All Ireland Palliative Care Research Network

(P.C.R.N.)

Annual Network Update Report

October 2014
It is now three years since we first put together our bid and application to HRB for the AllIHP Structured Research Network and just over two years since the AllIHC All Ireland Palliative Care Research Network was launched in September 2012. We have worked hard as a collaborative over the past three years, firstly to develop a vision of how to make the most of this exciting opportunity and secondly to make the vision a reality. In our first year as a Network we focused our attention largely on building relationships and developing management and leadership structures and processes. In essence these first two years could be considered largely as the ‘start up’ period. As a result, we believe that we have begun to achieve our overall vision: “International recognition for research and development enhancing knowledge, expertise and scholarship for hospice and palliative care in Ireland”. I hope the evidence we present in this report is supportive of this. This report will provide an update on key aspects of progress and elements related to our overall strategic objectives. These are focused in areas such as: developing a collaborative research community; research capacity building; high quality innovative research; interdisciplinary collaboration and meaningful user involvement.

In conclusion, the PCRN has been successful in its first two years in turning its vision of a research collaborative into a reality. The collaborative has met its objectives and milestones, as evidenced by the HRB successful interim review panel meeting that took place in April 2014. There is also some indication of the PCRN success in that we have new investigators, programmes of work and research projects within the network, alongside success in attracting 6 additional research grants totalling nearly 5 million euros. This is a mixed funding portfolio with success in obtaining research grants from the National Institute for Health Research, Marie Curie UK, the DHSSPS, Public Health Agency and Atlantic Philanthropies. Our first outputs are also starting to emerge in terms of publications resulting directly from the research projects within the Network. We have appointed our first AllIHP/ Irish Cancer Society Post-Doctoral fellowship and have awarded four AllIHP Clinical Fellowships, to enable practicing clinicians to have dedicated research time to begin to build research career. Collaboration by its very nature is a creative, dynamic activity and
change therefore is to be expected and welcomed. During the summer we hosted a strategic review meeting of the activities of the Network to consider how we may need to adapt and change to bring about progress for palliative care research in Ireland.

I would like to thank the many PCRN members who have made this progress possible. We are not, however, complacent about the future. The Network clearly recognises the challenges involved in further meeting the aims, and sustaining both the quality and quantity of research for the future. We look forward to working together to continue to address these challenges.

Dr Sonja McIlfatrick

Head of Research
Introduction

In late 2011, AIIHPC identified two thematic areas for research focused around the central concept of generating knowledge and understanding in order to improve the experience of patients and their families. These are:

RESEARCH STRAND 1: ‘PATHWAYS TOWARD SOCIAL JUSTICE: UNDERSTANDING EQUALITY AND INCLUSION IN PALLIATIVE CARE’.

RESEARCH STRAND 2: ‘MEASUREMENT AND EVALUATION OF OUTCOMES FOR PALLIATIVE CARE’.

These are widening and expanding with new research projects, teams, leaders, and funding to become a dynamic and leading network for palliative care research in Ireland. The overall aim of the Network is to offer the all-Island palliative care research community opportunities to create and engage within a collaborative environment that supports the development of excellent, high quality, clinically-relevant and innovative research projects that will advance understanding of AIIHPC’s research strategy.

This report is an account of the PCRN in its second year of funding, detailing activities from September 2013-September 2014. This report first gives an account of particular highlights in 2014, an update on the current status of the current funded projects within the Network; detail on research capacity building activities, and developments for user involvement in research. Updated information on research grants and publications are also provided.
An interim evaluation review of the Network, facilitated by the HRB, took place in March 2014. The following feedback was received:

- The Health Research Board (HRB) review panel strongly recommended proceeding with the award and highly commended the network for their presentation. The committee stated that enthusiasm, commitment and vision were clearly demonstrated by the network and they were impressed by the vision and leadership shown by the representatives and in particular the Director of Research, Dr Sonja McIlfatrick.

