be equitably distributed across settings and regions according to population-based needs.		
Strategic action		
14. Optimise palliative care staffing and ways of working. Over a phased basis, ensure interdisciplinary specialist palliative care services are equitably distributed across regions.		
Activities	**Responsibility**	**Timeframe Commence before end:**
14.1 Address deficits in staffing and services identified in the current Adult Palliative Care Model of Care between 2023-2028.	HSE/Service Providers	**2024**
14.2 Update the National Palliative Care Competence Framework to incorporate key workforce and service delivery developments and to include identification of pathways for career progression.	HSE	**2025**
14.3 Advance the implementation of the National Palliative Care Competence Framework. Specifically, its utility will be promoted as a tool that can contribute to the description of relevant jobs and roles; help employers articulate the education and training required by individuals; help managers and individuals identify progression routes; and help education and training providers to develop programmes of learning and qualifications.	Service Providers	**2026**
14.4 Engage with General Practitioners to develop principles of best practice and appropriate contractual arrangements to enable General Practitioners to provide primary palliative care.	Department of Health	**2026**

14.5 Complete a review of international models of primary palliative care provision to inform the ongoing development of principles of best practice, contractual arrangements, and Model of Care.	Department of Health	**2025**
14.6 Provide funding to develop methodology for workforce planning for specialist palliative care health and social care professionals; for pilots to test, demonstrate and evaluate new or expanded roles for healthcare professionals and innovative interdisciplinary approaches in palliative care provision	HSE	**2028**

Recommendation 15. Education infrastructure and systems will be developed so that palliative care is integrated as a routine part of undergraduate health and social care professional education.

Strategic action

15. Develop undergraduate palliative care infrastructure and systems.

Activities	Responsibility	Timeframe Commence before end:
15.1 Support the further development of a national Palliative Care Education Network as a community of practice with the aim of bringing educators, clinicians, and stakeholders together to improve the national organisation and delivery of education through effective collaboration.	HSE/Service Providers/ Higher Education Institutes	**2025**
15.2 Conduct a review of palliative care education for undergraduate healthcare professionals and support the further development of curricula so that essential palliative care learning outcomes are achieved.	HSE	**2026**
15.3 Strengthen the development of academic departments that link palliative care and university settings by expanding faculty capacity and capability.	Higher Education Institutes/HSE	**2026**
15.4 Increase student placement opportunities in palliative care.	Higher Education Institutes/HSE	**2026**
15.5 Work with statutory regulators of the health and social care professions and educators to ensure relevant courses deliver learnings on palliative care, including placement experience.	DOH/ statutory regulatory bodies	**2025**

Recommendation 16. Education infrastructure and systems will be developed so that post-qualification education and training in palliative care is easily and equitably accessible to all health and social care professionals who provide care to people with life-limiting conditions and their families.		
Strategic action		
16. Develop palliative care education infrastructure and systems.		
Activities	**Responsibility**	**Timeframe Commence before end:**
16.1 Update, maintain and promote the Palliative Care Education and Bereavement Education Database.	HSE/Voluntary Agencies	**2024**
16.2 Review the curricula of postgraduate degrees or Higher Specialist Training in palliative care to incorporate content relating to the end-of-life care of children and young people in the home setting by specialist palliative care teams.	Royal College of Physicians Ireland/ Higher Education Institutes	**2024**
16.3 Provide funding for the review and ongoing development of educational materials and courses for GP and primary care staff.	Irish College of General Practitioners/ HSE	**2024**
16.4 Work with statutory regulators of the health and social care professions and educators to ensure relevant courses deliver appropriate training at the postgraduate level.	DOH/ statutory regulatory bodies	**2026**
Recommendation 17. Organisations and service providers will recognise, develop and support leadership capability.		
Strategic action		
17. Develop leadership capability in palliative care		
Activities	**Responsibility**	**Timeframe Commence before end:**
17.1 Demonstrate board/management support and release of staff for leadership training, networking, and practice development opportunities.	Service Providers	**2025**
17.2 Develop and implement action plans for Public and Patient Involvement (PPI) engagement in palliative care.	Service Providers	**2025**

17.3 Ensure there is active Public and Patient Involvement (**PPI**) representation in the National Clinical Programme for Palliative Care Working Group.	HSE	**2024**
17.4 Develop and support a national public, patient, and carer forum for engagement with palliative care research and innovation.	Patient and Public Interest Organisation	**2026**

Recommendation 18. Services providing palliative care will have improved ability to engage in workforce planning and will be able to identify current and forecast future requirements.

Strategic action

18. Conduct and implement workforce planning in palliative care.

Activities	Responsibility	Timeframe Commence before end:
18.1 Establish a sectoral register to track specialist workforce capacity, distribution and flows in specialist palliative care services	HSE	**2024**
18.2 Incorporate the principles that underpin the Framework for Safe Nurse Staffing and Skill Mix in workforce planning for specialist palliative care.	HSE	**2025**
18.3 Update and implement the National Doctors Training and Planning workforce model for palliative medicine.	HSE	**2024**
18.4 Include gap analysis and consideration of requirements in each region for the provision of end-of-life care for children and young people in community settings in workforce planning and implementation.	HSE	**2025**
18.5 Include gap analysis and consideration of requirements in each region for specialist Quality and Patient Safety staff in workforce planning and implementation.	HSE	**2025**
18.6 Include gap analysis and consideration of requirements in each region for data analytics staffing in workforce planning and implementation.	HSE	**2025**

Recommendation 19. Volunteering in palliative care will be promoted and supported.		
Strategic action		
19. Promote and support volunteering in palliative care.		
Activities	**Responsibility**	**Timeframe Commence before end:**
19.1 Implement a volunteer coordinator post in the integrated palliative care network of each Health Region.	HSE	**2026**
19.2 Establish a National Palliative Care Volunteer Coordinators network.	Service Providers	**2026**
19.3 Develop and implement a public information and engagement programme on volunteering in palliative care which includes consideration of how to enable diverse populations of people to volunteer.	Service Providers	**2027**
19.4 Ensure the availability of task-based and role-based volunteering opportunities to potential volunteers.	Service Providers	**2027**
19.5 Implement a standard code of conduct for volunteers to offer protection and clarity on expectations while volunteering and to ensure best practice.	Service Providers	**2026**

Strategic Objective 4. Good Governance

Governance is central to improving health system performance and achieving universal palliative care.

At the national level, governance involves ensuring that a strategic policy framework exists and is combined with effective oversight, coalition building, regulation, attention to system-design and accountability. At the service level, governance involves ensuring that an organisation's objectives are aligned with national and local objectives and interests, that resources are deployed accordingly, and results achieved.

Good governance requires staff to put safe, effective, and person-centred care at the heart of everything that is done in palliative care. This means developing systems, processes and behaviours that continuously strive to strengthen access, quality of services and financial protection. Increasingly, it means cultivating staff awareness that their responsibilities often extend to working beyond organisational boundaries in order to provide integrated care that meets the needs of patients and their families.

To achieve this, we will ensure that:

20. Governance and Systems

Governance and systems will be continually strengthened to ensure legitimacy, transparency, and trust, and to achieve results.

21. Quality and Safety

A defined patient safety and quality operating framework will be developed and implemented.

22. Information Systems

Effective sharing of data and information, knowledge generation, and ICT enablement of palliative care service provision will be achieved.

23. Medicines and Technologies

Essential medicines in palliative care will be easily and safely accessible. Medications will be used in safe and effective ways in order to achieve the best possible outcomes for patients.

24. Accountability

The Health Information and Quality Authority will be supported to monitor palliative care provision ensuring that services adopt a human rights-based approach to care that promotes safety and wellbeing, responsiveness, and accountability.

25. Research and Innovation

Research and innovation infrastructure and systems will be developed in palliative care and a sustainable academic workforce will be developed.

Why are the 'good governance' recommendations important and how will they be actioned?

▸ Governance and systems (Recommendation 20)

Governance involves having the necessary structures, processes, standards and oversight in place to ensure that safe, person-centred and effective services are delivered.[45] In any healthcare organisation, including those providing palliative care, clinical governance processes must work with financial, risk and other corporate governance processes as an integrated system. Recommendation 20 recognises the central importance of good governance to achieving universal palliative care and reflects a commitment to continual strengthening of governance and systems.

Prominent in international experience are six key components to improving the quality and safety of care. These are: clinical leadership and accountability; cultural change; relationships; knowledge and skills; intelligent use of information; and quality improvement capability.[46] All components require dedicated focus and action in order to ensure they are continually driving excellence in the delivery of palliative care.

In 'Right People,' several Activities highlighted the importance of development of leadership capability, and in 'Right Place and Right Time,' the importance of service reorganisation aligned with Health Region structures was emphasised. Activities related to Recommendation 20 aim to further develop governance with the appointment of Palliative Medicine Clinical Directors. As previously described in Recommendation 10, development of the Integrated Palliative Care Fora will advance consideration of integrated governance across services and areas.

Recognising the importance of having staff that understand quality improvement science at all levels of an organisation to help put it into practice, it will be essential to consider issues of staff resourcing for quality-of-care activities. Other Activities commit services to leveraging and participating in national initiatives and collaboratives related to quality and patient safety. These will build on collaboratives already established that focus on common causes of harm or identified priority topics

45. Health Service Executive, "Framework for Improving Quality in Our Health Service" (ISBN: 978-1-78602-014-7, Ireland, May 25, 2016), 1-28, https://www.hse.ie/eng/about/who/qid/framework-for-quality-improvement/framework-for-improving-quality-2016.pdf

46. Health Service Executive, "Framework for Improving Quality in Our Health Service" (2016)

and will expand to include consideration of new HSE initiatives as they are developed.

Given the need for high-quality guidelines that promote evidence-based, cost-effective, and patient-centred care, two Activities are focused on the development and implementation of guidelines on management of cancer pain and end-of-life care (including decision-making and care planning). These guidelines will be developed using the NCEC Standards for Clinical Practice Guidance (2015)[47] as a reference. Similarly, a national audit on end-of-life care will be developed and implemented. This audit will first be conducted in the hospital setting and will triangulate with findings from the National End of Life Survey and staff survey to provide a rich insight into care provided at this important time. In addition to this national project, all palliative care services will continue to conduct local audit and use the findings to drive continuous quality improvements.

▸ Quality and safety operating framework (Recommendation 21)

The approach many organisations have taken to improving care quality and manage risks is to develop risk management and quality departments. This is an important first step, but additional Activities will be required to ensure real change and embed a culture of safety and quality across organisations. Central to achieving this goal will be the establishment of a quality and safety framework to inform planning, delivery, and monitoring of services. The framework will address key components such as service user advocacy, complaints, use of data for patient safety and quality, open disclosure, incident management and response, learning systems and service improvement, and will foster a patient safety culture. It will be developed in line with the national patient safety priorities and relevant policy. Each palliative care service will operationalise this in accordance with their business planning and clinical and corporate governance processes.

