ADULT PALLIATIVE CARE SERVICES MODEL OF CARE FOR IRELAND

The National Clinical Programme for Palliative Care

National Clinical
& Integrated Care Programmes
Person-centred, co-ordinated care

PALLIATIVE CARE

ROYAL COLLEGE OF PHYSICIANS OF IRELAND

ACKNOWLEDGEMENTS

ACKNOWLEDGEMENTS

Patients, carers, advocacy organisations, managers, academics, health and social care professionals have worked together to produce a document that describes best practice and communicates a compelling and inspiring vision of care. The programme is truly grateful to them all for their tremendous contributions. We would like to also thank all members of the Working Group and Clinical Advisory Group who have worked so tirelessly and given so generously of their time.

Collaboration with our partners in the Department of Health, Royal College of Physicians of Ireland and the HSE, the Office of the Chief Clinical Officer, Clinical Strategy and Programmes, Strategy and Planning for Older People and Palliative Care and National Primary Care Operations has also been hugely valued and key to the success of the programme to date.

A final word of thanks goes to Kellie Myers, Programme Manager and Mary Marsden, Nurse Lead and their predecessors without whom the Model of Care would not be possible.

READER INFORMATION

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FOREWORD

PROF KAREN RYAN, CLINICAL LEAD

There is scarcely a conversation about healthcare in Ireland that does not reference the challenges of ageing demographics, constrained resources and constant change. Increasing demands, combined with a sense of urgency, produce an environment that is often complex and pressured. With so many forces at work, it can be difficult to move from a focus on immediate problem-solving to a broader perspective that asks how the healthcare system can be redesigned without damaging its foundations. Nevertheless, National Clinical Programmes aim to do exactly that in its development of Models of Care that optimise health, care and value.

Berger wrote in 1972: "We only see what we look at. To look is an act of choice." This document is reflective of the priority placed in Ireland on palliative care provision. Our country has a long and proud tradition of caring for those with life-limiting conditions, and the publication of the Report of the National Advisory Committee on Palliative Care was a seminal moment that marked government commitment to growing and sustaining services begun by communities and voluntary organisations. 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 provided within five years of report implementation.

The aim of the Palliative Care Model of Care is that: *"Every person with a life-limiting or life-threatening condition can easily access a level of palliative care appropriate to their needs, regardless of care setting or diagnosis, in order to optimise quality of life".* Implementation of the Model of Care has already started, but there remains much yet to do. We are fortunate that Dr Brian Creedon, Consultant Physician in Palliative Medicine, has taken up the role as Clinical Lead and will guide the National Clinical Programme for Palliative Care into the next phase of action. Brian's experience and skills ideally place him to support cross-organisational and professional change, and I wish him every success in this important role.

DR DAVID HANLON, NCAGL PRIMARY CARE

The aim of the Palliative Care model of care is that:
"Every person with a life-limiting condition can easily access a level of palliative care appropriate to their needs regardless of care setting or diagnosis in order to optimise quality of life."

This is an aim which has wide support not only in the Health Services but across Irish society. I believe that this document makes an important contribution by guiding those who commission, plan and deliver services for people with life-limiting conditions.

The National Clinical Programme for Palliative Care has been particularly successful and productive. It has contributed hugely to broadening the scope of palliative care beyond malignant disease alone, and highlighted the importance of a palliative care approach in all service delivery.

I wish to thank the many people who contributed to this excellent document. It was developed using a robust and inclusive process, and its scope extends from technical questions of funding and ICT to the clinical domains of needs assessment, guidelines and patient pathways. It also takes a broad view of workforce, identifying the competency needs of healthcare professionals, but also recognising the contributions of volunteers, creative arts and complementary therapies to the wellbeing of the people we all care for. This content is presented in a way which makes it easy to access and navigate.

I wish to acknowledge in particular the leadership, expertise and vision of Prof Karen Ryan in the development of this document. Our next step must be to make use of this resource to guide us in delivering our common aim.

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ABBREVIATIONS

ABBREVIATIONS

AHPs	Allied Health Professionals
AIIHPC	All Ireland Institute for Hospice and Palliative Care
CHOs	Community Health Organisations
CIO	Chief Information Officer
CIT	Community Intervention Team
CVAD	Central Venous Access Device
DON	Director of Nursing
ECHO	Extension for Community Healthcare Outcomes
EHR	Electronic Health Record
EoL	End of Life
EPaCCS	Electronic Palliative Care Coordination Systems
GPs	General Practitioners
HFH	Hospice Friendly Hospitals Network
HGs	Hospital Groups
HIQA	Health Information and Quality Authority
HSCP	Health and Social Care Professionals
HSE	Health Service Executive of Ireland
ICS	Irish Cancer Society
ICT	Information & Communication Technology
IHF	Irish Hospice Foundation
MDT	Multidisciplinary Team
NACPC	Report of the National Advisory Committee on Palliative Care 2001
NCEC	National Clinical Effectiveness Committee
NCHDs	Non-Consultant Hospital Doctors
NCPPC	National Clinical Programme for Palliative Care
NDTP	National Doctors Training and Planning
OOH	Out of Hours
PAL.M.ED	Palliative Medicine in the Emergency Department
PCNA	Palliative Care Needs Assessment
PCRN	Palliative Care Research Network
PCSBs	Palliative Care Support Beds
PHN	Public Health Nurse
QA&I	Quality Assurance & Improvement
QI	Quality Improvement
SPC	Specialist Palliative Care
WHA	World Health Assembly
WTE	Whole Time Equivalent

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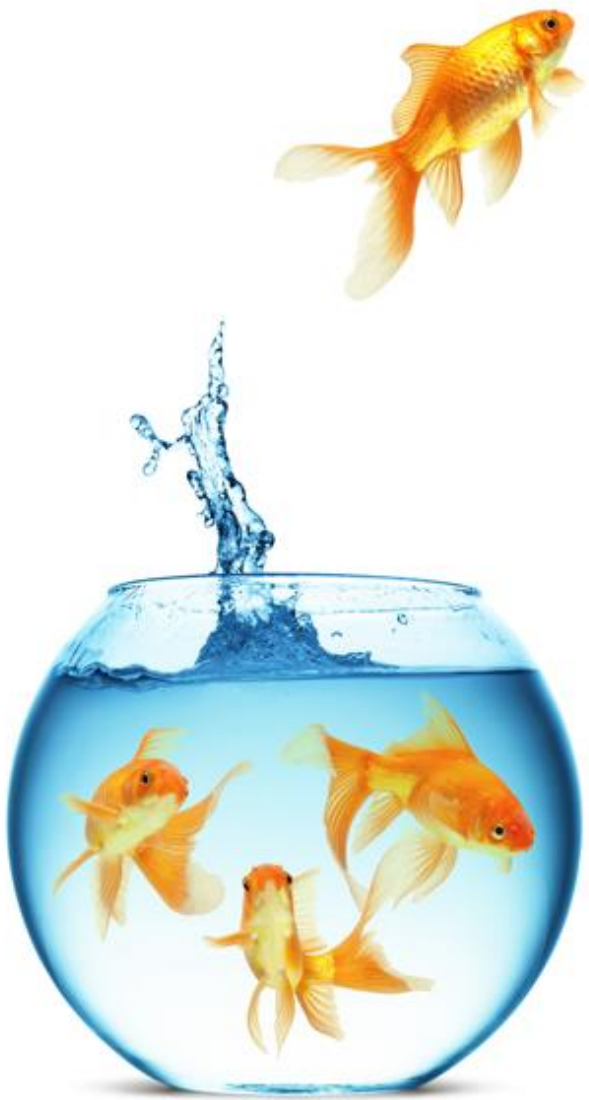

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PALLIATIVE CARE

Palliative care is care that improves the quality of life of patients and their families who are facing the problems associated with life-limiting or life-threatening illness. Palliative care prevents and relieves suffering by means of early identification, impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems. [1] Palliative care is best understood as both a set of principles that underpin an approach to care, and as a type of service that is provided. In Ireland, palliative care services are organised into specialist and non-specialist services that operate in partnership as part of an integrated network of providers.

Many people still think of palliative care as care provided at the very last stage of life, around the time of death. However, in the last twenty years, the scope of palliative care has 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. While the broader definition is far from the original idea of 'terminal' or 'end of life' care, it does still include it. As 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'.[2]

A number of patients and carers have generously lent their voices to this model of care and in the links below, describe what palliative care means to them and their families:

These and videos of other personal experiences can be viewed at www.adultpalliativehub.com

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WHAT IS A MODEL OF CARE?

A Model of Care broadly describes a framework that brings together regulatory, organisational, financial, and clinical aspects of service provision to outline best practice in patient care delivery. A 'model of care' is a multifaceted concept but one that is important because of the link between adoption of best practices (as outlined in the Model of Care) and the delivery of improved patient outcomes.

HOW WAS THIS MODEL OF CARE DEVELOPED?

In developing the Palliative Care Model of Care, the National Clinical Programme for Palliative Care:

- Built on the work of the National Advisory Committee for Palliative Care, [3] the HSE Three Year Development Framework (2017-2019) [4] Cancer Strategy (2017-2027) [5], the Oireachtas Committee on the Future of Healthcare (Sláintecare) [6] and other relevant national policy and strategy documents,
- Reviewed national and international models of care,
- Took cognisance of other clinical programmes' Models of Care,
- Took cognisance of the national 'Let's Talk About' survey, [7]
- Involved stakeholders (patients, carers, clinical and non-clinical staff, managers and commissioners) in its co-design.
- Engaged in a consultation process (51 submissions received, summary document available from clinicalprogrammeadmin@rcpi.ie)

THE LET'S TALK ABOUT SURVEY

The All Ireland Institute of Hospice and Palliative Care 'Let's Talk About' palliative care survey had input from 528 people across the island of Ireland who were either living with a life-limiting condition or who had experience of providing care to someone in this situation. Their responses provide a picture of what matters to people when they are living with a progressive medical condition which is unlikely to be cured.

When we know what matters, services and support can be designed, delivered and improved to address these issues and help people to have as good a quality of life as possible.

Key messages from the survey were that:

- People need help to plan for the future,
- People experience too little autonomy,
- People value clear and sensitive communication,
- People value timely and appropriate information,
- There are emotional and psychological needs that are not met,
- People would like their family and friends more involved.

More information on Let's Talk About can be found at the following links: videoscribe; infographic; Executive Summary or Full Report

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WHAT IS THE PURPOSE OF THIS MODEL OF CARE?

The purpose of the palliative care model of care is to provide a framework for the organisation of care for people with life-limiting or life-threatening conditions. Essentially, it is a tool to help commissioners and providers ensure that people get the right care, at the right time, by the right team and in the right place. A model of care defines 'what good looks like' and offers actionable steps to help commissioners and services provide such care. Without a model of care to guide decision-making, decisions may be based on the opinions of a small number of stakeholders or be constrained by local availability of resources.

WHO SHOULD USE THIS MODEL OF CARE?

Commissioners, managers, clinical and non-clinical staff should all use different parts of this model of care to guide their work.

- Commissioners and managers should use the model of care as a practical guide for the provision of specialist palliative care services and for the integration of the palliative care approach into hospital, community and primary care services.
- Clinical staff should use the model of care as a reference for best practice.

Patients, carers and advocates may be interested in using the model of care to understand how services are being provided, what they can expect from service providers and how care will be further developed in the future. Overall, the document should be used to encourage and support dialogue between commissioners, service providers and service users about what is required to provide the best possible care to patients and their families. It provides a platform for all to play active parts in national and local co-design of services.

TERMINOLOGY

A specific word on the terminology used when referring to staff providing palliative care services in the Model of Care. The Report of the National Advisory Committee on Palliative Care recommended that palliative care services should be structured in three levels of ascending specialisation. These levels refer to the expertise of the health professionals delivering the palliative care services:

- **Level one- palliative care approach:** Palliative care principles should be practiced by all health care professionals. The palliative care approach should be a core skill of every clinician at hospital and community level. Many patients with progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel.
- **Level two – general palliative care:** At an intermediate level, a proportion of patients and families will benefit from the expertise of

health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care, perhaps to diploma level. Such intermediate level expertise may be available in hospital or community settings.

- **Level three – specialist palliative care:** Specialist palliative care services are those services whose core activity is limited to the provision of palliative care. These services are involved in the care of patients with more complex and demanding care needs, and consequently, require a greater degree of training, staff and other resources. Specialist palliative care services, because of the nature of the needs they are designed to meet, are analogous to secondary or tertiary health care services.

Commonly, since the publication of the Report, the term 'generalist palliative care provider' is used to refer to those health and social care professionals practicing at level one or two. However, we have learned over the course of engaging with stakeholders that the term 'generalist palliative care provider' is not liked or comprehended by many. Therefore, we use the term 'professionals providing a palliative care approach as part of usual care provision' in its place.

Additionally, throughout this document the term 'palliative care' is used when referring to both services providing a palliative care approach as part of usual care provision (level 1 and 2) *and* specialist palliative care services. The term 'specialist palliative care' is used when referring to specialist palliative care only.

The National Clinical Programme for Palliative Care has produced a Glossary of Terms that provides explanations for other terms commonly used in this Model of Care.

WHEN WILL THE MODEL OF CARE BE REVIEWED?

This document is envisaged as being a 'living' document that will be updated regularly to reflect emerging practice and the developing evidence base. A full-scale review of the document will be carried out in 2023.

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KEY POINTS

- Palliative care is care that improves the quality of life of patients and their families who are facing the problems associated with life-limiting or life-threatening illness.
- Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions.
- The purpose of the palliative care model is to provide a framework for the organisation of care for people with life-limiting or life-threatening conditions. Essentially, it is a tool to help commissioners and providers ensure that people get the right care, at the right time, by the right team and in the right place.
- Commissioners, managers, clinical and non-clinical staff should all use different parts of this model of care to guide their work.
  - Commissioners and managers should use the model of care as a practical guide for the provision of specialist palliative care services and for the integration of the palliative care approach into hospital, community and primary care services.
  - Clinical staff should use the model of care as a reference for best practice.
- Throughout this document the term 'palliative care' is used when referring to both services providing a palliative care approach as part of usual care provision (level 1 and 2) and specialist palliative care services.
- The term 'specialist palliative care' is used when referring to specialist palliative care only.
- This document is envisaged as being a 'living' document that will be updated regularly to reflect emerging practice and the developing evidence base. A full-scale review of the document will be carried out in 2023.

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The aim of the Palliative Care Model of Care is that:

'Every person with a life-limiting or life-threatening condition can easily access a level of palliative care appropriate to their needs regardless of care setting or diagnosis in order to optimise quality of life.'

To realise this aim and deliver care according to the Model of Care, the following **eight foundations** should be in place:

1. People with life-limiting or life-threatening illness receive regular, standardised assessment of palliative care need and individualised care plans are co-developed to meet identified need, with the aim of optimising quality of life.
2. Carers receive practical, emotional, psychosocial and spiritual support including into bereavement.
3. An enabling environment is created where hospital, community and primary healthcare providers are supported to provide a palliative care approach as part of their normal service provision.
4. Access to specialist palliative care is provided for those patients with complex needs and the capability of services is developed.
5. Hospital, community, primary care and specialist palliative care providers are supported to work together to provide an integrated model of care provision.
6. Effective and timely flow of information between hospitals, community, primary healthcare and specialist palliative care providers is in place. Communication is inclusive of patients and carers.
7. A culture of quality improvement is embedded in palliative care provision.
8. A research and innovation agenda that improves the quality and value of palliative care is supported.

The eight foundations are illustrated in the graphic on page 20. The overview patient pathway is illustrated on page 21. Detailed explanation of the eight foundations and the overview patient pathway are provided in the Model of Care section of this document. Action points for implementation of the Model of Care are provided in the Implementation section of the document.

EXECUTIVE SUMMARY- EIGHT FOUNDATIONS

THE EIGHT FOUNDATIONS OF THE PALLIATIVE CARE MODEL OF CARE

1. People with life-limiting or life-threatening illness receive regular, standardised assessment of palliative care need and individualised care plans are co-developed to meet identified need, with the aim of optimising quality of life.
2. Carers receive practical, emotional, psychosocial and spiritual support, including into bereavement.
3. An enabling environment is created where hospital, community and primary healthcare providers are supported to provide a palliative care approach as part of their normal service provision.
4. Access to specialist palliative care is provided for those patients with complex needs and the capability of services is developed.
5. Hospital, community, primary care and specialist palliative care providers are supported to work together to provide an integrated model of care provision.
6. Effective and timely flow of information between hospitals, community, primary healthcare and specialist palliative care providers is in place. Communication is inclusive of patients and carers.
7. A culture of quality improvement is embedded in palliative care provision.
8. A research and innovation agenda that improves the quality and value of palliative care is supported.

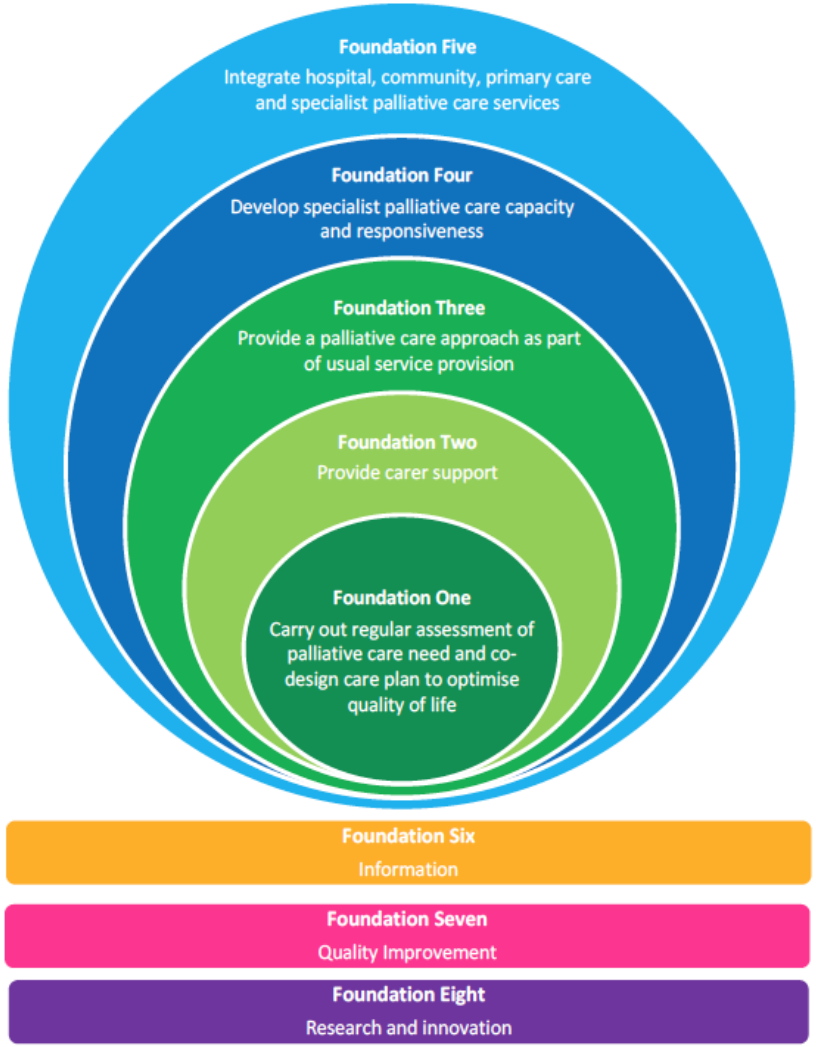

Figure 1. Eight Foundations

EXECUTIVE SUMMARY- OVERVIEW PATHWAY

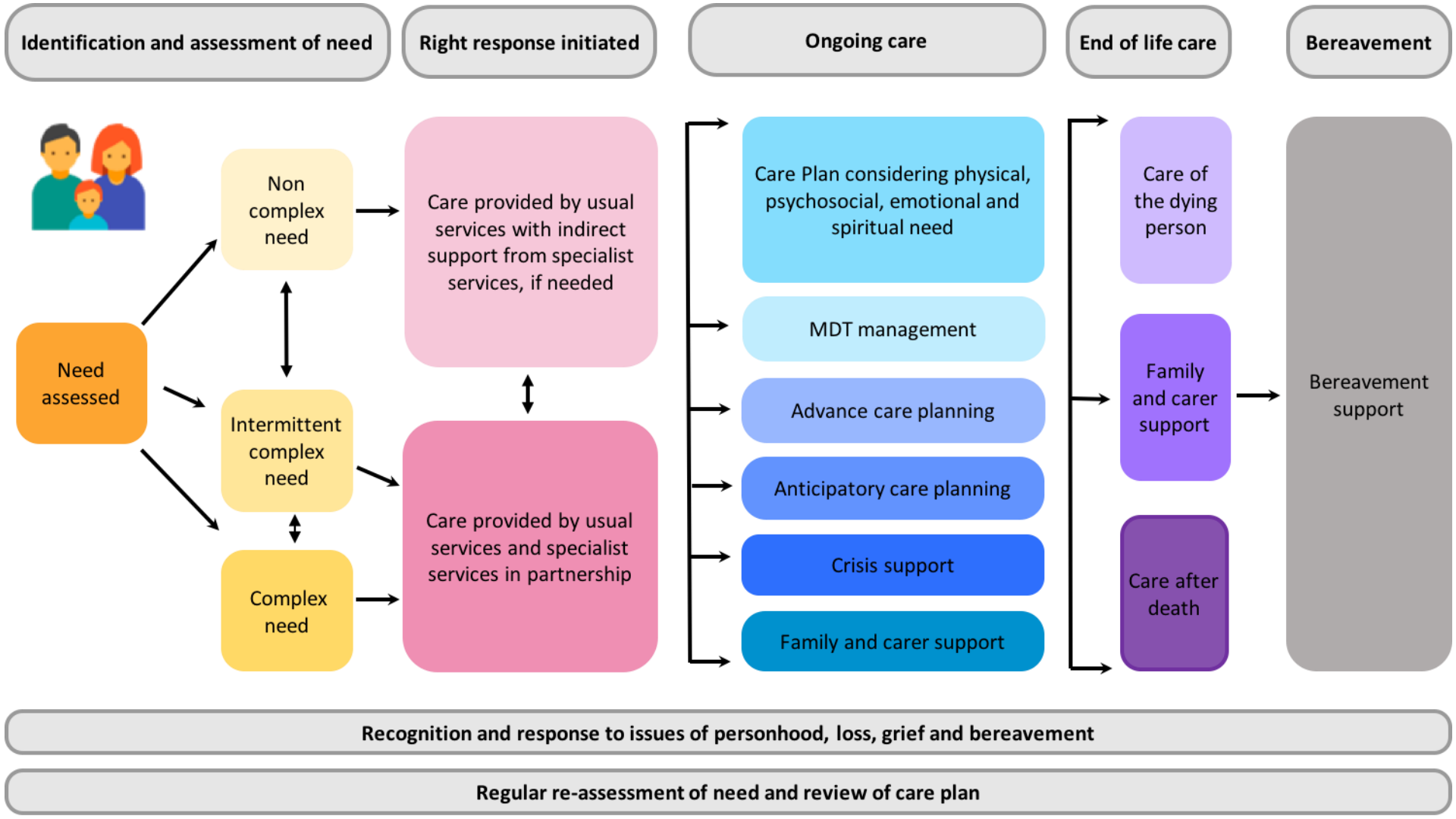

Figure 2. Overview Pathway

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DRIVERS OF CHANGE

Ageing

As a result of Ireland's ageing population, between 2011 and 2031, the estimated increase in deaths is projected to be 27%. [1] In addition, many more people will be dying at an older age and will therefore be likely to have more complex needs and multiple co-morbidities as they near the end of their lives. These demographic changes will lead to a rapidly escalating need for all levels of palliative care provision.

Non-malignant disease

Historically, palliative care has been associated with caring for people with cancer, but future provision must also care for other chronic diseases such as dementia and other neurological diseases, cardiovascular, renal and respiratory diseases. Together with cancer, the prevalence of these diseases is increasing rapidly.

Cultural diversity

Cultural diversity is an increasingly important issue in the Irish healthcare sector, both in regard to staff working in the healthcare sector and the people seeking to avail of healthcare services. We need to ensure that services are accessible, user friendly and equitable. We also need to ensure that our workplaces are inclusive and respectful of cultural diversity. Harnessing and managing diversity is both a key opportunity and challenge for palliative care.

Shortcomings in care

Caring for people nearing the end of life is one of the most important things we do, as clinicians and managers and, at a human level, as people. However, in the 21st century, we have witnessed fundamental changes in the way that we die and there have been profound shifts in the expectations of patients and families. These changes are challenging the traditional ways in which care is provided by our health services to people with serious illness and life-limiting conditions. Unfortunately, staff and services are often sub-optimally prepared to respond to the changed and increasingly complex needs of patients and supports for practice are lacking.

HIQA and the Ombudsman have recognised the importance of the issue and both have focused attention to the problem. End of life care was the first thematic review conducted by HIQA in the residential care sector and the Ombudsman published a report titled 'A Reflection on Ombudsman Complaints about End of Life Care in Irish Hospitals' in 2014. [2] Although examples of good practice were described, evidence of shortcomings in

practice were also recorded. All of the people in the Ombudsman's Report believe that they and their loved ones suffered distress during the time of a final illness and death, that could have been avoided. Most of the complaints made to the Ombudsman were multifaceted; a person may have complained about communications, record keeping, pain control, nutrition, privacy, decision making and a wide range of concerns that arise when providing care at end of life.

Shortcomings in practice are not unique to the Irish setting and for this reason, the World Health Assembly committed to improving palliative and end of life care in Resolution 67.19 of the World Health Assembly, 'Strengthening of palliative care as a component of comprehensive care throughout the life course'. [3] Ireland is a signatory to the resolution. Significant work has been done in Ireland to date and this Model of Care aims to build on that foundation.

Health system reform

There has been significant change in the landscape of Irish healthcare provision since the publication of the 2001 NACPC Report. The HSE was established in 2005 with control over all executive, managerial and budgetary decisions. While it continues to be the core structure of Irish public healthcare, there are a series of reforms, whose implementation is underway, which will further restructure the healthcare landscape in Ireland. These reforms include the establishment of Hospital Groups and Community Healthcare Organisations (CHOs), devolution of authority to these organisations, increased focus on health and wellbeing, introduction of a commissioning cycle, and the implementation of key patient safety and quality reforms.

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Figure 3. The National Clinical Programme for Palliative Care carried out a review of existing service provision that has identified a number of gaps in palliative care provision that, in addition to the drivers of change, inform the development of this Model of Care:

Gaps	Issue
Needs assessment	Inadequate recognition of palliative care need
Inequity in service provision, limited capacity of services	Access to palliative care and supporting services varies according to age, socioeconomic considerations, geographic location and diagnosis. Inequities in service provision includes access to GPs and other healthcare professionals providing palliative care approach services
Referral pathway	Referral to specialist palliative care criteria and processes are variable across regions
Communication and coordination of care	Fragmented, inefficient care with patients experiencing significant difficulties in care transitions
Out of hours service provision	Variable out of hours service provision and quality of care
Carer support	Lack of assessment of the needs of carers and provision of supports
Community supports	Variability of financial assistance, equipment, care packages and respite care
Advance care planning	Lack of standardised process in advance care planning
Palliative care education	Lack of knowledge and skills in palliative care provision (formal and informal carers)
Absence of competency and role delineation frameworks	Lack of clarity on the role and responsibilities of those providing a palliative care approach as part of their usual care provision and those providing specialist palliative care.
Standards	Lack of guidance as to what 'good palliative care' is
Data and performance management	Limited collection of data to inform practice, particularly in the area of outcome measurement

ESTIMATION OF NEED

For national and regional service planning and development, it is essential to know the numbers in a population who need palliative care. Need may be defined as 'the ability to benefit from care'.

Higginson undertook one of the first population-based palliative care needs assessments in the 1990s. In Higginson's original calculations, deaths from cancer and from six non-malignant disease groups were multiplied by symptom prevalence. [4] As a result, she suggested that as a conservative estimate in the UK, between 15- 25% of patients who die from cancer required in-patient specialist palliative care and between 25- 65% of patients required input from community palliative care services. Patients with non-malignant disease were estimated to have 50-100% of the needs of patients with cancer. This method was used as the basis for planning for specialist palliative care service provision in the regional needs assessments that were carried out in Ireland following the publication of the Report of the National Advisory Committee on Palliative Care in 2001. [5]

Since then, a number of different methods have been used to determine palliative care population needs. For example, Rosenwax and colleagues identified ten conditions (cancer and non-cancer) known to have palliative care needs using the *International Statistical Classification of Diseases and Related Health Problems – 10th Revision (ICD-10)* and suggested three estimates of potential palliative care need: minimal, mid-range and maximal. [6]

The minimal estimate is derived from the ten identified conditions. The mid-range estimate incorporates hospital admissions for any of these ten conditions in the year prior to death. The maximal estimate includes all deaths apart from those attributed to injury, poisoning, maternal, perinatal and neonatal deaths. More recently, Murtagh and colleagues further developed the Australian work to refine the ICD-10 codes identified to more comprehensively encompass non-malignant diagnoses.[7]

In 2014, Kane et al used the Murtagh method to provide an updated Irish population based palliative care needs calculation. [8] However, the authors were only able to calculate minimal estimates for palliative care need due to limitations in Irish data sources- namely the fact that the Central Statistics Office does not collate data on contributory cause of death and that it is not possible to link hospital with mortality data due to lack of a unique identifier. **Nevertheless, the estimated minimal level of palliative care need in Ireland is considerable- annually, 80% of deaths in Ireland are from conditions considered to have palliative care needs. Overall, at least 0.5% of the population have palliative care needs at any one time.** These figures are considerably higher than the minimal levels of palliative

care need calculated in Australia (50%) and the U.K. (63%). It has been noted that, Ireland is one of the countries with the highest need for palliative care globally. [9]

CURRENT LEVEL OF SERVICE PROVISION

The following provides an overview of specialist palliative care services for adults in Ireland in 2017:

- 236 inpatient beds are provided by nine specialist palliative care organisations in 11 locations.
- 110 Day Hospice places are provided by 9 specialist palliative care units.
- Community specialist palliative care services are provided in each Local Health Office. 26 teams provide these services across the country.
- Hospital-based consultant-led specialist palliative care teams are provided by teams in 37 acute hospitals.

The following provides an overview of specialist palliative care services for children in Ireland in 2017:

- One hospital-based consultant-led specialist palliative care service is provided in Our Lady's Children's Hospital Crumlin. Consultant-only services are provided in The Coombe Women & Infants University Hospital, Dublin.
- 10 Clinical Nurse Coordinators for Children with Life-Limiting Conditions' (CNCs) provide care to children across the country.
- One eight-bedded children's hospice is located in Dublin.
- Each of the community specialist palliative care teams across the country provides care for children at home, when required.

Every month in Ireland:

3370 patients are seen by community palliative care services

1340 patients are seen by hospital palliative care services

438 patients receive in-patient unit services

642 families receive bereavement services

POTENTIAL BENEFITS OF PALLIATIVE CARE

Multiple studies have shown that, across a range of serious illnesses, palliative care services improve clinical and quality of care outcomes. [10-16]

Palliative Care Services:

- enable patients to avoid acute hospitalisation and remain safely and adequately cared for at home.

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- lead to better patient and family satisfaction, and significantly reduce prolonged grief and post-traumatic stress disorder among bereaved family members.
- lower costs by delivering care that is aligned to patient and family needs, and that enables avoidance of unnecessary hospitalisations, diagnostic and treatment interventions, and inappropriate intensive and emergency department care. [17]

WHAT IMPLEMENTATION OF THE PALLIATIVE CARE MODEL OF CARE WILL MEAN FOR IRELAND'S POPULATION

- Improved well-being for patients
- Improved well-being for carers
- Faster, fairer and free access to palliative care- reduced waiting times and geographical equity in service provision
- More people cared for in the community
- Improved quality, safety and value of care
- Advancement of Sláintecare's goal of providing universal palliative care to all.

KEY POINTS

- The estimated minimal level of palliative care need in Ireland is considerable:
  - At least 0.5% of the population have palliative care needs at any one time.
  - Annually, 80% of deaths in Ireland are from conditions considered to have palliative care needs.
- It has been noted that Ireland is one of the countries with the highest need for palliative care globally because of demographic changes.
- Currently, every month in Ireland:
  - 3370 patients are seen by community palliative care services.
  - 1340 patients are seen by hospital palliative care services.
  - 438 patients receive in-patient unit services.
  - 642 families receive bereavement services.

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BACKGROUND

The Government's commitment to Palliative Care was first reflected in the National Health Strategy in 1994, which recognised the important role of palliative care services in improving quality of life. [1] It gave a commitment to the continued development of these services in a structured manner, in order to achieve the highest possible quality of life for patients and their families.

The development of a National Cancer Strategy in 1996 gave an undertaking that there would be a programme of phased development of specialist palliative care in regional cancer services. [2] Three years later, the Minister for Health and Children established the National Advisory Committee on Palliative Care (NACPC) with a view to preparing a report on palliative care services in Ireland. [3]

The Report of the National Advisory Committee on Palliative Care in 2001 provided a blueprint for the development of palliative care services that is still relevant today. For this reason, the principles that underpin the Report are repeated in this Model of Care:

- Palliative care is an important part of the work of most health care professionals, and all should have knowledge in this area, and feel confident in the core skills required.
- Primary health care 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.
- Specialist palliative care should be seen as complementing and not replacing the care provided by other health care professionals in hospital and community settings.
- Specialist palliative care services should be available to all patients who need them, regardless of their disease, location or income.
- Specialist palliative care services should be planned, integrated and coordinated, and assume responsibility for education, training and research.
- 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.
- Patients should be enabled and encouraged to express their preference about where they wish to be cared for, and where they wish to die.
- The ultimate aim should be for all patients to have access to specialist palliative care services where these are required.

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CHILDREN'S PALLIATIVE CARE

National policy on children's palliative care is detailed in the 2009 document 'Palliative care for children with life- limiting conditions in Ireland'. [4] While this model of care focuses on the provision of adult palliative care, it is acknowledged that adult community palliative care services have an important role to play in supporting the care of children at home. The implications of this are considered but a detailed review of children's palliative care is outside of the scope of this document.

PALLIATIVE CARE SERVICES THREE YEAR DEVELOPMENT FRAMEWORK 2017-2019

Acknowledging delays in implementation of the NACPC Report, the Three Year Development Framework was published in November 14th 2017. [5] The Development Framework was commissioned by the HSE with the objective of informing and directing the development of adult palliative care services in specialist and non-specialist settings for the three-year period. In so doing, the focus of the Framework was to identify the gaps that exist in the current level of service provision and to present a set of recommendations and actions which over the duration of the Framework (and at times beyond) would seek to address these service issues / deficits, subject to available resources.

