



AIIHPC

Palliative Care Research Network

**ALL IRELAND INSTITUTE OF
HOSPICE AND PALLIATIVE CARE**

**Palliative Care Research Network
Strategic Plan 2023-2027**



Palliative Care on the island of Ireland

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual. (World Health Organisation (WHO)).

With an ageing population and people living longer with serious illness, the predicted growth for palliative care on the island is 75% in the Republic of Ireland by 2046 and 31% in Northern Ireland by 2040.

This plan was developed in consultation with people with life-limiting conditions, family carers and interested citizens through AIIHPC's Voices4Care, Palliative Care Research Network and Early Career Researcher Forum members, Palliative Care Research Network Strategic Scientific Committee members, AIIHPC's Council of Members and member organisations, research funders and key stakeholders. The plan was co-ordinated by Dr Mary Rabbitte, AIIHPC Research Programme Manager and the AIIHPC team. AIIHPC would also like to acknowledge the support of Dr Claudine Kearney, Senior Lecturer/ Programme Director RCSI Graduate School of Healthcare Management.

The plan is underpinned by detailed annual implementation plans overseen by the Palliative Care Research Network Strategic Scientific Committee who guide the work of the network as part of AIIHPC's governance structures. Annual reports on progress will be published on AIIHPC's The Palliative Hub Professional website at professionalpalliativehub.com.

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AIHPC Chair and Director Message

As we look to the future and growing demand for palliative care on the island of Ireland, it is of critical importance that we further expand palliative care research across universities and hospice and palliative care providers and the wider health sector to address practice and policy priorities, the changing landscape for palliative care, and support health and social care on the island.

All Ireland Institute of Hospice and Palliative Care (AIHPC) is a collaborative of universities, hospices, health and social care providers and charities on the island of Ireland that advances education, research, policy, and practice to improve the palliative care experience of people with life-limiting conditions and their families. We established the Palliative Care Research Network (PCRN) in 2012 and the Early Career Researcher Forum (ECRF) the following year. Today we have 53 Palliative Care Research Network members who are leading researchers in palliative care from AIHPC's member organisations across nursing, medicine, psychology, pharmacy, occupational therapy, speech and hearing therapy, physiotherapy, health economics and law disciplines across the island of Ireland. Over 215 further researchers, who are at an earlier stage of their involvement with palliative care research, are now members of our Early Career Researcher Forum across the island of Ireland.

AIHPC's Palliative Care Research Network Strategic Plan 2023-2027 sets out our core principles and commitments to continue to advance outcomes that have a positive impact on the quality of life and death for people with life-limiting conditions and supports for their families. This plan builds on our work over the last 5 years to develop a collaborative and coherent community, build research leadership and capacity, involve service user, carers, and communities, disseminate knowledge from research and ensure PCRN sustainability.

As we look to the future, we do it as an established network in palliative care research on the island and internationally. Our 5-year plan will grow the Palliative Care Research Network across the island of Ireland by facilitating academic-clinical collaborations involving people with life-limiting conditions and their families for critical research to improve quality of life and death for people with life-limiting conditions.

We will do this in continued partnership and engagement with the HSE National Clinical Programme for Palliative Care and Children's Palliative Care Special Advisory Group in the Republic of Ireland and Palliative



Care in Partnership Regional Board and Paediatric Palliative Care Network in Northern Ireland, and Departments of Health and key health agencies in both jurisdictions. We will ensure support and alignment to the Palliative Care Policy for Adults in Republic of Ireland, which will be published in 2023 and the Palliative care for children with life limiting conditions in Ireland - A National Policy (2014) and to the Living Matters, Dying Matters – a palliative and end of life care strategy for adults in Northern Ireland (2010) and A Strategy for Children's Palliative and End-of-Life Care 2016-26 in Northern Ireland.