▸ Information systems (Recommendation 22)

Quality information may be understood as information that is accurate, valid, reliable, timely, relevant, and complete.[48] Patients, families and carers need quality information to enable them to share in decisions made about their care and find out much more easily about services that are available. Healthcare professionals need quality information to help them plan, manage, deliver, and monitor care. Quality information, combined with the right support, is the key to better care, value-based service provision and better outcomes.

There are currently significant gaps in data infrastructure, health information systems, and knowledge generation capability across palliative care in Ireland. Moreover, there is limited deployment of digital health solutions in palliative care. The development of health information systems and the deployment of digital health solutions are strategic priorities both for the general healthcare system, and also palliative care. Given palliative care's relative immature state of development in these areas, multimodal actions are required to deliver solutions. Several Activities associated with this recommendation aim to accelerate development of a robust and rigorous palliative care data infrastructure.

The establishment of a Palliative Care Measurement and Reporting Working Group will be key. The group will have the aim of determining measurement priorities, addressing identified measurement gaps, and assessing the quality of core measurement sets. The group's work will align to the Health System

47. Department of Health, "National Clinical Effectiveness Committee Standards for Clinical Practice Guidance" (Dublin, November, 2015), 1-31, https://www.nmbi.ie/NMBI/media/NMBI/Forms/standards-for-clinical-practice-guidance-ncec.pdf

48. Smith et al., "Evidence on the cost and cost-effectiveness of palliative care".

Performance Assessment Framework for Ireland as it develops. The Minimum Dataset and performance management metrics will be further developed based on recommendations from this Working Group. It will be important to consider the development of patient reported outcome measures (PROMs) and experience measures (PREMs) as part of this process. As previously highlighted, relevant workforce will also need to be equipped with the necessary skills to analyse, interpret, disseminate, and utilise this data.

Other Activities will lead to development of a modern and standardised palliative care information and communications technologies (ICT) infrastructure that includes a Clinical Management System for Specialist Palliative Care. These systems are essential in addressing systemic barriers to integrated care. Their development will ensure that care planning conversations (including anticipatory and advance care planning) are always documented and accessible to all team members. This will serve as an important enabler to the implementation of person-centred decision-making and the delivery of coordinated care.

▸ Medicines and technologies (Recommendation 23)

Strengthening palliative care provision includes ensuring the availability of essential medicines for managing the symptoms of people with life-limiting or life-threatening illnesses. Pain is one of the symptoms most feared by people with a life-limiting illness, yet it remains frequently undertreated. The Lancet Commission on Global Access to Palliative Care and Pain Relief[49] highlights the imperative for a balanced approach between addressing pain and other symptoms for the seriously ill and limiting the risk for inappropriate use.

Evidence-based guidance for healthcare professionals is key to ensuring people with a life-limiting illness have timely access to safe and effective medication. Activities related to Recommendation 23 focus on the development and implementation of evidence-based guidelines on pharmacological treatment of cancer pain and an associated web-based symptom management resource. The importance of addressing factors related to the availability and affordability of medicines in the public health system is noted and optimising reimbursement arrangements for medicines for those with palliative care needs is planned. Consideration will be given to further developing the role of community pharmacists in palliative care.

▸ Accountability (Recommendation 24)

The regulation of care is a very important part of assuring standards, quality, and safety. Regulation demonstrates the fundamental accountability of services to the public and helps to build trust and transparency. In Ireland, the Health Information and Quality Authority (HIQA) is an independent authority established to drive high-quality and safe care for people using health and social care services in Ireland. HIQA assures the public that services adopt a human rights-based approach to care that promotes safety and wellbeing, responsiveness, and accountability.

HIQA's mandate extends across an expanding range of public, private, and voluntary sector services, and Recommendation 24 commits to more fully developing its function in relation to palliative care. Central to successful delivery of this recommendation is the development of a legislative framework to enable HIQA to fulfil a role in monitoring or regulation of services providing palliative care. The second activity considers the resourcing requirements necessary to further develop standards as required and to support the inspection and review of services.

49. Felicia Marie Knaul et al., "Alleviating the Access Abyss in Palliative Care and Pain Relief—An Imperative of Universal Health Coverage: The Lancet Commission Report," The Lancet 391, no. 10128 (April 2018): 1391-1454, https://doi.org/10.1016/S0140-6736(17)32513-8.

▸ Research and innovation (Recommendation 25)

Research and innovation are vital in providing new knowledge and new ways of working needed to improve health outcomes and reduce inequalities. They are even more important when resources are under pressure as they support the identification of new ways to improve quality and productivity while providing transparency regarding best use of resources. Accordingly, this policy promotes the development of palliative care research infrastructure and processes to unlock synergies between research, education, and patient care.

The Health Research Board (HRB) has played a key role in supporting the development of palliative care research as the lead funding agency for health research in Ireland. Cross-border collaboration between the HSC Public Health Agency and other stakeholders in Northern Ireland has been fostered with notable success, leading to the establishment of strong relationships as evidenced by the vibrancy of the Palliative Care Research Network (PCRN). The central importance of the Health Research Board in supporting the development of a thriving research environment is recognised and Activities build on existing work and are focused on growing infrastructure and researchers. This includes an Activity to strengthen the PCRN structure through the appointment of Integrated Research and Innovation Fellows in Palliative Care (IRIN-PC Fellows). The Fellows will be tasked with addressing prioritised issues of importance to implementation of this policy. Recognising the critical role that meaningful engagement with patients, carers, and the public plays in producing knowledge that delivers value, exemplar programmes of patient and public involvement will be supported as previously described in 'Right People.' In addition, a national palliative care research knowledge transfer function will be resourced to implement a comprehensive knowledge management programme.

The implementation of Sláintecare reforms such as the Health Regions, presents a unique opportunity to optimise structures and processes so that palliative care education, clinical research, informatics, innovation, and healthcare delivery have a unified strategic vision and direction. In particular, the development of Academic Health Science Systems (AHSS) promises that partnerships between universities and healthcare organisations will be enhanced, and quality care will be delivered hand in hand with teaching, training, research, and innovation. Activities associated with the recommendation recognise the potential of the AHSS structure and support the further development of Education and Research Centres of regional specialist palliative care organisations within AHSSs and Health Regions. This will require the development of capacity and expertise within the clinical academic workforce.

Research and innovation activity in palliative care in Ireland has grown considerably in recent years. There has been a corresponding increase in collaborative working nationally and internationally and the quantity and impact of research has increased.[50] However, to date, identified gaps in capacity and capability have slowed the pace of achievement. This policy marks a key step in the journey towards the development of a vibrant and high performing research and innovation community through the implementation of actions to support capacity building and infrastructure, governance, and oversight. In view of the transformative potential associated with this stage of development, a strategic review of palliative care research and innovation capacity, capability and performance will be conducted in 2026. The findings of this exercise should further guide implementation of policy and strategic plans.

50. Sonja J McIlfatrick et al., "Examining palliative and end of life care research in Ireland within a global context: a systematic mapping review of the evidence," *BMC Palliative Care* 17, no. 109 (September 2018): 1-10, https://pure.ulster.ac.uk/en/publications/89d4b46e-135b-45a1-917b-b0308ab4b4ef

Table 4: 'Good Governance' recommendations and associated core strategic actions

Recommendation 20. Governance and systems will be continually strengthened to ensure legitimacy, transparency, and trust, and to achieve results.		
Strategic action		
20. Strengthen palliative care governance.		
Activities	**Responsibility**	**Timeframe Commence before end:**
20.1 Appoint Clinical Directors for networks of specialist palliative care service providers operating at Health Region level.	HSE	**2025**
20.2 Embed quality improvement and data-driven, self-assessment systems alongside external review, so that continuous improvement becomes an integral part of service delivery.	HSE/Service Providers	**2025**
20.3 Develop and implement a national guideline, 'Caring for Adults in the Last Days and Hours of Life.'	National Cancer Control Programme/ HSE	**2025**
20.4 Develop and implement a national audit of end-of-life care in the hospital setting.	HSE/National Office of Clinical Audit	**2026**
20.5 Support the ongoing development of national collaboratives that provide system-wide leadership in quality improvement and shared learning.	HSE/Service Providers	**2026**
20.6 Support the continued implementation of the national quality improvement project on palliative, end-of-life and bereavement care for the nursing home sector and conduct an evaluation of effectiveness 3-5 years after commencement.	HSE/IHF (CARU)	**2024**

Recommendation 21. A defined patient safety and quality operating framework will be developed and implemented in education.		
Strategic action		
21. Develop and implement a patient safety and quality operating framework for palliative care.		
Activities	**Responsibility**	**Timeframe Commence before end:**
21.1 Develop and implement a patient safety and quality operating framework for palliative care.	HSE/Service Providers	**2027**
21.2 Ensure that service providers have sufficient numbers of staff competent and trained for quality-of-care activities.	Service Providers/HSE	**2025**
Recommendation 22. Effective sharing of data and information, knowledge generation, and ICT enablement of palliative care service provision will be achieved.		
Strategic action		
22. Develop knowledge generation and management capability.		
Activities	**Responsibility**	**Timeframe Commence before end:**
22.1 Review the set of performance management metrics for palliative care with the aim of strengthening the national information system, aligning with the new policy, and creating the conditions to link data across systems.	HSE	**2025**
22.2 Establish a Palliative Care Measurement and Reporting Working Group which will: • Establish measurement priorities that address the national aims for improvement and that meet the common information needs of the public, service providers, HSE, and Department of Health. • Address measurement gaps in palliative care and provide expert guidance on the development and maintenance of palliative care quality measurement, data collection, and reporting standards. • Review and quality assure proposed core sets of measures and standardised methods for measurement and reporting, prioritising alignment with the Health System Performance Assessment (HSPA) Framework wherever possible. • Make recommendations for further development of the Palliative Care Minimum Dataset	HSE	**2025**

22.3 Develop and maintain a modern and standardised palliative care ICT infrastructure.	Service Providers	**2025**
22.4 Develop and implement a national Clinical Management System for Specialist Palliative Care.	HSE	**2024**

Recommendation 23. Essential medicines in palliative care will be easily and safely accessible. Medications will be used in safe and effective ways in order to achieve the best possible outcomes for patients

Strategic action

23. Strengthen access to essential medicines in palliative care.

Activities	Responsibility	Timeframe Commence before end:
23.1 Develop a web-based symptom management resource.	HSE	**2025**
23.2 Update and implement national evidence-based guidelines on the pharmacological treatment of cancer pain.	National Cancer Control Programme	**2025**
23.3 Ensure that appropriate resources are given to the HSE to enable it to add new drugs required in the delivery of palliative care to reimbursement lists.	Department of Health	**2025**
23.4 Explore with the Irish Pharmacy Union ways in which community pharmacists can assist in the provision of holistic support, including information and the safe and timely supply of medicines to those in palliative care.	Department of Health	**2026**

Recommendation 24. The Health Information and Quality Authority will be supported to monitor palliative care provision ensuring that services adopt a human rights- based approach to care that promotes safety and wellbeing, responsiveness, and accountability.