- The committee commended the Network for the progress made against the originally stated objectives and were excited in relation to the innovative plans for user involvement for the Network. The HRB committee acknowledged the success of the Network in bringing together disciplines not usually associated with palliative care and the potential of this to assist in sustainability. The committee highlighted the “Education” strand within the AIIHPC has the potential to act as a lobbying mechanism within the wider environment for capacity building in palliative care research and furthermore acknowledged the added benefits of the SRN for the PhD and Post-doctoral researchers.

- The committee was pleased to see that the Network was utilising a range of methods to inform priority setting. This included building on the strengths and insights of the existing membership, completion of a systematic review looking at palliative care research on the island of Ireland and a collaborative project on priority setting with Marie Curie UK.

- The HRB committee suggested that the Network ensure all PIs use the corporate identity for the Network and use social media more widely to increase the visibility of the AIIHPC.
PCRN Strategic Review Meeting

In June 2014, following the feedback from HRB Interim Review, a strategic review meeting of the Network took place. This meeting focused on three key areas:

1. Strategic Development of the PCRN
2. Membership of PCRN
3. Key Performance Outcomes

Some key actions arising from this meeting were the need to develop 2-3 key foci moving forward; engagement with our community at three different levels from engagement with wider community, facilitated by the professional section of the Palliative Hub; research active community focusing on smaller research projects linked to providers and the third level develop research leaders, larger projects and funding. Overall the key performance indicators were considered as fit for purpose, focusing on targets relating to Knowledge production, Research Targeting; Capacity building and Knowledge Translation. The actions and outcomes are being led by the Research Steering Committee and Network Performance Committee.

AllHPC & Irish Cancer Society (ICS) award Postdoctoral Fellowship in Palliative Care

The AllHPC & ICS have awarded Dr Kathleen McLoughlin (Milford Care Centre) and Dr Sinead McGilloway (Maynooth University) an award of up to 200,000 euros for a Post-Doctoral Research Fellow for a period of two years. The fellowship will explore the relationship between the quality of a person’s life at the end of life and their social network to see how this affects where a person dies, their use of health services and their overall well-being. Additionally the research will also investigate how services can better organise these networks by means of a “Good Neighbour Scheme”.

The ISC Chief Executive John McCormack said “we are delighted that Dr McLoughlin has been awarded this Fellowship. She has a strong track record and we look forward to this opportunity to learn how we can ensure better experiences for patients and their families”
New Investigator

Professor Kevin Brazil
Professor of Palliative Care, School of Nursing & Midwifery, Queens University Belfast (QUB) & Department of Clinical Epidemiology & Biostatistics, McMaster University

Background: The societal shift towards an older population has implications on how palliative care should be provided. Providing this care presents a unique challenge ranging from social and medical considerations as well as understanding the diverse setting of care where palliation occurs. This research strand will identify considerations that policy makers and health care providers should regard in the provision of palliative care for older adults.
**Aim:** The initial foci in this strand will be twofold: (a) disease specific: dementia (b) structures of care: nursing homes. It is acknowledged that these two foci are not mutually exclusive.

Professor Brazil has acquired funding from the School of Nursing & Midwifery, QUB to support a doctoral student and is also involved in several initiatives:

<table>
<thead>
<tr>
<th>Year</th>
<th>Title</th>
<th>Investigator(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014-2017</td>
<td>Promoting informed decision making and effective communication through advanced care planning for people living with dementia and their family carers</td>
<td>Brazil K, Clarke M, Froggatt K, Hudson P, Kernohan G, McLaughlin D, Passmore P</td>
</tr>
<tr>
<td>2013-2014</td>
<td>General practitioners perceptions on palliative care for individuals with Alzheimer’s disease &amp; other progressive dementias</td>
<td>Brazil K, Galway K, Van Der Steen J, Watson M</td>
</tr>
<tr>
<td>2013-present</td>
<td>Improving palliative care in advanced dementia collaborative network</td>
<td>Brazil K, Watson M, Leavey G</td>
</tr>
<tr>
<td>2013-2015</td>
<td>Addressing ethical conflicts among qualified and non-qualified carers in nursing homes</td>
<td>Brazil K</td>
</tr>
</tbody>
</table>

