PREFACE

All Ireland Institute of Hospice and Palliative Care (AIIHPC) Palliative Care Research Network (PCRN) focuses on tackling questions relating to palliative, supportive and end of life care on the island of Ireland and internationally. With core funding from the Irish Health Research Board, our researchers have been able to undertake high-quality, interdisciplinary, and internationally competitive research with a view to addressing some of the most challenging and complex issues relating to palliative care. A significant action for the PCRN is translating the work done into wide-ranging benefits for service users and their carers. The KINDLE Project\(^1\) (Knowledge INnovation Dissemination Learning Exchange) is a noteworthy example of how pertinent research may be disseminated so as to promote understanding, knowledge, and best practice, as well as to inform future research activities.

This year we welcomed the launch of new health and social care research strategies from our funders - the Health Research Board and the HSC Research & Development Division (Public Health Agency, Northern Ireland). Both strategies place emphasis on building research capacity and leadership, responding to national health and social care priorities, patient and public involvement in research, along with creating a strong research culture within organisations. The launch of these strategies coincided with three new programmes of work being adopted by AIIHPC (in relation to the integration of research, education, policy and practice; service user and carer engagement; and the ongoing development of specialist palliative care). Reflecting this renewed energy and tighter focus on palliative and end of life care issues, the PCRN moved into a period of transition with the establishment of a new Strategic Scientific Committee and the expansion of the network with new members and research teams. As we look forward to the next five years, the Strategic Scientific Committee\(^2\) will drive the strategic development and future sustainability of the network, placing it on a par with other international leaders in palliative care research and development.

To conclude, the PCRN is the leading body for high quality research in palliative care on the island of Ireland and wider. At this present time when the world faces significant social, cultural, and political upheaval, we are reminded to hold true to our core principles and values, and for the PCRN these remain social justice, inclusivity, accountability, and evidence-base.

\(^1\)For further information about The KINDLE Project visit http://www.professionalpalliativehub.com/research/kindle

\(^2\)Representation on the SSC includes clinical and academic researchers, service users and carers, and funders.
People and Projects

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

**AIM**

1. Identify and explore key issues in the assessment and management of pain in patients with advanced dementia (AD) nearing the end of life (EOL) from the perspectives of bereaved carers and physicians, nurses and healthcare assistants from primary, secondary, hospice and nursing home care settings.

2. Develop a model to improve pain assessment and management in AD. Phase

3. Pilot the finalised model in primary, secondary, community and hospice care settings.

[Click here to view the full size poster]

Rehabilitation in Palliative Care: A Novel Exploratory Study

Dr Cathy Payne, Prof Phil J Larkin, Prof Sonja McIlfatrick, Dr Lynn Dunwoodoy, Dr Jackie Gracey

Lead Organisation: Ulster University

**AIM**

Palliative rehabilitation is defined in this research as “an educational, problem-solving process that focuses on activity limitations and aims to optimise social participation and well-being, thereby reducing stress on family and carers within the context of a life-limiting progressive illness” (adapted from Wade & de Jong, 2000).

The aim of the APRIL (Active Palliative Rehabilitation in Lung cancer) study was to determine the feasibility, acceptability and potential impact of palliative rehabilitation for people newly commencing systemic therapy with palliative intent for stage IIB or IV NSCLC.

[Click here to view the full size poster]
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

AIM
The aim of this research was to estimate patients’ and caregivers’ preferences and their trade-offs between attributes of palliative care supports and services using the DCE framework. The objectives of the study included:

1)To quantify and determine the relative importance of different attributes of palliative care-related services and supports.

2)Identify similarities and differences in preferences between various subgroups.

3)To explore how preferences are influenced by perceptions of and experience with and hospice and palliative care services.

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Neuropsychiatric Profile of Palliative Care Inpatients: Towards Improved Assessment

Brid Davis, Mas Mohamad, Dr Karen Ryan, Prof David Meagher

Lead Organisation: University of Limerick

AIM
To review and identify best practices for assessment of cognition and despression in palliative care settings

To document the severity, frequency and relationship of neuropsychiatric conditions (delirium, depression, dementia)

To identify features that are most helpful in distinguishing the presence of delirium and depression in this settings

To develop simple user-friendly tools which accurately identify cognitive disturbances and depression in everyday clinical practice

Click here to view the full size poster
People and Projects

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

AIM

The aim of this study was to evaluate the allocation of one bed within a regional Children’s Hospice to respond to children identified as having exceptional care needs.

The objectives were to:

• Determine demographics of children using the service and assess service activity
• Explore families’ experiences of using this aspect of hospice care and the impact on their lives.
• Establish the added, unique value that this model of exceptional care provides to families and to HSC Trusts.
• Explore the hospice experience of managing this model of care
• Establish evidence of need, including the perspectives of commissioners and service providers who make referrals to the service.

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: AllIHP, University College Dublin

AIM

The purpose of the KINDLE Project (Knowledge, INnovation, Dissemination, Learning, Exchange) is to unlock the knowledge from the PCRN by identifying shared learning from the network in the form of key themes evident in research output.

• Critically, the project aims to “re-package” these messages to reach all stakeholders in the means most likely to be effective.
• In line with these aims we conducted a thematic synthesis to identify high-level messages and themes from projects within the PCRN.
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**

**AIM**
To develop and test the feasibility and acceptability of a novel educational intervention for HCPs to help them manage constipation experienced by people in the hospice setting.

