All Ireland Position Paper on Rehabilitative Palliative Care

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AIIHPC
All Ireland Institute of Hospice and Palliative Care

HSE

HSC Public Health Agency

RCSI FACULTY of NURSING and MIDWIFERY

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AII Ireland Institute for Hospice and Palliative Care (AIIHPC)

This position paper was initiated and commissioned by the All Ireland Institute of Hospice and Palliative Care (AIIHPC). AIIHPC is a leading organisation with national and international influence promoting excellence in palliative care. AIIHPC is a collaborative of hospices, health and social care organisations, charities and universities on the island of Ireland. AIIHPC's aim, with our twenty-six member organisations, is to ensure excellent palliative care is available for everyone at the right time and place across the island of Ireland.

The AIIHPC is:

- involving service users, carers and communities in palliative care delivery and development
- working to integrate palliative care across the health system so people are supported as early as possible
- supporting the development of specialist palliative care services for everyone who needs them.

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Introduction

Rehabilitative Palliative Care (RPC)

Rehabilitative Palliative Care (RPC) is a person-centred approach that integrates rehabilitation principles into palliative care and end-of-life care for people with life-limiting illness[1]. RPC emphasises interprofessional care and support for **comfort, coping**, **and adaptation** while assuring the preservation of **dignity, autonomy and quality of life** at all stages of illness.

RPC provides care and support that is:

- **Person-centred** so that care is tailored and flexible to an individual's changing needs, wishes and preferences. Assessments and reviews are comprehensive and efficient, reducing the burden on the patient and family to provide information.
- **Interdisciplinary** so that patients benefit from the combined skills and knowledge of different professional groups, including medicine, nursing, physiotherapy, occupational therapy, speech and language therapy (SLT), dietetics, social work, and professions that provide spiritual, psychological or emotional support[2].
- **Ready and responsive** so that patients know that the right type and level of care is there for them, from general support for living with life-limiting illness right up to highly specialised palliative care should they need it.
- **Interconnected** so that patients experience continuous support from organisations and networks that are both within and outside of the healthcare service[3]. The transitions and pathways between curative, rehabilitative and palliative care are streamlined. The burden on patients and families to navigate services is reduced.

Rehabilitative palliative care is becoming a more important feature in the shifting landscape of healthcare. This is because healthcare systems in the Republic of Ireland (ROI) and Northern Ireland (NI), face the challenges of responding to ageing populations and their needs. Around the world people are living longer with life-limiting illnesses, and they are more likely to have **multiple long-term conditions and complex needs.**

In addition to this there have been advances in cancer treatments resulting in more people having palliative treatments where their disease is treatable but not curable. These advances in treatment, alongside other advances in care, mean that more people are **living longer with life-limiting illness**.

Rehabilitative palliative care offers a vital model of care to ensure people live with dignity, autonomy and maintain a good quality of life whilst living with illness. However, **there is much work to be done to develop the model of RPC and capacity to deliver** so that more people can benefit from the care and support they need. As this position paper argues, the work is urgent and it needs to include developing agreed definitions, strategic leadership, interdisciplinary networking, a plan for workforce skills and training, and a service framework to support management, access and equity.

This position paper provides a foundation for an all-island approach to RPC. The paper is designed to stimulate collaboration between policy, practice, education and research, with a focus on service

[1] Harding, Z., Hall, C., & Lloyd, A. (2022b). Rehabilitation in palliative care: A qualitative study of team professionals. BMJ Supportive & Palliative Care, 12(e1), e28–e38. https://doi.org/10.1136/bmjspcare-2019-002008
[2] Blinderman, C. D., & Schapiro, A. B. (2016). Integrating contemplative and spiritual care in outpatient palliative care: A pilot study. Journal of Clinical Oncology, 34(26_suppl), 247–247. https://doi.org/10.1200/jco.2016.34.26_suppl.247
[3] Coffey, S., Twomey, F., Callinan, J., O'Reilly, M., Coffey, A., Holmes, J., & Lucey, M. (2024). Specialist palliative care out of hours telephone advice in Ireland: a national survey. BMJ Supportive & Palliative Care, 14(e1), e1388-e1394.

development around the needs of people and quality of provision. **This approach will ensure that all individuals can live well, and be supported to self-manage where possible, even with life-limiting illness.**

This publication of this position paper initiates a period of consultation and further development with all relevant stakeholders to spread engagement and share ownership.

The Case for RPC

Why rehabilitative palliative care?

