Review of the Implementation of the 2001 Report of the National Advisory Committee on Palliative Care as it relates to Adult Palliative Care

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Disclaimer

Any views expressed in this report are those of the authors and not necessarily those of the Minister for Health or the Department of Health.

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List of abbreviations

Abbreviation	Term
CHI	Children's Health Ireland
CHO	Community Healthcare Organisations
CPD	Continuing Professional Development
CSO	Central Statistics Office
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
HSPA	Health System Performance Assessment
ICPCN	International Children's Palliative Care Network
ICPOP	Integrated Care Programme for Older Persons
IHF	Irish Hospice Foundation
KIS	Key Information Summary
MDS	Minimum Data Set
NACPC	National Advisory Committee on Palliative Care
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OECD	The Organisation for Economic Co-operation and Development
PBRA	Population-based Resource Allocation
PCOC	Palliative Care Outcomes Collaboration
PREM	Patient Reported Experience Measures
PROM	Patient Reported Outcome Measures
SPICT	Supportive and Palliative Care Indicators Tool
SRPC	Swedish Register of Palliative Care
TILDA	The Irish Longitudinal Study on Ageing
WHO	World Health Organisation

Glossary

Term	Definition
Advance care planning	A process that allows individuals to document their preferences around future healthcare. These plans can provide direction to healthcare professionals and loved ones when a person cannot communicate or make their own choices.
Informal carer	An individual, such as a family member or a friend, who provides help and care without monetary compensation.
Economic evaluation	The process of systematically analysing costs and outcomes to review the cost-effectiveness of an intervention using a comparator.
Efficiency	A concept relating to achieving the maximum possible output from a set level of resources within a system.
Equity	An ethical concept denoting the absence of disparities between population groups to ensure fair distribution of services and resources in health.
eHealth	A term that denotes the use of information technology (IT) in healthcare, including the maintenance of electronic records and telemedicine.
Generalist palliative care	Services providing a palliative care approach as part of usual care provision
Health system framework	The World Health Organisation (WHO) uses an analytic framework to describe health systems in terms of six core components or 'building blocks': *service delivery, workforce, information, essential medicines and technologies, financing and leadership and governance*.
Integrated care	The organisation and management of health services so that people get the care they need, when they need it, in ways that are user friendly, achieve the desired results and provide value for money.
Key Information Summary	A brief outline of an individual's medical record that is available on an IT platform for healthcare professionals to consult.
Life-limiting condition/illness	A condition or illness which cannot be reversed by treatment and from which a person is expected to die.
Macro level	A level of analysis that addresses the global perspective of analysis; examining systems at a societal, national, or international degree.
Meso level	A level of analysis that addresses systems from the perspective of organisational or community structures.
Micro level	A level of analysis that examines systems from the perspective of the individual or the household.
Minimum data set	A national dataset containing demographic and patient activity data for specialist palliative care services in the Republic of Ireland
Model of care	A framework incorporating regulatory, organisational, financial, and clinical aspects of service provision to outline best practice in care delivery.

Paediatric palliative care	A care approach that seeks to enable children with life-limiting illnesses to live as well as possible and to maintain a high quality of life, by alleviating symptoms and pain and supporting families from the point of diagnosis to bereavement (national model for paediatric).
Palliative care	The World Health Organization defines palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"
Palliative Care Outcomes Collaboration (PCOC)	A national palliative care outcomes and benchmarking programme for palliative care services in Australia.
Population needs assessment	A systematic method for reviewing the health issues facing a population
Population-based planning	Strategic development informed by the population need
Population-based resource allocation	A mechanism for distributing funding within population-based planning. It is used to address differences in population need with the aim of promoting equity and efficiency in health and health system outcomes
Sláintecare	A ten-year programme advanced by the Irish Government to transform the current health and social care system into a universal, single-tier system.
Sláintecare Implementation Strategy and Action Plan	A 2021 publication outlining the specific strategies of the government to implement the Sláintecare ten-year programme.
Specialist palliative care	Specialist palliative care is provided by healthcare professionals operating within the palliative care domain to cater to individuals presenting with complex, palliative care needs
Swedish Register of Palliative Care	A national quality register comprising data from hospitals, hospices, nursing homes and home care services delivering palliative care in Sweden.
Thematic analysis	A method of analysing qualitative data to identify potential patterns and construct 'themes' from the data.
Voluntary Hospice Group	Six specialist palliative care units in Ireland: North West Hospice in Sligo, Milford Care Centre in Limerick, Galway Hospice, Marymount University Hospice in Cork, Our Lady's Hospice in Dublin, and St. Francis Hospice in Dublin.

Executive Summary

Policy context

The Programme for Government of June 2020 commits to publishing a new palliative care policy for adults with the aim of ensuring universal provision of high-quality, integrated services based on need for people with life-limiting illness and their loved ones. Progressing the Policy Update is also a commitment in the Sláintecare Implementation Strategy and Action Plan 2021-2023 and the Department of Health's Statement of Strategy 2021-2023.

This will represent a major update of national palliative care policy set out in the 2001 report of the National Advisory Committee on Palliative Care (NACPC) and will be informed by recent developments including:

- the recommendations by the *Select Committee on the Future of Healthcare* in their Committee on the Future of Healthcare Sláintecare Report (published May 2017). This report details a roadmap to universal healthcare, including increased funding and staffing for universal specialist palliative care provided based on need;

- the enactment of Assisted Decision-Making (Capacity) Act in 2015. This Act is expected to be fully commenced in mid-2022;

- the National Cancer Strategy 2017-2026. This strategy, published in 2017, stated that that palliative care should be incorporated within an integrated approach to cancer treatment, which takes into consideration the individual requirements of each cancer patient. Key recommendations related to palliative care include the provision of specialist palliative care services in designated cancer centres, the delivery of specific training to oncology staff who may encounter patients with palliative care needs and the continued development of paediatric palliative care for children with life limiting cancer.

The central principles contained with the 2001 NACPC report continue to be relevant; however, the new palliative care policy for adults must reflect the various developments that have occurred since 2001.

Purpose of the review

The aim of this study is to inform this planned revision of Ireland's national palliative care policy by examining the implementation of existing national palliative care policy and identifying priority areas that should be addressed.

This review provides a complementary source of evidence to two other studies commissioned by the Department of Health. These are the Health Research Board International Evidence Brief of palliative care policy; and a report of the findings of a public consultation seeking views on palliative care services in Ireland and priorities for the new palliative care policy.

Review questions

This review addresses five research questions set out in the terms of reference:

1. What progress has been achieved to date in the implementation of the recommendations of the 2001 NACPC report and the respective 2009 and 2017 HSE Palliative Care Service Development Frameworks?

2. What gaps remain or barriers to progress exist in relation to the implementation of the 2001 policy, which should be addressed by the policy update?

3. Identify good examples and key enablers of policy implementation, which could be harnessed to ensure more effective implementation of the updated policy.

4. To what extent has the quality of palliative care and end-of-life care services in Ireland improved since 2001 in relation to:

    o Identifying and recognising the palliative care needs of individuals and their families in all care settings.

    o Providing timely and equitable access to specialist palliative care services, as appropriate, irrespective of diagnosis, geographic location or care setting.

    o Ensuring a palliative care approach by all health care professionals as part of usual care provision in line with NACPC 2001 recommendations on generalist palliative care.

    o Ensuring a seamless and integrated care pathway across inpatient, homecare, nursing home, acute hospital and day care services.

    o Addressing the interface between and transition from children's palliative care services to adult palliative care services.

    o Ensuring a person-centred approach which promotes quality of life and choice for individuals and their families.

    o Addressing the needs of families and carers of the person with a life limiting condition whilst the person is receiving services and following a bereavement.

    o Provision of standardised data sets at a national level and the utilisation of patient reported outcome (PROM) and experience (PREM) measures to evaluate the quality of specialist palliative care services.

5. What areas for improvement have been identified by the review to meet existing and emerging needs, which may not have been anticipated in 2001?

Methods

The review used a mixed methods design and had four components:

1. Recommendations in the NACPC report were grouped and characterised using the six 'building blocks' in the World Health Organization's health systems framework. The six 'building blocks' capture core functions of a health system: 1) service delivery; 2) health workforce; 3) information; 4) medicines and technologies; 5) financing; and 6) leadership and governance. We then measured implementation progress using available data sources;

2. Semi-structured qualitative interviews with stakeholders to identify successes and gaps in service provision; the barriers to and facilitators of implementation; and views on issues to be addressed in the policy update;

3. A documentary review to summarise international evidence of policy implementation and cost-effectiveness to compare and contextualise the Irish experience;

4. Combining and discussing the findings from across the review, drawing on relevant published and grey literature.

Key Findings

Chapter 2: Mapping the NACPC recommendations and measuring progress

- In total, 82 distinct recommendations were made in the NACPC report. While items related to all six building blocks within the Health Systems Framework were identified, the recommendations were primarily clustered around issues related to service delivery and workforce.

- Implementation progress could be assessed for 40 of the recommendations. Similarly, most of these were related to service delivery and workforce. The data indicate substantial progress has been achieved in developing specialist palliative care provision since 2001; however, deficits in workforce and infrastructure persist across most regions and services. The other 42 recommendations focused on the guiding principles and ethos that underpin the broad model of care outlined in the NACPC report and could not be evaluated in this component.

Chapter 3: Interviews with stakeholders

- We conducted eighteen interviews and six focus groups between October and December 2021, with a total of 39 participants. Participants included healthcare professionals (clinical and health and social care), representatives from within the statutory and voluntary sector, policy makers, academics, service users, carers and members of the public.

- Informants linked improvements in palliative care provision to the recommendations set out in the NACPC report. Interviewees described how progress was made across all core areas, such as the expansion of and access to specialist palliative care services, an increased awareness of palliative care, and the expansion of multidisciplinary teams, particularly specialist care teams. Significant gaps were also identified such as persistent geographic disparities in service provision, inadequate information and data to support audit and decision-making, and the need to review governance and leadership arrangements in the context of palliative care and general health systems change.

- Enablers and barriers to policy implementation were identified in the interviews. These include successes such as the establishment and activities of the National Clinical Programme for Palliative Care; sustained political support for palliative care; the Sláintecare reforms to increase service integration; increasing knowledge of palliative care; and resources such as the Model of Care and Competency Framework. Challenges included resourcing constraints; fragmentation of services; limited progress towards developing service capacity outside of routine hours; the absence of academic departments to lead training developments; and deficits in skills and knowledge among healthcare professionals outside specialist palliative care.

- Informants emphasised that much of the NACPC report remains relevant and provided recommendations as to how it can be updated to address gaps through a mix of targeted and aspirational policy areas and processes.

Chapter 4: Documentary Review

- Four examples of palliative care policy implementation were examined: the Palliative Care Outcomes Collaboration in Australia, the Swedish Register of Palliative Care in Sweden, primary palliative care in Scotland and paediatric palliative care in England. The cases highlight that successful policy implementation is contingent on the existing health system within which the initiatives will operate. Overall, sustained governance and leadership, resourcing, training and robust information systems enable the effective implementation of new health policies. Notable barriers to implementation include system fragmentation and limited collaboration between healthcare professionals.

- Learnings from integrated care initiatives in Ireland highlight that implementing service change needs clear policy with appropriate targets; commitment to the complex change process involved; sufficient resourcing; an ability to animate many sectors and empower local agents; and capacity to measure the right outcomes in ways that are meaningful and accessible.

- Existing studies have highlighted an economic benefit to palliative care in Ireland. However, the true economic value of current palliative care services remains unclear, as the evidence base is limited to a few studies and does not capture a complete perspective of service delivery. Increased emphasis should be placed on generating economic evaluations of current and future palliative care programmes, including assessments of the health and well-being effects of palliative care services, out-of-pocket costs of informal caregivers, and estimates of care costs from diagnosis to death.

Chapter 5: Synthesis

- Population need for palliative care services is projected to rise sharply over the next 25 years. Increasing generalist and specialist palliative care capacity to address current deficits and meet anticipated demand requires both sustained investment and strategic planning. Population-based planning and resource allocation will be important mechanisms for driving improvements in equity and efficiency across all settings. Proactive recruitment, training and retention strategies addressing issues particular to palliative care are also needed to support workforce development.

- Health information systems and infrastructure are inadequate to support resource, capacity and workforce planning. It will be essential to develop and resource an information strategy that supports robust data collection, information sharing across settings and service planning and evaluation.

- The findings highlight some other key enablers and barriers to palliative care service development. Enablers included the establishment and activities of the National Clinical Programme for Palliative Care, increased availability of education and training, and having clear delineation of roles and responsibilities. Developing strong leadership, clear governance structures and evaluative processes at both the national and regional level are also important enablers. Barriers identified included palliative care not being included in all applicable clinical and care pathways, poor system alignment, limited out-of-hours capacity across all settings, and a lack of detailed guidance around generalist palliative care in the NACPC report.

- Measures and recommendations in the NACPC report aimed at reducing financial hardship have either not been implemented or, in some instances, are not providing an adequate safety net.

- Informal carers are key partners in the care structure of their loved ones, yet little is known about the social or financial impact of this contribution. Further consideration is required in future policy and strategic planning to ensure appropriate access to services (e.g., respite, bereavement support) and avoid cost-shifting onto carers.

Recommendations

The recommendations were coproduced by members of the research team and the Research Advisory Group. They are grouped using the health systems framework Building Blocks and the ordering does not indicate priority.

1. The new policy should continue to provide commitment to universal access to palliative care on the basis of need, in keeping with the principles outlined in the NACPC report and proposals for palliative care as a component of universal healthcare in Sláintecare. In light of substantial changes that have occurred within the Irish health and social care system and the palliative care sector since 2001, the policy should address emerging priorities and issues identified in this review.

2. The new policy should align with the framework set out in the National Clinical Programme for Palliative Care Model of Care and support full implementation and integration of the Model, with ongoing evaluation.

3. The new policy should consider strategies for addressing inequities in specialist palliative care service provision.

4. There have been important developments related to palliative care practice and workforce planning since 2001 which will need to be reflected in the new policy.

5. The new policy should address factors influencing recruitment and retention within specialist palliative care services, utilising a whole-of-system approach.

6. Generalist palliative care capacity should be strengthened as this will be integral to ensuring people can easily access a level of palliative care service that is appropriate to their needs, regardless of care setting or diagnosis. The new policy should consider how this could best be achieved, taking account of priority areas identified in this evaluation.

7. The new policy should support the development of an information strategy for palliative care. This will be guided to a large extent by developments in national policy related to health information systems, the organisation of health and social care services and the shift towards population-based planning.

8. The new policy should build on the substantial achievements within palliative care research in Ireland and support further development of the evidence base for all levels of palliative care.

9. The new policy should address how changes to the resource allocation model will impact on service planning and delivery. This will be guided by key policy objectives such as promoting equity, efficiency and accountability but might also consider other relevant issues identified in this review.

10. Protecting households from financial hardship when accessing health and social care is one of the core components for achieving universal healthcare. The new policy should address the financial vulnerabilities of people with life-limiting illness and their loved ones.

11. Strong leadership and clear governance structures will be key enablers of universal provision of high-quality, integrated palliative care services based on need. In the context of current health system reforms and the establishment of regional health areas, the new policy should set out a model of governance to improve decision-making and collaboration.

12. Specialist palliative care has a key role to play in the delivery of palliative care across all settings. The new policy should support development of leadership capability and capacity within specialist palliative care.

13. The new policy should set out criteria for the development of an implementation plan to monitor progress.

Conclusion

Palliative care services in Ireland have been guided for more than twenty years by the NACPC report. In many ways, the report was ahead of its time within the Irish health and social care system, and most of the recommendations remain relevant today. Substantial progress has been achieved in enhancing the delivery of palliative care across all levels and settings since the NACPC report was published as national palliative care policy. However, many of the recommendations are not fully implemented and inequities in access to services persist. Developments in policy and practice since 2001 also mean that many of the recommendations require revision. The new national palliative care policy should build on the achievements provided through the NACPC report, while also considering priority areas identified in this evaluation and in the broader policy context. This is essential to ensuring universal provision of high-quality, integrated services based on need for people with life-limiting illness and their loved ones.

1 Introduction

1.1 Background

Palliative care is the interdisciplinary approach that aims to improve quality of life for people with life-limiting illness and for their loved ones through expert pain and symptom management, improved communication and goals-of-care discussions, and psychosocial and spiritual support. Although traditionally associated with end-of-life care, palliative care is now included in the early stages of treatment for life limiting illnesses, often delivered jointly with other treatments which are aimed at extending the patient's life, as well as bereavement support for loved ones (1).

Palliative care has a long history in Ireland, and this continues to influence the delivery of services. Services originated in the voluntary sector with the establishment of St. Patrick's Hospital in Cork and Our Lady's Hospice in Dublin by religious orders as places for care of the dying in the late 19th century (2). There have been significant advances in the provision of palliative care services in Ireland since 1995, when it became the second country in Europe to recognise palliative medicine as a distinct medical speciality.

In 2001, Ireland became one of the first countries in the world to publish a national policy on palliative care (3). The report of the National Advisory Committee on Palliative Care (NACPC) provided a comprehensive overview of the investment and requirements for developing palliative care and hospice services over a five to seven-year timeframe and the recommendations included in the report were subsequently adopted as government policy for the development of palliative care services (4,5).

The NACPC report advocates for universal palliative care access based on need and structured in three levels of ascending specialisation, each reflecting the expertise of the multidisciplinary teams providing services:

- Level one – palliative care approach: all healthcare professionals should be aware of, and appropriately apply, palliative care principles. Many patients with progressive disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel.

- Level two – generalist palliative care: healthcare professionals who are not engaged full time in palliative care but have some relevant training and experience.

- Level three – specialist palliative care: healthcare professionals whose core activity is providing palliative care.

The policy recommends that specialist palliative care units serve as the hub for regional specialist palliative care delivery. A fully developed specialist palliative care unit comprises in-patient unit beds, day hospice, out-patient and bereavement services. It serves as the base for the community palliative care team and for palliative care education and research activities for the region. The specialist palliative care unit has close links with neighbouring acute hospital specialist palliative care services because the Consultant in Palliative Medicine is contracted to provide services in both specialist palliative care units and hospital settings.

Per the 2001 NACPC report, all three levels of palliative care should be accessible to all patients. Specialist and generalist services should be offered in all healthcare settings, including inpatient and outpatient services in clinics and acute general hospitals, palliative day care facilities, and in the community, whether in the patient's home, in local hospitals, or in residential care facilities, such as

nursing homes. This is to ensure that these services are adaptable to the needs of the patient and allow for the transfer of the patient between settings in accordance with their needs and wishes (3).

The inception of the 2001 policy in Ireland occurred at a time when the development of palliative care was in its infancy as a specialty within Irish healthcare (with speciality status only being approved in June 1995 by the Irish Medical Council) (6). Since this time, the Department of Health and the Health Service Executive (HSE) have significantly enhanced the delivery of palliative care across all levels and settings, with the endorsement of consecutive Ministers for Health and collaboration with voluntary organisations (7). In 2015, Ireland's palliative care services were ranked 4th in the world in the Quality of Death Index report produced by the Economist Intelligence Unit (8). The countries that were ranked highest in this category all had in place a 'comprehensive strategy' to establish and progress palliative care services on a national level and had an established framework with clear goals, strategies for implementation and structures in place to realise their goals (8). A recent publication has ranked Ireland as second in the world for quality of end-of-life care, as ranked by expert stakeholders' and bereaved caregivers' weighted preferences of 13 key indicators at end-of-life (9). The indicators examine the degree to which patients' preferences and care needs, such as place of care and death, symptom management, emotional concerns, and their experiences of care were met (10).

While much has been achieved, previous evaluations have also highlighted gaps in service provision. Only a modest proportion of people are able to die at home (22.5% in 2018) (11), despite the desire of most Irish people to be in their own home if they were dying (74%) (12). Many people experience health issues in the last year of life which could be supported through the provision of appropriate palliative care services, such as unmanaged pain and depression (13). Furthermore, there are persistent inequities in access to some specialist palliative care services geographically and by diagnosis. Palliative care is often associated with cancer, resulting in delayed referral to specialist services for people living with other types of life-limiting illnesses (14).

The current distribution and scope of palliative care services across different regions reflects a mix of historical and modern factors. Services were originally localised to Dublin, Cork and Limerick, meaning these regions have advanced provision, while some other areas continue to lack a specialist palliative care inpatient unit. More recently, the planned expansion of palliative care services was delayed due to funding constraints when Ireland entered an economic recession in 2007 (5).

The need for palliative care services has continued to grow since 2001. The percentage of the people dying in Ireland that will require palliative care is projected to increase by 68-84% between 2016 to 2046 (15). As the life expectancy of the Irish population increases, people will also be living longer with more complex needs (15,16). Whilst palliative care is often associated with cancer, the importance of these services for people with other diagnoses such as neurological conditions (including dementia) and cardiovascular and respiratory diseases is also being increasingly recognised. People may also require palliative care for a longer period, or at different times or stages of their illness (17,18). Palliative care services in Ireland will need to adapt in order to address these needs and meet future demand.

1.2   Policy context and purpose of review

The Programme for Government of June 2020 commits to publishing a new palliative care policy for adults with the aim of ensuring universal provision of high-quality, integrated services based on need for people with life-limiting illness and their loved ones. This will represent a major revision of the 2001 policy and will be informed by recent developments including:

- the recommendations by the *Select Committee on the Future of Healthcare* in their Committee on the Future of Healthcare Sláintecare Report (published May 2017). This report details a roadmap to universal healthcare, including increased funding and staffing for universal specialist palliative care provided based on need (19).

- the enactment of Assisted Decision-Making (Capacity) Act in 2015. This Act is expected to be fully commenced in mid-2022 (20).

- the National Cancer Strategy 2017-2026. This strategy, published in 2017, stated that that palliative care should be incorporated within an integrated approach to cancer treatment, which takes into consideration the individual requirements of each cancer patient (21). Key recommendations related to palliative care include the provision of specialist palliative care services in designated cancer centres, the delivery of specific training to oncology staff who may encounter patients with palliative care needs and the continued development of paediatric palliative care for children with life limiting cancer (21).

The central principles contained with the 2001 NACPC report continue to be relevant; however, the new palliative care policy for adults must reflect the various developments that have occurred since 2001. In particular, the new policy must complement the fundamental principles of Sláintecare and best practice in palliative care. It must also integrate with the planned Programme of Government to introduce statutory home care and to provide for the care of people in their own homes after hospital discharge ('a 'home first' approach') (22). Furthermore, in light of changing demographics, the new policy must also address the increased demands that will be placed on the palliative care system in the future and must also consider how these demands can be met as the healthcare system in Ireland is remodelled into a network of Regional Health Areas (RHAs). The application of new technologies and the increasing relevance of tele-health during the COVID-19 pandemic must also be considered in this policy.

Workforce organisation within the health and social care system has also changed substantially in the twenty years since the NACPC report was published. For example, the nursing profession has expanded to include more skilled positions including advanced nurse practitioners (introduced in 2001) and registered nurse prescribers (introduced in 2007) (23,24). There is also increased recognition of the role of health and social care professionals (HSCPs) in the 'delivery of people-centred, integrated care' (the HSE National HSCP office was established in February 2017) (25). These developments will need to be taken into account in the new policy.

A specific policy focused on palliative care for children was issued by the Department of Health in 2009. This policy, 'Palliative Care for Children with Life-Limiting Conditions in Ireland, A National Policy', identified palliative care for children as a 'highly specialised field of healthcare' and that it fulfils a different function for children than adults (26). A report published in 2020 sets out an operational and governance framework for palliative care for children with life-limiting conditions in the community and makes recommendations for service provision, including the role of adult specialist palliative care teams in providing care (27). The new palliative care policy should focus on

the delivery of palliative care to adults but should also reflect how services provided to children and adults overlap, taking these key documents into consideration.

To provide a foundation for this new policy, the Department of Health commissioned a programme of research studies:

- an evidence brief produced by the Health Research Board, examining national palliative care policies in Australia, New Zealand, Scotland and the Netherlands.

- the current report, examining the implementation of the existing national palliative care policy (2001 NACPC report) and the linked HSE palliative care frameworks in the Irish healthcare system.

- a report of the findings of a public consultation seeking the views of the public on palliative care services in Ireland and the public's priorities for the palliative care policy update.

These three analyses will inform the updated national palliative care policy for adults in Ireland.

1.3   Terms of Reference

In August 2021, the Department of Health commissioned this external review of the implementation of the 2001 Report of the NACPC, insofar as it relates to palliative care services for adults.

The terms of reference specified for the review were:

- To assess progress achieved to date in the implementation of the recommendations of the NACPC 2001 Report and the respective 2009 and 2017 HSE Palliative Care Service Development Frameworks (2,3,28).

- To identify gaps in the implementation of the policy, including any barriers to progress, and how such issues could be addressed by the policy update.

- To comment on the relevance of the recommendations in the 2001 Report in the current context.

- To comment on whether the approach to service delivery in Ireland is cost effective having regard to existing international evidence on cost effective palliative care services.

- To make recommendations, in light of the above, on priority areas that should be addressed in the policy update, including areas of evolving and emerging need, having regard to international developments as outlined in the International Evidence Brief conducted by the Health Research Board on behalf of the Department of Health.

In addition, the review must address the key questions of interest for the Department of Health:

1. What progress has been achieved to date in the implementation of the recommendations of the 2001 NACPC report and the respective 2009 and 2017 HSE Palliative Care Service Development Frameworks?

2. What gaps remain or barriers to progress exist in relation to the implementation of the 2001 policy, which should be addressed by the policy update?

3. Identify good examples and key enablers of policy implementation, which could be harnessed to ensure more effective implementation of the updated policy.

4. To what extent has the quality of palliative care and end-of-life care services in Ireland improved since 2001 in relation to:

- o Identifying and recognising the palliative care needs of individuals and their families in all care settings.
- o Providing timely and equitable access to specialist palliative care services, as appropriate, irrespective of diagnosis, geographic location or care setting.
- o Ensuring a palliative care approach by all health care professionals as part of usual care provision in line with NACPC 2001 recommendations on generalist palliative care.
- o Ensuring a seamless and integrated care pathway across inpatient, homecare, nursing home, acute hospital and day care services.
- o Addressing the interface between and transition from children's palliative care services to adult palliative care services.
- o Ensuring a person-centred approach which promotes quality of life and choice for individuals and their families.
- o Addressing the needs of families and carers of the person with a life limiting condition whilst the person is receiving services and following a bereavement.
- o Provision of standardised data sets at a national level and the utilisation of patient reported outcome (PROM) and experience (PREM) measures to evaluate the quality of specialist palliative care services.

5. What areas for improvement have been identified by the review to meet existing and emerging needs, which may not have been anticipated in 2001?

1.4 Study scope and design

The aim of this evaluation study is to inform the planned update of Ireland's national palliative care policy. This aim is achieved by assessing the implementation of the recommendations of the current policy report (3) and related Service Development Frameworks (2,28); by identifying emerging issues not anticipated in the 2001 report; and by identifying examples of good policy implementation in the Irish health system and in international palliative care literature. This report offers multi-perspective insights into policy development over the last twenty years in Ireland and recommendations on the next steps and future priorities.

We utilised a mixed methods study design, comprising four workstreams (Figure 1) to address the research questions and terms of reference:

- Workstream 1 thematically maps the 2001 NACPC report recommendations and identifies relevant quantitative data measuring progress towards stated recommendations. (Questions 1,2, 4 and 5)

- Workstream 2 involves semi-structured qualitative interviews with key stakeholders to identify successes and gaps in service provision; the barriers to and facilitators of implementation; and views on issues to be addressed in the policy update. (Questions 1-5)

- Workstream 3 uses a documentary review to summarise international evidence of best practice and cost-effectiveness to compare and contextualise the Irish experience. (Questions 3, 4 and 5)

- Workstream 4 synthesises the results from Workstreams 1-3 to address the specific research questions and terms of reference for this evaluation, including recommendations on priority areas for the policy update.
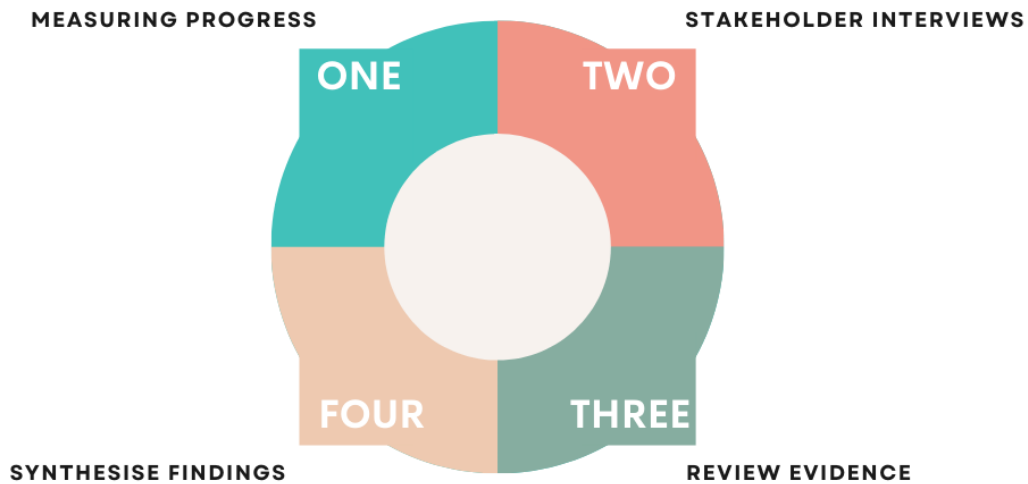
Figure 1 Project Workstreams

1.5   Structure of report

The remainder of the report is structured as follows:

- Chapter 2 presents the methods and results of the thematic mapping of the NACPC recommendations and available quantitative data that measures progress towards stated recommendations.

- Chapter 3 presents the methods and results of the qualitative interviews with key stakeholders.

- Chapter 4 presents the methods and narrative summary of both excellent examples of policy implementation in Ireland and internationally, and peer-reviewed evidence on cost-effectiveness relevant to the model of adult palliative care in Ireland.

- Chapter 5 combines research findings from the different workstreams and discusses their implications, providing a detailed mixed methods appraisal of the Department's specific research questions.

- Chapter 6 summarises the key findings and makes recommendations about the priority areas the updated policy should address.

2 Workstream 1: Mapping recommendations and measuring progress

2.1 Introduction

The aim of this workstream was to thematically map the 2001 NACPC report recommendations and identify relevant quantitative data for measuring progress towards achieving stated recommendations. The outputs provide evidence to help address Research Questions 1-4, specified in the previous chapter (Section 1.3).

The specific outputs from this workstream are:

1.1 Thematic map of the 2001 policy recommendations, supplemented with Service Development Frameworks, against which to benchmark progress [**Research Questions 1, 2**].

1.2 Quantitative data to address progress on 2001 recommendations [**Research Questions 1, 2**] and to measure quality improvements since 2001 [**Research Question 4**] and progress towards stated recommendations using available quantitative sources.

This chapter provides details on the methods used in this workstream and presents relevant results.

2.2 Methods

2.2.1 Thematic mapping of recommendations

Recommendations in the NACPC report were grouped and characterised using the six 'building blocks' within the World Health Organization's (WHO) health systems framework (29). The six 'building blocks' capture core functions of a health system: 1) service delivery; 2) health workforce; 3) information; 4) medicines and technologies; 5) financing; and 6) leadership and governance. We used the Building Blocks framework to structure this analysis as it provides a well-tested, common language for researchers and policy makers to evaluate the core functions of health systems (30). While the use of the Building Blocks is useful for organising information, it is important to note that the Building Blocks do not operate in silos. They are highly interactive and can support or constrain each other, such as where gaps in workforce training and education have a knock-on impact on the delivery of appropriate services. This will be explored in the analysis.

We also cross-referenced these themes with the key recommendations of Service Development Frameworks in 2009 and 2017 to identify possible changes in priorities during the interim period.

A structured template was developed in Excel to support the analysis. Two team members (BMJ, CB) independently reviewed and mapped the recommendations onto at least one subtheme within the six building blocks (Figure 2). In cases where more than one building block was applicable due to the interlinked nature of the recommendation, this was captured and reported in the analysis. Differences in opinion about classification were resolved through discussion.
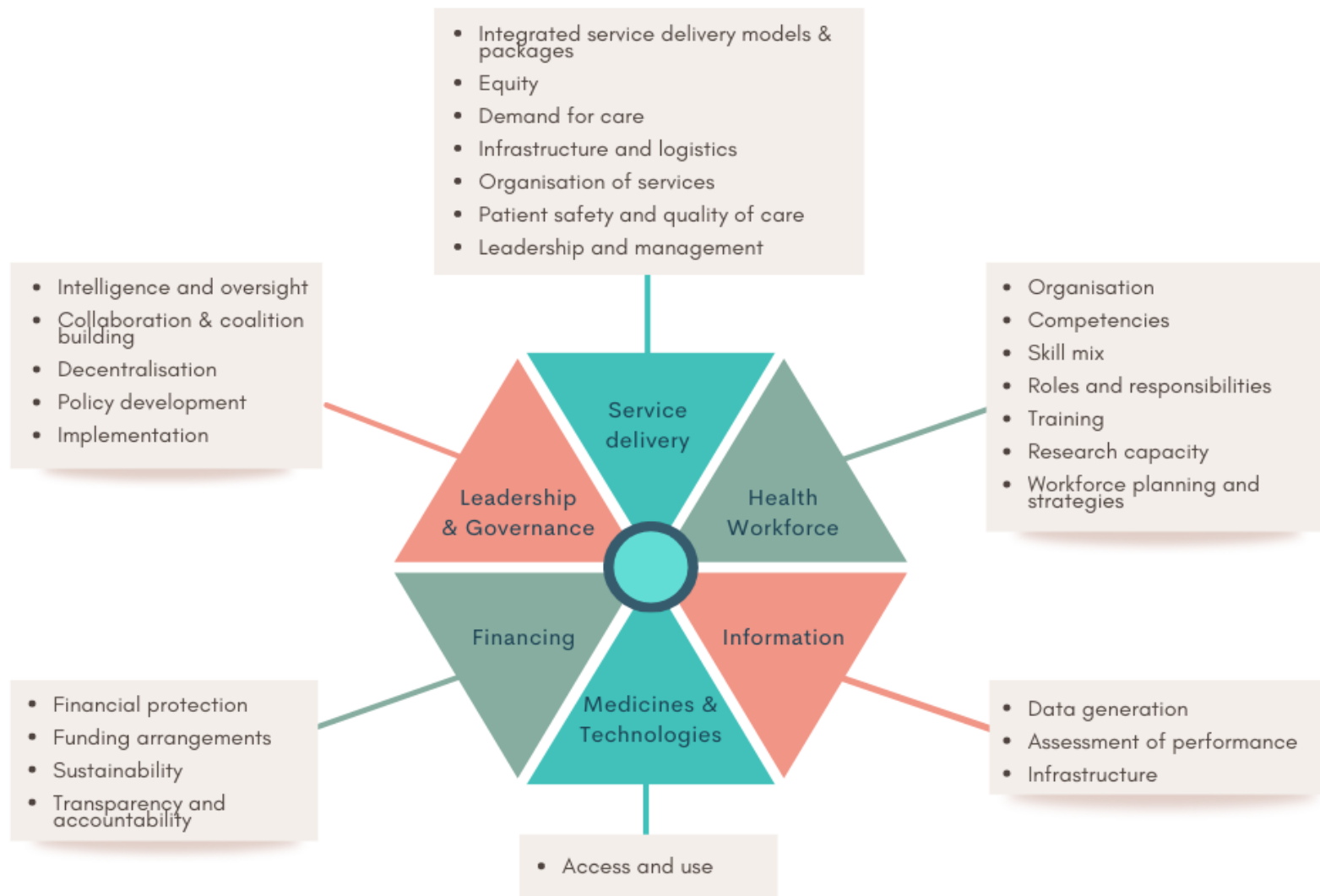
Figure 2 Subthemes included in the thematic mapping

2.2.2 Measuring progress towards recommendations

Following the thematic mapping, the recommendations were reviewed by three team members (BMJ, CB, PM) to identify those where progress could potentially be measured using quantitative data.