**Stage 1 Aim**
To identify current practice and explore views from patients/ carers and HCPs regarding constipation management within the hospice.

Click here to view the full size poster

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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**

**AIM**
To explore access, decision-making and experiences of children’s palliative care services (CPC) for families of children with non-malignant life-limiting conditions (NMLLC) on the island of Ireland. Specific objectives were to:

- Provide an understanding of the unique experiences of families caring for a child with a NMLLC including their experiences of CPC service provision at different points during their child’s life.
- Identify ways in which differences in identities and social class background impact on access to and experience of CPC services.
- Gain insight from healthcare professionals regarding CPC service provision.

Click here to view the full size poster
People and Projects

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

AIM
Using the Donabedian conceptual model the study has three components:
- to assess the current evidence concerning the effectiveness of PDCS on patient and care quality of life,
- to profile the current organisation and content of PCDS by looking back at what participating sites provided to patients in 2015
- follow people through the services throughout 2017.

By understanding the structure, processes and outcomes of the three PCDS, service models can be influenced to achieve better outcomes for people in need of palliative care, their carers and family members.

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

Background
Improvements in care and treatment have led to more young adults with life-limiting conditions living beyond childhood, which means they must make the transition from children’s to adult services. However, there is little evidence on transition services for young adults with life-limiting conditions, with few models of good practice in the literature.

Research aim
To identify the organisational factors, and interactions between factors, involved in promoting or hindering a successful transition for young adults with life-limiting conditions.
**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**

**AIM**

Cachexia is a complex syndrome associated with reduced quality of life and mortality. It is common among people with advanced cancer, affecting up to 80% of patients, and is also associated with other chronic diseases.

Cachexia has far reaching consequences for both patients and their carers, including negative social and psychological impacts. Previous research suggests patients and their family carers are not well supported by existing services.

This study aimed to develop and test a psycho-educational intervention aimed at improving the psychological well-being of advanced cancer patients who have cachexia and their lay carers. This intervention was based on best available evidence and was delivered via DVD.

[Click here to view the full size poster](#)

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**Social Justice and Palliative Care**

**Dr Luciana Lolich, Prof Kathleen Lynch**

**Lead Organisation: University College Dublin**

**AIM**

To critically examine the concept of choice in palliative care services in Ireland and to identify potential inequalities in the access and delivery of care for patients at the end of life.

[Click here to view the full size poster](#)
People and Projects

INSPIRE Study: INvestigating Social and Practical suppoRts 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

AIM
The aims of the INSPIRE study are:
• To develop a greater understanding of the practical and social needs of people living with advanced life-limiting illness; and
• To assess the feasibility, acceptability and subsequent effectiveness of The Good Neighbour Partnership (GNP), a volunteer-led model of social and practical care/support for community dwelling adults living with advanced life-limiting illness in Limerick, Ireland.

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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

AIM
To report on the feasibility and acceptability of an ACP model for individuals living with dementia in a sample of nursing homes in the United Kingdom.

Click here to view the full size poster
**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**

**AIM**
Examine the palliative care needs of caregiver’s of people living with advanced heart failure (HF) in Ireland & to explore any relationship between this & a range of other factors including the patient’s clinical profile & support available.

- Undertake a systematic review of the current literature
- Identify a cohort of suitable patients
- Evaluate dimensions of inequality & relate this to their psychological outcomes
- Explore the experience of current & bereaved caregivers of people with HF

[Click here to view the full size poster]

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**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**

**AIM**
To determine the feasibility of conducting a deferred entry RCT, alongside a mixed methods study, to evaluate Advance Care Planning (ACP) with older patients who have End-Stage Kidney Disease (ESKD). Objectives are to investigate: acceptability of the ACP intervention to patients, their carers and professionals; optimal intervention systems for delivering ACP; recruitment and retention rates; randomisation procedures; suitability of outcome measures; and methods for assessing cost effectiveness in a full trial.

[Click here to view the full size poster]
People and Projects

**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**

**AIM**

**Inner Strand**
- To identify the key elements of knowledge transfer in existing models
- To consider the relevance of these elements to palliative care
- To identify existing tools/techniques for knowledge transfer that can be applied in the palliative care setting

**Outer Strand**
- To exploit knowledge transfer for palliative care in Ireland, focusing upon actual exchange of information to enhance care
- To make use of the key elements of knowledge transfer (as outlined above)
- To examine them through certain contexts of care

**Palliative care in people with dementia and young onset dementia**

**Dr Siobhán Fox, Dr Suzanne Timmons**

**Lead Organisation: University College Cork**

**AIM**

Dementia causes impairment of memory, problem-solving, communication, and the ability to perform everyday tasks. People with dementia, and their carers, have been shown to have palliative care needs equal to those of cancer patients. Although palliative care is recognized as quality care at end-of-life, palliative care for people with dementia is still evolving.

People with young onset dementia (<65 years) and their families may experience a different journey through their illness, and have unique palliative care needs.