- **It provides the type of care and outcomes that people want:** RPC supports independence, dignity and choice, whilst living with life-limiting illness. RPC enables more people to live and be cared for in a home environment.
- **It reduces deconditioning and unplanned admissions:** By supporting patients to manage their illness more effectively through rehabilitative interventions, equipment provision, family/carer training, and rapid community response teams, for example, this can prevent deconditioning and unplanned hospital admissions.
- **Healthcare effectiveness:** Reductions in unplanned inpatient bed use and pressure on emergency departments contribute to a more cost effective healthcare service and longterm sustainability.
- **Equity lens built-in:** RPC models can be targeted to groups who are traditionally underserved by palliative care or often miss out on the opportunity to regain/maximise their own ability, such as those with non-malignant disease and younger adults.

The problem

- Although the vast majority of people express a preference to die at home or close to home, a large proportion of people still die in hospital across the island of Ireland. In the Republic of Ireland in 2022, **41.6%** of deaths occurred in general/orthopaedic hospitals. The Central Statistics Office reported 25.8% were domiciliary/home deaths; 17.0% in nursing homes, and deaths in hospices are approximately 11%[4].
- In Northern Ireland recent figures show around **45–47%** of deaths take place in hospital (for example, 46.1% in 2024)[5].
- Multiple studies and systematic reviews across the UK & Ireland consistently show a strong majority preference to die at home when asked: typically **~75–85%** of people express a wish to die at home. In an Irish hospice-team study >80% named home as preferred place of death. However, only 50% of people who wanted to die at home actually did so[6].
- This mismatch is harmful in several ways: it often means less opportunity to achieve person-centred goals (such as family presence and last days in a familiar environment), potentially more aggressive/undesired interventions, higher costs to the health system, and poorer bereavement experiences for families.

[4] https://www.cso.ie/en/releasesandpublications/ep/p-vsar/vitalstatisticsannualreport2022/deaths2022/
[5] https://www.nisra.gov.uk/news/weekly-deaths-tables-week-ending-6-december-2024
[6] Tiernan E, O'Connor M, Ó Sioráin L, Kearney M. A prospective study of preferred versus actual place of death among patients referred to a palliative care home-care service. Ir Med J. 2002 Sep;95(8):232-5.

- Several audits have shown that a notable fraction of hospital deaths did not require hospital-only interventions and could have been managed elsewhere with better community support and a different model of care[7].

Gaps in service provision and measurement

- Hospice and specialist palliative services across the island of Ireland are **not equitably distributed or equally accessed**. Systematic reviews and audits from Ireland and elsewhere, show consistent patterns: people with cancer, younger patients, and those from well-off areas (higher average income) are more likely to access hospice services. Meanwhile older people, people with non-cancer diagnoses, ethnically diverse, and less well-off groups (socioeconomically deprived), are less likely to receive hospice or specialist palliative care[8].
- Access to palliative care in acute hospitals and in long-term care settings, such as nursing homes, is **highly variable**. Audits such as the National Audit of Care at the End of Life (NACEL) and data from the National End of Live Care Survey in the UK/Northern Ireland, as well as multiple national reviews, point to inconsistent standards, variation by hospital and region, with gaps in staff training, care pathways and community integration[9].
- The **National End of Life Survey** (NELS) offers valuable national insight into people's experiences of end-of-life care in Ireland. Overall, 73.7% of respondents rated care as "very good", and 15.2% as "good", though 23.9% reported poor coordination between services in the last three months of life. However, NELS does not capture data specific to rehabilitative palliative care, which remains under-developed and under-measured nationally.
- Evidence from initiatives such as the Sláintecare Rehabilitative Palliative Care Project suggests that incorporating rehabilitation within palliative services can enhance patient confidence, function, and independence, highlighting gaps in service development and the need for **future national data collection** in this area.
- The recently published **European Association for Palliative Care (EAPC) White Paper**[10] provides an authoritative framework for integrating palliative, geriatric, and rehabilitative approaches to care for older people living with frailty and their family carers. Drawing on a 28-country Delphi consensus, it outlines eleven core domains and thirty-four recommendations that call for a shift from fragmented service delivery toward coordinated, person-centred, and function-focused care. The White Paper underscores the importance of rehabilitation within palliative care, promoting autonomy, participation, and quality of life throughout advanced illness and into bereavement support. Its recommendations offer a timely evidence base for advancing policy and practice across the island of Ireland.

[7] https://bereaved.hscni.net/palliative-care/
[8] Tobin J, Rogers A, Winterburn I, Tullie S, Kalyanasundaram A, Kuhn I, Barclay S. Hospice care access inequalities: a systematic review and narrative synthesis. BMJ Support Palliat Care. 2022 Jun;12(2):142-151. doi: 10.1136/bmjspcare-2020-002719.
[9] https://www.nacel.nhs.uk/home-ni
[10] Van den Block L, de Nooijer K, Pautex S, Pivodic L, Van Den Noortgate N, Nicholson C, Szczerbińska K, Pereira SM, Tiberini R, Hanratty B, Miranda R. A European Association for Palliative Care White Paper defining an integrative palliative, geriatric, and rehabilitative approach to care and support for older people living with frailty and their family carers: a 28-country Delphi study and recommendations. EClinicalMedicine. 2025 Aug 12;87:103403. doi: 10.1016/j.eclinm.2025.103403.