NATIONAL CANCER STRATEGY 2017 -2026

The National Cancer Strategy 2017 -2026 aims to meet the needs of cancer patients in Ireland for the next decade. The strategy makes recommendations on how cancer services should be resourced, organised and provided- ranging from the continuum of cancer prevention to the provision of palliative and end-of-life care. The recommendations that specifically focus on palliative care are:

- Recommendation 31- Designated cancer centres will have a sufficient complement of specialist palliative care professionals, including psycho-oncologists, to meet the needs of patients and families (such services will be developed on a phased basis to be available over seven days a week).
- Recommendation 32- Oncology staff will have the training and education to ensure competence in the identification, assessment and management of patients with palliative care needs and all patients with cancer will have regular, standardised assessment of their needs.
- Recommendation 33- The HSE will oversee the further development of children's palliative care to ensure that services are available to all children with a life limiting cancer.

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THE OIREACHTAS COMMITTEE ON THE FUTURE OF HEALTHCARE

The Oireachtas Committee on the Future of Healthcare published Sláintecare, its proposal for a single vision for healthcare and health policy over a 10-year period in May 2017. [6] The report represents the first time that cross-party consensus has been reached on a new model of healthcare to serve the Irish people over a long term period. The report contains specific timelines for its various proposals to be implemented. As defined by the World Health Organization, palliative care is an essential and needed health care service within Universal Health Coverage. [7] The report recognises this and recommends that universal palliative care is implemented within a 5-year timeline.

WORLD HEALTH ASSEMBLY RESOLUTION

The first ever resolution [8] to integrate hospice and palliative care into national health services was passed by member states at the 67th World Health Assembly in Geneva, Switzerland, in May 2014. The resolution "Strengthening of palliative care as a component of integrated treatment within the continuum of care" involves a set of standards and guidelines for palliative care and signals to national governments that palliative care must be part of their health policies, budgets and healthcare education. Ireland is a signatory to the Resolution.

KEY POINTS

- The Report of the National Advisory Committee on Palliative Care in 2001 provided a blueprint for the development of palliative care services that is still relevant today.
- The National Cancer Strategy 2017 -2026 strategy makes recommendations on how cancer services should be resourced, organised and provided- ranging from the continuum of cancer prevention to the provision of palliative and end-of-life care. Recommendations 31-33 specifically focus on specialist palliative care provision.
- The Oireachtas Committee on the Future of Healthcare's report, Sláintecare, recommends that universal palliative care is implemented within a 5-year timeline (recommendation 4.1)
- Ireland is a signatory to the World Health Assembly resolution on palliative care.

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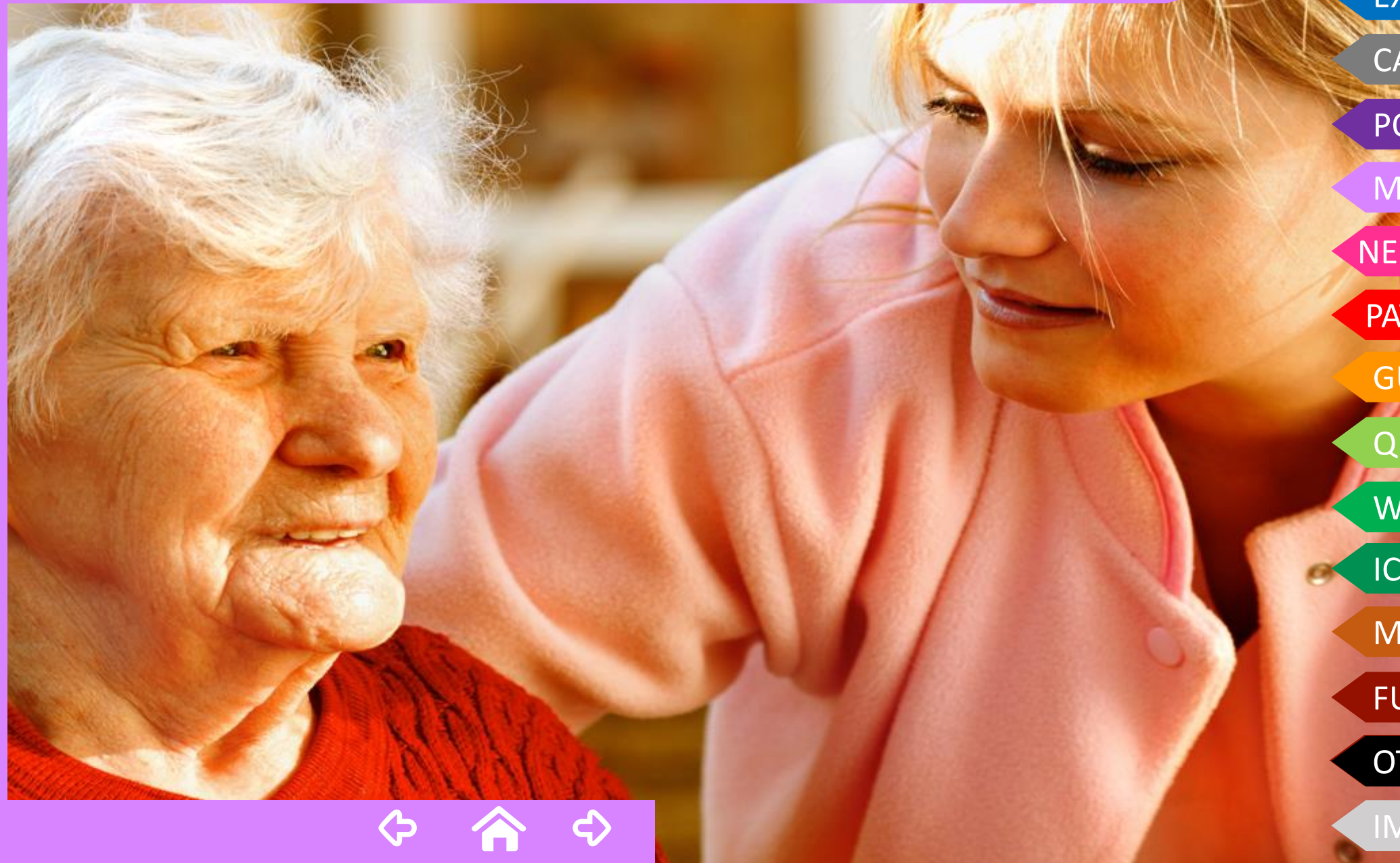

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The aim of the Palliative Care Programme Model of Care is that:

'Every person with a life-limiting or life threatening condition can easily access a level of palliative care appropriate to their needs regardless of care setting or diagnosis to optimise quality of life.'

To realise this aim and deliver care according to the Model of Care, the following **eight foundations** should be in place:

1. People with life-limiting or life-threatening illness receive regular, standardised assessment of palliative care need and individualised care plans are co-developed to meet identified need, with the aim of optimising quality of life.
2. Family and carer needs are assessed so that they receive practical, emotional, psychosocial and spiritual support, including into bereavement.
3. An enabling environment is created where hospital, community and primary healthcare providers are supported to provide a palliative care approach as part of their normal service provision.
4. Access to specialist palliative care is provided for those patients with complex needs and the capability of services is developed.
5. Hospital, community, primary care and specialist palliative care providers are supported to work together to provide an integrated model of care provision.
6. Effective and timely flow of information between hospitals, community, primary healthcare and specialist palliative care providers is in place. Communication is inclusive of patients and carers, where appropriate.
7. A culture of quality improvement is embedded in palliative care provision.
8. A research and innovation agenda that improves the quality and value of palliative care is supported.

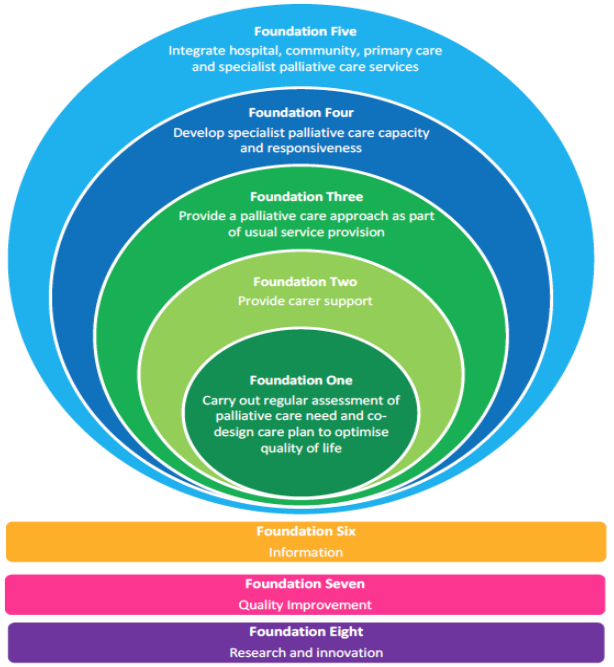

Figure 1. Eight Foundations

MODEL OF CARE- OVERVIEW PATHWAY

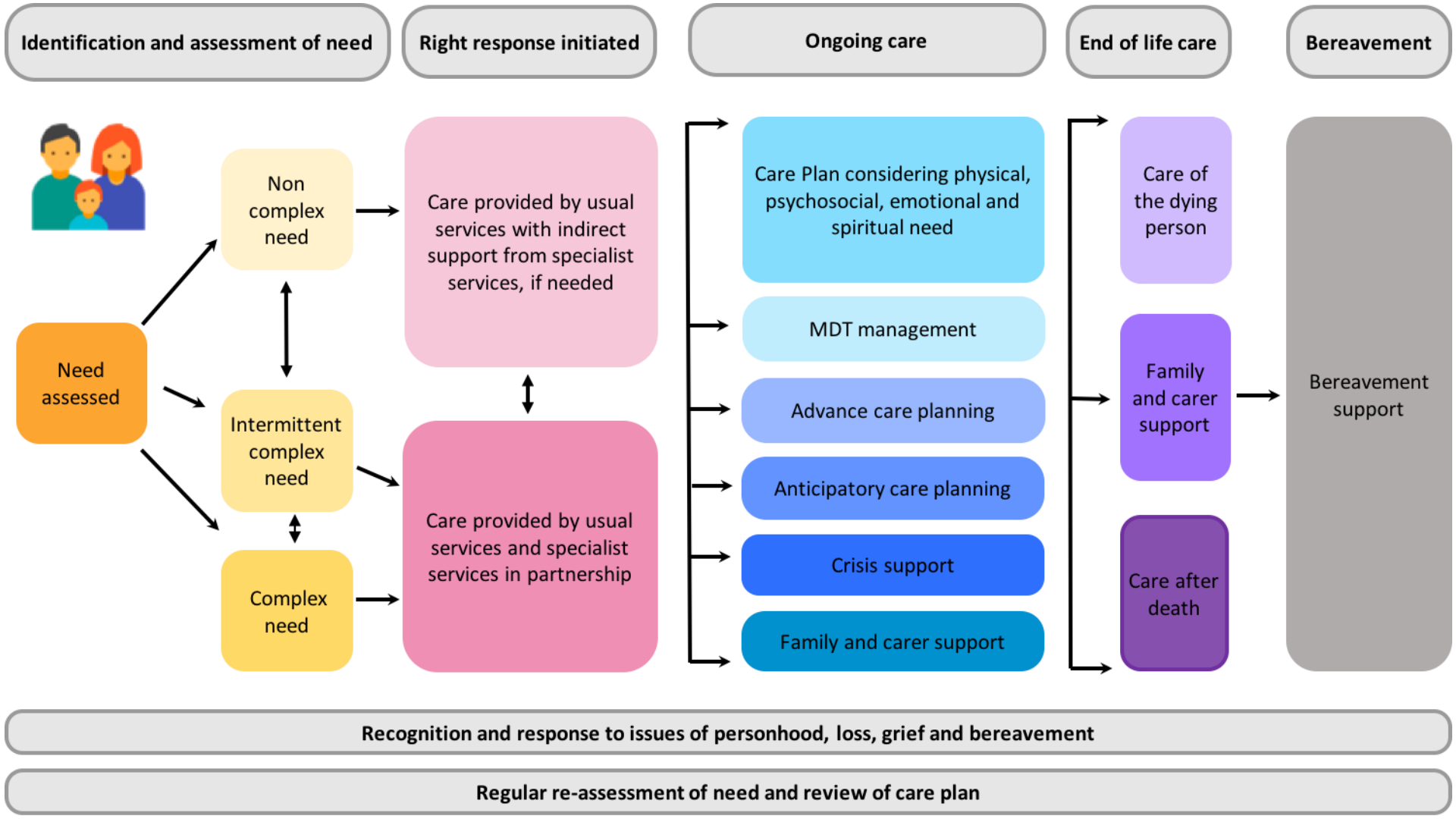

Figure 2. Overview Pathway

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FOUNDATION 1. People with life-limiting or life-threatening illness receive regular, standardised assessment of palliative care need and individualised care plans are developed to meet identified need, with the aim of optimising quality of life.

IDENTIFICATION AND ASSESSMENT OF NEED

The **Overview Patient Pathway** is a diagrammatic representation of the patient and carer pathways in the Model of Care. As outlined in the Pathway, identifying and assessing palliative care need is the essential first step in the Palliative Care Model of Care.

All health and social care professionals who care for patients with life-limiting or life-threatening illness should be able to carry out a palliative care needs assessment. The national Palliative Care Needs Assessment Guide and accompanying educational material are described in greater detail in the **Needs Assessment** section of this document.

A number of distinct groups of patients with varying levels of need may be identified as existing within the population of people with life-threating or life-limiting conditions:

1. **Non-complex palliative care needs:** A number of individuals will experience a relatively uncomplicated, though potentially distressing, trajectory after diagnosis. Patients in this category include physical, psychosocial, emotional and spiritual needs that are readily addressed using level 1 or 2 palliative care competences (i.e. needs can be met if a palliative care approach is provided as part of usual service provision).
2. **Intermittent complex palliative care needs:** Some patients will have a more variable course and may experience episodes of increased distress associated with physical, spiritual. emotional or psychosocial consequences of their illness. A period of consultation with specialist palliative care is required to manage increased distress levels and meet patient needs.
3. **Persistent complex palliative care needs:** A third group of people will experience persistent problems of high intensity or complexity. Patients in this category present with needs that require ongoing intervention by a specialist palliative care service. Ordinarily, specialist palliative care should be seen as complementing and not replacing the care provided by referring teams.
4. **End of life care:** End of life care is the term used to describe care that is provided during the period when death appears to be imminent, and life expectancy appears to be limited to a short number of hours or days. In many situations where people are in the last days and hours of life, staff caring for them will find it helpful to seek support from specialist palliative care teams because although needs may be of low / intermediate complexity, they are often of high intensity and can change rapidly.

5. **Bereavement:** Four levels of bereavement need may be identified- universal grief needs, organised support needs, professional counselling needs and complex grief needs.

INITIATION OF THE RIGHT RESPONSE

The assessment leads to health and social care professionals initiating the 'right response' to the person's needs. This involves professionals ensuring that patients can engage easily with staff with the right level of palliative care expertise to be able to devise a care plan that meets the palliative care needs of the patient and family. Each care location should ensure that they have the staff with the appropriate levels of expertise in place, as described in the **Role Delineation Framework**.

Many palliative care needs can be met by hospital, community and primary care staff providing a palliative care approach as part of their normal provision of care. However, the specialist palliative care team will usually be required to help meet the needs of patients who have complex problems. They may also be required to help meet the needs of patients who are dying and who have problems that are of high intensity and that are changing rapidly. Referrals to specialist palliative care services can be made according to the **Specialist Palliative Care Referral Pathway**.

Ordinarily, the specialist palliative care team adopt a supporting role to the referring team who retain primary responsibility for the patient. This is because studies have shown that a more integrated approach to care is associated with earlier referral to specialist palliative care; greater engagement with palliative care in non-malignant disease; and with skill-building of referring clinicians. [1]

PROVIDING CARE

Care plans should adopt a family systems perspective and address physical, emotional, psychosocial and spiritual needs. Care plans should have the primary goal of improving quality of life for both patients and their families. Efforts to improve quality of life should include a focus on rehabilitation and maximising functional ability, wherever possible. For those patients who are imminently dying, the goals of care shift towards trying to provide as good a death as possible and supporting families in their grieving. Quality of life and quality of death are both deeply personal constructs and care planning should be individualised and reflective of the beliefs and values of patients and their families.

Professionals must have the necessary skills to provide such 'whole person' care- the **Palliative Care Competence Framework** describes the competences required to address identified need. Information on, and links to, a number of resources that can help professionals provide care can be found in the **Guidelines** and **Pathways** sections of this document. Further guidelines and pathways will be added to this section over time. According to the patient's individual circumstances, care plans may also consider advance care and anticipatory planning, crisis support and carer support.

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Advance care planning is a process of discussion and reflection about goals, values and preferences for future treatment where there is anticipated deterioration in the person's condition, with loss of capacity to make decisions and/ or communicate them to others. Patients with life-limiting or life-threatening conditions should be afforded regular, timely and supported opportunities to engage in advance care planning, if desired. Work is currently being undertaken by the Quality Improvement Division in the HSE on advance care planning. Once completed, this Model of Care will be updated to link and align with HSE recommendations regarding advance care planning practice and the requirements of the The Assisted Decision-Making (Capacity) Act 2015.

Anticipatory care planning is a process where health and social care professionals try and anticipate what problems may arise due to the presence of a life-limiting or life-threatening condition and, where possible, put contingency plans in place to address these problems. Episodes such as symptom flares or exacerbations of the underlying condition can cause significant distress and often lead to patients seeking urgent access visits with their GP or attending Emergency Departments. While it is not possible to anticipate all situations, a surprisingly large number of problems can be addressed by relatively straightforward anticipatory care plans.

Planning should be tailored to individual circumstances but may include:

- Providing key worker contact details to patients and their families so that appropriate points of contact are accessible.
- Prescribing anticipatory or 'as required' medications for symptom control.
- Completing an 'Out of Hours Handover Form' so that health and social care professionals who are providing on call services have essential, up-to-date information in a readily accessible format.
- Supporting self-management by patients wherever possible e.g. understanding early or warning signs of deterioration, education about pharmacological and non-pharmacological approaches to symptom management.
- Booking a Night Nurse

People with urgent care or emergency needs must receive timely, effective treatment provided by staff with the appropriate skills and expertise. The Emergency Department is the 'default' choice **for crisis support** for many patients with life-limiting conditions due to real or perceived gaps in community-based urgent care services. This is despite the fact that a significant number of patients would prefer care based at or as close to home as possible. In situations where there is no alternative to hospitalisation, people should have direct admission into specialties without going through the Emergency Department.

Work is currently ongoing in the HSE that is focusing on the re-design of

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unscheduled, urgent and emergency care services. This Model of Care recognises the need for palliative care services to work closely with design teams to:

- Develop pathways that offer viable alternatives to patients with urgent palliative care needs who require crisis supports.
- Develop direct admission pathways to specialty care for those patients with palliative care needs who require specialist input.
- Develop the capacity of urgent and emergency care staff to recognise and respond to palliative care need within their usual service provision and to access specialist palliative care support in a timely manner when required.

Further work is required to detail clinical navigation services, improved responses and alternative integrated urgent care pathways. This model of care will be updated to include the description of these structures, pathways and expected outcomes once work is completed.

END OF LIFE CARE

Death is inevitable with many illnesses, but the process and timeline associated with dying varies widely. Some people remain ambulant and largely self-caring right up to the point of dying while others may have an extended period of ill-health and frailty. It can be difficult to recognise when a patient is in the last days or weeks of life even for experienced clinicians. However, recognising that a patient is beginning to die remains one of the most important responsibilities of a healthcare professional.

If it is thought that a patient may be beginning to die, it is important that the health or social care professional gathers and documents information on:

- The person's physical, psychological, social and spiritual needs
- Current clinical signs and symptoms
- Medical history and the clinical context, including underlying diagnoses
- The person's goals and wishes
- The views of those important to the person about future care. [2]

This information should then be used to guide the development of an individualised care plan. The care plan should be reviewed and updated at regular intervals to ensure that it responds to any changes in the patient's condition that may arise such as improvement in signs and symptoms or functional observations that could indicate that the person may be stabilising or temporarily recovering.

The National Clinical Effectiveness Committee has authorised the National Clinical Programme for Palliative Care to develop a national guideline on care of the dying adult. This will be added to the Model of Care when completed.

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BEREAVEMENT

The provision of bereavement care is part of comprehensive palliative care provision. Bereavement care is considered to begin at the point of first contact with the family/carers of the person with serious illness because support for family members/ carers during the patient's illness can mitigate or minimise the challenges experienced after the patient's death. Bereavement care is ordinarily provided over a period from pre-death to several months post-death; however for those experiencing complicated grief, care will be provided for longer periods.

Assessment of family / carer need for bereavement support should be conducted as part of the palliative care needs assessment process. Assessment should be carried out by individuals who have the relevant competences. [1] Assessment should lead to the 'right response' being initiated, as described in the bereavement support pathway. All individuals with loss, grief and bereavement support needs should have access to a comprehensive range of interventions in Primary Care, Specialist Palliative Care and Specialist Mental Health Services. This does not mean that every hospital, community, specialist palliative care and primary care organisation should provide a full range of bereavement support services. Rather, it means that a population-based and needs-based approach to service provision should be adopted where:

- Bereavement support services are planned on a regional basis and all levels of bereavement support need are considered in the planning process.
- Services have clearly defined pathways for assessing and responding to the various levels of need in bereavement.
- Services providing different levels of bereavement support work in collaboration across a defined catchment area.

Within this organised network of service provision, all organisations should be able to respond to universal grief needs i.e. they should be able to provide reassurance and information about the grieving process and they should provide information on how to access informal and formal support services. The provision of information enables and empowers families and carers to adjust to their grief and access further supports, if required. In addition to providing this level of support and information to family and carers, organisations should consider the bereavement support needs of staff (this may include providing access to death reviews, professional development and professional supervision).

Individuals with bereavement support needs that are beyond the organisation's scope of services, should be facilitated to access additional services within the region in as seamless a manner as possible. Further information on bereavement support services may be found in the loss, grief and bereavement support pathway.

Specialist palliative care services should have capacity to care for carers and families during the patient's illness and after the patient's death.

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Their scope of work should include working with individuals (adults and children), families and groups. Specialist palliative care services have a particular role in supporting vulnerable populations, such as children. Recent Irish standards for children's bereavement care remind us that providing informing and caring for bereaved adults is the first line in caring for the children in a family. Other vulnerable populations to consider in the proactive provision of support are those with a learning disability, the prison population, homeless people and those with estrangements within the family.

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

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

Specialist palliative care services may have some internal capability to meet complex grief needs (e.g. through the provision of counselling or psychology services) but all should have defined pathways of referral and established service links with regional mental health services.

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FOUNDATION 2. Family and carer needs are assessed so that they receive practical, emotional, psychosocial and spiritual support, including into bereavement.

Caring for a person throughout illness and at end of life is something that is both deeply rewarding and extremely challenging. Carers deserve recognition for their work and they require support themselves in order to sustain their role. The National Carers Strategy sets out the Government's plans to provide better support for carers. [3] Its four national goals are to:

- Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they are caring for;
- Support carers to manage their physical, mental and emotional health and well-being;
- Support carers to care with confidence through the provision of adequate information, training, services and supports;
- Empower carers to participate as fully as possible in economic and social life.

The Palliative Care Model of Care aligns to each of these goals, and by adopting a public health approach to palliative care, views the community as an equal partner in the task of providing quality healthcare. The Model promotes awareness and recognition of the role and contribution of carers and recommends that for those patients who consent, carers are included in needs assessment, care planning and decision making. Family meetings offer valuable opportunities to make this a reality. In responding to the needs of carers, there is a need to further develop supports and services that promote the health and well-being of carers. For example:

- Healthcare providers should be proactive in the provision of timely and clear information and advice regarding services (including respite services), allowances and entitlements.
- Carers should also be provided with relevant and accessible training opportunities.
- Carers should be able to easily access appropriate levels of bereavement support.
- Patients and carers should be able to easily access appropriate levels of respite care.

The role of a 'whole-government' response to supporting patients and carers is considered in Senator O'Donnell's report, 'Finite Lives. Dying, Death and Bereavement: An Examination of State Services in Ireland'. [4] The report begins a conversation between the State and the Citizen about end of life. A conversation that must span our social, artistic, environmental, legal, administrative, educational lives'. This Model of Care also recognises the value of specialist palliative care providers working in partnership with their local communities to develop programmes of health promoting palliative care and considering responses that lie outside of the traditional paradigm of medical care.

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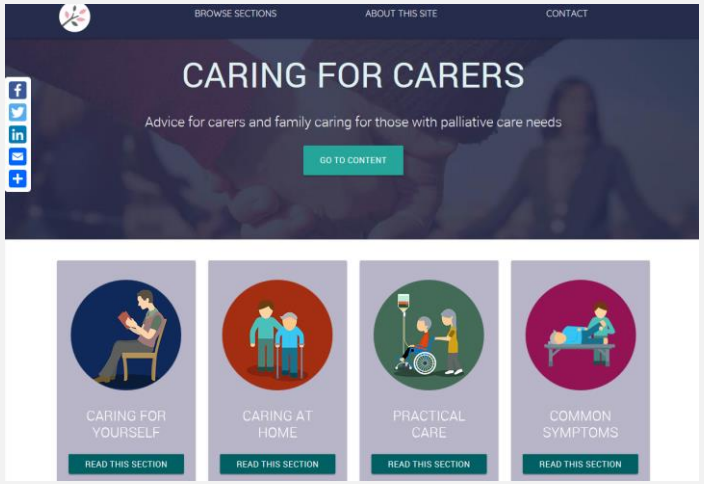
CARING FOR CARERS WEBSITE

The 'Caring for the Carers' website is an example of an initiative between AIIHPC and key stakeholders in the palliative care and health sector including carers' organisations that provides core information for family members and friends providing support to a person who needs palliative care. The website contains 8 sections - links to useful websites and factsheets can be found in each section.



THE COMPASSIONATE COMMUNITIES PROJECT

An example of the public health approach in action was the Compassionate Communities Project. The Project was started by Milford Care Centre in Limerick. It worked in partnership with individuals, groups and communities to enhance the social, emotional and practical support available to those living with a serious life-threatening illness, those facing loss and those experiencing bereavement. It did this by awareness raising through social media, printed media and local radio, and developing films and leaflets. It also worked with community organisations to promote discussion of death and dying, loss and care, and to develop initiatives that encouraged the community to engage more openly with these issues. The Good Neighbourhood Partnership provided free, social and practical support to people living with palliative care needs in their last year of life. In the Partnership, Milford Care Centre worked with community organisations to identify Compassionate Communities Volunteers who helped people living with serious illness to find additional social and practical support from within their local circle of community.

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VOICES 4 CARE

Voices4Care is an initiative involving people receiving palliative care, carers and the wider community in the work of All Ireland Institute of Hospice and Palliative Care and the wider palliative care arena across health and social care in both the Republic of Ireland and in Northern Ireland. Voices 4 Care members from across the island of Ireland are:

- Patients or service users receiving palliative care,
- Carers or former carers of people with palliative care needs,
- People from the wider community interested in palliative care.

Members have meaningful opportunities to influence and inform palliative care through participation in service user/ carer groups and consultation events.

To date, Voices 4 Care representatives have been involved in:

- The design, engagement and analysis of the Let's Talk About survey
- Palliative Care awareness videos
- Participation in palliative care public awareness campaigns
- Informing the Palliative Hub websites
- Identifying palliative care research opportunities
- Consultation on palliative care developments in Ireland
- AIIHPC governance structures.

NIGHT NURSING SERVICES

Night nursing services are available to provide nursing care, practical support and reassurance to patients and their families/carers. The Service is funded by the Irish Cancer Society (malignant diagnosis) and the Irish Hospice Foundation (non-malignant diagnosis) and is free of charge to the patients.

Families can avail of up to 10 nights care, subject to nurse availability in their locality and the Service can be accessed through Health Professionals i.e. GP, Public Health Nurse, or members of the Specialist Palliative Care services in the hospital and community teams.

In 2017, 1800 patients availed of 7300 nights of care with the demand for night nursing growing approximately 15% per year.

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FOUNDATION 3. An enabling environment is created where hospital, community and primary healthcare providers are supported to provide a palliative care approach as part of their normal service provision.

Palliative care is an important part of the work of most health care professionals, and all should have knowledge in this area, and feel confident in the core skills required of them. For this to happen, all healthcare professionals need to be provided with appropriate training and to be working in environments that support the provision of palliative care. Additionally, adequate staffing levels must be in place for hospital, community and primary care teams to be able to provide a palliative care approach as part of their usual service provision. Palliative care is time- and resource-intensive and deficits in staffing levels impact on hospital, community and GPs and primary care staff to provide care.

The Model of Care recognises that there are opportunities to lever existing structures to better support hospital, community and primary care staff. For example, in the hospital setting, the educational role of specialist palliative care teams remains under-developed. In the community, there is similarly scope to optimise the contribution of the Specialist Palliative Care Education Centres and community palliative care teams.

The Model of Care supports the development of organisational structures that enable hospital, community and primary care services embed a palliative care approach as part of their normal service provision. This includes:

- Supporting GPs to do home visits.
- Supporting MDT meetings between specialist palliative care teams and primary care and community teams, when required.
- Supporting GPs and members of hospital, residential care and primary care teams to engage in palliative care needs assessment and care planning - including the development of anticipatory care plans and advance care plans.
- Helping ensure that the care provided in palliative care support beds is of high quality, safe and effective.
- Optimising the alignment between the Hospice Friendly Hospitals Network and the National Clinical Programme for Palliative Care.
- Harnessing new technologies, such as tele-learning, to reach greater numbers of staff in ways that suit their busy schedules.
- Ensuring that palliative care is considered and integrated into National Clinical Programme models of care and National Integrated Care Programmes.
- Developing, piloting and implementing metrics to monitor, manage and support the effectiveness of integrated palliative care provision.

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ECHO AIIHPC NURSING HOMES PROJECT

An example of a methodology that can be utilised to create a supportive environment for palliative care in the community is Project ECHO (Extension for Community Healthcare Outcomes) which was developed at the University of New Mexico. Project ECHO uses tele-conferencing technology to improve access to specialised care through supporting and training primary health care professionals remotely (at 'spokes') from a centralised 'hub' of experts.

The ECHO AIIHPC Nursing Home project brings together the palliative care multidisciplinary team from a specialist palliative care service (the hub) and residential care staff (the spokes). Each ECHO usually lasts ninety minutes and is accessed from within each nursing home facility using teleconferencing software. Through fortnightly teaching sessions and case presentations, nursing home staff have the opportunity to discuss patient scenarios which they have found challenging and determine the best course of future treatment. The network fosters a spirit of learning from each other in a safe environment.

The main aim of the ECHO AIIHPC Nursing Homes project is to build skills and knowledge of staff to improve their residents' experiences and avoid unnecessary emergency department attendances. Additionally, residential care teams should feel empowered to access relevant specialist palliative care services appropriately and an effective connected learning community should develop.

HOSPICE FRIENDLY HOSPITALS PROGRAMME

An example of a structure that can be utilised to create a supportive environment for palliative care in hospitals is the Hospice Friendly Hospitals (HFH) programme. The HFH Programme is an initiative of the Irish Hospice Foundation, in partnership with the Health Service Executive. It was established in 2007 and seeks to ensure that palliative, end of life, and bereavement care are central to the everyday business of hospitals. 45 public and private hospitals are linked to the programme; this includes general, maternity and children's hospitals.

The work of the programme involves:

- Coordinating three networks for hospital staff to promote improvements in care- these are the Acute Hospital Network, the Children and Maternity Network and the End-of-Life Care Coordinator Network.
- Developing and promoting the use of resources for end-of-life care.
- Developing and promoting educational supports for all hospital staff.
- Operating the Design & Dignity Project, in partnership with the HSE, to transform the way hospital spaces are designed.
- Providing expert advice and guidance to hospital staff to support them implement the HFH Programme in their hospital.

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PALLIATIVE CARE SUPPORT BEDS

The concept of palliative care support beds (PCSBs) was first signalled in the National Advisory Committee on Palliative Care Report. [5] They were proposed as a means of providing an intermediate level of in-patient palliative care for patients in a local environment, typically in designated centres for older people. In 2014, the National Clinical Programme for Palliative Care (NCPPC) published a review of the organisation and function of PCSBs in Ireland in order to provide strategic direction on the future of the services provided. [5]

The review documented five key findings:

1. It appears that PCSBs have a role in improving patient outcomes, experience and assisting with hospital flow; however there is variation in the organisation, scope and functionality of PCSB beds across the country. It is not yet known whether differences in organisation and operation of PCSB beds are associated with differences in accessibility, efficiency and quality of outcomes.
2. An integrated model of palliative care provision is strongly supported by staff, who consider that PCSBs could be more effectively integrated with the healthcare system.
3. Appropriate staffing is integral to effective PCSB operation. There is a need to ensure a balanced workforce in order to provide a quality, safe and effective service.
4. There are a number of factors impacting on equity of access to PCSBs including diagnosis, age, availability and geography.
5. Ready access to key relevant metrics is essential if systems are to plan an integrated approach to PCSB care, understand its impact and further develop services.

The review recommended ten actions to improve the quality, safety and efficiency of PCSB provision. These actions are considered further in the implementation section of this Model of Care.

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FOUNDATION 4. Access to specialist palliative care is provided and the capability of services to deliver care is developed.

ROLE OF SPECIALIST PALLIATIVE CARE TEAMS

Specialist palliative care teams work in collaboration with referring teams to manage current or anticipated complexities relating to symptom control, end of life care-planning or other physical, psychosocial or spiritual needs that cannot reasonably be managed by the current care provider(s). The specialist palliative care team:

- Uses in-depth specialist knowledge and skills to alleviate symptoms, suffering and distress;
- Supports the management of complex clinical and ethical decisions relating to serious illness, end of life care and bereavement;
- Provides care and support to those important to the patient receiving care, including facilitating bereavement care;
- Offers specialist advice and support to the referring team providing palliative care approach services.
- Plays a lead role in developing best practice in palliative care and contribute to the delivery of education, training and CPD to the wider workforce.[6]

When providing care in the hospital or community, the specialist palliative care team ordinarily work as a support team working in an integrated way with the referring team. When providing in-patient or out-patient care, specialist palliative care teams ordinarily assume main responsibility for the care provided for those episodes of care.

ORGANISATION AND STAFFING OF SPECIALIST PALLIATIVE CARE SERVICES

Despite service developments, access to some elements of specialist palliative care services is not equitable across Ireland and services remain variably resourced. This means there is a risk that the quality of care provided may vary from region to region. In addition, the needs of some groups are not adequately met within current service models and arrangements- these include people with intellectual disabilities, communication disorders, chronic and enduring mental health problems and those from different cultural or linguistic backgrounds. These inequities in access and possible outcomes must be addressed.