**Aims:**

i) To demonstrate the benefit of a palliative care approach for people with dementia, through case studies.

ii) To gather data on people with young onset dementia who are admitted to hospital.
Palliative care in people with Parkinson’s disease

Dr Siobhán Fox, Dr Suzanne Timmons

Lead Organisation: University College Cork

AIM

Parkinson’s disease (PD) is the second most common neurological disorder, affecting approx. 12,000 people in Ireland.

People with PD experience symptoms similar to people with malignancy, including pain, fatigue, and depression. Symptom burden in advanced PD is similar to metastatic cancer.

People with PD benefit from palliative care, yet unmet palliative care needs are widely reported in this population, e.g. lack of information, ad hoc service delivery, low referral rates to Specialist Palliative Care.

Overall research aims:

To explore and raise awareness of palliative care needs in PD; To support healthcare workers to assess and treat palliative care needs in PD.

Click here to view the full size poster
Research Capacity Building

The following events and activities were co-led by the PCRN in 2016

Research Bursaries to attend the European Association for Palliative Care’s Pre-Congress Workshop:
List bursary recipients as follows:
• Ciaran Kenny, PhD Scholar, Our Lady’s Hospice & Care Services, Harold’s Cross, Dublin/ Trinity College Dublin
• Dr Luciana Lolich, Postdoctoral Researcher, University College Dublin
• Ann McAuliffe, Lecturer/ PhD Scholar, University College Cork
• Esther Ruth Beck, PhD Scholar, Ulster University, Belfast
• Dr Cliona Lorton, SpR Palliative Medicine, Our Lady’s Hospice and Care Services, Dublin/ Trinity College Dublin

Palliative Care in Neurodegeneration with a focus on Dementia: Addressing complex questions through interdisciplinary research and reflection:
An interdisciplinary research workshop on Palliative Care and neurodegeneration took place in Cork in May 2017. The event was funded by the Irish Research Council, and was led by the Centre for Gerontology & Rehabilitation, University College Cork in partnership with AllHPC and other collaborators including National University of Ireland Galway, the Alzheimer Society of Ireland (ASI), Dementia Research Education Advocacy in Motion (D.R.E.A.M), the Irish Association of Palliative Care (IAPC), and the Irish Hospice Foundation (IHF).

It is increasingly acknowledged that people with advanced neurological conditions have complex problems and needs that are often unrecognised and under-treated. Dementia is the most common neurological disorder and is a life-limiting condition, but very often is not recognised in this way. Yet, people with dementia, and their carers, have been shown to have palliative care needs equal to those of cancer patients. Similarly, other neurodegenerative conditions like Parkinson’s disease and Motor Neurone Disease cause significant physical and psychosocial issues for the person, and the best means to assess, and address, their palliative care needs requires further research.

To lead the discussion throughout the day an outstanding multidisciplinary panel of speakers were brought together, including both researchers and clinicians from across Ireland and the UK. Professor David Oliver, University of Kent: Palliative Care Physician with a special interest in neurological and neurodegenerative diseases, delivered the keynote address on “Research in neurodegenerative disease”. Link to video presentations: https://www.youtube.com/playlist?list=PLd_maP4B2N3FSmkbDow2Tb2VH3GtDaBvx

Seminar on “Communicating your research using social media: insights, tools and possibilities:
In June 2016 the Early Career Researcher Forum (ECRF) hosted an excellent seminar on communicating research using social media. The seminar was a timely opening to the 9th World Research Congress of the European Association of Palliative Care Conference at the University College Dublin which took place later that week.

The seminar was attended by local and international delegates representing a range of professions including medicine, nursing, psychology, and health economics. Dr Cathy Payne (outgoing ECRF chair/ Programme Manager, AllHPC) and Ragnhild Green Helgås (Head of PRC Administration, Norway & EAPC RN secretariat) provided valuable insights into the ECRF and PCR/ EAPC RN respectively, paying particular attention to the wider research context and capacity building opportunities offered at local and European levels.

Following this, Dr Helen Dixon (Trainer/Analyst, Queen’s
University Belfast) and keynote speaker delivered an outstanding presentation on using social media to communicate research. Dr Dixon focused on five pertinent areas for promoting and disseminating research including making research accessible, creating shareable content, tracking engagement with your research by others and nurturing your (contacts) network. Dr Dixon emphasised the value of having a strong online profile as it can reach diverse audiences, resulting in greater promotion of the research. Slides for this session may be found at the following link: http://www.slideshare.net/HelenDixon1/communicating-your-research-62814104

Evidence into practice: quality of life and palliative care needs of caregivers caring for a loved one with heart failure
This workshop was organised by researchers from Ulster University and the Palliative Care Research Network (Professor Sonja McIlfatrick, Professor Donna Fitzsimmons and Dr Leanne Doherty). This study was funded by AllHPC and the Health Research Board. The workshop launched the research findings and facilitated the development of an action plan for healthcare professionals working in palliative care and heart failure on the island of Ireland.