All Ireland Context

In both Northern Ireland and the Republic of Ireland, palliative care policy has increasingly recognised the importance of supporting patients with their comfort, function, independence, and quality of life. The *National Clinical Programme for Palliative Care*[11] in the Republic of Ireland and the *Regional Palliative Care in Partnership Board*[12] in Northern Ireland both endorse multidisciplinary person-centred palliative care as a priority. However, RPC remains relatively underdeveloped in practice.

Why is this so?

- **Formal integration** of rehabilitation within palliative pathways is not consistently present in policy or implemented across regions. Palliative pathways don't always recognise the role of rehabilitation in palliative care.
- **Lack of professional and public understanding** about the benefits of rehabilitative approaches for people who have life-limiting illness and also lack of understanding about how such care is delivered, when and where.
- **General misperceptions** that palliative care is only for people who are near the end of their life rather than a beneficial approach to supporting people to live well with illness.
- **Leadership and strategic coordination** with clear direction and opportunities for networking have not been as strong as the could be, within and between different professional groups.
- **Lack of research and evaluation** of RPC on the island of Ireland means the benefits for patients, professionals and healthcare systems are not well understood.
- **International evidence** is not always comparable or implementable in Ireland.

There are opportunities to build on existing palliative care frameworks by:

- **Facilitating interdisciplinary working** including embedding all health and social care disciplines and groups systematically into the model of care.
- **Improving assessment and reviews** so that patients have a comprehensive assessment and do not need to repeatedly tell their needs, wishes and preferences to different professionals and organisations.
- **Connected care** through creating links between RPC in acute, inpatient, outpatient, digital health, and community and home-based settings[13].

Origin and Development of the Position Paper

This position paper originated from discussions between the All Ireland Institute of Hospice and Palliative Care (AIIHPC) and the Health Service Executive (HSE) in the Republic of Ireland.

With funding from the HSE and PHA, the AIIHPC hosted a seminar and workshop in Dublin on 11 June 2025. The AIIHPC commissioned the Faculty of Nursing and Midwifery, Royal College of

[11] https://www.hse.ie/eng/about/who/cspd/ncps/palliative-care/

[12] https://pcip.hscni.net/

[13] Chan, H. Y., Chung, C. K., Tam, S. S., & Chow, R. S. (2021). Community palliative care services on addressing physical and psychosocial needs in people with advanced illness: A prospective cohort study. BMC Palliative Care, 20(1), 143. https://doi.org/10.1186/s12904-021-00840-0

Surgeons in Ireland (RCSI) University of Medicine and Health Sciences to undertake research and to develop the position paper. The project was undertaken between June and September 2025.

A three-part methodology was used to gather evidence and stakeholder insights to inform this position paper:

1) **Seminar and interactive workshop** hosted by the AIIHPC in Dublin in June 2025, brought together nearly 80 clinicians, researchers, policymakers, and service users. The event included keynote presentations, oral abstracts, panel discussions, and an interactive workshop designed to surface key themes and priorities for RPC development. Over 400 written comments were collected during the workshop to inform the position paper.

2) **Post-seminar discussion groups** involving a series of six 1-hour discussion groups with 18 participants who had attended the seminar. These semi-structured discussions allowed deeper exploration of key issues, including stakeholder reflections on key issues, healthcare and policy considerations, and audience engagement strategies for the position paper.

3) **Scoping review of the literature** using an established method[14] and conducted using international databases and targeted journals to map existing evidence on RPC for adults (+18 years of age) with life-limiting illness. Over 150 peer-reviewed papers were reviewed, with inclusion criteria focused on studies published in English from 2015 to 2025. The review identified models, outcomes, service innovations, and gaps in the evidence base.

The use of three methods ensured that the position paper is grounded in both current research and practice-based insights, reflecting the views of key stakeholders and aligning with strategic priorities of UK and ROI healthcare systems.

A detailed and comprehensive *full report* of the methods and findings from the research is available from RCSI Research Repository[15].

[14] Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. International Journal of Social Research Methodology, 8(1), 19–32. https://doi.org/10.1080/1364557032000119616
[15] Morrow E. and Lynch M. (2025) Rehabilitative Palliative Care: Evidence to Inform an All-Ireland Position Paper. RCSI University of Medicine and Health Sciences, Dublin, Ireland for the All Ireland Institute of Hospice and Palliative Care.

Summary Findings from the Seminar and Workshop

The seminar and integrated workshop on 11 June 2025, engaged a diverse group of health professionals, health service managers, policymakers, researchers, and service users to explore the role of RPC and views on developing the RPC approach.