This model of care details the deficits in capital and resource allocations that need to be addressed to ensure that specialist palliative care services are able to meet the demands of the population of people with life-threatening or life-limiting illness. However, the model of care also describes changes in the way that workforce should be deployed (see workforce section) or care delivered (see needs assessment, pathways, guidelines, QI, ICT and metrics sections) in order to ensure that the capability of services to provide care is developed and quality of care is

optimised.

Specialist palliative care services should be organised around the hub of the specialist palliative care unit. Each Community Healthcare Organisation (CHO) and Hospital Group should have a comprehensive specialist palliative care service to meet the needs of patients and families in the area. In areas with a wide geographical spread, it may be necessary to develop satellite specialist palliative care inpatient unit(s) to meet the needs of patients and families in the area. When there is more than one specialist palliative care unit in a CHO, it is important to optimise resource utilisation. Each CHO should have in place governance structures in line with national recommendations, service level and management arrangements in place to ensure integration and partnership.

The specialist palliative care unit should comprise an in-patient unit, community palliative care service, Day Hospice, Out-Patient Service and Bereavement Service. Hospital-based specialist palliative care teams, should have formal links with the specialist palliative care unit. Services should be configured to facilitate patients who are transitioning from one care setting to another depending on their clinical situation and care preferences.

A number of infrastructural deficits in service provision remain and are provided for in the Three Year Development Framework (2017 – 2019)

- 14-bed specialist palliative care unit in Mayo.
- 20-bed specialist palliative care unit in Waterford.
- 15-bed specialist palliative care unit in Wicklow.
- 30/36-bed specialist palliative care unit in Drogheda.
- 15-bed specialist palliative care unit in Tullamore.
- 16-bed specialist palliative care unit in Cavan.
- Re-development of existing specialist palliative care units to all single rooms and in some instances the expansion of services. [7]

The Report of the National Advisory Committee on Palliative Care recommended that specialist palliative care teams should be inter-disciplinary and consultant-led. It recommended that a specialist palliative care unit should be staffed with the following disciplines: medicine, nursing, physiotherapy, occupational therapy, pharmacy, pastoral care, and social work. [8] Sessional commitments from speech and language therapy and dietetics were recommended.

Considering the changing profile of patients receiving palliative care, interventional and workforce developments, the Model of Care recommends that the workforce planning recommendations of the Report are re-visited. This document recommends that specialist palliative care teams should comprise teams who have, or are in the process of acquiring, specialist palliative care competences as detailed in

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the Palliative Care Competence Framework. [9] It recommends that the specialist palliative care team comprises medicine, nursing, physiotherapy, occupational therapy, pharmacy, social work dietetics, speech and language therapy, psychology, psychiatry and pastoral care. It recommends that sessional commitments from Anaesthetic Pain teams and Radiology are available. (See Workforce section for further detail on all disciplines).

As the work underpinning the staffing recommendations of the NACPC Report is over 15 years old, It recommends that additional exercises in workforce planning are undertaken in order to determine optimal staffing levels according to case-mix and volume of service provided. There currently is a significant shortfall in health and social care professionals practicing in specialist palliative care according to the levels recommended in the Report. As an immediate step, the Model of Care recommends that this deficit is addressed while the workforce planning exercises are being carried out. The findings of the exercises should inform the next phase of workforce development.

Taking this phased approach to the implementation of workforce planning recommendations:

- The 1-3 year objective of specialist palliative care service development should be that in-patient unit services (including admissions) should be available on a 7-day basis. There should be at least 8 to 10 specialist palliative care beds per 100,000 population. This requirement may vary within each CHO depending on the demographic and socio-economic composition of the area. During core working hours, patients who are cared for in the in-patient unit should have access to all members of the specialist palliative care team. At a minimum, on-site nursing and off-site medical services should be available during out-of-hours periods.
- The 1-3 year objective of community specialist palliative care services should be that services are available on a 7-day basis to community palliative care patients (which includes patients in residential care). During core working hours, patients should have access to all members of the specialist palliative care team. At a minimum, nursing services should be available over evening and daytime weekend periods to patients who are under the care of a community palliative care team. Phone call support should be available for over-night periods.
- The 2-5 year objective of hospital-based specialist palliative care teams should be that services are available in model 3 and 4 hospitals on a 5-day basis. At a minimum, patients should have on-site access to specialist palliative care doctors, nurses, social workers and pastoral care during core working hours. At a minimum, on-site specialist palliative care nursing and off-site medical services should be available for daytime weekend periods. Phone call support should be available for over-night periods.

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- The 5-10 year objective of hospital-based specialist palliative care teams should be that services are available in all hospitals on a 7-day basis. At a minimum, patients should have on-site access to specialist palliative care doctors, nurses, social workers and pastoral care during core working hours. At a minimum, on-site specialist palliative care nursing and off-site medical services should be available for daytime weekend periods. Phone call support should be available for over-night periods.
- The National Clinical Programme for Palliative Care recognises that there is scope for increasing access to specialist palliative care services further e.g. provision of hospital-based specialist palliative care services over night-time periods or admitting new patients to community palliative care services during weekend periods. However, given the existing deficits in service provision and the limitations of current workforce planning calculations, the National Clinical Programme for Palliative Care recommends that a needs assessment of out-of-hours service provision, piloting and evaluation of new models of out-of-hours service provision is undertaken before extending services further. Evaluation of these extended hours of access should be made in the short term i.e. within a 1-3 year period in order to allow implementation within a 10-year time-frame, if effective.
- Day Hospice and Out-Patient and Bereavement service frequency should be dependent on the findings of regional needs assessments. These assessments should be conducted within a 1-3 year time-frame.

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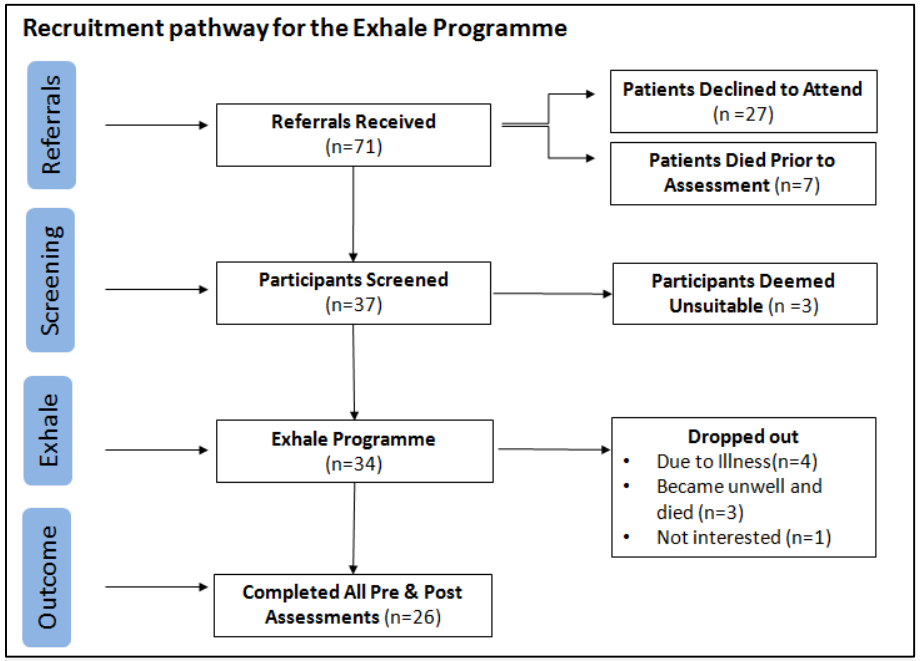
THE EXHALE PROGRAMME- A NOVEL EXERCISE AND EDUCATION PROGRAMME FOR PATIENTS WITH ADVANCED LUNG DISEASE RECEIVING SPECIALIST PALLIATIVE CARE

Patients with advanced lung disease are often unable to participate in mainstream pulmonary rehabilitation programmes. The Exhale Programme was designed in St Francis Hospice, Dublin to deliver and evaluate the benefits of a group exercise and education programme for this population.

A literature review was conducted and the programme was devised based on evidence-based practice. It comprised an initial assessment, followed by once-weekly OPD attendance where an SPC physiotherapist provided education (to patient +/- family member) and a programme of activity focused on improving exercise tolerance and self-mastery of breathlessness. A home exercise programme was prescribed. The programme lasted 5 weeks.

A pathway for referrals was established following meetings with relevant stakeholders. Participants were accepted with a diagnosis of advanced lung disease. Participants were excluded if they had a diagnosis of pulmonary hypertension or a cognitive impairment.

Outcome measures administered before and after the programme were: the Hospital Anxiety and Depression Scale (HADS), the Chronic Respiratory Questionnaire (CRQ), the Six Minute Walk Test (6MWT),and the Timed Up and Go (TUG). The programme ran for 12 months.



18 female and 16 male participants with an average age of 72.5 years enrolled. 26 had a diagnosis of COPD, 5 had pulmonary fibrosis, 2 had lung cancer (1 'other'). Pre-and post- programme assessments demonstrated clinically meaningful improvement in walking ability. Patients also showed improvements across all four domains of the CRQ. The completion rate was 76% demonstrating that this programme is safe and feasible in patients with advanced lung disease. Participants benefitted from peer support and and socialisation with other patients.

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FOUNDATION 5. All services are supported to work together to provide an integrated model of palliative care provision.

Quality palliative care provision is best realised when strong networks exist between organisations- when services work together to meet the needs of the population. This model of care requires that Hospital Groups and CHOs build service networks that are capable of responding to a diverse range of needs, from the relatively uncomplicated to those that require specialist support. Patients with life-limiting conditions must be able to engage easily with the level of expertise most appropriate to their needs regardless of location, care setting or diagnosis.

The settings in which palliative care services need to be provided are as varied as the living circumstances of the patients themselves. Services should be delivered where the patient is, which may be in:

- Hospital settings;
- Community settings;
- Organisations where palliative care support beds are located;
- Specialist palliative care units (referred to as 'hospices');
- The home of the patient or their carer (this includes residential care settings, residential care and such facilities as prisons / psychiatric units / hostels etc.).

In building such networks, it is important that care pathways should be built around the needs of the patient, not the structure. Patients and their carers deserve care that is joined up and coordinated, that is easy to access and easy to navigate. Unfortunately, patients and carers frequently report that the care they receive is fragmented and that multiple professionals and organisations work with little awareness of each other. Collaborative care requires joined up thinking and working by individuals and by organisations. It requires a focus on the patient and family, multidisciplinary ownership of the care experience over time, good information sharing across all dimensions of care, a true measurement of outcomes, and a strong focus on quality improvement.

There is no single way to put integrated care into practice. However, shared knowledge of patient and family need is the starting point; partnership is a key process; and communication of strategic vision can empower action in services and teams. [10] The barriers to integrated care are well described but it is useful to explicitly consider them in this Model of Care so that actions to overcome them can be considered and implemented, where relevant: [11]

- **Governance**- lack of clarity regarding clinical and/or operational responsibility.

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- **Operating procedures between organisations-** the absence of agreed procedures for the transfer of patients between organisations can create delays and gaps in the pathway. A lack of common assessment processes / tools also contributes to delay.
- **Clinical Practice-** different approaches to management of patients between different organisations can lead to inconsistency in care plans.
- **Quality of IT and communication systems-** information is a key enabler of integrated care and healthcare records, wherever possible, should be accessible at the point of care throughout the whole care journey.
- **Organisational cultural differences-** affect willingness to share information and resources and impact on patient flow.

Specialist palliative care services should demonstrate leadership in engaging constructively with hospital, community and primary care providers to identify and improve ways to provide integrated palliative care. This may include developing intersecting policies and procedures for inter-organisational working in order to facilitate a mutual understanding of roles, responsibilities and care pathways; sharing health records, where appropriate, across and within organisations involved in care; and developing mechanisms to measure people's experience of integrated care and support.

The National Clinical Programme for Palliative Care has produced a number of resources to assist in the development of a shared culture, standardisation of practices and improved communication and clarity over clinical roles and responsibilities:

- Glossary of Terms
- Palliative Care Competence Framework
- The Role Delineation Framework describes the place and relationships of individual service providers within the broad mosaic of palliative care provision. The aim of the document is to provide a consistent language and set of descriptors that healthcare providers and planners can use when describing palliative care services and planning service developments to improve the integration of care provided in an area.
- Palliative Care Needs Assessment Guidance
- Clinical Guidelines and Rapid Discharge Guidance
- National Specialist Palliative Care Eligibility, Referral and Discharge Criteria

The Programme has also collaborated with other national clinical care and integrated care programmes to undertake projects (such as Project Echo and the PAL.M.ED project) that demonstrate integrated working in practice.

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A NEW COMPONENT OF INTEGRATED CARE- DEVELOPING AN INTERVENTIONAL PAIN UNIT IN A SPECIALIST PALLIATIVE CARE UNIT

The WHO Analgesic Ladder has long been established as the gold standard in the treatment of cancer pain. Initially it was felt that it may offer good relief in up to 90% of patients. However more recent evidence has suggested that up to 30% of cancer pain sufferers may continue to experience pain, despite use of the analgesic ladder. That would imply that up to 48,000 cancer patients per year in Britain may endure severe pain (1).

It has been recognised for many years that interventional techniques may be extremely beneficial for the group of patients who continue to experience pain despite use of systemic analgesia. As a result, a revised analgesic ladder has been proposed incorporating a step 4 (major interventions such as intrathecal analgesia) and recommending that simple nerve blocks can be done at any step in the process to compliment analgesia (2). Despite this, under-utilisation of interventional techniques in the management of cancer pain remains commonplace. Reasons for this include poor interdisciplinary communication, ad hoc referral arrangements, lack of funding and inadequate planning (3, 4).

Historically, there have been strong links between the Pain Medicine service, the Oncology Service and Palliative Medicine in Cork.

Interventional procedures for cancer pain were carried out in the acute hospital, frequently necessitating the transfer of sick patients out of the hospice setting to a busy interventional pain clinic, which was neither patient appropriate nor economically sensible. Consequently, when the new Marymount University Hospital and Hospice was being planned it was decided to incorporate an interventional pain unit. This now consists of an outpatient suite, secretarial offices, a procedure room with x-ray and ultrasound facilities and a three-bedded recovery.

In 2017, there were 625 outpatient consultations, with 85 new patients seen. 181 procedures were carried out. A further 90 inpatient consultations occurred. All patients were reviewed expeditiously and typically procedures were performed within 2 weeks of review.

This project resulted from co-operation between various specialties and involved interdisciplinary collaboration between medical, nursing, radiology, pharmacy and clerical staff. Patients were treated without delay in an appropriate setting, avoiding acute hospital attendance and admission. Results have been extremely encouraging and demonstrate the feasibility of incorporating the use of interventional techniques at all stages of cancer pain management, not just when standard analgesia has been unsuccessful.

1. O Brien et al. Pain services and palliative medicine – an integrated approach to pain management in the cancer patient. British Journal of Pain 2014, 8(4): 163-171.
2. Raphael et al. Cancer pain, a perspective from the British Pain Society. Pain Medicine 2010, 11: 742-764.
3. Linklater et al. Pain management services in palliative care: a national survey. Palliative Medicine 2002, 16: 435-439.
4. Kay et al. Provision for advanced pain management techniques in adult palliative care; a national survey of anaesthetic pain specialists. Palliative Medicine 2007, 21: 279-284.

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FOUNDATION 6. Effective and timely flow of information between hospitals, specialists, community and primary healthcare providers is in place.

Data and information-sharing are essential aspects of a robust and effective healthcare infrastructure. It is particularly important that shared access to patient information is established in palliative care, as care is typically provided by a number of health and social care professionals working in different services and settings.

Electronic Health Records (EHRs) make information for decision-making available at the point of care. There is a particular need for specialist palliative care providers to have out of hours access to electronic information in order to respond effectively to palliative care emergencies and maintain care in the persons home as far as is possible. Accessibility also enables healthcare providers to reduce costs associated with duplicating tests, since providers have access to results of tests already performed. Additionally, electronic data collection enhances the abilities of organisations to monitor trends in quality, safety and cost information.

Through the Office of the Chief Information Officer (CIO) of the HSE, eHealth Ireland is progressing a number of strategic programmes that act as the catalyst for a change in how technology is delivered to health. Of particular relevance to palliative care are the EHR (Electronic Health Record) programme, and the initiatives in relation to information sharing such as eReferrals, NIMIS, MedLis, healthmail, healthlink projects and the GP Out of Hours Palliative Care Handover form. These are further discussed in the ICT (information and communication technology) section of the Palliative Care Model of Care. In particular, the role that specialist palliative care services can play in becoming early adopters of national EHR and shared record projects is discussed.

INTERNATIONAL INFORMATION AND COMMUNICATION TECHNOLOGY INITIATIVES IN PALLIATIVE CARE

Useful international examples of Information and Communication Technology (ICT) initiatives in palliative care include Electronic Palliative Care Coordination Systems (EPaCCS), in use in the UK.

EPaCCS are a variety of electronic registers or tools and processes for sharing data which aim to enable access to information about dying patients. [12] EPaCCS aim to provide up-to-date key information to a range of service providers GP practices, primary and community care services, GP out of hours services, Emergency Departments, ambulance services, hospitals, and specialist palliative care services. While notable successes have been demonstrated such as 77.8% of patients registered with the 'Coordinate My Care' initiative dying in their preferred place, a number of challenges have been seen also. A recent review noted key challenges

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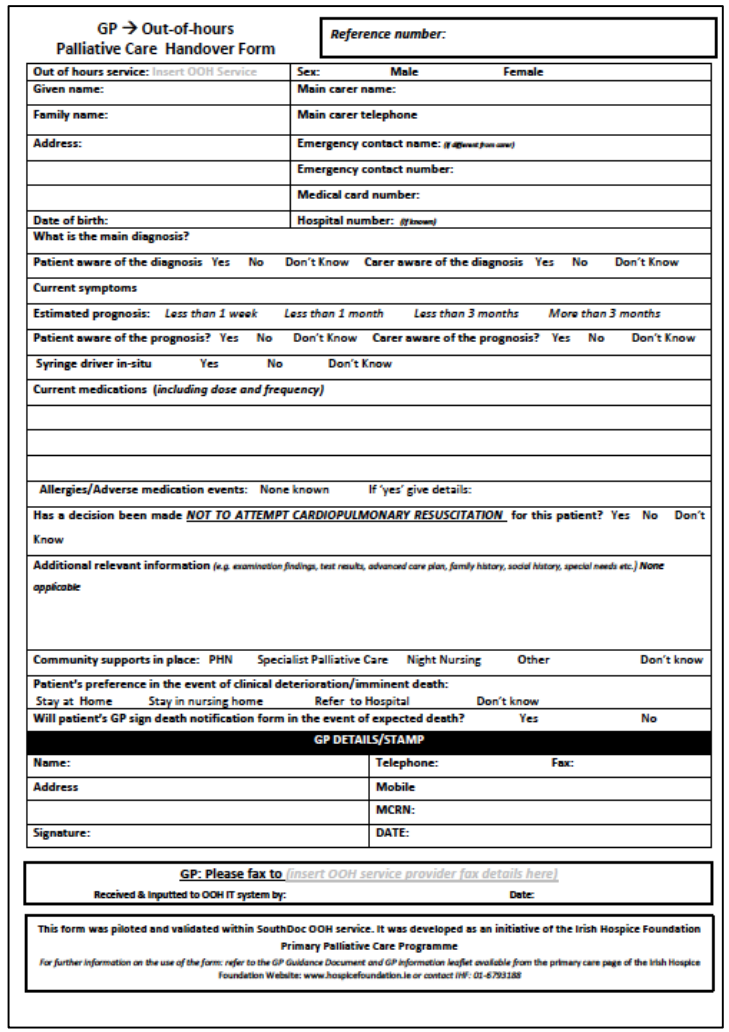
(scope of projects, unrealistic expectations set by existing guidance, the discrepancy between IT realities in healthcare and our broader lives, information governance and concerns regarding decision-making) and key drivers (robust concept, striking outcomes, national support and strong clinical leadership, clinician commitment, education and funding) that are of relevance to the Irish setting.

OUT OF HOURS PALLIATIVE CARE HANDOVER FORM

GPs play a pivotal role in the delivery of palliative care to patients in their homes. The need to develop a standardised information transfer process between GP and Out of Hours services was highlighted as a key priority in the report 'Primary Palliative Care in Ireland' that was produced by the HSE, the Irish Hospice Foundation, and the Irish College of General Practitioners. In 2012, the Primary Palliative Care steering group of the Irish Hospice Foundation commenced a project to produce a GP Out of Hours Palliative Care Handover Form. The document supports the transfer of relevant information from G.Ps to Out of Hours services to assist in the care of the patient with palliative care needs. It is not intended to replace usual medical assessment or management. An evaluation of the Handover form Pilot Project which was carried out by Southdoc is available on the Irish Hospice Foundation website



GP → Out-of-hours
Palliative Care Handover Form

Reference number:

Out of hours service: Insert OOH Service	**Sex:** Male Female
Given name:	**Main carer name:**
Family name:	**Main carer telephone**
Address:	**Emergency contact name:** *(if different from carer)*
	Emergency contact number:
	Medical card number:
Date of birth:	**Hospital number:** *(if known)*

What is the main diagnosis?

Patient aware of the diagnosis Yes No Don't Know **Carer aware of the diagnosis** Yes No Don't Know

Current symptoms

Estimated prognosis: *Less than 1 week* *Less than 1 month* *Less than 3 months* *More than 3 months*

Patient aware of the prognosis? Yes No Don't Know **Carer aware of the prognosis?** Yes No Don't Know

Syringe driver in-situ Yes No Don't Know

Current medications ***(including dose and frequency)***

Allergies/Adverse medication events: None known If 'yes' give details:

Has a decision been made *NOT TO ATTEMPT CARDIOPULMONARY RESUSCITATION* for this patient? Yes No Don't Know

Additional relevant information *(e.g. examination findings, test results, advanced care plan, family history, social history, special needs etc.)* ***None applicable***

Community supports in place: PHN Specialist Palliative Care Night Nursing Other Don't know

Patient's preference in the event of clinical deterioration/imminent death:
Stay at Home Stay in nursing home Refer to Hospital Don't know

Will patient's GP sign death notification form in the event of expected death? Yes No

GP DETAILS/STAMP

Name:	**Telephone:** **Fax:**
Address	**Mobile**
	MCRN:
Signature:	**DATE:**

GP: Please fax to *(insert OOH service provider fax details here)*
Received & inputted to OOH IT system by: **Date:**

This form was piloted and validated within SouthDoc OOH service. It was developed as an initiative of the Irish Hospice Foundation Primary Palliative Care Programme
For further information on the use of the form: refer to the GP Guidance Document and GP information leaflet available from the primary care page of the Irish Hospice Foundation Website: www.hospicefoundation.ie or contact IHF: 01-6793188

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FOUNDATION 7. A culture of quality improvement is embedded in palliative care provision.

Organisational culture refers to how things are done in an organisation, as well as prevailing attitudes, patterns of accepted and expected behavior, and the habits that become part of the organisation's principles and philosophy. [13,14,15] The development of a quality culture requires a commitment to leadership, communication, organisation-wide shared values, pervasive behaviours, and complementary performance metrics and incentives. The challenges of embedding such a culture are widely recognised. Indeed, continuous improvement doesn't happen overnight, it is a multiyear journey that requires long-term vision and commitment. Building the infrastructure for improvement takes time and there is often an investment threshold that has to be reached before these efforts demonstrate results.

The key goal of quality improvement is to achieve changes in practice which improve patient, carer and staff experiences and outcomes. In order to achieve this, services need to define what quality means, define quality goals, disseminate these objectives, measure group and individual performance and then reward those who are making it happen. In doing this, it is important to recognise that quality improvement needs to be more than simply a project-based strategy – quality must become *the* organisational strategy for palliative care services.

The implementation of Safer, Better Healthcare Standards is a key lever in developing a culture of quality improvement in palliative care and the wider healthcare system. [16] Importantly, the Standards should be used to encourage the alignment of quality improvement *across* organisations with an emphasis placed on whole system thinking and working rather than organisational performance alone. Quality, for the patients and their families should mean that services work effectively to support continuity of care and experience across the entirety of the patient journeys.

The National Clinical Programme for Palliative Care has developed a number of resources to support the establishment of a culture of quality improvement in palliative care. They are detailed in the QI section of this document and include the development of Quality Improvement workbooks and the formation of a national Palliative Care QI collaborative which serves as a meeting place for quality and culture.

Importantly, however, investment must be also made in capability building of staff to provide them with the skills needed to improve quality and clinical leadership. Specific goals for quality improvement should be set, based on evidence and supported by the use of information to assess progress towards achievement. Performance in relation to goals should be

published and comparative information used to benchmark performance and stimulate improvement. Openness to learning from organisations at home and abroad is a key characteristic that should be cultivated.

SPECIALIST PALLIATIVE CARE QUALITY ASSESSMENT AND IMPROVEMENT COLLABORATIVE

The specialist palliative care quality assessment and improvement collaborative aims to develop a nation-wide culture of improvement with a commitment to further continuous learning. Provider participation in this voluntary collaborative means that organisations access a valuable forum where there is sharing of best practices and comparison of data. This stimulates improvement efforts and increases transparency.

While specialist palliative care services are at different points on their quality paths, all are committed to improving patient safety and reducing adverse events. The development of standardised performance measures and sharing of data has highlighted opportunities for quality improvement and has created an impetus for action that is delivering tangible results for patients, families and staff. The collaborative shares best practices and successful case studies through various methods including regular meetings, a web-based repository of policies, protocols and guidelines, a web-based implementation toolbox and a shared learning e-forum.

The collaborative supports local change and provides the field with key insights. Lessons learned from local implementation efforts help with issues of spread and sustainability. The collaborative's quality improvement efforts are guided by the overarching aims of the National Standards for Safer, Better Healthcare. Enquiries about the QA+I collaborative can be made to clinicalprogrammesadmin@rcpi.ie

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FOUNDATION 8. A research and innovation agenda that improves the quality and value and lowers the cost of palliative care is supported.

The Irish health system is transforming to embrace a strong focus on quality and safety, value-driven payment and greater patient engagement in health care decision-making. The transformation is based on a command of knowledge and information and so research and innovation are critical enablers in this process. In the business world, it is accepted that every successful knowledge-based enterprise needs to make strategic investments in research, development, and innovation. The same is true for healthcare in general, including palliative care. This is because palliative care faces the same challenges as the rest of the healthcare system, how to improve quality, reduce harm, improve access, increase efficiency, eliminate waste, and maximise value for money. Under our present system, just doing our best or working harder will not be enough.

Health research plays an important role not only in improving health outcomes, but also in contributing to the overall societal and economic prosperity. Health research advances our fundamental understanding of the complex factors that influence our health and opens the door to innovative solutions that can affect our health, social and economic well-being [17,18]. Innovation involves improving the methods of working and developing products or services. Innovation involves doing something differently rather than doing the same thing and expecting different results.

For research and innovation to happen in palliative care, we need:

- **Culture:** open, supportive, adaptable, creative;
- **Capability:** interdisciplinary teams with knowledge and skills;
- **Capacity:** adequate resourcing in terms of time and money;
- **Collaboration:** between disciplines, specialties, patients and families.

A research and innovation agenda embedded in palliative care provision that gives all healthcare professionals working in palliative care the opportunity to engage in research is required. This should include the active engagement of patients and carers in all aspects of the process. Voices4Care provides a strong platform for developing this engagement further.

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THE PALLIATIVE CARE RESEARCH NETWORK (PCRN)

In 2012, the All Ireland Institute of Hospice and Palliative Care launched the Palliative Care Research Network (PCRN) to address the need for more collaborative multidisciplinary research in palliative care. The network's aim is to undertake excellent research for people who need palliative care that has high impact, builds research capacity and drives collaboration in palliative care research. Its three main objectives are to:

- Integrate palliative care research, education and practice development in the health and social care systems across the island of Ireland.
- Partner with users, carers and communities to ensure that palliative care provision continues to meet their needs.
- Support the development of generalist and specialist palliative care to meet the current and emerging demands of the health system.

The PCRN is constantly expanding its membership. Current members include academic institutions on the island of Ireland (UCD, TCD, DCU, NUIG, UCC, RCSI, QUB, UU), people with palliative care needs and their family/carers (through AIIHPC Voices4Care), hospices and palliative care providers, health agencies and funding organisations. Members have access to a directory of people, their research, and valuable resources to build research collaboration, to extend their capacity and apply for joint funding.

More information about the Palliative Care Research Network can be found at: https://aiihpc.org/our_work/research/

PAL.M.ED PROJECT

The contribution that research and innovation can make to the improvement of health services is illustrated by a National Clinical Programme for Palliative Care demonstration project that was funded by the Irish Hospice Foundation. **PAL.M.ED.** (**Pal**liative **M**edicine in the **E**mergency **D**epartmen**t)** was a project designed and undertaken by the Departments of Palliative Medicine and Emergency Medicine at St. Vincent's University Hospital aimed at improving access to specialist palliative care in the emergency department, and examining the effects of early referral to palliative care for patients. The team:

- Developed a new tool – P.A.U.S.E to identify patients previously not known to palliative medicine service at the hospital.
- The patient administration system in the ED was modified to "flag" patients known previously to the Hospital's palliative medicine service.
- An education programme was delivered to all doctors and nurses working in the emergency department.
- The palliative care team attended the Emergency Department each

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morning to liaise with the team there regarding potential referrals.

After the introduction of PAL.M.ED

- There was an eight fold increase in referrals from the Emergency Department to the palliative medicine team.
- A palliative medicine consultation in the ED (versus later in the hospital stay) was significantly associated with reduced length of hospital stay (**mean reduction in length of stay = 10.9 days**), as well as reduced laboratory tests.
- 11% of seriously ill patients reviewed by the specialist palliative care team in ED avoided a hospital admission.
- Patients reviewed by the palliative service in the ED were more likely to be discharged back to their own home.

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KEY POINTS- FOUNDATION 1

- The Overview Patient Pathway is a diagrammatic high-level representation of patient and carer pathways in the Model of Care.
- It comprises the key elements of:
  - Palliative care needs assessment.
  - Development of a care plan that addresses physical, emotional, psychosocial and spiritual needs.
  - Multidisciplinary team management.
  - Advance care planning.
  - Anticipatory care planning.
  - Crisis support.
  - Family and carer support.
- All health and social care professionals who care for patients with life-limiting or life-threatening illness should be able to carry out a palliative care needs assessment. The Palliative Care Needs Assessment guidance document and accompanying training materials support staff in carrying out palliative care needs assessments.
- A palliative care assessment should lead to the 'right response' being initiated.
  - Patients with non-complex needs should have care provided by usual services, with indirect support from specialist palliative care if needed. (Indirect support may take the form of education, training, phone call advice or the co-development of guidelines and care pathways).
  - Patients with complex needs should have care provided by usual services and specialist palliative care in partnership. The Specialist Palliative Care Referral Pathway describes referral criteria and accompanying resources for those patients with complex needs who require referral to specialist palliative care services.

KEY POINTS- FOUNDATION 2

- Family and carer needs should be assessed so that they receive practical, emotional, psychosocial and spiritual support, including into bereavement.
- Practical ways of providing support include:
  - Recognising the value and contribution of carers and promoting their inclusion in decisions relating to the person that they are caring for.
  - Being proactive in the provision of timely and clear information

and advice regarding services (including respite services), allowances and entitlements.

- Providing carers with relevant and accessible training opportunities.
- Ensuring that patients and carers can easily access appropriate levels of respite care.
- Ensuring that carers can easily access appropriate levels of bereavement support.

KEY POINTS- FOUNDATION 3

- An enabling environment should be created where hospital, community and primary healthcare providers are supported to provide a palliative care approach as part of their normal service provision.
- Practical ways this may be achieved include:
  - Supporting GPs and members of hospital and primary care teams to engage in palliative care needs assessment and care planning - including the development of anticipatory care plans and advance care plans.
  - Supporting GPs to do home visits.
  - Supporting MDT meetings between specialist palliative care teams and primary care and community teams, when required.
  - Providing training and education to hospital, community and primary care staff to gain and maintain palliative care competences. New technologies, such as tele-learning, should be used to reach greater numbers of staff in ways that suit their busy schedules (e.g. Project ECHO).
  - Optimising the alignment between the Hospice Friendly Hospitals Network and the National Clinical Programme for Palliative Care.
  - Implementing the findings of the Palliative Care Support Beds Review.
  - Ensuring that palliative care is considered and integrated into National Clinical Programme models of care and National Integrated Care Programmes.
  - Developing, piloting and implementing metrics to monitor, manage and support the effectiveness of integrated palliative care provision.
- The provision of palliative care is time- and resource-intensive and and deficits in staffing levels impact on hospital, community and GPs and primary care staff to provide care. Staffing deficits (both in terms of numbers and training) must be addressed in order for a palliative care approach to become embedded in usual care.

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KEY POINTS- FOUNDATION 4

- The role of specialist palliative care teams is to:
  - Apply in-depth specialist knowledge and skills to alleviate symptoms, suffering and distress;
  - Support the management of complex clinical and ethical decisions relating to serious illness, end of life care and bereavement;
  - Provide care and support to those important to the patient receiving care, including facilitating bereavement care;
  - Offer specialist advice and support to the referring team providing palliative care approach services
  - Play a lead role in developing best practice in palliative care and contribute to the delivery of education, training and CPD to the wider workforce.
- When providing care in the hospital or community, the specialist palliative care team ordinarily work as a support team working in an integrated way with the referring team. When providing in-patient or out-patient care, specialist palliative care teams ordinarily assume main responsibility for the care provided for those episodes of care.

- There are a number of infrastructural deficits in specialist palliative care service provision across the country that should be addressed:
  - 14-bed specialist palliative care unit in Mayo.
  - 20-bed specialist palliative care unit in Waterford.
  - 15-bed specialist palliative care unit in Wicklow.
  - 30/36-bed specialist palliative care unit in Drogheda.
  - 15-bed specialist palliative care unit in Tullamore.
  - 16-bed specialist palliative care unit in Cavan.
  - Re-development of existing specialist palliative care units to all single rooms and in some instances the expansion of services.
- There are a number of resource deficits in specialist palliative care service provision. While updated workforce planning has been conducted for the palliative care consultant workforce, there is an urgent need to complete workforce planning exercises for nursing, health and social care professionals and other disciplines such as psychology and psychiatry. These exercises should focus not only on the numbers of staff required for service provision, but should also consider new ways of working (including role expansion).