Concept Development Workshop for clinical and early career researchers in palliative care
The Palliative Care Research Network’s (PCRN) Early Career Researcher Forum together with the Irish Cancer Society (ICS) hosted a Concept Development Workshop for clinical and early career researchers in December. This workshop was a significant part of the PCRN’s efforts to foster the development of research of clinical relevance and importance in palliative care on the island of Ireland. It included a mixture of insightful presentations from Professor Sheila Payne (Emeritus Professor, International Observatory on End of Life Care, Lancaster University, UK), Dr Suzanne Guerin, (Associate Professor in Research Design & Analysis/ Deuty Head of School - UCD School of Psychology/ Senior Investigator, AllHPC), Dr Bella Bray (Programme Manager Research, Irish Cancer Society) and Professor Sonja McIlfatrick (Postgraduate Tutor, Lead Palliative Care Research Strand, Institute of Nursing and Health Research/ Chair, Palliative Care Research Network) as well as interactive sessions. Over twenty-five researchers participated in this event from a range of health and social care backgrounds.

PhDs awarded to Dr Helen Kerr and Dr Loreena Hill
AllHPC would like to congratulate Dr Helen Kerr who was recently awarded her PhD entitled “Transition to adult services by young people with life-limiting conditions in Belfast and Dublin: a realist evaluation using mixed methods (TASYL study)”. Under the supervision of Dr Peter O Halloran (Queen’s University Belfast), Helen’s study focused on the organisational factors, and interactions between factors, involved in promoting or hindering successful transition. The PhD was funded by the Health & Social Care Research & Development Division of the Public Health Agency (Northern Ireland) in conjunction with AllHPC. Dr Kerr first registered with the Nursing and Midwifery Council in 1993 and has largely nursed in oncology and palliative care settings. From 2002 Helen has worked as a lecturer in the School of Nursing and Midwifery, Queen’s University, Belfast. Helen was runner up in the Northern Ireland Royal College of Nursing Nurse Researcher of the Year. She is Secretary of the PCRN Early Career Researcher Forum. For further information about Dr Kerr and her research visit www.aiihpc.org/research.

AllHPC would also like to take this opportunity to congratulate Dr Loreena Hill (Ulster University/ Belfast Trust) who completed her PhD entitled “Management of Implantable Cardioverter Defibrillators (ICD) in Advanced Heart Failure: An exploratory study of heart failure patients’, carers’ and healthcare professionals’ perspectives”. Loreena was supervised by Professor Donna Fitzsimmons (Ulster University/ Belfast Trust & Senior Investigator, AllHPC) and it was funded by the HSC Public Health Agency Northern Ireland. This study explored the factors influencing the discussion of ICD deactivation and highlighted the views from services users/carers and professionals. Loreena has been a cardiac nurse for approximately twenty years which includes position of Specialist Heart Failure Nurse. During this time she established the nurse-led heart failure service in the Royal Group of Hospitals, Belfast and
chaired a multi-disciplinary team to develop regional symptom control guidelines for end-stage heart failure patients (2006-2007). She completed a MSc which focused on heart failure patients and palliative care. She is a committee member of the Irish Nurses Cardiovascular Association (INCA), an active member of the European Society of Cardiology’s Council on Cardiovascular Nursing & Allied Professionals (CCNAP) programme committee and a committee member of the PCRN Early Career Researcher Forum. She was awarded the prestigious title of Nurse Fellow of the European Society of Cardiology in 2015, with attainment of an ESC Nurse Training grant in 2016.

**Early Career Researcher Forum Executive Committee**

Bridget Johnston (PhD researcher, Trinity College Dublin) was appointed new Chair of the Early Career Researcher Forum in May. Bridget took over from Dr Cathy Payne (Programme Manager, AllIHP). Bridget completed her master’s degree in Health Economics at the National University of Ireland, Galway in 2012. She is employed as a research assistant in the Centre for Health Policy and Management at Trinity College Dublin. Bridget is currently undertaking work for the International Access, Rights and Empowerment Plus (IARE+) study, a project examining and comparing the experiences of patients and informal caregivers accessing specialist palliative care services across three regions in Ireland: Limerick, Mayo and North East Dublin. Her PhD thesis is examining palliative care service users’ preferences and priorities for support through the use of a discrete choice experiment.

**The KINDLE Project**

The KINDLE Project represents a commitment by AllIHP to engage in active and ongoing dissemination of the learning contained within the Palliative Care Research Network (PCRN). A key guiding principle is to engage in knowledge transfer from the beginning of the project and the KINDLE Project blog was set up to ensure that the activities of the project are continuously communicated to the palliative care community and beyond. The blog also publishes posts by members of the PCRN and the Early Career Researchers Forum covering a variety of topics. For further information visit [http://www.professionalpalliativehub.com/research/kindle](http://www.professionalpalliativehub.com/research/kindle)
The KINDLE Project Infographic

The KINDLE Project: Identifying key themes and messages from the Palliative Care Research Network

Nicholson, Emma¹; Murphy, Tara¹; Larkin, Philip²; Normand, Charles³ & Guerin, Suzanne²
¹ All Ireland Institute of Hospice and Palliative Care; ² University College Dublin; ³ Trinity College, Dublin

Aims

• The purpose of the KINDLE Project (Knowledge, Innovation, Dissemination, Learning, Exchange) is to unlock the knowledge from the PCRN by identifying shared learning from the network in the form of key themes evident in research output.
• Critically, the project aims to “re-package” these messages to reach all stakeholders in the means most likely to be effective.
• In line with these aims we conducted a thematic synthesis to identify high-level messages and themes from projects within the PCRN.