The values that underpin this research stream are shared with the AIIHPC Social Justice, inclusivity and promotion of an evidence based approach to policy development and service provision. Aligning these activities within the SRN of the AIIHPC will enhance the impact of this work on the provision of palliative care across the island of Ireland.
STRAND 1: ‘Pathways toward Social Justice: Understanding Equality and Inclusion in Palliative Care’ (SJS)

Led by
Professor Philip Larkin Associate Professor of Clinical Nursing (Palliative Care), School of Nursing, Midwifery and Health Systems, College of Health Sciences, University College Dublin (UCD)

Background
The Social Justice Strand (SJS) is based on the premise that inequality exists in relation to palliative and hospice care access and service delivery across the island of Ireland for certain groups of people. This strand will examine the experience of inequality towards and through hospice and palliative care service delivery across the island of Ireland as reported by individuals, their families and the health and social care workers who support them. It will utilise generated evidence to develop best practice approaches which strengthen relationships and facilitate greater awareness of the hospice and palliative care needs of people currently excluded by virtue of misunderstanding, diminished recognition and/or prejudice.

WP1: Identifying and addressing the needs of people with serious mental Illness

Co-Investigators
Dr Ann Sheridan, School of Nursing, Midwifery & Health Systems, UCD
Professor Gerard Leavey, Director Bamford Centre for Mental Health & Wellbeing
University of Ulster (UU)

Aim: To provide a better understanding of the need for and experiences of people with pre-existing diagnosed mental illness with regard to palliative care and end of life care in Ireland. The evidence from this work will then form the basis for innovation and change in service delivery for people with these conditions.
**Methods**: A mixed methods approach.

**PhD scholar**: Sarah Walsh

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**WP2: Identifying and Addressing the Needs of People with Intellectual Disability**

*Co-investigators*

Professor Mary McCarron, Dean of Health Sciences, School of Nursing & Midwifery, TCD

Dr Karen Ryan, Palliative Medicine Consultant, Mater Misericordiae Hospital & St Francis Hospice & Clinical Lead for Palliative Care, HSE

**Aim**: To understand the determinants of access and lack of access to palliative care for persons with intellectual disability (ID) and life-limiting conditions. (1) To better understand the factors influencing end-of-life care transitions and pathways and (2) to ascertain perceived QoL and QoD and personal, professional, organizational and policy-based practices that influence the continuation inequalities in access and treatment.

**Methods**: Mixed methods

**PhD Scholar**: Janet O'Farrell

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**WP3: An Exploration of access, decision making and experiences of palliative care services for families of children with a non-malignant life-limiting condition**

*Co-investigators*

Dr Gemma Kiernan, Lecturer, School of Nursing & Human Sciences, Dublin City University

Dr Honor Nicholl, Lecturer, School of Nursing & Midwifery, TCD

**Aim**: To explore access to, decision making regarding and experience of palliative care at critical time points during a child’s illness trajectory and to develop an evidence-based model of service provision for these families.

**Methods**: A multi-informant cross sectional mixed method design based on an emancipatory and participative

**PhD Scholar**: Fiona Hurley
WP4: Exploring Dimensions of Inequality in Current Palliative Care Provision for Carers of People with Advanced Heart Failure in Ireland

Co-investigators
Dr Donna Fitzsimons, Senior Manager for Nursing Research, Belfast Health & Social Care Trust and Professor of Nursing, Institute of Nursing & Health Research, UU
Dr Sonja McIlfatrick, Reader, Institute of Nursing & Health Research, UU, Head of Research, AIHPC

Aim: To evaluate the dimensions of inequality expressed by carers of patients with advanced heart failure in Ireland and to explore any relationship between this and a range of other factors including the patient’s clinical profile and support available.