We acknowledge the support of the Health Research Board and Health and Social Care R&D Division, Public Health Agency who provide essential funding to AIHPC which enables us to support the PCRN and ECRF and we look forward to continued collaboration. We would also like to acknowledge and thank AIHPC's 26 member organisations which include universities, hospices, health and social care providers and charities for their essential support and engagement with our work. In addition, AIHPC's funders which include the HSE and Public Health Agency, are also integral to the ongoing operation of the Institute and we are very appreciative of their ongoing contribution.

Together, as the Chair and Director of AIHPC, with the Palliative Care Research Network Strategic Scientific Committee, Palliative Care Research Network Early Career Researcher Forum members and AIHPC's Council of Members we are incredibly honoured to be involved in shaping the future of the network to contribute to positive change in palliative care on the island of Ireland and internationally. Palliative care research continues to be an underfunded area of health research and we look forward to working together collaboratively to address this to support much needed research which will directly impact on the quality of life for people with life-limiting conditions and their families.

Fintan Fagan

Chair AIHPC

Karen Charnley

Director AIHPC

What we have achieved

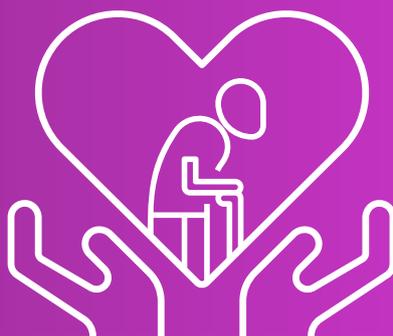
58%

increase in Palliative Care Research Network membership with 4 new disciplines introduced, occupational therapy, physiotherapy, speech and hearing therapy and law.



434%

increase in Early Career Research Forum membership with 10 members transitioning to Palliative Care Research Network membership.



>1,200

people participated at our 5 Annual PCRN Symposia, 2 All Ireland interdisciplinary seminars, 8 expert-led workshops, 10 PCRN webinars, 4 research webinars, 3 public webinars and hosted EAPC International Seminar.



PCRN members supported

to take up leadership positions including as a Board Member of European Association of Palliative Care.

90

requests from PCRN and ECRF members to involve AllHPC's Voices4Care members (people with life-limiting conditions, family carers, and interested citizens) in their research and > 85 research activities and projects involved Voices4Care members.

€3m

EU funding and > €2.3m national funding leveraged for palliative care research between 2017 – 2020.

550

peer-reviewed publications

24

research project web pages

16

blogs

8

podcasts

Vision, Mission and Values

Our vision

As the leading Network for palliative care research on the island of Ireland, Network members undertake internationally recognised research that enhances palliative care knowledge and expertise and improves the quality of life of people with life limiting conditions and their families.

Our mission

To support the conduct of research that improves the quality of life and death of people with life limiting conditions and that contributes to the achievement of AllHPC's strategic work programmes to:

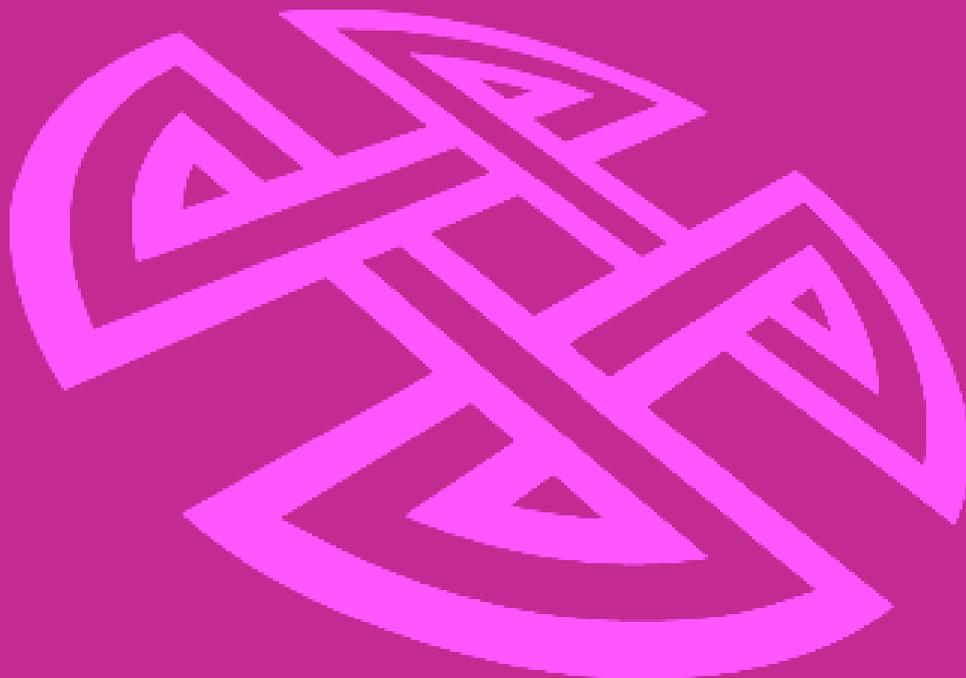
- Integrate research, education, and practice development of palliative care in the health and social care systems across both jurisdictions
- Partner with users, carers, and communities in relation to production of resources for palliative care
- Target the development of the specialist palliative care sector to meet current and emerging demands in respective health systems

Our values

- Research Excellence
- Respect, Trust, and Mutual Understanding
- Equality, Diversity, and Inclusiveness
- Curiosity, Collaboration, and Integration



**We will improve the quality of
life and death for people with
life-limiting conditions through
palliative care research**



Priorities

2023-2027

Strengthen and expand collaboration

We will work across disciplines on the island of Ireland to extend collaboration including internationally in areas of common interest that can improve the quality of life and death for people with palliative care needs.

Create an academic–clinical environment to foster innovation

We will act to improve the effectiveness of multidisciplinary academic-clinical studies to answer the most important questions by building academic-clinical capability and support structures to foster innovation.

Develop palliative care researchers and support career paths

We will support members to become recognised experts and leaders in palliative care by securing investment, mentoring, structured training, brokering involvement in national/international studies and supporting career paths.

Involve people with life-limiting conditions, family carers, and communities across research cycle

We will grow the level of involvement of people with life-limiting conditions, family carers, and interested citizens across all stages of decision making in palliative care research and evaluate their impact.

Maximise research impact on practice and policy

We will address practice and policy priorities by co-producing and mobilising research evidence with health and social care professionals, palliative care providers, commissioners, policy makers, people with life-limiting conditions and family carers.

Our Commitments

Strengthen and expand collaboration

Increasing interaction of PCRN members

We will develop Special Interest Groups for members in key areas aligned to research interests, programmes, priorities, and policies and Palliative Care Research Network (PCRN) database of members' clinical areas, studies, interests, and expertise.

Expanding our coherent research programmes

We will involve more clinical sites, academic institutions, policy makers, people with life-limiting conditions/family carers, AllHPC's Expert Collaborators, and funders in palliative care research as collaborators or partners on funding applications and membership of steering groups.

Strengthening collaboration

We will grow AllHPC academic institutions members and develop further links with networks and organisations on the island of Ireland and Internationally.

Examples of how we will do this:

- Develop Special Interest Groups in research interest areas aligned to priorities, policies, and needs of people with palliative care needs for PCRN and Early Career Researcher Forum (ECRF) members and include people with links to service challenges, with support of AllHPC
- Support Special Interest Groups to convene and manage their own membership to develop themed

research programmes, collaborate on research, organise events and create publications with support of AllHPC