Methods

• In line with PRISMA guidelines, a purposive structured search of dissemination products from the PCRN was carried out to ensure that all relevant materials from PCRN products were collected.
• Materials include conference presentations, study protocols, published peer-reviewed papers/abstracts, internal symposia, social media activity (e.g., tweets), workshops, and news reports.
• The projects included in the review were the core projects, aligned projects, doctoral and postdoctoral fellows, and clinical research fellows (N = 25).
• An infographic (presented right) was designed to announce and promote the project in order to collect dissemination output.
• A traditional search of databases was conducted to identify any additional output.

Findings and Conclusion

• A total of 142 dissemination products were included in the final review.
• The most common types of output were traditional academic products such as peer reviewed publications, conference presentations.
• Dissemination products targeted a range of audiences, including academics/researchers, policy makers/practitioners and the general public, though a focus on academic audiences was clear.
• Data extraction was conducted to extract the key messages from each of the products, a process which was verified through independent double extraction of data. Thematic synthesis was used to isolate key themes across the messages (presented left).
• Overall ten themes emerged from the initial analysis, reflecting issues of both service provision, patient and family needs and research methodology. These themes (left) show some overlap.

Contact

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Email: info@aiihpc.org
Website: http://www.professionalhubs.com/research/kindle

Key Reference
**PCRN 5th Annual Symposium**

**THEME: Priorities for Palliative Care Research on the island of Ireland and Internationally: Interdisciplinary Research Collaboration, Capacity Building and Leadership.**

*Background*

The 5th Annual Symposium of AIIHPC’s Palliative Care Research Network (PCRN) took place on 8th December 2016. The symposium brought together over 50 researchers, clinicians, service users and carers as well as service managers to celebrate and build on the wealth of expertise and innovation in palliative care research on the island of Ireland. This was a truly dynamic and productive day with opportunities for networking, shared learning and philosophical debate.

There were excellent presentations from several national and international speakers including Professor Lieve Van den Block (End of Life Care Research Group, Vrije University Brussel & Ghent University) who spoke about the achievements, challenges and future direction of palliative care research. Professor Sheila Payne (Emeritus Professor, International End of Life Observatory, Lancaster University) discussed the importance of supporting research activity and research leadership in hospices and other places of care while Professor Sonja McIlfatrick (Chair, PCRN Strategic Scientific Committee/ Ulster University) highlighted some of the advances in palliative care research on the island of Ireland as part of the PCRN.

As part of the symposium, a panel discussion explored some of the world’s societal, political, and economic challenges facing palliative care today. Members of the panel included the keynote speakers in addition to Dr Joan McCarthy (Lecturer, Healthcare Ethics Coordinator School of Nursing and Midwifery, University College Cork), Dr Regina McQuillan (Medical Director, St Francis Hospice), and Professor Philip Larkin (Professor of Clinical Nursing, University College Dublin and Our Lady’s Hospice & Care Services, President of the EAPC).
Opening Address

Future perspectives for palliative care research on the island of Ireland – what have we learnt and where to now?

Professor Sonja McIlfatrick, Chair Strategic Scientific Committee, Palliative Care Research Network/Ulster University

The opening address was given by Professor Sonja McIlfatrick, Chair Strategic Scientific Committee, AIIHPC PCRN, Ulster University, who presented on the future perspectives for palliative care research on the island of Ireland: what we have learnt and where to now? Professor McIlfatrick highlighted some of the key challenges, achievements and priorities of the PCRN over the last five years. The Network is built on a solid foundation of experienced researchers, successful teams and exciting research. She noted some of the major challenges to palliative care research on the island of Ireland and globally including the lack of targeted funding; diverse nature of research activity in terms of breadth and context (a hindrance as well as a benefit); lack of intervention studies; developing a critical mass of palliative care researchers; developing strategic career pathways within palliative care research; strong research collaboration; patient and public involvement (PPI) in research; and specifically for the island of Ireland, supporting cross-border research activity.

Focusing on the PCRN, some of the most notable challenges have been around recruitment into studies, developing a research culture within clinical settings, inter/multidisciplinary research, developing linkages with other networks (both national and international), sustaining and achieving funding, meaningful PPI, and for the PCRN itself, promotion of the Network.

Professor McIlfatrick identified key lessons which will be taken forward by the Network and its new Strategic Scientific Committee. These include a more people and community-orientated approach, developing new and maximising existing linkages with collaborators and other networks, and ensuring research reflects national and global priorities for palliative care. She emphasised the importance of undertaking research activity that will influence policy and practice within the context of the Health Research Board (HRB), Public Health Agency (PHA) and the two health care systems. The PCRN recognises the importance of building research leadership in palliative care and supporting opportunities for future leadership of clinical and early career researchers.