Methods: A sequential confirmatory mixed methods study including a systematic review, quantitative measures & qualitative interviews

Post-Doctoral Research Fellow:
Dr Leanne Doherty (nee Breslin)
Background
The Measurement and Evaluation Strand (MES) will explore methodological development for palliative care research with a focus on measurement of needs, measurement of impact and evaluation of service priority and delivery. MES will develop better understanding on how best to elicit preferences and views for service users and families and will support the development of measurement tools for palliative care research. This strand will utilise evidence to examine how best to disseminate complex findings in palliative care research. The MES team shares the social justice perspective of SJS, that access to care should depend on needs and not circumstance.

WP5: Towards Improved diagnosis and symptom management in palliative care

Co-investigators
Professor David Meagher, Consultant Psychiatrist, Department of Adult Psychiatry, Midwestern Regional Hospital, Limerick
Dr Karen Ryan, Palliative Medicine Consultant, Mater Misericordiae Hospital & St Francis Hospice & Clinical Lead for Palliative Care, HSE

Aims: To explore the relationship between various symptom domains (cognitive difficulties, mood disorder, pain, cachexia and fatigue in patients admitted to palliative care in Ireland) over the course of treatment and to identify a simple user-friendly testing procedure that allows for both applicability and efficiency in accurately identifying cognitive and mood disturbances in everyday clinical practice, and to test this in those settings to determine its appropriateness and efficacy.

Methods: A mixed methods approach to include longitudinal observation, and decision-making algorithms.
**WP6: Development & evaluation of a psycho-educational intervention for patients with refractory cachexia & their lay carers**

**Co-investigators**

Professor Sam Porter, Chair in Nursing Research, School of Nursing & Midwifery, QUB  
Dr Joanne Reid, Lecturer in Cancer Nursing, School of Nursing and Midwifery, QUB

**Aim:** To contribute to the psychological care of palliative patients and their lay carers by helping them to understand, adapt to, and cope with the distressing consequences of the loss of appetite and change in appearance that often accompanies the last stages of life. To utilise a range of research methods, including qualitative analysis, realistic research, randomized controlled trial, and economic evaluation, in order to assist in the development of skills in the measurement and evaluation of palliative care.

**Methods:** The UK Medical Research Council’s framework for developing and evaluating complex interventions. The intervention will be evaluated by a multi-centre single-blind randomized controlled trial.

**Post-Doctoral Research Fellow:** Dr David Scott
WP7: Eliciting preferences for complex packages of palliative care – extension of IARE

Co-investigators
Professor Charles Normand, Edward Kennedy Professor of Health Policy and Management,
Centre for Health Policy and Management, TCD
Original IARE Investigators

Aim: To extend the evidence on patterns and determinants of preferences for palliative care services in Ireland using discrete choice experiments, and to provide a basis for methodological work on measurement of outcomes and benefits. This will provide a wider database to explore the variation in patterns of preferences within Ireland. The research will be carried out in collaboration with the IARE study teams in New York and London led by Professor Irene Higginson.

Methods: Discrete choice experiments using the instrument developed in partnership with IARE.

Post-Doctoral Research Fellows: Bridget Johnson
WP8: Developing & implementing a ‘System’ of structured network-wide dissemination & knowledge transfer activities

Co-investigators
Professor W. George Kernohan, Professor of Health Research, Institute of Nursing & Health Research, School of Nursing, UU
Dr Suzanne Guerin, Centre for Disability Studies, School of Psychology, University College Dublin

Aim: To support knowledge transfer to enhance palliative care in Ireland.

Methods: The project will be focused on two key stages: (1) Adapting and validating a model of knowledge transfer and exchange (KTE) for palliative care; and (2) Implementing and evaluating the KTE model. This will be a mixed methods study. A number of case studies will be identified including at least two arising from the P.C.R.N. which will be used to evaluate and refine the KTE model.

