



# AIHPC

All Ireland Institute of  
Hospice and Palliative Care

## Palliative Care Research Network Strategic Plan: 2017 – 2022



# Introduction

As Chair of the Palliative Care Research Network (PCRN) Strategic Scientific Committee, it is my pleasure to launch the PCRN Strategic Plan: 2017 – 2022. This strategy document comes at a time of significant interest in the role of palliative care research in shaping and underpinning the expansion and redesign of services for people requiring all levels of palliative care across the island of Ireland. Since its inception in 2012, the PCRN has brought researchers together in a coherent network, encouraging and supporting research across a broad range of areas of relevance to palliative and end of life care.

This plan sets out a strategic direction for the PCRN as a confident and successful network, building and strengthening our research community and ensuring that research impacts at the local, national and international levels. The strategy provides a framework for all those seeking to undertake palliative care research, from early career researchers to those leading and shaping international projects.

Through this strategy the PCRN demonstrates its commitment to work collaboratively to strengthen palliative research, education, policy and practice on the island of Ireland and further afield. This is made possible through the

ongoing support of our partners and funders to establish two supporting posts, a PCRN project manager and a project manager for knowledge transfer. These new roles increase the ability of All Ireland Institute of Hospice and Palliative Care (AIHPC) to assist researchers in accessing potential collaborators, stakeholder groups and implementing effective knowledge transfer and exchange plans which meet the needs of healthcare professionals, policy makers, individuals involved in service development, advocacy groups, voluntary organisations and service users.

I am sure we all look forward to seeing the PCRN network build on successes to date and take advantage of future opportunities over the next five years.



Prof Sonja McIlfatrick  
Ulster University, Head of School of Nursing

## All Ireland Institute of Hospice and Palliative Care (AIHPC)

All Ireland Institute of Hospice and Palliative Care (AIHPC) is a leading organisation with national and international influence driving excellence in palliative care<sup>1</sup>. AIHPC is a collaborative of hospices, health and social care organisations and universities on the island of Ireland. AIHPC advances research, education and practice to improve the palliative care experience of people with life limiting conditions. As the palliative care sector's Institute AIHPC is:

- working to integrate palliative care across the health and social care system so people are supported as early as possible,
- involving people with life limiting conditions, carers and communities in palliative care delivery and development,
- supporting the development of specialist palliative care services for people who need them.

See Appendix A for details of AIHPC partners

## AIHPC's Palliative Care Research Network (PCRN)

In 2012, AIHPC established the Palliative Care Research Network (PCRN) to address the need for more collaborative multidisciplinary research in palliative care on the island of Ireland. The PCRN aims to offer the all-Island palliative care research community opportunities to create and engage within a collaborative environment, supporting the development of excellent, high quality, clinically-relevant and innovative research projects that reflect, inform and contribute to the advancement of AIHPC's work programmes.

The PCRN is a network of researchers with a commitment to high quality research and evidence-based practice in the area of palliative and end of life care. The Network has a broad membership comprised of academic and clinical researchers with experience of national and international research who have a wide variety of knowledge and expertise. The membership includes representatives from leading academic institutions and hospices from across the island of Ireland. The members are involved in and collaborate on research in the broad areas of palliative and end of life care. This includes projects that are formally affiliated to AIHPC and international collaborations with leading institutions and research networks.



### PCRN Research Objectives

<sup>1</sup>“Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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”. *World Health Organisation*

## AllHPC's Early Career Researchers Forum (ECRF)

The PCRN incorporates the Early Career Researchers Forum (ECRF), which is central to the Network's role in capacity building. The ECRF is open to researchers and practitioners in the early stages of developing their research profile in palliative and end of life care<sup>2</sup>. It has an executive committee consisting of a chair, vice-chair, membership secretary and ordinary members.

## AllHPC and AllHPC Research Team

Supporting the development of the PCRN is a key priority for AllHPC and the Institute is well positioned to support the PCRN maximising the ability of palliative care research to change practice, through education and informed evidence-based policy on the island of Ireland. AllHPC is well placed to broker relationships and support research collaborations between its academic, hospice and health and social care organisation partners and key stakeholders, including policymakers and health and research funders (see Appendix 1). In addition, through AllHPC's links with expert collaborators and international networks (see Appendix 2), the PCRN supports its members to ensure their research is relevant to the island of Ireland and international research priorities.