Two approaches were used to identify relevant data: 1) Rapid scoping review of literature on palliative care policy and research in Ireland; 2) Consultation with key informants within the Department of Health, the HSE and voluntary or academic organisations.

2.2.2.1 Rapid scoping review

For the rapid scoping review, we searched for policy and practice documents on the websites of national government bodies and voluntary sector organisations focused on palliative care. We searched for grey literature sources in two Irish research databases, Lenus and RIAN.ie. In addition, we undertook Google and Google Scholar searches using relevant keywords. These searches were conducted in October 2021. One team member (BMJ) completed the searches and reviewed the search results for potential relevance to the research questions.

2.2.2.2 Consultation with key informants

We contacted key informants involved in palliative care policy, practice and research in Ireland to confirm the completeness of our scoping review and to access unpublished materials, such as reports and data sets.

2.2.2.3 Data sources utilised

We extracted relevant information from the HSE's Minimum Data Set for Specialist Palliative Care, peer-reviewed and grey literature (13,28,31–47) and through consultation with stakeholders.

2.2.3 Results

2.2.3.1 Thematic mapping

There were 82 distinct recommendations included in the NACPC report (Appendix 1). Certain building blocks are overrepresented in the recommendations; however, examples of all six were identified in the thematic mapping analysis (see Figure 2). Some recommendations related to two or more of the building blocks.

2.2.3.2 Building Block One: Service Delivery

Forty of the recommendations were directly related to service delivery (Tables 1 and 2). This building block encompasses how services are organised, managed and delivered, with emphasis given to integration, infrastructure, safety, quality and equity.

Table 1 Recommendations related to service delivery

Subtheme	Summarised Recommendations
Integrated service delivery models and packages	• Early integration, available to all people with a life-limiting illness • Population-based service planning reflecting regional needs • Services should be available, wherever and whenever needed • Bereavement support should begin early and be available in all settings where specialist palliative care is offered
Equity	• Provision of palliative care services and equipment should be based on need, and not on the ability to pay • Services should recognise and facilitate cultural diversity • Needs assessments should consider the needs of people living with malignant and non-malignant disease
Demand	• Concept of palliative care should be promoted in the community • Proactive in provision of information about services, allowances and entitlements to patients and families
Infrastructure and logistics	• Ratio of specialist palliative care beds per 100,000 population, depending on population need • Satellite specialist palliative care units or hubs in areas of geographical spread • One specialist palliative care unit in each health board area; each providing day care services • Transportation for patients across different settings
Organisation of services	• The specialist palliative care inpatient unit should be the core of the specialist palliative care service. Specialist palliative care services in all other settings should be based in, or have formal links with, the specialist palliative care unit.
Patient safety and quality of care	• Quality standards set in all specialist palliative care settings in consultation with key service providers and consumers. Systems should be put in place to measure the quality of the services provided.
Leadership and management	• The decision to establish satellite bases in health board areas should be taken at regional level.

Most of the recommendations categorised within this block focused on establishing and promoting universal access to an integrated model of service delivery with seamless transition across settings (Table 2), detailing the types of services offered, the population covered and the importance of collaboration between different cadres of health care professionals. The report advocates for universal access to palliative care based on need, irrespective of location, age or diagnosis, with services structured in three levels of ascending specialisation. These levels refer to the expertise of the multidisciplinary teams providing services. Level one emphasises a palliative approach to care in the community. All healthcare professionals should practice these principles, as it is suggested that a proportion of ill or dying patients can have their care needs met without specialist palliative care intervention. Staff working in level two services have some additional training or expertise in palliative care provision. specialist palliative care services, or level three, are those where activity is centred on the delivery of palliative care. Palliative care should be available throughout the trajectory of illness, and through the bereavement phase. In terms of organisation, the report describes the specialist palliative care unit as the core element of the specialist palliative care service, acting as a centre for co-ordinating the delivery of specialist palliative care services in all care settings, including hospitals and the community. Additionally, recommendations are made about the ratio of beds per 100,000 population, with scope for variation based on local population need or geographic spread.

Table 2 Recommendations for integrated service delivery models and packages

Delivery and Access
• Palliative care should be incorporated into the care plan of patients at an early stage of their disease trajectory.
• Specialist palliative care services should be available to all patients wherever and whenever they require them.
• In A&E, patients should be rapidly assessed, and they should be referred to the appropriate team without delay.
• Palliative care services should be structured in three levels of ascending specialisation, and all three should be available in each health board. All patients should be able to engage easily with the level of expertise most appropriate to their needs.
• All palliative care patients should have adequate access to respite care in a setting of their choice.
• Specialist and non-specialist services should be available in all care settings. Services should be sufficiently flexible to allow movement of patients from one care setting to another, depending on needs and preferences.
• Bereavement support should be an essential part of all specialist palliative care programmes and should be available in all settings where specialist palliative care is offered. It should begin early in the disease process.
• Each health board area should have a comprehensive specialist palliative care service and all health care professionals should be able to access advice and support from specialist palliative care service providers.
• Joint outpatient clinics should be established in acute general hospitals, allowing the specialist palliative care team to become involved in-patient care at an early stage in the disease process.
• Arrangements should be made to 'fast-track' outpatient appointments for patients receiving palliative care.
• There should be one point of entry to hospital services for palliative care patients, and referrals should be speedily organised.
• Bereavement support should be provided by appropriately trained personnel in each service.

Meeting Population Need
• A needs assessment for specialist palliative care services should be completed at the regional level.
• The needs of different population groups, including children, should be addressed at the regional level when planning the future delivery of specialist palliative care services.
• Specialist palliative care facilities should be sensitive to the needs of patients, families and staff.
• Assessment of need for bereavement support should be routine in all specialist palliative care services.

Collaboration
• The concept of "shared care" for patients receiving palliative care in the community should be promoted
• The general practitioner, public health nurse and specialist palliative care team, when appropriate, should be contacted directly in advance of a patient's discharge from hospital.
• Primary care health professionals should have an open line of communication with each other, which should involve regular team meetings when possible, and regular communication by phone, fax or e-mail.
• Fundraising groups should identify objectives and strategies in relation to their activities and be accountable for all money raised. Projects funded should be in accordance with the overall palliative care development plan for the region.
• All acute general hospitals should have a consultant-led specialist palliative care service, offering advice and support to health care professionals in the hospital. The specialist palliative care team should work alongside other hospital teams, complementing their work, rather than taking over care of the patient.

Palliative Care for Children
• Palliative care for children is best provided at home, except in extraordinary circumstances, with the family closely supported by the general practitioner, the public health nurse and the specialist palliative care team, where available.
• Medical and nursing care of children in hospitals should be the responsibility of paediatric-trained medical and nursing staff, with support from the specialist palliative care service.
• There should be close co-operation and liaison between paediatric and specialist palliative care services.
• Palliative care services for children, including respite care, should be provided as close to the child's home as possible.
• Each paediatric unit should review requirements for providing palliative care and respite care for children in its catchment area

2.2.3.3 Building Block Two: Workforce

Thirty of the recommendations centred on workforce, including priorities related to organisation, skill mix, roles and responsibilities, and training (Tables 3 and 4).

Table 3 Recommendations related to workforce

Subtheme	Summarised Recommendations
Organisation	• Ratio of specialist palliative care health professionals to population • Ratio of specialist palliative care health professionals to beds in the specialist palliative care unit • Leadership within the specialist palliative care team
Competencies	• Professionals involved in the psychological aspects of specialist palliative care services should be suitably trained and experienced in this role
Skill mix	Composition of specialist palliative care team, including: • Consultant • Nutritionist • Chaplain • Nurse • Pharmacist • Volunteer co-ordinator • Physiotherapist • Occupational therapist • Speech and language therapist • Social worker • Care attendant
Roles and responsibilities	• Palliative care nurses provide information and support to patients, families and health care professionals in the community. This extends to support in bereavement. • The general practitioner has overall responsibility for the medical care of patients in the community
Training	• Training in communication skills for all staff involved in the care of people with progressive illness • Establish academic departments of palliative medicine in each medical faculty, with the development of inter-disciplinary courses for all professionals involved in the delivery of palliative care
Research capacity	• All health care professionals working in palliative care should have the opportunity to engage in research
Workforce planning and strategies	• Salaries and career structures should be standardised nationally across all health board areas. • Pilot study to explore the feasibility of physiotherapy-led clinics for people with progressive illness

A majority of these recommendations were specific to workforce organisation (Table 4), particularly the composition of specialist palliative care teams, staffing requirements, and staff-to-bed or staff-to-population ratios. Examples include: one specialist palliative care nurse per 25,000 of the population, at least one consultant in palliative medicine per 160,000 of the population; and at least one physiotherapist, occupational therapist and social worker per 125,000 of the population.

The report also proposed several recommendations around roles and responsibilities, training and research capacity. Some examples include: the role of the general practitioner in managing care for people in the community, the need for training in communication skills for all healthcare professionals, establishing academic departments, and opportunities for palliative care professionals to engage in research.

Table 4 Recommendations for organisation of workforce

Specialist Palliative Care Teams and Units
• Acute general hospital teams to consist at a minimum of: a consultant in palliative medicine, a specialist palliative care nurse, a social worker and a secretary. • Inter-disciplinary, consultant-led teams in the community, based in, and led by, the specialist palliative care unit in the area. • Physiotherapy, occupational therapy and social work departments should be developed in each unit, which would also meet the needs of palliative care patients in the community. • Specialist palliative care nurses should provide a seven-day service to patients in the community. • Care attendants should be available to support families of palliative care patients in the community. • Speech & language therapy sessions should be available in each specialist palliative care unit, minimum 1 session per week. • 1 x clinical nutritionist session in each specialist palliative care unit per week

Minimum Whole Time Equivalent (WTE) Staffing	
• 2 x suitably trained chaplains, available to patients and families 24 hours a day. • 1 WTE consultant in palliative medicine per 160,000 population; 2 in each health board area; 3x three non-consultant hospital doctors per consultant in the specialist palliative care unit. • Specialist palliative care nurse to bed ratio minimum 1:1. • 1 WTE specialist palliative care nurse to every 7 daily attendees; per 150 beds in each acute general hospital; and per 25,000 population in the community. • 1 WTE physiotherapist per 10 beds in specialist palliative care inpatient units and in each inpatient unit. • 1 WTE community physiotherapist specialising in palliative care per 125,000 population, and in each unit.	• 1 WTE occupational therapist per 10 beds in the specialist palliative care unit, and minimum 1 in each unit. • 1 WTE community occupational therapist specialising in palliative care per 125,000 population, and in each unit. • 1 WTE social worker employed per 10 beds in the specialist palliative care unit, and in each unit. • 1 WTE community social worker specialising in palliative care per 125,000 population, based in the specialist palliative care unit. • 1 WTE pharmacist in each specialist palliative care unit. • Care attendant to bed ratio in specialist palliative care units is minimum 0.5:1

2.2.3.4 Building Block Three: Information

The information building block can encompass a wide range of data and information (e.g., health outcomes, determinants, performance and inequities), the surveillance and data systems required for generating and analysing information, the quality of information, as well as the communication and use of information. Five of the recommendations in the report were about issues related to information such as data generation, performance assessment and infrastructure (Table 5). A Minimum Data Set was proposed as a framework to provide standardised information about specialist palliative care provision. The importance of data to support service quality and the need for adequate public funding to establish research infrastructure were also noted in the report.

Table 5 Recommendations related to information

Subtheme	Summarised Recommendations
Data generation	• A Minimum Data Set should be developed to provide standardised information on all patients of the specialist palliative care services. • Research undertaken in Ireland to evaluate specialist service models.
Performance assessment	• Performance indicators and outcome measures should be identified and utilised in specialist palliative care services to evaluate and maintain quality standards.
Infrastructure	• Establishment of research centres, linked to academic departments of palliative medicine. • Public funding should be allocated to establish research infrastructure.

2.2.3.5 Building Block Four: Essential Medicines and Technologies

Two recommendations related to essential medicines and technologies were made in the report (Table 6). This building block can encompass such issues as access and use (or the norms, standards and policies to ensure such access), affordability, availability, quality and safety or appropriate use. The two recommendations focused specifically on access and use and aimed to promote access to prescription medications and equipment.

Table 6 Recommendations related to essential medicines and technologies

Subtheme	Summarised Recommendations
Access and use	• Each health board should have a sufficient bank of equipment to meet needs in the community. • Arrangements between pharmacists across all setting should ensure that patients have access to all necessary medications.

2.2.3.6 Building Block Five: Financing

There were five recommendations specific to financing (Table 7). Almost all focused on funding for services and how resources should be allocated, with just one recommendation addressing concerns about financial hardship for people with life-limiting illness.

Table 7 Recommendations related to financing

Subtheme	Summarised Recommendations
Financial protection	• A 'fast-track' system should be in place to enable patients to access grants for housing alterations.
Funding arrangements	• Separate, protected budget for specialist palliative care services at health board level that meet total day-to-day expenditure.
Sustainability	• Statutory funding should be provided on a phased basis to meet the running costs of specialist services. • Future development requires a commitment to the ongoing provision of an adequate level of public funding, with a corresponding commitment to quality and accountability from service providers.
Transparency and accountability	• Funding through service plans adopted by each health board, and through service agreements between the health board and voluntary service providers in the region.

2.2.3.7 Building Block Six: Leadership and Governance

The leadership and governance building block encompasses a range of functions, including intelligence and oversight, collaboration and coalition building, policy development and implementation processes, stakeholder engagement, as well as indicators for measuring governance performance, or transparency and accountability mechanisms. Eight of the recommendations included in the report related to leadership and governance (Table 8). Several were centred around the establishment of different committees and expert groups to support policy implementation, service design and knowledge transfer. Notably, the report also recommended the importance of including service users (both patients and caregivers) in the development of policies. Recommendations were also made to foster regional autonomy for policy and planning.

Table 8 Recommendations related to leadership and governance

Subtheme	Summarised Recommendations

Intelligence and oversight	• Each health board should establish two regional committees for palliative care:
	  ○ A Regional Consultative Committee, for the exchange of information and ideas pertaining to palliative care.
	  ○ A Regional Development Committee, to advise the CEO on implementation of national policy.

Collaboration and collation building	• The opinions and preferences of patients and their carers should be incorporated into all policies. • Establish an Expert Group on Design Guides for Specialist palliative care Settings. • Health boards should work in partnership with voluntary service providers.
Decentralisation	• Decision-making about satellite bases at the regional level.
Policy development	• The process to develop service agreements between health boards and voluntary service providers should respect the independent identity and operational autonomy of individual voluntary service providers, and respect the statutory, regulatory and public accountability responsibilities of the statutory bodies.
Implementation	• Regional Development Committee to monitor and advise on policy implementation.
Stakeholder engagement	• The Minister should establish a National Council for Specialist palliative care to offer advice on the ongoing development and implementation of a national policy on palliative care services in Ireland. The National Council should be broadly based and have representatives from the appropriate statutory and voluntary agencies. There should be formal links between the National Council for Specialist palliative care and the National Cancer Forum.

2.2.3.8   Recommendations from other palliative care policy documents

Supplementing the mapping of the NACPC 2001 report (3), two further strategic planning documents were reviewed: The 2009 Five Year/Medium Term Development Framework and the Three-Year Development Framework (2017-2019) (2,28). Both policy documents endorsed the vision and principles of the NACPC 2001 report, and for the most part presented priorities, recommendations or actions in line with the 2001 report. The building blocks framework was similarly applied to organise the analysis.

The 2009 Five Year/Medium Term Development Framework set out 41 national priorities for resource utilisation based on a needs analysis, arranged within four categories: i) Home Care Deficits; ii) Specialist In-Patient Bed Deficits; iii) Capital Developments; and iv) Acute Hospital Support. As with the 2001 report, the priorities set out in the 2009 Framework disproportionately fall under the Service Delivery and Workforce building blocks and address such issues as Integrated Service Delivery Models and Packages; Organisation of Services; Infrastructure and Logistics; and Workforce Organisation, Roles and Responsibilities.

The 2009 Framework was followed up in 2017 with a Three-Year Development Framework (2017-2019) (28). This aimed to identify gaps in the level of service provision, and to present a set of recommendations and actions to inform and direct the development of adult palliative care services, both generalist and specialist, for that period. A total of eight recommendations were provided, within which a further 40 recommendations and actions were detailed. While the service delivery and workforce building blocks continued to feature prominently in the recommendations and actions, there was an enhanced focus relative to previous publications on issues of leadership and governance, such as for intelligence and oversight, policy development and implementation processes and guidance, as well as collaboration and coalition building.

2.2.3.9   Summary

The NACPC 2001 report provided an extensive list of recommendations, concentrated on two health systems building blocks, Service Delivery and Workforce. Seventy recommendations were categorised to these two building blocks. By contrast, 20 recommendations were categorised to, or overlapped with, the remaining four building blocks combined.

It is worth noting the NACPC 2001 report was developed at a time when palliative care was at a relatively early stage of development in Ireland. The focus on providing detailed recommendations to build up palliative care service delivery and health workforce capacity can be viewed in this context, namely one of detailing and establishing the structures and resources to support the development of a modern palliative care service in Ireland. The focus on other building blocks in later years potentially indicates a shift in focus once palliative care service delivery and workforce structures were more established, and as population health needs and the health system more broadly changes over time. These issues are explored in later chapters.

2.2.4   Quantitative data measuring progress

Forty of the NACPC recommendations could potentially be measured using quantitative data sources (Tables 9-11). The majority of these (n=30) were related to service delivery and workforce (Tables 9 and 10). The other 42 recommendations focused on the guiding principles and ethos that underpin the broad model of care outlined in the report and could not be evaluated in this component.

2.2.4.1   Service delivery

The infrastructure and logistics supporting the delivery of adult palliative care in Ireland varies by location (Table 9). In 2021, there were 276 inpatient specialist palliative care beds available nationally (See Appendix 2 for further details). This represents about 5.5 beds per 100,000 people. This is a substantial increase since 2013, when there were only 3.4 beds per 100,000. Only CHO 4 provides the minimum of eight specialist palliative care beds per 100,000 population (8.5 per 100,000); however, CHO3 is close to this target at 7.8 beds per 100,000. CHO 8 does not have an inpatient unit but plans for an inpatient unit with 30 beds in Drogheda are in the advanced stages and should be completed before 2024. There are also plans for an additional inpatient unit in CHO 8 with 16 beds, located in Tullamore; however, a completion date has not been finalised. The number of beds in CHO 1 will also increase with the establishment of a 16-bed inpatient unit in Cavan in 2023.

Out-patient/day care services are only available in services that have an in-patient unit and the availability of palliative care services outside of typical working hours varies regionally. The new inpatient units planned for introduction in 2023 and beyond will all offer day care services. This variability impacts the delivery of services to both adults and children, as the provision of adult palliative care services also provides important access for children who are being treated by paediatric teams. Further developments in palliative care service delivery including the availability of bereavement services and seven-day services are proposed by the National Clinical Programme for Palliative Care in their 2019 Adult Palliative Care Services Model of Care for Ireland (referred to as the Model of Care throughout this report) (35).

2.2.4.2   Workforce

Comparable to infrastructure, staffing for adult palliative care varies across Ireland (Table 10). It is important to note that most workforce data are from late 2016, and as a result do not fully reflect statutory funding increases and service developments. Data were also unavailable for two items: day care and care attendant staffing.

In 2021, there were 45 hospital consultant posts in palliative medicine, representing 0.9 consultants per 100,00 people. The ratio of non-consultant hospital doctor to consultant was less the half of the recommended 3:1 (the ratio of NCHD to consultant in 2016 was 1.3:1) in 2016. Data reported by the six organisations within the Voluntary Hospice Group indicate that most inpatient units have nurses, physiotherapists, occupational therapists, social workers and chaplains on staff. However, there are deficits between the recommended staff and the actual staff that are in place in several facilities. The availability of speech and language therapists and dieticians varies across specialist inpatient units, with few WTE posts. The structure of specialist palliative care teams (recommended to have one consultant, one special palliative care nurse, one social worker and one secretary) varies between different hospitals, even within the same hospital group.

2.2.4.3 Information, finance and leadership and governance

Findings related to implementing recommendations for information, finance and leadership and governance are summarised in Table 11. Systems are in place to monitor the operation of palliative care in Ireland through the Minimum Data Set (MDS). The HSE has established key performance indicators for palliative care and the performance of palliative care is reported as part of the HSE's Performance Assurance Reports. The provision of services by specialist palliative care units is reported monthly in the MDS with 100% compliance. A total of €117m was allocated for palliative care in the 2021 National Service Plan (42) and the delivery of specialist palliative care services is funded by block grant allocations (independent of the number of patients treated in each unit). Specific procedures for service arrangements are established under Section 38 and Section 39 of the Health Act 2004 (45) and per recommendations in the 2001 policy, design guidelines for specialist palliative care settings were published by an expert group in 2005 (46).

Table 9 Progress towards implementation of recommendations for service delivery

Area	Recommendation	Findings
Infrastructure and logistics	At least 8 to 10 specialist palliative care beds per 100,000 population, depending on population need	Only 1 CHO (CHO 4) has achieved a minimum of 8 beds. The national total was 276 beds, or 5.5 per 100,000 in 2021. See Appendix 2 for further details
	At least one specialist palliative care inpatient unit in each health board area	CHO 8 has no inpatient unit. Planning for a 30-bed inpatient unit in Drogheda is in the advanced stages and will be opened in 2023
	Day care facilities should be available in all specialist palliative care units	CHO 5 and CHO 8 do not offer day care facilities.2 New inpatient units in each CHO will offer services.
	Community hospitals should have designated beds for palliative care patients who require an intermediate level of inpatient care	There were no palliative care support beds (PCSB) reported in Counties Louth, Meath and Monaghan as of 2011.(34)
Integrated service delivery models and packages	A needs assessment for specialist palliative care services should be completed in each health board area (within 9 months of publication of 2001 report)	Estimates were published in 2017 using population size for the following: Workforce requirements in community-based services in each CHO; in-patient specialist palliative care beds; acute hospital staffing requirements for acute services; and workforce requirements in the six hospices within the Voluntary Hospice Group. All requirements were estimated using population size,
	The needs of different population groups, including children, should be addressed by each health board when planning the future delivery of specialist palliative care services	There is one the Specialist Paediatric Palliative Care (SPPC) Team for Children located in Children's Health Ireland. As of late 2021, there are 2.2 WTE consultants, with another 1 WTE post planned for 2022 This SPPC team provides a national advisory service and mainly takes referrals from primary paediatric care teams. The additional 1 WTE planned for 2022 will support expansion of the advisory service. The SPPC team provides support and advice via telephone to regional paediatric teams and the care of children with life-limiting conditions is currently supported regionally by adult palliative care service providers (33). This current system has deficits, with regional variation in training, provision out-of-hours and the availability of adult palliative care services.
	A comprehensive specialist palliative care service should be available in every health board area to provide support to patients, carers and other health care professionals	There is variation in availability of in-patient and day-care specialist palliative care services(41). Development of additional in-patient units proposed in HSE Framework 2017-2019. Service availability outside of typical working hours varies regionally(28)
	All acute general hospitals should have a consultant-led specialist palliative care service, offering advice and support to health care professionals.	In 2017, there were consultant-led palliative care team in 36 acute hospitals. All model 3 and 4 hospitals have a consultant-led palliative care team (35).
	Joint outpatient clinics should be established in acute general hospitals, to facilitate early intervention by the specialist palliative care team.	Outpatient care is provided in all CHOs that have an inpatient unit and in some locations where there is not an inpatient unit.
	Bereavement support should be part of all specialist palliative care services and available in all settings where specialist palliative care is offered.	Currently, all specialist palliative care services provide bereavement support. Source: MDS
	Palliative care services should be structured in three levels of ascending specialisation, available in each health board area. All patients should be able to engage easily with the level of expertise most appropriate to their needs.	There are variations in the general and specialist palliative care services available in different CHOs (28). Recent research indicates approximately half of individuals at the end-of-life experience symptoms such as pain and depression (issues which could be addressed by palliative care) (13).
	Specialist palliative care nurses should provide a seven-day service to patients in the community.	Services operating seven days per week are not available across Ireland(28). The development of 7-day services (which provides full specialist teams available during daytime hours and nursing care and phone call services during out-of-hours) is an objective in the Model of Care(35).
	Every specialist palliative care service should be committed to quality improvement and should have in place quality standards and systems for auditing their services.	The *Specialist Palliative Care Quality Assessment and Improvement Workbooks* have been developed to promote quality improvement in specialist palliative care (35,37). In addition, a national Quality Improvement Collaborative for Specialist palliative care has been established to promote shared approaches to quality improvement (35). The provision of high quality generalist palliative care is also promoted by the National Standards for Residential Care Settings produced by the Health Information and Quality Authority (standards 2.4 and 2.5) (35,36).

Table 10 Progress towards implementation of recommendations for workforce

Area	Recommendation	Findings
Organisation	Each specialist palliative care unit should develop its own physiotherapy, occupational therapy and social work departments	Physiotherapists, occupational therapists and social workers are not accessible in all CHOs(28).
	At least one Whole Time Equivalent (WTE) consultant in palliative medicine per 160,000 population, with a minimum of two consultants in each health board area. For each consultant in palliative medicine, there should be at least three non-consultant hospital doctors (NCHDs) in the specialist palliative care unit.	In late 2021, there were 45 posts in Palliative Medicine, of which 38 were filled. The ratio of consultants is 0.9 to 100,000 population, when all posts are filled. In 2016, the overall ratio of non-consultant hospital doctor (including those in training and not in training) to consultant was 1.3:1(32).
	The WTE specialist palliative care nurse to bed ratio should not be less than 1:1.	In 2016, data from the six inpatient units in the Voluntary Hospice Group indicates that inpatient units generally have the recommended number of nurses to bed ratio. Only Our Lady's Hospice and Marymount Hospice had reported deficits between the recommended number of nurses and the actual number of RGN on staff (45 nurses per the 48 beds were recommended for Our Lady's Hospice and this hospice had 41.5; 42 RGN per 44 beds were recommended for Marymount Hospice and this hospice had 40 RGN). All of the hospices had the recommended number of CNMI and CNM II (28).
	Day care centres should have at least 1 WTE specialist palliative care nurse for every 7 daily attendees.	Data were not identified to quantify day care staffing ratios.
	Acute general hospitals should have at least 1 WTE specialist palliative care nurse per 150 beds	In 2016, 9 of the 26 acute services had the recommended clinical nurse specialists (CNS). There were reported deficits in all hospital groups, except for University Limerick (28). Only 1 specialist palliative care acute service had no CNS as of 2016 (28).
	A minimum of one WTE specialist palliative care nurse in the community per 25,000 population.	In 2016, 5 CHOs had the recommended number of CNS/RGN (CHO 1, 2, 3, 5 and 8). CHO 4, 6, 7 and 9 did not have the recommended number and required between 2.8 and 7.7 CNS WTEs to be funded in their community services (28).
	There should be at least one WTE physiotherapist per 10 beds in the specialist palliative care inpatient unit, with a minimum of one physiotherapist in each unit. There should be a minimum of one WTE community physiotherapist specialising in palliative care per 125,000 population.	In 2016, only 2 CHOs, 3 and 8, had physiotherapists employed in community specialist palliative care services. CHO 1, 2, 4, 5, 6, 7 and 9 did not have any physiotherapist in their community services and there were staffing deficits identified in CHO 3 and 8. Data from the six inpatient units in the Voluntary Hospice Group indicate that inpatient units generally have physiotherapists on staff. However, only Milford Hospice had the recommended physiotherapists on staff (3 physiotherapists were recommended and this hospice has 3.26). There were deficits between the recommended number and actual number of physiotherapists in each of the other hospices (28).
	There should be at least one WTE occupational therapist per 10 beds in the specialist palliative care unit, with a minimum of one occupational therapist in each unit. There should be a minimum of one WTE community occupational therapist specialising in palliative care per 125,000 population. This post should be based in the specialist palliative care unit.	In 2016, only 3 CHOs had occupational therapists employed in community specialist palliative care services. CHO 1, 2, 4, 6, 7 and 9 did not have any occupational therapist in their community services and there were staffing deficits identified in CHO 3, 5 and 8. Data from the six inpatient units in the Voluntary Hospice Group indicate that inpatient units generally have occupational therapists on staff. The only hospice with no therapist on staff was Marymount hospice. However, there were deficits between the recommended number and actual number of occupational therapists in each of the other hospices and thus, no IPU achieved the desired one WTE occupational therapist per 10 beds (28).
	There should be at least one WTE social worker employed per 10 beds in the specialist palliative care unit, with a minimum of one social worker in each unit. There should be a minimum of one WTE community social worker specialising in palliative care per 125,000 population. This post should be based in the specialist palliative care unit.	In 2016, 7 CHOs had a social worker employed in community specialist palliative care services (CHO 2, 3, 4, 6, 7 and 9). There were no social workers in CHO 1 and 5. Both CHO 8 and 2 had in place the recommended 1 social worker per 125,000 population. However, there were staffing deficits identified in CHO 1, 3, 4, 5, 6, 7 and 9. In CHO 3, there were 2 social workers instead of the recommended 3 (approx. ratio of 1: 187,500). In CHO 4, there were 1.75 social workers instead of the recommended 5.5 (approx. ratio of 1: 392,857). In CHO 6, there were 0.5 social workers instead

		of the recommended 3.1 (approx. ratio of 0.5: 387,500). In CHO 7, there were 2.35 social workers instead of the recommended 5.4 (approx. ratio of 1: 287,234). In CHO 9, there were 2.1 social workers instead of the recommended 5.0 (approx. ratio of 1: 297,619). In relation to specialist palliative care inpatient units, data from the six inpatient units in the Voluntary Hospice Group indicate that inpatient units generally have social workers on staff. Both Galway Hospice and North West Hospice had the recommended one WTE social worker per 10 beds (ratio of 2: 18 beds and 2: 8 beds respectively)(28).
	There should be regular speech and language therapy sessions in each specialist palliative care unit, with a minimum of one session per week.	Data from the six inpatient units in the Voluntary Hospice Group indicate that none had the recommended number of speech and language therapist staff as of 2016 (28). There are regular sessions in four CHOs (CHOs 3, 4, 5 and 7), with varying availability for IPU and community-based services.
	At least one clinical nutritionist session in each specialist palliative care unit per week	Data from the six inpatient units in the Voluntary Hospice Group indicate only one had the recommended dietetics staff as of 2016 (28). There are dietitians in three CHOs, though not all provide care through specialist inpatient units: 1, 3 and 7.
	There should be at least one WTE pharmacist in each specialist palliative care unit.	In relation to specialist palliative care inpatient units, data reported in 2016 on the six inpatient units in the Voluntary Hospice Group suggests that all inpatient units have pharmacists on staff. Our Lady's Hospice reported a small deficit in WTEs (28).
	The care attendant to bed ratio in specialist palliative care units should not be less than 0.5:1	Data not available
	The specialist palliative care team in an acute general hospital should consist of at least a consultant in palliative medicine, a specialist palliative care nurse, a social worker, and a secretary.	Staffing for specialist palliative care teams in acute general hospital varies across Ireland (28). Deficits in clinical nurse specialists, social workers and clerical officers were reported across 26 specialist palliative care acute services in Ireland. The deficits were higher for clinical nurse specialists and social workers than for clerical staff. No hospital was reported as having the recommended staffing and variations in staffing existed between hospitals and within in each hospital group.
	Each specialist palliative care unit should have at least two suitably trained chaplains available to meet the spiritual needs of patients and families, providing a 24-hour service.	Data from the six inpatient units in the Voluntary Hospice Group indicate all have chaplains on staff. Marymount Hospice, Milford Hospice, Galway Hospice and North West Hospice all had the recommended number of chaplains on staff (28).
	Every specialist palliative care unit should have a volunteer co-ordinator, who should be responsible for the selection, training and placement of volunteers.	Statutory funding is not provided for volunteer co-ordinators, and data on the number of posts and geographical distribution are not collated nationally. Data collected by the Irish Hospice Foundation in 2007 indicated there were only 5.5 volunteer co-ordinators across the entire country and five health boards did not have a volunteer co-ordinator (38).
Education and training	Establish academic departments of palliative medicine in each medical faculty	There are no academic departments of palliative medicine in Ireland, and just one professor of palliative medicine post has been created since 2001.

Table 11 Progress towards implementation of recommendations for information, finance and leadership and governance

Area	Recommendation	Findings
System performance assessment	Suitable performance indicators and outcome measures should be identified and utilised to evaluate and maintain quality standards.	The HSE has established key performance indicators for palliative care services in Ireland[13] and the performance of Palliative care services is reported as part of the HSE's Performance Assurance Reports (PAR) (39). The provision of services by specialist palliative care services is reported on a monthly basis and is collated in the Minimum Data Set (MDS). Additionally, the Palliative Care Outcomes Collaboration (PCOC) programme is being introduced in some settings after piloting in one specialist unit (48).
Data generation	A Minimum Data Set should be developed in Ireland, providing standardised information on all patients of the specialist palliative care services	There is 100% compliance in responses to the MDS (41).
Funding arrangements	There should be a separate protected budget for specialist palliative care services at health board level, meeting all day-to-day expenditure.	Budget allocated through National Service Plan. €117m allocated in 2021 National Service Plan (42). Per the 2019 Adult Palliative Care Services Model of Care, specialist palliative care is funded by block grant allocations (which is independent of number of patients that are treated in each unit)(35).
Sustainability	The future development of specialist palliative care services requires adequate public funding, with a corresponding commitment to quality and accountability from service providers	The National Clinical Programme for Palliative Care provided guidance on the functions and levels of accountability of each sector of palliative care services in their 'Role Delineation Framework for Adult Palliative Care Services' (43). The Minister for Health is accountable for the allocation of funding and resources to palliative care services and to-date, parliamentary questions have explored the development of specialist palliative care units (44).
	Part a. Adequate and equitable statutory funding should be made available on a phased basis to meet the core running costs of all services.	Annual budgets allocated through National Service Plan, €117m allocated in 2021 National Service Plan to fund existing services and to fund new developments (€4m) (42).
Transparency and accountability	Distribution of funding should be through service plans adopted by each health board, and through service agreements between the health board and voluntary service providers in the region.	There are specific procedures and forms governing services arrangements for 'palliative care/chronic illness' under Section 38 of the Health Act 2004 (45).
Intelligence and oversight	Each health board should establish two regional: 1. A **Regional Consultative Committee**, which should provide a broadly based forum for the exchange of information and ideas on all matters pertaining to palliative care.; 2. A **Regional Development Committee**, which would advise the CEO on the implementation of the National Policy	Ongoing establishment of Regional Consultative Committee development in CHO 4 and 8; and CHO3 MidWest has well-functioning committee in place. Has strategy for pc for area.
Collaboration and coalition building	(Part b) An Expert Group on Design Guides for Specialist palliative care Settings should be established to inform all relevant parties, and to ensure a national consistency of standards for all specialist palliative care centres.	Design guidelines for Specialist palliative care Settings were published by an expert group in 2005 (46).
	Service agreements should form the basis of future working relationships between health boards and voluntary service providers.	The delivery of services by voluntary providers is governed by service arrangements t procedures (per Section 38 and 39 of the Health Act 2004) (45).
	The Minister should establish a National Council for Specialist palliative care to offer advice on the ongoing development and implementation of a national policy on palliative care services in Ireland.	National Council established in early 2000s, but its functions appear to have been replaced by the National Clinical Advisory Group. A National Network of Palliative Care Service Providers was also established.

2.3   Conclusion

We thematically mapped the 2001 NACPC report recommendations and assessed progress towards achieving stated recommendations drawing on available quantitative data sources.

In total, 82 distinct recommendations were made in the 2001 NACPC report. While items related to each of the six building blocks within the Health Systems Framework (29) were identified in the mapping exercise, the recommendations were clustered primarily around issues related to service delivery and workforce.

Recommendations under service delivery fell primarily into four categories: delivery and access of palliative care services; meeting population needs; collaboration; and palliative care for children. These recommendations generally centred on the promotion of an integrated palliative care service and the establishment of universal access to palliative care, with particular emphasis on ensuring equitable access across diagnoses, age, and location of service-users. This includes the early introduction of palliative care within the service-user's journey using the three-levels of specialisation; the palliative care approach, generalist palliative care services, and specialist palliative care services, where access to specific levels should be based on need.