Key findings from the discussions included:

- **Strong support for RPC principles:** Participants endorsed RPC as a person-centred approach that supports autonomy, dignity, and quality of life. There was consensus that RPC should be integrated across the palliative care continuum and through health professional education, training and development. It is key that the RPC approach is integrated across all dimensions of palliative care rather than confined to a single treatment option or pathway.
- **Desire for further interdisciplinary collaboration and multiprofessional working:** Effective RPC requires shared working between all health and social care disciplines and groups. Stakeholders called for a shift from multidisciplinary (multiple disciplines providing care) to truly interdisciplinary practice (providing integrated person-centred care).
- **Barriers and challenges to RPC:** Common challenges included inconsistent service availability, limited workforce capacity (particularly in community settings), lack of RPC leadership roles, and unclear referral pathways. Some participants felt there were barriers associated with current care cultures, which may not value, or see a role for, rehabilitative approaches in palliative care.
- **Opportunities for innovation and improvement:** Promising examples of integrated practice demonstrate that RPC can be embedded successfully. There was strong interest in developing competency frameworks, shared assessments between different professional groups, and better governance structures to support wider implementation.
- **Improving public understanding and ways of talking about RPC:** Stakeholders highlighted that language matters - terms such as "rehabilitation" and "palliative care" may need clearer explanation to reduce stigma and align with patient values, particularly when orientating care to “what matters to you” and maintaining quality of life.

The seminar and workshop reinforced that while RPC is already being practised in some organisations and places, scaling RPC requires - strategic investment, clear models and definitions, evidence of effectiveness and best practice, and opportunities for continued joint-working across NI and ROI.

Insights from the Stakeholder Discussions

A series of post-seminar discussion groups, with 18 participants, gained further in-depth perspectives on the priorities, challenges, and messaging needed to advance RPC across Ireland. Participants came from a range of backgrounds, including nursing, medicine, AHPs, health and social care professionals (HSCP) including social work, health policy and healthcare management roles.

Key insights included:

- **Broad support for RPC integration:** Stakeholders strongly supported integrating RPC within standard palliative care pathways, noting its potential to enhance patient autonomy, function, and quality of life.
- **Equity and access concerns:** There was concern about the ‘postcode lottery’ effect, with access to rehabilitative services varying significantly by region. Participants called for

consistent, equitable service provision across both the Republic of Ireland and Northern Ireland.

- **Workforce supply challenges and role clarity:** Participants emphasised the need for clearer roles and recognition for the contributions of different professional groups, as well as adequate workforce planning to meet demand in community and home settings. The issue of role blurring was discussed, as well as the need to work towards a shared goal.
- **Leadership and policy gaps:** The absence of dedicated leadership and strategic frameworks for RPC was seen as a major barrier. Stakeholders highlighted the importance of cross-sector leadership to implement RPC, in line with how it is defined in national policies.
- **Effective communication and messaging:** There was consensus on the need to use inclusive, accessible language in public and professional communications- emphasising wellbeing, ability, and living well with illness, rather than decline or dependency.
- **Key target audiences:** Suggested target audiences for the position paper included policymakers, service managers, clinical leaders, educators, patients, families and the wider public, with tailored messaging required for each.

Overall, the participants in the discussion groups expressed a shared commitment to collaborative action on RPC and welcomed the development of a position paper as a critical step toward advancing RPC across the island of Ireland. They also emphasised further consultation and inclusion of all professional groups is essential to gain the necessary momentum for change as quickly as possible.

Evidence from the Literature

The scoping review included over 150 peer-reviewed and grey literature sources. The scope was to map international evidence on rehabilitative palliative care (RPC) for adults (>18 years of age). The findings are available in the full report.

Key findings include:

- **Growing global interest**: The majority of studies originated from high-income countries- particularly the United States, Denmark, Canada, and the United Kingdom- highlighting growing international recognition of RPC as a valuable care approach.
- **Evidence rich in experience, limited in evaluation**: Most studies were qualitative or descriptive, focusing on patient and professional experiences, service models, and conceptual frameworks. However, there is a notable lack of high-level evaluative research, such as randomised controlled trials and cost-effectiveness studies.
- **Sparse island of Ireland evidence**: Very few studies were identified from the Republic of Ireland or Northern Ireland, revealing the need for locally relevant research and service evaluations.
- **Key themes of the literature:**
  - Benefits of interdisciplinary working to support patient function, independence, and quality of life whilst living with life-limiting or longterm illness[16,17,18]