Strategic action

24. Support the Health Information and Quality Authority to monitor palliative care provision.

Activities	Responsibility	Timeframe Commence before end:
24.1 Develop the legislative framework to enable HIQA (Health Information and Quality Authority) to inspect and review palliative care services to ensure that services adopt a human rights-based approach to care that promotes safety and wellbeing, responsiveness, and accountability.	Department of Health	**2026**

24.2 Determine the most appropriate approach for regulation or monitoring of palliative care services and resource HIQA accordingly to develop standards where required, to regulate/monitor services, and support informed decisions on how services are delivered.	Department of Health/ Health Information and Quality Authority	**2027**

Recommendation 25. Research and innovation infrastructure and systems will be developed in palliative care and a sustainable research workforce will be developed.

Strategic action

25. Develop palliative care research and innovation infrastructure and systems.

Activities	Responsibility	Timeframe Commence before end:
25.1 Develop a strong and supportive environment for palliative care research in Ireland through investment in infrastructure and researchers.	HRB	**2025**
25.2 Appoint Integrated Research and Innovation Fellows in Palliative Care (IRIN-PC) to support policy implementation and respond to and meet the needs of local populations and health and care systems.	HSE	**2026**
25.3 Develop and maintain a national palliative care research knowledge transfer function to develop a comprehensive knowledge management framework.	HSE	**2026**
25.4 Support the development of specialist palliative care Education and Research Centres within fully co-ordinated partnerships between universities and healthcare organisations	HSE	**2025**
25.5 Develop clinical academic posts with an explicit contractual remit for clinical service, research, and education across each integrated palliative care network and partner university as part of the academic health science system according to the workforce planning models. Include, at a minimum, a Professor in Palliative Medicine and a Professor in Palliative Care and adequate staffing to support clinical placements in each Health Region.	HSE	**2026**
25.6 Conduct a strategic review of palliative care research and innovation capacity, capability, and performance in 2026 and use to inform the ongoing implementation of this policy and the work of funding agencies for health in Ireland.	HSE	**2026**

Implementation Roadmap

Implementation of this policy will take place over a number of years and will require a sustained and programmatic approach.

A programmatic approach is required because the policy actions comprise a strategic arrangement of individual yet interlinked projects that aim to achieve synergistic and large-scale impact over the long-term.

The following principles-based approach to implementation will be adopted:

- *Participatory:* strategies for implementing actions will be developed and led by stakeholders, with external support where necessary. Implementation processes should be responsive to local conditions and contexts but should work within a single, comprehensive programme and budget framework.
- *Subsidiarity:* implementation decisions and functions will take place as close to the patient as possible within the evolving Health Region structure. Occasions may arise in situations where objectives cannot be satisfactorily achieved through implementation at regional level or where added value can be provided if the action is carried out at a national level.
- *Equity-focused:* efforts to enhance equity fundamental to the goal of universal palliative care and the implementation approach will consider the role of social determinants of health and the use of inter-sectorial strategies in the design of implementation strategies.
- *Iterative learning/action cycles are utilised:* success is most likely when there are iterative learning and action cycles that track changes in the service delivery system, identify emerging problems and bring stakeholders together to solve problems. Iterative learning and action cycles should be integral components of implementation strategies.
- *Goal-oriented:* a key focus should be on the ongoing monitoring of progress within a framework that includes specific and measurable objectives.

Proposed implementation structures

Proposed implementation structures are shown in Figure 5.

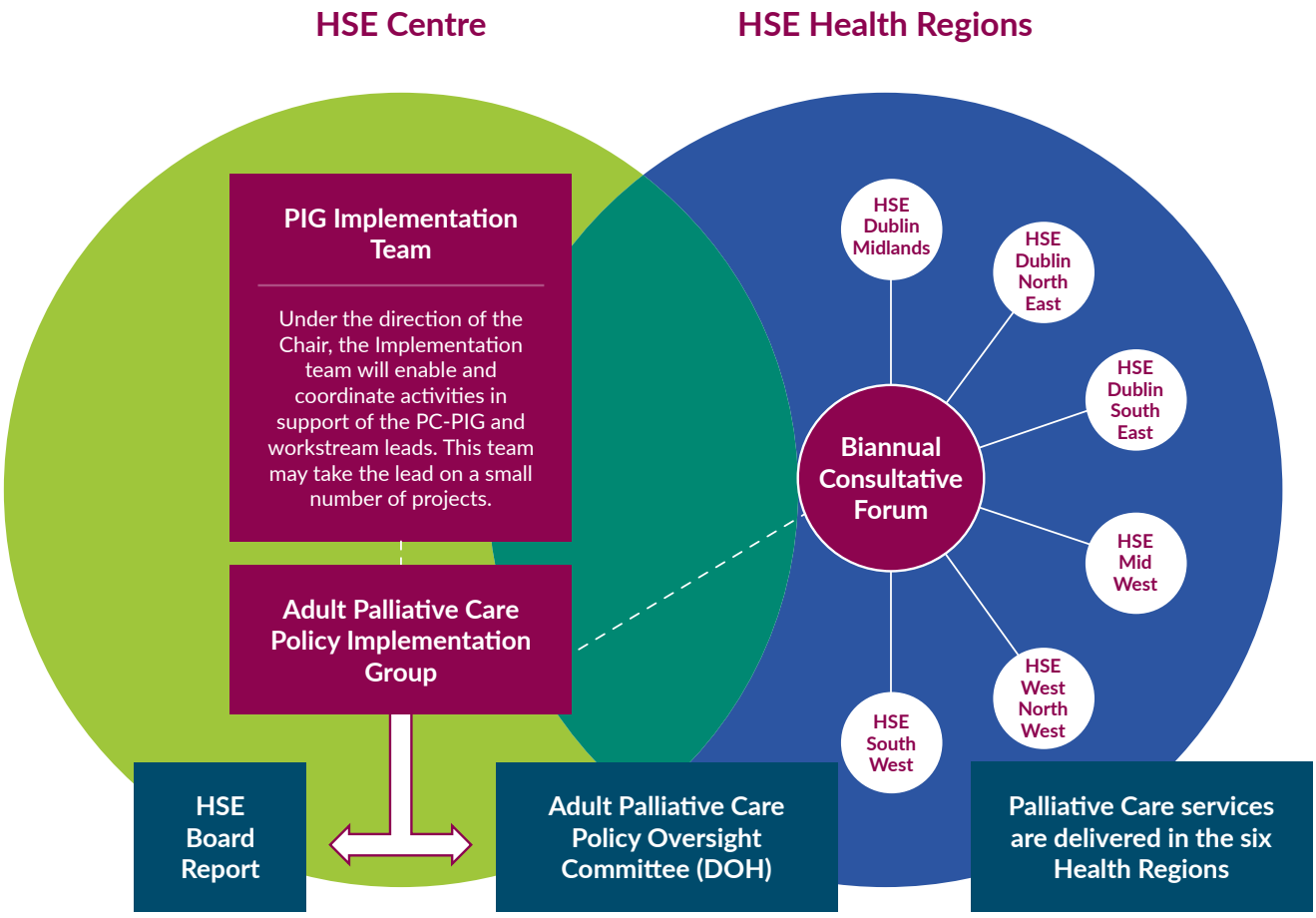
► Palliative Care Policy Implementation Oversight Committee

It is proposed that implementation of the policy will be overseen by a cross-sectoral and cross-Departmental group, the Palliative Care Policy Implementation Oversight Committee, which will be chaired by the Department of Health.

The role of the Committee will be to:

- Monitor the overall implementation of the policy and in particular, progress on the delivery of the individual actions (i.e., commitments) set out in the policy.
- Oversee and provide advice into the development of the Adult Palliative Care Policy Implementation Plan (that builds on this Policy Implementation Roadmap) by the Adult Palliative Care Policy Implementation Group and other partners.
- Establish sub-committees to support the implementation of relevant (non-HSE) policy recommendations.
- Oversee and monitor the work of the Adult Palliative Care Policy Implementation Group.
- Support and assist the Adult Palliative Care Policy Implementation Group in liaising with government departments and relevant agencies.
- Take account of policy developments in palliative care and universal healthcare, in Ireland and at European and international level.
- Address any high-level operational and cross-sectional challenges arising in the implementation of this policy, in consultation with HSE and other implementing bodies, and in accordance with the Policy Implementation Plan.
- Organise an independent evaluation on the implementation of the policy that includes in-itinere and ex-post components.

Figure 5: Proposed implementation structures.



▸ Adult Palliative Care Policy Implementation Group

It is proposed that implementation of this policy will be driven by the Adult Palliative Care Policy Implementation Group. The Implementation Group may establish sub-groups to support its work. Sub-groups may include members external to the Implementation Group but must include at least one member of the Group who will be responsible for reporting back to the Implementation Group.

The role of the Implementation Group will be to:

- Develop and operationalise an Adult Palliative Care Policy Implementation Plan which builds on the Implementation Roadmap presented in this policy. This should be submitted to the Palliative Care Policy Implementation Oversight Committee for review and a final version approved within 6 months of the launch of this policy.
- Ensure representation and involvement of all relevant interests in the development and operationalisation of the Adult Palliative Care Policy Implementation Plan.
- Provide clear direction and leadership on the delivery of the Adult Palliative Care Policy Implementation Plan.
- Monitor progress against plans and acting where required to address slippage.
- Act as champions of change within their organisations and communities.
- Resolve implementation issues and manage risks.
- Role model the desired cultural and behavioural change.
- Provide quarterly reports to the HSE Board and the Department of Health Adult Palliative Care Policy Implementation Oversight Committee, as well as early warning regarding potential obstacles in delivery of the Adult Palliative Care Policy Implementation Plan.

▸ Implementation Team

An Implementation Team will be established to support the work of the Adult Palliative Care Policy Implementation Group. Under the direction of the Chair of the Adult Palliative Care Policy Implementation Group, the team will enable and coordinate activities in support of the Palliative Care Policy Implementation Group and workstream leads. This team will also take the lead on a small number of specific projects where deemed appropriate by the Chair and Adult Palliative Care Policy Implementation Group.

The Implementation Team will work according to the implementation principles described above. The principle of subsidiarity will ensure that the team resource requirement at national level will be matched to the need for project management at national level, while implementation decisions and actions will be devolved wherever possible and appropriate to regional level.