AllHPC's research team consists of a programme manager, a PCRN project manager and a project manager to support knowledge transfer and exchange activities. PCRN members benefit from access to both this core AllHPC research team and the wider AllHPC team (including education, policy and practice). AllHPC provides support to researchers in:

- developing research proposals and projects
- accessing potential collaborators, people living with life limiting conditions, carers and community involvement
- knowledge transfer and exchange for research projects.

The directory of researchers in the area of palliative and end of life care is hosted on the Palliative Hub – Professional and maintained by AllHPC.

## AllHPC's Palliative Care Research Network Governance

The PCRN Strategic Scientific Committee is responsible for supporting the strategic development of the Network, supporting the management of proposals for activities and programmes of work in collaboration with AllHPC. The PCRN Strategic Scientific Committee's membership includes representatives from academic institutions, hospices, members of the Voices4Care Research Panel (Voices4Care is AllHPC's service user, carer and interested citizen group and within this group there is a Research Panel subgroup) and health funding organisations (see Appendix 3) across the island of Ireland.

<sup>2</sup>ECRF is open to researchers and clinicians from all disciplines who consider themselves in the early to mid stages of their research career in palliative and end of life care. This usually covers the first 5-10 years following initial qualification (e.g., those who are about to commence, currently undertaking or recently completed postgraduate studies relevant to palliative or end of life care; about to commence or are currently undertaking post-doctoral research relevant to palliative or end of life care; interested and committed to developing palliative care research on the island of Ireland).

## Our Strategic Plan

This is the five-year strategic plan for AllHPC's Palliative Care Research Network, setting out the content and direction over the next five years.

## 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<sup>3</sup> with life limiting conditions. This will contribute to the achievement of AllHPC's three strategic work programmes:

- working to integrate palliative care across the health and social care system so people are supported as early as possible
- involving people with life limiting conditions, carers and communities in palliative care delivery and development
- supporting the development of specialist palliative care services for people who need them

## Research Strategic Objectives

1. Facilitate the development of a collaborative and coherent research environment and culture
2. Strategically support the delivery of outstanding, innovative, internationally relevant research on an all-island basis
3. Develop research leaders and research capacity
4. Facilitate the advancement of knowledge and practice for hospice and palliative care through interdisciplinary collaborations and meaningful involvement of people with life limiting conditions and their carers
5. Facilitate the effective translation of knowledge on the island of Ireland and internationally, demonstrating the impact of research and development programmes on policy and strategic health priorities

## Activity Areas

The strategic objectives will be achieved through a focus on five activity areas over the next five years:

1. Support the Development of a Collaborative and Coherent and Research Community
2. Build Research Leadership and Capacity
3. Support Service User, Carer and Community Involvement
4. Effectively disseminate Knowledge from Research
5. Build Sustainability of the Palliative Care Research Network

<sup>3</sup>The PCRN's research interests including palliative care for all age and conditions including children, young people and adults

## Key Activity Areas

### 1. Support the Development of a Collaborative and Coherent Research Community

1. Work with AllHPC to expand partnership to include further academic institutions and organisations with an interest in palliative care research
2. Expand membership of PCRN to include senior researchers from within AllHPC partner organisations from a range of health and wider disciplines (i.e. ethics, law, arts, science, economics) through a transparent membership scheme
3. Organise and promote the PCRN Annual Symposium to facilitate and support the continued development of the Network and its impact
4. Organise at least one seminar/workshop per year to support members' continued professional or skills development (e.g. interdisciplinary workshop)
5. Continue to develop links with a range of networks and organisations including collaborative networks on the island of Ireland and internationally; condition-specific organisations and community groups/networks. Investigate opportunities for PCRN members to collaborate with these networks on research
6. Design, implement and continuously evaluate a PCRN Collaboration Plan that supports collaboration between AllHPC's partners, policy makers, key stakeholders, people with life limiting conditions and carer representatives (including AllHPC Voices4Care Research Panel) in activities such as funding proposals, dissemination activities etc.
7. Identify potential focussed research programmes informed by research priorities (Appendix 4) and ensure research informs and is informed by palliative care policy (Regional Palliative Care Board - Palliative Care in Partnership (NI) and National Clinical Programme for Palliative Care (RoI))
8. Ensure regular information flows to members in order to maximise collaboration opportunities (encourage two way communication)
9. Utilise AllHPC's expert collaborators (Appendix 2) to inform, support and potentially collaborate on research projects
10. Strengthen links with and between clinical sites, academic institutions, policy and service user/carer representatives and funders.