[16] Barawid, E., Covarrubias, N., Tribuzio, B., & Liao, S. (2015). The Benefits of Rehabilitation for Palliative Care Patients. American Journal of Hospice and Palliative Medicine®, 32(1), 34–43. https://doi.org/10.1177/1049909113514474
[17] Feldstain, A., Lebel, S., & Chasen, M. R. (2016). An interdisciplinary palliative rehabilitation intervention bolstering general self-efficacy to attenuate symptoms of depression in patients living with advanced cancer. Supportive Care in Cancer, 24(1), 109–117. https://doi.org/10.1007/s00520-015-2751-4
[18] Ibrahim, A. M., Wahba, N. M. I., Zaghamir, D. E. F., Mersal, N. A., Mersal, F. A., Ali, R. A. E.-S., Eltaib, F. A., & Mohamed, H. A. H. (2024). Impact of a comprehensive rehabilitation palliative care program on the quality of life of patients with terminal cancer and their informal caregivers: A quasi-experimental study. BMC Nursing, 23(1), 357. https://doi.org/10.1186/s12912-024-02028-2

  - The importance of taking a 'What matters to you' approach and structures that promote inclusive and collaborative care planning between patients, families and professionals[19]
  - Challenges of developing RPC, including structural barriers to service integration, workforce capacity development, and professional role boundaries
  - The cultural challenges of early assessment and engagement within existing palliative care pathways that tend to focus on end-of-life[20]
  - Scaling innovation at the practice level to whole service-level models[21]
  - The opportunities to expand community-based and home-delivered models of RPC, utilising digital care and new configurations of skill mix and care provision.

- **Terminology and conceptual differences**: A lack of consistent language and definitions in the research literature created challenges for evidence synthesis on the effectiveness of RPC, reflecting the evolving and interdisciplinary nature of RPC as a multidimensional approach to care rather than a discrete intervention or practice[22].

Overall, the review highlights a growing evidence base that supports the principles of RPC. There are research gaps in implementation and evaluation, outcome measurement, and Ireland-specific research- all of which are critical for informing future policy, service design and best practice.

A detailed bibliography and analysis of all of the 150+ included research papers is available in the full report that supports this position paper. The following figure draws together key findings to illustrate key dimensions of RPC as described in the literature.

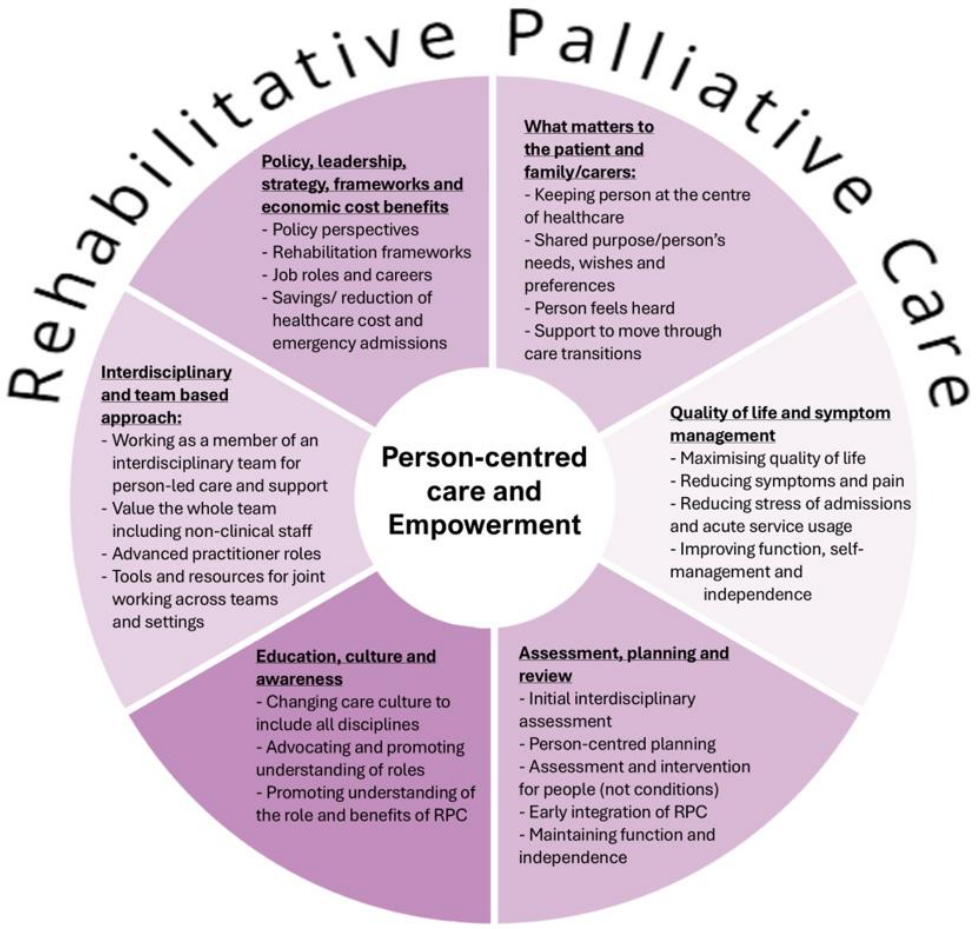
[19] Hwee Heng, C. S. (2024). Collaborative goal setting in palliative rehabilitation: A case report. BMC Palliative Care, 23(1), 179. https://doi.org/10.1186/s12904-024-01506-3