Measurement and monitoring

Measuring and monitoring progress are key management functions carried out with the ultimate aim of improving outcomes for patients and their families. There is a need to significantly advance capability in these areas given that it is not currently possible to describe comprehensively how palliative care is being provided or experienced by those who receive it across Ireland. A limited number of metrics are embedded in routine clinical practice in specialist palliative care, but there are no measures recorded in general palliative care provision. There is therefore an urgent need to develop and enhance measures that can be embedded in routine care to support the design, delivery, monitoring, quality improvement and benchmarking of services, as well as supporting the monitoring of the results achieved or impact of this policy.

▸ Programme Results Framework

A Programme Results Framework (PRF) approach will be employed in monitoring of this policy. The development of a PRF is, and should be, an iterative process. This policy's preliminary PRF is comprised of the following key items: action goals, action objectives, expected outcomes and expected outputs. This preliminary Framework will be further refined by the Adult Palliative Care Policy Implementation Group, when established and submitted for approval to the Adult Palliative Care Policy Oversight Committee.

The PRF provides a coherent framework for planning and management based on learning and accountability in a decentralised environment. While it is a management tool first, it also has utility as a performance reporting system by offering a mechanism that identifies key results and that captures and integrates learning. The PRF will allow for 'real-time' monitoring of implementation and measurement of results associated with policy actions. As such, the PRF will provide a mechanism for monitoring implementation progress and the immediate to short-term impact of this policy.

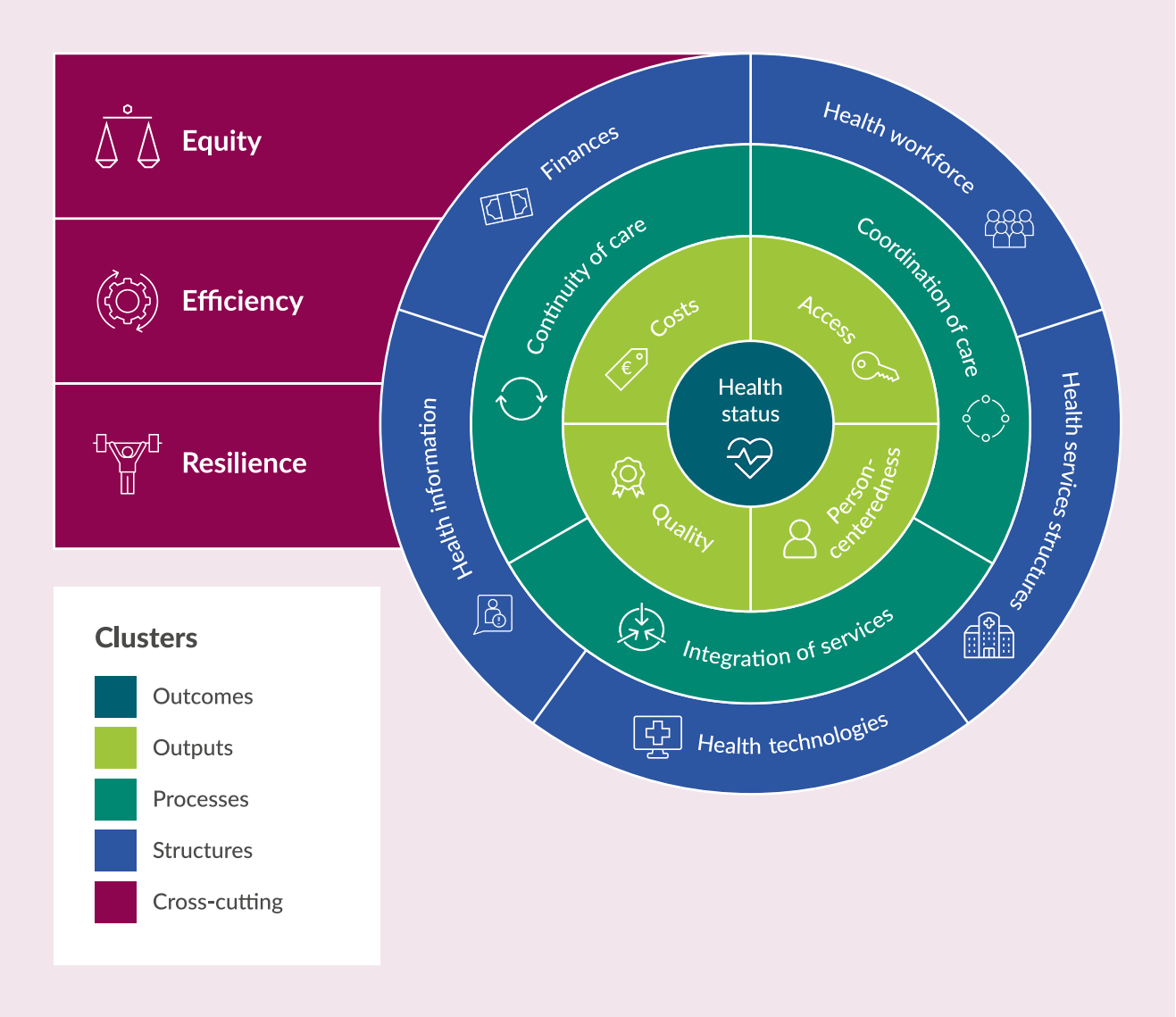
▸ Policy Indicator Framework

Higher level, medium to long-term impact of the policy will be monitored through the Policy Indicator Framework (Appendix 2) and existing performance, outcomes, and related delivery frameworks, including the Health Services Performance Assessment Framework (HSPA). The Policy Indicator Framework includes indicators related to each of the four strategic goals set out in this policy. As detailed in the policy recommendations and actions, the strengthening of palliative care data development, use and governance is a priority. Significant data gaps exist in specialist and general palliative care practice which must be addressed in order to have full understanding of palliative care provision and outcomes, and to be able to report on policy impacts. It is expected that over the lifetime of this policy, these gaps will be addressed in a phased manner. This represents a critical dependency for the capturing of the medium to long-term impact of this policy.

▸ Health System Performance Assessment Framework

The HSPA (Figure 6) has been established to measure, monitor, and report on achievements against the objectives of Sláintecare and broader policy and decision-making cycles. This will support a shift from the current system of planning and evaluation that relies primarily on activity-based metrics, towards a measurable and quantifiable outcome-based model strongly embedded in the policy making cycle which will monitor effective working of health sector performance, including policies and reform measures. The HSPA metrics provide a broad overview of how performance across national programmes and services are contributing to changes in population health and well-being, including palliative care. It is expected that some core measures related to palliative care provision will be included in the HSPA over the lifetime of this policy. Similarly, some of the existing metrics within the HSPA could be disaggregated to the service level for palliative care, to support the HSE with planning and priority setting across services delivery.

Figure 6: Health Services Performance Assessment Framework.[51]



51. Department of Health, "Developing a health system performance assessment framework in Ireland: Framework Overview" (Dublin, October 22, 2021), 3, https://www.gov.ie/pdf/?file=https://assets.gov.ie/202665/93bea91c-05ac-4764-8a13-79c1d8982171.pdf#page=null

Evaluation Strategy

Evaluation is an essential part of the policy cycle, making an important contribution to public governance and supporting evidence-based policy design and implementation.

While policy evaluation and monitoring are mutually reinforcing, evaluation more commonly adopts a 'whole picture' perspective; this involves external stakeholders and generates knowledge for the future by helping stakeholders understand what works, what does not and why.

The implementation of this policy will take place in a complex and adaptive environment, adding significantly to its challenges. **Process evaluation** will make an important contribution to the early stages of implementation by supporting learning and knowledge generation, as well as building trust and legitimacy across stakeholders. As implementation progresses, the focus of evaluation will shift to **examining whether the policy is having the desired impacts** or whether any unintended consequences are emerging.[52]

Key components of the evaluation strategy for this policy include:

- The Palliative Care Policy Implementation Oversight Committee will conduct an independent evaluation on the implementation of the policy that includes in-itinere and ex-post components through a competitive grant/tendering process. These evaluations will use both quantitative and qualitative data to assess implementation progress from the viewpoint of a range of stakeholders. The independent evaluation of the 2001 NACPC policy commissioned by the Department of Health to inform development of this policy will provide a baseline for these evaluations.
- Process evaluation will be utilised to document progress towards implementation (in-itinere). Process evaluation helps stakeholders identify how a policy outcome or impact was achieved. The approach provides additional information on the implementation process and how this might have impacted the outcomes, including: how different structures and resources were used; the role, participation, and viewpoint of different stakeholders; and contextual or external factors acting as either facilitators or barriers to implementation.
- The ex-post evaluation will be conducted five years after this policy is implemented. This analysis will draw on existing data, including the findings from the process evaluation, the Policy Indicator Framework, and the Programme Results Framework, and generate new data where required, to provide a rich insight into the policy's implementation and impact. The findings will be a valuable resource to inform future policy development.

52. HM Treasury, "Magenta Book 2020 Supplementary Guide: Handling complexity in policy evaluation" (ISBN 978-1-913635-23-7, London, March, 2020), 1-67, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/879437/Magenta_Book_supplementary_guide._Handling_Complexity_in_policy_evaluation.pdf

Appendix 1: Guiding Principles for Palliative Care

Report of the National Advisory Committee on Palliative Care (2001)[53]

- Palliative care is provided on the basis of needs, not diagnosis. It should be available early in the course of illness if needed, in conjunction with other therapies that are intended to support life.
- Healthcare professionals have a responsibility to ensure that patients are enabled and encouraged to express their preference about where they wish to be cared for, and where they wish to die and to engage in shared decision-making about their care.
- Palliative care should be provided in all care settings.
- Palliative care services should be sufficiently flexible and integrated as to allow movement of patients from one care setting to another, depending on their clinical situation and personal preferences.
- Statutory and voluntary organisations should work in partnership to provide palliative care.
- Palliative care is an important part of the work of most healthcare professionals, and all should have the skills, knowledge and confidence required.
- Palliative care services should be planned, integrated, and coordinated to meet population need, and have shared responsibility for education, training, and research.
- Primary healthcare providers in the community have a central role in and responsibility for the provision of palliative care and accessing specialist palliative care services when required.
- General practitioners (GPs) and Out of Hour GP Co Operatives have a central role as point of first contact for urgent care.
- Specialist palliative care services should be available to all people who need them, regardless of their disease, location, or income.
- All palliative care services should have clear governance structures and have an explicit commitment to quality and accountability.
- Specialist palliative care should be seen as complementing and not replacing the care provided by other healthcare professionals in hospital and community settings.
- Responding to loss, grief and bereavement is an intrinsic part of palliative care and should be incorporated into all specialist palliative care service provision.
- Specialist palliative care services should be delivered by interdisciplinary teams, in line with minimum core staffing requirements.
- Carers play a vital role in supporting the individual with a life-limiting illness. Their needs are assessed and practical, emotional, psychosocial, and spiritual supports, including into bereavement, are provided where needed.
- Communities have an important role in supporting individuals with a life-limiting illness and those important to them.
- The roles of volunteers in palliative care are many and varied and should be recognised and supported.

