Palliative Care Research Network

Working with people with palliative care needs to provide evidence-based research

In 2012, All Ireland Institute of Hospice and Palliative Care (AIIHPC) established the Palliative Care Research Network (PCRN) to address the need for more collaborative multidisciplinary research in palliative care on the island of Ireland.

About the PCRN

The PCRN's aim is to undertake excellent research for people who need palliative care that has high impact, builds research capacity and drives collaboration in palliative care focussing on three main objectives to:

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

Today the PCRN delivers evidence-based palliative care research prioritising social justice, inclusivity and accountability. Some examples of current research projects include those investigating the inequality of palliative care service delivery for people with serious mental illness, intellectual disability, dementia and advanced heart failure. As well as research on measuring and evaluating palliative care outcomes.

Members

The PCRN, currently comprises of 21 senior members, includes representatives from leading academic institutions, people with palliative care needs and their family/carers (through AIIHPC’s Voices4Care), hospices and palliative care providers, health agencies and funding organisations.

Benefits

The network provides members with valuable opportunities to:

- Collaborate with senior researchers, clinicians, service users, policy makers and funders in palliative care and other relevant areas
- Ensure research is relevant to global and national policy and practice priorities
- Lead, mentor and build research capacity
- Access AIIHPC’s vast experience and support in developing collaborative proposals, building partnerships including those with patient-public involvement and transferring knowledge to clinicians, educators, policy makers, service users and the wider community

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Funding

**Health Research Board**

The network received an initial investment of €1.26million (£1.06million) for palliative care research over four years from the Irish Health Research Board and AIIHPC.

The network has received additional joint-funding of €210,000 (£180,000) from the Health Research Board (ROI) and HSC Research and Development Division, Public Health Agency (NI) through funding two doctoral fellowships.

**Public Health Agency**

Financial contributions made by the HSC Research and Development Division, Public Health Agency (NI) through funding two doctoral fellowships.
Highlights
Since 2012 the PCRN has a number of notable achievements to-date that include:

- Collaboration and Partnership Agreements with 8 academic institutions including Dublin City University (DCU), National University of Ireland Galway (NUIG), Queens University Belfast (QUB), Royal College of Surgeons in Ireland (RCSI), Trinity College Dublin (TCD), University College Cork (UCC), University College Dublin (UCD) and Ulster University (UU)
- 8 ongoing core research projects in understanding equality and inclusion in palliative care and measurement and evaluation of palliative care outcomes, involving over 23 researchers
- Launched Top 10 Research Priorities in 2015 for palliative care on the island of Ireland in collaboration with people with life limiting conditions, family/carers, health care professionals, researchers, funders and policy makers
- 7 AIIHPC clinical research fellows, over 18 international bursary recipients, 2 Public Health Agency/AIIHPC doctoral fellows
- Over 40 peer reviewed publications including an award for ‘Best Paper 2014’ by Palliative Medicine
- Irish Cancer Society/AIIHPC postdoctoral fellow received 2015 EAPC Early Career Researcher Award

Knowledge Transfer and Exchange
The network aims to transfer research output to improve palliative care education and practice and influence policy in collaborative and innovative ways. This includes:

- Development of comprehensive and coordinated dissemination plans for all PCRN research projects via the KINDLE project
- Leveraging off the experience and expertise of AIIHPC to reach service users, carers, service providers, policy makers, researchers and other stakeholders including via the Palliative Hub
- Support for patient-public involvement through the AIIHPC Voices4Care research panel
- Measuring research outputs in person and public involvement, knowledge exchange activities for policy and practice, peer reviewed publications and conference presentations
- Opportunities for sharing, dissemination and networking at the Annual PCRN Symposium
- Presence of AIIHPC and PCRN at national and international events (e.g. USA, Australia, Europe)

National and International Collaboration
The PCRN is increasingly being recognised as a potential international leader in palliative care research through a strong emphasis on:

- Learning from evidence-based practice
- Dissemination of research at an international level
- Collaborative partnerships with key leaders in palliative care research through AIIHPC’s Expert Collaborator
- Links with international organisations and networks

AIIHPC’s Expert Collaborators includes a panel of 19 internationally recognised palliative care experts in the areas of clinical practice, research, education and policy provision who provide strategic advice and support to the Institute. Professor Sheila Payne, Director of the International Observatory on End of Life Care at Lancaster University, is a member of the PCRN governance committee.

Further Information
For information about the PCRN, please contact Dr Mary Rabbitte, AIIHPC Programme Manager Research mrabbitte@aiihpc.org or AIIHPC research visit: www.thepalliativehub.com
Understanding Equality and Inclusion in Palliative Care

**Social Justice and Palliative Care**
Dr Luciana Lolich, Prof Kathleen Lynch
Lead Organisation: University College Dublin

**Identifying and addressing the needs of people with serious mental illness**
Dr Ann Sheridan, Professor Gerard Leavey, Sarah Walsh

**Identifying and addressing the needs of people with intellectual disability**
Professor Mary McCarron, Dr Karen Ryan, Janet O’Farrell

**Improved identification, communication & service provision needed to relieve caregiver burden in advanced heart failure in Ireland: a mixed methods study**
Dr Leanne Doherty, Prof Sonja McIlfatrick, Prof Donna Fitzsimons
Lead Organisation: Ulster University

**An exploration of access, decision-making and experiences of palliative care services for families of children with non-malignant life-limiting conditions**
Dr Gemma Kiernan, Dr Jayne Price, Fiona Hurley
Lead Organisation: Dublin City University