[20] Mah, K., Chow, B., Swami, N., Pope, A., Rydall, A., Earle, C., Krzyzanowska, M., Le, L., Hales, S., Rodin, G., Hannon, B., & Zimmermann, C. (2023). Early palliative care and quality of dying and death in patients with advanced cancer. BMJ Supportive & Palliative Care, 13(e1), e74–e77. https://doi.org/10.1136/bmjspcare-2021-002893

[21] Bayly, J., Ahmedzai, H. H., Blandini, M. G., et al. (2023). Integrated Short-term Palliative Rehabilitation to improve quality of life and equitable care access in incurable cancer (INSPIRE): A multinational European research project. Palliative Care and Social Practice, 17, 26323524231179979. https://doi.org/10.1177/26323524231179979

[22] Timm H, Thuesen J, Clark D. Rehabilitation and palliative care: histories, dialectics and challenges. Wellcome Open Res. 2021 Jul 2;6:171. doi: 10.12688/wellcomeopenres.16979.1. PMID: 35118198; PMCID: PMC8790711.

Figure 1: Key Dimensions of RPC



Definition: Rehabilitative Palliative Care (RPC)

RPC is a person-centred approach that integrates rehabilitation principles into palliative and end-of-life care.

RPC emphasises interdisciplinary care and support for comfort, coping, and adaptation to life-limiting illness.

RCP aims to preserve dignity, autonomy and quality of life at all stages of illness.

RPC involves early assessment and responsive care and support tailored to a person's changing needs, wishes and preferences.

RPC involves and includes carers and families alongside the patient.

RPC benefits patients and families, makes best use of health professional's skills and abilities, and can reduce healthcare costs and unplanned hospital admissions.

Recommendations

Seven recommendations, derived from the research project, are put forward for further consideration.

1. Definition and Model of Rehabilitative Palliative Care

Recommendation: Improve understanding and collaboration by promoting a common definition, acronym, and core components of RPC

- Define Rehabilitative Palliative Care clearly, using a consistent definition and acronym, to align terms across different professions, healthcare contexts, and patient groups.
- Describe RPC as: *"A person-centred approach that integrates rehabilitation principles into palliative and end-of-life care for people with life-limiting illness. RPC emphasises interdisciplinary care and support for comfort, coping, and adaptation while assuring the preservation of dignity, autonomy and quality of life at all stages of illness".*
- Highlight the distinction from traditional palliative or supportive care, positioning RPC as a person-led interprofessional approach to practice, based on an enabling ethos. RPC is not limited to just a set of clinical interventions, protocols, or to the care given by a specific service or unit[23].
- Identify and promote the core components of RPC, to inform and shape the model of care for Ireland that will serve future populations with more complex long-term care needs.

2. Policy and Demographic Insights

Recommendation: Emphasise the growing societal need for RPC in the context of ageing populations, increasing multimorbidity, and complexity of needs

- RPC should be discussed in the context of the needs of ageing populations in both the ROI and NI, emphasising increased multimorbidity and complexity of need.
- Reference relevant health and palliative care policies in ROI and NI that support or have the potential to integrate RPC.
- Make links to broader national and international shifts towards community-based integrated care models, and connect RPC with health service transformation strategies[24].
- Advocate for the integration of RPC into national palliative care strategies.
- Promote the need for equitable funding and access across settings and jurisdictions, including specific consideration of underrepresented and marginalised groups[25].

[23] Brereton, L., Clark, J., Ingleton, C., et al. (2017). What do we know about different models of providing palliative care? Findings from a systematic review of reviews. Palliative Medicine, 31(9), 781–797. https://doi.org/10.1177/0269216317701890
[24] Van den Block, L., de Nooijer, K., Pautex, S., et al. (2025). A European Association for Palliative Care White Paper defining an integrative palliative, geriatric, and rehabilitative approach to care and support for older people living with frailty and their family carers: a 28-country Delphi study and recommendations. eClinicalMedicine, 87.
[25] Aljassem, A., Spickler, M., & Kapur, N. (2024). A path to recovery for overlooked populations and their unique challenges: Integrating rehabilitation in palliative care for patients with substance use disorders. Frontiers in Rehabilitation Sciences, 5, 1373857. https://doi.org/10.3389/fresc.2024.1373857