NACPC recommendations under workforce focused on the composition of specialist palliative care multidisciplinary teams and organisational arrangements for specialist palliative care inpatient units, including outlining the minimum WTE staff to adequately cover need. Staffing ratios were specified for specialist teams, in addition to distinct recommendations for the employment of health and social care professionals (physiotherapists, occupational therapists, speech and language therapists) to ensure a generous range of skill mix to cover diverse palliative care needs. The remaining 20 recommendations applied to the four building blocks of information, essential medicines and technologies, financing, and leadership and governance. These generally included the development of data generation and quality performance measures, ensuring individual health boards have access to necessary equipment, providing a separate budget for specialist services and financial protection measures for home modifications, as well as recommending the establishment of expert groups and committees to support policy development and implementation. Overall, similar recommendations have since been made in the 2009 Five Year/Medium Term Development Framework (2) and the Three-Year Development Framework (2017-2019) (28).

Of the 82 recommendations made in the 2001 NACPC report, 40 were suitable for evaluation using quantitative data. The remaining 42 recommendations focused on guiding principles and ethos. Most of the recommendations amenable to quantitative evaluation were related to service delivery and workforce. Most workforce data are from late 2016, and as a result do not fully reflect statutory funding increases and service developments. Data related to day care and care attendants in specialist palliative care units were not available. The data indicate substantial progress has been achieved in developing specialist palliative care provision since 2001; however, notable deficits in workforce and infrastructure persist across most regions and services.

The next chapter details the semi-structured, qualitative interviews with key stakeholders.

3 Workstream 2: Stakeholder interviews

3.1 Introduction

This workstream focused on qualitative interviews with key stakeholders to identify successes and gaps in service provision; the barriers to, and facilitators of, implementation; and views on issues to be addressed in the policy update. These interviews generated data to address each of the five research questions (see Section 1.3).

The outputs from this workstream are summary data of key stakeholder perspectives on:

3.1 Progress addressing the NACPC recommendations, including quality improvements and persistent gaps [**Research Questions 1, 2 and 4**].

3.2 Examples of enablers and barriers to policy implementation **[Research Questions 2 and 3**].

3.3 Relevance of the NACPC recommendations, as well as emerging issues since 2001 [**Research Question 5**].

3.4 Priorities that should be addressed in the updated policy [**Research Question 5**]

This chapter provides details of the methods used to conduct and analyse the interview data and presents the main results.

3.2 Methods

3.2.1 Sampling and recruitment

All participants were purposively recruited for this research, using the following inclusion criteria:

- Participants specified in the Request for Tender issued by the Department of Health, or in agreement between the research team and Department of Health's palliative care policy team;

- Nominees identified through communication between the Department of Health's palliative care policy team and the relevant organisations/groups;

- Adult (>17 years of age);

- Able to provide informed consent to participate in the study.

No exclusion criteria were applied.

Participants specified in the Request for Tender were directly contacted via email by the study team, once the Department of Health's palliative care policy team had liaised with relevant organisations or groups to identify and agree nominees for interview. Contact details were only shared with the research team once an individual had volunteered to be contacted and knew those data would be shared.

On initial contact with potential participants, a member of the study team (BMJ) provided a participant information letter, outlining the purpose and design of the study (Appendices 3 and 4). If they subsequently agreed to participate in an interview, a member of the study team then sent a consent form (Appendix 5), topic guide (Appendices 6 and 7) and a summary of the thematic mapping of the 2001 NACPC recommendations by email. Participants provided written confirmation of informed consent prior to the interview, which was either emailed or posted to the study lead (BMJ).

3.2.2 Data collection

A topic guide was used during semi-structured qualitative interviews or focus groups with key stakeholders (Box 1). The topic guide was informed by the findings from the thematic mapping in Workstream 1 and the National Clinical Programme for Palliative Care's Model of Care.

Box 1 Topic guide

> 1. Reflecting on the implementation of the 2001 national palliative care policy, are there particular recommendations you believe have been implemented well?
>
> 2. Again, reflecting on the implementation of the 2001 national care policy, are there particular recommendations that you believe have not been implemented well?
>
> 3. Overall, how well do the recommendations of the 2001 national palliative care policy align with the wider context of the Irish health system and policy?
>
> 4. Given the changes that have taken place since the 2001 policy, what should the focus be into the future, and what would 'full' implementation of the national palliative care policy look like?
>
> 5. Looking to the future of palliative care in Ireland, what do you see as the three priorities required to achieve successful implementation of palliative care policy nationally?
>
> 6. Is there anything else that you would like to add?

Interviews were conducted using a secure online platform (Microsoft Teams or Zoom). The interviews were audio recorded and interviewers took detailed notes to capture relevant data.

3.2.3 Analysis

The interview responses were thematically analysed to identify gaps, barriers to and enablers of implementation and issues to be addressed in the policy update. Thematic analysis is primarily focused on coding, categorising, and theme development (49). The findings were first broadly organised using the research questions set out in the Request for Tender and the interview topic guide. Informants' views on progress towards implementing the 2001 NACPC recommendations were grouped using the building blocks framework (See Section 2.2.1). Enablers and barriers identified were sorted at the micro, meso and macro level:

- Macro is the highest level of analysis, sometimes referred to as the policy environment, and typically analyses at the societal, national, or international level.

- Meso is the intermediate level of analysis, sometimes referred to as the service-delivery level and typically analyses at the community or organisational level.

- Micro is the smallest unit of analysis, sometimes known as the local perspective, and typically analyses at the individual or household level or at the health professional level.

Delineation across the three levels is not always clear for some factors. For example, population-wide trends in awareness of palliative care could be grouped at the macro-level but could also be linked to individuals' behaviours, making it a micro-level factor. We categorised enablers and facilitators once in our analysis.

3.3 Results

We conducted eighteen interviews and six focus groups between October and December 2021, with a total of 39 participants. Participants included healthcare professionals (clinical and health and social care), representatives from within the statutory and voluntary sector, policy makers, academics, service users, carers and members of the public.

In general, there was widespread agreement among participants that the 2001 report marked a turning point for palliative care in Ireland. Participants noted that it provided a clear framework for investment in, and development of, palliative care services, while also generating a more widespread sense of 'literacy' and understanding about palliative care. A common sentiment among participants was that the 2001 report was ahead of its time in some respects; equally, the health system continues to grapple with similar issues, while changing system structures, processes, and population health needs make some of the recommendations less relevant today.

3.3.1 Progress towards addressing the recommendations

3.3.1.1 Service delivery

Expansion of specialist palliative care services

There was consensus among informants that substantial progress had been made around the organisation, management and delivery of high-quality specialist palliative care services (Table 12). Most linked this directly to the vision laid out in the NACPC report, which provided a framework for national service provision. A crucial component of this framework is the structuring around three levels of specialisation, which has driven sustained investment in services, particularly specialist palliative care units. As one informant said:

> '…the specialist palliative care unit should be the core central element of the specialist palliative care service…in some ways, that is the legacy of this policy.'

While it was clear the expansion of specialist palliative care units was an important achievement, informants did raise concerns. For example, related services, such as community palliative care, were not as well-developed because emphasis was given to the specialist palliative care units, given their role as the hub for specialist palliative care delivery within the 2001 policy. Some felt it was difficult to address these gaps or plan for future need, because the recommendations for capital development described in the NACPC report, or conceived at the local level, remain a key priority. However, they did note that despite regional variation in development of specialist units, all counties have community-based teams providing care in the home.

The availability of acute hospital palliative care services has also improved. Informants highlighted that all acute hospitals have a specialist palliative care team, providing consultative services and education and training for colleagues. However, the composition of multidisciplinary teams varies across acute services and in the main, there is no coverage at weekends or holidays. Referral patterns have been changing, with informants indicating that the gateway into specialist palliative care has shifted from the GP towards acute hospital. Acute services may struggle to meet this growing demand within current capacity.

Access to palliative care

Informants described considerable advancements towards providing equitable and timely access to specialist palliative care based on need. The expansion of specialist palliative care teams in both the community and acute hospitals was frequently cited as central to improving access to services and

support. Additionally, there have been steady increases in the number of people with noncancer illnesses utilising specialist palliative care services. And while informants acknowledged progress continues to be made in addressing well-established concerns around geographic inequities, they also drew attention to perceived gaps, in both urban and rural settings:

> *'There are palliative care teams now in all hospitals. And some people are able to access palliative care in the community. But it's still to some extent a postcode lottery…'*

Specific examples mentioned were the lack of specialist palliative care units in some areas of the country, regional differences in the composition of specialist palliative care teams, limited availability of services for consultation or advice outside routine office hours and variation in generalist palliative care provision. Community-based specialist palliative care services are dependent on nursing services provided by the Irish Cancer Society and Irish Hospice Foundation, with significant statutory funding, to deliver care to patients and families outside of 'typical' working hours in the last days of life. Differences in generalist palliative care provision were often attributed to training and experience among healthcare professionals, but also resourcing constraints. As a result, providers of generalist palliative care often lack the knowledge, confidence, or time to identify and support palliative care needs. Informants raised concerns about matching capacity with sharply increasing demand for services across the country if these gaps are not prioritised. Additionally, many stressed the need to improve access to all levels of palliative care for vulnerable groups such people living in residential care or institutional settings, ethnic minorities and those experiencing homelessness.

Palliative care for children

Like adult services, the 2001 report was seen to provide a pathway to the development of paediatric palliative care in Ireland. Informants linked this to the report recognising children have distinct needs and its recommendation that an assessment of service provision and requirements be completed, which in turn supported the development of a national policy for children's palliative care in 2009. The appointment and ongoing recruitment nationally of doctors with expertise in paediatric palliative medicine demonstrates paediatric palliative care is integral within paediatric care delivery in Ireland.

The interface between children's and adult palliative care services was described as well-established, supported in large part by collaborative, multidisciplinary networks both regionally and nationally. The Clinical Nurse Coordinator plays a key role in bringing primary care, paediatric and palliative care services together in the community. This integration of services has resulted in improved access for children in the community across Ireland. Once children are known to palliative care, the transition to adult services can often be straightforward:

> *'…when they transition out of children's services, they're already linked in with the palliative care team. So it's kind of seamless, if they're already linked in.'*

However, informants also noted inequities in access by diagnosis, location and age. For example, not all adult palliative care services provide services to children, particularly for more complex diagnoses and neuro-disabilities, in part due to service and resource variation in capacity between child and adult hospital settings. There may also be a hesitancy to refer children to palliative care services whilst they are receiving curative treatment. Many informants were hopeful that a report published in 2020 setting out an operational and governance framework for palliative care for children with life-limiting conditions in the community will help address persistent gaps in access and improve the quality of care (27).

Awareness and knowledge of palliative care

Improved awareness and understanding of palliative care among both healthcare professionals and the wider population was emphasised as another area where tremendous progress had been realised. One informant outside specialist palliative care described it as:

> *'…palliative care has completely transformed itself… we view it as part of a person's ongoing care that can be quite extensive.'*

Others added that while there has been an improvement in awareness and understanding, a perception remains of palliative care as end-of-life care as opposed to a service that can be accessed at different times and for different life-limiting conditions. Concern was expressed that this perception may contribute to delays in seeking access, or making referrals, to palliative care.

The changing understanding of palliative care also extends beyond issues related to timing of access, and many informants cited improved awareness among healthcare professionals that access must be based on need, rather than diagnosis. This was brought into sharp focus during the COVID-19 pandemic, with specialist palliative care teams playing a significant role in the response. However, some informants argued that specialist palliative care remains focused on cancer, with limited scope to support people living with conditions such as dementia.

Integration of specialist palliative care services

Integration of palliative care across different care settings has also moved from strength to strength, with notable progress in defining roles and responsibilities and deep links between the statutory and voluntary sector in service provision. This integration and other quality improvements have been driven by several factors highlighted by informants. These included strong governance and oversight and increased resourcing through the Office of the National Lead Health Service Executive and the Department of Health, and collaborations in recent years led through the National Clinical Programme for Palliative Care. Regarded as 'the gold standard' by many informants, the programme has set out clear pathways to care through the co-development of resources with stakeholders across the statutory and voluntary sectors such as the Model of Care (35), needs assessment guidance and quality assessment and improvement workbooks. In addition, national clinical guidelines have been published by the National Clinical Effectiveness Committee, which are viewed by informants as being instrumental in driving improvements in quality of care.

The National Clinical Programme for Palliative Care has fostered meaningful collaboration both in the field and across the health system, which informants attributed to the multidisciplinary approach taken within the programme:

> *'…a programme that are very much multidisciplinary, there's very much a recognition of the value of all of the different expertise across the group, whereas there are some clinical programmes which are very medically driven…'*

While the National Clinical Programme for Palliative Care has helped progress palliative care provision, informants suggested it will have limited impact on scaling up the Model of Care or supporting further integration of services. For example, the National Clinical Programmes sit within the Royal College of Physicians and will always be medicine centric. That is a significant limitation for a discipline such as palliative care, where much of the care and support is delivered through multidisciplinary teams. Additionally, collaboration between statutory and voluntary service providers should be standardised to address persistent regional variation in service provision and quality. Informants indicated these

factors mean local governance structures with a strong management function from the statutory sector, will need to be developed and implemented to support further integration across services:

> *'The palliative care programme is a bit better bringing different disciplines together…but it's not the same as actually having a governing body that is populated by people from senior leadership roles and senior leadership organisations who are feeding out into their members, and actually including them in the discussions around practice, around policy development, and what that looks like.'*

Bereavement support

Finally, there was consensus that bereavement support provided through specialist palliative care services makes an invaluable contribution to those who have lost a loved one. This is through both therapeutic counselling and support with practical matters such as funeral planning, repatriation and accessing financial support. Substantial progress has been made in expanding the availability of these supports through the specialist palliative care in-patient units; however, deficits remain in acute hospitals and access is usually limited to those already known to the specialist team. Recommendations in the 2001 report related to bereavement support were generally regarded as vague, lacking important details such as who should coordinate and lead services, or the workforce requirements. As a result, bereavement support is seen as taking lowest priority when providers have competing demands on time:

> *'I think bereavement is often the Cinderella of the service…it's often forgotten and the first thing that's let go when services get under pressure.'*

3.3.1.2   Workforce

Expansion of multidisciplinary teams

Informants perceive many of the recommendations related to workforce as having been successfully implemented. They pointed to the establishment and expansion of multi-disciplinary specialist palliative care teams across acute hospital and community settings as key examples of the progress made. The most significant gap in progress reported during the interviews was variation in the composition of multidisciplinary teams (MDTs) across settings and geographically, particularly for health and social care professionals such as social workers, occupational therapists, physiotherapists, speech and language therapists and dieticians. In the case of speech and language therapists and dieticians, many attributed this to the lack of prescriptive staffing ratios for these roles in the 2001 report. Some also believed that funding for these roles is determined to a certain extent in the voluntary sector through advocacy by management, rather than the structured framework:

> *'…I think a lot of the development of palliative care has been very ad hoc. And I think we're the same, it comes down to sometimes a manager or consultant fighting for the post and pushing really, really hard.'*

Skill mix

Participants emphasised that nurses are central to delivering specialist palliative care across all settings, representing the largest number of healthcare professionals working in the sector. Many also noted that the role of nursing has evolved over the past twenty years, offering valuable opportunities to improve service provision. Examples cited during interviews included leadership in community-based services, advising and providing training in acute services, supporting the development of

paediatric palliative care, and nurse prescribing. Workplace practices were reported as hampering the ability of nurses to fulfil their enhanced roles in some instances, as was accessing appropriate training. Informants also highlighted there are very few advanced nurse practitioners in palliative care, and little succession planning evident to address this as existing practitioners move elsewhere or retire, in contrast with other services. Many directly linked the lack of progress in driving forward innovation in nursing within palliative care to gaps in leadership.

While recognising the important role of general practitioners and primary care teams in delivering palliative care in the community, some informants highlighted slow progress in addressing geographical disparities. Many questioned the feasibility of having primary care teams deliver palliative or end-of-life care without a detailed framework and resourcing to support service delivery. Others raised the need for advancing integrated health and social care services in the community to ensure healthcare interfaces with other services. Additionally, many believed there is scope for skill mix innovation in palliative care, particularly in the community, where care could be led by or transferred over to someone other than doctors or nurses in some instances.

Education and training

Advances in education and training for all three levels of palliative care were commented on by informants. The two examples mentioned frequently were training in palliative care skills and competencies across all healthcare settings, and the efforts to embed palliative care into undergraduate and postgraduate programmes and continuous professional development courses. Curricula are now standardised in undergraduate nursing programmes and the numbers of hours in palliative care training has increased over the past 20 years. While palliative care is also included in undergraduate medical programmes, the curricula are not standardised resulting in variation across the higher education institutions. For other health and social care professionals, training in palliative care within undergraduate programmes varies across institutions, but accounts for just a few hours at most. There are no academic departments of palliative medicine in Ireland, and just one professor of palliative medicine post has been created since 2001. There are a growing number of postgraduate palliative care courses offered throughout the country; however, some suggested they do not provide a clear pathway to specialisation in palliative care for some health and social care professionals:

> *'…Even though a lot of them say that they are multidisciplinary, in practice really, they're targeted at nursing, and they're driven out of schools of nursing.'*

Informants indicated the breadth of Continuing Professional Development (CPD) courses related to palliative care offered outside higher education institutions is in decline, despite clear demand. For many, the trend could be traced to austerity measures introduced after 2009, although this was reversing in the past few years. Some also suggested links between specialist palliative care inpatient units and higher education institutions are not well-developed in some regions, resulting in most courses being delivered directly through specialist palliative care units. This was viewed by many as a positive trend as specialist palliative care units can offer short courses, tailored to meet local demand, often to health and social care professionals they collaborate with. However, it also leaves training provision vulnerable to factors such as staff turnover (i.e., certain expertise may no longer be available) or changes in service activity (i.e., services become too busy providing core services and cannot prioritise education and training). Informants also highlighted other potential challenges such as variation in skills or expertise in centres, meaning people may need to access training in other regions, and competition among education providers.

The Competency Framework has helped address key gaps in both supply and demand for training. On the supply side, it has been used to inform curriculum reviews and design research. On the demand side, informants reported the Competency Framework provides a framework which allows healthcare professionals to assess their own skills, or the people they supervise, and make the case for additional training:

> *'…it allows for clinicians, particularly nurses working in the nursing home sector, to articulate to the managers I need to do advanced education…'*

Research capacity

There was general agreement among informants that research on palliative care has been strong in Ireland, characterised as having a knowledge translation component that has helped to move palliative care forward. More specifically related to research capacity among the workforce, some participants noted that while recommendations in the 2001 NACPC report indicate the need for a workforce with strong research capacity, this is an area that has not been implemented as well as envisaged. A lack of protected time and insufficient resourcing were most cited as the reasons for this. There was also a recognition that some cadres of healthcare professionals had been able to engage in research more successfully than others. Ensuring that research capacity and opportunities were developed and expanded across all cadres was considered important for future delivery of palliative care. Frequently mentioned examples of research priorities included workforce planning and retention, outcome measurement, bereavement support and integration of services.

3.3.1.3 Information

An area most participants identified as not having advanced as well as envisaged in the 2001 report is around data generation, standardisation and use for decision-making. Given the substantial deficits in data generation and use, and in e-health more broadly in the Irish health system, there was general agreement that this is an area that requires substantial review.

A frequently cited challenge was the lack of electronic health records. Instead, health records are handwritten and filed manually, limiting the potential for information sharing across settings, service providers and outside of routine office hours.

However, advances were noted in data generation for specialist care. For example, the Minimum Data Set (MDS) has 100% reporting compliance across all specialist palliative care settings and efforts are ongoing to embed patient-centred measures through use of the Palliative Care Outcome Collaboration (PCOC) tools (See Section 4.3.1 for further details on PCOC). The MDS was viewed by many as a valuable mechanism for generating real-time information about trends in specialist palliative care activity, highlighting areas of strong performance and services that may require additional support or resources. Gaps identified included the types of data being captured (i.e., limited to activity-based data as opposed to outcome or quality of care data); low levels of data generation on generalist palliative care provision; an emphasis on the contribution of medical and nursing professionals within specialist palliative care services; and the need for data-informed audit function to improve decision making and planning. Several informants suggested the PCOC measures will help address many of these limitations but offered few details on how this approach will be implemented or evaluated.

Participants highlighted how research output more generally has been strong in Ireland, despite the identified challenges related to generation of specific data for audit and decision-making, or capacity of healthcare professionals to engage in research.

'We are seeing how evidence and research is supporting changes in practice in care, ultimately, improving outcomes for patients and their families.'

They attributed growth in high-quality research to several factors, such as the coordinating role of organisations like the All-Ireland Institute of Hospice and Palliative Care (AIIHPC), or instances where academic departments work closely with service providers for both research and education. Many factors identified as hampering the advancement of research were similar to those noted for education and training, including the lack of palliative care or palliative medicine departments and associated senior academic staff to provide leadership and link academic and service provider settings.

3.3.1.4   Essential medicines and technologies

Much like the relatively scant attention given to essential medicines and technologies in the 2001 recommendations (see Section 2.3.1.4), essential medicines and technologies were seldom the focus in interviews. When discussed, it was most often related to issues of availability.

They noted that the HSE does prioritise equipment requests for people known to specialist palliative care, but supplies and timing of delivery are variable:

> *'It's hit and miss. It depends…people will be prioritised because of the nature of their illness, but it doesn't necessarily mean that there'll be all of the suitable equipment available, it means that they are referred will get picked up quickly. But it doesn't always mean that what they need is there and there in a timely manner.'*

Charitable organisations often fill gaps as they arise, but this is usually dependent on diagnosis. Another area of concern was access to assistive communication technology and environmental controls. These technologies are often essential to facilitate everyday activities, support social interaction and promote quality of life. Yet participants noted substantial barriers to their appropriate use, including delayed assessment and the absence of guidelines or a funding model. Health and social care professionals often assist to secure financial support through the HSE and charities.

A few interviewees also raised this topic beyond the 2001 recommendations. They suggested that while technology is a potential enabler for improved outcomes - such as through uptake of digital health technology - the focus on technological innovation and use has for the most part not extended into end-of-life care.

3.3.1.5   Finance

There was consensus among interviewees that specialist palliative care has received substantial and sustained statutory funding, which coupled with non-statutory funding has been a key driver in the development and expansion of palliative care in Ireland. Some participants questioned however why substantial elements of palliative care, such as infrastructure and some service provision, continues to largely remain outside of the public health system, with these participants contrasting it with services such as primary care. Others noted how significant funding for capital costs and some services, are expected to be raised by communities. Regional inequities in service provision are likely to persist given the limited capacity of community organisations in some areas to raise sufficient resources to build services that meet the Palliative Care Model of Care, and recommendations set out in the NACPC report.

Participants expressed some uncertainty around how statutory funding for core costs is calculated and allocated. There was a widely held perception that this is clearer for new in-patient units and services than existing inpatient units and services.

In terms of financial protection, some indicated that the medical card provides a crucial safety net for people with life-limiting illnesses, and approval is granted quickly in most instances. Others expressed concerns about services and costs not currently covered by the programme:

> *'…finances are a big thing, particularly for medicines and or equipment that might be required… affordability would be a huge issue…'*

Informants also highlighted that there is no 'fast-track' system for home modification grants as recommended in the 2001 report.

3.3.1.6 Leadership and governance

While there were relatively fewer recommendations in the 2001 NACPC report compared to other health system functions, leadership and governance received greater attention in later policy documents. Issues of leadership and governance similarly featured more prominently in interviews, focused at both the national and local levels.

Collaborative networks within palliative care are well-established and are central to the ongoing development of palliative care policy and practice. Informants emphasised the need to reach out and establish deeper links with difficult to reach populations and the wider health sector as population need for palliative care continues to grow:

> *'…there's no way specialist palliative care is going to be able to meet all that need and perhaps the role of specialist palliative care is to support and educate the staff across settings, because they're the ones who have the expertise [with these population groups] … And that's what we do, we reach in there to say that palliative care has something to add to the work that you're doing.'*

Significant changes to the organisation of the health system since 2001 has meant that many of the recommendations are no longer relevant or require revision, particularly related to decision-making and planning at the health board level. Reflecting on leadership and governance as it is currently practiced, interviewees raised several observations. Most of these related to managing collaboration between the statutory and voluntary sectors, but also addressing education and training deficits:

- a perceived tension in leadership and governance functions between the statutory and voluntary sectors, particularly around workforce management, capital development projects and accountability for how statutory funding is utilised by service providers;

- the need to deepen the national palliative care leadership to promote integration. This could be achieved by developing a corporate function and strengthening leadership within the National Clinical Programme for Palliative Care by making key positions such as the programme manager and nurse lead longer term. Informants reported risks associated with a rotating post for the national palliative care lead, including disruption to continuity of implementation plans;

- a need to expand the palliative care function through widening participation in leadership and governance processes to include non-medical health and social care professions, given their role in service planning and provision;

- a need for increased senior leadership in educational settings with links to specialist palliative care units in order to improve curriculum design and address training gaps across the different healthcare professions;

- a need to improve and standardise decision-making structures (service delivery and workforce management) within acute and community-based settings, which remain inconsistent. While there is a strong national leadership function through the HSE, local managers were seen as essential in driving service development and collaborative networks:

  'there's no local manager in [most] statutory services, whose job it is to oversee developments in palliative care happening in their area, it's very much driven by the local palliative care services deciding what it is that they are able to do'.

Table 12 Informants' views on progress towards implementation of the NACPC recommendations

Area and theme	Summary of views on progress
Service Delivery	
Expansion of specialist palliative care services	Substantial progress has been made on in-patient units. Gaps identified include community palliative care; composition and availability of MDTs; responding to changing referral pathways.
Access to services	General advancements on equitable, timely access to specialist palliative care services expanded with specialist palliative care services. On-going issues identified include geographic inequities; urban-rural service disparities; generalist palliative care capacity constraints; and access to underserved and vulnerable groups.
Palliative care for children	Supported the development of 2009 national policy for children's palliative care. While the interface between children's and adult palliative care is generally well-established in 8 of 9 CHOs, inequities in access by diagnosis, location and age persist.
Awareness and knowledge of palliative care	Significant improvement in awareness and knowledge. Continued perception of palliative care as end-of-life care was noted as potentially contributing to delays in seeking access or making referrals.
Integration of specialist palliative care services	Notable integration and quality improvements led by the National Clinical Programme for Palliative Care. Further integration and scale-up requires greater inclusion of non-medical professions; standardised statutory and voluntary provider collaboration; a strong statutory management function at local governance levels.
Bereavement support	Substantial progress on expanding availability of support services. However, deficits remain in different settings and regarding who gets access, while support is sometimes treated as the lowest priority when providers have competing demands.
Workforce	
Expansion of multidisciplinary teams (MDTs)	Many recommendations have been successfully implemented, particularly specialist care teams. However significant variation in team composition was noted across settings and geographically, with gaps in health and social care professionals highlighted.
Skill mix	Roles and skills were noted as having significantly evolved since 2001, particularly in nursing. Despite potential, the pace of innovation remains slow. Additionally, the need for advancing integrated health and social care and skill mix innovation in all settings were identified as priorities.
Education and training	The Competency Framework helped address key gaps in supply and demand for training. Efforts to embed palliative care training successful in some programmes, though remains uneven and varied, with unclear pathways to specialisation in palliative care for some professions.
Research Capacity	Research perceived as being strong, coordinated, and collaborative, with an ongoing knowledge translation component. Research capacity and opportunities within the workforce have not been developed as well for many cadres.
Information	
Data	While some progress has been made, gaps identified include the limited nature of data collected and a lack of transparency. Processes and infrastructure for data generation, standardisation, use for audit and decision-making requires substantial review, transparency and investment.
Research Output	Despite data challenges, there has been an expansion in research output, research coordination and collaboration. Progressing and scaling this up viewed as being hampered by similar resourcing, capacity and coordination issues identified in workforce education and training.
Essential Medicines and Technologies	
Availability	Issues of availability included variability in supplies and timing, and a dependency on charitable organisations to fill gaps. Substantial barriers to accessing assistive communication technology and environmental controls were identified, despite their significant potential for service users.
Finance	
Sustainability	Significant statutory funding, coupled with resourcing from voluntary sector, has been a key driver for in the development and expansion of palliative care. Some funding for development and some core services remains outside the public health system, limiting potential to address some regional inequities.
Financial protection	No progress has been made on a 'fast-track' system for home modifications as recommended in 2001.
Governance	
Structures and functions	Governance and organisation have changed significantly since 2001, making specific recommendations less relevant. Structures and functions, such as oversight, information exchange, collaboration, decision-making and stakeholder engagement, remain key to developing future practice.

3.3.2 Enablers or barriers of policy implementation

3.3.2.1 Macro level: The health system and policy environment

The macro level is where health strategies are developed and resource allocations decisions are made, underpinned by societal values and principles. Informants described many enablers and barriers to implementation of national palliative care policy at this level (Table 13). Some of these are specific to palliative care service provision, while many are applicable more generally.

Increased resourcing from both the statutory and voluntary sectors has been central to infrastructure and workforce development, as well as supporting research and innovation. Informants noted that annual increases in statutory funding for palliative care services were higher than seen in other countries. Despite the progress achieved, geographical inequities in funding and service provision remain. Informants linked these persistent inequities to factors such as ongoing reliance on voluntary sector funding arrangements and increased costs associated with capital development projects, and also perhaps lower priority for funding palliative care relative to other health services:

> *'I think the problem with palliative care is it can often be the opportunity cost.'*

Identifying solutions to resourcing constraints has been challenging. While informants highlighted the need to further expand community-based services and support non-specialist palliative care provision, this must be balanced with ongoing efforts to fully implement the NACPC recommendations around development of specialist palliative care in-patient units. As one informant described it:

> *'There's a sense that it's difficult to change that policy, because otherwise, then people are being treated differently, or regions are being treated differently'.*

Developments such as the establishment of the National Clinical Programme for Palliative Care have also facilitated implementation in important ways. Informants highlighted that the programme has created a clear clinical leadership channel for palliative care, which in turn has strengthened collaboration across the health system. However, there are also important limitations around the role that may hinder its potential for supporting development and implementation of national policy:

> *'…if you have leadership and you have a common roadmap, and it needs a number of years to bed that in…you need to have more than somebody in a post for two years or for three years, you need to have very clear guidance around it.'*

While some noted the potential limitations of having rotating clinical leads, others recognised these as necessary given other clinical responsibilities that remain for those who take up the role. Developing more permanent supporting roles for the leadership functions, including the programme manager and nursing lead, was identified as a potential enabler for enhancing the leadership function of the National Clinical Programme for Palliative Care.

Another key enabler of implementation at the macro level is sustained political support for palliative care. It was described by many informants as a 'high-profile issue' that is valued across society and brings engagement from all levels of government. A commonly cited example was politicians campaigning for the development of specialist palliative care in-patient units and funding for associated services in their constituencies. Additionally, successive Ministers for Health, the Department of Health and the HSE have promoted and supported palliative care development.

Data generation, analysis and reporting were all linked to implementation, both as enablers and barriers. The minimum data set has generated information about service provision across Ireland.

Reporting for the MDS is mandatory, driven by the HSE, which has facilitated 100% reporting compliance. Some informants suggested the value of the data for informing service planning or monitoring quality is limited because the metrics are mainly activity-based. However, others highlighted that the MDS provides valuable information about how people are accessing services across all settings and is an important mechanism for ensuring accountability. Implementation of the PCOC programme was seen as an important development to further support quality improvement within specialist palliative care.

Collecting and reporting patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) will be central to improvements, but there are challenges to implementing these types of measurements. Commonly cited barriers were data infrastructure, the lack of a unique patient identifier, the interface between statutory and voluntary services and a perceived reluctance to move beyond activity-based metrics.

Informants noted there was a lack of specificity in many of the NACPC recommendations, making it difficult to implement them or measure progress. However, most also believed that the policy has guided service development in Ireland for more than twenty years because much of the content focuses on the values and principles underpinning palliative care.

> *'…we can't measure it, we can't quantify it always, but the core of the policy was about the approach, the philosophy, the culture of palliative care. And that's why in a way, it has stood the test of time, that there was the inherent belief that people have a right to be treated with dignity and respect…'*

Table 13 Macro-level enablers and barriers to implementation of the NACPC recommendations

Domain	Enablers	Barriers
Resourcing	• Capital development projects completed • Expansion of palliative care services across settings • Developing research capacity and evidence base for palliative care	• Variation in statutory funding • Capital development not adequate resourced through statutory funding • Low priority • Dependency on voluntary funding; however, has reduced substantially since 2019
National Clinical Programme	• Development of frameworks and guidelines, all underpinned by best-available evidence • Visible leadership for palliative care	• Limited tenure for Clinical Lead • High turn-over of supporting roles • Developments can vary depending on the Clinical Lead
Information	• Equitable access • Population-based planning • Accountability	• Data collected across statutory and voluntary sector • Varying support for using PROMs and PREMs • Few validated PROMs and PREMs for palliative care
Political input	• High-profile issue • Generates sustained resourcing and strategic support	• Local input varies
Policy development and content	• Stakeholder engagement • Validated and feasible performance indicators • Collaborative networks within and beyond palliative care	• Lack of specificity in recommendations

3.3.2.2 Meso level: Healthcare organisations and interprofessional integration

At the level of local health system organisation and provision, informants described some enablers and barriers specific to implementation of national palliative care policy and some which are observed more generally within the health system (Table 14).

The establishment of the national lead role within the HSE has driven forward important developments in service delivery, access and oversight. However, fragmentation of healthcare services across settings and regions creates significant barriers for implementing palliative care policy. The current configuration of hospital groups and CHOs have also contributed to challenges in accessing appropriate care. Sláintecare is seen as essential to addressing these structural issues, with its emphasis on integrated care, regionalisation and shifting care from acute hospitals to the community.

In acute hospitals, enablers and barriers cited included:

- Resourcing to establish and expand multidisciplinary teams and collaboration;
- Communication from specialist palliative care teams has improved awareness of palliative care;
- Variation in composition of palliative care multidisciplinary teams;
- Limited availability out-of-hours;
- Acknowledgement of expertise;
- Having clearly defined roles and responsibilities.

These factors were also mentioned in the context of community-based services, in addition to:

- Regional variation in governance and operational arrangements between statutory and voluntary services, including service availability and workforce management:

    '…when issues arise or if services aren't being delivered in the way that might have been anticipated with whatever funding was provided, there's no go-between to manage that situation.'

- Inadequate resourcing for general practitioners to provide palliative care (e.g., extended consultations and home visits);
- Inadequate capacity or preparedness in many services to meet growing demand or complex needs;
- Information and data sharing is hampered by underdeveloped e-health infrastructure;
- Delays in securing homecare packages.

The importance of nursing in providing high-quality care in the community was emphasised during interviews. For example, public health nurses and practice nurses were regarded as essential to supporting access through timely identification of needs and engagement with general practitioners. Specialist palliative care liaison nurses and advanced nurse practitioners (ANPs) were also seen as a vital resource to support service users and healthcare professionals in the community. A specific barrier to expanding the number of ANPs nationally cited by some informants was resistance to nurse prescribing. This suggests the role of the advance nurse practitioner role is being conflated with nurse prescribing at times, as Clinical Nurse Specialists can also be nurse prescribers. Some indicated

however that the underlying challenge is a lack of clarity about governance and operational arrangements. Significant changes in working practices also take time and effort to implement, and this needs to be communicated more explicitly.