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- While this work is awaited, it is recommended that the following specialist palliative care staffing ratios are applied (further detail may be found in the workforce section of the Model of Care):
  - Consultants in Palliative Medicine- as per National Doctors Training and Planning report
  - Nursing- as per the Report of the National Advisory Committee on Palliative Care with the modification that specialist palliative care nursing is provided in model 3 and 4 hospitals on a 7-day basis
  - Health and Social Care professionals– as per the Report of the National Advisory Committee on Palliative Care with the modification that posts are appointed at senior or specialist grade.
- In-patient unit services (including admissions) should be available on a 7-day basis.
- There should be at least 8 to 10 specialist palliative care beds per 100,000 population. This requirement may vary within each CHO depending on the demographic and socio-economic composition of the area.
- During core working hours, patients who are cared for in the in-patient unit should have access to all members of the specialist palliative care team. At a minimum, on-site nursing and off-site medical services should be available during out-of-hours periods.
- Community specialist palliative care services should be available on a 7-day basis to community palliative care patients (which includes patients in residential care settings).
- During core working hours, patients should have access to all members of the community palliative care team. At a minimum, nursing services should be available over evening and daytime weekend periods to patients who are under the care of a community palliative care team. Phone call support should be available for over-night periods.
- Hospital-based specialist palliative care teams should be available on a 7-day basis. At a minimum, patients should have on-site access to palliative care doctors, nurses, social workers and pastoral care during core working hours. At a minimum, on-site specialist palliative care nursing and off-site medical services should be available for daytime weekend periods. Phone call support should be available for over-night periods.
- Day Hospice and Out-Patient and Bereavement service frequency should be dependent on the findings of regional needs assessments.

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- The National Clinical Programme for Palliative Care recognises that there is scope for increasing access to specialist palliative care services further e.g. provision of hospital-based specialist palliative care services over night-time periods or admitting new patients to community palliative care services during weekend periods. However, given the existing deficits in service provision and the limitations of current workforce planning calculations, the National Clinical Programme for Palliative Care recommends that a needs assessment of out-of-hours service provision, piloting and evaluation of new models of out-of-hours service provision is undertaken before extending services further.

KEY POINTS- FOUNDATION 5

- Quality palliative care provision is best realised when strong networks exist between organisations- when services work together to meet the needs of the population.
- The model of care requires that Hospital Groups and CHOs build service networks that are capable of responding to a diverse range of needs, from the relatively uncomplicated to those that require specialist support.
- Specialist palliative care services should demonstrate leadership in engaging constructively with hospital, community and primary care providers to identify and improve ways to provide integrated palliative care.
- This may include:
  - Developing intersecting policies and procedures for inter-organisational working in order to facilitate a mutual understanding of roles, responsibilities and care pathways
  - Sharing health records, where appropriate, across and within organisations involved in care
  - Developing mechanisms to measure people's experience of integrated care and support
  - Developing models of integrated care such as the Interventional Pain Service.

KEY POINTS- FOUNDATION 6

- Enhanced ICT for Palliative Care is a key capability requirement for the future delivery of healthcare and a core component of the Palliative Care Model of Care.
- Practical ways this can be achieved, include:
  - Including palliative care services providers (both services providing a palliative care approach and those providing specialist palliative care services) as early adopters of the national shared record.

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- Supporting the use of Healthmail by palliative care services providers (both services providing a palliative care approach and those providing specialist palliative care services)
- Supporting the development of Healthlink in order to ensure that specialist palliative care services can avail of the full functionality of the service.
- Supporting specialist palliative care services to develop a functional interface with MedLIS.
- Supporting specialist palliative care services to use NIMIS.
- Developing video-conferencing facilities in order to lower the feasibility threshold for timely and essential case conferences.
- Supporting the use of out-of-hours handover forms by GPs and members of ambulance, community and specialist palliative care teams.

KEY POINTS- FOUNDATION 7

- The National Standards for Safer, Better Healthcare represent an important opportunity for staff to work together to make Irish health services better for everyone, by establishing a shared understanding of quality and committing to place it at the heart of everything that is done.
- High quality, safe and effective palliative care provision is an essential component of healthcare and its importance is recognised by the Health Information Quality Authority (HIQA).
- Implementation of this model of care will assist services in meeting the standards of care detailed in the National Standards for Safer, Better Healthcare and the National Standards for Residential Care Settings for Older People In Ireland.
- Specialist palliative care services may also wish to participate in the national Quality Improvement Collaborative for Specialist Palliative Care in order to share learning and methods of improvement.

KEY POINTS- FOUNDATION 8

- A research and innovation agenda embedded in palliative care provision that gives all healthcare professionals working in palliative care the opportunity to engage in research is required.
- The Palliative Care Research Network provides a structured support to the development of palliative care research capacity in Ireland.
- The research and innovation agenda should include the active engagement of patients and carers in all aspects of the process. Voices4Care provides a strong platform for developing this engagement further.

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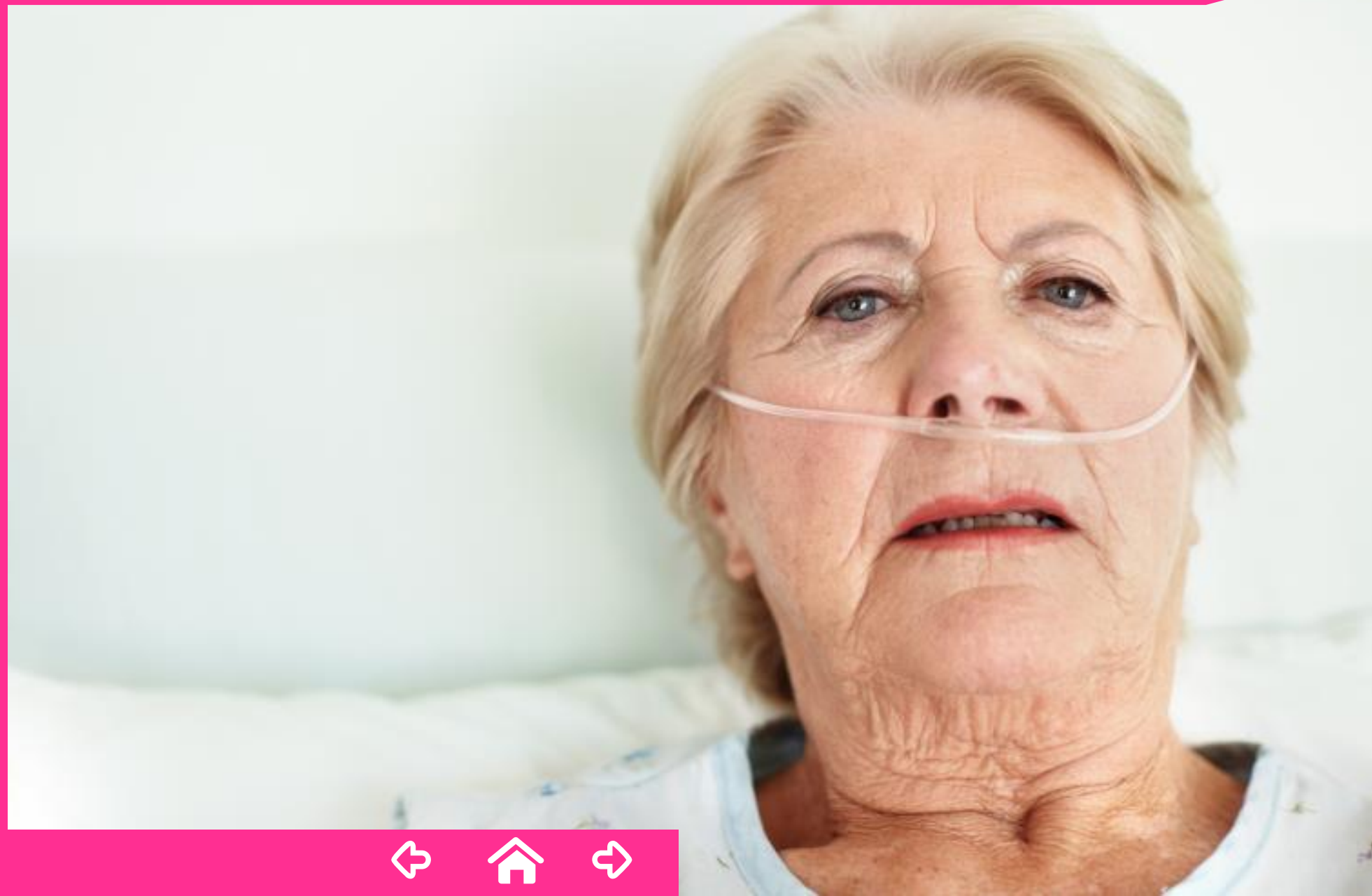

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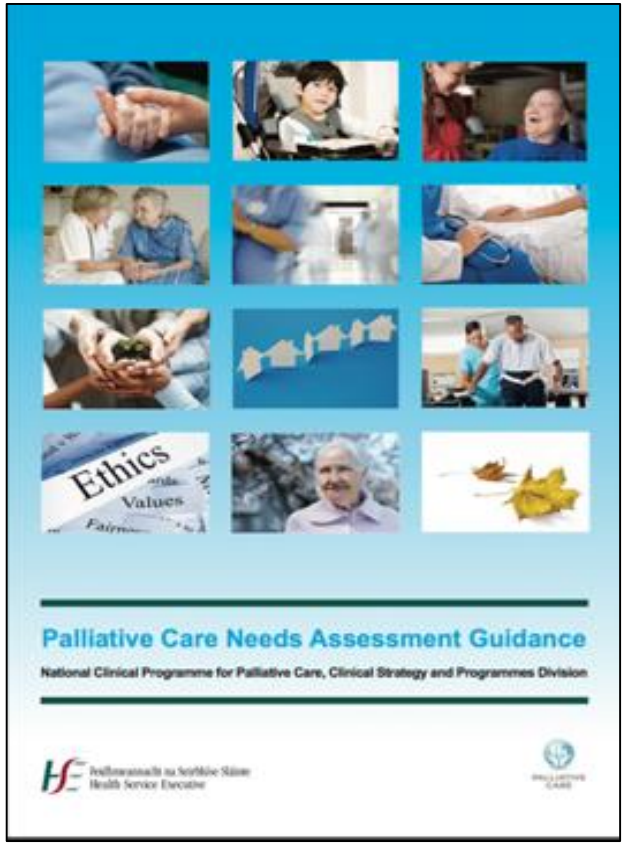
BACKGROUND

This section provides practical guidance on how to conduct effective needs assessments and care planning with patients and their families. **The Palliative Care Needs Assessment is a key component of the palliative care model of care.** Needs assessments are often not undertaken in a formal, structured or holistic way. As a result, distressing symptoms and concerns, experienced by patients may remain unrecognised. [1-4] Research has highlighted that symptoms and concerns are best managed if they are identified in a timely manner and if prompt referral is made to specialist teams for those who need it.

Theoretically, implementing a prescribed suite of clinical tools might improve assessment and outcomes. However, there is not yet clear evidence as to which tools are the most appropriate or useful for palliative care needs assessment. For this reason, rather than mandating a specific assessment tool, the National Clinical Programme for Palliative Care has developed guidance for healthcare professionals to help them understand essential elements and best practice in palliative care needs assessment. Organisations may choose to use standardised assessment tools (e.g. IPOS, ESAS, comprehensive geriatric assessment) as long as they ensure that a comprehensive and holistic assessment of patient and family needs *in the context of a life-limiting or life-threatening illness* is conducted as described in the Palliative Care Needs Assessment Guidance.



NEEDS ASSESSMENT

PALLIATIVE CARE NEEDS ASSESSMENT GUIDANCE

What is a palliative care needs assessment?

A needs assessment is a process of identifying the needs of the patients by focusing on the whole person and their well-being. A palliative care needs assessment looks at the individual through the lens of life-limiting or life-threatening illness and asks whether the individual is experiencing physical, emotional, psychosocial and spiritual needs as a result of illness. If needs are identified, then the healthcare professional should develop a care plan to meet those needs in partnership with the patient.

Who should be assessed?

All people with life-limiting conditions irrespective of age or setting.

When should the assessment take place?

Good clinical practice dictates that assessment should be an ongoing process throughout the course of a patient's illness. We suggest that assessments be carried out at key transition points in the patient pathway, for example

- At diagnosis of a life-limiting or life-threatening condition,
- At episodes of significant progression/exacerbation of disease,
- A significant change in the patient's family/social support,
- A significant change in functional status,
- At patient or family request,
- At end of life.

Where should the assessment take place?

Assessing the palliative care needs for a patient can be carried out in any physical setting that ensures comfort and privacy and could include the patient's home or hospital.

Who should undertake the assessment?

The patient's current health and social care team is responsible for ensuring that the assessment takes place. For continuity of care, it is often helpful to have a single team member responsible for assessing an individual's need. In line with good clinical governance, the patient's physician should be involved in the decision to carry out an assessment. The assessor should be a clinical professional with an appropriate level of knowledge of the disease, its symptoms, treatment and likely prognosis. The assessor should have reached an agreed level of competence in key aspects of the assessment process.

NEEDS ASSESSMENT

What action should follow the assessment?

Where specific need is identified or anticipated, establish whether this can be met by the current health and social care team or whether referral to additional services is required. Then decide on the appropriate action – assessment may trigger the implementation of other care plans.

If the outcome is to refer to the specialist palliative care service, this should be discussed with the patient and consent sought for referral and sharing of information.

ADDITIONAL RESOURCES

To support the implementation of Palliative Care Needs Assessment a suite of educational resources has been developed, comprising an A3 poster that can be used in clinical and/or consultation areas, a power point presentation for sharing information with staff, an online educational module, and a 'train the trainer' programme.

The two on-line lessons provide an understanding of the principles and levels of palliative care, how to use a palliative care approach and how to facilitate person-centred practice development. Specific skills such as the use of open sensitive communication when undertaking an assessment or breaking bad news are included, and the full meaning of person-centredness is explored and how this can be used to provide care to individuals and their families within a person-centred workplace culture. The e-learning lessons take approximately 1½ hours to complete and can be used on their own or accessed as part of the training programme. The online educational module on palliative care needs assessment may be found at:

THE PALLIATIVE HUB
Learning Platform

Further information on the training programme may be obtained by emailing the National Clinical Programme for Palliative Care.

NEEDS ASSESSMENT

KEY POINTS

- All health and social care professionals who care for patients with life-limiting or life-threatening illness should be able to carry out a palliative care needs assessment.
- Palliative care needs assessments should be carried out at the following key points in the patient journey:
  - At diagnosis of a life-limiting or life-threatening condition,
  - At episodes of significant progression/exacerbation of disease,
  - A significant change in the patient's family/social support,
  - A significant change in functional status,
  - At patient or family request,
  - At end of life.
- The Palliative Care Needs Assessment guidance document and accompanying training materials support staff in carrying out palliative care needs assessments.

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2. Homsi J, Walsh D, Rivera N, et al. Symptom evaluation in palliative medicine: patient report vs systematic assessment. Support Care Cancer 2006;14:444-453.
3. Sigurdardottir KR, Haugen DF. Prevalence of distressing symptoms in hospitalised patients on medical wards: a cross- sectional study. BMC Palliat Care 2008;7:16.
4. White C, McMullan D, Doyle J. ''Now that you mention it, doctor.'': symptom reporting and the need for system- atic questioning in a specialist palliative care unit. J Palliat Med 2009;12:447-450.

PATHWAYS

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PATHWAYS - 1. Overview Patient Pathway

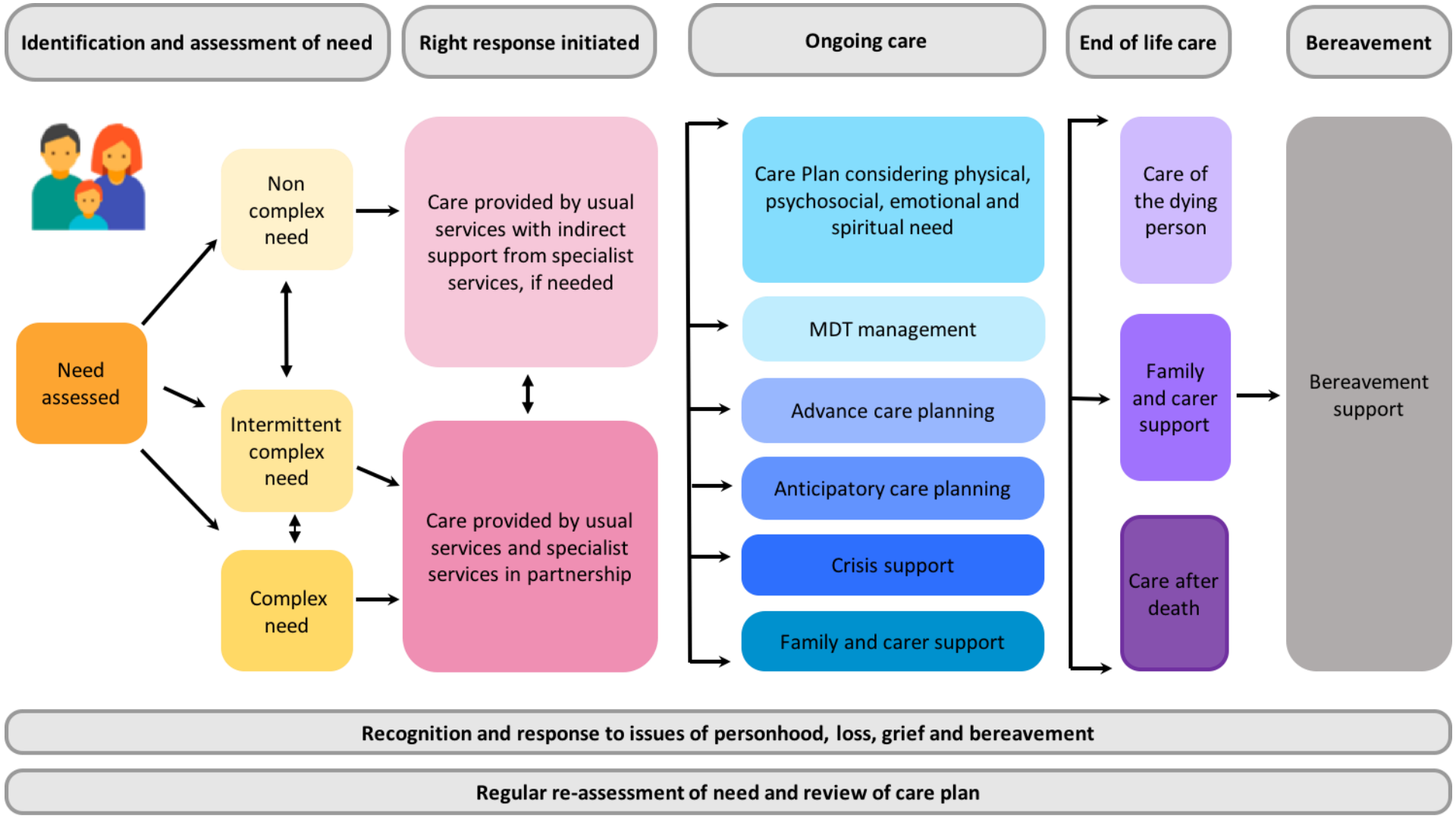


Figure 2. Overview Pathway

DETAILED DESCRIPTION OF THIS PATHWAY MAY BE FOUND ON PAGE 39

PATHWAYS - 2. Referral to SPC Pathway

WHY DEVELOP A REFERRAL PATHWAY TO SPECIALIST PALLIATIVE CARE?

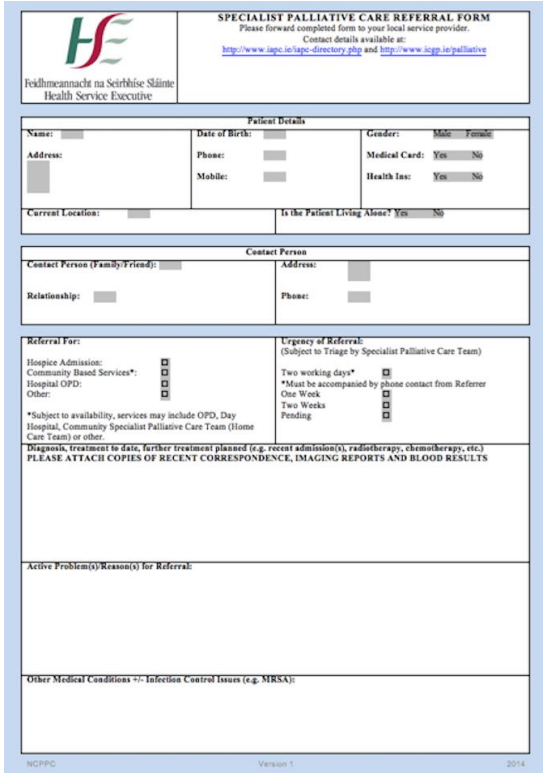
Referrals are a critical component of healthcare and it is important that systems exist to make sure that they are done in a patient-centred, efficient and consistent way. Unnecessary, inappropriate or misdirected referrals delay care needed by patients and their families and increase costs.

REFERRAL TO SPECIALIST PALLIATIVE CARE

Organisations providing the palliative care approach play a cornerstone role in the care of people with a life-limiting illness. As previously described, community, primary care and acute hospital staff are responsible for incorporating a palliative care approach as part of the care that they are already providing to their patients. This model of care supports referral of patients with high complexity palliative care needs to specialist palliative care services early in the path of their illness in order to promote patient autonomy and quality of life.

Referrals may be made to the most appropriate part of the specialist palliative care service (community, hospice or hospital-based) according to the patient's needs at the time of referral. Once the patient has accessed one of these services, the specialist palliative care service will support the individual to move between service settings as their needs or condition changes (e.g. a patient who initially is referred to the hospital-based palliative care service may later be transferred to community palliative care).

The National Clinical Programme for Palliative Care has developed a single national referral form for specialist palliative care services that is available for download.



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

SPECIALIST PALLIATIVE CARE REFERRAL FORM

Please forward completed form to your local service provider.
Contact details available at:
http://www.iapc.ie/iapc-directory.php and http://www.icgp.ie/palliative

Patient Details

Name: | Date of Birth: | Gender: Male Female
Address: | Phone: | Medical Card: Yes No
Mobile: | Health Ins: Yes No
Current Location: | Is the Patient Living Alone? Yes No

Contact Person

Contact Person (Family/Friend): | Address:
Relationship: | Phone:

Referral For:

Hospice Admission:
Community Based Services*:
Hospital OPD:
Other:

*Subject to availability, services may include OPD, Day Hospital, Community Specialist Palliative Care Team (Home Care Team) or other.

Urgency of Referral:
(Subject to Triage by Specialist Palliative Care Team)

Two working days*
*Must be accompanied by phone contact from Referrer
One Week
Two Weeks
Pending

Diagnosis, treatment to date, further treatment planned (e.g. recent admission(s), radiotherapy, chemotherapy, etc.)
PLEASE ATTACH COPIES OF RECENT CORRESPONDENCE, IMAGING REPORTS AND BLOOD RESULTS

Active Problem(s)/Reason(s) for Referral:

Other Medical Conditions +/- Infection Control Issues (e.g. MRSA):

NCPPC Version 1 2014

PATHWAYS - 2. Referral to SPC Pathway

NATIONAL REFERRAL CRITERIA FOR SPECIALIST PALLIATIVE CARE

The National Clinical Programme for Palliative Care has developed national criteria to guide referrals to specialist palliative care. They are as follows:

Patients with both:

- A progressive, life-limiting condition or a serious illness where prospects of recovery are not certain

and

- Current or anticipated complexities relating to symptom control, end of life care- planning or other physical, psychosocial or spiritual needs that cannot reasonably be managed by the current care provider(s)

It is recognised that there are "grey areas" and individual referrals may be discussed with the local Specialist Palliative Care team so as to assess their appropriateness

Specialist Palliative Care teams are always available to advise or support other professionals in their delivery of palliative care.

NATIONAL DISCHARGE CRITERIA FOR SPECIALIST PALLIATIVE CARE

There is a change in disease status such that the patient no longer has any specialist palliative care needs e.g.

  - Following response to treatment,
  - Disease evident as only slowly progressive,
  - Investigations reveal less advanced disease than previously thought.

- There is symptomatic improvement such that the patient no longer has Specialist Palliative Care needs.
- Rehabilitation goals have been achieved.
- Following initial Specialist Palliative Care assessment, it is determined that the patient does not have Specialist Palliative Care needs and that ongoing needs are more appropriately met by other health care agencies.
- The patient, following informed discussion, requests discharge from Specialist Palliative Care.
- The patient or family persistently prevent effective Specialist Palliative Care input e.g. restricting access for assessment.

The Specialist Palliative Care team should always be available to re-engage as appropriate or to offer support to other involved Health Care Professionals.

PATHWAYS - 2. Referral to SPC Pathway

SPECIALIST PALLIATIVE CARE DIRECTORY OF SERVICES

A directory of specialist palliative care services may be found on the Irish Association for Palliative Care website

PATHWAYS - 2. Referral to SPC Pathway

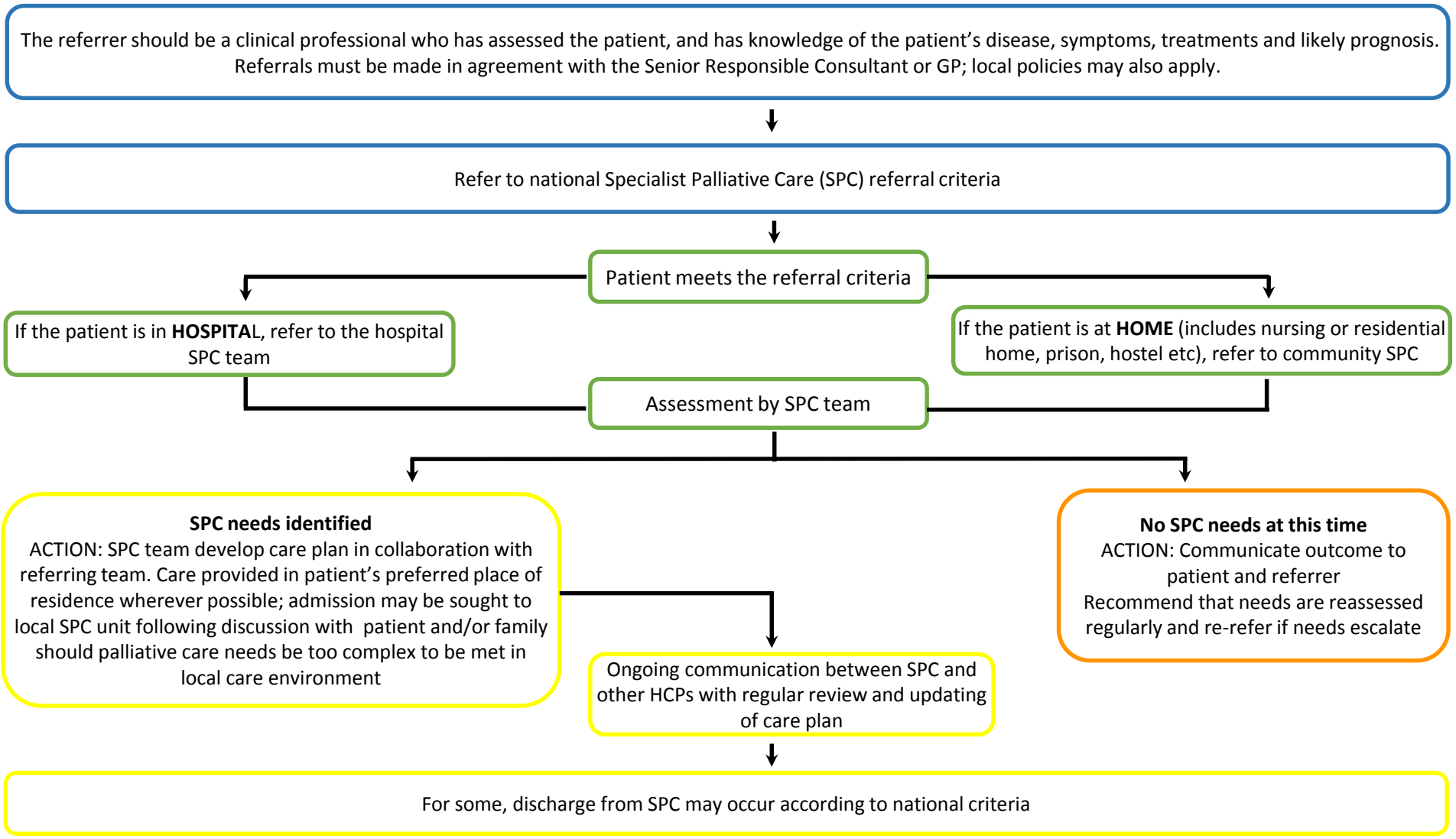


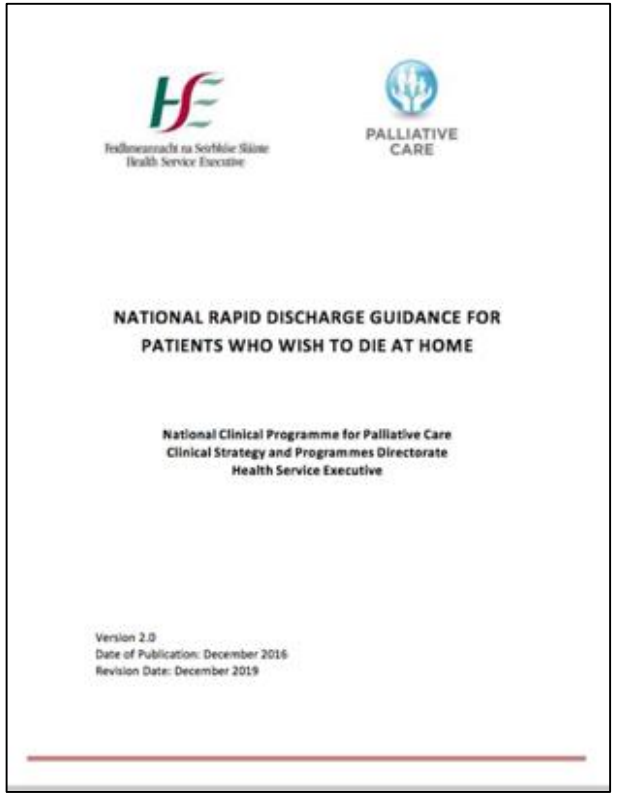
Figure 4. Referral to SPC Pathway

PATHWAYS - 3. Rapid Discharge Pathway

WHAT IS THE RAPID DISCHARGE PATHWAY FOR PATIENTS WHO WISH TO DIE AT HOME?

Enabling people to die where they choose is an important aim of palliative care. Numerous studies have suggested that patients most commonly express a wish to die at home, but a number of factors, in addition to preference also influence place of death. Nevertheless, when a seriously ill patient who is in hospital expresses a wish to die at home their request should not be simply viewed as impractical or impossible. Rather, a realistic evaluation of the feasibility of different options should be undertaken.

In many instances this may lead to a consensus decision being made by the patient, family and multi- professional team, that end-of-life care at home is now the priority. The Rapid Discharge Guidance document aims to support healthcare professionals by describing the model of discharge planning that should be adopted in such circumstances. Rapid Discharge Planning (RDP) is a form of integrated discharge planning that begins when a seriously ill patient expresses the wish to die in their home environment. The National Rapid Discharge Guidance For Patients Who Wish To Die At Home is a supplement to the HSE National Integrated Care Guidance.[1] The guidance is accompanied by an algorithm, checklist, ambulance transfer letter template, and teaching aide.



PATHWAYS - 3. Rapid Discharge Pathway

Rapid discharge guideline

Additional special considerations may apply for:
- Patients who wish to act as organ donors
- Patients for whom it is anticipated that a coroner's post mortem will be required

To activate:
Focus of care is solely on palliation AND Patient's choice is to die at home/ discussion reflects patient's previously expressed wishes AND Family/ carer support decision

Once activated, the CNM/ deputy contacts the GP and PHN/ DON within 24 hrs

Confirm RDP is appropriate

- Contact PHN/ DON to finalise care plan involving GP, SW, CIT, SPC as needed
- If support is required, develop clear action plan
- Agree planned date of discharge
- If same day contact not made with GP/ PHN, reason must be documented

Communicate care plan with patient/ family

Agree

Organise as needed: equipment; SPC; CIT; night nurse; discharge medications; carer education/ support; transport; timing of discharge; handover.

Confirm RDP is appropriate

Appropriate but contingent on supports

Disagree

Poses a risk to patient/ carers

- Clinical risk to safety must be considered carefully
- Efforts made to address concerns
- Case conference convened if necessary
- Patient and family kept informed of progress

Family support is needed to care for patient at home
Consensus approach to care planning

In the event of the patient dying while being transported home:
- Ambulance should continue to the agreed destination
- Coroner should be informed of the circumstances of patient death prior to completion of death cert or commencement of funeral arrangements
- Community services should be notified of death

CIT: Community Intervention Team; DON: Director of Nursing; PHN: Public Health Nurse

PATHWAYS - 4. Loss, Grief and Bereavement Care Pathway

LOSS, GRIEF AND BEREAVEMENT CARE PATHWAY

The loss, grief and bereavement care pathway is a tiered one based on a public health model of bereavement support. [1] It considers both the needs of individuals and families facing loss and those who have experienced bereavement and it adopts a family systems perspective as part of the needs assessment process. The tiered pathway describes a range of interventions, matching different types of interventions with levels of need. The pathway presented is aligned with the Bereavement Care Pyramid of the Irish Childhood Bereavement Network [2] and the Model of Hospital-Community Psycho-oncology and Psycho-social Care. [3]

The families of people with life-limiting illnesses face cumulative losses over time that may progressively involve issues such as loss of normalcy, relationships, identity and income. Ultimately, family members face loss of the individual with serious illness. Dealing with loss, grief and bereavement is, therefore, intrinsic to palliative care provision.

Most people manage their loss by combining their own resources with support from family and friends. However, some require additional supports and a minority of people are at risk of developing complications or difficulties in their grieving. Professionals using the palliative care approach have an important role to play in supporting family members by acknowledging current or anticipated losses, supporting the expression of emotions and providing information about the grieving process. All services providing a palliative care approach as part of usual service provision should be able to meet these 'universal grief needs'. Importantly, professionals working in these services also have a role in identifying those who require additional supports such as counselling or bereavement therapy and this issue will be addressed in greater detail in later paragraphs.

The loss, grief and bereavement pathway commonly begins in the pre-death period with an assessment of need that may be conducted either as part of the palliative care needs assessment process or as a separate, focused interview. However, some individuals or families will only make themselves known to services in the post-death period. The loss, grief and bereavement pathway therefore has two points of assessment and this is indicated on the pathway by the symbol:

Children and vulnerable adults merit particular attention in the needs assessment process. Currently, there is no clear evidence in favour of any one instrument to assess issues of loss, grief and resilience. Rather than mandating a specific assessment tool, the National Clinical Programme for Palliative Care recommends that the following principles should underpin the approach to assessment:

- Services should take a systematic approach to the assessment of need

that provides clear rationale for decision-making and that considers known risk and resilience factors.