3. Evidence to Inform Development of RPC

Recommendation: Use evidence and practice knowledge to develop an appropriate model of care for the island of Ireland

- The international evidence highlights the benefits of RPC as including function, autonomy, QoL, reduced emergency/hospital admissions, and potential healthcare savings (see full report[26]).
- Existing definitions and conceptual models should be used to develop a contextually appropriate model for Ireland, drawing on Integrated Interdisciplinary Models, Community and Home-Based Models, Oncology-Specific Rehabilitation Frameworks, Sector-Spanning and Systemic Models, and Innovative and Emerging Approaches (see full report).
- There is evidence to demonstrate the valuable role of allied health professionals in advocating, researching, developing, planning and delivering RPC.
- There are gaps in the evidence, implementation and evaluation of RCP that need to be addressed to inform the model of care.
- New and innovative ways to exchange and promote evidence must be developed. For example, to make it easy for professionals to access peer-reviewed studies, grey literature, and international guidance, such as relevant reports from the World Health Organization[27] and European Association of Palliative Care[28].
- Develop outcomes frameworks and standardised data collection for RPC, to capture data on the benefits for patients, families, staff and healthcare services.
- Fund economic, implementation and evaluation studies to build the evidence base for best practice and innovation.

4. Stakeholder Engagement

Recommendation: Involve stakeholders and their perspectives at a strategic level in discussions about RPC

The stakeholder consultations revealed that:

- Healthcare professionals experience the value of RPC for patients, families and staff however this value can be overlooked within health systems and needs to be surfaced. Networks, communities of practice and consultation work can ensure all perspectives are heard, understood and used to influence discussions at a strategic level.
- There is a need to ensure early and visible engagement of all professional groups in the development process, with particular emphasis on consultation with palliative care doctors and nurses - the largest and most influential segments of the workforce. Their active participation from the outset will help build ownership, minimise the risk of passive resistance, and increase the likelihood of successful implementation of RPC models.

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[26] Morrow E. and Lynch M. (2025) Rehabilitative Palliative Care: Evidence to Inform an All-Ireland Position Paper. RCSI University of Medicine and Health Sciences, Dublin, Ireland for the All Ireland Institute of Hospice and Palliative Care.

[27] Policy brief on integrating rehabilitation into palliative care services. Copenhagen: WHO Regional Office for Europe; 2023. Licence: CC BY-NC-SA 3.0 IGO.

[28] Payne S, Harding A, Williams T, Ling J, Ostgathe C. Revised recommendations on standards and norms for palliative care in Europe from the European Association for Palliative Care (EAPC): A Delphi study. Palliat Med. 2022 Apr;36(4):680-697. doi: 10.1177/02692163221074547. Epub 2022 Feb 3. PMID: 35114839; PMCID: PMC9006395.

- Healthcare professionals feel strongly that they need to be able to define their own role and responsibilities and to understand the contributions of other disciplines to RPC. Training and tools can support these needs.
- Healthcare professionals value the lived experience of patients and families and recognise the importance of involving them in codesigning services to develop RPC. This will ensure services are relevant, responsive and fit for purpose.
- Healthcare professionals want strategic leadership for RCP and models of care that allow them to deliver care that aligns well with patient's needs, wishes and preferences.
- Allied health professions are strong leaders and innovators in practice and seek acknowledgement for their role as advocates in advancing RPC.
- Clinical and managerial professionals emphasise the need for greater opportunities for shared learning, decision-making and evaluation, to develop and deliver RPC.

There is a clear need to give greater consideration to how palliative care and dying are discussed publicly. In our society, these topics remain difficult to talk about with honesty and openness, with many, including the media, avoiding direct terms such as "died" or "dying," often substituting euphemisms such as "passed" or "lost." This reluctance to discuss palliative care needs with patients, carers, families and the public more widely, creates a significant barrier to public understanding and acceptance of RPC. Therefore, any future work must incorporate proactive strategies to consider different public and cultural perceptions around death and dying.

5. Informed Implementation

Recommendation: Gain insights into the systemic barriers to RPC to inform implementation plans

The seminar and stakeholder discussion groups highlighted:

- There is a need to build evidence on the current limitations of workforce shortages generally, and specifically in relation to posts in RPC.
- Identify ways to promote standardised terminology and a shared definition of RPC, e.g. drawing on implementation science and evidence of what works to change models of care.
- Examine referral pathways and where access barriers and inequities might occur.
- Demonstrate variable and inequitable access to RPC across regions and services.
- Address underrepresentation and low visibility of health and social care professional groups in decision making structures.
- Identify specific gaps and opportunities for RPC through coordinated practice improvement projects[29].
- Highlight weaknesses in integration between rehabilitation and palliative care pathways.