Academic departments and research centres have not been established, leaving critical gaps in leadership to drive innovations in training and research forward. As a result, there limited formal links between specialist palliative care in-patient units and higher education institutions. Ethics approval process vary across settings, making it challenging to design and implement high-quality studies. Informants noted that education is improving, but an important barrier to full implementation is the lack of consistency in training within disciplines or education levels. The Competency Framework provides guidance to support curriculum review and development, but many informants felt this resource is used primarily by specialist palliative care providers and educators. A supportive learning environment is also needed to foster skill development, and informants said one crucial barrier is that organisations are not providing protected time:

> *'…people aren't given time to develop their research capacity and capability…it's really critical to get it right and to call it out and to ensure this protected time'*

Differing views were put forward about the contribution the three-level model of palliative care service provision has made. For some, it has provided a framework to design services and training programmes. Others noted that the levels empower non-specialist and specialist providers alike through the delineation of roles and transparency around care pathways. However, informants expressed concerns that while delineation had been beneficial in many ways, there was the potential for the approach to disenfranchise those not providing specialist palliative care. Similarly, there were some who questioned how meaningful or accessible the framework is outside of specialist palliative care:

> *'…outside of palliative care, how well that is kind of accepted or recognised, or means anything to the healthcare professionals that it's talking about.'*

Integration also requires an understanding of how care is delivered within services or settings. As one informant described it:

> *'How do you support the specialist to learn about what's what it's like in the community as well? …the reality of being, say an OT in the community, of being a physio in the community? And you know that there's mutual learning'*

Initiatives such as the Project ECHO training within nursing homes and the Hospice Friendly Hospitals programme were seen as central to supporting this type of mutual learning between specialist and generalist palliative care providers.

Informants expressed concern about the untapped potential for Ireland to continue to contribute to innovation and evidence development in palliative care. Most resourcing goes into delivering core services and capital development, leaving little space for research, piloting new delivery models and supporting future planning initiatives.

Table 14 Meso-level enablers and barriers to implementation of the NACPC recommendations

Domain	Enablers	Barriers
Organisation	• HSE national lead role • Sláintecare reforms focused on integrated care in the community	• Fragmentation of services
Community-based services	• PHNs and practice nurses supporting communication and referral to specialist services • Liaison from specialist palliative care unit • Improved understanding of each others' settings and strengths	• Increasing demand without sufficient capacity • Information-sharing limited by IT infrastructure • Gaps in governance and workforce oversight in the voluntary sector • Very limited availability at evenings, weekends or public holidays
Acute hospitals	• Palliative care is a resource for other services to utilise (e.g., consultations, advice and training) • Having clearly defined roles and responsibilities	• Very limited availability at evenings, weekends or public holidays • Varying development of multidisciplinary team
Model of care	• Empowering non-specialist providers • Promotes consistency and transparency • Driving improvements in efficiency and quality	• Limited knowledge or application outside specialist palliative care
Training and research	• Competency Framework provided structure for curriculum development	• No academic departments to lead training developments • Few formal links between specialist palliative care units and Higher Education Institutions • Protected time not always supported • Research ethics processes

3.3.2.3 Micro level: The Individual perspective

Micro level enablers and barriers are those observed at the individual or household level or at the health professional level. Informants cited relatively few enablers or barriers to implementation of the NACPC recommendations at the micro-level (Table 15). Some micro-level factors are also applicable at the meso- or macro-level and were reported accordingly.

Awareness or knowledge of palliative care was viewed as an important influence on demand, acting either as an enabler or barrier. Informants reported that misperceptions about palliative care being for those near the end-of-life are common and contribute to delays in accessing services:

> '…there's almost a stigma associated with palliative care…'

However, many emphasised that knowledge about palliative care is improving and that there is increased awareness that palliative care is applicable at any point in the disease trajectory. They attributed these positive changes to ongoing efforts from voluntary sector organisations, supported in part by the HSE, including advocacy and information campaigns such as 'Palliative Care Week' that highlight service users' experiences with palliative care:

> 'I think there's no stronger way of getting your message across then through service users and their family, because they'll tell you the added value.'

Variation in skills and knowledge for health and social care professionals was another factor mentioned by informants. Education and mentorship are key facilitators in improving confidence in palliative care. While training and further education were seen as key to facilitating exposure to

palliative care and improving knowledge, there were concerns that it can be challenging to apply these skills in practice:

'…in terms of going on training, and then utilising the training there's huge gaps.'

Opportunities for career advancement for some health and social care professionals within specialist palliative care are limited given the lack of senior clinical posts. Additionally, a lack of hours or stability in night nursing has made recruitment challenging.

Table 15 Micro-level enablers and barriers to implementation of the NACPC recommendations

Area	Enablers	Barriers
Patient or carer perspective	• Increasing awareness of palliative care, especially for cancer patients	• Costs • Availability of equipment • Delays in accessing homecare packages • Support for home modifications • Timely access to home care packages
Healthcare professionals	• Switch to remote delivery of courses has increased participation	• Reduced availability of CPD courses • Limited exposure to palliative care • Limited opportunities for career advancement • Inconsistent working hours in night nursing services
Public perspective	• Awareness and advocacy campaigns led by voluntary sector organisations	• Palliative care seen as end-of-life

3.3.3   Relevance of the NACPC recommendations and emerging issues

Informants felt the NACPC report has made a valuable, long-term contribution to the development of palliative care in Ireland. One described it as:

'…a type of policy, where its sum is more than the individual parts…'

Some highlighted aspects of the policy as being 'ahead of its time' and still broadly relevant, for example, commitments to patient-centred care, equitable provision, regional planning and early integration. Others argued the health sector is rapidly evolving through the implementation of Sláintecare and the NACPC report does not adequately reflect these changes:

'And it definitely read of its time to me…it didn't reference things like population-based planning, or planning for a changing population demographic, in the same way that we might speak about it now'

'What we're missing is a gap at the local and regional level around population planning for palliative care developments…'

Irish society and culture have been transformed over the past twenty year and many voiced concerns that the NACPC report does not align with current needs. Examples given include religious changes, immigration and differences in social networks. At the same time, people are also living longer with more complex needs, such as multimorbidity. Some also suggested that understanding of palliative care has evolved and there is awareness that needs will differ among population groups, with one saying:

> *'Culturally, age wise, paediatrics is going to look very different to old age, is going to look very different to cancer… we need to be a little bit more focused and recognise the diversity of what's going to be required'*

While the report advocates for universal access based on need, some informants voiced concerns that services and information throughout the health system are currently designed to cater to specific populations, leaving some groups poorly represented:

> *'…if you are well-educated, white, middle class, understand medical language and data, there's a service waiting for you…And I think that anybody outside of the norm is seen as somebody who needs extra or special or more…but actually, diversity is the norm not the exception.'*

The NACPC report focused to a large extent on providing recommendations related to specialist palliative care service delivery and health workforce capacity. Informants indicated this was necessary at the time the report was published as there was no framework to steer the development of national service provision. However, they contrasted this with the relatively low emphasis given to providing the same type of guidance for generalist palliative care capacity or quality. Most emphasised the need for implementing and evaluating the Model of Care nationally and strengthening collaboration between the three levels of specialisation to meet the policy goal of universal provision:

> *'…not relying completely on primary care, because primary care up to date seems to have become the area that we all put things in and hope to goodness that it delivers on.'*

Many questioned the appropriateness into the future of the prescriptive staffing ratios in light of differing organisational, geographic or population health needs, and the potential for skill mix innovation among different cadres. Instead, greater attention should be given to issues such as recruitment and retention, the composition of multidisciplinary teams to reflect population need, and delivering training and education that improves skills and confidence among generalists:

> *'…the multidisciplinary team is really important, but also needs to be widened way beyond those with clinical skills, I think it's about a much wider set of skills that is required.'*

> *'I think the breadth of the challenge is significant. I'm not aware of any comprehensive palliative care training programme going on within the HSE.'*

Informants indicated that Sláintecare presents an opportunity for implementation but will require substantial changes in how palliative care is planned and delivered:

- Robust, timely data are needed to support population-based planning and resource allocation
- Leadership will need to be strengthened to embed integrated care and collaboration across all settings.
- Incorporating a wider perspective of care (e.g., deeper collaboration between health and social care professionals, inclusion health, equal partnership with patients) than taken in the 2001 policy.

COVID-19 has also brought ongoing deficits in workforce, infrastructure and resourcing to the fore:

'there's very little resilience in some services, it takes something like COVID to shine a real light on a lot of our services, and we appreciate just how vulnerable they are'

Informants praised the commitment shown by health and social care professions throughout the pandemic, and also advised on some of the challenges requiring consideration in the updated policy:

- Ongoing outreach and support for nursing homes and other residential care settings

- Ensuring the well-being of the workforce more generally, who are at increased risk of burnout

- Upgrading existing IPUs to have single room accommodation to meet infection control requirements.

3.3.4   The Future

Informants emphasised that much of the NACPC report remains relevant and the updated policy should seek to build on what has been achieved. They made suggestions around how the policy should be developed, what it might prioritise and measures to support implementation.

3.3.4.1   The process of updating

Most believed the policy development process should be inclusive with broad representation from different stakeholders throughout the country. This includes input from across the health sector, voluntary organisations, relevant government departments (e.g., Department of Social Protection and Department of Children, Equality, Disability, Integration and Youth), service users and members of the public. Informants emphasised the need to proactively support marginalised or vulnerable populations to participate. Many indicated that a collaborative process would help generate sustained commitment and build trust:

'…a process that is engaged, is open for those outside of specialist palliative care to engage and input into it…that they have trust, because it is a policy for them, really, for the public and for other health care professionals…there's true ownership of this and more of a true policy to shape…'

'You're more likely to get buy in if people feel that they've had a little bit of involvement...'

3.3.4.2   Priorities

Informants described a mix of targeted and aspirational priority areas the updated policy might incorporate.

'Will it be a policy for 2022 and where our healthcare system is? Or will it be aspirational for where we think our healthcare system will be in 2032? And I would suggest the latter. We shouldn't plan for now, we should plan for where we are going.'

For many, this means ensuring the updated policy aligns with Sláintecare reforms and the Palliative Care Model of Care. At its core, the policy should continue to advocate for universal access to high-quality palliative care services based on need. It requires service development and funding be guided by current and future population health need. The transition towards community-based, integrated care means there must be greater support for developing generalist palliative care capacity and community-based specialist services.

'Empowerment of others outside of specialist palliative care and the recognition of their vital important role in delivering the vast majority of palliative care.'

Alongside this, the policy will need to acknowledge the expertise health and social care professionals have and promote collaborative practice across all three levels of palliative care. Establishing and strengthening collaborations across the national clinical programmes would help support this.

'Some would feel that palliative care tends to get into the specialist mode and forget the needs of them, these services just had to come in and work into that approach, whereas actually, the shared expertise is required.'

Emphasis should also be given to delivering patient-centred care, based on an equal partnership between patients and healthcare professions:

'…the next iteration of the palliative care strategy should take the ethical and rights considerations to the core of the policy.'

For patients, accessibility was described as a characteristic that makes a good service, where teams or hubs bring palliative care and related services to people, whether in the hospital or the home. Informants suggested the policy should reflect the needs and preferences of vulnerable and marginalised populations.

Some also want to see palliative care develop stronger collaborations within inclusion health, with one saying:

'…palliative care has something to actually offer as a leader in that inclusion health space, because of the vulnerability of the population that's being looked after.'

Several priorities related to workforce development were raised by informants, including:

- incorporating skill mix innovations drawing on examples from other areas of health and social care

- workforce planning that reflects regional variation in population need and service organisation

- ensuring education and training is available at all levels of the qualification framework for all health and social care professionals

- developing palliative care capacity in service delivery and research across the entire multidisciplinary team.

Priorities related to funding were also discussed:

- Budgeting based on both current and future population need

  '…look down the road further than one single budgetary year, because building up a service as specialist as palliative care takes a bit of time and future planning…it's not specific to palliative care, but it's particularly relevant to palliative care.'

- Full statutory funding for core service costs across all services, which continues to be guided by a transparent framework

> *'The voluntary will always be different...But it's the statutory that needs to be very clear, transparent, that if you have 16 beds, it's an amount per patient or per bed, in the first instance.'*

- Funding for research to support innovation in areas such as service delivery, workforce planning and policy implementation.

- Financial protection for service users, particularly for home renovation fast-tracking, but also for medical and other technology that can improve quality of life.

- Payments for general practitioners to provide home-based care and other supports such as extended consultations and facilitating advance care planning.

3.3.4.3   Implementation

Development and implementation of the updated palliative care policy should be underpinned by the principles of coherent and strategic integration across related services, 'reaching in' or bringing palliative care to where it is needed across the system by enabling others to provide it. Informants suggested that recommendations and key performance indicators (KPIs) should be focused and measurable, and warned about the implications of not testing their feasibility prior to inclusion in strategic planning:

> *'be careful in terms of coming up with KPIs, they need to be stress tested in terms of, Are they realistic? Are they actually measurable?'*

> *'you can set yourself up to fail if you identify KPIs and it's not achievable to get them'*

While it is important to specify measurable recommendations and KPIs, this should be balanced with the need to continue promoting the broader ethos, principles and holistic view of palliative care enshrined in the 2001 NACPC report.

Development of an implementation plan with clear indicators, timelines and role/responsibility allocation should be prioritised to support performance and accountability. A working group within each administrative area, including the HSE national lead for palliative care, should suffice to support implementation and oversight. Implementation should be evaluated annually, accompanied by a published annual update on progress and plans for the following year.

> *'it almost takes until the policy gets reviewed, but we should be able to tell in real time where recommendations are at'*

Informants emphasised that the implementation plan should ensure a particular focus is set out on actions and enablers at the primary care level to support the ongoing development of generalist palliative care:

> *'...it's now become a very complex area. So anything in the implementation plan that can be as specific as possible around primary care level delivery...'*

3.4   Conclusion

This chapter presented findings from qualitative interviews with stakeholders to identify successes and gaps in service provision; the barriers to, and facilitators of, implementation; and views on issues to be addressed in the policy update.

We conducted eighteen interviews and six focus groups between October and December 2021, with a total of 39 participants. Participants included healthcare professionals (clinical and health and social care), representatives from within the statutory and voluntary sector, policy makers, service planners, academics, service users, carers and members of the public.

Overall, there has been substantial progress in the development of specialist palliative care in Ireland since 2001, and informants linked this to the recommendations set out in the NACPC report. Interviewees described progress as having been made across all core areas, such as the expansion of and access to specialist palliative care services, increased awareness of palliative care, and ongoing growth of multidisciplinary teams across all settings. Significant challenges and gaps were also identified, such as persistent geographic disparities in service provision across all settings, deficits in data generation and use and the need to review and strengthen governance and leadership arrangements.

Informants also described enablers and barriers to implementation of the NACPC report. These include successes such as the establishment and activities of the National Clinical Programme for Palliative Care, sustained political support for palliative care, increasing service integration through Sláintecare reforms, and improving awareness of palliative care among the public and healthcare professionals. Progress has been hampered by several factors, such as resourcing constraints, service fragmentation, limited availability of services outside office hours, deficits in skills and knowledge among health and social care professionals and persistent gaps in academic leadership

Informants emphasised that much of the NACPC report remains relevant and provided recommendations as to how it can be updated to address gaps through a mix of targeted and aspirational policy areas and processes. Key priorities include the revision of the NACPC report to reflect the changing landscape of the health and social care system since 2001, in addition to the ongoing empowerment of healthcare professionals to engage with the palliative care approach and ensuring adequate funding is provided to support innovation and development within palliative care policy and practice.

The next chapter presents an evidence review examining implementation of palliative care policy initiatives, insights related to organisational reform within the Irish health and social care system and summarising peer-reviewed evidence on the cost-effectiveness of specialist palliative care.

4 Workstream 3: Evidence Review

4.1 Introduction

The aim of this workstream was to review evidence of best practice in implementation of palliative care policies and programmes, organisational reform, and cost-effectiveness to help compare and contextualise the Irish experience of implementing national palliative care policy. By thematically analysing documents, we generated the following outputs:

3.1 Descriptive case studies of excellent examples and key enablers of policy implementation across different country contexts to inform more effective implementation of the updated policy [**Research Question 3**]

3.2 A descriptive summary of organisational reform in Ireland's health and social care system [**Research Question 3**]

3.3 A summary of peer-reviewed evidence on cost-effectiveness relevant to the model of adult palliative care in Ireland [**Research Question 5**]

This chapter describes the methods used in the workstream and presents the findings.

4.2 Methods

4.2.1 Case studies

To understand what works best, we undertook a cross-country comparative review of excellent examples of palliative care policy implementation relevant to Irish national policy from across a select range of countries (Australia, Sweden, Scotland and England; See Table 16). These countries were chosen based on:

- Classified as having advanced integration of palliative care services (level 4b) in the Global Atlas of Palliative Care at the End of Life (50);
- Membership of the Organisation for Economic Co-operation and Development (OECD);
- Proving universal healthcare, predominantly publicly-funded;
- Published documentation related to palliative care in languages the lead investigator can read.

Key documents were sourced using two approaches: 1) a detailed search of national and regional government and palliative care organisation websites for palliative care policy, strategic planning or implementation documents; and 2) search of the electronic databases to identify peer-review articles and grey literature relevant to this analysis.

4.2.2 Irish policy and context

We drew on recent research to identify and summarise insights related to organisational reform within the Irish health and social care system which are particularly relevant to palliative care:

- Examination of the implementation of the Integrated Care Programme for Older Persons

- Analysis of service reorganisation in the Irish health & social care system from 1998-2020

4.2.3 Cost-effectiveness

We undertook a rapid literature review to identify what international evidence exists on the cost effectiveness of adult palliative care services similar to those provided in Ireland. The review focused on peer-reviewed systematic reviews. After screening and identifying relevant reviews, findings were extracted and reported in a narrative summary.

Table 16 Health system overview for case study countries

Country	Type of system	Funding sources	Palliative care delivery
Australia	Regionally administered, universal public health insurance program (Medicare). Citizens are automatically enrolled and receive free public hospital care, substantial coverage for physician services, pharmaceuticals and some other services. Approx. half of Australians purchase private health insurance to pay for private hospital care, dental care and other services. The federal government provides a tax rebate for this premium and charges a tax penalty for higher income householders who do not purchase private health insurance (51).	Health expenditure in Australia is financed by government schemes (65%), compulsory health insurance (1%), voluntary health insurance (13%), out of pocket expenses (18%) and other (3%) (52).	Australia is categorised by WHO Global Atlas of Palliative Care (2020) as a country 'where hospice-palliative care services are at a stage of advanced integration into mainstream service provision' (Level 4b) (50). Palliative care in Australia is delivered in the community (home and residential care) and in hospitals and specialist palliative care units (53).
England	National Health System. All residents in England are entitled to free public health care through the National Health Service. Resources and funding are distributed by NHS England to 191 Clinical Commissioning Groups, which manage the delivery of health services at a local level. Approx. 10.5% of the population has voluntary health insurance to gain quicker access to elective services (51).	Health expenditure in the United Kingdom is financed by government schemes (79%), voluntary health insurance (3%), out of pocket expenses (16%) and other (3%) (52).	As part of the United Kingdom, England is categorised by the WHO Global Atlas of Palliative (2020) as having 'advanced' integrated palliative care system (Level 4b) (50). Palliative care is provided in patient's homes, hospitals, care homes, nursing homes, and in hospices (54).
Ireland	Public health system that is government funded. Individuals who are 'ordinarily resident' in Ireland for at least one year are entitled to either full eligibility (Category 1) or limited eligibility (Category 2) for health services. Individuals who are possession of a medical card (Category 1) (approx. 36% of the Irish population) are entitled to receive free inpatient, day and outpatient care and have a low minimum payment for prescription drugs. Individuals who do have a medical card (Category 2) must pay out-of-pocket expenses for medical services. These payments may be paid in full (GP consultation fees), payable within a monthly deductible threshold (DPS) or may be paid as a co-payment for the public hospital system (55,56).	Health expenditure in Ireland is financed by government schemes (74%), compulsory health insurance (1%), voluntary health insurance (12%), out of pocket expenses (12%) and other (2%)(52) .	Ireland is categorised by the WHO Global Atlas of Palliative (2020) as having 'advanced' integrated palliative care system (Level 4b) (50). There are three levels of palliative care in Ireland; the adoption of a palliative care approach by non-palliative care professionals (level 1), general palliative care that is provided at an intermediate level in hospitals and the community (level 2) and specialist palliative care services (level 3) (35).

Scotland	National Health System. The National Health Service Scotland is a public funded healthcare system, which provides services (including GP and hospital care) to all patients without any cost. NHS Scotland is comprised of 14 regional health boards, 7 special health boards and one public health body. Services such as dental or optical care are generally paid for by patients (57,58).	Health expenditure in the United Kingdom is financed by government schemes (79%), voluntary health insurance (3%), out of pocket expenses (16%) and other (3%) (52).	As a part of the United Kingdom, Scotland is categorised by the WHO Global Atlas of Palliative (2020) as having 'advanced' integrated palliative care system (Level 4b) (50). Specialist palliative care in Scotland is provided by palliative care specialist teams in hospices, in-patient units and acute hospitals. Generalist palliative care is provided by healthcare professionals in the patient's community (59).
Sweden	National universal health system that is administered locally. Health policy is determined by the Ministry of Health and Social Affairs and individual regions then finance and deliver the health care services. Funded by grants from the central government. All citizens are automatically enrolled. Services that are covered included inpatient, outpatient, dental, mental health, long-term care and prescription drugs. Regions determine the fees for all levels of care and rates for primary care and hospital stays. Dental and pharmaceutical benefits are determined nationally and subsidised. Approx. 13% of citizens pay for private cover to get better access to private specialists (51).	Health expenditure in Sweden is financed by government schemes (85%), voluntary health insurance (1%), out of pocket expenses (14%) and other (1%) (52).	Sweden is categorised by the WHO Global Atlas of Palliative (2020) as having 'advanced' integrated palliative care system (Level 4b).1 Palliative care is provided in hospitals, in the community (at home and in nursing homes and residential care) and in hospices (7).

4.3 Case studies

This section presents details of four exemplars of palliative care policy implementation. Details of health systems in the four countries, along with Ireland to facilitate further comparison, are provided in Table 16.

4.3.1 Australia: Palliative Care Outcomes Collaboration

4.3.1.1 Background

The Palliative Care Outcomes Collaborative (PCOC) is a national palliative care outcomes and benchmarking programme used throughout Australia. The initiative was introduced in 2006, to assist services in measuring the quality of symptom control, and to develop a national benchmarking system to understand outcomes across services. A core part of the programme is to create a national, longitudinal database for palliative care that captures information across a patient's disease trajectory to facilitate improved patient outcomes, by improving the process of care.

4.3.1.2 How PCOC is operationalised

PCOC combines information submitted by specialist palliative care services. This comprises inpatient services, which includes patients seen in designated or non-designated beds under the direct care of the palliative care team, and community services, which includes patients seen in the community and through ambulatory (outpatient) clinic episodes.

Each patient is registered once by the service and given a unique patient ID (Statistical Linkage Key (SLK)), which facilitates linking records on the different episodes and the phases within each episode . This unique ID allows patient data reported by different service providers and settings to be matched, enabling a more accurate picture of client numbers and patterns of assistance. Data is captured at three distinct levels: the patient-level, episode-level and phase-level. Phase-level information describes the clinical condition of the patient and is derived from five tools:

- Palliative Care Phase

- Palliative Care Problem Severity Score (PCPSS)

- Symptom Assessment Scale (SAS)

- Australia-modified Karnofsky Performance Status (AKPS) scale and

- Resource Utilisation Groups – Activities of Daily Living (RUG-ADL)

Point-of-care data collection occurs at four distinct points: on admission; a minimum of daily in the inpatient setting / patient contact in the hospital consultative setting / patient contact in the community setting or in outpatient clinics, by phone or in-person; at change in plan of care; at discharge. For patients in hospital, this means data is collected daily and at phase change. For patients at home or attending outpatient clinics, the assessments are collected at each encounter (i.e., each visit), whether in-person or by telephone/telehealth or other, and at phase change. The same protocol applies regardless of the model of care. Clinicians record the PCOC information in two ways:

- using paper forms that are stored with the patient's medical record. Data entry personnel then enter this information into PCOC's required 'phase level' format.

- direct entry into an electronic patient record. The IT systems then implement an algorithm to convert this assessment level data into PCOC's required phase level data.

Palliative care services participating in PCOC submit data twice yearly.

4.3.1.3   How PCOC data are used

The programme aims to improve clinical outcomes in palliative care through an audit and feedback quality cycle. Each individual service has password-protected access to their own service reports. Quality Improvement Facilitators work with the service to interpret their data and to initiate clinical change processes where opportunities to improve outcomes through focusing on quality of care are identified. Benchmarks applied to the data present participating services with the opportunity to compare their service to other services from across the country. They are presented separately for services in hospital/hospice and community setting, and cover aspects such as: time from referral to contact; time in unstable phase; change in symptoms/problems; and change in symptoms relative to the national average. Benchmarking is at a national, jurisdictional or peer group level. Services implement their own quality improvement initiatives based on this benchmarking, but there are limited details available about what these initiatives entail, how they vary across settings or their effectiveness.

The most recent national strategy for palliative care, which was published in 2018 outlined several priority goals, including robust data collection, monitoring and reporting. In 2017, the Australian Institute of Health and Welfare began working with stakeholders to develop a strategic plan encompassing a framework to improve data collection for palliative care. The result is 'Palliative care services in Australia'; an online web report on the activity and characteristics of palliative care services across Australia, updated twice a year (60). The report uses national administrative datasets as well as data from PCOC.

4.3.1.4   Governance and oversight

The national PCOC office, located within the Australian Health Services Research institute (AHSRI), University of Wollongong, is responsible for the database and routine reporting and analysis. AHSRI is the custodian of the database and owner of the intellectual property.

To achieve national consistency, PCOC developed a data-collection framework to ensure that the data are useful in understanding quality at a patient, service and health system level.

PCOC holds information on more than 250,000 people. A 2020 report by the Collaboration highlights the improvements achieved by participating services over the span of more than a decade (40). However, there has been no external evaluation of the dataset or its impact on patient care.

4.3.1.5   Factors supporting sustainability and implementation

Several factors have been recognised as influencing the implementation and sustainability of PCOC:

- The publication of a national framework in 2000 with associated funding;

- The National Palliative Care Standards, which state that services are expected to participate in benchmarking processes to compare their service delivery over time and/or with external organisations;

- The broad engagement of the clinical community, who recognise that the measures are clinically useful and can inform practice and service planning, is essential;

- Clinicians leading the process of measuring patient-centred quality of care and leading the response to the data that are collected;

- Clinical training to improve data quality, but also to demonstrate how the data can be used as part of clinical practice, is essential. Quality Improvement Facilitators have responsibility for recruiting and training palliative care services, and for working with them to optimise local processes;

- Timely feedback of data to services allows local quality initiatives to be reflected in the data, with changes in practice rapidly evaluated;

- Close collaboration between peer services in order to participate in benchmarking and continue to improve outcomes systematically;

- The support provided by the University of Wollongong's Centre for Health Service Development, which provides a national training and analysis unit, and publishes user documentation.

4.3.1.6   Limitations and future direction

The data collected as part of PCOC only reflect people who are referred to specialist palliative care services, not other people with life-limiting illnesses. In Australia, an over-representation of individuals with cancer and a subsequent under-representation of individuals with non-cancer life-limiting illnesses may be a concern for evaluating the PCOC, as about 60% of people in specialist palliative care are individuals who will die from cancer (61). Additionally, it is anticipated that extending the use of the PCOC into primary care and other specialties that provide care to individuals with palliative care needs who are not referred to specialist care will be far more challenging (61).

Practical concerns regarding PCOC have also been raised. Data collection relies on a large number of clinicians to collect data at the time of clinical service provision, potentially limiting the consistency of data. For example, the interpretation of the distinction between the unstable and deteriorating phases has been raised by some clinicians. Some have argued that there may be an element of subjectivity in this measure. To address such concerns each clinician (nurse or medical practitioner) and their clinical team are provided with training at the time when their service commences data collection. A study evaluating the validity of one of the measures in PCOC reported fair to substantial inter-rater reliability levels, suggesting there are often significant differences in ratings of symptom burden between patients and proxy reporters (62). Additionally, while quality improvement tools are available to participating clinics on the website of the University of Wollongong, a recent review of international policy and practice highlights the absence of a transparent or external auditing system to guide the development and evaluation of PCOC (63).

4.3.2   Sweden: Swedish Register of Palliative Care

The Swedish Register of Palliative Care (SRPC) is a national quality register, established in 2005 (64). It collects data from hospitals, hospices, nursing homes and home care, with an end-of-life questionnaire (ELQ) about palliative care, focusing on the last week of life, independent of diagnosis.

4.3.2.1   Population included

Compared to international registers, the SRPC is unique in that it is a nationwide register that collects data about end-of-life care regardless of age, diagnosis, place of death or level of care. Registration occurs online in the period shortly after death, by healthcare staff. The register contains information on approximately 60% of all deaths each year. The majority of those that die from cancer are included, given that registration of cancer deaths in the register is a national quality indicator in Sweden.

4.3.2.2 Data collected

At the inception of the register, the items in the End-of-life Questionnaire (ELQ) were based on clinical knowledge and general values of good end of life care among the founding member, using the British Geriatrics Society's statement on what constitutes a good death as an important inspiration and guide. These have been modified over time. Aspects addressed include: prevalence and severity of symptoms; prescriptions of essential parenteral drugs as needed; the use of palliative consultation services and bereavement support; whether the death was expected or not; and information provided to patient and family. The responsible physician and/or registered nurse at the health care setting of the patient's death complete the 29-question ELQ questionnaire after the patient's death, using data from medical records and personal knowledge of the patient during the patient's last week of life. Median time from patient death to data entry online is 7 days.

A second questionnaire called a 'related party questionnaire', is completed by a close relative after the death has occurred. This contains, in part, the same questions as in the ELQ, but also some questions directed to related parties regarding treatment and information.

4.3.2.3 How are the information used?

The data collected in the SRPC supports the estimation of national quality of care indicators, agreed by the National Board of Health and Welfare in 2013, and updated in 2016. Based on these indicators, the SRPC has formulated several measurable criteria:

- The patient is informed about his situation;

- Relatives are informed about the patient's situation;

- The patient is ensured good care, for example regarding oral health or pressure ulcer prevention measures;

- The patient's pain is assessed with pain assessment instruments and is pain relieved;

- The patient's symptoms are assessed with symptom assessment instruments and are relieved;

- Prescribing and administration of drugs when needed for pain breakthrough, anxiety, nausea and difficulty breathing;

- The patient does not have to die alone;

- The patient is given the opportunity to die at the place he/she wishes;

- Relatives are offered follow-up calls after death.

The main use of the SRPC in policy is to assess the quality of care using the indicators and targets set by the National Board of Health and Welfare, and the measurable criteria defined by the SRPC. An SRPC output portal produces results of these indicators, which provide details of variation in compliance across setting, region and time. Standardised reports are created from the database, enabling transparent comparisons down to the level of single care units. Healthcare professionals can access the results of their own unit and a comparison with equivalent units in the country.

4.3.2.4 Governance and oversight

The SRPC has an executive committee and a steering committee with a depth of expertise. These committees participate in local conferences and visit units to give feedback and information.

Sweden's Municipality and Regions have a requirement that all registers must perform validation and monitoring. There are several ways to do so: using logical controls, against source data and against external registers. The SRPC currently performs all three methods.

The validity of the ELQ has been examined in specialised palliative healthcare units, mainly with patients with cancer, but not in non-specialised palliative care settings, given issues with poorer documentation in medical records.

4.3.2.5 Factors to consider in implementation

Several factors influence the implementation and sustainability of the SRPC:

- Sweden's long tradition and experience in developing and using population-based registers;

- The combination of oversight and operation by the local authorities and management by the Swedish Association for Palliative Medicine;

- A delegated registry office which provides support and, practical advice from entering and interpreting output data to improvement work and activity reports. It answers nursing questions, requests for data extraction research and business, follow-up questions from decision-makers, politicians and the media;

- The register is straight-forward, user-friendly and web-based; and allows participating units, local authorities, patients and the public to have immediate online access to the results;

- The presence of a unique personal identification number in Sweden, which simplifies data compilation, and cross-matching between different databases.

4.3.2.6 Limitations and future direction

The SRPC specifically addresses the care provided during the last week of life and the findings should not be extrapolated to palliative care in general.

Not all units report to the SRPC. Reporting units actively decide to join the SRPC, which also means that they may be more attentive to end of life care, thus possibly resulting a more favourable picture of end-of-life care, given that registration in SRPC is associated with improved quality of care.

Even though the data reported to the SRPC is based on documentation in medical charts, validity is not absolute, in particular regarding symptom prevalence. The planned technical approach to future data gathering is to transfer data directly from the medical records into the register, which would require better structure for documenting end of life care in the patients' regular medical records. A further concern is that data are clinician-reported and not reported by the patient. Thus, there is a lack of insight into the patients' own experiences of the end-of-life care provided. Finally, the reliability of the ELQ should be examined to identify problems and develop the ELQ further.

4.3.3 Scotland: Primary Palliative Care

4.3.3.1 Background

In December 2015, the Scottish Government set out their goal to make palliative care accessible to all Scottish people by 2021 in their 'Strategic Framework for Action on Palliative and End of Life Care: 2016-2021' (65). This framework followed the establishment of national palliative care guidelines in 2014 and was developed upon the government's previous 2008 palliative care plan, 'Living and Dying Well: A national action plan for palliative and end of life care in Scotland' (66,67). The role of primary care in the delivery of palliative was recognised in the 2008 action plan (66) and in their most recent strategic framework, the Scottish government re-emphasised their aim to make palliative care accessible to all by connecting palliative care services across all healthcare sectors, including GPs and in private homes (68).

4.3.3.2 National Health Service (NHS) Scotland and palliative care in Scotland

The National Health Service (NHS) Scotland is a public funded healthcare system, which provides services (including GP and hospital care) to all patients without any cost (57,69). NHS Scotland is comprised of 14 regional health boards, 7 special health boards and one public health body [Public Health Scotland 2021]. It is run independently by the Scottish Government (since the devolution of powers from Westminster to the Scottish Parliament in 1999) (70) and the Scottish Government determines the budget that is allocated to the NHS in their annual budget (see 64). However, as most tax revenue in the UK is centrally collected by the UK government and then redistributed to the Scottish government, the funding for NHS Scotland is impacted by the delivering of an 'annual block grant' by the UK Government (which is calculated annually according to the previous year's block grant and the UK government's expenditure in England) (72,73).

Palliative care is an area of specific focus of development for the Scottish government and in December 2015, the Scottish Government's apportioned £3.5 million in additional funding to implement their 'Strategic Framework for Action on Palliative and End of Life Care: 2016-2021' (65). This funding is intended to support the development of palliative care in Scotland, which is delivered through specialist palliative care services and generalist palliative care services. Specialist palliative care is provided by palliative care specialist teams in hospices, in-patient units or acute hospitals. Generalist palliative care is provided by healthcare professionals in the patient's community (59,67). Primary palliative care falls within this latter category and involves the provision of palliative care services to patients by their primary care teams (GPs and district nurses) (74).

4.3.3.3 Factors that facilitate strong primary palliative care in Scotland

In Scotland, there is an established infrastructure to support the role of primary palliative care. The delivery of palliative care by GPs to patients with various life-limiting illnesses in Scotland is facilitated by several factors, including:

- Developed measures/tools, such as SPICT™;
- A linked eHealth system ('Key Information Summary (KIS)');
- Financial supports for GPs (Scottish Palliative Care Directly Enhanced Service).

With regards to measurement tools, the early identification of patients who are suitable for palliative care is facilitated in Scottish primary care by the availability of tools and measures such as the Supportive & Palliative Care Indicators Tool (SPICT). The SPICT is a measure that was developed by the Primary Palliative Care Research Group in the University of Edinburgh. It can be used by GPs to screen

patients according to a set of clear criteria and from the patient's score the GPs can detect patients who are 'at risk of dying' and who be suitable for palliative care (75).

This information can then be recorded in a Key Information Summary (KIS). The KIS is an IT platform that allows GPs to input patient information (with their permission) and this information can then be shared with other healthcare professionals in the NHS including with members of the ambulance service (76). The information inputted can include the patient's 'medical diagnoses, medications, carers, social care and next of kin details, baseline function and cognition, understanding of illness, wishes about resuscitation and place of care and any drugs or equipment at home'. Most significantly, there is also a specific section in the KIS for recording palliative care information for the patient. This section can include any palliative care plans for the patient (including information on the 'anticipatory prescribing' of medication for the patient) and can be adjusted in accordance with the progression of the patient's condition (77).