## 2. Build Research Leadership and Capacity

1. PCRN members to support AllHPC in seeking and securing funding to enable a range of capacity building activities including Research Project Seed Funding, Clinical Fellowship Awards, Doctoral Collaborative Awards, and Travel Bursaries (conferences, methodology courses; on the island of Ireland and internationally)\*
2. Expand the membership of the ECRF and deliver a programme of activity to support career progression and the next generation of research leaders (two events per year), including promotion of ECRF
3. Encourage ECRF members to 'graduate' from the ECRF to become full members of the PCRN as their career progresses to ensure palliative care research expertise is not lost
4. Create an interactive coaching / mentoring scheme within the PCRN and ECRF, including two way exchange, across disciplines\*
5. Provide leadership development training for PCRN/ECRF members\*
6. Support PCRN members to lead on or support collaborative funding applications (including supporting early career researchers as co-applicants)
7. Build on the knowledge, skills and expertise of senior PCRN members and AllHPC Expert Collaborators to enhance research capability and quality (e.g. senior member of PCRN/Expert Collaborator deliver one workshop per year)
8. Support development of thematic groups, research clusters and themed research programmes (e.g. develop special interest groups such as condition/age /rural communities)
9. Maximise use of AllHPC Palliative Hub Professional to support the PCRN and ECRF and their members including:
  - 'spaces' to facilitate collaboration on research projects
  - promotion of Network, members and their research interests and projects including regular Blogs, and research in focus section
  - providing a focal point for resources to support researchers
10. Broker collaborative relationships with clinical sites including via AllHPC Partners (hospices and health and social care providers). Support hospices to utilise resources such as 'Research Ready Hospices' (Research in palliative care: can hospices afford not to be involved? A report for the Commission into the Future of Hospice Care. London: Help the Hospices; 2013)
11. Support collaboration initiatives by collating PCRN member research interests (including previous, current, and future research projects, PhD students etc.)

\* Funding dependent

### 3. Support Service User, Carer and Community Involvement

1. Develop a mechanism to ensure people with life limiting conditions, carers and the wider community (including Voices4Care Service User/Care Group and Voices4Care Research Panel) can actively become involved in palliative care research from planning through to evaluation
2. Further develop AllHPC Voices4Care Research Panel by:
  - assessing and supporting training needs
  - developing training (e.g., to develop service users' skills as research panel members, project advisory group or steering group members, public reviewers and peer interviewers)
  - facilitating Task and Finish Subgroups
  - ensuring members can inform the entire research process
  - embedding service user experience within research applications coming from PCRN members and AllHPC
  - developing collaborations and links with the research community and other Patient and Public Involvement initiatives
3. Support PCRN members to meaningfully engage with and involve people with life limiting conditions, carers and communities
4. Advocate and actively promote wider public engagement and involvement in research activities
5. Promote and ensure the centrality of people with life limiting conditions and their carers' experiences in the planning and evaluation of relevant research
6. Evaluate the impact of service user, carer and community involvement in the PCRN