- Increase PCRN interactions and collaborations by developing a central repository on The Palliative Hub Professional Research zone with PCRN members clinical areas and interests, with support of AllHPC
- Increase involvement of hospice and palliative care providers, academic institutions, Departments of Health, and health agencies, Voices4Care members, AllHPC Expert Collaborators and funders on island of Ireland as collaborators on research proposals with AllHPC support
- Strategically focus on building relationships with academic institutions not currently members and international organisations not currently aligned to AllHPC PCRN

We will measure success by:

- Number of strategically planned PCRN collaborations and PCRN collaborations developed through Special Interest Groups submitted for funding and/or successful in attracting national, EU and international funding for palliative care research every year
- Number of PCRN members in leading and senior roles on projects at EU and international level that have been supported by AllHPC PCRN every two years



Create an academic–clinical environment to foster innovation

Developing academic-clinical research capability

We will support our members with a Community of Practice for Evidence-Based Care, deliver research training for hospice and palliative care providers and learn from other clinical trial networks.

Fostering innovation through funding partnerships

We will proactively establish and grow partnerships that support the development of innovative multidisciplinary intervention studies based in hospice, hospital, or community settings.

Developing capacity in trial methodology

We will work with established trial supports on island of Ireland to develop members' knowledge of trial methodology and reporting.

Examples of how we will do this:

- Bring together health and social care professionals from AllHPC hospice and palliative care providers and researchers in a Community of Practice for evidence-based care to share information on ongoing research, findings and potential studies linked to practice questions.
- Identify barriers and facilitators to clinical site involvement in palliative care research by surveying hospice and palliative care providers, Voices4Care, PCRN and ECRF; and generate baseline of hospice and palliative care providers involvement

- Develop capacity building activities with action learning to support hospice and palliative care providers involvement in research
- Develop links with clinical trials networks, such as HRB Rare Disease Clinical Trial Network and NI Clinical Research Network, to support multicentre clinical trials in palliative care
- Establish relationships with potential industry, national and international partnerships that could develop into funding opportunities for multidisciplinary intervention studies
- Build strong links to Clinical Research Facilities and Centres, such as HRB Clinical Research Centres/ Facilities, HRB Trials Research Methodology Research Network, HSC R&D NI Clinical Trials Unit and NI Clinical Research Facility and internationally
- Plan for at least one strategically planned PCRN multisite clinical intervention study in palliative care and develop clinical intervention

We will measure success by:

- 20% increase in number of health and social care professionals and hospice and palliative care provider sites involved in palliative care from baseline identified 2023
- At least one strategically planned PCRN multisite clinical intervention study in palliative care



Develop palliative care researchers and support career paths

Securing investment in researchers

We will strategically plan and support PCRN-led collaborations to secure funded PhD and postdoctoral programmes in palliative care across our academic partner sites involving AIIHPC member organisations. We will support PCRN members to develop academic-clinical PhDs with AIIHPC hospice members in collaboration with AIIHPC.

Developing research experts

We will support a mentoring scheme delivered by PCRN members for PCRN and ECRF members transitioning to PCRN. We will build research expertise and knowledge in areas of identified need with expert led events and workshops.

Supporting career paths

We will support members to lead on or support funding applications involving ECRF members through mentoring, training, and brokering their involvement in national and international studies. We will seek opportunities to support career paths for researchers and clinical academics at all stages of their careers.



Examples of how we will do this:

- Strategically plan PCRN-led collaborations for PhD/ postdoctoral programmes to funding schemes, such as, HRB Collaborative Doctoral Scheme, HEA North South Programme; and broker relations with AIIHPC members for academic-clinical PhD opportunities
- Develop mentorship process, identify mentors, provide mentor training on yearly basis, and align mentors to mentees with support of AIIHPC; and engage with AIIHPC Expert Collaborators as potential mentors
- Identify and address competence needs of PCRN and ECRF with expert-led workshops/events involving PCRN, AIIHPC Expert Collaborators and Special Interest Groups on topics, such as, research in clinical settings, health economics, technology, children's palliative care
- Support PCRN to lead on collaborative funding applications at international level and involve ECRF as co-applicants with AIIHPC support
- Meet with Health Research Board (HRB), Health and Social Care R&D Division, Public Health Agency (HSC R&D, PHA) and funders on researchers' funding challenges; and meet with Higher Education Authority and HSE National Doctors Training and Planning and Higher Education Division and Clinical Academic Training Board on clinical academic pathways
- Deliver funding/grant writing workshops, provide mentoring and brokering support to support members' collaboration on national/international studies to secure contract/permanent posts.