53. Department of Health and Children, "Report of the National Advisory Committee on Palliative Care" (2001).

Appendix 2: Indicators

▸ Overall progress

Degree to which universal palliative care has been achieved.

▸ Progress by strategic goal

Strategic Goal 1: **Right Care**	> Carers' view on quality of care at the end-of-life. > Carers reporting they felt involved in designing the care and support plan for the person that they care for. > Out-of-pocket spending on health, by type of services in last year of life.
Strategic Goal 2: **Right Place and Right Time**	> Trends in hospital death rates. > Place of death while in receipt of community palliative care services. > Percentage of time in the last six months of life spent at home or in a community setting.
Strategic Goal 3: **Right People**	> Professionals providing general palliative care per 1,000 population. > Specialist palliative care healthcare professionals per 1,000 population. > Palliative care worker job satisfaction. > Number and distribution of volunteers in palliative care.
Strategic Goal 4: **Good Governance**	> Proportion of services achieving a low rating in HIQA inspections that require intervention. > Share of specialist palliative care organisations with an integrated Clinical Management System. > Palliative care clinical academic workforce per 1,000 population.

Figure 7: Progress indicators

Goal - to deliver

1 Right Care

Recommendations

1. Provide holistic care that respects dignity and autonomy
2. Regularly assess needs and plan care
3. Recognise and support carers
4. Develop bereavement services
5. Develop compassionate communities
6. Ensure universal access
7. Provide financial protection

Indicators

Overall goal: Degree to which universal palliative care has been achieved

Progress by Strategic Objective

- Carers' view on quality of care at the end-of-life
- Carers reporting they felt involved in designing the care and support plan for the person that they care for
- Out-of-pocket spending on health, by type of services in last year of life

Universal Palliative Care

2 Right Place and Right Time

Recommendations

8. Plan and resource services according to population need
9. Define core palliative care services
10. Organise services to function as integrated networks
11. Improve public understanding of palliative care
12. Support people to be cared for in their preferred place of care for as long as possible
13. Improve out of hours and emergency palliative care supports

Indicators

Overall goal: Degree to which universal palliative care has been achieved

Progress by Strategic Objective

- Trends in hospital death rates
- Place of death while in receipt of community palliative care services
- Percentage of time in the last six months of life spent at home or in a community setting

Figure 7 (continued): Progress indicators

Goal - to deliver

3 Right People

Recommendations

14. Ensure availability of adequate numbers of appropriately trained staff working in interdisciplinary teams
15. Strengthen undergraduate palliative care education
16. Strengthen postgraduate palliative care education and training
17. Develop leadership capability
18. Develop palliative care workforce planning capability
19. Promote and support volunteering in palliative care

Indicators

Overall goal: Degree to which universal palliative care has been achieved

Progress by Strategic Objective

- Professionals providing general palliative care per 1,000 population
- Specialist palliative care healthcare professionals per 1,000 population
- Palliative care worker job satisfaction
- Number and distribution of volunteers in palliative care

Universal Palliative Care

4 Good Governance

Recommendations

20. Strengthen systems of governance
21. Develop a safety and quality operating framework
22. Strengthen palliative care information systems
23. Ensure medicines are accessible and are used safely and effectively
24. Regulate palliative care service provision
25. Develop and support research and innovation in palliative care

Indicators

Overall goal: Degree to which universal palliative care has been achieved

Progress by Strategic Objective

- Proportion of services achieving a low rating in HIQA inspections that require intervention
- Share of specialist palliative care organisations with an integrated Clinical Management System
- Palliative care clinical academic workforce per 1,000

Appendix 3:

Logic model: **Right Care**

The starting point and problem

The burden of serious health-related suffering is very significant and could in large part be relieved by palliative care. Palliative care is a core component of universal coverage and Sláintecare commits to the development of universal palliative care.

Right Care goal

- To relieve health-related suffering and to optimise the quality of life of those with a serious illness by providing universal palliative care that is person-centred, safe, and effective, and that is accessible to all those with a life-limiting illness without the risk of financial hardship.
- To maintain the well-being of families and carers and involve them as partners in care.
- To empower communities to be ready and able to help people in their journey through illness, death, and bereavement.

Inputs (Recommendations)	Processes (Activities)	Outputs
• Provision of a model of palliative care that is person-centred and optimises quality of life (Rec. 1) • Strengthening of information provision, shared decision-making, and care planning (Rec. 2) • Recognition of family & carers as partners in care provision (Rec. 3) • Provision of support to family & carers (Rec. 3) • Strengthening of bereavement services (Rec. 4) • Development of compassionate communities (Rec. 5) • Universal and equitable care provision (Rec. 6) • Ensuring financial protection (Rec. 7)	• Service design that embodies the principles of palliative care (Activity 1.1-1.10) • Implementation of needs assessment & care planning (Activity 2.1-2.5) • Support the implementation of the Assisted Decision-Making Act (2015) (Activity 2.3) • Development of training and supports for family caregivers (Activity 3.1-3.2) • Strengthening of psychosocial supports (Activity 4.1-4.2) • Bereavement service review, service planning & resourcing (Activity 4.1-4.2) • Strengthening communities (Activity 5.1-5.3) • Identifying inequity and meeting needs (Activity 6.1-6.6) • Strengthening financial protection for patients and carers (Activity 7.1-7.3)	• Comprehensive and accessible palliative, end-of-life, and bereavement care • Person-centred care • Care that optimises quality of life • Engaged and supportive communities

Medium and long-term outcomes

- Percentage of population accessing specialist palliative care.
- Percentage of population with a terminal illness medical card.
- Reduced financial hardship experienced by those with a life-limiting illness (out-of-pocket spending on health, by type of services in the last year of life).
- Improved quality of care at the end-of-life (proxy report).
- Improved carer health (report of self-perceived health).
- Carers reporting they felt involved in designing the care and support plan for the person that they care for.

Short-term outcomes

- Achievement of milestones and deliverables associated with Activities 1.1-7.3

Critical enablers

GP, primary and community care resourcing and engagement (Activity 14.4, 14.5, 16.3); ICT development including transfer of information (Activity 22.1 – 22.4); adequate and competent staffing (Recommendations 14-19 and all associated activities); development and implementation of an end-of-life care guideline and audit; development and implementation of cancer pain guideline; development and implementation of web-based symptom management resource (Activity 20.3, 20.4, 23.1, 23.2).

Logic model: **Right Place and Right Time**

The starting point and problem

- Many people who could benefit from palliative care do not receive such support, or access services late in their illness trajectory.
- Services are planned and funded to a large extent based on historical arrangements rather than reflecting population need. Care is often disjointed and fragmented.

Right Place and Right Time goal

- To plan, resource and provide services so that people can access high-quality palliative care, when and where they need it.
- To develop and support integrated palliative care provision.
- Improve knowledge about the nature and availability of services among healthcare professionals and the public.

Inputs (Policy Recommendations)	Processes (Activities)	Outputs
• Services that are provided on the basis of population-based planning (Rec. 8) • Services that are resourced according to population-based funding (Rec. 9) • Integrated networks of palliative care services (Rec. 10) • Raising public awareness & understanding of palliative care & services (Rec. 11) • Services that support provision of care in the patient's preferred place of care whenever possible (Rec. 12) • Provision of out-of-hours care (Rec. 13)	• Organisation of services into regional networks (Activity 8.1) • Population-based information to inform service planning (Activity 8.2) • Utilisation of population-based information to inform funding (Activity 9.1) • Strengthening of infrastructure (Activity 9.2-9.4) • Integrated palliative care networks (Activity 10.1-10.4) • Promote public understanding & awareness (Activity 11.1) • Signposting & provision of information (Activity 12.1) • Strengthening of night support services (Activity 12.2-12.4) • Review of urgent & out-of-hour service provision (Activity 13.1-13.4)	• Services that are available and accessible • Resources that are equitably distributed • Integrated networks of general and specialist providers • People remaining in their preferred place of care whenever possible • Information on local palliative care provision accessible to the public and healthcare professionals • Health and Wellbeing Plan

Medium and long-term outcomes

- Percentage of time in the last six months of life spent at home or in a community setting.
- Trends in hospital death rates.
- Place of death while in receipt of community palliative care services.
- Total specialist palliative care beds per 1,000 population.
- Unmet need for SPC services due to waiting lists.

Short-term outcomes (to be evaluated between ...)

- Achievement of milestones and deliverables associated with Activities 8.1-13.4

Critical enablers

GP, primary and community care resourcing and engagement (Activity 14.4, 14.5; 16.3); health information system development including transfer of information (Activity 22.3, 22.4); adequate and competent staffing (Recommendations 14-19 and all associated activities); development and implementation of end-of-life care guideline and audit; development and implementation of cancer pain guideline; development and implementation of web-based symptom management resource (Activity 20.3, 20.4, 23.1, 23.2); research on methods (Activity 25.3)

Logic model: **Right People**

The starting point and problem

The move towards integrated, person-centred care can only happen if the power of people – workforce, volunteers, and community – is harnessed through new ways of working, open approaches, and social innovation. In order to ensure the achievement of universal palliative care, having the 'right people' means supporting the ongoing development of an appropriately resourced, accountable workforce who are skilled in palliative care practice and who are supported and valued.

Right People goal

- To support the development of an appropriately resourced, accountable workforce who are skilled in palliative care provision and who are supported and valued.
- To further develop and enhance the role of volunteers and encourage volunteering as a means of developing engaged and supportive communities.

Inputs (Recommendations)	Processes (Activities)	Outputs
• Appropriate staffing (Rec. 14) • Undergraduate education (Rec. 15) • Continuing professional development (Rec. 16) • Leadership capacity (Rec. 17) • Workforce planning (Rec 18) • Volunteering (Rec. 19)	• Supporting interdisciplinary team working through appropriate staffing and role development (Activity 14.1-14.6) • Strengthening palliative care education in undergraduate education (Activity 15.1-15.5) • Development of palliative care education infrastructure and systems (Activity 16.1-16.4) • Embedding leadership (Activity 17.1-17.4) • Strengthening workforce planning (Activity 18.1-18.6) • Strengthening volunteering (Activity 19.1-19.5)	• Equitable workforce distribution • Healthcare professional graduates who are competent in palliative care • Volunteer networks • Diverse volunteering community

Medium and long-term outcomes

- Proportion of medical and nursing schools with palliative care formal education in undergraduate curricula.
- Health worker job satisfaction.
- Health worker absenteeism rates in SPC services.
- Number and distribution of volunteers.
- Density of recent graduates from: a) ICGP certificate in Palliative Care; b) Postgraduate degrees in Palliative Care; c) Higher Specialist Training in Palliative Medicine.
- General PC workers per 1,000: a) GPs; b) PHNs; c) Nursing Home IHF liaison.
- SPC health workers per 1,000: a) SPC consultants; b) CNSs; c) HSCPs & HCAs.