Notably, the role of GPs in palliative care (including their use of measures by like SPICT and their role in recording of the palliative care information for their patients through KIS) is promoted in Scotland by the availability of a financial support system. The Scottish Palliative Care Directly Enhanced Service (DES) is a reimbursement system for primary care that was introduced in April 2012 (78). The objective of DES is to 'promote earlier identification and intervention for those who might benefit from palliative care' (67). Engaging with the DES system primarily involves anticipatory care planning, wherein early symptom management strategies are prioritised by the general practitioner. The DES system functions at two levels, which reflect different demands on the GP or practice for each case. Level 1 involves registering a patient on the KiS system with an anticipatory care plan, while practices functioning at Level 2 are expected to complete all tasks contained within Level 1 but are additionally responsible for completing a programme of reflective writing practices as a multidisciplinary team to improve service provision. These reflective practices are divided between key areas of care, for instance whether death occurred unexpectedly and the potential reasons for such, in addition to whether additional tools may have been helpful in pinpointing particular needs of this patient. It is also expected that the anticipatory care plan be evaluated at the end of each service. At Level 1, general practitioners are entitled to £68.00 following the completion of a KIS entry, while at Level 2, practices are reimbursed for administration and infrastructural costs to the value of £250 and receive £58 pounds for each reflective practice completed, to a maximum of 15 (78). Generally, once a patient with palliative care needs has been identified by a general practitioner engaged with the scheme, the DES reimbursement will be payable within four weeks of the patient registration on the KIS system (77,78).

Research, Education and Training

There is a well-developed research and education infrastructure supporting the delivery of primary palliative care in Scotland.

With regards to research, there is a rich environment of research being produced in Scotland that promotes the development of primary palliative care. The Primary Palliative Care Research Group, located in the Usher Institute in the University of Edinburgh, is a research unit that brings together leading academics, researchers and healthcare partners in Scotland to produce research focused on enhancing palliative care in primary care. Their research concentrates on the providing evidence to support the early delivery of holistic palliative care to all individuals with life-limiting illnesses. Notable developments from this research group include:

- the development of the SPICT™ (75).

- research fellow contribution to the World Health Organisation on incorporating palliative care in primary care (79).

- central contributor to the European Association for Palliative Care task force on the development of a Toolkit for 'promoting palliative care in the community (Primary Palliative Care)' in Europe (80,81).

The Primary Palliative Research Group is also a member of the Palliative Care Research Network for South East Scotland (PCRN-SES), which is a research network combining the expertise of researchers and healthcare professionals. This research network is comprised of the following research clusters. These clusters are currently undertaking research focused on a number of different aspects of palliative care, including the delivery of primary palliative care to patients with life-limiting conditions (not including cancer) and how palliative care can deliver broader care to patients and can address their social and mental needs (82).

With regards to education, a national committee was established in 2011 to improve the delivery of palliative care teaching for all doctors. This committee brought together members of the Scottish government, individuals from the five Scottish medical schools and members of the Children's Hospice Association. A 'consensus curriculum' of central palliative care learning points was developed by this committee and then agreed upon by the five medical schools in Scotland. As a result, palliative care education is now further incorporated into all the medical school courses in Scotland (67,83).

In addition, qualified general practitioners in Scotland have opportunities to undertake further postgraduate training and continuous professional development post-qualification (such as, as the 'Graduate Certificate in Palliative Care' from Queen Margaret University or a CPD award for 'Exploring and Developing Palliative and End of Life Care' from the University of the Highlands and Islands) (84,85). Furthermore, they are also supported in their delivery of palliative care by the Royal College of General Practitioners, which has a developed a 'Palliative and End of Life Care Toolkit'. This toolkit provides GPs with access to guidelines, links to education and training and other relevant resources to support GPs in their delivery of palliative care (86).

4.3.3.4 Benefits of an integrated palliative care model

In Scotland, successive government policies in the last twenty years have focused on the development of end-of-life and palliative care as part of the broader amalgamation of the healthcare system across local, primary and secondary care (87,88). During this time, the pattern of end-of-life care in Scotland have begun to change and notably, from 2011 to 2020, Public Health Scotland reported that there was a continual decrease in the amount of time that patients were spending in hospitals at the end-of-life. In their most recent statistics (2020/21), it was reported that individuals who died in Scotland spent approximately 90.4% of their last six months in their home or community and only were admitted to hospital for approximately 9.6% (or 17 days) in their final months (89). Given that patients with a KIS (Key Information Summary) are also more likely to die outside of a hospital setting (77), this pattern suggests that more care is being delivered to patients at the end-of-life in their community. This is significant feature of the Scottish palliative care system, as the facilitation of the process of dying outside of a hospital environment is regarded as a 'key component of a good death' (87).

4.3.3.5 Challenges for primary palliative care in Scotland

Research suggests that the effective provision of primary palliative care requires four essential features:

1. It should promote the 'early identification' of patients suitable for palliative care;

2. It should have measures and procedures in place to facilitate 'high quality assessment and care planning';

3. It should have a structure which synchronises the delivery of palliative care across different services in a health system, and

4. It should promote greater awareness amongst patients, members of the public and practitioners of the advantages of timely palliative care intervention (74).

These features are reflected in the primary palliative care model in Scotland, as measures such as SPICT and digital platforms such as the Key Information Summary (KIS) are in place to facilitate the delivery of palliative care between the primary care sector and other healthcare practitioners in the NHS (see discussion above). There are also education programmes for practitioners (see discussion above) and for members of the public (including supports offered through the 'Good Life, Good Death, Good Grief' alliance) (82).

However, it should be noted that palliative primary care in Scotland has faced challenges. Indeed, in the initial years following the development of the 'Scottish Palliative Care Directly Enhanced Service (DES)' in 2012 (see discussion above), research indicated that it was challenging for GPs to identify patients for palliative care intervention when they had a life-limiting condition other than cancer (90). GPs also indicated that coordinating care with other core members of a community-team, like district nurses, was particularly difficult to arrange, as district nurses in Scotland are divided between distinct regional hubs. The organisational structure under which district nurses operate was identified as a barrier to communication between GPs and nurses (90).

Furthermore, despite the range of structures in place to promote primary palliative care in Scotland, palliative care in the primary sector was highlighted as an area requiring specific support in the 2015 national review on the delivery of 'Primary Care Out of Hours Services' (65,74).

Given these challenges, primary palliative care in Scotland continues to be a focus for review and improvement. In the 'Supporting Evidence Summary' for the Scottish Government's 'Strategic Framework for Action on Palliative and End of Life Care: 2016-2021', the importance of enhancing palliative care in Scotland and of promoting a 'collaborative culture' across the broader palliative care system in Scotland was recognised (65). This suggests that the development of a primary palliative care model should be a part of the broader improvement of palliative care.

4.3.4   Palliative Care for Children in England

4.3.4.1   Background

The World Health Organisation (WHO) defined paediatric palliative care as:

> *'..the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes.'* (50).

This is the guiding definition for children's palliative care internationally and this definition has been adopted or adapted in several countries including Ireland and the Netherlands (26,91). In England, a comparable definition is included in the 'Together for Short Lives' guide for children's palliative care in England, which defines paediatric palliative care as:

> *'…an active and total approach to care, from the point of diagnosis or recognition throughout the child's life and death. It embraces physical, emotional, social, and spiritual elements, and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.'* (92).

In England, the organisation 'Together for Short Lives' (which was formally known as the Association for Children's Palliative Care (ACT) before the ACT joined with Children's Hospices UK in 2012) categorises the life-threatening conditions of paediatric patients that may require palliative care into four groups: 1) 'Life-threatening conditions for which curative treatment may be feasible but can fail', 2) 'Conditions where premature death is inevitable', 3) 'Progressive conditions without curative treatment options' and 4) 'Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death'. Each of these categories may require palliative care at different stages in the illness progression and Together for Short Lives notes that this highlights the potential value of palliative care for children with a 'range of different conditions' (92).

In England, paediatric palliative care is very well developed within their healthcare systems. In 2019, the International Children's Palliative Care Network ranked the UK as having the highest level (Level 5) of integration of paediatric palliative care across their national health services (International Children's Palliative Care Network 2019). This degree of integration notably complies with the advice of the World Health Organisation who recommends that paediatric palliative care 'be integrated into all sectors and all levels of child health care' (93).

4.3.4.2   Service provision

The United Kingdom is considered a leader in the field of paediatric palliative medicine, as it was the first country to open a children's hospice (Helen House opened in Oxford in 1982) and it has evolved its children's palliative care model to be delivered across general, specialist and community services (94). In England, palliative care services for children are delivered through the National Health Service (NHS) and through the voluntary sector (such as hospices, which receive a small percentage of state funding) (95). The delivery of palliative care to children within the NHS is determined by clinical

commissioning groups (CCGs) in combination with local authorities, who are responsible for determining what respite and palliative care services for children are required in their area (96). CCGs are comprised of several general practices (GPs) in one area, which are given the power and budget by NHS England to determine what healthcare services are required and should be purchased for their local community (97). The delivery of specialist palliative care to children in hospitals is commissioned by NHS England and NHS Improvement within the national programmes of care (NPocC) for Women and Children (98) and is overseen by the Paediatric Medicine Clinical Reference Group (99).

In England, in-patient and outpatient specialist paediatric palliative care is provided in specialist palliative care units by 'consultant-lead multi-professional team(s)…[which are] led by a paediatric consultant' (100,101). The delivery of palliative care to children in their community is then co-ordinated through local 'clinical networks' who receive support from the specialist paediatric palliative care teams (100). However, these regional networks are 'informal' (92) and have been critiqued for not being 'centrally coordinated' (102).

4.3.4.3 Enablers and barriers

There are a number of enabling features and barriers within paediatric palliative care in England that impact the delivery of palliative care services to children.

The primary barrier to the delivery of paediatric palliative care services is that informal clinical networks facilitate these services. These informal networks between specialist palliative care, 'core palliative care services' in the community and 'universal' non-palliative services have traditionally developed sporadically and are not distributed evenly across the country (92,102). In a review for the Secretary of State for Health of paediatric palliative care services in England in 2007, 'inequity of service provision and access' was noted as being a significant issue in English children's palliative care. The review noted that paediatric patients are 'doubly disadvantaged' by regional variations in the availability of paediatric palliative care and by the absence of clarity surrounding when practitioners should refer them to palliative care (103).

In light of this, the replacement of this informal system with 'managed clinical networks' (MCNs) was recommended by the National Institute for Health and Care Excellence (NICE) in their 2016 guidelines on 'end of life care for infants, children and young people with life-limiting conditions' (104). A managed clinical network is a collaboration between varied healthcare professionals and 'organisations from primary, secondary and regional health care' who come together 'to make sure that high quality clinically effective services are fairly distributed' (105). Since the publication of these guidelines, there has been a move in some areas of England towards the development of MCNs for children's palliative care (see, for example, the East of England Children's Palliative Care Managed Clinical Network) (106). In December 2017, the organisation 'Together for Short Lives' produced guidance for providers and organisations entitled, 'Setting up a Managed Clinical Network in Children's Palliative Care' (107). Furthermore, in 2021, the first evaluation of a regional MCN for children's palliative care in England was published. This study identified both enablers and barriers to success within MCNs as a model for children palliative care. These enablers included 'having a funded MCN co-ordinator' and 'a governance structure that fosters collaboration', whilst the barriers included 'limited funding for the MCN and children's palliative care' and a 'shortage of community nursing and specialist palliative care staff' (102).

4.3.4.4 Future

The number of children with life-limiting conditions in England has been increasing year-on-year since 2001 and recent research suggests that this number is expected to continue to rise from 26.7 per 10,000 population in 2001/2 to between 67.0 and 84.2 per 10,000 population in 2030 (108). To meet the growing demand for palliative care and end-of-life services amongst children, investment in children's palliative care was listed as a priority in NHS England's 'Long Term Plan' in 2019 (109). In this plan, the NHS committed to increasing their budget for children's hospices by £13 million to £25 million in 2023/24 (109). This funding increase is significant as a report published in 2017 by the organisation 'Together for Short Lives' indicates that there is a need for more nursing staff within hospices in England, as these services have a greater number of unfilled nursing posts in children's palliative care than exist within the NHS and this is negatively impacting the care delivered to children in these hospices (110).

Within specialist palliative care, there are measures in place to promote the use of palliative care including the existing of specific financing system (called 'palliative care currencies') (111) and education and oversight structures (including a palliative care clinical data set, an audit tool for children's palliative care education, and an All-Party Parliamentary Group that is focused on children's palliative care) (111–113). However, there continue to be gaps in service provision within the NHS that need to be addressed. Research published in July 2021 indicates that a higher percentage of children (73%) continue to die in hospitals in contrast to other countries (114). This suggests that palliative care may not be delivered in all appropriate cases, as children who have palliative care are 'eight times more likely to die in the community than children who were not referred to palliative care' (114,115). In this respect, the paediatric palliative care model in England is one that continues to require re-examination and further improvements.

4.3.5 Summary of Case Studies

Issues related primarily to governance, service delivery and information have influenced implementation of the policies and initiatives examined (Table 17):

- In Australia, PCOC implementation has been supported through sustained public investment and the establishment of structures within the University of Wollongong. In terms of service delivery, Quality Improvement Facilitator roles were created for PCOC to aid clinicians to engage with the programme. Moreover, PCOC uses a national framework for all active users and assigns each patient a unique identifier code, ensuring data from all participating specialist palliative care units can be effectively collated and analysed. However, there are important limitations. PCOC is only used in specialist palliative care services and cannot capture generalist palliative care input.

- In Sweden, the SRPC is not managed in part by an academic body, but by an executive committee and a steering committee of experts in palliative care. Similar to the Australian PCOC programme, the SRPC assigns patients unique identifier codes to ease the processes of collation and analysis. Users of the SPRC are supported by a delegated registry office offering guidance on entering data into the SPRC and extracting all relevant results. Notably, the SRPC undergoes regular and compulsory validation appraisals due to municipal and regional mandates. The SRPC is not used in all settings, but participation is voluntary and there is significant engagement from users. SRPC necessitates manual input of data from patient records into the system and there are no patient-reported outcome measures within the dataset.

- Primary palliative care in Scotland is supported by input from both the Usher Institute in the University of Edinburgh and the NHS at regional and national levels to ensure collaboration between health services and research centres. Training for clinicians is provided by a national committee, in addition to the ready availability of a 'toolkit' for general practitioners in primary care. The existing national eHealth system also provided clear sections for data on palliative care services and acts as a platform for cross-unit and cross-service collaboration. Some issues surrounding the service delivery of primary palliative care in Scotland, however, include the lack of integration between palliative care services to aid a coordinated health approach and a similar bias towards treating cancer-based palliative care needs, as noted in the case of Australia.

- The provision of paediatric palliative care in England is enabled by clear and supportive governance structures. The national health service (NHS) acts as a central commissioning body, while smaller clinical commissioning groups make decisions on local service provisions, and managed clinical networks (MCNs) collaborate with specialist palliative care teams to enhance service delivery. Close collaboration with voluntary organisations, like Together for Short Lives, has enhanced the guidance available to acting practitioners on the specific needs of children receiving palliative care.

- Across each case study, however, areas of needed improvement persist, such as inequity of service provision in England, Sweden and Australia, where access to care is determined to a great extent by location or diagnosis.

Table 17 Enablers and barriers to policy implementation identified in the international case studies

Case	Domain	Enablers	Barriers
Australia: *PCOC*	Service Delivery	• Delivery led by clinicians: top-down process. • Audit and quality feedback cycle • Clear outcome measures	• Requires many clinicians to input. • Operates through Specialist palliative care units only • Limited documentation of the impact on patient care
	Health Workforce	• Quality Improvement Facilitators • Clinical training available	
	Information	• Feedback available to clinicians • Guidance provided by the University of Wollongong • Uses a consistent national framework for data collection • Unique identifiers for each patient	• Clarity issues in the rating measures included in PCOC
	Medicines and Technologies		
	Financing	• Availability of national funding (2000)	
	Leadership and Governance	• The National Guiding Framework established in 2000 and the National Strategy for Palliative Care (2018) • Maintained by the University of Wollongong	• No external audits conducted
Sweden: *SRPC*	Service Delivery	• Delegated registry office to assist clinicians • National survey • Detailed validation checks performed	• Opt-in system only for joining the SRPC
	Health Workforce		
	Information	• Information sharing systems in place • Peer-wide access to comparable results • User-friendly interface • Unique identifiers for data • Standardised reports for comparability	• Manual inputting process, with no automatic mapping from medical records to the SRPC registers.
	Medicines and Technologies		
	Financing	• Fully funded by central government and the SALG	
	Leadership and Governance	• Managed by (i) an executive committee and (ii) a steering committee • Local authorities oversee SRPC processes • Managed nationally by SAPM	

Scotland: *Primary Palliative Care*	Service Delivery	• Early identification of patients for PC aided by measurement tools • National committee established for training	• Low recruitment of individuals with non-cancer life-limiting illnesses • Low levels of integration between palliative care services • Organisational structures limit communication
	Health Workforce	• Research leadership • Capacity to undertake research	• Lacking training in the identification of palliative care needs for life-limiting illnesses other than cancer
	Information	• Development of the Palliative and End of Life Toolkit for doctors • Adequate research and educational infrastructure • eHealth system in place • Development of measurement tools	
	Medicines and Technologies		
	Financing	• GPs are financially supported to deliver PPC • Additional resourcing for palliative care in national budgets	
	Leadership and Governance	• Guiding governmental frameworks available • Supported by the Usher Institute in the University of Edinburgh • Supported by the Palliative Care Research Network for Southeast Scotland	
England: *Palliative Care for Children*	Service Delivery	• Palliative care model delivered at (i) general (ii) specialist and (iii) community services. • Moving from informal clinical networks towards using 'managed clinical networks' (MCNs).	• Reliance on informal clinical networks • Availability is restricted by region
	Health Workforce	• MCN Coordinators	
	Information	• Guidance from Together for Short Lives on the formation of MCNs	
	Medicines and Technologies		
	Financing	• NHS Budget allotment	
	Leadership and Governance	• NHS England as the central commissioning body • Clinical Commissioning Groups and local authorities responsible for local service provision decision-making • Collaborative governance structure between national and local authorities.	

4.4   Organisational Reform in the Irish Health and Social Care System

Examination of organisational reforms highlight a national health and social care system unable to implement policy over the long term (116). Examined from a whole-of-systems perspective organisational change to support forms of care integration, improved access, and capacity to deliver the right care in the place at the right time with the right team (and at the right price) have failed.

There have been five distinct phases of reorganisational change since the early 1990s (Box 2). Several factors resulted in poor implementation, transitions and progress overall including:

- The absence of clear and sustained policy purpose
- Insufficient planning
- Weak change management
- Inadequate resourcing

Box 2 Five Phases of Service Reorganisation

> #### 1.   From Health Boards to Eastern Regional Health Authority (1990s)
>
> Service delivery, organised through Health Boards established under the 1970 Health Act, entered a period of transition during the 1990s as the need for system-wide services management and decision making emerged. This was motivated by trends in population health, including the prevalence of chronic disease and multimorbidity.
>
> #### 2.   Eastern Regional Health Authority and the drive towards a system-based model (1990-2003)
>
> Early-stage rationalisation and reorganisation represented by the establishment of the Eastern Regional Health Authority (EHRA). The ERHA was 'responsible for ensuring that the services provided [were] closely coordinated around the individual patient, even though they may be provided by different agencies'. Emerging emphasis on person-centred care is clear.
>
> #### 3.   Emergence and development of the HSE and Integrated Service Areas (2004-2011)
>
> The HSE was designed with three main functions, a National Hospitals Office (NHO), a Primary Community and Continuing Care Directorate (PCCC), working across four Regional Health Organisations, and a National Shared Services Centre. The Health Information and Quality Authority (HIQA) was established in 2007 to monitor and drive performance and quality standards. The Integrated Service Areas were subsequently established under the HSE, merging the NHO and PCCC Directorate into an integrated care model under several national director-led areas.
>
> #### 4.   Future Health: Directorates, Hospital Groups and Community Health Organisations (2012-2016)
>
> This period included dissolution of the HSE Board, establishment of a National Directorate Structure reporting on service lines, Hospital Groups, provision for Community Health Organisations (CHOs) from 2014 and new Mental Health Areas.
>
> #### 5.   Sláintecare: towards a system for integrated, universal healthcare (2017-current)
>
> This phase includes the emergence of Sláintecare and subsequent implementation and action plans. Implementation has been slow, and reforms are largely unrealised in organisational terms to-date.

Some reforms were not evidence based, while others were abandoned before they were embedded. Resistance to change from within the operational system has also affected reform giving rise to losses of momentum, people and belief in reform proposals and processes overall. This loss of belief is now exacerbated by a system overstressed and fatigued by the experience of COVID-19 and related shocks.

Drawing heavily from the early lessons reported by the Integrated Care Programme for Older Persons (ICPOP) in 2018 (117) for scaling integrated care nationally, it is clear that:

- National policy targets need to be made explicit and outcome measures agreed early on for progress.

- Commissioning processes need to support incremental, strategic redesign of services in ways that empower local leaders to develop services that are sensitive to local context.

- The interface between local redesign and national policy is critical to support sustainable change and integrated care needs to be built incrementally at community network level with partners from primary and acute domains, third sector agencies, business, academic and others.

- Strategic funding is required to drive policy by repurposing existing funding along with ensuring seed funding is in place. Alignment of existing and new resources is also essential.

- The change process needs dedicated expertise at local, regional and national levels as change is a dynamic social process, not a technical task, that takes time and energy.

- Developing sustainable means of gathering and using data is needed to support change.

An overview of these studies and initiatives shows that implementing service change needs clear policy, commitment to the complex change process involved, sufficient resourcing, an ability to animate many sectors and empower local agents and measure the right outcomes in ways that are meaningful and accessible.

4.5 Evidence on the cost-effectiveness of adult palliative care services

4.5.1 Policy context

People approaching end-of-life account disproportionately for health care budgets. In high-income countries, the 1% of people who die each year account for about 10% of health spending (118). This spending usually yields poor value. End-of-life care is often characterised by inadequate management of pain and other distressing symptoms, and challenges for loved ones (119,120).

4.5.2 Economic evaluation

Health economics' main tool to inform policy is economic evaluation, sometimes called cost-effectiveness analysis (121,122). This method measures, for a given time period and from a given perspective, the costs and health improvements associated with an intervention and a comparator. Based on the results of such analyses, decision-makers can fund interventions that yield the greatest improvements for the available resources.

A systematic review of economic evaluations in palliative care identified five such studies to 2017 (123). These studies examined home care (n=3), hospital care (n=1) and community/hospice care (n=1), and they all found that palliative care was cost-effective compared to usual care. The effectiveness measures included place of death, length of stay, days at home, emergency department visits, differences in scores using the Palliative Outcomes Scale and re-hospitalisation rates. However,

this is a very small number of studies relative to the large number and wide variety of palliative care interventions and patients. This can be illustrated with comparison to other healthcare interventions. For example, there were 102 economic evaluations of radiation oncology to 2014; 75 economic evaluations of statins to 2011 (124) and 97 evaluations of intensive care units to 2018 (125).

A recent systematic review (126) examined evidence about the effects of out-of-hours specialist and generalist palliative care services on patient and family/caregiver outcomes, and on cost and cost-effectiveness considering both a health system and societal perspective. The Department of Health (Ireland) commissioned this review to inform the revision of national palliative care policy and address the recognised challenges in provide out-of-hours palliative care. No studies were identified that reported on the impact of out-of-hours palliative care for adults, in terms of patient/carer outcomes or costs. The results of this review highlight the need for future studies to measure both the effectiveness and cost-effectiveness of out-of-hours services, either by utilising routine data sources or conducting original research to capture the outcomes of interest across relevant settings. Out-of-hours palliative care is a recognised priority for research and policy, without substantive answers in the published literature.

4.5.3 Why is the number of economic evaluations so small?

Studying people near end of life brings well-known challenges (127). Randomised trials face practical and ethical difficulties (128), and trials predominantly occur in United States (129), where economic evaluation is not a core policy tool. Recruiting and interviewing people with high illness burden, anxiety and distress, is complex (130).

Seriously-ill people receive care across multiple settings so costs are spread between payers, providers and patients in ways that are hard to measure. This population also takes multiple medications, some of which are paid for by patients directly, and some covered by various publicly funded schemes. Measuring health care costs near end of life therefore requires complicated data linkage, and original data collection for out-of-pocket costs. Also important, unpaid care costs are high. Family and friends pay out of pocket on behalf of the person who is ill; they may also provide care and transport or forego work and income. Carers are themselves at risk of worse health and lower workforce productivity both during the illness and in bereavement. Few of these factors are captured in any routine data.

Knowing the costs of providing an intervention only tells part of the story. To determine if an intervention is worth paying for, policy makers need to also have evidence about the impact of the intervention on individuals. To this effect, outcome measurement serves three very important purposes: it guides healthcare resource allocation by allowing for comparison of costs and outcomes across different interventions; aids in measuring the quality of service provision to inform the management of service delivery; and it provides evidence about the impact of treatments on individuals (131). There are a number of criteria that an outcome measure should meet if it is to be used to generate information about cost-effectiveness (132):

- Established reliability and validity in the patient population

- Captures clinically relevant information

- Sensitive to important changes over time

- Can be integrated into clinical routines

- Easy to administer and interpret

- Suitable for use across various care settings

Although outcome measurement is routinely used to inform decision-making, there is no wide agreement on suitable measurement tools in palliative and end-of-life care (131,133,134). For example, most outcome measures used in economic evaluation concerned entirely with health; however, there is evidence to suggest that people nearing the end of their life value attributes beyond health such as psychosocial and spiritual wellbeing (135,136). Additionally, outcome measures used in economic evaluation typically do not capture the impact of interventions on the health and wellbeing of caregivers.

4.5.4 Alternatives to economic evaluation

In the context of data limitations for full economic evaluations, multiple literature reviews have surveyed palliative care's 'economic effects' more broadly. Some have focused on a specific setting such as hospital care (137,138); others on specific populations such as late-stage cancer (139,140); and others on all interventions and populations (141,142).

For the most part these broader reviews don't require the health outcomes part of an economic evaluation and instead just assess effect on costs. Three key issues emerge across these cost reviews. First, studies do not operate for the full timeframe of interest, e.g., from diagnosis to death. Instead, they heavily focus on episodes of care where data are routinely collected: acute hospital inpatient admissions and/or the end-of-life phase. Second, perspective on costs is narrow, using data from the hospital or health service, but not counting out-of-pocket costs or unpaid care. Third, palliative care appears cost-saving in the 5%-20% range, although the methodological quality of some studies is low and the estimated effects are smallest among those reviews with the highest quality threshold (129,143).

Identified savings appear to accrue through lower intensity of care – e.g., fewer tests and invasive procedures – and better integrated care – e.g., prompt hospital discharge, connection with home care teams. Alongside the evidence that palliative care improves these types of outcomes, this suggests palliative care is a dominant strategy (reducing costs and improving outcomes) in at least some circumstances. However, much less is known on informal care and out-of-pocket costs (144), so it is largely unclear how much observed savings reflect true improvements and how much they reflect cost-shifting from the health care system to the household.

4.5.5 Summary

Relative to policy recognition, the economic evidence base on palliative care is modest. A small number of full economic evaluations suggest that palliative care is cost-saving, but more studies in different settings and populations are needed. A larger number of cost studies using routine data also find savings, but the quality of some studies is low meaning that bias may inflate estimated savings. A paucity of good data on household economic effects, including out-of-pocket spending, unpaid care and lost income, makes it hard to assess the true overall effects of palliative care programmes on economic factors.

4.6   Conclusion

We undertook a review of evidence related to best practice, organisational reform and cost-effectiveness to help compare and contextualise the Irish experience of implementing national palliative care policy.

Four examples of palliative care policy implementation were examined: the use of the PCOC in Australia, the SRPC in Sweden, primary palliative care in Scotland and paediatric palliative care in England. The cases highlight that the success of policy implementation is contingent on the existing health system within which the initiatives will operate. Sustained governance and leadership, resourcing, training, and robust information systems enable the effective implementation of new health policies. Notable barriers to implementation include system fragmentation and limited collaboration between healthcare professionals. It is important to note, however, that the enablers and barriers within each building block do not exist in a silo. For instance, governance structures determine how funding is allocated within a system, which likely has direct implications for all other domains.

It is notable, however, that while there may be similarities across the four case studies in relation to specific enablers and barriers to policy implementation, drawing direct comparisons between case studies is a challenge, as contexts of health systems vary between the selected countries, in addition to different modes of governance and organisation. As such, in-depth consideration of the Irish context is necessary to understand the aims, enablers, and barriers of successful policy implementation in palliative care in Ireland.

In the last three decades, the Irish health and social care system has undergone five phases of organisational reform, the most recent being the introduction of Sláintecare as a means of providing integrated, universal healthcare in Ireland. Though reforms were prompted by emergent changes in population health and a drive towards improving standards of care, implementation of initiatives has not been sustained. Learnings from integrated care initiatives in Ireland highlight that clear policy targets are required and improved monitoring strategies. The findings also indicate that sustainable changes in service provision are underpinned by collaboration between national, regional and local levels of governance and the use of appropriate outcome measures.

While existing studies have highlighted an economic benefit to palliative care in Ireland, the true economic value of current palliative care services remains unclear, as the evidence base is limited to a few studies and does not capture a complete perspective of service delivery in Ireland. Emphasis should be placed on generating economic evaluations of current and future palliative care programmes, including assessments of the health and well-being effects of palliative care services, out-of-pocket costs of informal caregivers, and longitudinal estimates of care costs (rather than episodic) from diagnosis to death.

The next chapter presents a synthesis of research findings from the different workstreams and discusses their implications.

5 Workstream 4: Synthesis

5.1 Introduction

The aim of this chapter to synthesise research findings from the different workstreams and discuss their implications, providing a detailed mixed methods appraisal of the research questions set out in the Terms of Reference. These are:

1. What progress has been achieved to date in the implementation of the recommendations of the 2001 NACPC report and the respective 2009 and 2017 HSE Palliative Care Service Development Framework?

2. What gaps remain or barriers to progress exist in relation to the implementation of the 2001 policy, which should be addressed by the policy update?

3. Identify good examples and key enablers of policy implementation, which could be harnessed to ensure more effective implementation of the updated policy.

4. To what extent has the quality of palliative care and end-of-life care services in Ireland improved since 2001 in relation to:

   a. Identifying and recognising the palliative care needs of individuals and their families in all care settings.

   b. Providing timely and equitable access to specialist palliative care services, as appropriate, irrespective of diagnosis, geographic location or care setting.

   c. Ensuring a palliative care approach by all health care professionals as part of usual care provision in line with NACPC 2001 recommendations on generalist palliative care.

   d. Ensuring a seamless and integrated care pathway across inpatient, homecare, nursing home, acute hospital and day care services.

   e. Addressing the interface between and transition from children's palliative care services to adult palliative care services.

   f. Ensuring a person-centred approach which promotes quality of life and choice for individuals and their families.

   g. Addressing the needs of families and carers of the person with a life limiting condition whilst the person is receiving services and following a bereavement.

   h. Provision of standardised data sets at a national level and the utilisation of patient reported outcome (PROM) and experience (PREM) measures to evaluate the quality of specialist palliative care services.

5. What areas for improvement have been identified by the review to meet existing and emerging needs, which may not have been anticipated in 2001?

5.2 Methods

5.2.1 Synthesis

We took the outputs from the three prior workstreams and match these to the specific research questions. Table 18 illustrates how these outputs (O) relate to the research questions (RQ).

Table 18 Mapping project outputs to the research questions

	O1.1	O1.2	O2.1	O2.2	O2.3	O2.4	O3.1	O3.2	O3.3
RQ1	X	X	X						
RQ2	X			X					
RQ3				X			X	X	
RQ4		X			X				
RQ5		X				X			X

We combine and reflect on key research findings from the different workstreams, drawing on relevant published and grey literature. The analysis is organised using a modified version of the health systems framework (Figure 3) (29). The system building blocks are inputs, of which five are most relevant to this analysis: service delivery infrastructure, workforce, information systems and health information, financing and leadership and governance. These are all influenced by population need. The process mechanisms are access and coverage and safety and quality. Finally, we examine goals and outcomes: improved experiences, responsiveness, financial and social risk protection and improved efficiency. The health systems framework is useful for organising information; however, it is important to note that all components are highly interactive and can support or constrain each other.
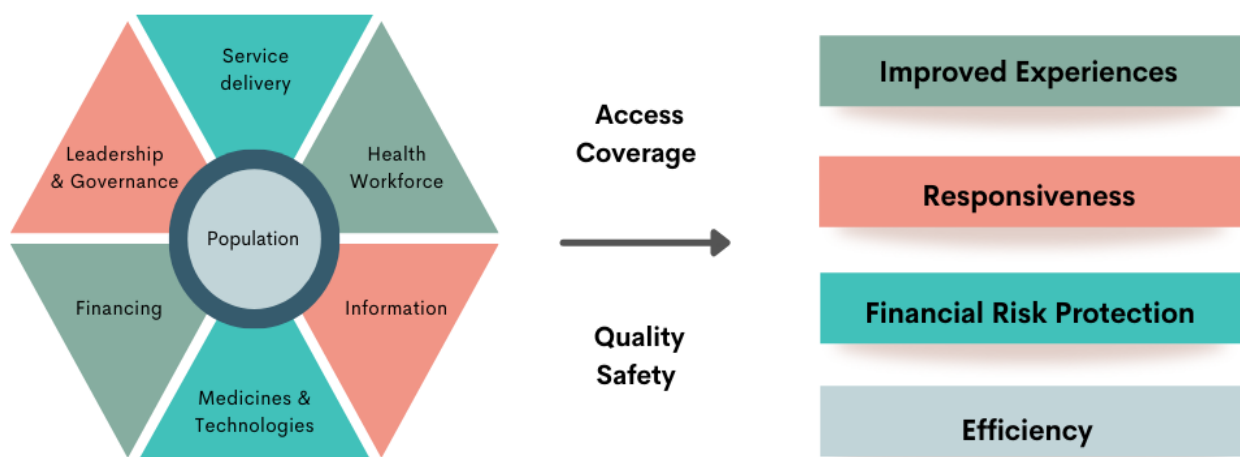
Figure 3 Adapted health systems framework

5.3 Results

5.3.1 Inputs and population

5.3.1.1 Population need for palliative care

The need for palliative care services has continued to grow since the release of the NACPC report in 2001. While some high-income countries have already experienced the peak of population ageing, that period has yet to come in Ireland. The percentage of the people dying in Ireland that will require palliative care is projected to increase by 68-84% between 2016 to 2046 (15), compared to 25%-47% in England and Wales. However, this only accounts for people in their last year of life. People will often be living longer periods with complex needs. When taking all older people with serious diseases into consideration, those living with conditions indicating palliative care need (i.e., expected to live through the year) outnumber those expected to die within the year by approximately 12:1 (15). While many living or dying with serious diseases will have their needs met through a palliative care approach, it is reasonable to assume that at least a proportion would benefit from either episodic or ongoing specialist palliative care support.

These changing demographics mean that some capacity would need to expand by approximately 80% by 2050 to maintain services as outlined in the NACPC report. However, many specialist services have ongoing deficits in both infrastructure and workforce, suggesting current capacity and funding are insufficient (19,32). Given the rapid increase in population need projected over the coming 25 years, increased annual resourcing to meet growing population need is a priority. Generalist palliative care capacity faces many of the same challenges (19) and will also need to be strengthened across all settings, particularly primary care.

Key findings

- Population need for palliative care is projected to rise sharply over the next 25 years. For every person over the age of 55 in the last year of life, there are at least 12 living in the earlier stages of an illness indicating palliative care needs.
- Capacity in both generalist and specialist palliative care will need to expand to meet this growing need.

5.3.1.2 Service delivery

Specialist palliative care units

Projects addressing infrastructure deficits continue to roll-out across regions which previously had no access to specialist palliative care units. However, reliance on local groups to fundraise for palliative care infrastructure projects has resulted in protracted delays in establishing or upgrading inpatient units within some regions. There were also substantial cuts in funding for palliative care over a period of several years following the financial crisis of 2008, resulting in a lack of resources to support expansion into regions without a specialist palliative care unit (5). Informants suggested that statutory funding may need to be provided through national capital development plans in instances where local groups are struggling to raise or pool adequate funds in the face of rising costs for both sites and construction. The possibility that some funding would need to be allocated through the HSE capital development plan was highlighted in the Palliative Care Three Year Development Framework (2017-2019) (28).