- Assessment should be a collaborative process with family members that aims to enhance resilience and coping and enables them to access the level of service required.

Following assessment, the challenge is to ensure that the right level of support is available when need is identified and, conversely, that help is not provided to those not requiring it. [4] It is important, therefore, that organisations have a planned and defined response to each level of need described in the loss, grief and bereavement pathway so that responses are provided in transparent and evidence-based ways.

For most people, although associated with distress, grief takes the form of an adaptive and healthy response to loss. For those individuals and families, the provision of information, explanation and reassurance is sufficient to meet their needs. All organisations should be able to provide this response and relevant staff should possess the appropriate palliative care approach competencies.

In the pre-death period, a range of interventions may also be undertaken to meet specific needs identified through the assessment process. These interventions are indicated by the symbol ** on the pathway. Organisations providing these interventions should ensure that staff possess the requisite competencies for these services.

Some individuals or family groups in the pre-death period will be identified as either having high levels of distress or complex need. Organisations should offer specialist palliative care support proactively to the patient with life-limiting illness and their family in situations where this is likely to lead to the patient themselves developing complex need. In some situations, it may be necessary to provide additional counselling or mental health services as well as specialist palliative care support.

Re-assessment of bereavement support need should be offered pro-actively in the post-death period to those individuals and families who were previously identified as being vulnerable to experiencing complexities or complications in grief. Assessment of need should also be carried out with individuals and families who newly self-present to organisations following death of a family member.

It is not necessary (or advisable) for every organisation to provide a full range of bereavement support services. However, organisations should be able to signpost individuals and families with needs that are beyond the organisation's scope of services to external services. In such situations, defined pathways of referral should be in place in order to facilitate smooth transitions of care.

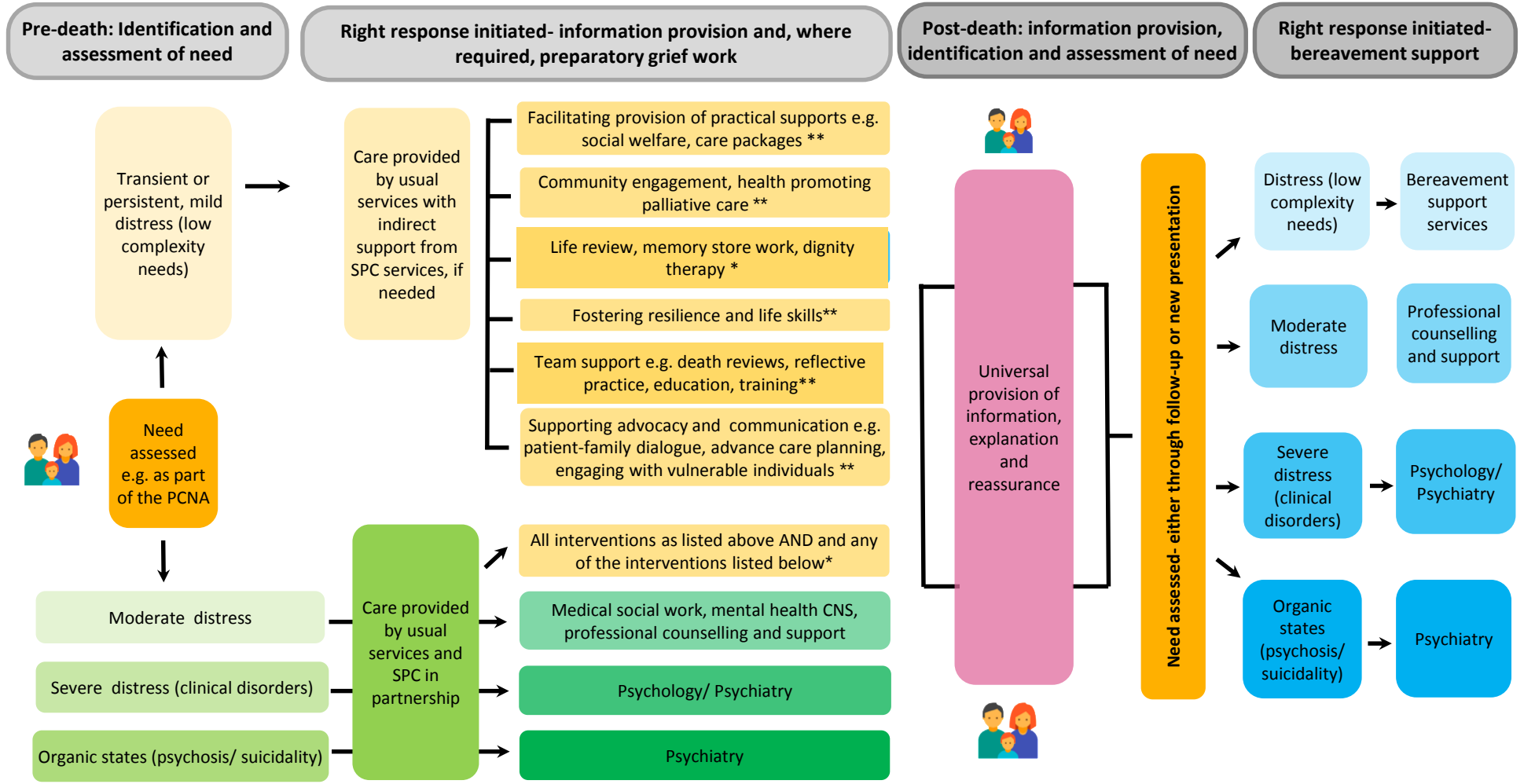
The Model of Care recommends that specialist palliative care services should have a designated bereavement coordinator and at a minimum, have the capability to provide:

PATHWAYS - 4. Loss, Grief and Bereavement Care Pathway

- Pre-death services to meet high levels of distress,
- Post-death services to meet universal grief, low complexity and intermediate complexity needs, for adults, children and family groups.

Specialist palliative care services may have some internal capability to meet complex grief needs (e.g. through the provision of counselling, complicated grief interventions or psychology services) but all should have defined pathways of referral and established service links with regional mental health services.

PATHWAYS - 4. Loss, Grief and Bereavement Pathway



PCNA: Palliative Care Needs Assessment; SPC: specialist palliative care;
** Preparatory grief work interventions

PATHWAYS - 5. Referral to Night Nursing Pathway

WHAT IS THE NIGHT NURSING SERVICE?

The Night Nursing Service is the provision of nursing care to patients in their own home by registered experienced nurses at night.

The Night Nursing Service is a welcome integral support to specialist palliative care services. Night Nurses provides symptom control and nursing care (free of charge) to patients who are in the final stages of their illness in the comfort and dignity of their own home. They also offer reassurance and psychological support to families and carers, during the difficult night hours and enable carers to rest, if they so wish.

The Irish Cancer Society approves and funds nurses for up to 14 nights for patients with a cancer diagnosis. The Irish Hospice Foundation provides support and funding for nurses for patients with non-malignant diagnoses. The Irish Hospice Foundation generally approve and fund for 10 nights, extended to 14 nights in exceptional circumstances.

The Night Nursing Service relies heavily on care planning and effective communication, with the Specialist Palliative Care Services and General Practitioner in order to deliver the highest standard of care.

Both services are provided subject to nurse availability in the patients' locality.

The booking process for night nursing is, in the main, managed centrally by the Irish Cancer Society and the Irish Hospice Foundation and can be requested by phone, fax or online, using the appropriate software package. Details of the booking process, including contact numbers, are outlined in the pathways on the following pages.

CONTACT DETAILS:

Cancer Nurseline Freephone: 1 800 200 700

Email: cancernurseline@irishcancer.ie
Confidential advice, support and information
Mon-Fri 9am - 5pm

The Irish Hospice Foundation – Night Nursing Service Referral

The development team, Irish Hospice Foundation, 32 Nassau Street, Dublin 2

Email: NNC@hospicefoundation.ie Fax: 01-6730040

Mon-Fri 9am – 5.30pm

PATHWAYS - 5a. Night Nursing- Patients with a Malignant Diagnosis

The referrer must be a GP, Public Health Nurse or specialist palliative care professional who has assessed the patient, and has knowledge of the patient's disease, symptoms, treatments and likely prognosis.

↓

Refer to Irish Cancer Society (ICS) referral criteria

↓

Patient meets the referral criteria

↓

Call in / email / fax referral to ICS (within Office hours 09.00 – 17.00), early referral preferable

↓

Referrer will be contacted with the name and contact details of the nurse later that day (depending on availability)

↓

A detailed handover must be given by the referrer to the Night Nurse ideally before 6.30pm

↓

For some, discharge from Night Nursing may occur according to national criteria

Irish Cancer Society Referral Criteria:

- The patient has a malignant condition
- The referral is made by a SPC professional / GP or Public Health Nurse
- The patient has not already received the maximum number of nights from the ICS

Irish Cancer Society Discharge Criteria

- The service is generally approved and funded by the ICS for 10 nights
- An extension for a further 4 nights can be given in exceptional circumstances
- 14 nights is the maximum for which ICS funding will be granted
- If alternative funding can be sourced (e.g. through the HSE locally) a further 14 nights' nursing may be provided if a nurse is available locally
- The ICS will not be in a position to facilitate the service after this point

Figure 7. Night Nursing, Malignant Diagnosis

PATHWAYS - 5b. Night Nursing - Patients with Non-Malignant Diagnoses

The referrer must be a specialist palliative care professional who has assessed the patient, and has knowledge of the patient's disease, symptoms, treatments and likely prognosis.

↓

Refer to Irish Hospice Foundation (IHF) referral criteria

↓

Patient meets the referral criteria

↓

Fax or email a fully completed referral form to development team in IHF (within office hours, 09.30 – 17.30)

↓

Once approval granted the IHF will communicate to the applicant by phone and to the ICS by email.

↓

The applicant may then contact the ICS to arrange for a nurse.

↓

For some, discharge from Night Nursing may occur according to national criteria

Irish Hospice Foundation Referral Criteria:

- The patient has a non-malignant condition
- The patient is in the terminal phase of illness and is being cared for at home
- The individual is a patient of a community SPC team
- The patient has not already received the maximum number of nights from the IHF
- Referral is made in writing, using fully completed official application form
- Referral is made by a SPC professional, who must sign the form

Irish Hospice Foundation Discharge Criteria

- The service is generally approved and funded by the IHF for 10 nights
- An extension for a further 4 nights can be given in exceptional circumstances
- 14 nights is the maximum for which IHF funding will be granted
- If alternative funding can be sourced (e.g. through the HSE locally) a further 14 nights' nursing may be provided if a nurse is available locally
- The ICS will not be in a position to facilitate the service after this point

Figure 8. Night Nursing, Non-Malignant Diagnosis

PATHWAYS - 5c. Booking Night Nurses during out of hours periods

The ICS send a list of contact details of nurses available to work in each locality in the out of hours period i.e. weekends, bank holidays or after close of business.

↓

The SPC professionals can check the availability of these nurses with them directly and make the booking.

↓

The SPC professional is responsible for providing to the nurse, contact information and detailed directions to the patient's home

↓

The SPC professional or GP must also provide a detailed medical handover to the attending nurse, including medication history.

↓

At the first available opportunity, the referrer must inform the ICS of the booking made out of hours, including patient details, contact information and number of shifts booked.

↓

If the patient had a non malignant condition, a referral form must be sent to the IHF at the first available opportunity requesting retrospective approval for funding for night nursing.

ICS: Irish Cancer Society; SPC: specialist palliative care

Figure 9. Booking Night Nurses during OOH periods

PATHWAYS

KEY POINTS

- To date, the National Clinical Programme for Palliative Care has developed the following pathways to guide the provision of care:
  - Palliative Care Overview Patient Pathway
  - Referral to Specialist Palliative Care Pathway
  - Rapid Discharge Pathway
  - Loss, Grief and Bereavement Care Pathway
  - Night Nursing Pathway
- Further pathways and guidance documents will be produced and added to the Model of Care over time.

References

1. Aoun SM, Breen LJ, Howting DA, Rumbold B, McNamara B, Hegney D. Who needs Bereavement support: A population A Population Based Survey of Bereavement Risk and Support Need. PLoS ONE 10(3): e0121101. doi:10.1371/journal.pone.0121101
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3. DOH. National Cancer Strategy 2017-2026. Dublin: Department of Health; 2017
4. Waller A, Turon H, Mansfield E, Clark K, Hobden, B, Sanson-Fisher R. Assisting the bereaved: A systematic review of the evidence for grief counselling Pall Med 2016; 30(2): 132-148

GUIDELINES

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GUIDELINES

NATIONAL CLINICAL EFFECTIVENESS COMMITTEE GUIDELINES

National Clinical Guidelines are systematically developed statements, based on a thorough evaluation of the evidence, to assist practitioner and service users' decisions about appropriate healthcare for specific clinical circumstances across the entire clinical system. The aim of National Clinical Guidelines is to provide guidance and standards for improving the quality, safety and cost effectiveness of healthcare in Ireland.

PHARMACOLOGICAL MANAGEMENT OF CANCER PAIN IN ADULTS, NCEC GUIDELINE NUMBER 9.

The clinical burden of cancer pain is significant. Despite the advances in the management of pain since the first publication of the WHO cancer pain guidelines in 1986, there is evidence that there are significant variations in the success rates of its management. The purpose of the National Clinical Guideline on the Pharmacological Management of Cancer Pain is to provide recommendations based on best available evidence for the pharmacological treatment of cancer pain in adults. The aim is to benefit patients suffering with cancer pain. The expected outcome of the treatment as highlighted by this guideline is to reduce a cancer patient's pain and improve their quality of life.

SCOPE OF GUIDELINE NUMBER 9, CANCER PAIN

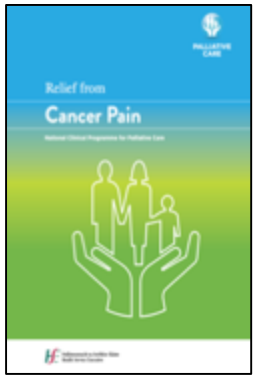
The National Clinical Guideline applies to healthcare professionals involved in the management of cancer pain. This includes Palliative Care staff, Physicians, Surgeons, General Practitioners, Pharmacists and Nursing staff in hospital, hospice and community-based settings. The guideline recommendations indicate where specialist advice should be sought. The Guideline does not apply to cancer survivors, to patients who do not have a cancer diagnosis or to other forms of acute or chronic non-malignant pain. The Guideline does not apply to children.

GUIDELINES

SUPPORTING RESOURCES

The National Clinical Programme has produced a number of supporting resources for the Guideline. There is an **audit tool** which contains clinical audit standards based on the Guideline. It is an implementation tool which should be used alongside the published guidance. The information does not supersede or replace the guidance itself. There are a number of **quick user guides** providing easy-to-access synopses of key aspects of the guideline. There are **online educational modules, a teaching powerpoint,** and importantly, **patient information leaflets**.

THE PALLIATIVE HUB
Learning Platform



MANAGEMENT OF CONSTIPATION IN ADULT PATIENTS RECEIVING PALLIATIVE CARE, NCEC GUIDELINE NUMBER 10

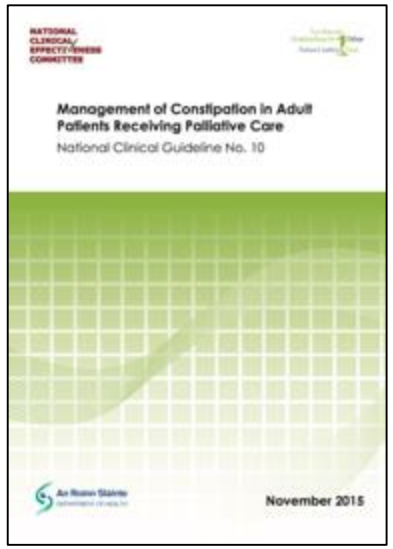
Constipation is one of the most frequently encountered symptoms in the palliative care population. It can significantly impact on a patient's quality of life and may necessitate the use of additional medications, emergency visits and hospitalisation. The consequences of untreated constipation place a significant burden on the healthcare system. Prescribing practice lacks consistency and despite laxative therapy, up to seventy percent of patients receiving palliative care continue to experience symptomatic constipation.

The purpose of this guideline is to provide recommendations based on best available evidence for the management of constipation in adult patients with life-limiting conditions in receipt of level 1 or 2 or specialist palliative care across all healthcare settings. This guideline aims to benefit adult patients with a life-limiting condition who are suffering from constipation. The expected outcome of the recommendations made in this guideline is to prevent or reduce constipation and improve quality of life.

GUIDELINES

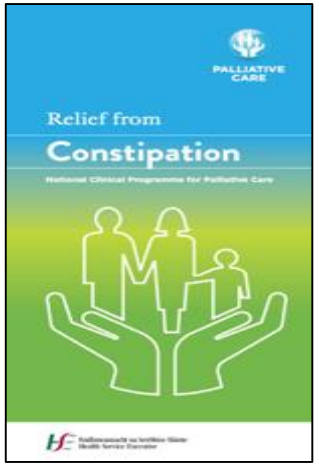
SCOPE OF GUIDELINE NUMBER 10, CONSTIPATION IN PALLIATIVE CARE

This guideline applies to adult patients with a life-limiting illness and is for use by healthcare professionals providing level 1 or 2 or specialist palliative care in hospital, hospice and community-based settings. This includes specialist palliative care providers, physicians, surgeons, general practitioners, nurses, pharmacists and dietitians. For those, providing level 1 or 2 palliative care, the guideline recommendations indicate where specialist advice should be sought.



SUPPORTING RESOURCES

The National Clinical Programme has produced a number of supporting resources for the Guideline. There is an **audit tool** which contains clinical audit standards based on the Guideline. It is a implementation tool which should be used alongside the published guidance. The information does not supersede or replace the guidance itself. There are **online educational modules** and importantly, **patient information leaflets**.



THE PALLIATIVE HUB
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PREVALENCE STUDIES

A one-day prevalence study targeting patients attending Cancer Centres (in-patients and day ward attendances) above 18 years of age was carried out in 2017. The study gathered information on the prevalence of pain and constipation in this population and will provide important national data that will be used to drive Guideline implementation and quality improvement activities.

OTHER NCEC GUIDELINES

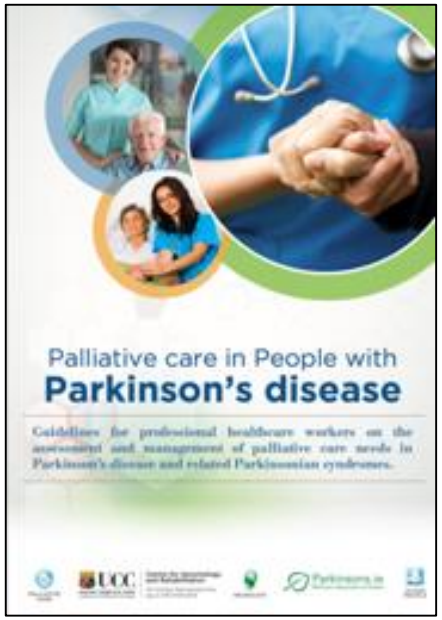
Recommendations on palliative care are included in two other NCEC guidelines- **Guideline No. 7, Diagnosis, staging and treatment of patients with breast cancer** and **Guideline No. 8, Diagnosis, staging and treatment of patients with Prostate Cancer**. The guidelines recommend that for patients with cancer, early provision of palliative care can improve patient outcomes. They also recommend that assessment of palliative care needs should be an ongoing process throughout the course of a patient's cancer illness and services provided on the basis of identified need.

CARE OF THE DYING ADULT GUIDELINE:

Approval has been granted by the National Clinical Effectiveness Committee for the development of a clinical guideline on Care of the Dying Adult. Work on this guideline commenced in Q4 2017.

PALLIATIVE CARE IN PARKINSON'S DISEASE:

The National Clinical Programme in Palliative Care has also endorsed a guideline on **Palliative Care in People with Parkinson's Disease**.



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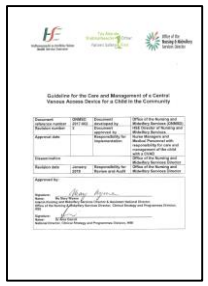
OTHER NATIONAL POLICIES, GUIDELINES AND STANDARDS

Documents *specifically focus on areas of palliative care practice* are detailed in this section.

A number of additional national documents, such as the national policy on Open Disclosure, are of course relevant to palliative care practice but it is not feasible to provide a comprehensive listing in this Model of Care document. Instead, a listing is provided in annual services level agreement documents.

Guideline for the Care and Management of Central Venous Access Device (CVAD) for a Child in the Community

This guideline supports nurses, health and social care professionals who are required to care for a child with a CVAD in the community.



National Do Not Attempt Resuscitation Policy

This guideline support healthcare professionals who are engaging with a patient and/ or family about making a Do Not Attempt Resuscitation Order.

National Policy for Pronouncement of Expected Death by Registered Nurses

This guideline relates to pronouncement (not certification) of expected deaths by registered nurses in HSE Residential Care, Long Stay Care and Specialist Palliative Care settings. The guideline may be accessed at:

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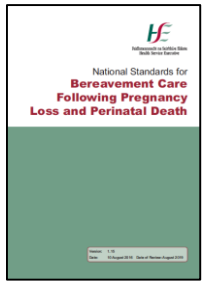
National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death

The purpose of the Standards for Bereavement Care is to enhance bereavement care services for parents who experience a pregnancy loss or perinatal death. These Standards cover all pregnancy loss situations that women and parents may experience, from early pregnancy loss to perinatal death, as well as situations where there is a diagnosis of fetal anomaly that will be life-limiting or may be fatal. These Standards for Bereavement Care following Pregnancy Loss and Perinatal Death are a resource for both parents and professionals. The Standards intend to promote multidisciplinary staff involvement in preparing and delivering a comprehensive range of bereavement care services that address the immediate and long-term needs of parents bereaved while under the care of the maternity services.



KEY POINTS

- A number of national guidelines, policies and supporting resources have been produced that are of particular relevance to palliative care provision (both hospital, community and primary care services providing a palliative care approach as part of usual care and specialist palliative care providers). These include:
  - Pharmacological Management of Cancer Pain in Adults, NCEC Guideline Number 9.
  - Management of Constipation in Adult Patients Receiving Palliative Care, NCEC Guideline Number 10
  - Palliative Care in People with Parkinson's Disease.
  - Guideline for the Care and Management of Central Venous Access Device (CVAD) for a Child in the Community.
  - National Policy for Pronouncement of Expected Death by Registered Nurses.
  - National Do Not Attempt Resuscitation Policy.
  - National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death.

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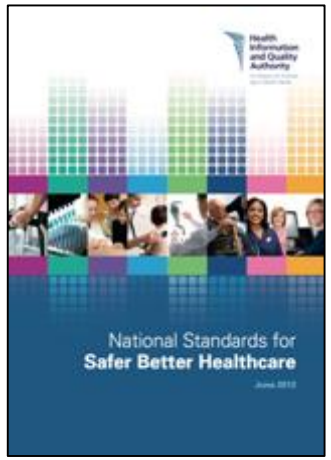
NATIONAL STANDARDS FOR SAFER, BETTER HEALTHCARE

The National Standards for Safer, Better Healthcare represent an important opportunity for staff to work together to make Irish health services better for everyone, by establishing a shared understanding of quality and committing to place it at the heart of everything that is done. [1]



Staff working in palliative care have long shared the vision of high quality healthcare services. The ethos of care and commitment extends back to the nineteenth century when the Irish Sisters of Charity established St Patrick's Hospital in 1870 in Cork and Our Lady's Hospice in Dublin in 1879. These achievements have been recognised internationally and, Ireland was ranked 4th of 80 countries in the Economist Intelligence Unit Quality of Death Index.

However, there are ever-increasing challenges to the delivery of reliable and responsive high quality palliative care today. These include increased public expectations, changes in lifestyles, demographic change, and the current economic climate that brings with it significant financial constraints. While work to date provides a firm foundation to meet these challenges, we will need to continue to grow and develop services by doing some things in better ways. The following resources have been produced in order to embed quality improvement as a central element to the Palliative Care model of care and to help services meet the standards required of them by the Health Information and Quality Authority.

ACUTE HOSPITAL QUALITY ASSESSEMENT AND IMPROVEMENT WORKBOOKS

In 2013, the Acute Care Collaborative and the Quality and Patient Safety Directorate developed a series of workbooks to support acute hospitals in their self-assessments and preparation for inspection against the Safer, Better Healthcare Standards. The importance of palliative care provision is recognised by the inclusion of palliative care as an **Essential Element to Standard 2** (Effective Care). The Essential Elements are specific, tangible translations of the National Standards. They represent those key aspects of quality you would expect to see within a service that is delivering safe,

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sustainable, high quality care. Using the workbooks allows services and teams to assess the current quality of the service that they are providing and supports them in prioritising improvement actions to move further along their quality improvement journey.

SPECIALIST PALLIATIVE CARE QUALITY ASSESSMENT AND IMPROVEMENT WORKBOOKS

Specialist Palliative Care Quality Assessment and Improvement workbooks have been developed by the National Clinical Programme for Palliative Care to provide a basis for enabling specialist palliative care staff to be engaged, valued and empowered in leading and driving quality improvement activities. The workbooks are based on knowledge about what works well in quality improvement, and build on the range of work already underway at local and national levels. As part of this Model of Care, organisations should use the QA+I workbooks to guide their quality improvement activities.

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SPECIALIST PALLIATIVE CARE QUALITY IMPROVEMENT

A quality improvement collaborative has been established that involves a dynamic partnership of specialist palliative care organisations who share a mission to work with one another toward the common goal of improving performance. Moving away from an insular approach and actively sharing learning between organisations is a vital way to help drive improvement. It is anticipated that the QI collaborative will lead to the development of a community of practice within specialist palliative care focused on embedding a culture of quality improvement within usual care provision. Membership is open to all SPC organisations.

NATIONAL STANDARDS FOR RESIDENTIAL CARE SETTINGS FOR OLDER PEOPLE IN IRELAND, 2016.

The Health Act 2007 (as amended) provides the legislative basis for the monitoring, inspection and registration of residential services ('designated centres'), where older people live, against the associated regulations and the National Standards for Residential Care Settings. The Standards apply to residential and residential respite services for older people in Ireland, whether they are operated by public, private or voluntary bodies or organisations. Two of the 35 outcome-based standards relate specifically to palliative and end of life care:

- **Standard 2.4** Each resident receives palliative care based on their assessed needs, which maintains and enhances their quality of life and respects their dignity.
- **Standard 2.5** Each resident continues to receive care at the end of their life which respects their dignity and autonomy and meets their physical, emotional, social and spiritual needs**.**

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KEY POINTS

- The National Standards for Safer, Better Healthcare represent an important opportunity for staff to work together to make Irish health services better for everyone, by establishing a shared understanding of quality and committing to place it at the heart of everything that is done.
- High quality, safe and effective palliative care provision is an essential component of healthcare and its importance is recognised by the Health Information Quality Authority (HIQA).
- Implementation of this model of care will assist services in meeting the standards of care detailed in the National Standards for Safer, Better Healthcare and the National Standards for Residential Care Settings for Older People In Ireland.
- Specialist palliative care services may also wish to participate in the national Quality Improvement Collaborative for Specialist Palliative Care in order to share learning and methods of improvement.

REFERENCES

1. Health Information and Quality Authority. National Standards for Safer Better Healthcare. Dublin: Health Information Quality Authority; 2017.

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DEVELOPING AND SUPPORTING STAFF

The **HSE's People Strategy** recognises the central importance of high-quality, motivated staff to the delivery of care. [1] It commits to engaging, developing and valuing the workforce to deliver the best possible care and services to the people who depend on them. This has a particular resonance for palliative care where historical gaps in the training provided to undergraduate students mean that healthcare professionals often lack appropriate knowledge and skills to feel confident in their provision of palliative care. The deficit is further compounded by the fact that there is often not a clear or consistent focus on ensuring competence in palliative care provision in continuing professional development.

EXAMPLE OF STAFF SUPPORT AND DEVELOPMENT IN ACTION

Schwartz Rounds™ were developed by the Schwartz Centre for Compassionate Care in Boston, USA. Schwartz Rounds™ place in more than 430 healthcare organisations throughout the U.S., Canada, Australia, New Zealand and more than 150 sites throughout the U.K. and Ireland.

Schwartz Rounds are tightly structured, monthly meetings for multi-professional groups of staff working in health care environments. The Rounds provide an opportunity for staff from all disciplines across a healthcare organisation to reflect on the emotional aspects of their work.

The focus is on the human dimension of care. Each round is based on the story of a particular patient or a theme and is briefly presented by 3 or 4 members of staff. This is followed by a facilitated discussion which involves the wider audience and is an opportunity to listen, share and support. Schwartz Rounds provide a framework which helps to improve staff well-being, resilience and support which ultimately has an impact on improved patient-centred care.

Schwartz Rounds represent an innovative way to support staff and improve care. Although not specifically focused on palliative care, their emphasis on holistic care, the human dimensions of care and team-working are all highly relevant to palliative care. Our Lady's Hospice and Care Services in Dublin has acted as a pilot site for the implementation of Schwartz rounds in Ireland.

Services interested in introducing Schwartz Rounds™ may contact the Quality Improvement Division of the HSE for further information.

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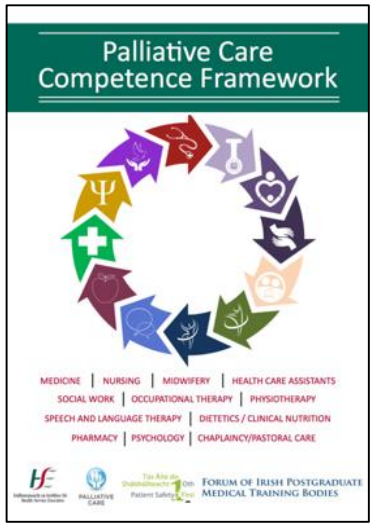
PALLIATIVE CARE COMPETENCE FRAMEWORK

The national Palliative Care Competence Framework is a valuable tool in developing and supporting staff as it helps staff in all care settings to understand the attributes, knowledge and skills required for the provision of palliative care. [2] This means that staff and managers are better able to engage in self-assessment, performance appraisal and the identification of training and education needs. The Framework also clearly signals to our partners in education what competences we would like staff to attain when engaging in continuing professional development activities.



EDUCATION, TRAINING AND CONTINUING PROFESSIONAL DEVELOPMENT

Commissioned training must ensure that the workforce has the right skills, behaviours and training, and is available in the right numbers, to support the delivery of excellent palliative care and health improvement. The HSE should make it clear through its communications and workforce planning that palliative care skills are needed by all staff working with people with life-limiting or life-threatening conditions. Also, it should ensure that a system-wide response is taken that pays attention to the need for more evidence-based education in all settings in the provision of palliative care. Commissioned annual training should focus on ensuring that staff have the competences commensurate with their role and responsibilities as described in the Palliative Care Competence Framework. The key areas of focus mirror the six domains described in the document:

- Principles of palliative care,
- Communication,
- Optimising comfort and quality of life,
- Care planning and collaborative practice,
- Loss, grief and bereavement,
- Professional and ethical practice in the context of palliative care.

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Education and training should not be divorced from the context in which they occur. As the Report on Training and Education in End of Life Care produced for Health Education England notes: 'Time pressures incurred through staff shortages and the resultant need to safeguard service delivery undermines both formal education and informal training opportunities (such as mentoring). Time pressures also impact on the way learning translates to care: an individual may have learned skills around personal care planning (for example), but may have insufficient time to implement that knowledge. More frontline staff may reduce pressures on existing teams and create an environment more conducive to learning and delivery'.

WORKFORCE PLANNING

The provision of high quality health and social care services depends on having a sufficiently numerous and appropriately trained workforce in place at national, regional and local levels. The staffing recommendations of the National Advisory Committee on Palliative Care Report have guided the development of the specialist palliative care workforce since its publication in 2001. However, it should be noted that the Report focused mainly on the development of the specialist workforce and there was no detail provided on workforce planning implications for those providing a palliative care approach as part of usual care.

As the National Strategic Framework for Health and Social Care Workforce Planning (2017) points out 'health workforce planning is not an exact science and needs regular updating: Assessing the future supply and demand for doctors, nurses or other health workers 10 or 15 years down the road is a complex task, fraught with uncertainties on the supply side and to a greater extent on the demand side. Projections are inevitably based on a set of assumptions about the future, which need to be regularly re-assessed in light of changing circumstances, new data, and the effect of new policies and programmes.'

As part of the process of developing this Model of Care, it has become clear that a re-assessment of workforce planning for both specialist and generalist palliative care provision is overdue. In the time since the NACPC Report's publication, there have been significant changes in heath and social care delivery, technological advances and changes in population profile and needs. Extending the workforce for delivery for palliative care was a consistent request arising from stakeholder engagement- from heath and social care professionals, patients and caregivers. Palliative care cuts across specialties, settings (home, residential care centres, hospital and specialist palliative care in-patient unit) and geographies. Extension of the palliative care workforce must therefore consider the two issues of ensuring that:

- Staff providing palliative care approach services are adequately resourced and appropriately trained so that they can deliver palliative care to a level commensurate with their role.

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- There is an adequate number of staff to deliver specialist services

Workforce planning is an iterative and dynamic process that can have multiple time horizons: short- (1 year), medium- (3-5 years), and long-term (10+ years). Recognising that high quality, complete and timely data, information and analysis are required to inform decision-making, the work of the National Clinical Programme for Palliative Care has focused on building the evidence-base for workforce planning in palliative care. This process has highlighted the fact that there is currently varying capability across disciplines for carrying out workforce planning and that there is a need to build or support workforce development and planning capacity in palliative care.

Ideally, workforce training and planning should move from a uni-disciplinary to a multi-disciplinary approach and it should consider the evolution of roles and responsibilities of different disciplines. As clearly articulated by World Health Organisation, 'health systems can only operate with a health workforce'. The importance of workforce planning to the development of disciplines and the provision of high quality care cannot be under-estimated The Model of Care identifies short- and medium-term actions necessary to deliver long-term solutions. These include:

- Proactive recruitment and training to address the recognised deficits in health and social care professionals working in both services providing palliative care approach as part of their usual care and services providing specialist palliative care.
- Support for education and training for staff that includes protected staff time with forward planning and cover for the absent staff member. The costs of a course may need, from the employer perspective, to include the costs of cover for the staff member and this should be factored into funding.
- Support for integrated learning through encouraging programmes that bring different sectors together in a particular setting. In this way, the provision of integrated care will be encouraged.