Researcher: Lucia Prihodova
Lucia Prihodová completed her master’s degree in psychology at the University of Trnava, Slovakia. Her qualifying areas were clinical, counselling and educational psychology, and in her master thesis she explored the interactions between coping skills, hope, social support and quality of life in patients with an oncologic disease. Lucia successfully defended her PhD thesis entitled “Psychosocial and medical determinants of long-term patient outcomes” in September 2014. She is employed as a doctoral fellow on an All-Ireland Institute of Hospice and Palliative Care (AIHPC) research project aimed at developing and implementing a system of structured based at the School of Psychology, University College Dublin.
Research Capacity Building (RCB)

P.C.R.N. seeks to enhance the capacity of the palliative care community, particularly in the use of innovative research approaches, multi-disciplinary research capability, output and high quality training and learning opportunities. Whilst the primary focus may be innovative research methods, which tend to be advanced in terms of the skills and knowledge required to use them, P.C.R.N. recognises the need to provide opportunities for capacity building at what might be considered a less advanced level, in order to facilitate development and progression towards more advanced levels.

P.C.R.N. is therefore adopting a multi-tiered approach to RCB by:

- Raising awareness of research,
- Providing more extensive support to those who want to progress elements of palliative care research, and
- Seeking to provide tailored support to the few who wish to progress to the most advanced level.
EAPC Travel Bursaries

The World Research Congress of the European Association for Palliative Care (EAPC) took place in Lleida, Spain in early June.

Pictured at the AIIHPC stand at the EAPC Conference 2014 were (L-R): Mr Joss Watson, Ms Martina O’Reilly, Dr Isae Kilonzo, Ms Debbie Hayden, Ms Fiona Hurley, Dr Audrey Roulston and Dr Sonja McIlfatrick

‘Conference Quotes’ from the AIIHPC Travel Bursary recipients:

One of my highlights included attending the EAPC Spiritual Care in Palliative Care Task Force meeting to discuss our progress and plan future initiatives to promote spiritual care education, research and practice. Debbie Hayden

I had a long discussion with Professor Peter Hudson from Australia as I was very interested in hearing about the theoretical perspective which he used on ‘Conducting Research with Family Caregivers’. Fiona Hurley
The travel bursary received from the AIIHPC provided me with a wonderful opportunity to hear first-hand the insights of some of the world leaders in Palliative Care Research. Martina O’Reilly

The highlight was the opportunity to hear from international experts and rising stars about a vast range of interesting research projects that are being conducted in palliative care settings. Dr Audrey Roulston

Clinical Research Fellows

As part of its drive to develop research capacity in palliative and end of life care, AIIHPC launched four Clinical Research Fellowships worth €10,000 each in May 2013. The Fellowships are targeted at health and social care professionals involved in clinical practice in the Republic of Ireland and Northern Ireland who are currently conducting or intend to undertake small-scale research-related projects relevant to palliative care. The successful Fellows and their respective projects are:

**An examination of healthcare professionals’ barriers and facilitators to adopting e-learning in palliative care education**

led by Joanne Callinan, Librarian, Milford Care Centre, Limerick

Ethical approval was sought and obtained from Research Ethics Committees in the Republic of Ireland and Northern Ireland. Quantitative data was collected by questionnaire from a convenience sample of healthcare staff employed in specialist palliative care in hospice, day care or the community on the Island of Ireland. Phase 2 of the study involved collecting qualitative data from a purposeful sample of hospice educators on the Island of Ireland using semi-structured interviews. The inclusion criteria for participation in the interview was that participants must be employed in an education facility within a hospice environment, have clinical experience and be involved in the delivery of palliative care education as their primary role. I am currently in the process of the analysing the quantitative and qualitative data and I plan to disseminate the research as a report by the end of October. It is my
intention to present at a conference and to publish in a journal in a palliative care or e-learning journal.