Measurement and Evaluation of Outcomes for Palliative Care

**Towards improved diagnosis and symptom management in palliative care**
Professor David Meagher, Dr Karen Ryan, Dr Mas Mohamed, Brid Davis

**Patients’ and caregivers’ preferences for services and support near the end of life: evidence from a discrete choice experiment**
Bridget M Johnston, Dr Karen Ryan, Prof Charles Normand
Lead Organisation: Trinity College Dublin

**Evaluation of a Psycho-educational intervention for patients with advanced Cancer who have Cachexia and their lay carers**
Dr Joanne Reid, Dr David Scott, Dr Olinda Santin, Dr Chris Cardwell, Prof W. George Kernohan, Dr Peter O’Halloran, Dr Joan Regan, Prof Sam Porter
Lead Organisation: Ulster University

Knowledge Transfer and Exchange

**Developing and implementing a ‘System’ of structured network-wide dissemination and knowledge transfer activities**
Dr Suzanne Guerin, Prof W. George Kernohan
Lead Organisation: University College Dublin

**The KINDLE Project: Identifying key themes and messages from the Palliative Care Research Network**
Dr Emma Nicholson, Dr Tara Murphy, Prof Philip J Larkin, Prof Charles Normand, Dr Suzanne Guerin
Lead Organisation: AIIHPC, University College Dublin

Specialist Palliative Care - Neurodegeneration, Cancer, Non-malignant, End-stage Kidney

**Pain assessment and management for patients with advanced dementia nearing the end of life**
Dr Bannin De Witt Jansen, Prof Kevin Brazil; Prof Peter Passmore, Dr Hilary Buchanan, Dr Doreen Maxwell, Prof Sonja McIlfatrick, Dr Sharon Morgan, Prof Max Watson and Dr Carole Parsons
Lead Organisation: Queen’s University Belfast
Palliative care in people with dementia and young onset dementia
Dr Siobhán Fox, Dr Suzanne Timmons
Lead Organisation: University College Cork

Perceptions of family and staff carers on an advance care planning intervention in UK dementia care homes
Prof K Brazil, Dr G Carter, Dr D McLaughlin, Prof G Kernohan, Dr C Cardwell, Prof P Hudson, Prof M Clarke, Prof P Passmore, Prof K Froggatt
Lead Organisation: Queen’s University Belfast

Palliative care in people with Parkinson’s disease
Dr Siobhán Fox, Dr Suzanne Timmons
Lead Organisation: University College Cork

Developing and testing an educational intervention for the management of constipation for people with advanced cancer: a feasibility intervention study (DEMCoN)
Phase 1: Examining current practice in constipation management in palliative care settings
Prof Sonja McIlfatrick, Dr Felicity Hasson, Deborah Preshaw
Lead Organisation: Ulster University

Rehabilitation in palliative care: a novel exploratory study in lung cancer
Dr Cathy Payne, Prof Phil J Larkin, Prof Sonja McIlfatrick, Dr Lynn Dunwoody, Dr Jackie Gracey
Lead Organisation: Ulster University

An exploration of access, decision-making and experiences of palliative care services for families of children with non-malignant life-limiting conditions
Dr Gemma Kiernan, Dr Jayne Price, Fiona Hurley
Lead Organisation: Dublin City University

Advance care planning in end-stage kidney disease
Dr Peter O’Halloran, Prof Kevin Brazil, Prof Mike Clarke, Dr Helen Noble, Dr Chris Cardwell, Dr Fliss Murtagh, Dr Rachael Morton, Dr Robert Mullan, Dr Damian Fogarty, Joan Brown, Dr Joanne Shields, Prof Peter Maxwell
Lead Organisation: Queen’s University Belfast

Palliative Services – Hospice, Day Care, Community Based Services
The provision of additional care to respond to children with exceptional healthcare needs and their families: a service evaluation of a regional children’s hospice service
Dr Dorry McLaughlin, Dr Tracey McConnell, Dr Patricia McNeilly and Prof Sam Porter
Lead Organisation: Queen’s University Belfast

Transition to adult services for young adults with life-limiting conditions in Ireland: a realist evaluation using mixed methods
Dr Helen Kerr, Dr Honor Nicholl, Dr Jayne Price, Dr Peter O’Halloran
Lead Organisation: Queen’s University Belfast

Costs and effectiveness of UK palliative care day services (PCDS): a three-centre mixed methods study of impact upon patients and carers
Prof G Kernohan, Prof K Brazil, Dr K Armour, Dr C Bailey, P Buckle, Prof J Coast, Dr A Finnucane, P Gilbert, L Graham-Wisener, Dr E Harraldsdottir, Dr F Hasson, L Jones, Dr J Jordan, Dr N McCorry, Prof S McIlfatrick, Dr F Ricciardi, V Vickerstaff
Lead Organisation: Ulster University

Investigating Social and Practical suppoRts (INSPIRE) at end of life
Dr. Kathleen McLoughlin, Prof Sinead McGilloway, Jim Rhatigan, Prof Allan Kellehear, Dr. Emilio Herrera-Molina, Dr. Mairead Furlong, Joanne Callinan
Lead Organisation: NUI Maynooth
About AllHPC

All Ireland Institute of Hospice & Palliative Care (AllHPC) is a leading organisation with national and international influence driving excellence in palliative care.

AllHPC is a collaborative of hospices, health and social care organisations and universities on the island of Ireland. AllHPC advances education, research and practice to improve the palliative care experience of people with life limiting conditions and their families. As the palliative care sector’s institute, AllHPC is:

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