Short-term outcomes (to be evaluated between ...)

- Achievement of milestones and deliverables associated with Activities 14.1 – 19.5

Critical enablers

Development of research and innovation infrastructure (25.1-25.6) Health information system development including data generation and analysis (22.1-22.4); Integrated network (10.1-10.4); Demand and capacity analyses (4.1, 4.2).

Logic model: **Good Governance**

The starting point and problem

- Governance involves having the necessary structures, processes, standards and oversight in place to ensure that safe, person-centred and effective services are delivered. Governance requires ongoing attention to ensure that systems are strengthened and excellence in patient and family outcomes is achieved.
- Research and innovation are vital in providing new knowledge and ways of working.

Right governance goal

- To deliver universal palliative care.
- To provide safe, effective, and person-centred care.
- To generate new knowledge and ways of working in order to improve patient and family care and to support staff well-being.
- To improve patient outcomes.

Inputs (Recommendations)	Processes (Activities)	Outputs
• Strengthening governance (Rec. 20) • Patient safety & quality operating framework (Rec. 21) • Implementation of effective information systems (Rec. 22) • Safe & rational use of medicines (Rec. 23) • Strengthened accountability (Rec. 24) • Development of research & innovation capability & capacity (Rec. 25)	• Governance & systems (Activity 20.1-20.6) • Clinical Directors; QI (Activity 20.1-20.2) • Quality and Safety operating framework (Activity 21.1-21.2) • Information systems (Activity 22.1-22.4) • Medicines & technologies (Activity 23.1-23.4) • Monitoring by HIQA (Activity 24.1-24.2) • Development of a strong and supportive environment for palliative care research (Activity 25.1) • Establishment of IRIN-PC (Activity 25.2) • KTE for research & innovation (Activity 25.3) • Development of specialist palliative care Education and Research Centres in partnership with universities and healthcare organisations (Activity 25.4) • Development of clinical academic posts (Activity 25.5) • PC research & innovation review (Activity 25.6)	• Safe, effective & person-centred services • Timely, safe access to medicines • Patient safety & quality framework • Quality improvement collaboratives • CMS-SPC • Palliative Care Clinical Academic Directorates • IRIN-PC • Researchers • Publications

Medium and long-term outcomes

- Proportion of services achieving a low rating in HIQA inspections that require intervention.
- Organisations with net expenditure variance from plan (pay + non-pay- income) <0.1%
- Share of SPC organisations/services with a CMS-SPC in place
- Palliative care research completed in the country estimated by peer reviewed articles.
- Proportion of staff reporting good/excellent patient safety culture in their service.
- Implementation of national guidelines on pain management and end-of-life care.
- Proportion of SPC services with Clinical Directors in place.

Short-term outcomes (to be evaluated between ...)

- Achievement of milestones and deliverables associated with Activities 20.1 – 25.6.
- Rate of medication incidents as reported to NIMS that were classified as major or extreme.
- The percentage of slip, trip or fall incidents as reported to NIMS that were classified as major or extreme.

Critical enablers

Development of leadership capability (Activity 17.1 – 17.4); integrated governance through establishment of Palliative Care Fora (Activity 10.1, 10.2); staff with sufficient skills and training to analyse, interpret, disseminate, and utilise palliative care data (Activity 18.6).

Appendix 4: Workforce Planning Estimates

The following tables on workforce contain disaggregated detail for clarity. Data were provided by service providers to the National Office of Palliative Care in a survey conducted in August 2022.

Table 5: Community palliative care staffing (2022-2029)

Note: figures in the tables are rounded to the nearest decimal place and may result in some slight differences between the actual and recommended figures.

Area / Unit Min. = Minimum Rqd. = Required Diff. = Difference	CNS (1:25,000)			Physio (1:125,000)		
	Min.	Actual	Rqd.	Min.	Actual	Rqd.
CHO 1	15.7	19.2	-3.5	3.1	1.0	2.1
CHO 2	18.1	29.2	-11.1	3.6	0.0	3.6
CHO 3	15.4	23.6	-8.2	3.1	2.0	1.1
CHO 4	27.6	33.2	-5.6	5.5	0.3	5.3
CHO 5	20.4	22.7	-2.3	4.1	1.0	3.1
CHO 6	15.3	15.7	-0.3	3.1	0.3	2.8
CHO 7	28.3	29.4	-1.1	5.7	0.0	5.7
CHO 8	24.8	32.8	-8.0	5.0	4.8	0.2
CHO 9	24.9	21.4	3.5	5.0	1.0	4.0
Totals (2016)	**190.5**	**227.1**	**-36.7**	**38.1**	**10.3**	**27.8**
West Regional deficits	-	-	**9.9**	-	-	**27.9**
2022 Population	**204.0**	**227.1**	**10.6**	**40.8**	**10.3**	**30.6**
2029	**224.7**	**227.1**	**-2.5**	**42.8**	**10.3**	**32.5**

Note: *West Regional deficits are calculated based on teams deficits.

OT (1:125,000)			MSW (1:125,000)			CNM			Psychology (0.25 WTE: 100,000)		
Min.	Actual	Rqd.	Min.	Actual	Rqd.	Min.	Actual	Diff.	Min	Actual	Diff.
3.1	1.2	**1.9**	3.1	2.8	**0.3**	-	3.0	-	1.0	0	**1.0**
3.6	0.0	**3.6**	3.6	3.2	**0.4**	-	1.7	-	1.1	0	**1.1**
3.1	1.0	**2.1**	3.1	1.0	**2.1**	-	7.0	-	1.0	0	**1.0**
5.5	0.3	**5.3**	5.5	1.4	**4.2**	-	1.0	-	1.7	0	**1.7**
4.1	4.0	**0.1**	4.1	1.0	**3.1**	-	4.5	-	1.3	0	**1.3**
3.1	0.3	**2.8**	3.1	1.7	**1.4**	-	3.8	-	1.0	0	**1.0**
5.7	0.0	**5.7**	5.7	2.0	**3.7**	-	4.0	-	1.8	0	**1.8**
5.0	3.5	**1.5**	5.0	8.0	-3.0	-	6.0	-	1.5	0	**1.5**
5.0	0.7	**4.3**	5.0	4.5	**0.5**	-	4.5	-	1.6	0	**1.6**
38.1	**11.0**	**27.1**	**38.1**	**25.5**	**12.6**	**-**	**35.5**	**-**	**11.9**	**0**	**11.9**
-	-	**28.2**	-	-	**17.5**	-	-	-	-	-	-
40.8	**11.0**	**30.9**	**40.8**	**25.5**	**20.2**	**-**	**-**	**-**	**12.8**	**0.0**	**12.8**
42.8	**11.0**	**31.8**	**42.8**	**25.5**	**17.3**	**-**	**-**	**-**	**13.4**	**0.0**	**13.4**

Table 6: Specialist palliative care inpatient unit staffing (2022-2029)

Area / Unit	RGN (1.0 WTE: BED)			PHYSIO (1.0 WTE: 10 BEDS)		
Min. = Minimum *Rqd. = Required*	Min.	Actual	Rqd.	Min.	Actual	Rqd.
Donegal Hospice	8	14.0	-6.0	0.8	0.2	0.6
North West Hospice	8	11.4	-3.4	0.8	0.5	0.3
Galway Hospice	18	20.0	-2.0	1.8	1.6	0.2
Mayo Hospice	14	14.0	0.0	1.4	1.0	0.4
Milford Care Centre	30	34.0	-4.0	3	2.5	0.5
Marymount Hospice	44	51.7	-7.7	4.4	5.0	-0.6
Kerry SPC inpatient unit	15	18.5	-3.5	1.5	1.0	0.5
South East Palliative Care Centre (SEPCC)	20	20.8	-0.8	2	1.0	1.0
Our Lady's Hospice Blackrock	12	11.7	0.4	1.2	1.2	0.0
Our Lady's Hospice Wicklow	15	15.4	-0.4	1.5	0.6	0.9
Our Lady's Hospice Harold's Cross	36	33.8	2.2	3.6	3.0	0.6
St. Brigid's Hospice, Kildare	13	13.0	0.0	1.3	1.0	0.3
St. Francis Hospice Blanchardstown	24	27.4	-3.4	2.4	1.0	1.4
St. Francis Hospice Raheny	19	22.0	-3.0	1.9	1.0	0.9
Current totals	**276**	**307.6**	**-31.6**	**27.6**	**20.6**	**7.0**
Regional deficits	**-**	**-**	**2.6**	**-**	**-**	**7.1**
Additional beds and new build totals	**83**	**0**	**83**	**8.9**	**0**	**8.9**

OT (1.0 WTE: BEDS)			MSW (1.0 WTE: BEDS)			PHARMACIST (1 WTE per IPU)			SLT (0.5 WTE: BEDS)		
Min.	Actual	Rqd.	Min.	Actual	Rqd.	Min.	Actual	Rqd.	Min.	Actual	Rqd.
0.8	0.8	0.0	0.8	1.0	-0.2	1	0.6	0.4	0.40	0	0.4
0.8	0.5	0.3	0.8	1.0	-0.2	1	0.0	1.0	0.40	0	0.4
1.8	1.6	0.2	1.8	3.9	-2.1	1	1.4	-0.4	0.90	0	0.9
1.4	1	0.4	1.4	1.7	-0.3	1	0.8	0.2	0.70	0	0.7
3	5.1	-2.1	3	5.2	-2.2	1	1.9	-0.9	1.50	0.7	0.8
4.4	2	2.4	4.4	4.8	-0.4	1	3.3	-2.3	2.20	1	1.2
1.5	1	0.5	1.5	0.5	1.0	1	0.8	0.2	0.75	0.3	0.5
2	1	1.0	2	1.0	1.0	1	1.0	0.0	1.00	0.5	0.5
1.2	1.22	0.0	1.2	0.6	0.6	1	0.5	0.5	0.60	0.5	0.1
1.5	0.71	0.8	1.5	1.1	0.4	1	0.5	0.5	0.75	0.51	0.2
3.6	3	0.6	3.6	2.7	1.0	1	2.0	-1.0	1.80	1	0.8
1.3	1	0.3	1.3	1.0	0.3	1	0.8	0.2	0.65	0.5	0.2
2.4	2	0.4	2.4	2.0	0.4	1	1.3	-0.3	1.20	0	1.2
1.9	1	0.9	1.9	0.9	1.0	1	1.1	-0.1	0.95	0	1.0
27.6	**21.9**	**5.7**	**27.6**	**27.3**	**0.3**	**14**	**16.1**	**-2.1**	**13.8**	**5.0**	**8.8**
-	-	**7.8**	-	-	**5.6**	-	-	**3.0**	-	-	**8.8**
8.9	**0**	**8.9**	**8.9**	**0**	**8.9**	**6**	**0**	**6**	**4.5**	**0**	**4.5**

Table 6: Specialist palliative care inpatient unit staffing (2022-2029).