**Physiotherapy led palliative exercise program for Parkinson’s disease (PEP-PD) patients in an out-patient setting: a feasibility study**
led by David Hegarty, Physiotherapist, St Francis Hospice, Dublin

The aim of the study is to examine the feasibility of a lower limb strength-based progressive exercise program for people with H&Y Stage 3 or 4 PD in a hospice setting. We conducted a small scale feasibility study with a single patient cohort and pre-test post-test design using mixed methods in the form of quantitative outcome measures and qualitative semi-structured interviews. Eighteen referrals were received from the recruitment sites. Fourteen participants took part in the program with 13 patients completing the entire program. The results of the quantitative and qualitative research methods are in the analysis stage at present. The preliminary results suggest that it is feasible to run a high intensity strength training program for people with advanced PD. The results show a high level of satisfaction and participation in the program, as well as improved perceived self-efficacy in the semi-structured interviews.

**The role of connected health in the measurement of autonomic dysfunction in cancer**
led by Dr Brenda O’Connor, Specialist Registrar, Palliative Medicine, Our Lady’s Hospice & Care Services, Dublin

From November 2013-August 2014 several collaborative meetings were held with the chief project engineer at Tyndall National Institute (TNI) Cork, to discuss the exact features of the technology to maximise comfort and utility. The existing technology needed adjustment for the advanced cancer population. Prototype technology has since been reviewed by the researcher, feedback has been given to technology partners and final design adjustments are in progress. Final handover of the technology and education sessions on its use are scheduled for October 2014. Data collection on the first stage of the project (10 healthy
volunteers) will be completed by the end October with patient recruitment planned to begin in early November. It is estimated that data collection will be completed in February 2015.

A prospective observational cohort study of the assessment of quality of care provided by a specialist palliative care service in Ireland, from patients’ reported perspectives, using a validated outcome tool led by Martina O’Reilly, Quality & Safety Coordinator, Milford Care Centre, Limerick

A total of 69 patients were approached to seek their consent to participate in the study. A total of 52 or 75% of those approached patients completed the initial SKIPP measure. Overall, results of the initial evaluation (SKIPP T1) indicate that the patient’s perception of their contemporaneous quality of life (QOL) is significantly better (MD = 5, IQR = 3, n = 52), in comparison to their rating of their retrospective QOL, prior to receipt of service, (MD = 4, IQR = 3, n = 52) P = 0.002, across the three services, (inpatient unit, hospice at home and day care). In respect of dissemination I hope to write a paper and submit an abstract for the 2016 EAPC which will be located in Dublin.

Clinical Research Fellowships from the All Ireland Institute of Hospice and Palliative Care were (l-r): Martina O’Reilly (Milford Care Centre, Limerick), Joanne Callinan (Milford Care
Centre, Limerick), David Hegarty (St Francis Hospice, Dublin) and Dr Brenda O’Connor (Our Lady’s Hospice & Care Services, Dublin).

**All Ireland Early Career Researcher Forum**

AIIHPC is establishing an Early Career Researcher Forum in partnership with the Irish Association of Palliative Care (IAPC). The establishment of this forum is central to the Institute’s broader aim of creating, developing, and promoting collaboration and capacity building in research on the island of Ireland. The Forum will be situated within the P.C.R.N. and has already developed initial links with its European equivalent, the European Association of Palliative Care’s (EAPC) Junior Forum. An executive committee has been established, Chaired by Cathy Payne, AIIHPC, Doctoral Fellow. In May 2014, another successful meeting of this Forum was held. This day included presentations from each of the Clinical Fellows, as well as presentations by Professor Peter Hudson, Director for the Centre for Palliative Care (St Vincent’s Hospital and Collaborative Centre of the University of Melbourne, Australia) on *Challenges in undertaking palliative care research with carers* and Professor Sam Porter, Queen’s University, Belfast and Senior Investigator All Ireland Hospice and Palliative Care Research Network, on *Challenges in designing and evaluating complex interventions for palliative care research*. This group met in May 2014 and hosted a successful meeting, with presentations from Professor Peter Hudson, outlining challenges when undertaking palliative care research with carers.