Informants also indicated that continued emphasis on realising the capital development model envisaged in the 2001 report (or conceived at the local level after its publication), with the specialist unit as the hub for regional palliative care services, is now holding back other important areas such as the development of community-based palliative care. This tension in balancing resources across care settings is not unique to specialist palliative care. The need to shift towards service delivery in the community is well recognised in policy, planning and strategy documents but development of acute and inpatient services continues to garner a large proportion of both resourcing and strategic planning focus (116,145).

Key findings

- Substantial investment from both the statutory and voluntary sector has facilitated the establishment of specialist palliative care units, addressing long-standing regional inequities in access to services.
- Future investment and strategic planning are needed to support a similar expansion of community-based palliative care services, and to ensure a more appropriate balancing of resourcing across care settings.

The Adult Palliative Care Services Model of Care for Ireland

The NACPC report set out a broad model of care that has served as a roadmap for service development over the past 20 years. In 2019, the National Clinical Programme for Palliative Care published the Model of Care which provides a detailed framework for the organisation of care for people with life-limiting illness. Informants indicated the Model of Care (35) has played an important role in facilitating greater integration of palliative care across healthcare settings by providing clear guidance for both providers and service planners. Additionally, there was strong consensus that the new policy should align with the Model of Care, and many emphasised the need for strategic action to support the implementation and evaluation of the model across all settings. Additional resources provided through the National Clinical Programme for Palliative Care such as the Competency Framework, Palliative Care Needs Assessment Guidance and the Quality Assessment and Improvement Workbooks were also viewed as supporting the delivery of high-quality palliative care services.

Key findings

- The National Clinical Programme for Palliative Care has supported integration of palliative care across all settings through multidisciplinary collaboration to develop resources such as the Adult Palliative Care Services Model of Care for Ireland and the Competency Framework.
- The updated national palliative care policy should align with and advance the implementation, integration and evaluation of the Model of Care, such as through targeted workforce education and training actions and indicators.

5.3.1.3 Workforce

Organisation

Persistent variation in the composition of MDTs across services and regions came through in both quantitative data and interviews with key informants, indicating inequities in access and availability. For example, the ratio of Palliative Medicine consultants per 100,000 of the population is approximately 0.9. This is less than the ratio of 1 per 100,000 recommended by 2017 to implement the Model of Care (32) and indicates that it will be very difficult to meet increasing demand for services, implement a shift towards community-based services, improve education and training or strengthen leadership capacity. Data on staffing ratios for other healthcare professionals are from 2016; however, informants in this evaluation highlighted that ongoing variation is particularly notable in the case of health and social care professionals. These gaps within the multidisciplinary team are a barrier to providing essential components of palliative care services such as rehabilitative palliative care and bereavement support.

Informants raised concerns that generalist services have not developed at the same pace as specialist services and emphasised that strengthening this capacity is an urgent priority. Although the NACPC report did not set out a detailed plan for how this could be achieved, important progress has been made through initiatives such as the Model of Care. However, there is ongoing uncertainty about what a palliative care approach is and how it could best be delivered in Ireland. Informants suggested any plans to develop generalist palliative care provision should include a detailed implementation plan with specific actions, timelines and role delegation, underpinned by available evidence and measured by appropriate indicators.

There were mixed views on the prescriptive workforce ratios included in the 2001 NACPC report. Some saw value in having the clear benchmarks provided by the ratios, particularly in demonstrating the need for additional resourcing. However, others suggested more flexible, evidence-based approaches are needed that focus on multidisciplinary service provision, responding to local population need. This is in keeping with The National Strategic Framework for Health and Social Care Workforce Planning which emphasises that health workforce planning is a dynamic process with multiple time horizons, where the starting point is always current and future population health need (146). Given the planned service changes outlined in the Model of Care, and advancements in healthcare organisation and delivery in Ireland since 2001, such as Sláintecare, the establishment of cancer centres of excellence and safe staffing ratios in relation to nursing (21,147), workforce ratios and multidisciplinary team composition need to be revised within the updated policy to align with the wider health system.

Key findings

- Despite being core to the delivery of palliative care services, there is significant variation in the composition of multidisciplinary teams across all settings, particularly for health and social care professionals. Generalist capacity remains uneven and has not developed at the same pace as specialist services, which could be addressed through the updated policy.

- Future workforce planning can help to address this and other variations, for example through resourcing and expanding capacity across regions as part of a wider policy implementation plan, measured against appropriate actions, timelines and indicators.

Skill mix

Findings from workstreams 1 and 2 indicate that skill mix has not been applied to the same extent within specialist palliative care delivery as other areas within the health and social care system. Informants viewed this an area that requires additional consideration and strategic planning. One action point frequently recommended was increasing the number of Advanced Nurse Practitioners and nurse prescribers working within specialist palliative care. Some also suggested examining the potential for health and social care professionals to lead in care delivery in some instances, such as community-based specialist care, where patients may require specific support (e.g., rehabilitation, advance care planning, counselling) to maintain a high quality of life at home.

Barriers to changing working practices were described during interview, mostly centred around a lack of clarity about roles, governance and operational arrangements. Limited knowledge related to skill mix is common throughout healthcare settings, and resources such as conceptual models have been developed to improve understanding (148). Measures aimed at supporting further development of skill mix practice within the Irish health and social care system have recently been implemented. For instance, skill mix for nurses has been supported through the establishment of a taskforce on staffing and skill mix for nursing in 2014 (147). Notably, this taskforce accounts for the roles of healthcare assistants in tandem with nursing staff to ensure appropriate representation of the profession, particularly as they contribute substantially to supporting patients and caregivers.

Key findings
• Skill mix has not been applied to the same extent within specialist palliative care delivery as other services
• Clarity on roles, governance and operational arrangements could help support further implementation of skill mix within specialist palliative care

Education and training

The delivery of palliative care is dependent on the availability of a health workforce with the skills and confidence to identify and meet the care needs of people living with life limiting illness and their families. The NACPC report made key recommendations to ensure all professionals have adequate education and training to develop these core competencies. These included developing inter-disciplinary courses for all professionals involved in the delivery of palliative care, providing training in communication skills for all healthcare professionals, establishing academic departments in all medical faculties, and recommending the specialist palliative care units provide facilities for research and education. Findings across the different workstreams suggest that progress towards achieving these recommendations has been mixed.

Education in palliative care competencies has improved across all three levels, with resources such as the Competence Framework (149) helping support these developments in recent years. For example, curricula are now standardised in undergraduate nursing programmes and the number of hours in palliative care training has increased. While palliative care is also included in undergraduate medicine programmes, the curricula are not standardised, resulting in variation in training and exposure to palliative care across the higher education institutions. Similarly, training in palliative care within undergraduate programmes for health and social care professionals varies, ranging from zero to a few hours at most. Ireland faces many of the same challenges incorporating palliative care into

undergraduate medical education seen in other countries, including overcrowded curricula, poor resourcing, fragmentation and insufficient leadership (150,151). Gaps also arise at the postgraduate level, with informants indicating that postgraduate palliative care courses do not carve out a clear pathway for health and social care professionals seeking to upskill as many courses on offer are strongly linked to nursing.

Ensuring practical learning opportunities for professionals delivering generalist palliative care was regarded as a priority area, with informants noting it can be challenging to apply theoretical learning into practice. This aligns with findings made in the development of both the Dutch and Scottish competency frameworks for palliative care curricula, where emphasis is placed on practical skill development, as theoretical knowledge alone is considered insufficient (83,152). An additional barrier to improving palliative care education in Ireland noted by informants was a perceived decline in the number of continuous professional development courses available. Some suggested actions to help increase the breadth of courses and ensure continuity, including strengthening ties between specialist palliative care units and higher education institutions, and developing leadership capacity at both the national and regional level to guide the development and evaluation of training and education programmes.

These persistent gaps in medicine and for some health and social care disciplines are concerning as evidence suggests education is a key enabler for integrating palliative care within the health and social care system (153). Informants linked the lack of progress primarily to ongoing deficits in academic leadership posts and the absence of departments in palliative medicine. Ireland is not unique in this respect, but notable examples from other countries may provide important learnings for improving palliative care education, such as the case study of Scotland. In addition to providing mandatory modules on palliative care at undergraduate level for medical students, the Scottish General Medical Council have formed a 'consensus curriculum' comprising several key learning outcomes (83). These include identifying, understanding, and monitoring aspects of psychological, spiritual, cultural, and religious issues concerning dying and bereavements, understanding principles of the prevention of tertiary disease, and developing an in-depth understanding of the current palliative care framework in the UK. Since 2014, all Scottish medical schools have been provided information about these learning outcomes and access to all necessary educational materials to facilitate wider learning (83).

Key findings

- Significant improvements were identified in education and training for palliative care competencies, though curricula are not standardised and major gaps for upskilling and practical learning remain.

- Palliative care education can be further improved through developing academic leadership capacity with clear links to care settings, in addition to reviewing curricula to advance palliative care competencies and leadership.

Recruitment and retention

While issues of recruitment and retention are common across the health system in Ireland (154–157), this review identified specific issues for specialist palliative care services in maintaining a skilled, multidisciplinary workforce. For example, participants highlighted that opportunities for career progression for some health and social care professionals within specialist palliative care were limited, notably in physiotherapy, occupational therapy, and speech and language therapy. Many of the

advancements that have taken place with respect to clinical grading for these disciplines occurred after the NACPC report was published, meaning Clinical Specialist posts in these disciplines are either scarce or do not exist within specialist palliative care. As a result, professionals with this specialist knowledge remain on lower grades indefinitely or, more commonly, leave specialist palliative care to explore career options in other domains. There are also challenges specific to night nursing services, where staff are typically do not have consistent or guaranteed minimum hours of work per week. Organisation of services also leads to recruitment challenges, with differences in pay, pension and other arrangements across Section 38 and Section 39 agencies and the HSE.

Informants emphasised that protecting and promoting staff wellbeing is central to scaling up and strengthening the health workforce. This is particularly important in the context of palliative care, as evidence suggests the prevalence of burnout and fatigue among healthcare professionals in the field is substantial (17.3%) (158). Moreover, burnout among residential care staff providing end of life care appears to reduce the likelihood of engaging in further educational training in palliative care (159). The challenges have been exacerbated by the COVID-19 pandemic, which has been linked to higher instances of anxiety, emotional exhaustion and burnout among medical and nursing staff in Ireland (160–162).

Key findings
- The lack of senior clinical posts within specialist palliative care for some health and social care professionals is a barrier to recruitment and retention.   - Differences in employment arrangements between different organisations also leads to recruitment challenges   - There is a need to further develop strategies to protect and promote the health and wellbeing of staff providing palliative care

5.3.1.4   Information

While not specific to palliative care, informants did note that gaps in information systems are limiting the potential for implementing and delivering integrated care. Palliative care service providers rely on handwritten charts and manual filing systems, which are barriers for information sharing across settings or services. Previous studies have shown that robust information sharing is central to providing palliative care outside of routine office hours (126). Systems that facilitate shared-access to patient records, such as the Key Information Summary (KIS) in the UK (76), can enable generalist and specialist palliative care providers, as well as out-of-hours and emergency services, to input data and access an individual's full medical record and their current care plan. Generally, this shared-access approach may improve care efficiency, overall team responsiveness, and facilitate greater integration between palliative care services (126). However, informants indicated difficulties in engaging with data sharing, citing a lack of infrastructure to implement e-health platforms to coordinate care. New concerns regarding data sharing across settings and services have also emerged following the publication of the 2001 report, including cyber security and legislation for the General Data Protection Regulation (163).

There is a Minimum Data Set (MDS) for specialist palliative care with 100% compliance across acute, community and specialist in-patient unit services. This is a remarkable achievement, demonstrating strong collaboration between relevant stakeholders within the sector. Informants emphasised that the MDS provides a valuable data source that supports the mapping of specialist service provision in

'real-time'; however, they also described some important limitations associated with the MDS. For example, the data are linked mainly to activity, there has not been an external audit of the data and there is no unique identification number to allow for linkages. These issues are not unique to Ireland though. A central limitation across health service datasets related to palliative care internationally is that important domains of evaluation, such as patients' and caregivers' experiences, have yet to be incorporated into national datasets (63). Similarly, the internal validity of existing tools and the reliability of data generated has not been examined in many settings.

As Ireland moves towards population-based planning, robust data are needed to support core functions such as resource management, service planning and monitoring outcomes. This monitoring function is a key reason for the establishment of the new Health System Performance Assessment (HSPA) framework (164). The HSPA will support a shift from the current system of planning, which relies primarily on activity-based metrics, towards that measures performance across multiple clusters and domains. The five clusters focus on outcomes, outputs, structures for financial, technological and workforce numbers evaluation, processes related to the coordination and integration of care, and cross-cutting issues such as efficiency and equity of access.

These developments will need to be incorporated into the palliative care sector. However, the MDS and PCOC might have limited applicability in population-based service planning or resource allocation, given the types of data each approach collects. Systems to routinely collect data on workforce capacity and distribution across settings and regions will also be required to support service planning and evaluation.

Key findings

- Current IT infrastructure and data management practices are hindering information sharing across settings, particularly out-of-hours.
- The MDS and PCOC generate valuable data on service activity and quality; however, both may have limited application in population-based planning.
- Systems that collate data related to workforce capacity and distribution are needed to inform service planning and evaluation.

5.3.1.5 Financing

Funding allocation

Increased resourcing from both the statutory and voluntary sectors has been central to the development of specialist palliative care. While annual increases in statutory funding for palliative care are much higher in Ireland than many other countries, the voluntary sector continues to contribute substantially to capital development and some core palliative care services. Informants noted the voluntary sector has driven important reforms and innovation, advocating for service needs and developing facilities and services at the local level. A significant risk, however, is that regional inequities will persist if some core components of service provision are not 100% statutory funded. For example, community organisations in some areas may find it more challenging to raise sufficient resources to establish and expand services than in other regions. Additionally, services established since 2017 do receive 100% statutory funding for core services; however, there is a lack of clarity when similar levels of funding will be extended to existing services where statutory funding ranged from 45%-93% in 2016 (28).

A key challenge is that this will require annual increases in statutory funding for palliative care services, as well as more efficient use of current resources. Using population-based approaches to allocate resources can enhance cost-effectiveness and address regional variation (165). Population-based resource allocation (PBRA) is a methodological approach within population-based planning that is used to address differences in population need to promote equity and efficiency in both health outcomes and the distribution of resources. It is important to note that there is no generally accepted definition of 'need'. Instead, decisions about which variables to include in PBRA funding models are largely subjective and often influenced by factors such as the availability of data, health service entitlements and policy priorities (166).

Ireland has not implemented PBRA to guide resource allocation, which is repeatedly cited as a weakness within the healthcare system (167). Instead, resources are primarily allocated based on existing level of service – an approach not designed to re-orient the Irish health and social system to primary and community care services, nor support the delivery of integrated care (166). The Sláintecare report (19) recommended the introduction of regional areas to facilitate PBRA and improve clinical and managerial governance and accountability. The 2019 Sláintecare Action Plan sets out specific quarterly targets, with a view to test, refine and implement PBRA in 2022 and 2023 (168). Similarly, the Independent Review Group (169) proposed reforming the current resource allocation system to prioritise a commissioning model as a means of alleviating regional funding inequities, wherein an essential list of health and social care services should be devised based on population need, funded directly by the State, and delivered by both public and voluntary health organisations.

In addition to calls for increased statutory funding, informants suggested that adapting payment models for general practitioners would enable palliative care delivery by facilitating greater engagement with patients with life-limiting illnesses in the community. This included support such as extended consultations, home visits and advance care planning. This is the approach taken in Scotland, where general practitioners can apply for financial support under the 'Directed Enhanced Service Scheme' (DES) system for using tools to identify patients with palliative care needs, discussing care planning and registering their details in relevant information sharing systems (77,78). Allocation of this funding encourages general practitioners to engage in the early stages of palliative care service delivery in primary care settings and results in enhanced care planning, as registration of patients on the KIS system requires their advanced care plan to be uploaded along with key details on their health and condition. These details are then made accessible to all healthcare professionals engaged in their care (78).

Key findings
- Increased statutory funding is needed to address regional inequities in capital development and upgrading, as well as some core palliative care services   - Population-based resource allocation is a mechanism to promote equitable and efficient use of statutory funding. It is currently being piloted in Ireland.   - Delivery of palliative care in the primary care setting can be enhanced through the development of payment models to incentivise and support GP engagement

Sustainability

A key concern frequently linked to population ageing is its impact on health and social care use and expenditure trends. In most high-income countries, age and per person spending on health and social care appear related. However, research from Ireland and internationally shows much of the high costs of health and social care for older people occurs near the end of their life, with little or no direct link to age itself (120,170,171). For example, research drawing on data from the Irish Longitudinal study on Ageing (TILDA) indicate that mean expenditure for formal and social care during the last year of life is €33,129, and age was not strongly associated with total costs (120). Costs near the end-of-life are variable and are driven to a large extent by a small proportion of service users. Estimates from TILDA indicate that just 10% of decedents accounted for approximately two-thirds of expenditure, with much of this spending going towards hospital care (171).

Where some high-income countries have already experienced their fastest rates of population ageing, this period is still approaching for Ireland, meaning the relationship between older age and healthcare expenditure will require greater attention in the coming years (120,172). However, projections suggest the overall effects of ageing on spending will be moderate compared to other factors, such as price increases and technological innovations, and that this growth will be slow (173). Instead, increases in the numbers of people living with complex needs will drive growth in demand for services and health and social care expenditure over the coming years (171). This means planning will need to be informed by projections of both deaths and disease patterns, where a significant proportion of people will have needs that require a palliative approach, with a focus on symptom management, rather than curative treatment. Moreover, measures to reduce high-cost, low-value care near the end-of-life are likely to improve patients' and carers' experiences and increase efficiency (171).

Cost-Effectiveness

Although the evidence base is small, evaluations indicate palliative care is cost-effective compared to usual care (123,141). However, most evaluations only consider the economic benefit of palliative care in terms of formal service utilisation, leaving the role of informal care and costs (e.g., out-of-pocket charges, reduced working hours, care provided) and their impact on formal costs unexplored. This is a significant limitation, as informal carers contribute hugely to an individual's experience at end-of-life. For example, a recent study estimated informal care can account for more than half of care at end of life in the UK (174). In Ireland, Higginson and colleagues (175) noted that informal caregivers on a weekly basis provide an average of 21 hours of personal care, 21 hours completing necessary household tasks, 7 hours transporting their loved one to medical appointments and 73 hours being 'on-call'. Therefore, it is important to ensure that interventions which appear to be cost-effective have not simply shifted more costs and care provision onto patients and informal carers. For example, while informants emphasised the need to expand access to primary palliative care, such planning should take the needs and preferences of patients and their loved ones into consideration when estimating overall costs and outcomes.

> **Key findings**
>
> - Population ageing has little influence on healthcare expenditure; instead, costs are driven by care near the end-of-life
> - Measures to reduce high-cost, low-value care near the end-of-life is likely to improve patients' and carers' experiences and increase efficiency
> - Informal costs and care provision are substantial yet remain largely unexplored in evaluations of palliative care interventions.

5.3.1.6 Governance

Oversight and collaboration

Coordinating and monitoring the development of palliative care services is a complex task. While there have been important developments such as the establishment of the National Clinical Programme for Palliative Care and a HSE lead for palliative care, there is currently no single regional or national body to lead and implement palliative care policy. Additionally, services are situated within both hospital groups and CHOs, which have different governance structures and follow different geographical distributions. Furthermore, while the strong partnership between the voluntary and statutory services has served the sector well, coordination between voluntary organisations and the publicly funded health and social care system remains challenging. Ongoing variation persists in adherence to statutory governance principles, how services are planned, funded and delivered, and how workforce development is addressed. Previous recommendations on the roles of voluntary organisations in publicly funded health and personal social services remain relevant (28,169).

To strengthen oversight and collaboration more generally, informants recommended that implementation and governance of palliative care services and policy should be driven by groups at the regional and national level, led through a palliative care corporate function with participation from all relevant stakeholders, medical and non-medical. This is in keeping with a recommendation made in the Three-Year Framework, advising that an adequately funded and staffed palliative care function be re-established (28). Similarly, the establishment of both (i) local governance groups and (ii) national governance structures have acted as key components aiding implementation of ICPOP (ICPOP: 109). Organisational reform within the ICPOP structure promotes a grounded approach to restructuring governance levels, where engagement at local levels is key to sharing information about the regional needs and developments.

At national and regional levels, broader health system governance and oversight structures have transformed substantially since the NACPC report in 2001. Further reforms are planned through Sláintecare, and these will directly impact the governance and oversight of palliative care. New regional health areas have been established, which in turn will reshape the governance, coordination and implementation of palliative care policy and services with the potential of strengthening governance and coordination between local, regional and national levels. As informants indicated, this presents opportunities to build on existing collaborative networks by establishing governance and coordinating structures comprised of key stakeholders in each regional level. Regional authorities would be responsible for developing and implementing a palliative care strategy responsive to the needs of that regional population, and would in turn be accountable for delivering this and managing allocated resources.

Central to oversight is the need for evaluation. This broadly comprises the assessment of service provision and quality, resource allocation strategies, workforce recruitment and retention, and governance structures leading operations. Currently, there is no evaluative framework for comprehensive palliative care in Ireland to monitor implementation and report on progress (126). As a result, there are limited data readily available for analysis related to key indicators such as workforce capacity and distribution.

Key findings

- Governance, oversight and coordination of palliative care can be strengthened through the establishment of local, regional and national structures involving relevant stakeholders at each level, and with clearly demarcated roles and responsibilities.
- An evaluative framework and oversight body are required to monitor implementation of the updated national palliative care policy, report annually on progress and to promote accountability and quality of care.

Policy development

Changes in Irish health policy and service organisation since 2001, mean many of the recommendations included in the NACPC report need to be updated. While implementation of Sláintecare represents the most substantive system-wide reform in decades, informants expressed confidence that specialist palliative care services are well-positioned to adapt to these changes. This is because many services are already integrated and delivered across all settings, which is supported through long-established networks between the statutory sector and voluntary organisations.

A common theme across interviews was that the process of updating the policy should be inclusive and collaborative, with broad representation and input from key stakeholders within and external to specialist palliative care. Inclusivity and collaboration were deemed necessary principles to ensure both input and buy-in from the range of stakeholders that can or could deliver or access palliative care. A single preferred model of participation was not identified, suggesting the potential use of a range of participatory processes, from consultation through to direct collaboration. Informants also indicated the process should be underpinned by evidence where available and guided by a structured framework to ensure all relevant areas, and the interactions between different health system components, are given adequate consideration in the updated policy.

Key findings

- Palliative care services and the updated palliative care policy are well-positioned to align with and adapt to Sláintecare reform priorities and actions, given the level of service integration already in place.
- The update process should be inclusive and collaborative, informed by evidence where available, and guided by a structured framework.

5.3.2 Process

5.3.2.1 Access and coverage

Equitable access to specialist palliative care

Substantial progress has been achieved around the organisation, management and delivery of high-quality specialist palliative care services across all settings since the NACPC policy was implemented. While significant regional variation in the availability of some specialist palliative care services persists, in terms of both infrastructure and workforce, there are important advancements to acknowledge. For example, all medical, nursing and health and social care professionals throughout the country have direct access to phone advice from specialist palliative care providers. Additionally, all acute general hospitals have specialist palliative care services, and every county has a community palliative care team.

Access to specialist palliative care is based on need rather than diagnosis, and the proportion of patients with a non-malignant disease continues to increase. Informants did note however that more work needs to be done to incorporate palliative care earlier in the disease trajectory for people with a non-cancer condition. This is reflected in research from TILDA which found that people with cancer are more likely to die at home or in hospice, while deaths in non-specialist facilities, like nursing homes, tended to be the result of non-cancer conditions (120). The analysis also found a high prevalence of modifiable problems in the last year of life such as pain (50%), depression (45%) and falls (41%), suggesting potential gaps and difficulties in identifying palliative care needs and accessing appropriate services for some older people in Ireland. The lack of identification of palliative care needs is concerning and suggests that resources such as the Needs Assessment Guidance (176), are not being fully utilised. Implementing strategies to improve utilisation is essential as comprehensive needs assessments are crucial to ensure prompt access to specialist palliative care when required (177,178).

Informants also noted that equitable service provision will also require a focus beyond well-established concerns about diagnosis or geographic location. The new policy will also need to consider how best to extend services to vulnerable or underrepresented populations such as those with psychiatric conditions, intellectual disabilities, people with dementia, people in institutional settings such as prisons, those experiencing homelessness, ethnic minorities, non-English speakers and people who identify as LGBTQI+.

Key findings

- While regional variation persists, substantial progress has been achieved around the organisation, management and delivery of high-quality specialist palliative care services.

- Improvements in access can be supported through the updated national policy, such as incorporating palliative care earlier in the disease trajectory, extending services to vulnerable or underrepresented populations, and ensuring resources such as the Needs Assessment Guidance are utilised to support timely referral to specialist palliative care service.

Population-based planning

The NACPC report recommended that service development should be guided by population need, which was linked primarily to population size. However, the concept of planning for population need has evolved within the Irish health and social care system since 2001 and now incorporates a more holistic assessment of needs (e.g. age, deprivation, rurality) rather than focussing on specific diseases, settings or service utilisation patterns. Additionally, informants emphasised that moving beyond yearly budgets or service plans would be more supportive of medium-term service planning and addressing regional variation.

The 2019 Sláintecare Action Plan has population health planning as one of the nine components of the Sláintecare Implementation Framework (168). Processes around linking data reflecting population need with health service planning remain in the early phases of development. A key development related to population-based planning is the establishment of the six Regional Health Areas, with explicit reference to utilising a population-based approach to service planning and funding, and the integration of community and acute services. These developments will also need to be reflected in service planning and evaluation across voluntary organisations.

Key findings
• The concept of planning for population need has evolved within the Irish health and social care system since the NACPC report and requires a shift to medium-term service planning and budgeting. • Regional Health Areas have been established and will utilise a population-based approach to service planning, integration, and funding. This will also need to be reflected across services provided by the voluntary sector.

Paediatric palliative care

Paediatric palliative care is an evolving specialty in Ireland, supported by both the NACPC and a dedicated policy, but remains relatively underdeveloped compared to adult services. This is reflected in global rankings, with Ireland's paediatric palliative care services characterised as having 'localised palliative care provision for children and availability of training' (93). Similarly, a mapping of paediatric palliative care within the WHO-European region found that Israel and Ireland are the only countries that provide some paediatric palliative services by adult specialists who do not have any special training in paediatrics (179). This interface between paediatric and adult palliative care services is necessary for providing end of life care at home, as Ireland does not have specialist paediatric palliative care available regionally.

Informants indicated service provision is well-established, supported in large part by multidisciplinary networks such as GPs, paediatricians, specialist palliative care providers and clinical nurse coordinators. There is one the Specialist Paediatric Palliative Care (SPPC) Team for Children located in Children's Health Ireland. As of late 2021, there are 2.2 WTE consultants, with another 1 WTE post planned for 2022. This SPPC team provides a national advisory service and mainly takes referrals from primary paediatric care teams. The additional 1 WTE planned for 2022 will support expansion of the advisory service. There is one paediatric palliative care inpatient unit in Dublin, with a homecare team providing some supports through paediatric nurses in parts of Leinster.

However, there are notable short- and long-term challenges in ensuring children receive high-quality palliative care based on need. For example, not all specialist palliative care teams provide services to children. This has been linked to concerns such as adequate training, the absence of clarity regarding clinical governance and insufficient workforce capacity or resourcing (27). Some informants indicated these barriers could be addressed by a recent report outlining the clinical governance and operational arrangements for supporting children with palliative care needs at home (27). A total of 14 recommendations are included in the report, grouped into four themes: governance and professional practice; strategic planning; education and training; and workforce.

Some informants raised concerns that this approach will limit much of paediatric palliative care in the community to the last days and weeks of life. Further, there is limited scope for further development of paediatric palliative care without changes in education and training, increased resourcing, and service delivery. Specific training in palliative care is not compulsory within paediatric specialisation, which is an ongoing barrier to appropriate access (180) and limits the potential for palliative care to eventually be further integrated within paediatric services.

Key findings

- Ireland does not have specialist paediatric palliative care available regionally; instead, paediatric palliative care service provision is supported in large part by multidisciplinary networks such as GPs, paediatricians, specialist palliative care providers and clinical nurse coordinators.

- Paediatric palliative care is underdeveloped, relative to adult services.

- Ongoing gaps may be addressed through full implementation of recommendations related to clinical governance and operational arrangements included in the report on paediatric palliative care published by the HSE in 2020.

- Further development and integration of paediatric palliative care could be supported through measures such as expanding education and training and increasing funding.

Out-of-hours service provision

Meeting the policy goals of having universal palliative care that is available according to need and provided appropriately throughout three levels of specialisation also requires comprehensive out-of-hours service provision. Findings from Workstreams 1 and 2 indicate there is significant regional variation in the availability of generalist and specialist palliative care services outside of 'typical' working hours across all settings. As a result, large gaps exist in sources of pain and symptom management, prescribing and advice, particularly for those living at home or in residential care settings. The IHF Primary Care Programme has developed an out-of-hours palliative care handover form, but it is not embedded across systems and its impact on care has not been evaluated.

A review of international policy and practice commissioned on behalf of the Department of Health (Ireland) found that that Ireland's current position is similar to other high-income countries with well-developed palliative care services (126). The importance of integrated, 24-hour care for people with serious illness is widely acknowledged, but there are relatively few details on how to organise, provide, and evaluate out of hours palliative care. Efforts to address recognised deficits in out of hours palliative care in Ireland can build on the examples of other countries in defining elements of services and in designing specific models. Specific measures identified in the evidence review to improve out of hours access included resourcing for additional specialist palliative care capacity, training generalist palliative care providers, utilising telehealth facilities and improving information sharing across settings.

Bereavement

Bereavement support is a core element of specialist palliative care service provision in Ireland. The Palliative Care Three-Year Development Framework outlines two action points to ensure adequate support for bereavement services is provided in any future revision of the NACPC report: (i) each specialist palliative care inpatient unit should include a comprehensive bereavement service with a designated bereavement coordinator; and (ii) HSE should develop and deliver national guidance strategies for bereavement services at each level of palliative care provision (28).

These recommendations reflect the views of informants, who highlighted the importance of providing bereavement support because of its impact on loved ones and also described existing gaps in practice that were hindering development and access. For instance, guidance within the NACPC report on bereavement support was found to be ambiguous and lacking clear instruction for implementation. Additionally, some reported that bereavement support is often not prioritised within service planning.

Gaps in provision of bereavement support have been reported in other countries with highly integrated palliative care services, with recent studies from Australia (181), the UK (182), and the Netherlands (183) all indicating that support services vary substantially in their approach and accessibility. Moreover, support provision in Ireland has been challenged during the COVID-19 pandemic, as providers experienced greater demands and difficulties to meet increased needs (184). It is unclear if there is sufficient capacity within specialist palliative care services to meet these changing needs. A related issue is that bereavement support through specialist palliative care is generally only available to those whose loved ones were known to those services, while those who engage with other services may not gain access to appropriate supports (185). These limitations all underscore the importance of developing and implementing bereavement care across all levels of palliative care provision, utilising a population health approach (28).

Key findings

- Measures such as resourcing for additional specialist palliative care capacity, training generalist palliative care providers, utilising telehealth facilities and improving information sharing across settings can help to address existing deficits in out-of-hours access to palliative care services.

- Bereavement support is an essential component of palliative care, yet significant gaps in provision were identified, underscoring the importance of developing and implementing bereavement care across all levels of palliative care provision, utilising a population health approach.

Essential Medicines and Technologies

Informants described some persistent gaps in access to equipment and technologies. For example, although requests to the HSE for essential equipment are prioritised, supplies are limited at times or there can be significant delays in delivering equipment to people. Similarly, the use of assistive technologies is often suboptimal owing to a lack of guidelines or procedures. In both instances, voluntary organisations have acted as a safety net by providing equipment or financial assistance.

In Ireland, a general development within the HSE for telehealth is the Attend Anywhere online platform which enables healthcare professionals to conduct medical consultations with their patients online at their convenience. Attend Anywhere was originally founded in 1998 under the title 'Global Telehealth' but has recently been adapted to the Irish health system in June 2020 to support care provision during the COVID-19 pandemic (186). Attend Anywhere consultations are conducted on secure network pathways and the platform is encrypted to ensure data are securely managed (186). Healthcare professionals are provided with guidance documentation and the option to attend a weekly training and information session online (187). A recent report of the National Telehealth Steering Committee examined healthcare professionals' and service-users' experiences on the platform in Ireland (188). The authors report that service users and providers reflected positively on the use of digital health platforms and the majority (88%) were likely to recommend the service to a friend (188). There are no data on utilisation rates of Attend Anywhere in specialist palliative care services and its impact on service delivery are not known.

A recent rapid review examined the use of video-based care consultations during the COVID-19 pandemic for individuals with palliative care needs in the UK (189). Notably, service-users appear to rate the online consultation experience as acceptable, with some suggesting they would have availed of the service sooner if it had been available. While not all medical discussions are fit to be replaced with online consultations, they may provide useful and cost-effective supplementary care sessions to address information needs of service-users and their families. There should also be protocols in place to maintain confidentiality and security on potential platforms.

Awareness and knowledge about palliative care

Public awareness campaigns are helping to improve current awareness and understanding about palliative care. This is an important contribution as misperceptions about palliative care are common, and studies show ongoing variation in service provision across Ireland may contribute to differences in knowledge and experience for both members of the public and health and social care professionals (136,190). Addressing this gap is essential as poor knowledge may hinder development of informed preferences about acceptable trajectories of care. For example, recent studies in Ireland found that participants' satisfaction ratings were influenced by their knowledge and experience of a range of services, with lower ratings given to hospital care in regions where specialist palliative care in-patient unit services were also available (31,191).

While a number of factors influence peoples' preferences for specialist palliative care, knowledge may be the most modifiable (192). Appropriate knowledge would help people develop informed preferences around specialist palliative care services before they are diagnosed with a life-limiting illness (190), which would facilitate conversations about end-of-life care and advance care planning (193). Additionally, improved awareness of these services among the public is essential given the role of family and other close persons in providing care and support or making treatment decisions. The need for a common language and definition of palliative care to improve knowledge among the public and health and social care professionals in Ireland has been highlighted in previous research (136,190).

5.3.2.2 Quality and safety

Integration

Integrated care is central in the Sláintecare vision, underpinning the Sláintecare Implementation Strategy and Action Plan between 2021-2023 (168), and is a core foundation of the Adult Palliative Care Services Model of Care for Ireland (35). Quality palliative care is best realised through strong integrated networks between generalist and specialist providers, and when all healthcare professionals work together to meet the needs of all people (194). The National Clinical Programme for Palliative Care was viewed by many informants as a platform for integrating palliative care within the wider health system. This was linked to the programme's outputs such as the Model of Care, Competency Framework, Needs Assessment Guidance, and Improvement Workbooks for Acute Hospital Services (37,149,176). Many also highlighted the positive impact of having a strong leadership function within palliative care.

However, some also noted that palliative care is not currently incorporated in models of care or clinical and care pathways for all life-limiting conditions and discussed the limitations of the National Clinical Programmes in facilitating further integration. For example, the National Clinical Programmes are primarily medically driven programmes, with limited collaboration between many programmes. Others indicated that the National Clinical Programme for Palliative Care was not sufficiently resourced to enable its work or build broad leadership capacity within the programme. These observations are in keeping with previous research examining implementation of the National Clinical Programmes (195), which found progress had been slowed by resourcing constraints, resistance to change within the existing system, and inadequate IT systems. Resistance to change was also discussed by informants in relation to the integration of palliative care into the wider healthcare system; however, resistance to change is a widely documented phenomenon within health systems (195–197). Informants in this evaluation identified other barriers to increased integration, including underdeveloped IT infrastructure and poor system alignment between settings and fields.