## 4. Disseminate Knowledge from Research

1. Support effective dissemination through the promotion and utilisation of the Evidence-based Model for the Transfer and Exchange of Research Knowledge (EMTReK) in palliative care including facilitating workshops
2. Support Health Research Board PCRN projects that have been completed in 2017 with knowledge transfer activities in order to maximise impact
3. Establish knowledge transfer activities, for example develop workshops to interpret data (e.g. involving policy/ key decision-makers, people with life limiting conditions/carers), provide training opportunities on using social media platforms to disseminate research
4. AllHPC knowledge transfer project manager to actively support PCRN to utilise traditional and non-traditional knowledge transfer techniques (i.e. peer review publications, presentations, social media, arts, blogs etc.)
5. Promote the use and accessibility of the Palliative Hub as a central point for knowledge transfer
6. AllHPC to actively seek opportunities for PCRN members to influence and inform policy and strategy in palliative care in both jurisdictions on the island of Ireland (e.g., present their research to key policy makers/funding organisations; link appropriate departments with PCRN member)
7. Maximise use of Palliative Hub as a 'shop window' for PCRN and utilise media / social media to highlight research

## 5. Build Sustainability of the Palliative Care Research Network

1. Support PCRN members to ensure projects respond to identified palliative care research priorities (i.e. All Island Research Priorities, Let's Talk About Palliative Care, Knowledge Innovation Dissemination Learning Exchange (KINDLE) project) (Appendix 4)
2. Secure funding to ensure continued infrastructure support for the PCRN within AllHPC
3. Continue two-way engagement with key policymakers, stakeholders and funding organisations<sup>4</sup> so that current and emerging policy and strategy (including priorities from the Regional Palliative Care Board - Palliative Care in Partnership (NI) and National Clinical Programme for Palliative Care (Rol)) can reflect work led by PCRN members and vice versa
4. Regularly seek feedback from PCRN members to encourage ongoing engagement and ensure the Network is meeting members' needs. Continue to support collaboration between members, AllHPC and wider AllHPC partners (member buy-in order to ensure ongoing sustainability)
5. AllHPC and PCRN to continually seek opportunities to support collaborations with organisations and networks on the island of Ireland and internationally
6. Create opportunities for PCRN to be recognised on the island of Ireland and internationally as a leading research network
7. Promote and market PCRN through conference attendance, Palliative Hub content, marketing materials, links on the island of Ireland and internationally, media etc.
8. Promote awareness and understanding of PCRN activities, progress and outcomes within generalist and specialist palliative care communities, AllHPC partners and key stakeholders on the island of Ireland
9. Support PCRN members to collaboratively respond to funding calls

<sup>4</sup>Including Departments of Health (NI and Rol), Health Services Executive, Health Research Board, Health and Social Care Board, Public Health Agency.

## Appendix 1: AllHPC Partner Organisations 2017

Belfast Health and Social Care Trust  
Dublin City University  
Foyle Hospice  
Galway Hospice Foundation  
Irish Hospice Foundation  
Lauralynn Children's Hospice  
Marie Curie  
Marymount University Hospital and Hospice  
Milford Care Centre  
National University of Ireland Galway  
Northern Health and Social Care Trust  
Northern Ireland Hospice  
Our Lady's Hospice & Care Services  
Public Health Agency  
Queen's University Belfast  
Royal College of Surgeons in Ireland  
South Eastern Health and Social Care Trust  
Southern Health and Social Care Trust  
St. Francis Hospice  
Trinity College Dublin, the University of Dublin  
Ulster University  
University College Cork  
University College Dublin  
Western Health and Social Care Trust