SPECIALIST PALLIATIVE CARE WORKFORCE PLANNING - MEDICINE

The population of doctors working in Palliative Care in Ireland is made up of Consultants in Palliative Medicine, specialists in other areas of medicine (e.g. GP, oncology) and Non-Consultant Hospital Doctors (NCHDs). The National Clinical Programme for Palliative Care has collaborated with National Doctors Training and Planning in the production of a report titled 'Review of the Palliative Medicine Workforce in Ireland - 2017'. The report focuses on those doctors working in specialist palliative care services in the public and private sectors. It describes current and projected workforce requirements for implementation of the Model of Care.

Consultant-provided care in specialist palliative care necessitates significant changes in existing consultant work practices. Most notably,

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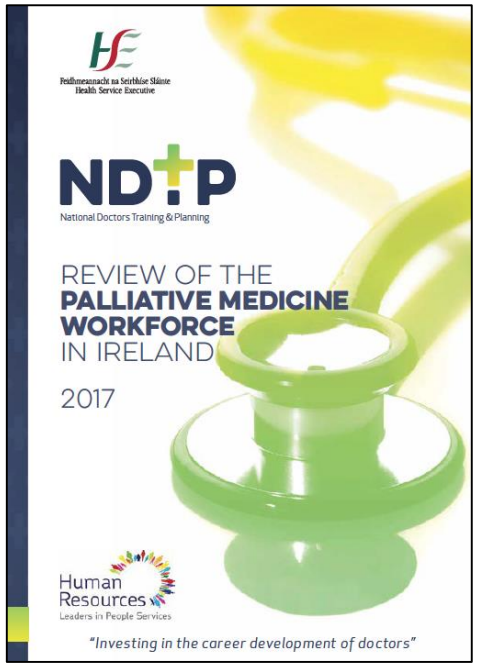
there is a requirement for increased availability of consultants in hospital and community settings. At present, consultants provide the majority of their clinical input to patients admitted to specialist palliative care in-patient units (hospices). Typically, one-third of consultant sessions are allocated to hospitals. It is not common practice for consultants to carry out consultations in the community.

This model of care recommends that the current preferred configuration of consultant posts is maintained i.e. consultants are appointed to work across both hospital and specialist palliative care settings rather than in one setting alone. This ensures that posts are configured to follow the patient journey and promotes continuity of patient care. The model of care proposes that early access to consultant-provided specialist palliative care is expanded as palliative care is integrated with the management of chronic and serious illness. In order to ensure appropriate access to senior decision-making capability, additional posts must be created so that consultants are available in all settings of care during normal working hours. A move to this model of service provision will support the provision of services to complex patients in their preferred place of care (most often the community).

As specialists, consultants in Palliative Medicine also have obligations to provide education and training to the wider workforce of healthcare professionals in order to support integration of a palliative care approach into usual care provision. Time and resources are required to do this and this is considered in the workforce models described in the NDTP report.



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SPECIALIST PALLIATIVE CARE WORKFORCE PLANNING – NURSING

The population of nurses working in Palliative Care is broad-based. All nurses should include a palliative care approach as part of their usual practice. In addition, a range of nurses work solely in specialist palliative care. The National Clinical Programme for Palliative Care (NCPPC) has carried out a national mapping exercise that follows the methodology of the Taskforce on Staffing and Skill Mix (Department of Health). The survey predominantly focuses on the specialist palliative care workforce but does also provide some information on nurses that are providing a palliative care approach as part of their usual practice. Additionally, the NCPPC has conducted a review of nurse prescribing in specialist palliative care.

In 2016, there were 524 nurses working in specialist palliative care. This comprises 1.3% of the general nursing workforce. 31% were over 50 years of age. The workforce was made up of:

- **RGNs** working in specialist palliative care units (IPU, Day Hospice and OPD settings).
- **CNSs** working as part of a specialist palliative care team in acute hospitals or in specialist palliative care units (CPC setting); and working in other areas of specialist practice (e.g. infection control) in specialist palliative care units.
- **CNMs, ADONs, and DONs** caring for people with life limiting and life-threatening illnesses in specialist palliative care (all settings).
- **Nurse Practice Development Facilitators** caring for people with life limiting and life threatening illnesses in specialist palliative care (based in the hub of the specialist palliative care unit but providing support to all service settings).

The mapping exercise highlighted a number of considerations:

- Nursing staffing and skill mix requirements in specialist palliative care are based on data which is over 15 years old. Both the wider healthcare and the specialist palliative care environments have changed significantly in the intervening years. There is a lack of national or international data to provide more up-to-date guidance on staffing and skill mix in palliative care.
- The specialist palliative care workforce is a highly skilled one. 72% hold a Level 8 or 9 Diploma in specialist practice; 16% have Masters level specialist qualification.
- Although the CNS role is well established and accounts for 34% of the specialist palliative care nursing workforce, the educational support, audit and research pillars of the CNS role are inconsistently delivered upon nationally and require ongoing development.
- The ANP role is not established in specialist palliative care. No ANP post was identified in practice in the 2016 mapping exercise. In 2017,

two ANP candidates are in development.

SPECIALIST PALLIATIVE CARE WORKFORCE PLANNING – HEALTH CARE ASSISTANT

Health care assistants (HCAs) have important roles to play in the delivery of palliative care. The recognised qualification for healthcare assistants in the Further Education and Training Awards Council (FETAC) Level 5 healthcare support certificate. The role of the health care assistant is to 'support the delivery of patient care under the direction and supervision of qualified nursing and midwifery personnel'. [3] The NACPC Report recommended that the health care assistant to bed ratio in specialist palliative care units should not be less than 0.5:1. This Model of Care recommends that a review of care attendant workforce should be conducted as part of the nursing workforce planning exercise.

SPECIALIST PALLIATIVE CARE WORKFORCE PLANNING – HEALTH AND SOCIAL CARE PROFESIONALS, PHARMACY AND PASTORAL CARE

The Health and Social Care Professions of Physiotherapy, Occupational Therapy, Social Work, Dietetics and Speech and Language Therapy along with Pharmacy and Pastoral Care Practitioners are all core members of the specialist palliative care interdisciplinary team and access to these professionals is essential in all specialist palliative care settings. Teams also require close and regular working relationships with other disciplines for example creative arts therapy and complementary therapy.

The recommendations regarding staffing and skill mix requirements for allied health professionals (AHPs) in the NACPC Report are based on data which is now over 15 years old. In the intervening years, significant drivers for change have emerged that have had a significant impact on role and function of allied health professionals. Importantly, these outdated calculations fail to adequately consider the important contribution that allied health professionals make to supportive care, symptom management and end of life care, including the emergence of rehabilitative palliative care as an intrinsic component of service provision.

As palliative care moves upstream in the disease trajectory, the importance of **rehabilitative palliative care** is increasingly recognised as a core part of service provision. Rehabilitative Palliative Care is an interdisciplinary approach in which the roles of HSCPs have particular importance. Team members work collaboratively with the patient, their families and carers to support them to achieve their personal goals and priorities. Rehabilitative palliative care aims to optimise people's function and wellbeing and to enable them to live as independently as possible, with choice and autonomy within the limits of advancing illness. It is an approach that empowers people to adapt to their new state of being with dignity, and provides an active support system to help them anticipate and cope constructively with losses resulting from deteriorating health. [4]

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Rehabilitative palliative care has necessitated the development of novel methods of care delivery. Traditional roles and methods of care delivery have been adapted to meet needs and challenges that are particular to palliative care. These challenges include, but are not limited to, dynamic clinical scenarios, the need to frequently re-adjust goals, adapt to psychological distress and to help individuals and families cope with the impact of progressive decline.

Early integration of palliative care in the disease trajectory offers many opportunities as evidenced when occupational therapists and physiotherapists provide short rehabilitative and symptom management programmes of care in ambulatory care settings e.g. breathlessness and fatigue management programmes. However, early integration is also associated with some challenges for care provision. The role of nutritional support in the palliative care setting is one such challenge, and the important role that dietitians and speech and language therapists have in this area is increasingly recognised.

In addition, all team members, but particularly Social Workers, are operating in an increasingly **complex social environment** and roles have had to evolve to meet the layered complexities of patients and their families/carers. Important drivers for change include legislative changes (capacity), risk assessments (safeguarding), increasing cultural diversity, the growth of blended family units, and societal changes where families are increasingly geographically dispersed and where carers are balancing work, childcare and caring responsibilities. Importantly, care provision is becoming more complex as patients live with higher levels of comorbidity and long-term sequelae associated with interventional therapies e.g. problems associated with cancer survivorship.

The **scope of practice** for many allied health has expanded since publication of the Report of the National Advisory Committee on Palliative Care. For example, there have been many advances and developments in pharmaceutical practice especially in the area of clinical pharmacy. Best practice now mandates that core clinical pharmacist activities should include medicines reconciliation and review, prescribing and administration advice and guidance, audit, patient education and counselling. Despite the body of evidence supporting clinical pharmacy services, many of the pharmacists employed in specialist palliative care primarily occupy dispensing and supply roles, with limited development of clinical pharmacy activities.

All team members are operating in an increasingly **regulated** health and social care environment. While clinical governance structures were at an early stage of development at time of publication of the Report of the National Advisory Committee on Palliative Care, the contribution of allied health professionals to quality improvement, safe and effective care provision in now established. For example, there is widespread acknowledgement of the critical role played by AHPs in supporting

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governance structures and accountability arrangements in relation to issues such as medication management, falls management, pressure area reduction, and safeguarding. This extends, but is not limited to developing and supporting safety structures and standards such as policy, procedures and guidelines, risk management, audit and evaluation, facilitation of training and education and contributing to regional and national committees and working groups.

The AHP workforce in specialist palliative care practice remains significantly under developed, both in terms of access, numbers, role and professional grading. Many of the developments that have taken place with respect to clinical grading of AHPs, arose after the publication of the Report of the National Advisory Committee on Palliative Care. For example, the Clinical Specialist roles in physiotherapy, occupational therapy and dietetics were not established at the time of publication of the Report. Clinical Specialists have a key contributions to make to practice by demonstrating advanced knowledge and skills, and acting as educator, researcher and clinical leader in the field. With the establishment of the Community Healthcare Organisations and the Hospital Group structures, the Clinical Specialist role offers opportunities to enhance expertise and quality, while ensuring the development and progression of professions in a uniform manner across all areas.

Our understanding of the role and contribution of basic grade, senior grade and clinical specialists has been enhanced through experiential learning. It is now more clearly recognised that as a specialist service, senior grade clinicians are vital to provide clinical input in both Specialist Palliative Care Inpatients Units and Specialist Palliative Care community services. The full potential of service development can only be achieved through careful consideration of skill mix and grade of allied health professionals working as members of the Specialist Palliative Care team.

Discipline specific recommendations based on the Report of the National Advisory Committee on Palliative Care are as follows:

Physiotherapy and Occupational Therapy:

- There should be at least one WTE Senior Physiotherapist and one WTE Senior Occupational Therapist per 10 beds in the specialist palliative care inpatient unit.
- There should be a minimum of one WTE Senior Physiotherapist and one WTE Senior Occupational Therapist and working as part of the community specialist palliative care team per 125,000 population. These posts should be based in, and led by, the specialist palliative care unit in the area. They should work in support of and in collaboration with established community health care professionals.
- Designated physiotherapists and occupational therapists should be assigned to spend time with palliative care patients in acute hospitals. Each hospital should provide adequate staffing levels to ensure that the needs of palliative care patients are met.

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Social Work:

- There should be at least one WTE Senior Social Worker per 10 beds in the specialist palliative care inpatient unit.
- There should be a minimum of one WTE Senior Social Worker and working as part of the community specialist palliative care team per 125,000 population. They should be based in, and led by, the specialist palliative care unit in the area. They should work in support of and in collaboration with established community health care professionals.
- Specialist palliative care services should have a designated bereavement coordinator.
- There should be at least one Senior Social Worker in the acute hospital specialist palliative care team.

Speech and Language Therapy & Dietetics:

- There should be at least one Dietetic session and at least one Speech and Language Therapist session in each specialist palliative care unit per week.

Pastoral Care:

- There should be at least two suitably trained pastoral care practitioners in each specialist palliative care unit.

Pharmacy:

- There should be at least one Chief II Pharmacists in each specialist palliative care unit.
- In the acute general hospital setting, the pharmacy department should be sufficiently resourced to enable staff to become involved with the specialist palliative care team.

WORKFORCE PLANNING – CREATIVE ARTS AND COMPLEMENTARY THERAPY

Complementary and creative arts therapists are valued components of the multidisciplinary team and offer a unique contribution to patient care. With respect to these disciplines the development of a regulatory framework is to be welcomed and will offer greater clarity on their role within specialist palliative care.

WORKFORCE PLANNING- ADMINISTRATIVE, SECRETARIAL AND GENERAL SUPPORT STAFF

Specialist palliative care units should have an appropriate level of administrative, secretarial and general support staff to provide services.

SPECIALIST PALLIATIVE CARE WORKFORCE PLANNING – EDUCATION

As described in the Report of the National Advisory Committee on Palliative Care, the specialist unit should act as a resource for other health professionals in the area, by providing support and advice when needed.

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The specialist unit should also provide facilities for research and education in palliative care. Specialist palliative care services should have a librarian and educational personnel to support this work.

WORKFORCE PLANNING – VOLUNTEERS

Volunteers in hospices are an important and valued part of the palliative care team who contribute to the high-quality care and support for people and their carer givers at the end of their lives. There are currently 2,700 palliative care volunteers involved with the hospice and palliative care sector. Many more volunteers are involved in fundraising in the community and telling local communities about the palliative care services.

Volunteer Managers or Volunteer Coordinators have a very significant role in directing and supporting volunteers in hospices and involved in palliative care and therefore in providing support for the service as a whole. The time given by volunteers is free however significant resources are required to provide effective and adequate support to volunteers. The role of a volunteer coordinator is wide ranging and demanding, they are responsible for the:

- Recruitment of hospice volunteers, including Garda clearance,
- Orientation and training of hospice volunteers,
- Matching hospice volunteers to appropriate roles,
- Liaising with other hospice staff in the overall running of the volunteer programme,
- Performance review and ongoing development of volunteers,
- Ensuring volunteer recognition,
- Handling grievances and complaints,
- Policy development and Strategic Planning for future development of volunteer programme.

WORKFORCE PLANNING INTERFACING WITH OTHER SPECIALTIES: PSYCHIATRY AND PSYCHOLOGY

Over the past 20 years, the important roles that Psychiatry and Psychology have to play in the care of people with life-limiting and life-threatening illness have been increasingly recognised. [5,6] Psychiatric and psychological problems in patients with life-limiting and life-threatening conditions exist on a continuum of complexity and severity from appropriate distress (adaptive levels of fear and sadness) to clinical disorders (clinical depression, anxiety psychosis, organic states). In palliative care settings, these conditions are recognised to occur as commonly (and in some studies more commonly) as physical symptoms such as pain or breathlessness. [7]

In the field of cancer, the recognition of the burden of 'cancer distress' and the benefits of proactively addressing problems have led to the development of psycho-oncology as a sub-specialty of oncology. Psycho-oncologists make a vital contribution to patient care by dealing with the

psychological dimensions of life-limiting diseases: the patients', families' and staff's emotional reactions to life-limiting disease and the psychological, social and behavioural factors that may influence the disease process.

The growth of psycho-oncology as a sub-specialty has been associated with the development of a body of evidence-based practice, including recommendations regarding staffing and organisation of services. To date, the development of similarly organised responses to the psychiatric and psychological needs of patients who are living with other serious, non-malignant conditions has been variable. The field of Psychiatry of Old Age, for example, is well-developed; arguably, the needs of younger populations living with life-limiting or life-threatening non-malignant disease are not met in a similar fashion.

Considering the fact that the burden of psychiatric and psychological illness is high in palliative care settings (indeed, the prevalence of psychiatric/ psychological conditions increases in the terminal stages of illness), there is an urgent need to develop an organised response to the needs of this population. Recommendations regarding workforce planning for psychiatry, psychology and bereavement care were not made in the National Advisory Committee Report on Palliative Care and it is timely, therefore, to begin to consider this aspect of service design in the Palliative Care Model of Care.

As a first principle, the design of the psychological, psychiatric and bereavement care aspects of the Palliative Care Programme Model of Care should be aligned with the design of the Cancer Strategy Model of Care for Psycho-oncology, and the design of psychiatry services more generally. Liaison psychiatry and psycho-oncology are areas of multi-disciplinary interest and both share boundaries with specialist palliative care. Considering the potential overlaps in service provision, there is a clear need for co-operation between services in order to ensure continuity of care for patients and to minimise duplication or fragmentation of services. Preliminary work has begun in this area with alignment of the loss, grief and bereavement care pathway with the proposed Psycho-oncology Model of Care. Additionally, a representative from the National Clinical Programme for Palliative Care sits on the National Cancer Control Programme Psycho-oncology Steering Group.

As a second principle, and consistent with the National Cancer Strategy (section 10.9) a stepped care approach should be provided that is flexible enough to meet the needs of all patients receiving palliative care. The stepped care approach recognises that a range of interventions and expertise is required to meet the needs of the continuum of patients with psychological or psychiatric distress.

As outlined in figure 1, Level 3 to 5 care requires a specialist multidisciplinary team including consultant psychiatrists, psychologists, clinical nurse specialists and social workers. This team should provide

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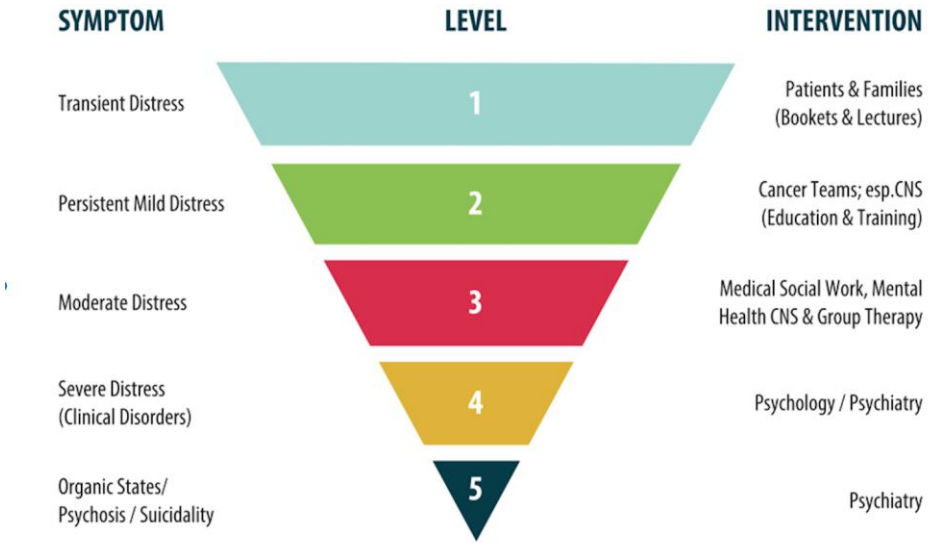
education and support to all health professionals to facilitate level 1 and 2 care. The team should integrate patient care into the primary and secondary care mental health services.

The National Cancer Strategy details the establishment of psycho-oncology teams which will meet some of the needs of patients with a cancer diagnosis who are receiving palliative care. However, additional resources will be required to i) meet the needs of patients receiving specialist palliative care without a cancer diagnosis and to ii) address the morbidity unmet by the psycho-oncology service (e.g. morbidity of patients admitted to palliative care units or those patients with a cancer diagnosis who are not under the care of an oncology service).

The National Clinical Programme for Mental Health and the National Clinical Programme for Palliative Care are currently collaborating on this area of service design and this Model of Care document will be updated with service design (including workforce) recommendations.

***Figure 10*. Proposed Model of Hospital-Community Psycho-oncology and Psycho-social Care (National Cancer Strategy, [8] Model adapted from O'Dwyer and Collier, St. James's Hospital. 2003)**



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RADIOLOGY

Access to diagnostic radiology and advanced imaging is essential for the effective management of patients with life-limiting of life-threatening conditions.

Imaging provides an assessment of the burden of disease which is may help prognostic decision making, and it can pin-point the reason for patient symptoms so that accurate therapeutic measures can be taken. For example, patients with possible spinal cord compression require urgent MRI evaluation as they may be candidates for emergency neurosurgery or radiation therapy to maintain function and alleviate symptoms. Moreover, Interventional Radiology (IR) can deliver many minimally invasive percutaneous procedures that can be complementary to pharmacologic approaches, or can be the first-line palliative treatment in certain situations. For example, patients with recurrent malignant pleural effusions often achieve significant benefit from percutaneous drainage. Access to IR procedures is increasingly allowing patients with palliative care needs to be cared for more successfully in the community setting.

The following recommendations have been developed in collaboration with the National Clinical Programme for Radiology:

- Depending on workloads, it may be appropriate for 0.2 WTE Diagnostic Radiologists and 0.25 WTE Interventional Radiologists to be appointed to support referrals from a specialist palliative care unit (including consideration of the needs of the community palliative care service).
- Where palliative facilities are co-located close to acute general hospitals, access to Diagnostic and Interventional Radiology services should be established and under-pinned by a service level agreement. Where services are not co-located, a service level agreement should be established with the nearest appropriate Radiology Department in order to minimise the burden of travel for patients and their families.
- Multi-disciplinary team meetings should be considered for discussing complex patients – attendance by the appropriate health and social care personnel should be supported personnel e.g. Consultants in Palliative Care, Oncologists, GPs and Radiologists, and others as indicated.

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KEY POINTS

Palliative Competence Framework

- The HSE should make it clear through its communications and workforce planning that palliative care skills are needed by all staff working with people with life-limiting or life-threatening conditions.
- Hospital, community, GP, primary care and specialist palliative care providers should demonstrate use of the Framework as part of their provision of care.
- Commissioned annual training should focus on ensuring that staff have the competences commensurate with their role and responsibilities as described in the Palliative Care Competence Framework.
- Support for education and training for staff should include protected staff time with forward planning and cover for the absent staff member. The costs of a course may need, from the employer perspective, to include the costs of cover for the staff member and this should be factored into funding.
- Proactive recruitment and training is required to address the recognised deficits in health and social care professionals working in both services providing palliative care approach as part of their usual care and services providing specialist palliative care.
- Support for integrated learning should be provided through encouraging programmes that bring different sectors together in a particular setting. In this way, the provision of integrated care will be encouraged.
- Support should be provided for conducting a workforce planning exercise for nurses, health and social care professionals, pharmacists and pastoral care that follows the methodology of the Taskforce on Staffing and Skill Mix (Department of Health).

Staff providing a palliative care approach as part of usual service provision

- Staff providing palliative care approach services must be adequately resourced and appropriately trained so that they can deliver palliative care to a level commensurate with their role.
- Proactive recruitment and training is needed to address the recognised deficits in health and social care professionals working in both services
- Support for education and training for staff that includes protected staff time with forward planning and cover for the absent staff member should be provided. The costs of a course may need, from the employer perspective, to include the costs of cover for the staff member and this should be factored into funding.

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- Support for integrated learning should be provided through encouraging programmes that bring different sectors together in a particular setting. In this way, the provision of integrated care will be encouraged.

Specialist Palliative Care- Medicine

- The Model of Care proposes that early access to consultant-provided specialist palliative care is expanded as palliative care is integrated with the management of chronic and serious illness.
- It is recommended that consultants are appointed to work across both hospital and specialist palliative care settings rather than in one setting alone.
- It is recommended that the work of consultants in hospital and community settings should continue to be seen as complementing and not replacing the care provided by other health and social care professionals.
- Consultants in hospital and community settings ordinarily act in a liaison role; they act as Responsible Consultant in the specialist palliative care unit in-patient setting.
- It is recommended that additional consultant posts are created so that consultants are available to patients in all settings during normal working hours.
- A number of scenarios are modelled in the medical workforce planning work of the Clinical Programme and published in the National Doctors Training and Planning Desktop Review. Over a Training and Planning Desktop Review. Over a 10-year horizon, an additional 46.4 WTE consultant posts are required for full implementation of the Model of Care. The development of an academic workforce is considered in a fourth modeling scenario.

Nursing

- The Model of Care proposes that early access to specialist palliative care is expanded as palliative care is integrated with the management of chronic, serious illness.
- The contribution of nurses to specialist palliative care provision in all settings of care is critical. This Model of Care has been developed in response to growing service need and increasing complexity of care provisions (particularly in the community setting). This service need should act as a key driver for nurse role expansion.
- There is an urgent need for the development of a framework to determine the staffing and skill mix requirement that is based on assessment of individual patient need, monitoring patient outcomes, measurement of staff experience and working climate,

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as well as assessment of the required nursing hours per patient.

- There is also an urgent need to align the development of specialist and advanced nurse practice posts to the Model of Care and develop roles to meet service need.

Health & Social Care Profeessionals, Pharmacy and Pastoral Care

- The Model of Care proposes that in the short term deficits according to NACPC Report recommendations are addressed. Provision should be made for proactive recruitment and training to increase the number of Health & Social Care Professionals working in specialist palliative care.
- The Model of Care recommends that in the short-term, a clinical governance structure to further develop HSCPs and to align the clinical reporting relationships is developed.
- Further work is also needed to develop a workforce framework to determine the staffing and skill mix requirement that is based on assessment of individual patient need, monitoring patient outcomes, measurement of staff experience and working climate, as well as assessment of the required HSCP hours per patient.

Physiotherapy and Occupational Therapy:

- There should be at least one WTE Senior Physiotherapist and one WTE Senior Occupational Therapist per 10 beds in the specialist palliative care inpatient unit.
- There should be a minimum of one WTE Senior Physiotherapist and one WTE Senior Occupational Therapist and working as part of the community specialist palliative care team per 125,000 population. These posts should be based in, and led by, the specialist palliative care unit in the area. They should work in support of and in collaboration with established community health care professionals.
- Designated physiotherapists and occupational therapists should be assigned to spend time with palliative care patients in acute hospitals. Each hospital should provide adequate staffing levels to ensure that the needs of palliative care patients are met

Social Work:

- There should be at least one WTE Senior Social Worker per 10 beds in the specialist palliative care inpatient unit.
- There should be a minimum of one WTE Senior Social Worker and working as part of the community specialist palliative care team per 125,000 population. They should be based in, and led by, the specialist palliative care unit in the area. They should work in support of and in collaboration with established community health care professionals.

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- Specialist palliative care services should have a designated bereavement coordinator.
- There should be at least one Senior Social Worker in the acute hospital specialist palliative care team.

Speech and Language Therapy & Dietetics:

- There should be at least one Dietetic session and at least one Speech and Language Therapist session in each specialist palliative care unit per week.

Pastoral Care:

- There should be at least two suitably trained pastoral care practitioners in each specialist palliative care unit.

Pharmacy:

- There should be at least one Chief II Pharmacists in each specialist palliative care unit.
- In the acute general hospital setting, the pharmacy department should be sufficiently resourced to enable staff to become involved with the specialist palliative care team.

Administrative, secretarial and general support staff

- Specialist palliative care units should have an appropriate level of administrative, secretarial and general support staff to provide services.

Educational staff:

- The specialist unit should act as a resource for other health professionals in the area, by providing support and advice when needed.
- Specialist palliative care services should have a librarian and educational personnel to support this work.

Volunteers

- As per NACPC Report, every specialist palliative care unit should have a volunteer coordinator, who should be responsible for the selection, training and placement of volunteers.

Psychiatry and Psychology

- The Model of Care recommends that work is carried out in partnership with the National Cancer Control Programme and National Clinical Programme for Mental Health in order to describe the optimal model for the provision of mental health supports to people with life-limiting disease.

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Radiology

- Depending on workloads, it may be appropriate for 0.2 WTE Diagnostic Radiologists and 0.25 WTE Interventional Radiologists to be appointed to support referrals from a specialist palliative care unit (including consideration of the needs of the community palliative care service).
- Where palliative facilities are co-located close to acute general hospitals, access to Diagnostic and Interventional Radiology services should be established and under-pinned by a service level agreement. Where services are not co-located, a service level agreement should be established with the nearest appropriate Radiology Department in order to minimise the burden of travel for patients and their families.
- Multi-disciplinary team meetings should be considered for discussing complex patients – attendance by the appropriate health and social care personnel should be supported personnel e.g. Consultants in Palliative Care, Oncologists, GPs and Radiologists, and others as indicated.

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BACKGROUND

Enhanced Information and Communication Technology (ICT) for Palliative Care is a key capability requirement for the future delivery of healthcare and a core component of the Palliative Care Model of Care. Palliative Care supports patients and their families wherever they are – at home, in hospital, in residential care or elsewhere. The ability to record and share key information on patients and carers interactions across organisations and care settings is fundamental to providing safe, effective and efficient care. In particular, access to reliable information about a patient's current medications is important in palliative care as a patient may be prescribed medication by a number of healthcare professionals.

Connected health or technology enabled care involves the convergence of health technology, digital, media and mobile telecommunications and is increasingly seen as an integral part of the solution to many of the challenges facing healthcare. In particular, connected health has the power to improve access to healthcare services, especially for people with mobility problems. Connected health seeks to improve people's ability to self-manage their health and wellbeing, alert healthcare professionals to condition changes and support medication adherence. Although opportunities for using connected health in palliative care are yet in their infancy, the field offers considerable potential to deliver safer, more efficient and cost-effective care.

eHEALTH IRELAND

Ireland's **eHealth Strategy**, launched December 2013, describes eHealth (Electronic Health) as involving *"the integration of all information and knowledge sources involved in the delivery of healthcare via information technology-based systems. This includes patients and their records, caregivers and their systems, monitoring devices and sensors, management and administrative functions. It is a fully integrated digital 'supply chain' and involves high levels of automation and information sharing".*

E-health can improve productivity and provide significant benefits to patients, carers, health and social care professionals and wider stakeholders in the health system. To deliver on the eHealth Strategy, the Office of the Chief Information Officer (CIO) of the HSE published **the Knowledge and Information Plan** in May 2015. The plan provides the Irish health system with a defined structure to deliver results, a roadmap for the benefits to be released, and governance to ensure delivery is appropriately managed. EHealth Ireland are progressing several strategic programmes nationally. Summarised below are those most pertinent to Palliative Care.

THE ELECTRONIC HEALTHCARE RECORD AND PALLIATIVE CARE

An EHR for Ireland is the cornerstone of the eHealth Strategy. A **national EHR** is a comprehensive and combined solution that supports the creation and sharing of key patient information. The national EHR will consist of core operational solutions, with functions such as ePrescribing and Case Management. Healthcare in Ireland is delivered by varied organisations and by varied systems in different care settings (for example GP systems, pharmacy systems, community operational systems and acute hospitals systems). Thus, a key component of deployment of a national EHR is the development of a Shared Record. **The national Shared Record** will combine patient data from disparate organisations into a single patient-centric record and provide collaboration and coordination tools to enable more integrated care. It will not deliver the functions of acute or community operational systems; rather it will pull information from varied data and EHR sources together to a common accessible shared record. It will be accessible to health and social care professionals, and also to patients, service users and carers.

Representatives of the National Clinical Programme for Palliative Care (NCPPC) contributed as clinical experts to the market capability analysis sessions hosted by eHealth Ireland in 2016/2017 to define and develop the high level functional requirements for a national shared record. The most important functional areas that we tested were patient data, collaboration and coordination, workflow, patient information, audit, access and consent eHealth Ireland anticipates this significant transformation to a fully electronic EHR and shared national record will necessitate an 8-10 year period of development and deployment. Given that palliative care services are a discrete, cross service, enthusiastic and collaborative community, we are in a position to act as early adopters of eHealth initiatives. Palliative care is well placed as a development site, and can thus contribute to shaping EHR project. Thus , within the palliative care community in Ireland, services are collaborating to design and implement an **EHR for people receiving specialist palliative care services**, with the support of the NCPPC and the Office of the CIO.

This record will allow all information to be shared with relevant providers of care as and when required. The key benefits will be:

- Improved patient care as a result of better communication, supported decision making and effective planning of care.
- More effective and efficient recording of information reflecting best standards in documentation.
- Enhanced clinical audit and research locally as a result of better quality data.
- Informed business intelligence that will drive local and national

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management decisions.

The project pilot sites are Our Lady's Hospice, Dublin and Milford Care Centre, Limerick. The project is currently at the design specification stage and it is anticipated that following public procurement in 2017 a preferred vendor will be appointed and project initiation will commence in 2018.

ELECTRONIC REFERRALS

Following the completion of phase one of the HSE National eReferral Programme, GPs can now electronically refer patients into every acute hospital across the country. Using the eReferral solution, a GP can directly submit an electronic referral from their practice management system to the hospital in question using the HIQA-approved referral form, and immediately receive an acknowledgement confirming receipt. The system also enables the hospital to send a response message to the GP once the patient has been triaged.

In partnership with the Irish College of General Practitioners ICT Committee, the Clinical Programme has developed a single national referral form for Specialist Palliative Care. This specialist referral form comprises all the fields of the general e-referral form with additional detail to facilitate triaging. It is anticipated that this document will form the basis for a national palliative care electronic referral system. However a solution that also allows for the transfer of essential ancillary information (e.g. radiology and laboratory results, relevant prior correspondence) will need to be found in order to allow for transition to a wholly electronic referral system. Several national initiatives support the development of such a system, and are outlined below. A key enabler will be national roll-out of the Individual Health Identifier (IHI).

HEALTHMAIL

Healthmail is a private and secure clinical email service of the Primary Care Directorate of the HSE, managed by eHealth Ireland and supported by the ICGP and the Irish Pharmacy Union. Healthmail allows healthcare providers to send and receive clinical patient information in a secure manner. Users are issued with an @healthmail.ie email account to enable them to communicate patient identifiable clinical information with clinicians in primary and secondary care. All HSE and Voluntary Hospital email addresses are automatically connected to Healthmail along with another 30+ healthcare agencies nationally. All major palliative care service providers form part of the Healthmail network.

HEALTHLINK

The National Healthlink Project is the national messaging broker. It provides a web-based messaging service which allows the secure transmission of clinical patient information between hospitals, healthcare agencies and General Practitioners. The process of connecting palliative care service providers began in 2015 and all major organisations have Healthlink capability.

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NATIONAL MEDICAL LABORATORY INFORMATION SYSTEM (MedLIS)

The strategic goal for the MedLIS Project is to ensure Irish healthcare providers have 24-hour access to complete and up-to-date accurate laboratory results across all sites. Palliative Care organisations will seek the implementation of a functional interface with MedLIS once the project has reached that stage of development.