[29] Ansari, A., Baron, A., Nelson-Becker, H., Deamant, C., Fitchett, G., Fister, E., O'Mahony, S., & Levine, S. (2022). Practice Improvement Projects in an Interdisciplinary Palliative Care Training Program. American Journal of Hospice and Palliative Medicine®, 39(7), 831–837. https://doi.org/10.1177/10499091211044689

6. Innovations in RPC

Recommendation: Draw together examples of innovation from across the island of Ireland and internationally

The workshop and discussion groups identified example initiatives from across the island of Ireland, including:

- The Palliat-Rehab pilot (Sláintecare ROI)[30]
- EMPOWER group programme[31]
- Community-based integrated clinics[32]
- Compassionate Communities initiatives[33]

There was agreement that future work could draw together what works and emphasise opportunities to scale effective initiatives. Innovation was seen as being a necessary part of the development of an evidence-based model of care, align with health policy goals, and strengthen community partnerships.

7. Training and Education

Recommendation: Invest in education and training in RPC

Service Delivery:

- Work with training and education providers to embed RPC into existing palliative care education at all levels and for all disciplines.
- Interdisciplinary training to support flexible, person-led goal-setting and interdisciplinary assessments.

Workforce Development:

- Invest in optimal skill mix of professional groups and clarify professional roles in RPC.
- Increase health and social care professional's capacity and leadership skills to ensure representation in service planning.

Leadership and Governance:

- Establish regional and national leads for RPC implementation and integration with peer learning support structures.
- Training for clinical governance models and management structures that support safe, collaborative practice, professional development and shared responsibility.

[30] https://palliativerehab.ie/
[31] https://aiihpc.org/wp-content/uploads/2025/06/Lauren-Bolland-EMPOWER-11-6-2025.pdf
[32] Vélez-López A, Carmona-Torres JM, López-González Á, Laredo-Aguilera JA, Callado-Pérez D, Rabanales-Sotos J. Community-Based Interventions in People with Palliative Care Needs: An Integrative Review of Studies from 2017 to 2022. Healthcare (Basel). 2024 Jul 25;12(15):1477. doi: 10.3390/healthcare12151477.
[33] Graham-Wisener, L., & Crawford, A. (2025). Compassionate communities position paper: Fostering compassionate communities: A call to transform caregiving, dying, death and grieving on the island of Ireland. All Ireland Institute for Hospice and Palliative Care & Queen's University Belfast.

Potential Areas for Further Work

While the recommendations previously presented offer a broader strategic direction, the study also identified a number of practical areas for further work and discussion. These are listed below as themes, not in any order of priority:

- **Ownership:** Increase momentum and ownership of RPC approach through further consultation and networking with all stakeholder groups. Invite consultation on the recommendations put forward in this position paper and engage with professional communities of practice and patient representatives to develop the model of care.
- **Policy engagement:** Policymakers and stakeholders can develop national and local strategic leadership through ongoing policy debate on RPC.
- **Research**: Develop a research agenda and research priorities for RPC in Ireland.
- **Economics:** Examine the economics of RPC and build evidence such as social return on investment.
- **Networking**: Strengthen cross-border collaboration, networking opportunities, and shared learning.
- **Education**: Advocate for a review of RPC education and training, making sure that it is available for all professionals who require it to advance their knowledge and skills in this area of practice.
- **Community-based care**: Review the expansion of community and home-based RPC services in line with policies for care closer to home and what matters to patients.
- **Digital**: Explore patient views and preferences on digital health, including electronic health records, digital healthcare and smart technology innovation, to increase capacity and capabilities for community-based RPC[34].
- **Community engagement**: Connect the development of RPC with community initiatives and voluntary sector developments such as Compassionate Communities and Creative Ireland initiatives.
- **Public awareness:** Promote public awareness and societal engagement around living well with advancing illness and opportunities for conversations about RPC.

Conclusion

This position paper has outlined the foundations for advancing rehabilitative palliative care (RPC) across the island of Ireland. While further work is required, the evidence already highlights the significant benefits of RPC for patients, families, service providers, and the wider healthcare system. By enhancing quality of life, fostering coping strategies, and supporting self-management, RPC can help reduce reliance on health services and contribute to more sustainable models of care. Moreover, the research underpinning this paper demonstrates that RPC promotes higher standards of care through interprofessional collaboration, alongside a strong commitment among professionals to drive meaningful change. RPC therefore represents a vital step in transforming healthcare systems to meet the evolving needs of populations. The recommendations and priorities outlined here offer a roadmap for future consultation, priority-setting, and the continued development of this vital and growing area of healthcare.

[34] Chahal, A., & Chaudhuri, P. (2022). Smart health rehabilitation in palliative care during the COVID-19 era. International Journal of Palliative Nursing, 28(12), 558–561. https://doi.org/10.12968/ijpn.2022.28.12.558

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