Cathy Payne, Chair, Early Career Researcher Forum
Dignity Care Intervention Project

Project Update: Dr Sonja McIlfatrick and Professor Phil Larkin, were awarded funding from the Irish Hospice Foundation and the Irish Cancer Society to implement and evaluate a dignity care intervention for individuals nearing the end of life in rural versus urban community settings.

The dignity care intervention was originally developed, implemented and evaluated by Dr Bridget Johnston and colleagues based in the University of Dundee (Scotland). Previous research clearly indicates that the tool added to the quality of nurses’ work with patients who have palliative care needs across a range of illnesses, chronic diseases and cancer. Patients and Family Carers reported a greater sense of worth in being respected and listened to by nurses and ultimately, that dying with dignity was achieved. It is envisaged that the project will have several positive outcomes towards improving care at the end-of-life and improving support for informal caregivers. It will also act as a demonstrator project for planning and implementing effective knowledge transfer activities in clinical practice.

AllHPC: Other developments

User/Carer Involvement in Research

AllHPC recently launched the new Voices4Care group as part of its commitment to having the views of patients and their families at the heart of what we do. This group will share and discuss issues which will inform how best to care for people with an illness or condition which may limit or shorten their lives. After a successful recruitment campaign, a total of 23 members of Voices4Care were selected bringing a wealth of experience, wisdom and commitment to the group. Dr McIlfatrick had a recent meeting with this group discussing Patient and Public Involvement in Research and seeking to develop a AllHPC Palliative Care User Research Forum. A number of individuals have expressed an interest in this.
### APPENDIX 1- Funding Update 2014: acquired by PCRN members

<table>
<thead>
<tr>
<th>Year</th>
<th>Title</th>
<th>Investigators</th>
<th>Funders</th>
<th>Amount (£)</th>
<th>Amount (€)</th>
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<tbody>
<tr>
<td>2014-2017</td>
<td>The Evaluation of Healthcare Passport to improve quality of care and communication for people living with dementia: (EQuIP)</td>
<td>PI: G Leavey; Co-investigators: S Mcllfatrick, V Coates, B McCormack, Todd McCormack, Todd McCormack, Todd McCormack</td>
<td>R&amp;D, Public Health Agency &amp; Atlantic Philanthropies</td>
<td>329,000</td>
<td>418,000</td>
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<td>2014-2017</td>
<td>The MARQUE Study: Managing agitation and raising the Quality of life in dementia: ESRC-NIHR</td>
<td>PI: G Livingston; Co-investigator: G Leavey</td>
<td>ESRC-NIHR</td>
<td>3.22million</td>
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<td>2014</td>
<td>Delirium Research</td>
<td>PI: D Meagher</td>
<td>Strategic Research Fund: University of Limerick</td>
<td>40,000</td>
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<td>2014-2017</td>
<td>Promoting informed decision making and effective communication through advance care planning for people living with dementia and their family carers.</td>
<td>PI: K Brazil, Co-investigators: M Clarke, K Froggatt, P Hudson, G Kernohan, D McLaughlin, P Passmore</td>
<td>The Atlantic Philanthropies &amp; HSC Public Health</td>
<td>426,738.52</td>
<td>541,286</td>
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<td>2014-2017</td>
<td>Costs and effectiveness of UK palliative care day services: a three-centre mixed methods study of impact upon patients and family carers.</td>
<td><strong>PI: G Kernohan, K Brazil</strong> Co-investigators: F Hasson, M Donnelly, N McCorry, J Coast, S Mcllfatrick</td>
<td>Marie Curie Cancer Care Research</td>
<td>275,896</td>
<td>349,936</td>
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Grants submitted by members of AllHPC and awaiting results