The implementation of the Integrated Care Programme for Older Persons (ICPOP) offers important learnings as the Irish health and social care system moves towards integration of health services (197–199). ICPOP currently provides a patient-centred care programme with multidisciplinary input for older individuals, where 'integration' is operationalised as the active alliance between services in the community to address complex needs (198). A number of 'ingredients' are highlighted as core drivers of integration in this case, including the provision of clear integrated care pathways for patients, ensuring population-based planning is central to service provision, and establishing multidisciplinary teams with regular meetings to integrate between disciplines early on. While the NACPC report set out a broad model of care emphasising the importance of multidisciplinary teams and population-based planning, it did not provide a road map for achieving integration between specialist palliative care services and other teams. Informants highlighted the importance of addressing this gap in the updated policy.

> **Key findings**
>
> - Identified barriers to integration include palliative care not being included in models of care for all life-limiting conditions or in all applicable clinical and care pathways; underdeveloped IT infrastructure; and poor system alignment.
> - The implementation of the Integrated Care Programme for Older Persons (ICPOP) demonstrates the importance of having clear integrated pathways for people to access services across settings.

Developing the evidence base for palliative care

Robust evidence is needed to inform clinical decision-making, improve service quality and guide strategic planning in palliative care. This is reflected in the NACPC report, with recommendations aimed at building research capacity and generating evidence about the effectiveness of service models. Informants also cited specific research priorities they viewed as central to improving palliative care services in Ireland, including workforce planning and retention, outcome measurement, cost-effectiveness, bereavement support and integration of services.

However, the ability for researchers and clinicians to develop and conduct high-quality research studies in palliative care, both in Ireland and internationally, has been limited by a number of factors, resulting in a low evidence base. There are substantial logistical and ethical complexities associated with most study designs (128), while recruitment is often constrained by the nature of the patient population (200) and gatekeeping by healthcare professionals (201). Despite the challenges, there has been substantial progress in Ireland towards improving the evidence base for palliative care. Research activity in palliative care is growing, with collaborative networks nationally and internationally (202). This can be attributed to initiatives such as the All-Ireland Institute of Hospice and Palliative Care (AIIHPC) and the Palliative Care Research Network, which provide structured research support and opportunities to build multidisciplinary collaborations. The AIIHPC also coordinate Voices 4 Care, a forum comprised of service users, carers and members of the public who help inform and shape policy and research related to palliative care.

While the difficulties associated with conducting palliative care research are well-documented in the literature and were frequently discussed by informants, there are some practical ways to address identified barriers in Ireland. These include:

- Using a multidisciplinary 'bottom up' approach to determine the research questions and appropriate study design. Whenever feasible, studies should be co-designed and carried out through collaborations between health and social care professionals, academic researchers, service users and members of the public.

- Specialist palliative care in-patient units must be properly resourced if they are to realise their full potential as research orientated centres. For example, adequate IT infrastructure would facilitate identification, recruitment and follow-up of participants (both patients and caregivers).

- Measures such as providing protected time with adequate cover and mentorship would increase research and audit capacity among all members of the multidisciplinary team.

- Appropriate gatekeeping of potential research participants and streamlined ethics approval processes.

- Building leadership capacity within palliative care research and training through the establishment of academic posts and departments.

- Increased resourcing for initiatives and programmes that address research priorities

Monitoring quality

Some informants viewed the implementation of PCOC as an important step towards measuring and evaluating the quality of care provided by specialist palliative care services. The approach is well-established in Australia with a high response rate across services (203,204). Quality indicators within PCOC include monitoring referral times within services, logging changes in service-users' symptoms and comparing across the national averages (203,205).

However, some informants also raised concerns about the use of PCOC in Ireland. For example, the measures are perceived to focus primarily on care provided by doctors and nurses, creating a sense of exclusion for some health and social care professionals delivering specialist palliative care. Additionally, the approach is designed to capture data about specialist palliative care services, leaving the input of generalist palliative care unexplored. There is also limited literature detailing the methods for benchmarking and designing quality improvement initiatives using PCOC data (63).

Key findings

- Despite a range of challenges, there has been substantial progress in Ireland towards improving the evidence base for palliative care. This can be advanced further, for example through resourcing to build the research and audit capacity of service providers.

- Monitoring and improving the quality of care requires a range of measures and indicators to evaluate both specialist and generalist palliative care.

5.3.3 Outcomes

5.3.3.1 Improved experiences

Providing appropriate and high-quality care across all settings that aligns with the preferences of patients and their loved ones is central to improving care experiences. For instance, hospital care at end-of-life is sometimes unnecessary but may be one of few available options (120). As a result, a significant proportion of people die in hospital, though research suggests most would prefer to die at home (206,207). Addressing this disparity between preference and practice, however, requires substantial reform to ensure that hospitals are not the only settings equipped and available to provide care at the end-of-life. One key measure would be reducing regional deficits around specialist inpatient units. Evidence from the Report on the Economic Evaluation of Palliative Care in Ireland indicates that in regions where inpatient specialist palliative care services are available, the level of admissions to acute hospitals is significantly lower in the last three months of life (31). This leads to a more appropriate trajectory of care, and an improved experience for patients and their loved ones. In addition, there could be some savings within hospitals (though this may not necessarily amount to a total cost saving). Initiatives aimed at supporting people to remain in their homes will have to consider the needs of caregivers and the potential resource implications, as a substantial amount of end-of-life care in the community often falls to unpaid loved ones (208).

High-quality care for individuals with palliative care needs also includes access to rehabilitation (28). A rehabilitative approach centres the priorities of the service-user and aims to bolster their independence by providing them with interdisciplinary input, such as occupational therapy, physiotherapy, and mental health services, to maintain a high quality of life in line with their set goals (28,209,210). Rehabilitation is a promising approach to minimise disability burden in older age and may be highly cost-effective (141,211). Generally, rehabilitation interventions and approaches in palliative care improve quality-of-life (212), reduce unmet psychological needs (213) and improve physical function outcomes (214). Yet rehabilitative palliative care services is an underutilised and underdeveloped facet of palliative care in Ireland (35). Addressing this gap should be a priority as the rates of disability are set to increase sharply between now and 2046 (15). A novel palliative care rehabilitation service in Ireland funded by the Sláintecare Integration Fund may aid future implementation of rehabilitative approach in Ireland by evaluating how rehabilitative palliative care services can be effectively integrated across acute and community settings (215).

Beyond specific service approaches, in difficult times, people may have their overall experiences improved by facing as few barriers as possible when accessing care (31,127,136,216). Previous research in Ireland with people utilising specialist palliative care services and their loved ones found that people have strong preferences for services that are coordinated, supportive and accessible (127,136). Preferences are influenced by age and personal circumstances and there are important differences between service-users and informal caregivers. Patients' priorities were focused on ease of access to health services, advice from supportive healthcare professionals and adequate symptom management. Caregivers often prioritised on ensuring their loved ones were actively involved in decision-making about their own care, in addition to having direct access to information healthcare professionals (136).

Key findings

- Regions where inpatient specialist palliative care services are available report lower levels of hospitalisation in the last three months of life, providing an improved trajectory of care and experience for patients and their loved ones.
- Rehabilitative palliative care remains an underutilised and underdeveloped component of palliative care in Ireland.
- Overall experiences can be improved through minimising barriers when accessing care, with people having strong preferences for services that are coordinated, supportive and accessible.

5.3.3.2   Responsiveness

According to the WHO (2003), responsiveness is:

> *'…the degree to which the health system meets the legitimate expectations of the population for the non-enhancing (non-clinical) aspects of the health system. It incorporates seven elements: dignity, confidentiality, autonomy, prompt attention, social support, basic amenities, and choice of provider.'*

Irish culture and society have undergone enormous changes since the NACPC policy was developed in 2001. Informants emphasised the importance of ensuring person-centred care remains at the core of the updated policy, and that it is sensitive to the needs, preferences, and social circumstances of different populations.

Dignity is often highlighted as a component of system responsiveness that warrants emphasis in palliative care. A recent systematic review underscored some practical considerations related to dignity at end-of-life (217). As a significant proportion of people die in hospital (11,207), ensuring that acute care settings are equipped to provide peaceful environments for end-of-life care is a priority (217). This includes accounting for appropriate treatment measures, such as deciding to move from invasive treatment approaches to comfort-based care where death is expected (218) ensuring that privacy is available for patients and their families and promoting the use of respectful language in end-of-life settings (217). Moreover, specific emphasis has been placed on ensuring that the wellbeing of the patient and their loved ones is promoted by the provision of care and bereavement services (217).

Dignity is also addressed within the Palliative Care Services Three Year Development Framework (2017-2019), where providing individuals with palliative care needs single-occupancy rooms is explicitly endorsed:

> *"Existing specialist inpatient units should develop plans to move to all single room patient accommodation in order to ensure the privacy and dignity of each person and to be in compliance with HIQA standards" (28)*

There are also ongoing efforts to provide dignified and peaceful environments for individuals with palliative care needs in acute hospitals. One example is the Hospice Friendly Hospitals programme, an initiative of the Irish Hospice Foundation, which has developed 'the Quality Standards for End-of-Life Care in Hospitals' to cater to those who die in hospital settings and their loved ones (219). The Hospice Friendly Hospitals programme is currently active across 47 hospitals in Ireland and has driven responsiveness to dignity in acute care settings by introducing environmental resources and supports to aid families and patients at end-of-life. These include family-oriented facilities in some settings for the loved ones of patients to access refreshments, bathrooms, and overnight accommodation (220). The Hospice Friendly Hospitals programme also promotes the use of compassionate signage, such as the use of the End-of-Life spiral in hospital wards to indicate specific areas in a hospital where an individual is dying or has died (221).

Research within the Hospice Friendly Hospitals programme identified gaps within acute hospitals for end-of-life care, such as inadequate resources and facilities to aid the provision of comfortable and dignified end-of-life care and a lack of critical evaluation to examine the impact of the programme (220). The Palliative Care Services Three Year Development Framework (2017-2019) specifically recommended that the Hospice Friendly Hospital programme be adopted by hospitals nationally and that collaborative efforts are made to design and implement appropriate measures to evaluate the impact of the programme (28). However, given the lack of evaluation or validation of the measures, it is advisable to undertake a review before proceeding with implementation.

Key findings
• Person-centred care should remain at the core of the updated palliative care policy, and that it is sensitive to the needs, preferences, and social circumstances of different populations.
• Dignity of each person is a key component of patient-centred care and responsiveness, and requires appropriate treatment, care services and care settings as advanced, for example, through the Hospice Friendly Hospitals programme.

5.3.3.3   Social and financial protection

Although financial protection is a core element of universal healthcare, there was only one recommendation within the NACPC report aimed at addressing reducing financial hardship. Findings from Workstreams 1 and 2 suggest that this recommendation, and subsequent policy measures aimed at reducing financial hardship have either not been implemented or, in some instances, are not providing an adequate safety net. This is a worrying trend as protection from financial risk associated with health spending is one of the three core components of universal healthcare. Informants indicated there are no 'fast track' systems for housing modifications, resulting in many patients and/or their loved ones paying out-of-pocket for adaptations needed to support them remaining at home. This finding is in keeping with previous research from Ireland, which found most costs for home modifications in the last year of life (74%) were borne by individuals and their loved ones (31). Estimates from the Irish TILDA found similar trends for spending in the last year of life.

Some participants also highlighted out-of-pocket charges are not always affordable, particularly for services, drugs and equipment. Such concerns about affordability are supported by studies of financial protection among Irish households, which found evidence that even relatively low user charges can lead to financial hardship for very poor households and present a substantial barrier to access (126). Although the medical card system successfully protects many households from financial hardship, there are clearly gaps in coverage for the poorest households. Additionally, there is no automatic entitlement to the programme when diagnosed with a life-limiting illness. Eligibility is instead determined by prognosis, which was increased from 12 to 24 months in February 2021 (222).

Supporting carers

The wellbeing of informal carers is considered central to the 2012 National Carers' Strategy, where they are identified as partners in the care structure of their loved one (Department of Health, 2019). The Three Year Development Framework (2017-2019) notes that the person-centred philosophy underpinning palliative care should be extended to caregivers, to ensure their contribution to the care of their loved one does not result in their own unmet needs (28). Moreover, it is recommended within the framework that an understanding of carers' needs be incorporated into widespread specialist palliative care services. These needs include, but are not limited to: (i) information regarding their loved one's condition, plan, and prognosis, in addition to information on available services and supports while caring for their loved one; (ii) access to all necessary support, whether based on physical, emotional, social and/or respite needs for the caregiver or those in their care; and (iii) connection to key professionals involved in their loved one's care to ask questions and remain fully informed (28). It was not possible to determine the best way to identify and meet needs amongst caregivers or estimate the associated resource requirements within the Three Year Development Framework (28) and both issues should be given consideration in future policy and strategic planning.

Although informal caregivers make substantial contributions to supporting people in the community, little is known about the social or financial impact of this contribution as it is often excluded from cost analysis (31,223). Evidence from Ireland indicates that informal caregivers provide as much as half of the social care people receive in the community near the end of life (119,175). Additionally, high utilisation of informal care can result in poorer health outcomes for informal caregivers (224), including higher reports of depression (225), reports of pain affecting everyday activities (226), and higher perceptions of stress (227). As costs and outcomes associated with informal care are usually overlooked in economic evaluations, a key concern is that future reforms may result in 'cost-shifting' – reducing costs for the health system but placing an increased financial or social burden on caregivers (127).

There are also notable gaps in access to bereavement services for families, despite the emphasis placed on bereavement within the NACPC report. Similarly, access to appropriate supports for informal caregivers, including bereavement supports, is one of eight core foundations of the Adult Palliative Care Services Model of Care for Ireland (35). A study undertaken by Aoun and colleagues (2020) found that one third of bereaved individuals surveyed in Ireland did not receive adequate bereavement supports following the death of their loved one. Moreover, most respondents reported receiving informal bereavement support from their family members and friends, rather than receiving professional guidance as they grieved. This is particularly concerning, as an estimated 7-15% of individuals may to develop symptoms of 'complicated grief'; a condition in which individuals remain in the acute stage of grief for prolonged periods (228,229). A study of current standards in bereavement services in Ireland indicated that service availability varies greatly between regions (230), raising further issues of access inequities. The impact of the COVID-19 pandemic on patterns in demand, access and need in Ireland is not yet fully known, but studies suggest people bereaved during the pandemic have complex support needs and difficulties accessing appropriate support (184,231).

Key findings

- Measures aimed at reducing financial hardship have either not been implemented or, in some instances, are not providing an adequate safety net, particularly for the poorest households.
- Informal carers are key partners in the care structure of their loved ones, yet little is known about the social, personal or financial impact of this contribution. Further consideration is required in future policy and strategic planning to ensure appropriate access to supports and services and to avoid cost-shifting onto carers.

5.3.3.4 Improved efficiency

People approaching end-of-life account disproportionately for health and social care budgets. In Ireland, just 10% of decedents accounted for approximately two-thirds of health and social care expenditure for people in the last year of life, with the costs dominated by hospital and nursing home care (171). While this care is often necessary, there is evidence that many hospital admissions near the end of life are avoidable or inappropriate. Studies also indicate that care is often not aligned with patients' and caregivers' preferences (119,191). Overall, the evidence suggests a significant proportion of people are receiving expensive care that yields poor value (120).

Although the evidence base remains limited, studies show that specialist palliative care interventions can change care trajectories, leading to better outcomes for patients and families and reduced costs for healthcare systems (142,232). Multidisciplinary assessment of needs and discussions about goals of care through specialist palliative care teams supports patients and caregivers to choose care pathways that align with their needs and preferences. Identified savings for the health and social care system are driven by a reduced intensity of care (e.g., interventions and tests), in conjunction with better integration of care (e.g., timely hospital discharge and supporting access to community-based services) (177,178). The effects are greatest when people are referred early in the disease trajectory, in cases where people have complex needs with multiple chronic conditions, and for those who have a cancer diagnosis (although not necessarily their primary illness) (171).

Advance care planning is also seen as central to supporting care efficiency, as this promotes coordination and preparation for an advancing health trajectory (233). In the United States, it is estimated that the prioritisation of advance care planning may actively reduce costs associated with intensive care at the end of life by 25% (234) In Ireland, it has been suggested that advance care planning is associated with lower hospitalisation rates and potential savings on a national scale, if implemented country-wide (235). Since the publication of the NACPC report, 'Think Ahead', a specific advance care planning project was established by the Irish Hospice Foundation and launched in phased progression in 2011. It has since been and gradually promoted in various care settings (236), but the implementation and impact of these measures have not been evaluated.

> **Key findings**
>
> - Multidisciplinary assessment of needs and discussions about goals of care through specialist palliative care teams supports patients and caregivers to choose care pathways that align with their needs and preferences. In some instances, it can also reduce costs for health systems.
> - Advance care planning can also support care appropriateness and cost efficiencies, though has yet to be implemented and evaluated throughout Ireland.

5.4 Conclusion

This workstream has synthesised findings from across the different workstreams and discussed their implications. It provided a detailed mixed methods appraisal of the research questions set out in the Terms of Reference. To do this, outputs from the three prior workstreams were matched to the specific research questions. Relevant published and grey literature was incorporated in the synthesis discussion. Analysis was organised using a modified version of the health systems framework, which extends beyond the core building block inputs and functions to include discussion of health system processes and outcomes.

Overall, significant progress has been made towards achieving the vision set out in the NACPC report, particularly for specialist palliative care. This has been underpinned by sustained increases in resources from both the statutory and voluntary sectors. At the same time, many of the recommendations are not fully implemented or are no longer relevant, and inequities in access to services persist. Added to this, the need for palliative care services is projected to rise sharply over the next 25 years.

Key gaps and barriers identified in the workstream synthesis include ongoing regional inequities in access to specialist care services, as well as uneven progress in expanding generalist palliative care services relative to specialist services. Related to this, another common gap identified across the workstreams was the significant variation in the composition of MDTs across services and regions. Deficits in IT infrastructure and data generation and management practices were also identified, rendering it inadequate to support service delivery and strategic planning. While palliative care has benefited from sustained financing, including the substantial contribution of the voluntary sector to both capital development and some core services, synthesised findings highlight the need for increased statutory funding for core components of service provision to ensure financing does not become a barrier to addressing priority issues such as regional inequities, future capital development plans, and re-orienting towards delivery of integrated care across services. Future financing strategies will also need to strengthen measures aimed at reducing financial hardship. Addressing these and other financing gaps will be particularly important given projected increases in demand for services.

Key enablers to the implementation of the 2001 NACPC report identified in the workstreams include the establishment and activities of the National Clinical Programme for Palliative Care, creating the HSE Lead post, increased availability of education and training, and having clear delineation of roles and responsibilities. This provides a strong base for the updated policy to build on to ensure strong leadership, clear governance structures and to put in place evaluative processes at both national and regional levels in order to address gaps identified in current decision-making, collaboration and oversight arrangements.

Recognising the substantial systems, policy and population changes that have taken place since 2001, this review has identified areas that the updated policy can improve on to meet existing and emerging needs. These include expanding access to specialist palliative care to include vulnerable or underrepresented populations, as well as developing a more detailed understanding of the social or financial impact on informal carers to ensure equitable access to services (e.g., respite, bereavement support) and avoid cost-shifting onto carers. Two further issues identified in the synthesis were the need to move towards population-based planning and resource allocation in the policy update, as well as the importance of developing and resourcing strategies for building the evidence base and health information system for palliative care. Throughout the workstreams, information systems emerged as a key requirement for informing health systems functions, processes and outcomes. Information systems represent a critical infrastructure for planning and implementing population-based service delivery and resource allocation, for monitoring quality and progress, and for informing collaboration and oversight across national, regional and local levels of service provision.

The next chapter concludes this report, offering a summary of key findings and recommendations.

6   Conclusion

6.1   Purpose of review

The Programme for Government of June 2020 commits to publishing a new palliative care policy for adults with the aim of ensuring universal provision of high-quality, integrated services based on need for people with life-limiting illness and their loved ones. This will represent a major update of the 2001 policy and will be informed by recent developments.

The aim of this study is to inform this planned update of Ireland's national palliative care policy by examining the implementation of existing national palliative care policy and identifying priority areas that should be addressed.

We achieved this by assessing the implementation of the recommendations of the current policy report (3) and related Service Development Frameworks (2,28); by identifying emerging issues not anticipated in the 2001 report; and by identifying examples of good policy implementation in the Irish health system and in international palliative care literature. This report offers multi-perspective insights into policy development over the last twenty years in Ireland and recommendations on the next steps and future priorities.

6.2   Summary of key findings

6.2.1   Workstream One: Mapping recommendations in the NACPC policy and measuring progress

- In total, 82 distinct recommendations were made in the 2001 NACPC report. While all items related to six building blocks within the Health Systems Framework were identified in the mapping exercise, the 2001 recommendations were primarily clustered around issues related to service delivery and workforce.

- Implementation progress could be assessed for 40 of the recommendations. Similarly, most of these were related to service delivery and workforce. The data indicate substantial progress has been achieved in developing specialist palliative care provision since 2001; however, notable deficits in workforce and infrastructure persist across most regions and services. The other 42 recommendations focused on the guiding principles and ethos that underpin the broad model of care outlined in the report and could not be evaluated in this component.

6.2.2   Workstream Two: Stakeholder interviews

- We conducted eighteen interviews and six focus groups between October and December 2021, with a total of 39 participants. Participants included healthcare professionals (clinical and health and social care), representatives from within the statutory and voluntary sector, policy makers, academics, service users, carers and members of the public.

- Informants linked improvements in palliative care provision to the recommendations set out in the NACPC report. Interviewees described how progress was made across all core areas, such as the expansion of and access to specialist palliative care services, an increased awareness of palliative care, and the expansion of multidisciplinary teams, particularly specialist care teams. Significant gaps were also identified, such as persistent geographic disparities in service provision, inadequate health information systems to support audit and decision-making, and the need to review governance and leadership arrangements in the context of health systems reform.

- Informants also described enablers and barriers to policy implementation. These include successes such as the establishment and activities of the National Clinical Programme for Palliative Care, sustained political support for palliative care, the Sláintecare reforms to increase service integration, increasing knowledge of palliative care and resources such as the Model of Care and Competency Framework. Challenges included resourcing constraints, fragmentation of services, limited progress towards developing service capacity outside of routine hours, the absence of academic departments to lead training developments, and deficits in skills and knowledge among health and social care professionals.

- Informants emphasised that much of the NACPC report remains relevant and provided recommendations as to how it can be updated to address gaps through a mix of targeted and aspirational policy areas and processes. Key priorities include the revision of the NACPC report to reflect the changing landscape of the health and social care system since 2001, in addition to the ongoing empowerment of healthcare professionals to engage with the palliative care approach and ensuring adequate funding is provided to support innovation and development within palliative care policy and practice.

6.2.3   Workstream Three: Evidence review

- Four examples of palliative care policy implementation were examined: the use of the PCOC in Australia, the SRPC in Sweden, primary palliative care in Scotland and paediatric palliative care in England. The cases highlight that successful policy implementation is contingent on the existing health system within which the initiatives will operate. Sustained governance and leadership, resourcing, training, and robust information systems enable the effective implementation of new health policies. Notable barriers to implementation include system fragmentation and limited collaboration between healthcare professionals.

- Learnings from integrated care initiatives in Ireland highlight that implementing service change needs clear policy with appropriate targets, commitment to the complex change process involved, sufficient resourcing, an ability to animate many sectors and empower local agents and capacity to measure the right outcomes in ways that are meaningful and accessible.

- While existing studies have demostrated an economic benefit to palliative care in Ireland, the true economic value of current palliative care services remains unclear, as the evidence base is limited to a few studies and does not capture a complete perspective of service delivery. Increased emphasis should be placed on generating economic evaluations of current and future palliative care programmes, including assessments of the health and well-being effects of palliative care services, out-of-pocket costs of informal caregivers, and longitudinal estimates of care costs (rather than episodic) from diagnosis to death.

6.2.4   Workstream Four: Synthesis

- There has been significant progress towards achieving the vision set out in the NACPC report. However, many of the recommendations have not been fully implemented and inequities in access to services persist. Developments in policy and practice since 2001 also mean that many of the recommendations require revision. The updated national palliative care policy should build on the achievements provided through the NACPC report, while also considering priority areas identified in this evaluation and in the broader policy context.

- Population need for palliative care services is projected to rise sharply over the next 25 years. Increasing generalist and specialist palliative care capacity to address current deficits and meet anticipated demand requires both sustained investment and strategic planning. Population-based planning and resource allocation will be important mechanisms for driving improvements in equity and efficiency across all settings. Proactive recruitment, training and retention strategies addressing issues particular to palliative care are also needed to support workforce development.

- Health information systems and infrastructure are inadequate to support resource, capacity and workforce planning. It will be essential to develop and resource an information strategy that supports robust data collection, information sharing across settings, and service planning and evaluation.

- The findings highlight other key enablers and barriers to developing palliative care services. Enablers included the establishment and activities of the National Clinical Programme for Palliative Care, creating the HSE Lead post, increased availability of education and training, and having clear delineation of roles and responsibilities. Developing strong leadership, clear governance structures and evaluative processes at both the national and regional level are also important enablers. Barriers identified included palliative care not being included in all applicable clinical and care pathways, poor system alignment, limited out-of-hours capacity across all settings, and a lack of detailed guidance around generalist palliative care in the NACPC report.

- Measures aimed at reducing financial hardship have either not been implemented or, in some instances, are not providing an adequate safety net, particularly for the poorest households.

- Informal carers are key partners in the care structure of their loved ones, yet little is known about the social or financial impact of this contribution. Further consideration is required in future policy and strategic planning to ensure equitable access to services (e.g., respite, bereavement support) and avoid cost-shifting onto carers.

6.3   Recommendations on priority areas to address in the new national palliative care policy

The recommendations were coproduced by members of the study team and Research Advisory Group during a workshop in January 2022. Participants discussed study findings and identified areas of consensus and outliers. These discussions were facilitated by members of the research team.

The recommendations are grouped using the health systems framework Building Blocks and the ordering does not indicate priority. It is important to note that the Building Blocks are interconnected, and they must function together to effectively deliver high-quality palliative care services.

Service delivery

Recommendation 1

The policy should continue to provide commitment to universal access to palliative care on the basis of need, in keeping with the principles outlined in the NACPC report and proposals for palliative care as a component of universal healthcare in Sláintecare. In light of substantial changes that have occurred within the Irish health and social care system and the palliative care sector since 2001, **the policy should address emerging priorities and issues** identified in this review, including:

- Strengthening and promoting the multidisciplinary approach within specialist palliative care;

- Strengthening generalist palliative care provision;

- Developing and implementing systems to ensure service planning and delivery are based on population need;

- Ensuring all intrinsic elements of the palliative care model and culture are incorporated into service provision, including rehabilitative palliative care and bereavement support;

- Delivery of 7-day and out-of-hours specialist palliative care services;

- Promoting a person-centred approach to care that considers the needs, preferences, and social circumstances of different populations;

- Delivering enhanced community-based care in line with Sláintecare, enabling people to remain in their homes and communities whenever possible;

- Integration of palliative care within models of care for all life-limiting conditions;

- Recognising the role and needs of carers and other loved ones;

- Improving awareness and knowledge about palliative care among healthcare professionals outside specialist palliative care and the public;

- Supporting implementation of recommendations related to the organisation and governance of paediatric palliative care published by the HSE in 2020;

- Ensuring that terminology used to delineate different levels of specialisation in palliative care is comprehensible and inclusive;

- Recognises the importance of the continuing involvement of the voluntary sector in the planning and delivery of specialist palliative care services in Ireland.

Recommendation 2

The National Clinical Programme for Palliative Care published a full Model of Care describing best practice in providing care for people with life-limiting illness. **The new policy should align with the framework set out in the National Clinical Programme for Palliative Care Model of Care and support full implementation and integration of the Model,** with ongoing evaluation.

The new policy should consider strategies for addressing the inequities in specialist palliative care service provision identified within this review, including:

- Regional variation in the availability of specialist palliative care inpatient units and the services and supports provided by units. The number of beds relative to local population size and the availability of single room patient accommodation also differs across the country. One important measure will be to revise the model used to determine bed ratios;

- Timely referral to specialist palliative care is often determined by diagnosis, rather than need;

- Persistent gaps and variation in staffing levels and staff mix within multidisciplinary teams across all settings;

- Availability and access to services outside of office hours, including weekends and public holidays;

- Regional variation in access to input from adult specialist palliative care services for children in the community to the last days and weeks of life;

- Access to services for vulnerable or underrepresented populations;

- Improving awareness and utilisation of resources such as needs assessment guidance.

Workforce

Recommendation 4

The NACPC report made recommendations for workforce requirements within the multidisciplinary team across different settings based on factors such as population size or the number of beds within the specialist palliative care unit. **There have been important changes related to palliative care practice and workforce planning since 2001 which will need to be reflected in the new policy**:

- A shift towards population-based planning for health services, which incorporates a more holistic assessment of needs, rather than focussing on specific diseases, settings or service utilisation patterns;

- Skill mix developments such as advance nurse practitioners and nurse prescribers, and the clinical specialist roles for health and social care professionals;

- Development of integrated and dynamic approaches to workforce planning that consider team composition and skill mix such as the methodologies applied by the Taskforce on Staffing and Skill Mix;

- Integrate the Review of Palliative Medicine Workforce in Ireland report into workforce development;

- Workforce planning and development should incorporate all healthcare staff, to meet service needs.

The new policy should address factors influencing recruitment and retention within specialist palliative care services, utilising a whole-of-system approach. Key priorities identified in this evaluation included:

- Proactive recruitment measures to address recognised deficits in workforce capacity across all settings and regions;

- Addressing challenges within the recruitment process;

- Developing clear pathways for career progression and professional grading for all members of the multidisciplinary team;

- Ensuring all members of the multidisciplinary team have equal access and opportunity to avail of education, training and clinical mentorship;

- Developing and implementing strategies to support staff and to promote and protect staff health and well-being.

Recommendation 6

Generalist palliative care capacity should be strengthened as this will be integral to ensuring people can easily access a level of palliative care service that is appropriate to their needs, regardless of care setting or diagnosis. The new policy should consider how this could best be achieved, taking account of priority areas identified in this evaluation:

- Recruitment measures to address recognised deficits in workforce capacity;

- Evaluating the skills gap and developing education and training programmes at all levels to provide healthcare professionals with the confidence and competence to identify, assess and respond to palliative care needs;

- Development of an implementation plan with specific actions, timelines and role delegation, and measured by appropriate indicators.

Information

Recommendation 7

The new policy should support the development of an information strategy for palliative care. This will be guided to a large extent by developments in national policy related to health information systems, the organisation of health and social care services and the shift towards population-based planning. Measures which could support robust data collection and improve information sharing within the sector, that align with the goals of Sláintecare and support delivery of high-quality services, include:

- Mapping current data management practices and the content of available datasets across all settings;

- Examining potential for data linkages;

- Validation of routinely collected datasets, such as the MDS and PCOC;

- Identifying the characteristics most likely to reflect need for palliative care;

- Embedding routine outcome measurement across all settings, using validated tools and appropriate performance indicators that are aligned with the aims of the interventions and services;

- Implementing eHealth initiatives and programmes such as unique identification numbers and electronic health records;

- Mapping existing needs, assets and pathways;

- Establishing best practice with respect to information sharing across settings.

Recommendation 8

The new policy should build on the substantial achievements within palliative care research in Ireland and support further development of the evidence base for all levels of palliative care. Promoting a research agenda that improves the quality and value of palliative care services could include:

- Establishing academic departments and senior posts in palliative care to build leadership within research and education;

- Providing protected time and mentorship for all members of the multidisciplinary team;

- Sustained strategic investment in research programmes addressing priority areas;

- Improving information infrastructure across all settings;

- Utilising and strengthening initiatives that support collaborative networks.

Finance

Recommendation 9

In Ireland, resources are generally allocated based on existing levels of service provision rather than being guided by current or future population need. However, plans are underway to introduce population-based resource allocation as a component of Sláintecare. **The new policy should address how changes to the resource allocation model will impact on service planning and delivery.** This will be guided by key policy objectives such as promoting equity, efficiency and accountability but might also consider how to identify:

- The palliative care services that should be included;

- If additional adjustments to funding are required based on factors such as population dispersion and unmet need;

- The extent of transition funding required;

- The appropriate timeframe for implementation;

- The role of funding provided through the voluntary sector for capital development projects and core generalist and specialist palliative care services.

Recommendation 10

Protecting households from financial hardship when accessing health and social care is one of the core components for achieving universal healthcare. Delivering universal healthcare as detailed in the 2017 Oireachtas Sláintecare report would do most to prevent financial hardship by facilitating access to care at low or no cost. Implementation of the Sláintecare Strategy and Action Plan 2021-2023 is key to delivering this policy goal. **The new policy should address the financial vulnerabilities of people with life-limiting illness and their loved ones**. Efforts to improve financial protection could focus on:

- Incorporating patients' and caregivers' costs into evaluations to reduce the potential for cost-shifting – namely, lowering costs for the health system but placing an increased financial burden on patients and caregivers;

- Addressing gaps in the supply of necessary equipment;

- Reducing the financial burden associated with home modifications;

- Reviewing eligibility criteria for medical cards to ensure all people with a life-limiting illness at risk of hardship are supported;

- Improving protection for medical card holders with palliative care needs by removing out-of-pocket charges.

Leadership and governance

Recommendation 11

Strong leadership and clear governance structures will be key enablers of universal provision of high-quality, integrated palliative care services based on need. In the context of current health system reforms and the establishment of regional health areas, **the new policy should set out a model of governance** to improve decision-making and collaboration that:

- Defines clear roles and responsibilities for strengthening coordination and collaboration between local, regional and national levels;

- Establishes regional governance structures comprised of key stakeholders, and enables them to be responsive to regional population health needs;

- Facilitates strategic planning and evaluation at and between national and regional levels;

- Strengthens existing governance structures and functions and incorporates public and community participation and involvement.

Recommendation 12

Specialist palliative care has a key role to play in the delivery of palliative care across all settings. **The new policy should support development of leadership capability and capacity within specialist palliative care**. This could include:

- Enabling the National Clinical Programme for Palliative Care to continue its work in supporting integration of high-quality palliative care across all settings;

- Developing a palliative care education strategy.

The new policy should set out criteria for the development of an implementation plan to monitor progress. This could be achieved, for example, through development of an evaluation framework for comprehensive palliative care, as well as establishing a monitoring structure and mechanism for reporting on key indicators and reviewing progress towards targets.

6.4   Summary

Palliative care services in Ireland have been guided for more than twenty years by the NACPC report. In many ways, the report was ahead of its time within the Irish health and social care system, and most of the recommendations remain relevant today. Substantial progress has been achieved in enhancing the delivery of palliative care across all levels and settings since the NACPC report was published as national palliative care policy. However, many of the recommendations are not fully implemented and inequities in access to services persist. Developments in policy and practice since 2001 also mean that many of the recommendations require revision. The new national palliative care policy should build on the achievements provided through the NACPC report, while also considering priority areas identified in this evaluation and in the broader policy context. This is essential to ensuring universal provision of high-quality, integrated services based on need for people with life-limiting illness and their loved ones.