Area / Unit	Dietician (0.5 WTE: 10 BEDS)			Pastoral Care (2 WTE per IPU)		
Min. = Minimum Rqd. = Required	Min.	Actual	Rqd.	Min.	Actual	Rqd.
Donegal Hospice	0.4	0.0	0.4	2	0.0	2.0
North West Hospice	0.4	0.0	0.4	2	0.0	2.0
Galway Hospice	0.9	0.0	0.9	2	1.0	1.0
Mayo Hospice	0.7	0.0	0.7	2	1.0	1.0
Milford Care Centre	1.5	1.0	0.5	2	3.0	-1.0
Marymount Hospice	2.2	1.0	1.2	2	3.8	-1.8
Kerry SPC inpatient unit	0.8	0.3	0.5	2	0.8	1.3
South East Palliative Care Centre (SEPCC)	1.0	0.5	0.5	2	1.0	1.0
Our Lady's Hospice Blackrock	0.6	0.5	0.1	2	0.0	2.0
Our Lady's Hospice Wicklow	0.8	0.0	0.8	2	0.0	2.0
Our Lady's Hospice Harold's Cross	1.8	1.2	0.6	2	1.0	1.0
St. Brigid's Hospice, Kildare	0.7	0.5	0.2	2	1.0	1.0
St. Francis Hospice Blanchardstown	1.2	0.0	1.2	2	1.5	0.5
St. Francis Hospice Raheny	1.0	0.0	1.0	2	1.8	0.2
Current totals	**13.8**	**5.0**	**8.8**	**28**	**15.9**	**12.2**
Regional deficits	**-**	**-**	**8.8**	**-**	**-**	**15.0**
Additional beds and new build totals	**4.5**	**0**	**4.5**	**6**	**0**	**6**

Psychology (0.2 WTE: 6.7 BEDS)			HCAs (0.5 WTE: BED)			Bereavement Co-Ordinator (1 WTE: PER IPU)			Pharmacy Technician (0.5 WTE: 10 BEDS)			Beds
Min.	Actual	Rqd.	Min.	Actual	Rqd.	Min.	Actual	Rqd.	Min.	Actual	Rqd.	No.
0.2	0	0.2	4.0	5.0	-1.0	1.0	0.0	1.0	0.4	0.0	0.4	8
0.2	0	0.2	4.0	6.1	-2.1	1.0	0.0	1.0	0.4	0.0	0.4	8
0.5	0	0.5	9.0	12.0	-3.0	1.0	0.0	1.0	0.9	0.5	0.4	18
0.4	0	0.4	7.0	10.0	-3.0	1.0	0.0	1.0	0.7	0.0	0.7	14
0.9	0	0.9	15.0	18.8	-3.8	1.0	0.0	1.0	1.5	0.6	0.9	30
1.3	0	1.3	22.0	20.5	1.5	1.0	0.0	1.0	2.2	0.0	2.2	44
0.4	0	0.4	7.5	10.0	-2.5	1.0	0.0	1.0	0.8	0.0	0.8	15
0.6	0	0.6	10.0	0.0	10.0	1.0	0.0	1.0	1.0	1.0	0.0	20
0.4	0.5	-0.2	6.0	7.1	-1.1	1.0	0.0	1.0	0.6	0.5	0.1	12
0.4	0	0.4	7.5	8.3	-0.8	1.0	0.0	1.0	0.8	0.0	0.8	15
1.1	0.4	0.7	18.0	16.2	1.8	1.0	0.0	1.0	1.8	1.0	0.8	36
0.4	0	0.4	6.5	7.5	-1.0	1.0	0.0	1.0	0.7	0.0	0.7	13
0.7	0	0.7	12.0	14.9	-2.9	1.0	0.0	1.0	1.2	0.0	1.2	24
0.6	0	0.6	9.5	10.8	-1.3	1.0	0.0	1.0	1.0	0.0	1.0	19
8.2	**0.9**	**7.3**	**138.0**	**147.2**	**-9.2**	**14.0**	**0.0**	**14.0**	**13.8**	**3.6**	**10.2**	**276**
-	-	**7.5**	-	-	**13.3**	-	-	**14.0**	-	-	**10.2**	-
2.7	**0.0**	**2.7**	**44.5**	**0.0**	**44.5**	**3.0**	**0.0**	**3.0**	**4.5**	**0.0**	**4.5**	**89**

Table 7: Current workforce requirements and future projections (2022-2029)

	Current (6-11/22 workforce census; 2022 pop. census)					Future (2029)		
	Census	CPC deficit	IPU deficit	Acutes deficit	Total deficit	Pop growth (cpc)	New beds	Total new WTE
CNS	295.9	10.6	0.0	5.3	16.0	-2.5	0.0	13.5
OT	33.4	30.9	7.8	8.0	46.7	2.0	8.9	57.6
Physio	32.0	31.6	7.1	8.5	47.2	2.0	8.9	58.1
MSW	60.8	20.2	5.6	18.0	43.8	2.0	8.9	54.7
RGN (Staff nurse)	310.4	0.0	2.6	0.0	2.6	0.0	83.0	85.6
Pharmacist	16.1	0.0	3.0	0.0	3.0	0.0	6.0	9.0
SLT	5.0	0.0	8.8	0.0	8.8	0.0	4.5	13.2
Dietician	5.0	0.0	8.8	0.0	8.8	0.0	4.5	13.3
Pastoral Care	15.9	0.0	15.0	0.0	15.0	0.0	6.0	21.0
Psychology	0.9	12.8	7.5	0.0	20.2	0.6	2.7	23.5
ANP	7.8		21.3		21.3	2.9		24.2
HCA	147.2	0.0	13.3	0.0	13.3	0.0	44.5	57.8
Bereavement Coordinator	0.0	0.0	14.0	0.0	14.0	0.0	3.0	17.0
Pharm Tech	3.6	0.0	10.2	0.0	10.2	0.0	4.5	14.7
Consultants	-	-	-	-	-	51.0		51.0

Staffing data provided by HSE's Office of the National Lead for Palliative Care (Census July 2022).

Table 8: Sources used for estimating workforce requirements.

Type	CPC	SPC IPU	Acute Hospitals	Source
CNS	1 WTE per 25,000	Not applicable	1 WTE per 250 beds	1) NACPC report; 2) NACPC report
OT	1 WTE per 125,000	1 WTE per 10 beds	0.25 WTE in Model 3 and 0.50 WTE in Model 4	1) NACPC report; 2) NACPC report; 3) NICE guidance for cancer centres
Physio	1 WTE per 125,000	1 WTE per 10 beds	0.25 WTE in Model 3 and 0.50 WTE in Model 4	1) NACPC report; 2) NACPC report; 3) NICE guidance for cancer centres
MSW	1 WTE per 125,000	1 WTE per 10 beds	1 WTE in Model 3 and Model 4	1) NACPC report; 2) NACPC report; 3) NACPC report
RGN	Not applicable	1 WTE per bed	Not applicable	1) NACPC report
Pharmacist	Not applicable	1 WTE per unit	Not applicable	1) NACPC report
SLT	Not applicable	0.5 WTE per 10 beds	Not applicable	1) New build allocations
Dietician	Not applicable	0.5 WTE per 10 beds	Not applicable	1) New build allocations
Pastoral Care	Not applicable	TBD	Not applicable	TBD
Psychology	0.25 WTE per 100,000	0.2 WTE per 6.7 beds	Not applicable	1) Palliative Care Service Development Guidelines 2018 (Australia)
ANP	3% of nursing workforce across CPC, IPU and acutes			CNO Office, DoH (Department of Health)

Appendix 5: Steering Group Membership and Terms of Reference

Professor Karen Ryan (Chair)	UCD Clinical Professor and Consultant in Palliative Medicine, Mater Hospital, and St. Francis Hospice Dublin.
Ms. Karen Charnley	CEO, All Ireland Institute of Hospice and Palliative Care.
Dr. Eibhlín Connolly	Deputy Chief Medical Officer, Department of Health.
Mr. Maurice Dillon	National Lead for Palliative Care Operations Planning, HSE.
Mr. Fintan Fagan	CEO, St. Francis Hospice Dublin.
Ms. Mary Flanagan	Director of Nursing, Our Lady's Hospice and Care Services; Member of the Irish Association of Directors of Nursing and Midwifery (IADNAM).
Ms. Sharon Foley (to June 2022)	CEO, Irish Hospice Foundation.
Ms. Siobhan Murphy (from July 2022)	Director of Healthcare, Irish Hospice Foundation.
Ms. Terry Hanan	Cancer Control Programme, HSE.
Mr. Brendan Kennelly	Member of Voices 4 Care.
Ms. Margaret McMahon	Physiotherapist Manager, Our Lady's Hospice and Care services; member of the working group of the National Clinical Programme for Palliative Care.
Dr. Siobhán Ní Bhriain	National Lead of the Integrated Care Programme, HSE.
Dr. Brendan O'Shea	General Practitioner and member of the Irish College of General Practitioners.
Ms. Marian O'Mahony	Member of Voices 4 Care.
Ms. Michelle Quinn	Nursing Project Officer in the Chief Nursing Office, Department of Health.
Mr. Paul Rowe	Principal Officer of Older Persons Strategy Unit, Department of Health.
Ms. Sarah Treleaven	Principal Officer of the Sláintecare Citizen Care Masterplan, Department of Health.
Dr. Feargal Twomey	Consultant in Palliative Medicine, Milford Hospice and University Hospital Limerick; National Clinical Lead for Palliative Care.

The terms of reference of the steering group are as follows:

1. Develop a draft adult palliative care policy for the approval of the Minister for Health which will set out a vision and implementation plan for delivery of palliative care and end-of-life care in Ireland.

2. Having regard to Sláintecare and the National Clinical Programme's Model of Adult Palliative Care, consider how best to improve access and address gaps in generalist and specialist palliative care to ensure patients and their families receive the right care at the right time in the right place.

3. Agree appropriate outcome measures and key performance indicators to assess the future effectiveness of the revised policy.

4. Agree a timebound, task orientated action plan of key priorities, milestones, associated costs, and owners.

5. Agree and detail structures to ensure implementation of the new policy including arrangements for review and evaluation.

6. Reflect best available evidence and incorporate the relevant learnings from the:

    - Department of Health public consultation on the update of the adult palliative care policy

    - External review of the implementation of recommendations of the 2001 policy

    - HRB International Evidence Brief of palliative care policy in four high performing jurisdictions.

Appendix 6: Secretariat to the Steering Group

The secretariat to the Adult Palliative Care Policy Steering Group was provided by the following officials from the Older Persons' Strategy Unit of the Department of Health:

Deirdre King-De Montano, Project Manager
Rory Egan, Assistant Principal Officer
Aisling McGrath, Administrative Officer
Caoimhe Doyle, Administrative Officer

Appendix 7:
Research and Technical Support

Academic support was provided to the Steering Group and Secretariat by Dr. Bridget Johnston, Research Assistant Professor, Trinity College Dublin.