We will measure success by:

- Number of PCRN members who credit PCRN support in taking up leadership roles (academic, clinical, board level) every two years
- 50% increase in ECRF members transitioning to PCRN membership with support of AIIHPC.
- Number of strategically planned PCRN-led PhD/ postdoctoral programmes submitted for funding and/or successful in attracting national and EU funding every two years

Involve people with life-limiting conditions, family carers, and communities across research cycle

Empowering people's involvement

We will advocate and actively promote wider public involvement in research through Voices4Care and empower Voices4Care members to feel confident and comfortable in being involved in decision making in design, delivery, and interpretation of research.

Supporting researchers to enable PPI

We will make it easier for our researchers to include PPI (Personal and Public Involvement or Public and Patient Involvement) through Voices4Care involvement, contacts for other PPI groups, and support for researchers on PPI from proposal through to project delivery, and beyond.

Evaluating impact of PPI

We will evaluate the impact of Voices4Care involvement in research projects and activities by co-creating a PPI Impact Evaluation Framework for researchers to use in their research studies using quantitative and qualitative methods.



Examples of how we will do this:

- Promote wider public involvement in research activities, for example, by working in partnership with other organisations to build the children's voice in palliative care.
- Continue to develop and deliver training on involvement in research for Voices4Care, AllHPC's volunteer group, and make it available to other organisations.
- Promote Voices4Care involvement across research cycle including at PCRN Annual Symposium
- Publish the Voices4Care involvement request process on The Palliative Hub Professional and promote within members' organisations
- Encourage members to use an island of Ireland approach to PPI, through Voices4Care and engagement with other PPI groups including condition specific organisations
- Continue to develop and deliver training for researchers on engaging PPI and support them to develop links with HRB PPI Ignite Networks and use UK Standards for Public Involvement supported by HSC R&D, PHA, to support development, such as, equitable costing models for PPI
- Work with Voices4Care, PCRN, and ECRF members to develop and publish an impact evaluation framework informed by HRB PPI Ignite Networks and UK Standards for Public Involvement supported by HSC R&D, PHA.

We will measure success by:

- Number of Voices4Care members involved in research projects/activities and PCRN and ECRF members' requests for involvement every year
- Number of case studies on measured impact of Voices4Care involvement in research projects using impact evaluation framework

Maximise research impact on practice and policy

Planning for impact from the start

We will support and encourage our members, at the research proposal stage, to consider how their research could be implemented into practice or impact policy - and to involve the people with the knowledge, skills, networks, and influence needed to make this happen.

Improving research, practice, and policy connections

We will support our members to engage with health and social care professionals at hospice and palliative care sites and policy makers in the Departments of Health and health agencies in both jurisdictions, to develop shared understanding and mobilise research evidence that can support decision making in practice and policy.

Increase dissemination to the public

We will support our members to engage with the public and disseminate their research using accessible content and language to improve the public's awareness and knowledge of palliative care research on the island of Ireland.

Examples of how we will do this:

- Develop and promote a support area for implementation on The Palliative Hub Professional Research zone with case studies, resources, and support tools
- Support site visits and/or online meetings between Special Interest Groups and clinicians from AllHPC's hospice and palliative care members to increase understanding of clinical and research challenges and facilitators

- Continue to engage policy makers at research events and support researchers to plan for engagement with policy makers with a policy/practice engagement request form and process.
- Develop and deliver workshop on 'developing an effective policy and/or practice brief in palliative care' for PCRN and ECRF members; and publish and promote workshop video recordings and support materials on The Palliative Hub Professional
- Provide mentoring support from AllHPC, such as reviewing draft policy briefs, blogs etc. for members and provide opportunities for them to promote through AllHPC networks
- Continue to support researchers to develop public facing messages on research, with infographics, webinars, podcasts, blogs, and content and promoting publications published on The Palliative Hub Professional.