In looking to the future, Professor McIlfatrick highlighted some of the key strengths of the island of Ireland including the high level of interconnectivity of people and centres of excellence; highly motivated clinicians and researchers; a strong track record in palliative care; and strong patient advocacy in this area. Strategically, we aim for a coherent and collaborative research environment and culture; innovative and internationally relevant research; ongoing research capacity building of research leaders; effective knowledge transfer and exchange particularly with clinical sites; and meaningful PPI. A key task for the PCRN's Strategic Scientific Committee in 2017 is to develop a robust research strategy for 2017-2022. The strategy will be informed by the HRB's and PHA's research strategies. The strategy will also seek to expand and develop hospice and clinical-based research into larger scale project development as well as supporting collaborative opportunities, identifying new projects and pursuing relevant funding streams.
Keynote address 1

Priorities for palliative care research: taking stock of successes, challenges and future directions

Professor Lieve Van den Block, End of Life Care Research Group, Vrije University Brussel & Ghent University

The first keynote address was delivered by Professor Lieve Van den Block (Professor of Ageing and Palliative Care Research, Vrije University Brussel & Ghent University, Belgium, Chair Ageing and Palliative Care Research Programme, End of Life Care Research Group. Professor Van den Block’s work focuses on national and international public health and interventional research aimed at monitoring and improving palliative and end of life care for older people. Her research is multidisciplinary in nature and located at the intersection of primary care, palliative care, long-term care and geriatrics.

Professor Van den Block started by identifying key parts to her presentation which focused on successes, challenges and moving forward in palliative care research. Two areas of success were highlighted – (i) public health research and (ii) intervention studies for palliative care. In terms of challenges, Professor Van den Block emphasised some key challenges for research particularly with non-cancer populations and moving forward in terms of methodological improvements in intervention studies.

In terms of studies that have impacted, Professor Van den Block referred to The National Survey of Bereaved People (VOICES) led by Professor Julie Addington-Hall (University of Southampton) which became National Voices in the UK. A further example of informing public health policy is the Place of Death Study which was co-led by Professor Joachim Cohen (End of Life Care Research Group, Belgium) and examined place of death across 14 countries. A significant output from this study was the establishment of a database with information on 2 million deaths. While the data itself may be limited, policymakers can use it to examine potential or future trends e.g. are more people dying in nursing homes? A study published in the Journal of Epidemiology and Community Care by Dr Lara Pivodic (End of Life Care Research Group) explored population dying diseases indicative of palliative care need. In this case, researchers developed criteria based on cause of death data to identify where specific populations were dying. Another example of using public health data in palliative care planning is the IPOD study (International Place of Death study) which gathers population data from death certificates, which can be quite limited across countries. In response to these limited datasets, the End of Life Research Group used Sentinel GP networks to gather cross-country comparative data. The database is utilised by early career researchers in palliative care for training purposes. These are good examples of palliative care researchers influencing public health policy.

What are the most referenced/cited studies in palliative care research? The Temel study (1995) was carried out in the US and compared patients with metastatic non-small-cell lung cancer receiving standard oncology care with patients receiving early palliative care. Significant differences were found between the groups with palliative care patients achieving better outcomes in terms of quality of life, mental health and symptomatology. Another example is the Enable III Trial which examined differences between early and delayed palliative care patient groups which found no differences in all patient-reported outcomes. A number of intervention studies led by Professor Irene Higginson (King’s College London) examine the effects of short-term integrated palliative care for different patient populations (including cancer, COPD, MS, ALS and more recently, frailty). Professor Van den Block also highlighted the significant number of Cochrane reviews which have examined the effectiveness of palliative care.

A key challenge, which is documented is palliative care for older people. A public health perspective (Van den Block et al. 2015) is to identify future effective interventions for older people with multiple comorbidities (frailty, dementia and other chronic disease populations) and interventions that are no longer based on the “old” model of palliative
care which mainly focussed on cancer trajectories and the end of life. Professor Van den Block proposed that in relation to specialist palliative care, a step-up/step-down approach should be implemented when the need arises for patients and that this should happen earlier in the disease trajectory. A cross-country (Italy, Poland, Finland, Belgium, The Netherlands and UK) study led by the End of Life Care Research Group on dying in nursing homes, highlighted the need for improvements in primary care and in nursing care.

Looking to the future, Professor Van den Block emphasised the need for more robust evidence based models of general and specialist palliative care demonstrating their effectiveness. There is also a need for better referral criteria and instruments to specialist services; a step-up/step-down approach to palliative care; multidisciplinary collaboration in medicine and in social care (e.g. general and specialist palliative care, gerontology, primary care). In terms of promising research methodology, Professor Van den Block highlighted the significance of implementation science, realist evaluation and logic models in terms of helping to identify the effective components of an intervention and the contextual factors that really matter. Using the Process Evaluation Guide1 (Moore et al., 2015), she and her colleagues are currently piloting an advanced care planning intervention in nursing homes where each component of the intervention includes a theory of change2,3. An important step in this process is consultation with stakeholders to identify the long term outcome for the intervention. The evaluation itself will measure those elements that have been implemented effectively as well as the extent to which they have had an effect on the primary outcome with a view that the intervention, if it is proven to be effective, may be replicated with fidelity in other regions.

Keynote address 2:
Why supporting research activity and research leadership in hospices and other places of care matters.

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

Professor Payne is Emeritus Professor at the International Observatory on End of Life Care, Division of Health Research, Lancaster University. Professor Sheila Payne is a health psychologist with a background in nursing. She is the Director of the International Observatory on End of Life Care at Lancaster University. She holds honorary visiting chairs at Monash University, Melbourne, Australia and Trinity College, Dublin, Ireland. She is the Past President of the European Association of Palliative Care. Professor Payne has a long track record in palliative care research and scholarship. Her research focuses on palliative and end-of-life care for older people. She holds a number of major international grants and has supervised over 30 PhD students. She has published widely in academic and professional journals and published 11 books.