NATIONAL INTEGRATED MEDICAL IMAGING SYSTEM (NIMIS)

In 2008, the HSE initiated a programme called NIMIS to capture and store Radiology, Cardiology and other diagnostic images electronically. NIMIS will make Ireland's radiological services 'filmless' and enable secure and rapid movement of patient image data throughout the health service. This new imaging system will allow doctors to electronically view their patient's diagnostic images, such as X-Rays and CT Scans, quickly and easily. When fully live, NIMIS will support 36,000 medical users at over 60 locations; will store over 3.5 million studies per year on an infrastructure with over 1,000 medical device workstations. Palliative Care organisations are in the process of connecting to NIMIS.

KEY POINTS

- Enhanced ICT for Palliative Care is a key capability requirement for the future delivery of healthcare and a core component of the Palliative Care Model of Care.
- Practical ways this can be achieved, include:
  - Including palliative care services providers (both services providing a palliative care approach and those providing specialist palliative care services) as early adopters of the national shared record.
  - Supporting the use of Healthmail by palliative care services providers (both services providing a palliative care approach and those providing specialist palliative care services)
  - Supporting the development of Healthlink in order to ensure that specialist palliative care services can avail of the full functionality of the service.
  - Supporting specialist palliative care services to develop a functional interface with MedLIS.
  - Supporting specialist palliative care services to use NIMIS.
  - Developing video-conferencing facilities in order to lower the feasibility threshold for timely and essential case conferences.

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KEY POINTS

- Supporting the use of out-of-hours handover forms by GPs and members of the ambulance service, community and specialist palliative care teams.

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METRICS

HOW WILL WE KNOW IF WE ARE IMPROVING?

Measurement is critical to the effective evaluation of any model of care; it is crucial that good measures are identified and reviewed from the beginning of the implementation process. Peter Drucker is often credited with popularising the maxim "What gets measured gets managed." But the maxim doesn't address an obvious follow-on question: What, exactly, should be measured? Applying metrics and measurements to behavior can have profound effects- yet measuring the wrong things can be counterproductive.

It has been argued that measurement is particularly challenging in palliative care. Palliative care adopts a holistic approach, where psychosocial and spiritual dimensions to care provision are considered in addition to the management of physical suffering. How can these aspects of care provision be measured easily, accurately and reliably? Moreover, when we consider implementation of a model of care, outcome measures may take a long time to show change at a whole systems or population level, so how can this be captured in immediate or short-term performance metrics?

There are no easy or definite answers to these questions. However, we are not the only ones grappling with these challenges, and for many countries the response has been that 'the perfect should not be the enemy of the good'. Palliative care is at an early stage of performance measurement and major improvements are still needed in data collection and analytical methodologies. Nevertheless, it is generally accepted that metrics (structure, process, and outcome measures, as well as balancing metrics) can still be used to drive improvements, as long as the following caveats are noted:

- We are very precise about what is being measured,
- We are explicit about what metrics are assessing,
- We make sure that both commissioners and providers are clear about these aspects of measurement,
- Metrics alone are not used to manage performance.

It is vitally important to maintain dialogue between commissioners and providers when tracking 'imperfect' metrics and managing services. Timely and effective communication between commissioners and providers who share an understanding of a common purpose to improve patient care, means that everyone can see more easily when metrics are not fit for purpose. Moreover, meaningful engagement 'beyond the numbers' is key to ensuring that patients and their families benefit from the respective expertise of both groups- the relative independence and advocacy role of the commissioner, and the expertise and mission of the provider.

Currently, a number of metrics are in place. A summary report of activity in adult specialist palliative care services, sponsored by the Irish Hospice

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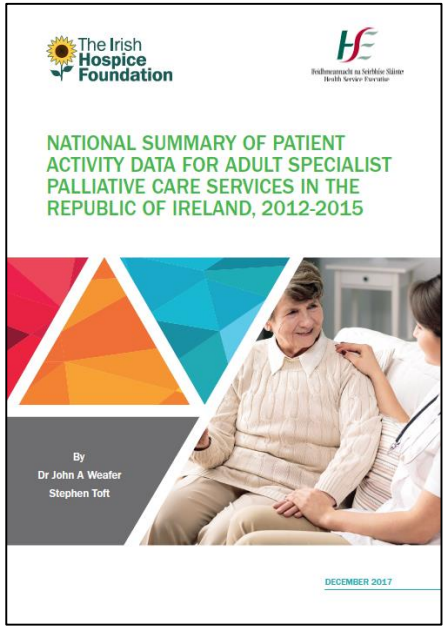

Foundation was published in December 2017. Building on this work, achievement of the Model of Care objectives will be evidenced by:

- The existence of a referral process that includes a system for prioritisation that is auditable,
- Reduced waiting times for patients as they navigate the system,
- Patients and carers reporting that they can more easily navigate the health system and receive palliative care services,
- Improved access to specialist palliative care,
- An improved patient experience, better quality of life and death,
- More people being cared for in a place that is acceptable to them and their families and choices being respected as far as is possible.

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Figure 11. Metrics

Domain	Metric descriptor	Development stage of metric
Access	The existence of a referral process that includes a system for prioritisation that is auditable	Local pilot of metric complete; nation-wide piloting due to commence 2018
Access	Reduced waiting times for patients as they navigate the system	Data currently being collected and reported
Access	Improved access to specialist palliative care	Cancer Strategy KPI
Coordination of care	Patients and carers reporting that they can more easily navigate through specialist palliative care services	Patient experience survey- NEW PROPOSAL
Quality of life and death	An improved patient experience, better quality of life and death	Patient experience survey- NEW PROPOSAL Bereavement survey of carers- NEW PROPOSAL Evidence of implementation of NCEC guidelines relevant to palliative care- NEW PROPOSAL
Place of care	People being cared for in a place of care that is acceptable to them and their families	Bereavement survey of carers- NEW PROPOSAL
Place of care	Proportion of people discharged home within 24 hours of activation of Rapid Discharge Pathway	Pilot of metric in progress
Harm reduction	Medication errors; falls reporting; pressure ulcer reduction;	Data collection through NIMS
Harm reduction	Percentage of people receiving systemic therapy in last month of life	Cancer Strategy KPI

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KEY POINTS

The achievement of the Model of Care objectives will be evidenced by:

- The existence of a referral process that includes a system for prioritisation that is auditable,
- Reduced waiting times for patients as they navigate the system,
- Patients and carers reporting that they can more easily navigate the health system and receive palliative care services,
- Improved access to specialist palliative care,
- An improved patient experience, better quality of life and death,
- More people being cared for in a place that is acceptable to them and their families and choices being respected as far as is possible.

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PALLIATIVE CARE AND UNIVERSAL HEALTHCARE

Integrating palliative care into the health system in all settings and levels of care is an essential step along the journey to Universal Health Coverage. This is recognised in the Oireachtas Committee on the Future of Healthcare (Sláintecare) which recommends that universal palliative care is provided within five years of the implementation of the report (Recommendation 4.1).

To achieve Universal Health Coverage countries need funding systems that enable people to access health services. Health funding, however, is much more than a matter of raising money for health. It is also a matter of who is asked to pay, when they pay, and how the money raised is spent. The manner in which countries design and combine the components of funding systems varies significantly and there is no one 'perfect solution'.

It is important to remember, that health funding systems are a means to an end- not an end in themselves. Strengthening the financial aspects of palliative care provision must occur in tandem with strengthening other aspects of palliative care provision in the health system, such as consideration of service delivery, workforce skills and public awareness. Unless there is adequate consideration and management of all aspects of palliative care systems strengthening, the likelihood of successfully achieving Universal Health Coverage for palliative care will be jeopardised.

REVENUE FUNDING FOR PALLIATIVE CARE

Revenue funding for specialist palliative care services is provided through the budget allocation headed 'Palliative Care' in the HSE annual service plan, and also through acute hospital and social care budgets. Revenue funding labelled 'palliative care' amounted to €78.20m* in the 2018 national Service Plan.

Revenue funding for palliative care approach services is provided through acute hospital, social care and primary care budgets- but as such care considered to be an integral part of healthcare provision, there are no budget headings for this activity in the annual service plan. A minority of palliative care approach services are somewhat arbitrarily identified as such (e.g. palliative care support beds are recognised as a specific form of intermediate care bed; domiciliary care provided by a GP for the final phase of care for patients with cancer, HIV or progressive neurological conditions is reimbursed using a palliative care claims form). However, the vast majority of level 1 or level 2 palliative care service provision is not 'separated out' from the usual business of service provision. Palliative care approach activity and costs are, therefore, mainly invisible at both regional and national levels of service provision.

** Due to co-location of some services, this figure includes funding for a number of residential care beds. It does not include acute hospital specialist palliative care funding.*

FUNDING

CURRENT FUNDING MECHANISMS FOR SPECIALIST PALLIATIVE CARE

A process of payment reform has been underway in the public hospital system since 2014, and activity-based funding has been introduced. Under activity-based funding, a prospective case-based payment system (Diagnosis Related Group system) replaces previous block grant allocations on a phased basis.

Block grant allocations are still used to fund specialist palliative care services. In block budgets, the payment for all services to be provided is bundled together and a prospective lump sum is paid to a provider at defined intervals, independent of the number of patients treated or the amount of activity undertaken. A block budget provides an overall spending limit that in some circumstances may act to constrain the volume and/or quality of the services provided.

As a positive, it can be argued that block grant allocations have been successful in devolving specialist palliative care service provision and accountability locally and that services have responded with the development of services that are of a high quality and are responsive to local stakeholder needs. Services meet (or exceed) performance standards required of them by the HSE and internationally, Ireland places highly in world rankings of quality. Additionally, transaction costs are low.

However, the historic basis for grant allocation means that some services are finding it challenging to meet growing demands and a dependency on fund-raising has arisen. There is a risk that, as a result, rationing of services will occur in the future. Another disadvantage is that the nature of the block grant means that allocation of funding to service areas or individual patients is less visible than with other payment methods. Importantly, historic block grant allocations do not incentivize specialist palliative care organisations to further develop their services and inequities in service provision (geographic and diagnosis-related) persist.

The Diagnosis Related Group system as currently structured (where diagnosis and procedures are the main determinants of payment) is not fit for purpose for palliative care as it does not predict the cost of care**.** Therefore, alternative approaches will need to be used if payment reform is considered for palliative care. The Model of Care recommends that in any move from block grant allocation, the following objectives should guide specialist palliative care payment redesign:

- Improve equity in the distribution of health care resources and improve access to SPC services for those with complex needs,
- Improve SPC service delivery and expand the scope of SPC care services,
- Improve the transparency of resource allocation,
- Create incentives for SPC providers to improve efficiency through more rational resource use, including increasing health promotion, and supplying higher-quality services with the resources available.

FUNDING

KEY POINTS

- Revenue funding for specialist palliative care services is provided through the budget allocation headed 'Palliative Care' in the HSE annual service plan, and also through acute hospital and social care budgets. Revenue funding labelled 'palliative care' amounted to €78.20m* in the 2018 national Service Plan.
- Revenue funding for palliative care approach services is provided through acute hospital, social care and primary care budgets- but as such care considered to be an integral part of healthcare provision, there are no budget headings for this activity in the annual service plan.
- Block grant allocations are used to fund specialist palliative care services.

** Due to co-location of some services, this figure includes funding for a number of residential care beds. It does not include acute hospital specialist palliative care funding.*

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OTHER MODELS OF CARE

The development of models of care by the Clinical Care and Integrated Care Programmes, as well as by other parts of the health service offers important opportunity to deliver whole-person care that responds to physical health, mental health, and social needs together. There is a danger, however, that artificial boundaries may develop between services if different models of care are disconnected from each other. In order to realise the full opportunities to improve care, it is vital that active efforts are made to ensure that different Programmes align with each other (at a minimum) and integrate with each other (wherever this is necessary). Programmes should not be seen as separate entities but rather as components of a whole-system blueprint for care.

Recognising that palliative care is one of the core components of universal healthcare, palliative care should be integrated within models of care for people with life-limiting or life-threatening illness. In reviewing existing models and in developing new models of care, there is significant scope to make more progress in the following areas:

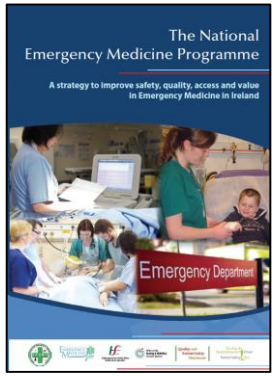
- Making the palliative care approach a core component of models of care so that hospital, community and primary care teams are better equipped to meet the physical, emotional, psychosocial and spiritual needs of people with serious illness.
- Ensuring that integrated care teams designed to support people with complex and ongoing care needs due to chronic illness or old age can access specialist palliative care expertise, and that adequate specialist palliative care capacity and capabilities exists to meet needs.
- Strengthening the palliative care components of urgent and emergency care pathways in Emergency Departments and elsewhere.

The design of other models of care should ensure that palliative care provision is 'early and planned' rather than 'late and reactive'. Partnership working across programmes can lead to innovative solutions- two examples of this to date are the PAL.M.ED project (joint initiative with the Emergency Medicine Programme) and Project ECHO AIIHPC Nursing Homes (joint initiative with Care of the Older Persons Programme).

PALLIATIVE CARE AND PUBLISHED MODELS OF CARE

This section of the document signposts readers to other models of care where palliative care has been considered.

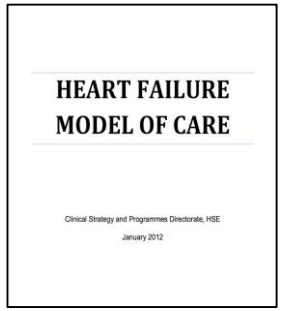
National Clinical Programme for Emergency Medicine (2012)



OTHER MODELS OF CARE

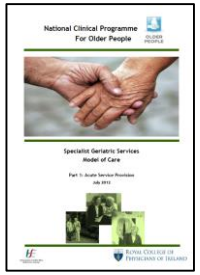
The Emergency Medicine model of care recognises the need to work with the National Clinical Programme for Palliative Care to 'ensure that patients with life-limiting conditions and their families can easily access a level of palliative care that is appropriate to their needs'. It also states that 'Clinical guidelines and care protocols will be developed to support the delivery of high-quality palliative care for patients who present to Emergency Departments'.

National Clinical Programme for Heart Failure (2012)



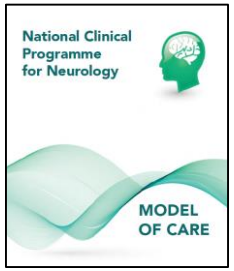
Palliative Care is referenced broadly in the model of care and recommendation 4.8 states- 'A programme should be developed to increase and support the capacity of primary care to detect heart failure at an early stage and to provide proactive care, including Specialist palliative care for heart failure patients'.

National Clinical Programme for Care of the Older Person (2012)



The model of care highlights the importance of cross specialty activities with relevant services including palliative care and specifically recommends supporting implementation of advanced care/ end of life protocols in association with the National Clinical Programme for Palliative Care.

National Clinical Programme for Neurology (2015)

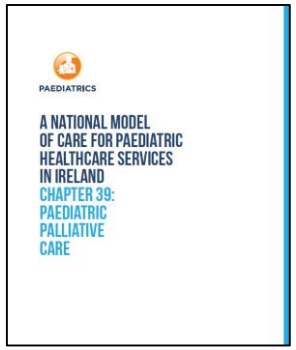


The model of care references palliative care extensively with a focus on

OTHER MODELS OF CARE

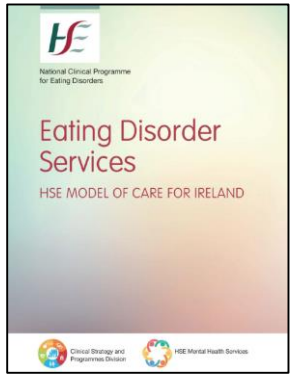
interface and integration with palliative care services and the National Clinical Programme for Palliative Care. The model of care recognises there is a place for palliative care in patients with long term neurological conditions.

National Clinical Programme for Paediatrics (2017)



Chapter 39 of the model of care is dedicated to 'Paediatric Palliative Care'. As in adult palliative care services, the aim is to enable every child with a life-limiting illness to live as well as possible until he/she dies.

National Clinical Programme for Eating Disorders (2018)



The model of care considers issues regarding the management of patients with Eating Disorders, mainly anorexia nervosa, who are dying from their illness. Developed in collaboration with the National Clinical Programme for Palliative Care.

Models of Care currently in draft that have consulted with the National Clinical for Palliative Care

- Chronic Obstructive Pulmonary Disease (Draft)
- Cystic Fibrosis (Draft)
- Transition from Paediatric to Adult Healthcare Providers in Rare Diseases (Draft)

OTHER MODELS OF CARE

KEY POINTS

- The development of models of care by the Clinical Care and Integrated Care Programmes, as well as by other parts of the health service offers important opportunity to deliver whole-person care that responds to physical health, mental health, and social needs together.
- In order to realise the full opportunities to improve care, it is vital that active efforts are made to ensure that different Programmes align with each other (at a minimum) and integrate with each other (wherever this is necessary).
- Recognising that palliative care is one of the core components of universal healthcare, palliative care should be integrated within models of care for people with life-limiting or life-threatening illness.
- The design of other models of care should ensure that palliative care provision is 'early and planned' rather than 'late and reactive'.

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Building Integrated Palliative Care Programs and Services. Gomez-Batiste X, Connor S. (eds). Available http://kehpca.org/wp-content/uploads/Gómez-Batiste-X-Connor-S-Eds.-Building-Integrated-Palliative-Care-Programs-and-Services.-2017-b.pdf Accessed 19th February 2018.

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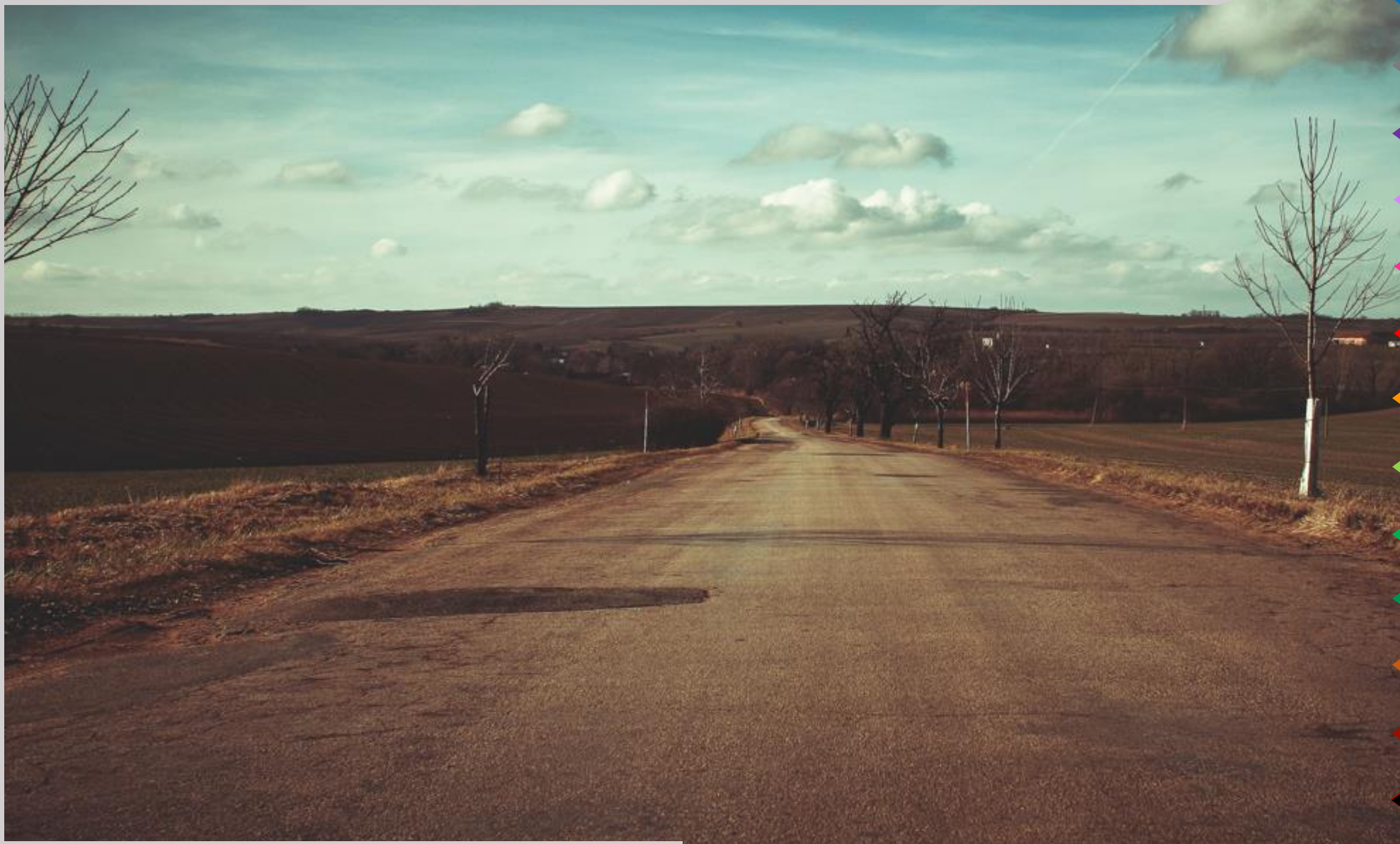

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Note:

- **A Model of Care is more likely to achieve the best possible outcomes when the question of how the Model is to be implemented has been an integral part of its design.**
- **The material that is currently included in this section (logic models and listing of management objectives) has been drafted in order to provide an initial overview of the actions required to implement the draft Model of Care.**
- **The costings provided are indicative costings drawn from the Palliative Care Services Three Year Development Framework 2017-2019 (HSE, 2017) and Sláintecare (Action 4.1, provision of universal palliative care).**

IMPLEMENTATION

IMPLEMENTATION TO DATE- LEARNING FROM LESSONS OF PAST EXPERIENCE

The Report of the National Advisory Committee on Palliative Care (NACPC) was one of the first dedicated national palliative care policies published in the world. May and colleagues conducted an appraisal of policy implementation to date, which provides useful lessons for implementation of this Model of Care. [1] Initially the authors note that implementation was slow. Between 2001 and 2004 statutory funding increased by €10 million to €54 million. This increase was some €90 million short of the NACPC-specified budget and rate of increase was slower rate than the rate of increase of national healthcare spending generally.

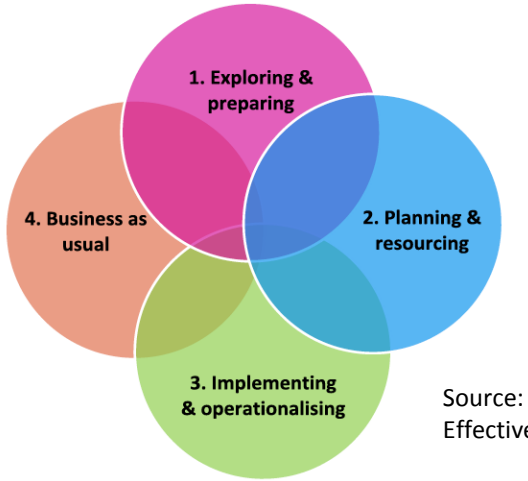
This delay was largely explained by the necessary delay while regions performed needs assessments and developed strategies to implement policy, but this work consumed three years of the original five-year timeframe. Of note, geographic variation in development of services was clearly evident- locations where services were reasonably well developed grew at a faster pace than locations where no infrastructure and personnel were present. The most significant period of service expansion occurred between 2004- 2007. Annual government spending rose from €54 million to €76 million, equivalent to 40% in three years, [1] and palliative care availability expanded in nearly all regions of the country.

By the start of the global recession, the annual government budget for palliative care remained approximately 50% of that required to fulfil policy. In common with other services, spending reduced for a number of years until 2014, when investment in palliative care again recommenced.

LOOKING FORWARD

There is broad agreement that implementation is a complex process that takes time and which occurs in incremental stages, each requiring different conditions and activities. The first two stages (stages 1 & 2) involve exploratory and planning activities. Following this, the innovation is implemented (stage 3), before it is fully embedded in the system and evaluated (stage 4).[2]

Figure 12. Stages of implementation



Source: Centre for Effective Services [2]

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Each stage is essential to the implementation process and cannot be skipped. The development of the Model of Care represents the completion of stage 1 of the process. Stage 2 (Planning and Resourcing) will require a clear plan for implementation, including identification of the team of qualified individuals identified who will take responsibility for guiding the process and the securing of necessary resources.

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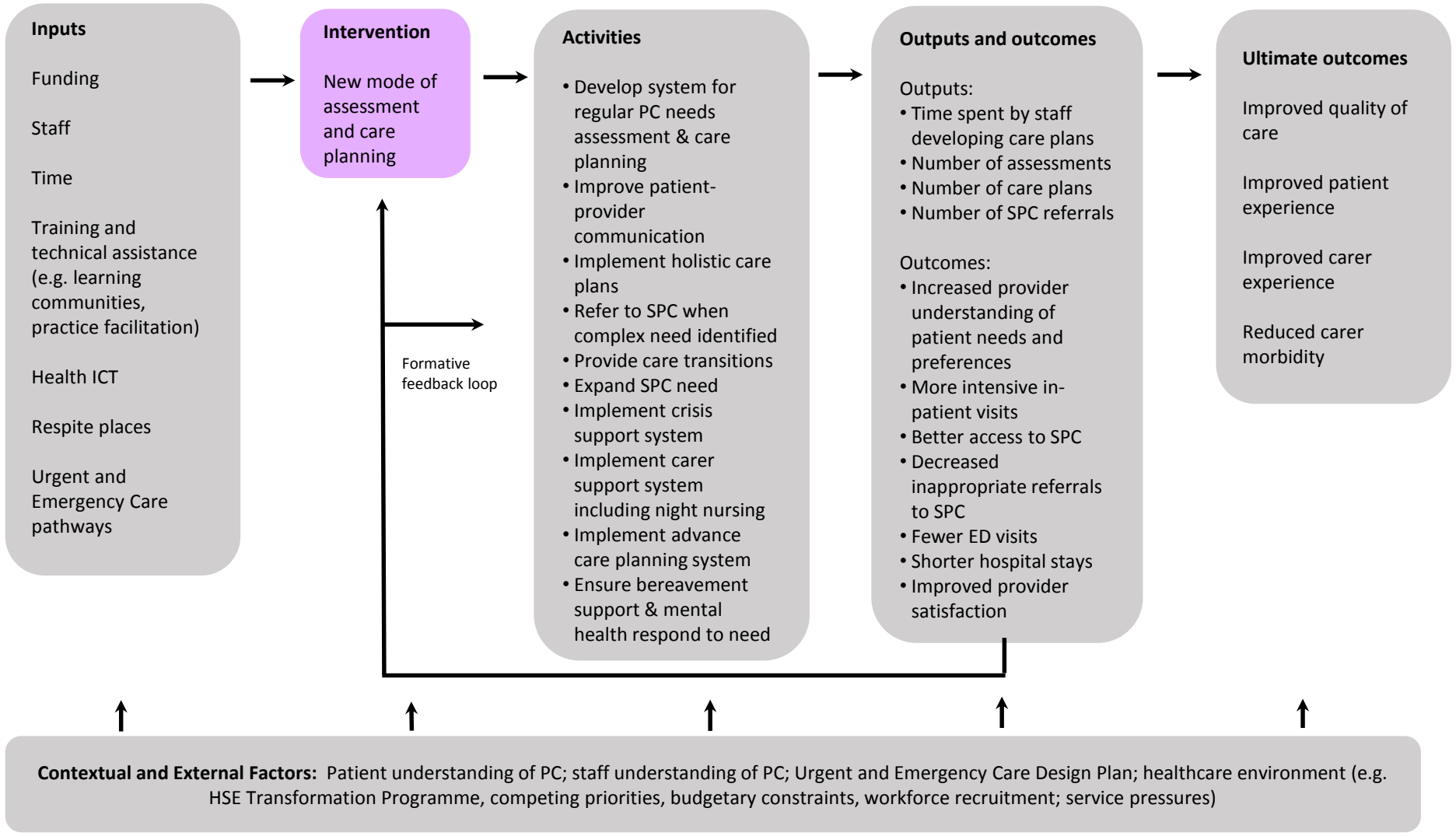
IMPLEMENTATION Logic Model- Foundation 1



PC= palliative care; SPC= specialist palliative care; ED= Emergency Department

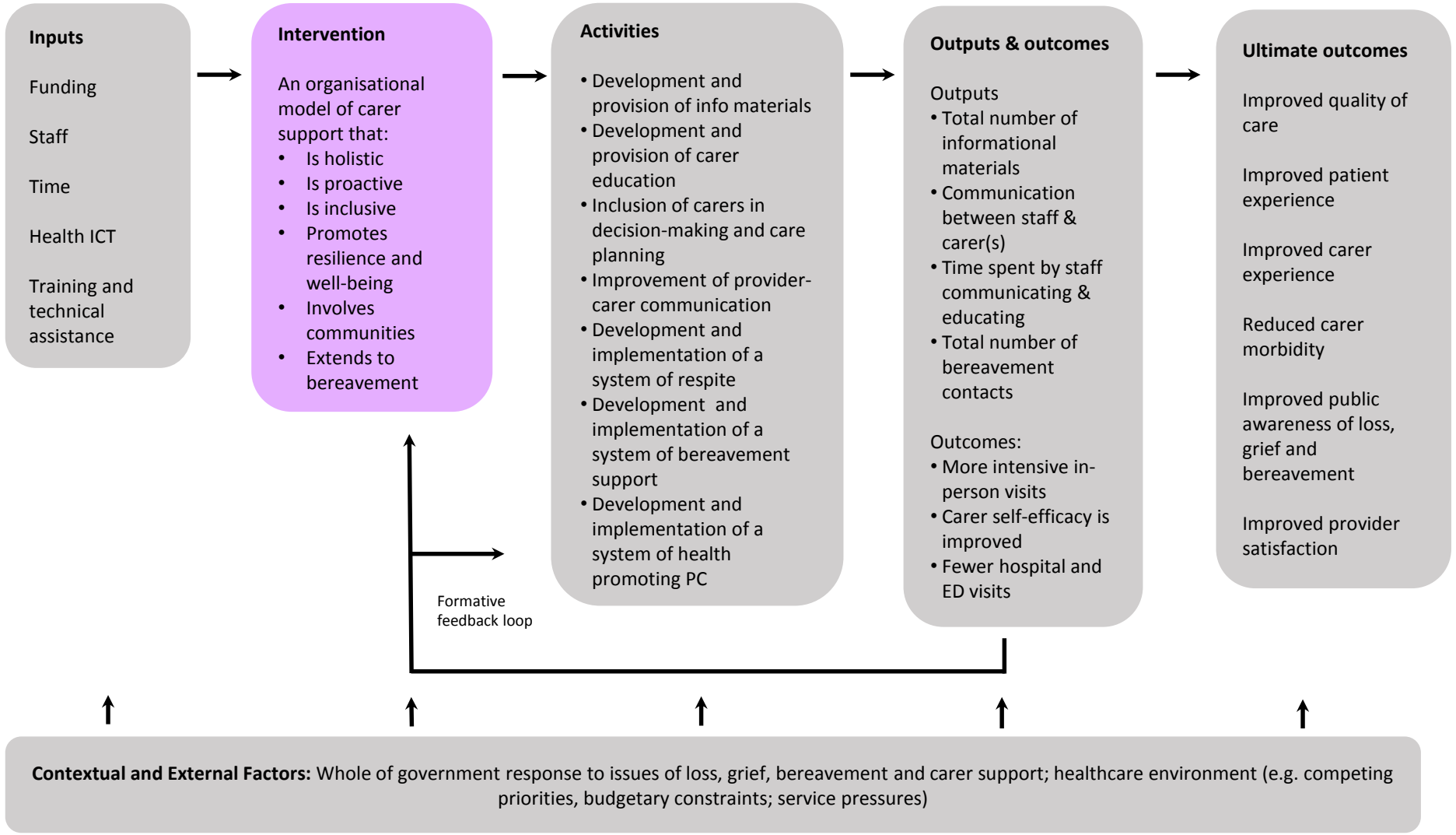
IMPLEMENTATION Logic Model- Foundation 1

1. People with serious or life-limiting illness receive regular, standardised assessment of palliative care need and individualised care plans are developed to meet identified need.				
Management objectives	**2019 goals/ measures**	**2020 goals/ measures**	**2021 goals/ measures**	**Strategic goals/ measures**
a) Palliative care assessment becomes an ongoing process throughout the course of a patient's illness and hospital, community and primary care staff carry out assessments at key transition points in the patient pathway.	Goal: TBC	Goal: TBC	Goal: TBC	Goal: TBC
	Measure:	Measure:	Measure:	Measure:
b) The care plan addresses physical, emotional, psychosocial and spiritual domains of need.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
c) A multidisciplinary specialist palliative care team is available to meet the multifaceted needs of patients and their families, when required.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
d) Patients, with their families, are afforded opportunities to engage in discussion and reflection about goals, values and preferences for future treatment.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
e) Healthcare professionals put contingency plans in place, where possible, to anticipate situations where the patient may deteriorate or in the event of a carer crisis.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
f) Crisis supports such as rapid access clinics, emergency respite and out of hours services are available to people with life-limiting or life-threatening illnesses.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:

IMPLEMENTATION Logic Model- Foundation 1

1. People with serious or life-limiting illness receive regular, standardised assessment of palliative care need and individualised care plans are developed to meet identified need.				
Management objectives	**2019 goals/ measures**	**2020 goals/ measures**	**2021 goals/ measures**	**Strategic goals/ measures**
g) Carers are provided with practical, emotional, social and spiritual support, as needed.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
h) Healthcare professionals recognise, where possible, when a person may be entering the last days of life and provide appropriate care and support to the patient and family at this time.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:

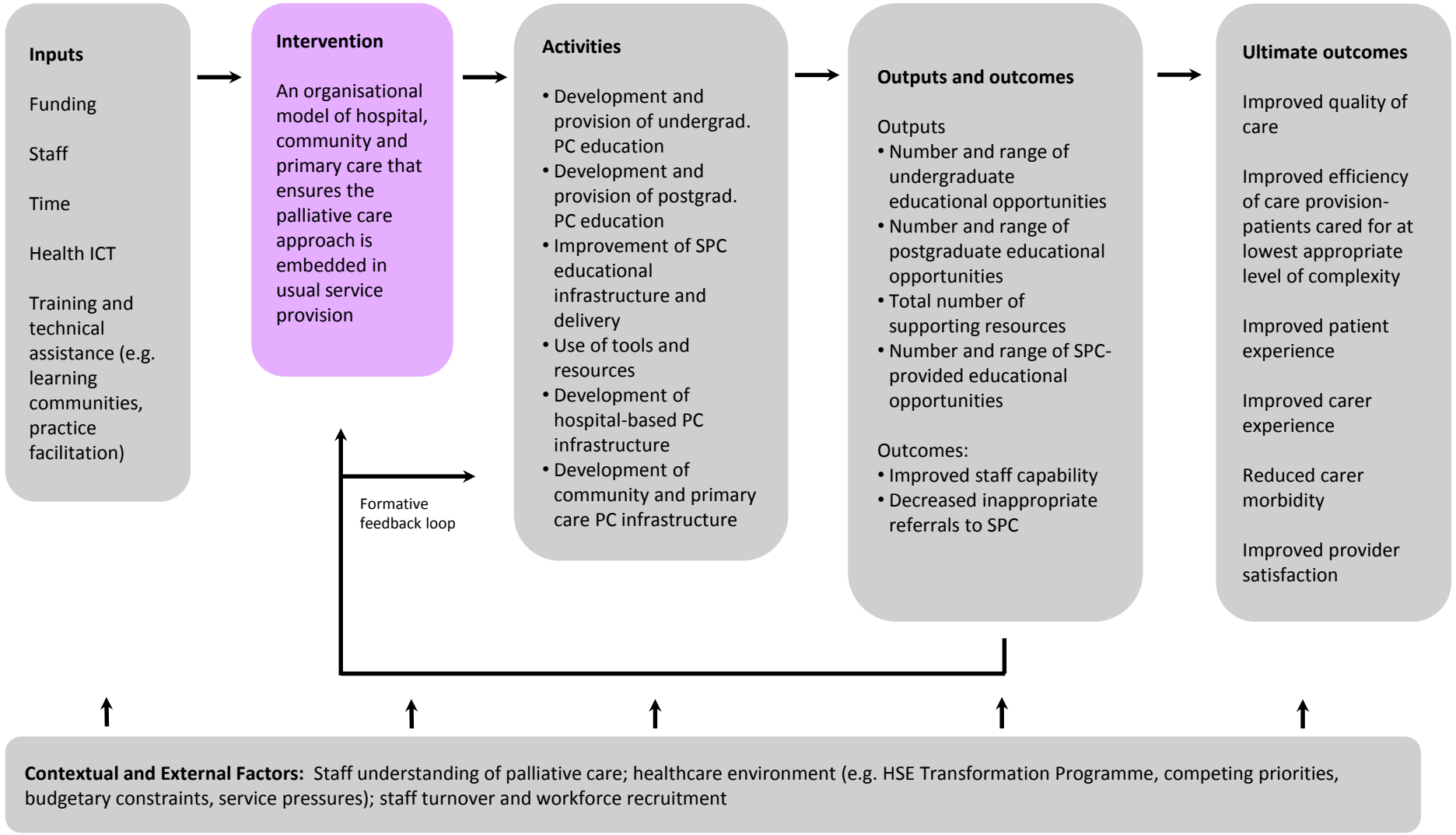
IMPLEMENTATION Logic Model- Foundation 2



IMPLEMENTATION Logic Model- Foundation 2

2. Carers are provided with practical, emotional, psychosocial and spiritual support.				
Management objectives	**2019 goals/ measures**	**2020 goals/ measures**	**2021 goals/ measures**	**Strategic goals/ measures**
a) Awareness and recognition of the role and contribution of carers is promoted.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
b) For those patients who consent, carers are included in care planning and decision making.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
c) Supports and services to promote the physical, mental and emotional health and well-being of carers are developed.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
d) Clear and timely information and advice is developed and promoted.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
e) Relevant and accessible training opportunities for carers are provided.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
f) Patients and carers are provided with access to respite.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
g) Specialist palliative care providers work in partnership with their local communities to develop programmes of health promoting palliative care.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:

IMPLEMENTATION Logic Model- Foundation 3



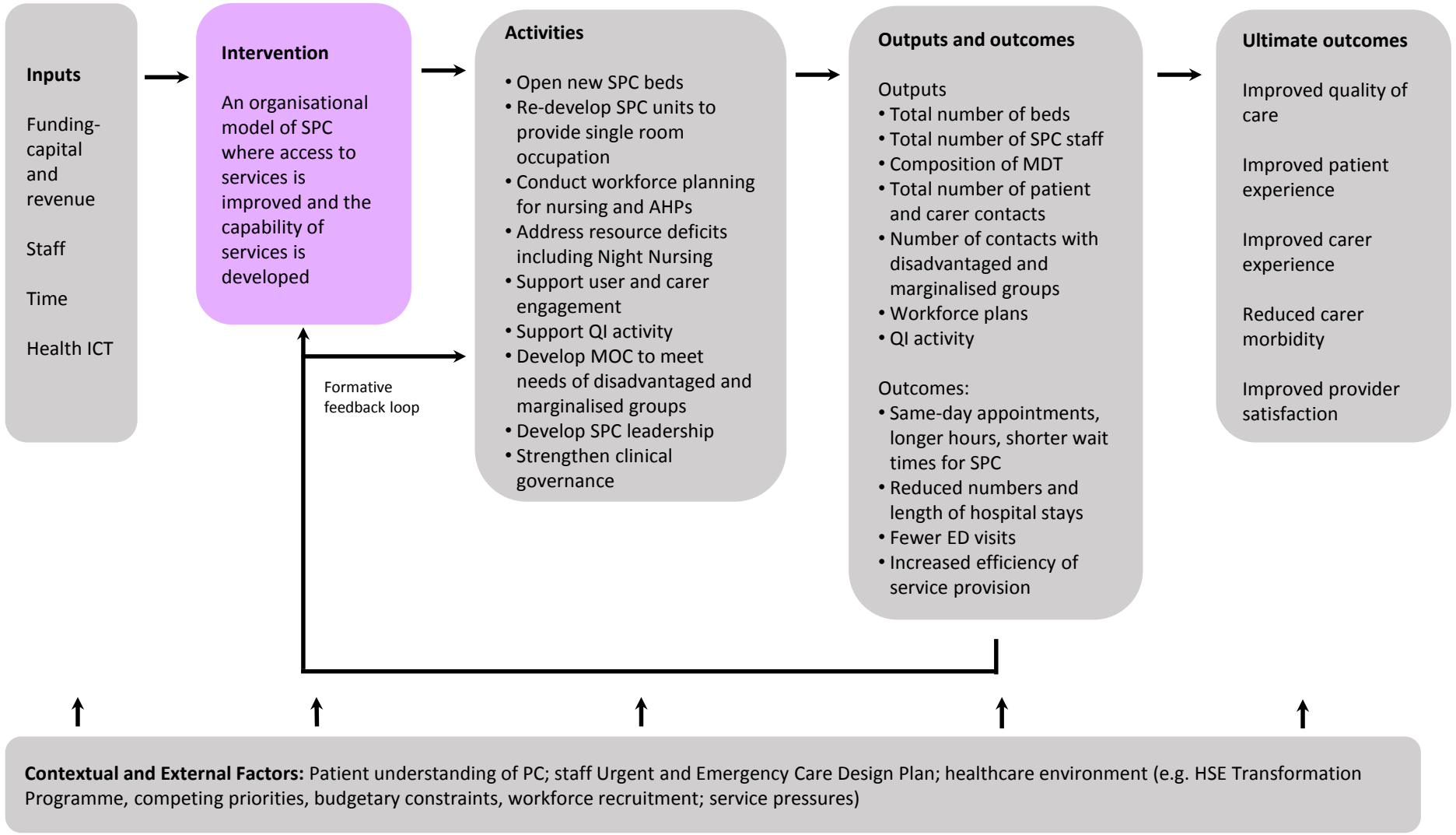
IMPLEMENTATION Logic Model- Foundation 3

3. An enabling environment is created where hospital, community and primary healthcare providers are supported to provide a palliative care approach as part of their normal service provision.				
Management objectives	**2019 goals/ measures**	**2020 goals/ measures**	**2021 goals/ measures**	**Strategic goals/ measures**
a) Opportunities for interdisciplinary education in palliative care at undergraduate level are expanded.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
b) Pre- and post-registration postgraduate opportunities in palliative care are expanded.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
c) Continuing Professional Development training opportunities in palliative care are increased.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
d) The contribution of Specialist Palliative Care Education Departments to the education and training of hospital, community and primary healthcare staff is optimised.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
e) Resources such as guidelines, care pathways to support palliative care provision are provided.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:

IMPLEMENTATION Logic Model- Foundation 3

3. An enabling environment is created where hospital, community and primary healthcare providers are supported to provide a palliative care approach as part of their normal service provision.				
Management objectives	**2019 goals/ measures**	**2020 goals/ measures**	**2021 goals/ measures**	**Strategic goals/ measures**
f) Organisational structures are developed that support palliative care provision in the hospital setting. This includes optimising the alignment between the Hospice Friendly Hospitals Programme and the National Clinical Programme for Palliative Care, and developing the educational role of specialist palliative care teams.	Goal: Measure:	Goal: Measure:	Goal: Measure:	Goal: Measure:
g) Organisational structures are developed that support palliative care in the primary care & community settings. This includes supporting multidisciplinary team meetings between specialist palliative care teams and primary care and community teams and developing the educational role of specialist palliative care teams (for example in such innovative programmes as Project ECHO). It also includes development of the role of Palliative Care Support Beds.	Goal: Measure:	Goal: Measure:	Goal: Measure:	Goal: Measure:

IMPLEMENTATION Logic Model- Foundation 4



IMPLEMENTATION Logic Model- Foundation 4

4. Access to specialist palliative care is provided and the capability of services is developed.				
Management objectives	**2019 goals/ measures**	**2020 goals/ measures**	**2021 goals/ measures**	**Strategic goals/ measures**
a) Infrastructure deficits in service provision as detailed in the Three Year Development Framework are addressed	Goal: 14 bed SPC unit Mayo; 20 bed SPC unit Waterford; 15 bed SPC unit WIcklow	Goal: 30 bed SPC unit Drogheda; 16 bed SPC unit Cavan; 15 bed SPC unit Tullamore *	Goal: 30 bed SPC unit Drogheda; 16 bed SPC unit Cavan; 15 bed SPC unit Tullamore * Phase 1 Re-development to 20 single rooms St Francis Hospice, Raheny	Goal: At least 10 beds per 100,000 population organised and provided on a regional basis
	Measure: Total number of beds opened	Measure: Total number of beds opened	Measure: Total number of beds opened	Measure: Total number of beds per 100,000
b) Resource deficits in service provision as detailed in the Three Year Development Framework are addressed	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
c) Resource deficits and skills pathways as detailed in forthcoming Palliative Care Medical, Nursing and Health and Social Care workforce planning exercises are addressed	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:

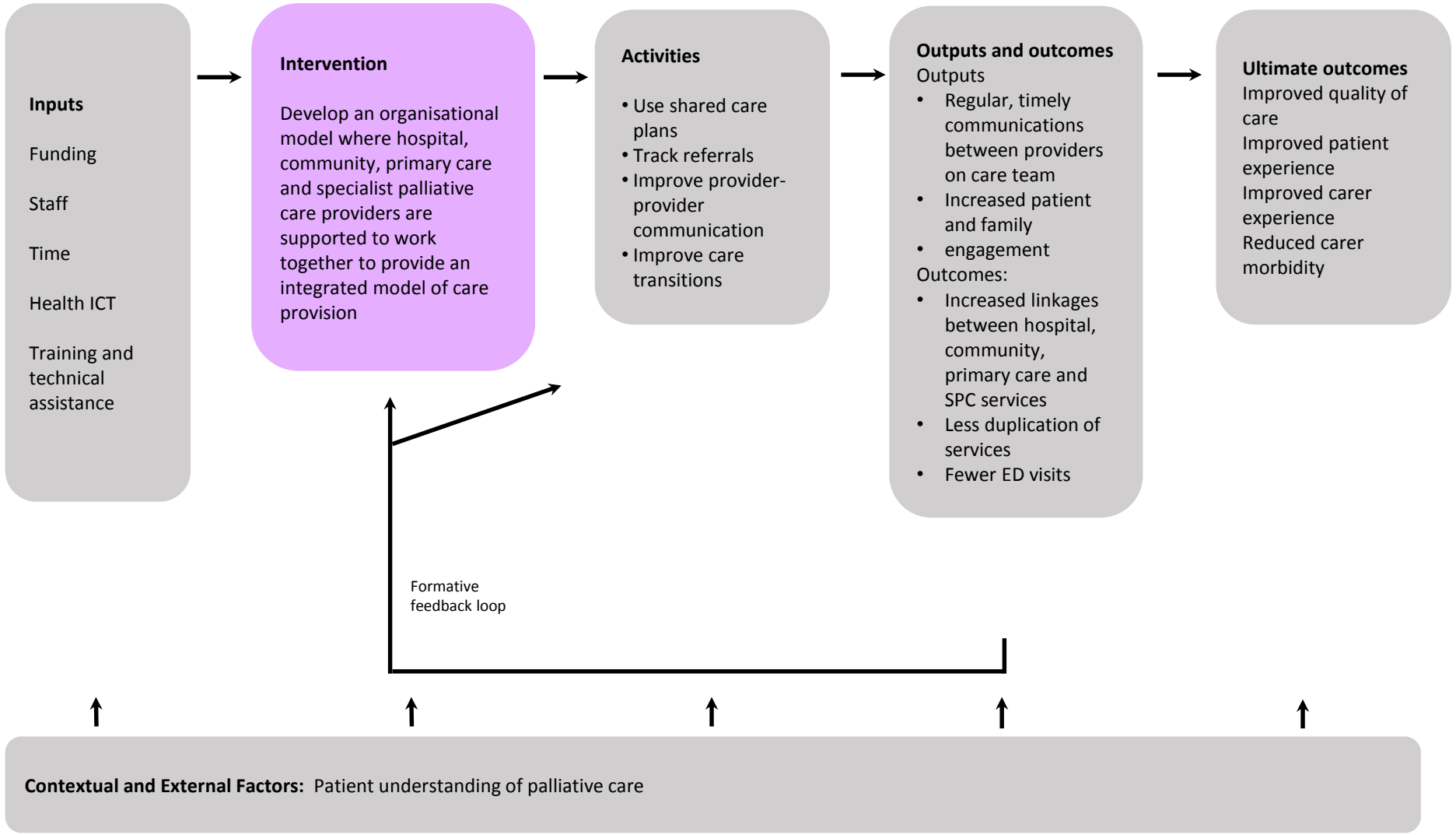
* All developments planned for 2020/2021 in Three Year Development Framework

IMPLEMENTATION Logic Model- Foundation 4

4. Access to specialist palliative care is provided and the capability of services is developed.				
Management objectives	**2019 goals/ measures**	**2020 goals/ measures**	**2021 goals/ measures**	**Strategic goals/ measures**
d) Specialist palliative care services embed quality improvement in service provision	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
e) Specialist palliative care services engage patient, families and partner organisations in co-design of local implementation plans for this Model of Care	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
f) The needs of marginalised, vulnerable, or socially excluded populations are considered in the further design of this Model of Care and effectiveness of pilot projects is evaluated and reported.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
g) The leadership capability and capacity of specialist palliative care staff is developed and clinical governance arrangements are strengthened.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:

* Recommendation 2 Three Year Development Framework

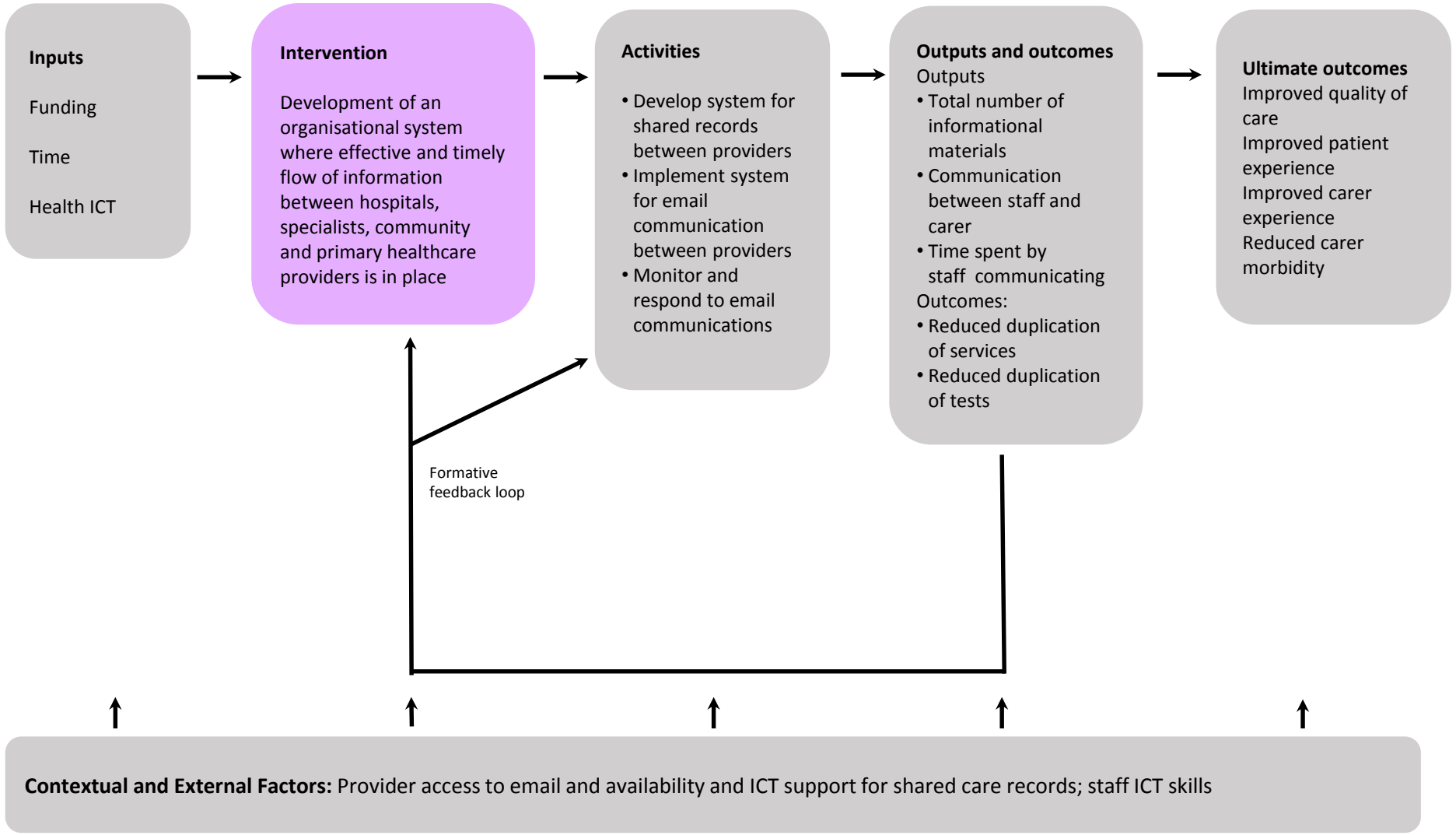
IMPLEMENTATION Logic Model- Foundation 5



IMPLEMENTATION Logic Model- Foundation 5

5. Hospital, community, primary care and specialist palliative care providers are supported to work together to provide an integrated model of care provision.				
Management objectives	**2019 goals/ measures**	**2020 goals/ measures**	**2021 goals/ measures**	**Strategic goals/ measures**
a) Specialist palliative care services demonstrate leadership in engaging constructively with hospital, community and primary care providers to identify and improve ways to provide integrated palliative care.				
b) There is promotion of a shared awareness of intersecting policies and procedures for inter-organisational working in order to facilitate a mutual understanding of roles, responsibilities and care pathways.				
c) Care plans are developed with patients, and families where appropriate, to create active participation and ownership.				
d) Appropriate sharing of healthcare records and information, is facilitated across and within organisations involved in care.				
e) Mechanisms that measure people's experience of integrated care and support are developed and used to improve the way palliative care is delivered.				
f) Case studies and experiences of integrated palliative care are disseminated across the sector through tools such as seminars, webinars and websites.				

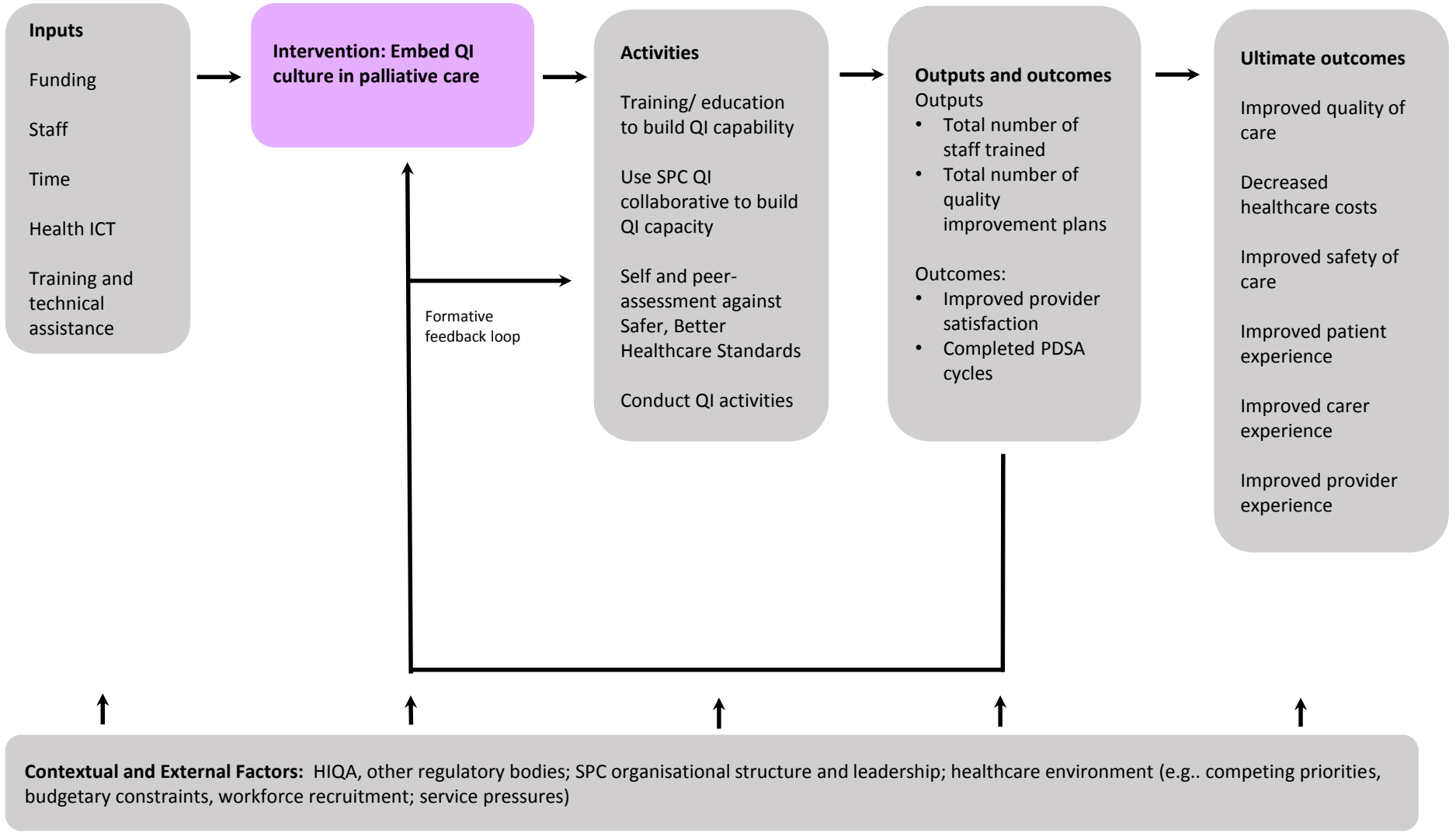
IMPLEMENTATION Logic Model- Foundation 6



IMPLEMENTATION Logic Model- Foundation 6

6. Effective and timely flow of information between hospitals, specialists, community and primary healthcare providers is in place.				
Management objectives	**2019 goals/ measures**	**2020 goals/ measures**	**2021 goals/ measures**	**Strategic goals/ measures**
a) The healthcare records of people living with any life-limiting or life-threatening illness should include a palliative care needs assessment, an agreed care plan and with the person's consent, these records should be shared with all those involved in their care.	Goal Measure	Goal Measure	Goal Measure	Goal Measure
b) Specialist palliative care services are supported to become early adopters of national EHR and shared record projects.				

IMPLEMENTATION Logic Model- Foundation 7

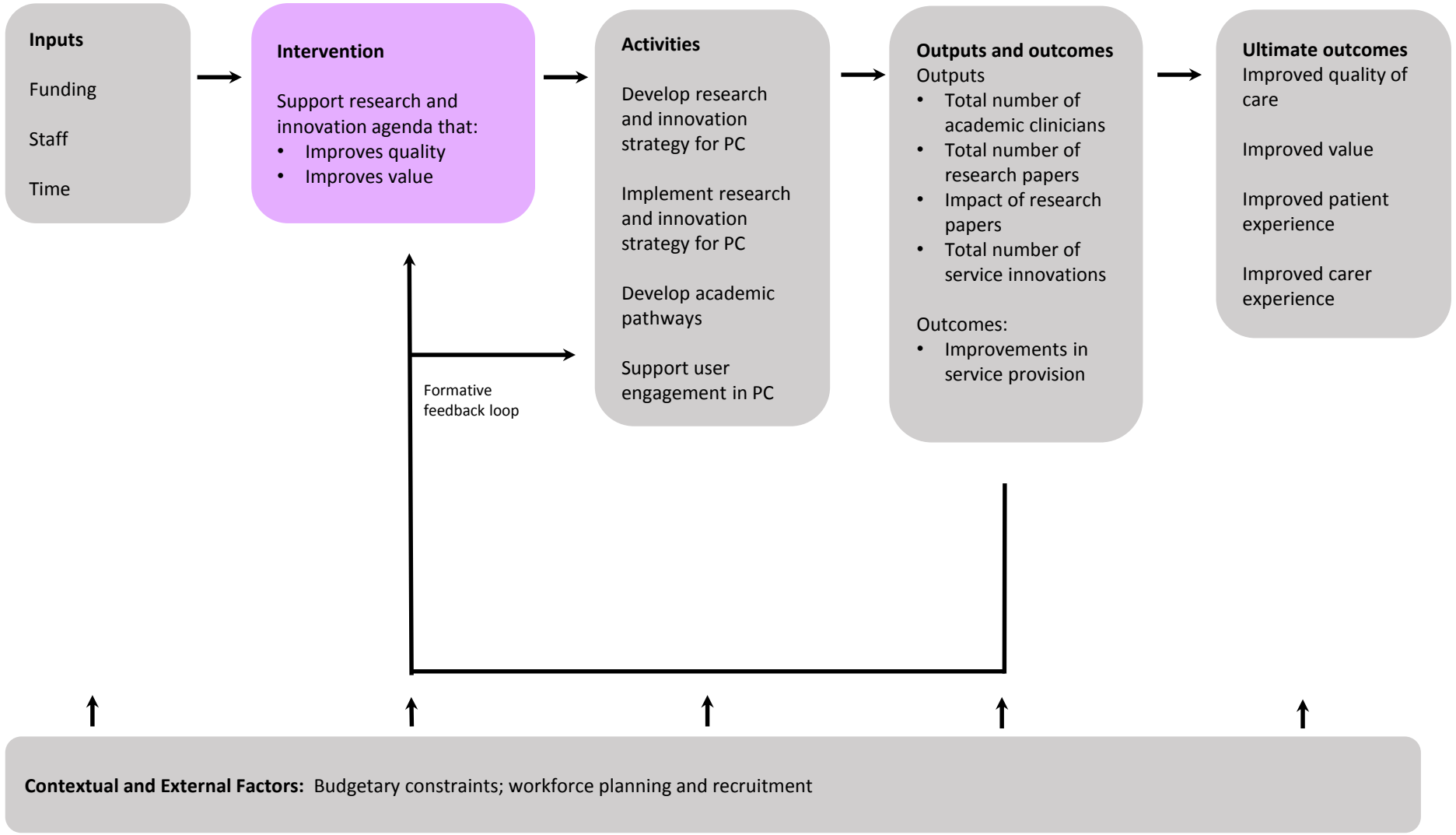


IMPLEMENTATION Logic Model- Foundation 7

7. A culture of quality improvement is embedded in palliative care provision.				
Management objectives	**2019 goals/ measures**	**2020 goals/ measures**	**2021 goals/ measures**	**Strategic goals/ measures**
a) Investment is made in capability building to provide all staff with the skills needed to improve quality. This includes skills in quality improvement methodology and techniques.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
b) Investment is made in the training and development of clinical leadership in palliative care.	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
c) Specific goals for quality improvement are set, based on evidence and supported by the use of information to assess progress towards achievement (see metrics section)	Goal:	Goal:	Goal:	Goal:
	Measure:	Measure:	Measure:	Measure:
d) Collection and reporting of data on performance is in a clear and easy to use format. (see metrics section).	Goal: QA+I workbooks used by all SPC services *	Goal:	Goal:	Goal:
	Measure: 100% have completed self-assessment	Measure:	Measure:	Measure:

* Three Year Development Framework Action 3

IMPLEMENTATION Logic Model- Foundation 8



IMPLEMENTATION Logic Model- Foundation 8

Foundation 8. A research and innovation agenda that improves the quality and value of palliative care is supported.

To establish Foundation 8, the following actions are required:

a) A research and innovation agenda is embedded in palliative care provision.

b) Stronger user engagement in research and innovation is supported, including the further development of Voices for Care.

c) There is continued capacity building in research and innovation.

d) Workforce planning includes the development of academic pathways in palliative care.

IMPLEMENTATION- Indicative costings

ANNEX E

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

(EXCLUDING CONSULTANT DEFICITS)

	Our Lady's Hospice (48 beds)			Marymount Hospice (44)			St. Francis' Hospice (43)			Milford Hospice (30)		
	Rec.	Actual	Deficit	Rec.	Actual	Deficit	Rec.	Actual	Deficit	Rec.	Actual	Deficit
CNM II	3	4	0	2	2	0	3	4	0	2	5	0
CNMI	3	4	0	2	2	0	3	3	0	2	2	0
RGN	45	41.5	3.5	42	40	2	40	45.39	0	28	30	0
HCA	24	25	0	22	21	1	21.5	25.09	0	15	15.6	0
Social Worker	4.8	3	1.8	4.4	3.6	0.8	4.3	1.8	2.5	3	2.4	0.6
Physiotherapist	4.8	3.5	1.3	4.4	3.6	0.8	4.3	2	2.3	3	3.26	0
Occupational Therapist	4.8	3.5	1.3	4.4	0	4.4	4.3	1.81	2.49	3	2.44	0.56
Speech & Language Therapist	0.5	0	0.5	0.5	0	0.5	0.5	0	0.5	0.3	0.1	0.2
Dietician	0.5	0	0.5	0.5	0	0.5	0.5	0	0.5	0.3	0.9	0
Pharmacist	2	1.5	0.5	1	2.4	0	1	1.14	0	1	2	0
Chaplain	3	1	2	2	2.4	0	2	1.27	0.73	2	2.55	0
	Galway Hospice (18)			North West Hospice (8)			Total Deficits		Salary Incl. PRSI*		Cost €	
CNM II	1	1	0	1	1	0	0		€65,997		0	
CNMI	3	3	0	1	1	0	0		€61,676		0	
RGN	18	18	0	7	11.6	0	5.5		€49,715		273,433	
HCA	8	11	0	4	5.6	0	1		€40,606		40,606	
Social Worker	1.8	2.0	0	0.8	2	0	5.9		€67,168		382,858	
Physiotherapist	1.8	1.3	0.5	0.8	0.5	0.3	5.4		€60,445		314.314	
Occupational Therapist	1.8	0.8	1.0	0.8	0.5	0.3	10.25		€60,445		607,472	
Speech & Language Therapist	0.1	0.0	0.1	0.1	0.1	0	1.8		€60,445		108,801	
Dietician	0.1	0	0.1	0.1	0.1	0	1.6		€60,445		96,712	
Pharmacist	1.0	1.0	0	0.6	0.6	0	0.5		€70,857		35,429	
Chaplain	1	1	0	1	1	0	2.73		€55,148		150,554	
Total							34.64				€2,010,179	

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

IMPLEMENTATION- Indicative costings

ANNEX F

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

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

(Rec: Recommended; Def: Deficit)

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

Cost of rectifying the deficits:

CNS	23.1 @ €65,997 = €1.5m
Physiotherapy	32.8 @ €60.445 = €2.0m
Occ. Therapy	29.8 @ €60.445 = €1.8m
Soc. Work	20.2 @ €67,168 = €1.4m
Total:	**€6.7m**

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

IMPLEMENTATION- Indicative costings

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

(EXCLUDING CONSULTANT DEFICITS)

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

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

Cost of rectifying the deficits:

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

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

IMPLEMENTATION- Indicative costings

	Details	Year 1	Year 2	Year 3	Year 4	Year 5	Year 6	Year 7	Year 8	Year 9	Year 10
4. SOCIAL CARE EXPANSION											
4.1 Palliative Care	Increase from previous year	€8,036,157	€8,900,125	€9,856,977	€10,916,701	€12,090,355	€0	€0	€0	€0	€0
	Cumulative spend	€8,036,157	€16,936,282	€26,793,259	€37,709,960	€49,800,000	€49,800,000	€49,800,000	€49,800,000	€49,800,000	€49,800,000
4.2 Homecare	Difference from previous year	€24,000,000	€24,000,000	€24,000,000	€24,000,000	€24,000,000	€0	€0	€0	€0	€0
	Cumulative spend	€24,000,000	€48,000,000	€72,000,000	€96,000,000	€120,000,000	€120,000,000	€120,000,000	€120,000,000	€120,000,000	€120,000,000
4.3 Expansion of services for people with disabilities	Difference from previous year	€29,090,855	€29,090,855	€29,090,855	€29,090,855	€29,090,855	€29,090,855	€29,090,855	€29,090,855	€29,090,855	€29,090,855
	Cumulative spend	€29,090,855	€58,181,711	€87,272,566	€116,363,422	€145,454,277	€174,545,132	€203,635,988	€232,726,843	€261,817,699	€290,908,554

The Report of the Oireachtas Committee on the Future of Healthcare (Sláintecare) p.177

IMPLEMENTATION

KEY POINTS

- Implementation is a complex process that takes time and which occurs in incremental stages, each requiring different conditions and activities.
- According to the implementation model of the Centre for Effective Services, the development of the Model of Care represents the completion of stage 1 of the process.
- Stage 2 (Planning and Resourcing) will require a clear plan for implementation, including identification of the team of qualified individuals identified who will take responsibility for guiding the process and the securing of necessary resources.

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1. May, P., Hynes, G., McCallion, P., Payne, S., Larkin, P., McCarron, M, Policy analysis: Palliative care in Ireland, Health Policy 2014; 115 (1): 68 – 74
2. Burke K, Morris K, McGarrigle. An Introductory Guide to Implementation. Centre for Effective Services; Dublin: 2012