**24 Partners as of September 2017**

## Appendix 2: AllHPC Expert Collaborators

NAME	POSITION AND ORGANISATION
Dr Anthony Byrne	Director and Thematic Lead: Rehabilitation & Cachexia, Marie Curie Palliative Care Research Centre Cardiff
Ms Avril Jackson	News Editor, International Association for Hospice and Palliative Care
Prof Eduardo Bruera	Department Chair, Department of Palliative, Rehabilitation and Integrative Medicine, Division of Cancer Medicine, The University of Texas MD Anderson Cancer Centre, Houston, TX
Prof John Ellershaw	Professor of Palliative Medicine, University of Liverpool, Director, Marie Curie Palliative Care Institute Liverpool, Medical Director, Marie Curie Hospice Liverpool, Clinical Director, Directorate of Palliative Care, Royal Liverpool University Hospitals
Prof Irene Higginson	Professor of Palliative Care and Policy, King's College London Director, Cicely Saunders Institute, Director of Research & Innovation, (and Assistant Medical Director), King's College Hospital, London
Dr Jose Pereira	Director, Research, The College of Family Physicians of Canada Professor, Department of Family Medicine, University of Ottawa Clinical Professor, Division of Palliative Medicine, Department of Family Medicine, McMaster University Scientific Officer, Pallium Canada
Prof Keri Thomas	National Clinical Lead of The National Gold Standards Framework Centre in End of life Care, Honary Professor End of Life Care, University of Birmingham
Prof Lukas Radbruch	Chair of Palliative Medicine at the Rheinische Friedrich-Wilhem University Bonn, Director of the Department of Palliative Care at the University Hospital Bonn and Director of the Department of Palliative Medicine at the Malteser Hospital Bonn/Rhein-Sieg
Prof Mari Llyod-Williams	Professor and Director of Academic Palliative and Supportive Care Research Studies Group, Faculty of Medicine, University of Liverpool. Honorary Consultant in Palliative Medicine
Prof Michael King	Professor of Primary Care Psychiatry, Division of Psychiatry, Faculty of Brain Sciences, University College London
Prof Peter Lawlor	Associate Professor, Division of Palliative Care, Department of Medicine, University of Ottawa, Clinical Investigator, Bruyère and Ottawa Hospital Research Institutes, Medical Director, Palliative Care Unit, Bruyère Continuing Care

NAME	POSITION AND ORGANISATION
Dr Robin Fainsinger	Professor and Division Director Palliative Care Medicine, University of Alberta
Prof Anne Kenny	Professor of Medical Gerontology, Trinity College Dublin, the University of Dublin
Prof Sheila Payne	Emeritus Professor, International Observatory on End of Life Care, Lancaster University
Dr Suresh Kumar	Director, WHO Collaborating Centre and Consultant in Palliative Medicine, India
Prof Stein Kaasa	Head of Department of Oncology, Oslo University Hospital & University of Oslo, Director of European Palliative Care Research Centre, Institute of Cancer Research and Molecular Medicine, Faculty of Medicine, Norwegian University of Science and Technology, Trondheim (NTNU)
Dr Susie Wilkinson	Advisory Board member for Dimbleby Cancer Care, Consultant to Northern Ireland Cancer Network, Milford Cancer Care Centre, LOROS Hospice in communication skills training and International liaison lead for the Marie Curie Palliative Care Institute Liverpool, Department of Molecular and Clinical Cancer Medicine, University of Liverpool
Dr William Brietbart	Chief of the Psychiatry Service, Chair of Department of Psychiatry and Behavioural Sciences, Memorial Sloan Kettering Cancer Centre, New York

## Appendix 3: AllHPC Palliative Care Research Network – Strategic Scientific Committee

NAME	ORGANISATION
Professor Sonja McIlpatrick (Chair)	Ulster University
Associate Professor Suzanne Guerin (Vice-Chair)	University College Dublin
Professor Kevin Brazil	Queen's University Belfast
Dr Alice Coffey	University College Cork
Dr Frank Doyle	Royal College of Surgeons Ireland
Dr Lisa Graham	Marie Curie Hospice
Dr Gerlayn Hynes	Trinity College Dublin, the University of Dublin
Dr Bridget Johnston	Trinity College Dublin, the University of Dublin
Mr John Joyce	AllHPC Voices4Care Service User/Carer Research Panel
Professor Phil Larkin	University College Dublin
Ms Annie McHale	AllHPC Voices4Care Service User/Carer Research Panel
Dr Dorry McLaughlin	Queen's University Belfast
Professor Charles Normand	Trinity College Dublin, the University of Dublin
Dr Norma O'Leary	Our Lady's Hospice & Care Service Milford
Dr Martina O'Reilly	Care Centre, Limerick
Professor Eamon O'Shea	National University of Ireland Galway
Professor Anthony Staines	Dublin City University
Professor Sheila Payne	International Observatory on End of Life Care, Lancaster University
Dr Gail Johnston	HSC R & D Public Health Agency, Northern Ireland
Dr Donna Tedstone	Health Research Board, Republic of Ireland
Ms Karen Charnley	Head of Institute, AllHPC
Dr Mary Rabbitte	Programme Manager, AllHPC
Dr Jackie Boylan	PCRN Project Manager, AllHPC

## Appendix 4: Research Priorities

### Top 10 Palliative Care Research Priorities on the island of Ireland

AllHPC participated in a UK and Ireland project, developed by the Palliative and End of Life Care Priority Setting Partnership initiated by Marie Curie. The aim was to bring patients, carers, volunteers and health and social care professionals together to identify and prioritise research questions for palliative and end of life care. AllHPC extracted the data for Ireland from the overall study and held a consensus workshop, independently facilitated by the James Lind Alliance, to identify the Top 10 Research Priorities for the island of Ireland.