The presentation focussed on the principle of how we can support research activity and what we mean by leadership in research in hospices and other places. It also highlighted some of the key barriers to undertaking research in hospices and palliative care settings including, lack of time being a major barrier. There remains a significant gap between funding for cancer versus palliative care research in the UK and globally.

Professor Payne outlined a detailed framework for examining the level of research activity within hospice settings in the UK\(^4\). This work highlighted some of the key barriers to doing research including the culture and ethos in a hospice not always being conductive to do research; knowing what is best rather than being evidence-based in practice and a lack of research expertise. There is also the configuration of hospices, which in the UK, are predominantly funded by charities not necessarily affiliated with academic institutions. The framework may be used to develop and support research capacity building within hospices at three levels, depending on available resources:

**Level 1: Awareness of research**

All hospices should be at this level where all professional staff are critical consumers of research. Hospices and other clinical settings should endeavour to practice evidence-based care and offer evidence-based services. Professor Payne encouraged more hospices to develop linkages with other stakeholders including the local primary care network, academic institutions, etc.

**Level 2: Engagement in research activities which are generated by others**

At this level it is important that a hospice is sufficiently informed about the research projects it is being invited to participate in. Professor Payne emphasised the need to increase the number of patients and carers engaged in research by offering them opportunities to participate. What is useful at this point is to identify a research ‘champion’ and have a research policy which includes a consideration of ethical issues. Previous work by Professor Mari Lloyd Williams (University of Liverpool) supported hospices in the UK to develop research policies on how to examine ethical issues and make informed decisions regarding research studies to adopt and to decline. A further point noted by Professor Payne is helping staff to understand good recruitment practices for patients and carers.

**Level 3: Generating and leading research**

There are really good examples of hospices in the Republic of Ireland and the UK that are operating at this level, that is, where there is sustained research activities, generation of ideas in collaboration with others, research leadership in the development of research capacity, and so on.

Professor Payne proposed several ways that hospices can develop or build on existing research endeavours. For example:

- Identify guidelines on research activities and investment. These guidelines may be shared between hospices and other clinical settings
- Link with other research active groups, networks, consortia
- Develop an affiliation with an academic centre that can provide expertise, supervision, mentorship
- Identify opportunities for research capacity building
- Develop a culture of inquiry, respect and value research
- Earmark a proportion of the overall hospice budget for research and development
- Have a “research active hospice” plaque and use it as a quality marker
- Invest in research training and conference attendance
- Identify a research ‘champion’ from clinical staff and build this into their job description (e.g. research nurse or research leader)
- Adopt the framework for research in hospices
- Incentivise the label “research active hospice”

Referring to research leadership in palliative care and what that might look like in an idea world, Professor Payne provided some tangible examples of leading from the front, middle and behind. She emphasised the responsibility of experienced Principal Investigators to develop and support future research leaders, citing work on middle leadership by Dr Sally Watson (Watson & Shannon, 2006). In conclusion, Professor Payne invited the audience to consider the following questions in terms of their own clinical or academic setting – how research active is the environment that you work in right now? What are the strategies that will be useful for you to use? What are the strategies that will be useful for you to use? What is your research culture like? What styles of leadership do you think are necessary to make changes both within your hospice or university setting?

Panel discussion with audience participation: The potential impact of social, cultural and political changes at a national and global level on palliative care.

To kick-start the discussion, Professor McIlfatrick asked the panel what are the potential implications of Brexit and other recent electoral events for palliative care and palliative care research.

Professor Sheila Payne said that mass migration of people moving across national borders is a serious issue. The World Health Organisation states that there is currently 66.5million migrants globally and 10million are stateless. Entire families (and generations) are moving into Europe with the situation being worse in the Middle East. This raises questions about the how these regions and specific countries are going to provide palliative care for children and adults. What kinds of conditions are those people going to face at their end of life when the structures or support to provide palliative care are not available? Looking to the advantages of mass migration, will mass migration particularly of a younger generation change the population demographics which have been consistently aging?

Continuing, Professor Philip Larkin highlighted the ongoing need for the palliative care community to adopt a common language that clearly expresses to politicians what it does. He observed that countries which are successfully integrating palliative care into services are ones that have learned how to get a succinct message across. It is imperative that we convey who we are, what we do and what we do not do.

Dr Joan McCarthy stressed the importance of social justice and of being inclusive of different traditions and cultures in relation to death and dying. She referred to the issues and demands that Brexit may pose particularly for researchers who may already be struggling to create a longer-term career trajectory. Dr McCarthy suggested that hospices and other clinical settings have an opportunity to direct some of their funding towards research on a particular topic which might offer researchers some continuity.

Dr Regina McQuillan raised the point that there is still no right answer to the question of whether people should die at home or not and rather, it depends on what is culturally appropriate. She spoke about the collectivist view of a ‘good death’ versus the individualist view, emphasising that we must avoid imposing a model on other people. For example, in Ireland it is mainly about being symptom-free, knowing you are going to die, having made an advanced care plan, and dying in your chosen place. However, this might not be culturally or spiritually appropriate for others.