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Appendices

Appendix 1 Recommendations included in the Report of the National Advisory Committee on Palliative Care

Page	Chapter	Recommendation
31	2	Palliative care should be incorporated into the care plan of patients at an early stage of their disease trajectory.
32	2	Palliative care services should be structured in three levels of ascending specialisation. In each health board area, all three levels of specialisation should be available. All patients should be able to engage easily with the level of expertise most appropriate to their needs.
34	2	Palliative care services, both specialist and non-specialist, should be available in all care settings. Services should be sufficiently flexible to allow movement of patients from one care setting to another, depending on their clinical situation and personal preferences.
35	2	The concept of palliative care should be promoted in the wider community.
36	2	Further research should be undertaken in Ireland to evaluate the effectiveness of different models of specialist palliative care service delivery.
41	3	A needs assessment for specialist palliative care services should be completed in each health board area within 9 months of publication of this report.
43	3	When assessing the need for specialist palliative care services, each health board should consider the needs of patients with malignant and non-malignant disease.
45	3	Current available evidence suggests that there should be at least 8 to 10 specialist palliative care beds per 100,000 population. This requirement may vary within each health board, depending on the demographic and socio-economic composition of the area. Each health board should determine the bed requirements of its own population as part of a needs assessment for specialist palliative care services. Further research should be undertaken at national level to examine the needs of non-cancer patients for inpatient specialist palliative care.
45	3	Specialist palliative care services should recognise and facilitate cultural diversity.
48	3	The medical and nursing care of children in hospitals should be the responsibility of paediatric-trained medical and nursing staff. There should be close co-operation and liaison between paediatric and specialist palliative care services in each health board area.
48	3	The needs of different population groups, including children, should be addressed by each health board when planning the future delivery of specialist palliative care services.
54	4	In assessing the need for palliative care services, patients and their carers are prime stakeholders, and as such, their opinions and preferences should be sought and incorporated into national and regional policies.
58	5	Each health board area should have a comprehensive specialist palliative care service to meet the needs of patients and families in the area. All health care professionals should be able to access advice and support from specialist palliative care service providers when required.
61	5	There should be at least one Whole Time Equivalent (WTE) consultant in palliative medicine per 160,000 population, with a minimum of two consultants in each health board area. For each consultant in palliative medicine, there should be at least three non-consultant hospital doctors (NCHDs) working in the specialist palliative care unit.
62	5	The overall WTE specialist palliative care nurse to bed ratio should not be less than 1:1.
62	5	In each day care centre, there should be a minimum of one WTE specialist palliative care nurse to every 7 daily attendees.
62	5	There should be a minimum of one WTE specialist palliative care nurse per 150 beds in each acute general hospital
62	5	There should be a minimum of one WTE specialist palliative care nurse in the community per 25,000 population.
63	5	There should be at least one WTE physiotherapist per 10 beds in the specialist palliative care inpatient unit, with a minimum of one physiotherapist in each unit. There should be a minimum of one WTE community physiotherapist specialising in palliative care per 125,000 population. This post should be based in the specialist palliative care unit.

64	5	There should be at least one WTE occupational therapist per 10 beds in the specialist palliative care unit, with a minimum of one occupational therapist in each unit. There should be a minimum of one WTE community occupational therapist specialising in palliative care per 125,000 population. This post should be based in the specialist palliative care unit.
64	5	There should be at least one WTE social worker employed per 10 beds in the specialist palliative care unit, with a minimum of one social worker in each unit. There should be a minimum of one WTE community social worker specialising in palliative care per 125,000 population. This post should be based in the specialist palliative care unit.
65	5	Professionals involved in the psychological aspects of specialist palliative care services should be suitably trained and experienced in this role.
65	5	Each specialist palliative care unit should have at least two suitably trained chaplains available to meet the spiritual needs of patients and families. The pastoral care service should be available to patients and families 24 hours a day
66	5	There should be regular speech and language therapy sessions in each specialist palliative care unit, with a minimum of one session per week.
66	5	There should be at least one clinical nutritionist session in each specialist palliative care unit per week.
67	5	There should be at least one WTE pharmacist in each specialist palliative care unit.
67	5	The care attendant to bed ratio in specialist palliative care units should not be less than 0.5:1.
68	5	Every specialist palliative care unit should have a volunteer co-ordinator, who should be responsible for the selection, training and placement of volunteers.
72	6	The specialist palliative care inpatient unit should be the core essential element of the specialist palliative care service. Specialist palliative care services in all other settings, including general hospitals and the community, should be based in or have formal links with the specialist palliative care unit.
73	6	There should be at least one specialist palliative care inpatient unit in each health board area.
74	6	In areas with a wide geographical spread, it may be necessary to develop a satellite specialist palliative care inpatient unit to meet the needs of patients and families in the area. Satellite inpatient units would function as an extension of the lead specialist palliative care unit for the region. There should be no more than one satellite specialist palliative care inpatient unit in any health board area.
		In some health board areas, it may be necessary to establish a number of satellite bases, from where specialist palliative care staff would provide services in the local community, i.e. for the catchment area covered by the satellite base. **The decision to establish satellite bases in health board areas should be taken at regional level.** Satellite bases would function as an extension of the lead specialist palliative care unit for the region and would have close clinical, educational and administrative links with the lead unit.
76	6	All specialist palliative care units should provide day care facilities for patients and carers. Appropriate transport should be provided for patients to and from the centre.
76	6	(Part a) Specialist palliative care facilities should be sensitive to the needs of patients, families and staff. The environment should offer privacy to patients and their families when required.
76	6	(Part b) An Expert Group on Design Guides for Specialist palliative care Settings should be established to inform all relevant parties, and to ensure a national consistency of standards for all specialist palliative care centres.
81	7	The specialist palliative care team in an acute general hospital should consist of at least a consultant in palliative medicine, a specialist palliative care nurse, a social worker, and a secretary.
81	7	All acute general hospitals should have a consultant-led specialist palliative care service, offering advice and support to health care professionals in the hospital. The specialist palliative care team should work alongside other hospital teams, complementing their work, rather than taking over care of the patient.
82	7	Joint outpatient clinics should be established in acute general hospitals, allowing the specialist palliative care team to become involved in-patient care at an early stage in the disease process.
83	7	Arrangements should be made to "fast-track" outpatient appointments for patients receiving palliative care.
83	7	There should be one point of entry to hospital services for palliative care patients, and subsequent referrals should be speedily organised.
83	7	In A&E, the patient's condition should be rapidly assessed, and the patient should be referred to the appropriate team without delay.
87	8	The general practitioner has overall responsibility for the medical care of patients in the community.
87	8	The public health nurse provides nursing care to patients in the community on the basis of need.

89	8	The specialist palliative care team in the community should be an inter-disciplinary consultant-led team. The specialist palliative care team should be based in, and led by, the specialist palliative care unit in the area.
89	8	The specialist palliative care nurse provides information, advice and support to patients, families and health care professionals in the community. This extends to support in bereavement.
90	8	Community hospitals should have designated beds for palliative care patients who require an intermediate level of inpatient care.
91	8	The concept of "shared care" for patients receiving palliative care in the community should be promoted.
92	8	Specialist palliative care nurses should provide a seven-day service to patients in the community.
92	8	Each specialist palliative care unit should develop its own physiotherapy, occupational therapy and social work departments, which would also meet the needs of palliative care patients in the community.
93	8	Each health board should have a sufficient bank of equipment to meet the needs of palliative care patients in the community.
93	8	Local arrangements between pharmacists in specialist palliative care units, hospitals and in the community should be formalised to ensure that patients receiving palliative care have access to all necessary medications as and when required.
94	8	Care attendants should be available to support families of palliative care patients in the community.
94	8	All palliative care patients should have adequate access to respite care in a setting of their choice.
95	8	Arrangements should be made for the transport of patients receiving palliative care to different care settings, when required.
95	8	There should be a "fast-track" system in place to enable patients with advanced disease to access grants for housing alterations.
98	9	Bereavement support should be an essential part of all specialist palliative care programmes and should be available in all settings where specialist palliative care is offered. Bereavement support should begin early in the disease process, long before the death of the patient.
100	9	Bereavement support should be provided by appropriately trained personnel from the available pool of staff in each service. Assessment of need for bereavement support should be routine in all specialist palliative care services.
104	10	Academic departments of palliative medicine should be established in each medical faculty, with the development of inter-disciplinary courses for all professionals involved in the delivery of palliative care.
107	10	All health care professionals working in palliative care should have the opportunity to engage in research. A number of research centres, linked to academic departments of palliative medicine, should be established.
108	10	There should be a major public funding allocation to promote palliative care research in Ireland, and to put in place the necessary infrastructure to allow this to happen.
112	11	There should be specific training in communication skills for all staff involved in the care of patients with progressive illness.
113	11	The general practitioner, public health nurse and specialist palliative care team, when appropriate, should be contacted directly in advance of a patient's discharge from hospital.
114	11	Primary care health professionals should have an open line of communication with each other, which should involve regular team meetings when possible, and regular communication by phone, fax or e-mail.
114	11	Health care providers should be proactive in the provision of information regarding services, allowances and entitlements to patients and families.
118	12	The provision of services and equipment to palliative care patients should be based on need, and not on the ability to pay.
119	12	Specialist palliative care services should be available to all patients wherever and whenever they require them.
119	12	Every specialist palliative care service should have an explicit commitment to quality improvement. Quality standards should be set in all specialist palliative care settings, in consultation with key service providers and consumers. Systems should be put in place in all specialist palliative care services to measure the quality of the services provided.
120	12	A Minimum Data Set should be developed in Ireland, in order to provide standardised information on all patients of the specialist palliative care services.
121	12	Suitable performance indicators and outcome measures should be identified and utilised in specialist palliative care services in order to evaluate and maintain quality standards.

124	13	The future development of specialist palliative care services requires a commitment to the ongoing provision of an adequate level of public funding, with a corresponding commitment to quality and accountability from service providers.
124	13	Part a. Adequate and equitable statutory funding should be made available on a phased basis to meet the core running costs of all specialist palliative care services.
124	13	Part b. The distribution of funding should be through service plans adopted by each health board, and through service agreements between the health board and voluntary service providers in the region.
125	13	There should be a separate protected budget for specialist palliative care services at health board level. All day-to-day expenditure should be met by the health board specialist palliative care budget.
126	13	Health boards should work in partnership with the voluntary service providers in their areas.
127	13	Service agreements should form the basis of future working relationships between the health boards and all voluntary specialist palliative care service providers. The process should respect the independent identity and operational autonomy of individual voluntary service providers, and also respect the statutory, regulatory and public accountability responsibilities of the statutory bodies.
128	13	Fundraising groups should identify key objectives and strategies in relation to their activities, and should be fully accountable for all money raised. Any projects funded should be in accordance with the overall palliative care development plan for the region.
133	14	The Minister should establish a **National Council for Specialist palliative care** to offer advice on the ongoing development and implementation of a national policy on palliative care services in Ireland. The National Council should be broadly based and have representatives from the appropriate statutory and voluntary agencies. There should be formal links between the **National Council for Specialist palliative care** and the **National Cancer Forum**.
47	3	- In the meantime, the National Advisory Committee makes the following recommendations in relation to palliative care for children: Palliative care for children is best provided at home, except in extraordinary circumstances, with the family closely supported by the general practitioner, the public health nurse and the specialist palliative care team, where available. - The medical and nursing care of children in hospitals should be the responsibility of paediatric-trained medical and nursing staff, with support from the specialist palliative care service. - There should be close co-operation and liaison between paediatric and specialist palliative care services. - Palliative care services for children, including respite care, should be provided as close to the child's home as possible. Each paediatric unit should review its requirements for the provision of palliative care and respite care for children in its catchment area.
62	5	It is recommended by the Committee that salaries and career structures should be standardised nationally across all health board areas.
63	5	The Committee recommends that there should be a pilot study to explore the feasibility of physiotherapy-led clinics for patients with progressive malignant or non-malignant disease.

Appendix 2 Specialist palliative care unit inpatient bed capacity

	2013	2014	2015	2016	2017	2018	2019	2021
National	3.4 (156 beds)	4.3 (196 beds)	4.4 (200 beds)	4.6 (208 beds)	4.6 (221 beds)	4.6 (221 beds)	4.7 (223 beds)	5.5 (276 beds)
CHO 1	4.1	4.1	4.1	4.1	4.1	4.1	4.1	4.1
CHO 2	2.7	2.7	2.7	4.0	4.0	4.0	4.0	7.1
CHO 3	7.4	7.4	7.4	7.9	7.8	7.8	7.8	7.8
CHO 4	3.6	6.0	6.0	6.6	8.5	8.5	8.5	8.5
CHO 5	N/A	N/A	N/A	N/A	N/A	N/A	N/A	3.9
CHO 6	3.3	3.3	3.3	3.3	3.1	3.1	3.1	7.0
CHO 7	6.4	6.4	6.4	6.5	5.8	5.8	5.8	6.9
CHO 8	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
CHO 9	3.3	7.4	7.4	7.4	6.9	6.9	6.9	6.9

Appendix 3 Information letter for key informants participating in a personal capacity

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Name of Study: Review of the implementation of the of the 2001 report from the National Advisory Committee on Palliative Care as it relates to Adult Palliative Care

Site	Trinity College Dublin
Principal Investigator(s) and Co-Investigator(s)	**Principal Investigator:** Dr Bridget Johnston Research Assistant Professor Centre for Health Policy and Management, Trinity College Dublin bjohnst@tcd.ie (01) 896 2201 **Co-Investigators:** Dr Carlos Bruen, Centre for Health Policy and Management, Trinity College Dublin Dr Sarah Barry, Centre for Health Policy and Management, Trinity College Dublin Dr Sara Burke, Centre for Health Policy and Management, Trinity College Dublin Dr Peter May, Centre for Health Policy and Management, Trinity College Dublin Dr Regina McQuillan, Beaumont Hospital and Saint Francis Hospice Prof Steve Thomas, Centre for Health Policy and Management, Trinity College Dublin
Study Funder	Department of Health, Government of Ireland
Data Controllers	Trinity College Dublin Department of Health, Government of Ireland
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2

You are being invited to take part in a research study commissioned by the Department of Health to be carried out at Trinity College Dublin by Dr Bridget Johnston.

We are undertaking this research under article 6 (1)(e) Public Interest and under article 9 (2)(j) Scientific Research of the General Data Protection Regulations (GDPR) 2016. You are being invited to take part in the research as you have been identified by the All-Ireland Institute of Hospice and Palliative Care as a member of the Voices4Care forum who has accessed palliative care services in Ireland.

Before you decide if you wish to take part, please read this information sheet carefully and ask the Principal Investigator, Bridget Johnston, any questions you may have. Don't feel rushed or under pressure to make a quick decision. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. This process is known as 'Informed Consent'.

You don't have to take part in this study. You can change your mind about taking part in the study any time you like. Even if the study has started, you can still opt out. You don't have to give us a reason. If you do opt out, rest assured it won't affect the quality of treatment either you or your loved one gets in the future.

This leaflet has four main parts:

Part 1 – The Study

Part 2 – Data Protection

Part 3 – Costs, Funding and Approval

Part 4 – Further Information

If you have any questions, or if you would like to receive more information, please contact Bridget Johnston, bjohnst@tcd.ie.

Part 1 – The Study

Why is this study being done?

This research is being done to inform a planned update of Ireland's national palliative care policy. This will be achieved by carrying out interviews with different people who have an interest in the delivery of palliative care services. These interviews will help identify gaps in service delivery, factors that support or challenge the development of services; and views on issues that should be addressed in the policy update.

Why have I been invited to take part?

You have been chosen because of your experience in accessing palliative care services and participation in the All-Ireland Institute of Hospice and Palliative Care's Voices4Care forum.

Who is organising the research study?

This study is being organised and independently led by researchers in the Centre for Health Policy and Management in Trinity College Dublin. The lead researcher is Bridget Johnston, Trinity College Dublin. Other team members are from Trinity College Dublin, Beaumont Hospital and Saint Francis Hospice. The research is funded by the Department of Health.

How will the study be carried out?

The study is being carried out through face-to-face interviews with individuals (key stakeholders) who have an interest or experience with the delivery of palliative care services in Ireland.

What will happen to me if I agree to take part?

If you agree to take part, you will be invited to take part in an audio recorded individual interview with a member of research team. This interview will be held online, using Zoom or Microsoft Teams. It will take between 35-45 minutes to complete the interview.

Do I have to take part? Can I withdraw?

Participation in the research study is entirely voluntary. If you do not want to take part in the study, please let the research team know. You can change your mind about taking part in the study and opt out at any time even if the study has started. You don't have to give a reason for not taking part or for opting out. If you wish to opt out, please contact Bridget Johnston (bjohnst@tcd.ie) who will organise this for you.

What are the benefits of participating?

Participating in the study gives an opportunity to provide feedback about how palliative care services are organised and delivered in Ireland, and what the future priorities should be. Your input will contribute to the development of palliative care policy and hopefully improved care. While this may be something that helps participants to feel engaged, interested and valued, there will not be any additional benefits from participating.

What are the risks?

We have taken great care to ensure that the confidentiality of the information that you provide is maintained. However, we cannot be 100% certain that a data breach will not happen. We have provided some further information on how we safeguard and manage your data in the sections below. Of note, we wish to reassure you that your data will not be used in automated decision making or profiling.

Will it cost me anything to take part?

No, it will not cost anything to take part in this research study.

Will I be told the outcome of the study?

Neither you nor any other study participant will be identifiable in the write-up of the study findings. The findings will be published in a report for the Department of Health. A plain language summary of the results will also be written and shared with providers of palliative care services, individual users of services and charities. The findings of this study will be published in scientific journals and on the All-Ireland Institute of Hospice and Palliative Care website. The findings will be presented at meetings for policy makers and providers of palliative care services. If you wish, we can send you a summary of the results.

Part 2 – Data Protection

What information about me (personal data) will be used as part of this study? Will my medical records be accessed? What will happen to my personal data?

We will keep the following data about you: your name, email address, phone number, a consent form with your signature and the audio recording of your research interview.

We will keep information that might identify you, such as your name, separate from the transcripts of the research interview and this information will be kept securely in a password-protected database. This database is stored in a secure and dedicated Trinity College Dublin OneDrive cloud-based folder accessible only to the study team. Team members will only access these data using encrypted devices approved by Trinity College Dublin.

Who will access and use my personal data as part of this study?

Only members of the research team based in Trinity College Dublin will have access to any personal information you provide.

Will my personal data be kept confidential? How will my data be kept safe?

Your privacy is important to us. We take many steps to make sure that we protect your confidentiality and keep your data safe. For example, we have completed a Data Protection Impact Assessment (DPIA) to identity any risks posed to maintaining the confidentiality of your data.

All personal data will be kept securely in password-protected databases. These databases are stored in a secure and dedicated Trinity College Dublin OneDrive cloud-based folder accessible only to the study team. Team members will only access these data using encrypted devices approved by Trinity College Dublin. If you return a written consent form, it will be stored in a locked cabinet in the Centre for Health Policy & Management, Trinity College Dublin.

The research team as employees of Trinity College Dublin, Beaumont Hospital and Saint Francis Hospice understand their responsibilities as data controllers of personal information and will work to ensure that your rights that your personal information is sufficiently protected and that any data is always kept safe and secure. The research team have completed in-house training in GDPR within their organisations. This training included the following components: description of personal data, explanation of the importance of protecting personal data, an outline of the key principles of GDPR and a recognition of the rights of an individual and how these are implemented.

What is the lawful basis to use my personal data?

The researchers organising this study have a responsibility to ensure that participants understand the law around accessing and using individual's personal data as part of the research study. By law[1], we can use your personal information for scientific research[2] (in the public interest[3]). We will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations.

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[1] *The European General Data Protection Regulation (GDPR)*

[2] *Article 9(2) (j))*
[3] *(Article 6(1)(e)*

What are my rights?

You are entitled to:

- The right to access to your data and receive a copy of it

- The right to restrict or object to processing of your data

- The right to object to any further processing of the information we hold about you (except where it is de-identified)

- The right to have inaccurate information about you corrected or deleted

- The right to receive your data in a portable format and to have it transferred to another data controller

- The right to request deletion of your data

By law you can exercise the following rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting Dr Bridget Johnston (bjohnst@tcd.ie) or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie.

Dr Johnston (or another team member) will provide direct access to your data via OneDrive electronic file sharing. A link granting access will be emailed to your chosen email address. If you request corrections (rectification), Dr Johnston will provide written notification of changes made. You can review the changes directly using OneDrive electronic file sharing link.

Part 3 – Costs, Funding and Approval

Has this study been approved by a research ethics committee?

Yes, all research at Trinity College is looked at by an independent committee of people called a 'Research Ethics Committee', to protect your interests. However, if you have a concern about any aspect of this study, we suggest you speak to a member of the research team who will do their best to answer your questions. The lead researcher's (Bridget Johnston) contact details are included at the end of this information sheet.

Who is organising and funding this study? Will the results be used for commercial purposes?

The study has been funded by the Department of Health. It is led by a study team from Trinity College Dublin, Beaumont Hospital and Saint Francis Hospice. The results will not be used for commercial purposes.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, we are not paying to take part in the study. It will not cost you anything to participate in this research study. A researcher from the study team will meet with you using a secure online platform, Microsoft Teams or Zoom, at a time that is convenient to you.

Part 4 – Further Information

Who should I contact for information or complaints?

If you need any further information now or at any time in the future, please contact the lead researcher who will do their best to answer your questions (Bridget Johnston, Centre for Health Policy and Management, Trinity College Dublin; email: bjohnst@tcd.ie).

If you have any concerns or questions in relation to how your data has been processed, you can contact:

Data Protection Officer	**Data Protection Officer** **Secretary's Office** **Trinity College Dublin** **Dublin 2** **Email:** dataprotection@tcd.ie

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie.

Will I be contacted again?

If you would like to take part in this study, you will be asked to sign a Consent Form. This can either be posted or emailed to you. You will be given a copy of this information leaflet and the signed Consent Form to keep. It is entirely up to you to decide whether to take part. If even after completing the questionnaire or interview you can withdraw your participation by contacting the research team (Bridget Johnston, email: bjohnst@tcd.ie). All information will be confidentially destroyed. If you want to opt out of the study, you can rest assured it won't affect the quality of treatment you, or your loved one, get in the future.

Getting involved

Many thanks for taking the time to read this leaflet and considering taking part in the research study.

Appendix 4 Information letter for key informants participating in a professional capacity

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Name of Study: Review of the implementation of the of the 2001 report from the National Advisory Committee on Palliative Care as it relates to Adult Palliative Care

Site	Trinity College Dublin
Principal Investigator and Co-Investigator(s)	**Principal Investigator:** Dr Bridget Johnston Research Assistant Professor Centre for Health Policy and Management, Trinity College Dublin bjohnst@tcd.ie (01) 896 2201 **Co-Investigators:** Dr Carlos Bruen, Centre for Health Policy and Management, Trinity College Dublin Dr Sarah Barry, Centre for Health Policy and Management, Trinity College Dublin Dr Sara Burke, Centre for Health Policy and Management, Trinity College Dublin Dr Peter May, Centre for Health Policy and Management, Trinity College Dublin Dr Regina McQuillan, Beaumont Hospital and Saint Francis Hospice Prof Steve Thomas, Centre for Health Policy and Management, Trinity College Dublin
Study Funder	Department of Health
Data Controllers	Trinity College Dublin Department of Health
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2

You are being invited to take part in a research study commissioned by the Department of Health to be carried out at Trinity College Dublin by Dr Bridget Johnston.

We are undertaking this research under article 6 (1)(e) Public Interest and under article 9 (2)(j) Scientific Research of the General Data Protection Regulations (GDPR) 2016. You are being invited to take part in the research as you have been identified by the Department of Health as a key stakeholder in palliative care policy and provision in Ireland.

Before you decide if you wish to take part, please read this information sheet carefully and ask the Principal Investigator, Dr Bridget Johnston, any questions you may have. Don't feel rushed or under pressure to make a quick decision. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. This process is known as 'Informed Consent'.

You don't have to take part in this study. You can change your mind about taking part in the study any time you like. Even if the study has started, you can still opt out. You don't have to give us a reason. If you do opt out, rest assured it won't affect the quality of treatment either you or your loved one gets in the future.

This leaflet has four main parts:

Part 1 – The Study

Part 2 – Data Protection

Part 3 – Costs, Funding and Approval

Part 4 – Further Information

If you have any questions, or if you would like to receive more information, please contact Bridget Johnston, on 086 022 0888 or bjohnst@tcd.ie.

Part 1 – The Study

Why is this study being done?

This research is being done to inform a planned update of Ireland's national palliative care policy. This will be achieved by carrying out interviews with different people who have an interest in the delivery of palliative care services. These interviews will help identify gaps in service delivery, factors that support or challenge the development of services; and views on issues that should be addressed in the policy update

Why have I been invited to take part?

You have been chosen because the Department of Health has identified you as a key informant.

Who is organising the research study?

This study is being organised and independently led by researchers in the Centre for Health Policy and Management in Trinity College Dublin. The lead researcher is Bridget Johnston, Trinity College Dublin. Other team members are from Trinity College Dublin, Beaumont Hospital and Saint Francis Hospice. The research is funded by the Department of Health.

How will the study be carried out?

The study is being carried out using face-to-face interviews.

What will happen to me if I agree to take part?

If you agree to take part, you will be invited to take part in an audio recorded individual interview with a member of research team. This interview will be held online, using Zoom or Microsoft Teams. It will take between 35-45 minutes to complete the interview.

Do I have to take part? Can I withdraw?

Participation in the research study is entirely voluntary. If you do not want to take part in the study, please let the research team know. You can change your mind about taking part in the study and opt out at any time even if the study has started. You don't have to give a reason for not taking part or for opting out. If you wish to opt out, please contact Bridget Johnston (bjohnst@tcd.ie) who will organise this for you.

What are the benefits of participating?

Participating in the study gives an opportunity to provide feedback about how palliative care services are organised and delivered in Ireland, and what the future priorities should be. Your input will contribute to the development of palliative care policy and hopefully improved care. While this may be something that helps participants to feel engaged, interested and valued, there will not be any additional benefits from participating.

What are the risks?

We have taken great care to ensure that the confidentiality of the information that you provide is maintained. However, we cannot be 100% certain that a data breach will not happen. We have provided some further information on how we safeguard and manage your data in the sections below. Of note, we wish to reassure you that your data will not be used in automated decision making or profiling. Additionally, your individual data will not be made available to your employer or the Department of Health. Your comments will not be attributable to you in the project outputs by virtue of your role within an organisation or sector.

Will it cost me anything to take part?

No, it will not cost anything to take part in this research study.

Will I be told the outcome of the study?

Neither you nor any other study participant will be identifiable in the write-up of the study findings. The findings will be published in a report for the Department of Health. A plain language summary of the results will also be written and shared with providers of palliative care services, individual users of services and charities. The findings of this study will be published in scientific journals and on the All-Ireland Institute of Hospice and Palliative Care website. The findings will be presented at meetings for policy makers and providers of palliative care services. If you wish, we can send you a summary of the results.

Part 2 – Data Protection

What information about me (personal data) will be used as part of this study? Will my medical records be accessed? What will happen to my personal data?

We will keep the following data about you: your name, email address, phone number, a consent form with your signature and the audio recording of your research interview.

We will keep information that might identify you, such as your name, separate from the transcripts of the research interview and this information will be kept securely in a password-protected database. This database is stored in a secure and dedicated Trinity College Dublin OneDrive cloud-based folder accessible only to the study team. Team members will only access these data using encrypted devices approved by Trinity College Dublin.

Who will access and use my personal data as part of this study?

Only members of the research team working on this research project will have access to any personal information you provide.

Will my personal data be kept confidential? How will my data be kept safe?

Your privacy is important to us. We take many steps to make sure that we protect your confidentiality and keep your data safe. For example, we have completed a Data Protection Impact Assessment (DPIA) to identity any risks posed to maintaining the confidentiality of your data.

All personal data will be kept securely in password-protected databases. These databases are stored in a secure and dedicated Trinity College Dublin OneDrive cloud-based folder accessible only to the study team. Team members will only access these data using encrypted devices approved by Trinity College Dublin. If you return a written consent form, it will be stored in a locked cabinet in the Centre for Health Policy & Management, Trinity College Dublin.

Individual responses will not be made available to your employer and the Department of Health. Additionally, the researchers are committed to ensuring your comments cannot be attributed to you by virtue of your position within an organisation or sector.

The research team as employees of Trinity College Dublin, Beaumont Hospital and Saint Francis Hospice understand their responsibilities as data controllers of personal information and will work to ensure that your rights that your personal information is sufficiently protected and that any data is always kept safe and secure. The research team have completed in-house training in GDPR within their organisations. This training included the following components: description of personal data, explanation of the importance of protecting personal data, an outline of the key principles of GDPR and a recognition of the rights of an individual and how these are implemented.

What is the lawful basis to use my personal data?

The researchers organising this study have a responsibility to ensure that participants understand the law around accessing and using individual's personal data as part of the research study. By law,[4] we can use your personal information for scientific research[5] (in the public interest[6]). We will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations.

What are my rights?

You are entitled to:

- The right to access to your data and receive a copy of it

- The right to restrict or object to processing of your data

- The right to object to any further processing of the information we hold about you (except where it is de-identified)

- The right to have inaccurate information about you corrected or deleted

- The right to receive your data in a portable format and to have it transferred to another data controller

- The right to request deletion of your data

By law you can exercise the following rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting Bridget Johnston (bjohnst@tcd.ie) or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie.

Dr Johnston (or another team member) will provide direct access to your data via OneDrive electronic file sharing. A link granting access will be emailed to your chosen email address. If you request corrections (rectification), Dr Johnston will provide written notification of changes made. You can review the changes directly using OneDrive electronic file sharing link.

Part 3 – Costs, Funding and Approval

Has this study been approved by a research ethics committee?

Yes, all research at Trinity College is looked at by an independent committee of people called a 'Research Ethics Committee', to protect your interests. However, if you have a concern about any aspect of this study, we suggest you speak to a member of the research team who will do their best to answer your questions. The lead researcher's (Bridget Johnston) contact details are included at the end of this information sheet.

Who is organising and funding this study? Will the results be used for commercial purposes?

The study has been funded by the Department of Health. It is led by a study team from Trinity College Dublin, Beaumont Hospital and Saint Francis Hospice. The results will not be used for commercial purposes.

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, we are not paying to take part in the study. It will not cost you anything to participate in this research study. A researcher from the study team will meet with you using a secure online platform, Microsoft Teams or Zoom, at a time that is convenient to you.

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[4] The European General Data Protection Regulation (GDPR)
[5] *Article 9(2) (j))*
[6] *(Article 6(1)(e)*

Part 4 – Further Information

Who should I contact for information or complaints

If you need any further information now or at any time in the future, please contact the lead researcher who will do their best to answer your questions (Bridget Johnston, Centre for Health Policy and Management, Trinity College Dublin; email: bjohnst@tcd.ie)

If you have any concerns or questions in relation to how your data has been processed, you can contact:

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Will I be contacted again?

If you would like to take part in this study, you will be asked to sign a Consent Form. This can either be posted or emailed to you. You will be given a copy of this information leaflet and the signed Consent Form to keep. It is entirely up to you to decide whether to take part. If even after completing the questionnaire or interview you can withdraw your participation by contacting the research team (Bridget Johnston, email: bjohnst@tcd.ie). All information will be confidentially destroyed. If you want to opt out of the study, you can do so without any type of consequence.

Getting involved

Many thanks for taking the time to read this leaflet and considering taking part in the research study

Appendix 5 Consent form for qualitative interviews

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

STUDY NAME: Review of the implementation of the of the 2001 report from the National Advisory Committee on Palliative Care as it relates to Adult Palliative Care

Participant name:

Participant ID:

Consent Form

There are two sections in this form. Each section has statements and asks you to initial if you agree. The end of this form is for the researchers to complete.

Please ask <u>any</u> questions you may have when reading each of the statements.

Thank you for participating.

Please <u>Initial </u>the box if you agree with the statement. Please feel free to ask questions if there is something you do not understand.

General	Tick box
I confirm I have read and understood the **Information Leaflet** for the above study. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	
I understand that this study **is entirely voluntary, and if I decide that I do not want to take part, I can stop taking part in this study at any time without giving a reason**. I understand that deciding not to take part will not affect my future medical care or employment.	
I understand that I **will not be paid for taking part in this study**.	
I know how to contact the research team if I need to.	

	Tick box
I agree to take part in this research study having been fully informed of the **risks, benefits and alternatives** which are set out in full in the information leaflet which I have been provided with.	
I agree to being contacted by researchers by [email/phone] as part of this research study.	

Data processing	Tick box
I understand that personal information about me will be protected in accordance with the General Data Protection Regulation.	
I understand that there are **no direct benefits to me** from participating in this study. I understand that a copy of my interview transcript will be provided to me.	
I understand that **I can stop taking part in this study** at any time without giving a reason and this will not affect my future medical care.	

Centre for Health Policy and Management, Trinity College Dublin, 3-4 Foster Place, Dublin 2; Tel: 089 4390941

Thank You

Participant Name (Block Capitals)   Participant Signature   Date

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Witness Name (Block Capitals)   Witness Signature   Date

To be completed by the Principal Investigator or nominee.

I, the undersigned, have taken the time to fully explain to the above patient the nature and purpose of this study in a way that they could understand. I have explained the risks and possible benefits involved. I have invited them to ask questions on any aspect of the study that concerned them.

I have given a copy of the information leaflet and consent form to the participant with contacts of the study team

Researcher name:

Title and qualifications:

Signature

Date:

Appendix 6 Interview topic guide for informants acting in a personal capacity

Introduction

Greetings and review of ethics and consent form

Thank you all for agreeing to participate in this interview. We are interviewing you to understand more about your views and experiences as a user of palliative care services or an interested member of the public.

Could you please tell me a bit about yourself and how you came to join the Voices4Care forum?

Topics & Questions

Background

1. First, can you tell me a little about the type of care you or your loved one have received in the past few months?

    a. *From family? From medical professionals?*

2. How do you feel about the type of care that has been provided?

Thank you. Now I would like us to talk about palliative care in general.

Views on palliative care

3. Can you describe what palliative care means to you?

4. Who do you think can benefit from palliative care?

    a. *Are there any people you think cannot benefit?*

    b. *Why?*

5. Do you think palliative care helps people?

    a. *How does it do this?*

6. What do you think makes a good palliative care service?

Thank you for your answers so far. Now I would like to ask a few more questions about your experience of palliative care services.

Experience of palliative care services

7. What kind of palliative care services have you (people you know) used?

8. How would you rate the palliative care services you have used?

    a. *Have you experienced any problems with the services?*

    b. What are some of the things that work well with the services?

9. What was your experience of accessing palliative care services?

    a. *Anything that helped?*

    b. Anything that made it more difficult?

Thank you. Now I would like to ask some questions about what you think might help to improve palliative care policy and services.

Palliative care policy and future priorities

10. Reflecting on your own experiences of accessing palliative care services, are there particular recommendations from the policy report you believe have been achieved?

    a. *Can you tell me more about this?*

11. Again, reflecting on your own experience, are there particular recommendations from the policy report that you believe have not been achieved?

    a. *What do you consider to be the barriers or blocks? Why?*

    b. *What was the impact or effect for you?*

12. Overall, how well do you believe the recommendations in the palliative care policy fit within the Irish health system?

13. What do you think the focus of palliative care policy should be into the future?

    a. *Are there any recommendations you feel are no longer relevant? Why?*

14. Looking to the future of palliative care in Ireland, what do you see as the three priorities required to achieve successful delivery of palliative care policy nationally?

    a. *Any thoughts about what the policy development process should look like?*

15. Is there anything else that you would like to add?

    a. *Did I leave anything out? What questions should I be putting to other people I interview?*

Closing

Thank you for taking time to participate in this research. Do you have any questions for me?

Appendix 7 Interview topic guide for informants acting in a professional capacity

Introduction

Greetings and review of ethics/consent

Summary of study and purpose for interview

Could you please describe your background and role? Your links to palliative care policy and provision in Ireland?

Topics & Questions

1. Reflecting on the implementation of the 2001 national palliative care policy, are there particular recommendations you believe have been implemented well?

    a. *What factors do you think assisted this? Why?*

    b. *To what extent are these factors generic (could be applied to other policies/programmes) or context specific?*

2. Again, reflecting on the implementation of the 2001 national palliative care policy, are there particular recommendations that you believe have not been implemented well?

    a. *What do you consider to be the barriers or blocks? Why?*

    b. *What is the impact or effect of the(se) recommendation(s) not being implemented?*

3. Overall, how well do the recommendations of the 2001 national palliative care policy align with the wider context of the Irish health system and policy?

4. Given the changes that have taken place since the 2001 national palliative care policy, what should the focus be into the future?

    a. *Are there any recommendations you feel are no longer relevant? Why?*

    b. *Are there recommendations that you think should be included? Why?*

5. Looking to the future of palliative care in Ireland, what do you see as the three critical enablers required to achieve successful implementation of palliative care policy nationally?

    a. *Any thoughts or recommendations related to the process for updating the national palliative care policy, and how this can/should support implementation?*

6. Is there anything else that you would like to add?

    a. *Did I leave anything out? What questions should I be putting to other participants?*

Closing

Thank you for taking time to participate in this research. Do you have any questions for me?