Abbreviations

CHO	Community Healthcare Organisations
CPD	Continuing Professional Development
ECC	Enhanced Community Care
ED	Education
GPC	General Palliative Care
HIS	Health Information System
HIQA	Health Information and Quality Authority
HRB	Health Research Board
HSE	Health Service Executive
HSPA	Health System Performance Assessment
ICPOP	Integrated Care Programme for Older Persons
IHF	Irish Hospice Foundation
MDS	Minimum Data Set
NACPC	National Advisory Committee on Palliative Care
NICE	National Institute for Health and Care Excellence
PCRN	Palliative Care Research Network
POSTGRAD	Postgraduate
OECD	The Organisation for Economic Co-operation and Development
PBRA	Population-Based Resource Allocation
SPC	Specialist Palliative Care
WHO	World Health Organisation

Glossary of Terms

A

Advance Care Planning

Advance care planning is a process of discussion and reflections about a person's goals, values and preferences for future treatments that they would wish or would not wish to receive in the context of an anticipated deterioration in their health.

Advance Healthcare Directive

An Advance Healthcare Directive (AHD) is a document which sets out your instructions in relation to the healthcare treatments you wish to refuse, or would like to request, in the future, if and when you no longer have the decision-making capacity to do so, or to communicate your preferences to others.

B

Bereavement[54]

Bereavement is the period of grief after death.

C

Carer[55]

A carer is someone who is providing an ongoing significant level of care to a person who is in need of that care in the home due to illness, disability or frailty.

Children's Palliative Care[56]

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition throughout the child's life, death and beyond. It embraces physical, emotional, social, and spiritual elements and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

Complex Palliative Care Problems[57]

Complex palliative care problems are defined as those that are severe and intractable, involving a combination of difficulties in controlling physical and/or psychological symptoms, the presence of family distress and social and/or spiritual problems. They exceed the resources of the generalist palliative care provider to meet the needs and expectations of the patient/carer/family.

E

eHealth[58]

A term that denotes the use of information technology (IT) in healthcare, including the maintenance of electronic records and telemedicine.

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54. Health Service Executive, "Coping with grief after bereavement or loss," Hse.ie, September 1, 2022, https://www2.hse.ie/mental-health/life-situations-events/bereavement/coping-with-grief/.
55. Department of Health, "National Carers' Strategy'" (Ireland, July 19, 2012), 1-29, https://www.gov.ie/en/publication/a1e44e-national-carers-strategy/.
56. Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT) and the Royal College of Paediatrics and Child Heath (RCPCH), "A framework for the development of integrated multiagency care pathways for children with life-threatening and life-limiting conditions" (ISBN 1-898447-07-1, Bristol UK, December 1, 2004), 1-32, https://www.choiceforum.org/docs/actpathway.pdf
57. National Institute for Clinical Excellence, "Guidance on Cancer Services, Improving Supportive and Palliative Care for Adults with Cancer, The Manual" (ISBN: 1-84257-579-1, London, March 24, 2004), 1-209, https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005.
58. Johnston et al., Review of the Implementation of the 2001 Report of the National Advisory Committee on Palliative Care.

End of Life Care[59]

End of life care is a continuum of palliative care and is usually used to describe the care that is offered during the period when death is imminent, and life expectancy is limited to a short number of days, hours or less.

Equity[60]

Equity means ensuring fairness so that everyone can access the health services they need. It is defined as the absence of unfair and avoidable or remediable differences in health among population groups defined socially, economically, demographically, or geographically.

F

Family[61]

In the context of palliative care, the family is defined as any person who is significant to the patient.

Financial Protection[62]

Financial protection is at the core of universal health coverage (UHC) and one of the final coverage goals. Financial protection is achieved when direct payments made to obtain health services do not expose people to financial hardship and do not threaten living standards.

G

General Palliative Care[63]

Care provided by health and social care professionals who, although not engaged full time in palliative care, apply the principles of palliative care in the course of their work. Some health and social care professionals providing general palliative care will have additional training/ education and experience in palliative care.

General Palliative Care Providers

General palliative care providers refer to all those services, health, and social care providers who have a primary or 'first contact' relationship with the person with a life-limiting illness and palliative care needs. The use of the term 'generalist' in this context refers to general practitioners, primary care team members and staff of residential care services. It also includes other specialist services and clinical staff of emergency departments and acute care hospitals.

H

Health information systems

Health information systems (HIS) are the systems and technology used across the health system to collect, collate, store, and analyse medical and health utilisation data.

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59. Health Service Executive, "Palliative Care Programme, Clinical Strategy and Programmes Directorate, Glossary of Terms" (Ireland, May, 2012), 3-4.

60. World Health Organisation Commission on Social Determinants of Health, "Closing the gap in a generation: health equity through action on the social determinants of health: Commission on Social Determinants of Health final report" (WHO/IER/CSDH/08.1, Geneva, November 8, 2008), 1-40, https://www.who.int/publications/i/item/WHO-IER-CSDH-08.1

61. Department of Health and Children, "Report of the National Advisory Committee on Palliative Care" (2001).

62. World Health Organisation, "WHO Health Topics Financial Protection," WHO.int, Accessed January 9, 2024, https://www.who.int/health-topics/financial-protection#tab=tab_1

63. Health Service Executive, "Palliative Care Programme, Clinical Strategy and Programmes Directorate, Glossary of Terms" (2012)

Hospice care[64]

Hospice care is a term that may be used to describe both a place of care and a philosophy of care, which may be applied in a wide range of care settings.

I

Inequities[65]

Health inequities are differences in health status or in the distribution of health resources between different population groups, arising from the social conditions in which people are born, grow, live, work and age.

L

Life-limiting Illness[66]

Life-limiting illness means a condition, illness or disease that is progressive and cannot be cured.

M

Most Responsible Physician[67]

The physician who has final responsibility and is accountable for the medical care of a patient.

P

Palliative Care[68]

Palliative care is an approach that improves the quality of life of persons and their families facing the problems associated with a 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 Approach[69]

The palliative care approach aims to promote both physical and psychosocial wellbeing. It is a vital and integral part of all clinical practice, whatever the illness or its stage, informed by a knowledge and practice of palliative care principles.

Palliative Care Competence Framework[70]

The palliative care competence framework is a HSE document that describes competences required of healthcare professionals who provide care to people with life-limiting conditions.

Palliative Medicine[71]

Palliative medicine is the appropriate medical care of persons with active, progressive, and advanced disease, for whom the prognosis is limited, and the focus of care is the quality of life. Palliative medicine includes consideration of the family's needs before and after the patient's death.

64. Health Service Executive, "Palliative Care Programme, Clinical Strategy and Programmes Directorate, Glossary of Terms" (2012)
65. World Health Organisation, "Health inequities and their causes," WHO.int, February 22, 2018, https://www.who.int/news-room/facts-in-pictures/detail/health-inequities-and-their-causes
66. Citizens Information, "Palliative care," Citizensinformation.ie, May 12, 2021, https://www.citizensinformation.ie/en/health/health-services/cancer-services/palliative-care/
67. College of Physicians and Surgeons of Ontario, "Professional Responsibilities in Postgraduate Medical Education," College of Physicians and Surgeons of Ontario, Accessed January 9, 2024, https://healthsci.queensu.ca/source/Professional%20Responsibilities%20in%20Undergraduate%20Medical%20Education%20-%20CPSO.pdf
68. World Health Organisation, "Palliative care fact sheet," WHO.int, June 1, 2023, https://www.who.int/europe/news-room/fact-sheets/item/palliative-care
69. National Council for Hospice and Specialist Palliative Care Services, *Specialist Palliative Care: A Statement of Definitions* (London: National Council for Hospice and Specialist Palliative Care Services, 1995).
70. Palliative Care Competence Framework Steering Group, "Palliative Care Competence Framework".
71. National Council for Hospice and *Specialist Palliative Care Services*, *Specialist Palliative Care: A Statement of Definitions (1995).*

Palliative Care Rehabilitation[72]

Palliative rehabilitation attempts to maximise a patient's ability to function, to promote their independence and to help them adapt to their condition.

Palliative Care Support Beds[73]

Terms such as 'Level 2 beds' and 'intermediate palliative care beds' have been used as synonyms for palliative care support beds. It is recommended that the term 'palliative care support beds' replace all other descriptors.

Programme Results Framework

A Programme Results Framework (PRF) is a management tool used to improve the design of the projects under a programme and promote cohesiveness among the projects themselves. It facilitates implementation planning, execution, and evaluation. The development of a Results Framework is, and should be, an iterative process.

Q

Quality information[74]

Quality information may be understood as information that is accurate, valid, reliable, timely, relevant, and complete.

R

Resilience[75]

Resilience is the ability of a system, community, or society to resist, absorb, accommodate to, and recover from the effects of a hazard in a timely and efficient manner. For health systems this can be defined as 'the ability of all actors and functions related to health, to collectively mitigate, prepare for, respond to and recover from disruptive events with public health implications, while maintaining the provision of essential functions and services, and using experiences to adapt and transform the system for improvement.

Role Delineation[76]

Role delineation provides a framework that describes the minimum support services, workforce, and other requirements for clinical services to be delivered safely. It delineates the level of clinical services, not hospitals or health facilities as a whole.

S

Specialist Palliative Care Services[77]

Specialist palliative care services are those services with palliative care as their core speciality and which are provided by an inter-disciplinary team, under the direction of a consultant physician in palliative medicine.

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72. National Institute for Clinical Excellence, "Guidance on Cancer Services, Improving Supportive and Palliative Care for Adults with Cancer, The Manual" (2004).

73. Department of Health and Children, "Report of the National Advisory Committee on Palliative Care" (2001).

74. Health Information Quality Authority, "National standards for safer better healthcare" (Dublin, June 26, 2012), 1-160, https://www.hiqa.ie/sites/default/files/2017-01/Safer-Better-Healthcare-Standards.pdf

75. United Nations Office for Disaster Risk Reduction, "Sendai Framework Terminology on Disaster Risk Reduction: Resilience," UNDRR.org, January 9, 2024, https://www.undrr.org/terminology/resilience

76. NSW Ministry of Health, "NSW health guide to the role delineation of clinical services" (ISBN 978-1-76023-017-3, New South Wales, December 17, 2021), 1-166, https://www.health.nsw.gov.au/services/publications/role-delineation-of-clinical-services.PDF

77. Department of Health and Children, "Report of the National Advisory Committee on Palliative Care" (2001).

Telehealth[78]

The delivery of healthcare, health education, and health information services via remote technologies.

78. New England Journal of Medicine Catalyst, "What Is Telehealth?" NEJM Catalyst 4, no. 1 (February 2018): https://catalyst.nejm.org/doi/full/10.1056/CAT.18.0268

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