The Top 10 Research Priorities for Palliative and End of Life Care for the island of Ireland are:

1. What are the best ways of providing palliative care outside of 'working hours' to avoid crisis and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families?
2. What are the benefits, and best ways, of providing care in the patient's home and how can home care be maintained as long as possible? Does good co-ordination of services affect this?
3. What are the best ways to make sure that palliative care patients receive adequate pain and symptom relief and which drugs for pain management are best in terms of side-effects, such as drowsiness?
4. What are the best ways for healthcare professionals to tell patients, carers and families that a patient's illness is terminal and also explain the dying process compassionately and honestly? Can literature, including leaflets, be helpful? Who is the best person to provide this information and communication?
5. What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients' preferences? Who should implement this and when?
6. What are the best ways to make sure there is continuity for patients at the end of life, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case-coordinator improve this process?
7. What are the best ways to support children and young people when someone close to them is dying or has died? This includes communicating with them about the diagnosis and dying process, enabling them to talk about their experience and providing bereavement support.
8. What information and training do carers and families need to provide the best care for their loved one who is dying?
9. What are the best ways to begin and deliver palliative care for patients with non-cancer diseases (such as COPD, heart failure, MND, AIDS, multiple sclerosis, Crohn's disease and stroke)?
10. Are hospices, hospitals and care homes providing adequate staff training to deliver specialist palliative care, and to what extent does funding affect this? How can high quality trained staff be ensured no matter where the care is being delivered?

<http://aiihpc.org/research/launch-of-top-10-palliative-care-research-priorities/>

## Let's Talk About Palliative Care Report - Recommendations

The Let's Talk About Palliative Care Survey was developed in the context of the overall aim of AllHPC to improve the experience of palliative and end-of-life care on the island of Ireland by enhancing capacity, developing knowledge, promoting learning, influencing policy and shaping practice. A total of 528 people on the island of Ireland completed the survey during two phases of data collection in 2014 and 2015.

Based on the results of the survey, the following recommendations are proposed which are aimed at a wide range of audiences including policymakers, commissioners, statutory, voluntary and private agencies, including AllHPC, involved in the delivery of palliative care:

1. Develop practice models which (a) better coordinate care and treatment options and (b) reflect the emotional and psychological needs of the individual, their families and or carers and support their needs to plan for the future.
2. Build the capacity of professionals to respond to the needs of individuals through the development of competences (physical, psychological, social and spiritual) and communications skills and through access to ongoing and appropriate personal supports.
3. Deliver an information and awareness raising campaign targeted at professionals: GPs, community-based nurses and hospital based consultant teams who are key to the identification of patients' palliative care needs.
4. Enable individuals to exercise personal choice where possible through the timely provision of accessible and appropriate information on palliative care.
5. Develop principles for involvement and formalise support for family, friends or others where appropriate, in order to encourage participation in supporting an individual.
6. Promote a wider societal normalisation of planning for the future.
7. Promote public awareness and access to a palliative approach to care for all individuals with a serious or progressive condition from which they are unlikely to be cured and which may limit or shorten life.

<http://aiihpc.org/policy-practice/lets-talk-about-final-report/>

## KINDLE Project Themes

The aim of the Knowledge Innovation Dissemination Learning Exchange (KINDLE) project is to identify high-level themes from the dissemination products published by research projects conducted under the umbrella of the PCRN. The purpose is to maximise the learning from these projects by identifying cross-cutting issues with implications for palliative care research. The final report is due soon.

<http://www.professionalpalliativehub.com/research/kindle>





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