We will measure success by:

- Number of case studies demonstrating impact of research on practice and/or policy and number of policy briefs and/or practice briefs produced by members with AllHPC support
- Increase number of open access research peer-reviewed journal articles and retain (at a minimum) the current level of peer-reviewed journal articles, books/book chapters produced by PCRN members every year
- Number of policy makers and/or health and social care professionals/service providers involved in research impact activities/events every year



Appendix One

AIHPC Member Organisations 2022

Belfast Health & Social Care Trust	North West Hospice
Dublin City University	Our Lady's Hospice & Care Services
Dublin University Trinity College	Public Health Agency
Galway Hospice Foundation	Queen's University Belfast
Irish Cancer Society	South Eastern Health & Social Care Trust
Irish Hospice Foundation	South East Technological University
Lauralynn Ireland's Children's Hospice	Southern Health & Social Care Trust
Macmillan Cancer Support NI	St. Francis Hospice
Marie Curie	Ulster University
Marymount University Hospital & Hospice	University College Cork
Milford Care Centre	University College Dublin
Northern Health & Social Care Trust	University of Galway
Northern Ireland Hospice	Western Health & Social Care Trust

Appendix Two

AIHPC Palliative Care Research Network Strategic Scientific Committee

Professor Kevin Brazil, School of Nursing and Midwifery, Queens University Belfast

Monica Burns, Voices4Care Member

Dr Maura Dowling, Senior Lecturer, School of Nursing and Midwifery, University of Galway

Associate Professor Michael Connolly, Associate Professor, School of Nursing and Midwifery, University College Dublin

Dr Nicola Cornally, Senior Lecturer, School of Nursing and Midwifery, University College Cork

Professor Andrew Davies, Professor of Palliative Medicine, Trinity College Dublin, University College Dublin, Our Lady's Hospice and Care Services (Chair of PCRN)

Professor Suzanne Guerin, Professor of Research Design and Analysis, Head of School of Psychology, University College Dublin

Professor Sonja McIlpatrick, Professor in Nursing and Palliative Care, Head of School of Nursing, Dean of Ulster Doctoral College, Ulster University

Dr Gail Johnston, Programme Manager, HSC R & D Division, Public Health Agency, Belfast

Dr Mike Lucey, Consultant in Palliative Medicine, Milford Care Centre Limerick and HSE Mid-West

Dr Peter May, Research Assistant Professor, Public Health and Primary Care, Trinity College Dublin (Vice Chair of PCRN)

Dr Tracey McConnell, Marie Curie Senior Research Fellow, Queen's University Belfast

Dr Deborah Muldrew, Lecturer in Health Sciences, School of Nursing and Paramedic Science, Ulster University (Chair of Early Career Researcher Forum)

Professor Charles Normand, Professor Emeritus in Health Policy and Management, Trinity College Dublin, and Professor of the Economics of Palliative Care and Rehabilitation at King's College London

Professor Sheila Payne, Professor Emeritus, International Observatory on End of Life, Lancaster University, United Kingdom

Professor Joanne Reid, Professor of Cancer and Palliative Care, School of Nursing and Midwifery, Queen's University Belfast

Professor Anthony Staines, Professor of Health Systems, School of Nursing, Psychotherapy and Community Health, Dublin City University

Dr Mark White, Vice President Research, Innovation and Graduate Studies, South East Technological University



AIIHPC

Palliative Care Research Network



Health
Research
Board



Public Health
Agency

Research and Development