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<tr>
<th>Year</th>
<th>Title</th>
<th>Investigators</th>
<th>Funders</th>
<th>Amount (£)</th>
<th>Amount (€)</th>
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<tr>
<td>2015-2018</td>
<td>IARE 2</td>
<td>Co-investigators: I Higginson, C Normand, S Morrisson, D Meier’s, P McCrone, K Ryan, R McQuillan</td>
<td>American Philanthropies</td>
<td>1 million</td>
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<td>2015-2017</td>
<td>Improving nurses’ symptom related ethical decision making in the last days of life: an educational intervention study in 4 sites</td>
<td>PI: B Johnston B Co-investigators: J Seymour, J Brown, S McIlfatrick</td>
<td>Marie Curie, UK</td>
<td>164,597</td>
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APPENDIX 2: Publications co-authored by PIs this year (including but not limited to)


Fitzsimons, D., McIlfatrick, S., Taylor, B., (2014) *Using literature to inform vignettes designed to explore the perceptions of Implantable Cardioverter Defibrillator (ICD) Deactivation at end of life*. BMJ Supportive & Palliative Care, 4 (1).


McIlfatrick, S., Murphy, T., (2014) Palliative care research on the island of Ireland over the last decade: a systematic review. BMJ Supportive & Palliative Care, 4 (1)


APPENDIX C 3: Conference presentations January-September 2014

Work Package 1
Walsh, S., Sheridan Palliative Care for People with Serious Mental Illness in Ireland. Psychological Society of Ireland, Health Psychology and Medicine Conference, May 28th-29th Limerick Ireland . Oral Presentation

Work Package 2

Work Package 4

Work Package 5
Conference presentations at national ICU meeting Tallaght. Multiple presentations scheduled for forthcoming European Delirium Association and UHL research day November 2014. Prof David Meagher to give Key Note at EDA this year

Work Package 6
Porter, S., Reid, J., Santino, O., Scott, D., (2014) Developing, Implementing and Evaluating a psych-educational intervention for the management of cachexia in advanced cancer. EAPC World research Congress. 5-7 June. Lleida, Catalonia Oral Presentation

Work Package 7
Normand, C Eliciting preferences for complex packages of palliative care. Beaumont Hospital for the Annual Palliative Care Study Day, Beaumont Hospital, Sep 2014.
Work Package 8

Guerin S, Kernohan G (2014) PiCKUP: A Palliative care Knowledge Utilisation Project. 3rd Public Health Open Conference organised by IPH. Poster presentation
APPENDIX 4: EVIDENCE OF COLLABORATIONS

Work Package 1: Irish College of General Practitioner’s, Irish College of Physicians and Psychiatrists, The Institute of mental Health Nursing

Work Package 2: Collaboration with Last days of Life Study, Cross National Group researching the mortality of people with ID

Work Package 3: Collaboration with Dr Peter Hudson Director of the Centre for Palliative Care in the University of Melbourne, Cross Institutional Collaboration established with Northern Ireland’s Children’s Hospice, Collaboration with the National University of Ireland Galway.

Work Package 4: Collaboration with clinical colleagues in cardiology in, St Vincent’s Hospital, Dublin, the Belfast and South Easter Health & Social care Trusts and the project has been adopted as part of the Northern Ireland Cardiovascular Network.

Work Package 5: Collaboration with Milford Hospice.

Work Package 6: Parallel research in St Vincent’s Hospital Melbourne, The Mayo Clinic, Minnesota

Work Package 7: Collaboration with Trinity College Dublin, Beaumont Hospital, The Mater Hospital and St Francis Hospice. Further collaboration with Mt. Sinai Hospital, the University of California Medical School. Collaboration also with Kings College Hospital, the Cicely Saunders Institute and St Christopher’s Hospice.

Work Package 8: Collaboration between UCD and Ulster University