Professor Van den Block revisited the need for having a succinct message for palliative care, reflecting on Belgium’s successes. She believed that what really advanced palliative care in her country is having the right people at the right time with the right ideas.

Responding to a question from the audience in relation to supporting the next generation of palliative care researchers to preserve criticality in the face of the dominant culture (e.g. nationalism), Professor Larkin said that interdisciplinary collaboration can support this and cited the social justice strand within the Palliative Care Research Network as an example of leading from the middle.

There were several contributions and additional questions from the audience during the panel discussions, highlighting the need for palliative care and palliative care research to remain dynamic in terms of responding to changing social, cultural and political challenges now and into the future.
STRATEGIC DEVELOPMENT OF THE PCRN

Annual review of the Palliative Care Research Network (PCRN)
During an eighth-month period, AIIHPC together with representatives from the PCRN, Professor Philip Larkin (UCD) and Professor Charles Normand (TCD) participated in the HRB’s annual review of the Research Network. Following submission of an annual report for 2014-2015 which was approved by the PCRN’s Research Governance Committee, the Institute welcomed the opportunity to engage with an International Review Panel, exploring the challenges, achievements and strategic direction of the Network. There were also opportunities to address some pertinent items including research capacity building, service user engagement/carer involvement (PPI) and future actions. As part of the review, a strategic proposal was submitted to the HRB seeking further infrastructural funding for two new half-time project manager roles over three years. These two new roles in project management and knowledge transfer & exchange will support the strategic development and impact of the network as it continues to promote and produce palliative care research on the island of Ireland and internationally.

Palliative Care Research Network Strategic Scientific Committee
In 2016, AIIHPC launched a call to PCRN members for nominations to a new Strategic Scientific Committee. The purpose of the Committee is to influence the strategic direction and future work of the PCRN, helping to establish it as both a national and international leader for palliative care research. Following on from a very successful research symposium in December, the Committee held its first full meeting in January 2017. The Committee expanded to include representatives from all academic and a number of hospice organisations partnered with AIIHPC as well as members from the Institute’s service user/carer forum, Voices4Care. For a list of members see Appendix A.

Next steps (2017):
- Secure funding from the Health Research Board and the HSC Research and Development Division, Public Health Agency for the appointment of two new half time Project Manager roles
- Ensure quarterly meetings of the PCRN’s Research Governance Committee and the Strategic Scientific Committee
- Develop Research Strategy 2017 - 2022
- Attend EAPC’s 15th World Congress (May 2017)
- Organise 6th Annual PCRN Symposium 2017
- Disseminate PCRN core and aligned projects
## APPENDIX X: PCRN STRATEGIC SCIENTIFIC COMMITTEE MEMBERS

<table>
<thead>
<tr>
<th>NAME</th>
<th>ORGANISATION</th>
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<tbody>
<tr>
<td>Professor Sonja McIlfatrick, Chair</td>
<td>Ulster University</td>
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<tr>
<td>Dr Suzanne Guerin, Secretary</td>
<td>University College Dublin</td>
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<td>Professor Kevin Brazil</td>
<td>Queen’s University Belfast</td>
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<td>Dr Alice Coffey</td>
<td>University College Cork</td>
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<td>Dr Frank Doyle</td>
<td>Royal College of Surgeons Ireland</td>
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<tr>
<td>Dr Lisa Graham</td>
<td>Marie Curie Hospice</td>
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<td>Dr Geralyn Hynes</td>
<td>Trinity College Dublin</td>
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<tr>
<td>Ms Bridget Johnston</td>
<td>Trinity College Dublin</td>
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<tr>
<td>Mr John Joyce</td>
<td>AIIHPC Voices4Care</td>
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<tr>
<td>Professor Phil Larkin</td>
<td>University College Dublin</td>
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<tr>
<td>Ms Annie McHale</td>
<td>AIIHPC Voices4Care</td>
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<td>Dr Dorry McLaughlin</td>
<td>Queen’s University Belfast</td>
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<tr>
<td>Professor Charles Normand</td>
<td>Trinity College Dublin</td>
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<tr>
<td>Dr Norma O’Leary</td>
<td>Our Lady’s Hospice &amp; Care Service</td>
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<tr>
<td>Dr Martina O’Reilly</td>
<td>Milford Care Centre, Limerick</td>
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<tr>
<td>Professor Eamon O’Shea</td>
<td>National University of Ireland Galway</td>
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<tr>
<td>Professor Anthony Staines</td>
<td>Dublin City University</td>
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<tr>
<td>Professor Sheila Payne</td>
<td>International Observatory on End of Life Care, Lancaster University</td>
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### IN ATTENDANCE:

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<tr>
<th>Name</th>
<th>Organisation</th>
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<tbody>
<tr>
<td>Dr Gail Johnston</td>
<td>HSC R&amp;D, Public Health Agency, Northern Ireland</td>
<td>Funder</td>
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<tr>
<td>Dr Donna Tedstone</td>
<td>Health Research Board, Ireland</td>
<td>Funder</td>
</tr>
<tr>
<td>Dr Tara Murphy</td>
<td>Programme Manager Research, AIIHPC</td>
<td>AIIHPC rep</td>
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PCRN | Early Research Career Forum
KINDLE Project