All Ireland Palliative Care Research Network (PCRN)

ANNUAL NETWORK REPORT - 2015

All Ireland Palliative Care Research Network

2015

Palliative Care Research Network

Health Research Board
Welcome to the Annual Network Update Report for the Palliative Care Research Network. 2014/2015 has been a busy period for the researchers who make up the membership of the PCRN, as you will see from the contents. We are delighted to present some of the highlights for 2014/2015, with congratulations to the researchers involved.

A key development during this period has been the development of the PCRN from a collection of funded research projects to an individual member based and member driven network of researchers. This is the structure that will be carried forward into the future and our aim is to be the premier network for researchers in the area of palliative and end of life care on the island of Ireland. Our vision of the Network is one of dynamic and supportive activity with the shared focus of informing best practice in care. An overview of the strategic vision for the PCRN is outlined later in this report.

The final section of this report presents an update on the activities of PCRN members, which we hope captures the significant activity by members of the Network.

To conclude, we are looking forward to the third Annual PCRN symposium, which takes place on Wednesday 25th November in the Ashling Hotel, Dublin. This will be a valuable opportunity to come together and reflect on current and future plans.
As part of its drive to develop research capacity in palliative and end of life care, AIIHPC launched a second wave of Clinical Research Fellowships worth €10,000 each in July 2015. 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 (e.g. symptom management, psychosocial interventions, health services research). Applicants were shortlisted in September and three Fellowships were awarded to the following individuals:

**High CRP as a predictor of specialist palliative care needs: a pilot study**

Dr Cliona Lorton, SpR Palliative Medicine/ Clinical Lecturer, Our Lady’s Hospice & Care Services.

Dr Lorton’s research, which she is undertaking as part of her PhD, aims to assess if inflammation, as defined by high C-Reactive protein, predicts symptoms and quality of life in cancer and could be used as a prompt for detailed holistic assessment and SPC referral. This will be a prospective observational pilot study. Some anticipated outcomes include (i) establishing a basis for studies of immune-modulatory agents to improve symptoms, quality of life and survival in advanced cancer; (ii) improving understanding of the inflammatory process; and (iii) promoting the development of personalised cancer care.

**Neonatal palliative care: a systematic literature review to support the development of integrated care pathways for neonates with life limiting conditions**

Denise McGuinness, Clinical Midwife Specialist (Lactation), National Maternity Hospital / Clinical Tutor Midwifery, TCD

Similar to other countries, Ireland has a national policy for palliative care provision requiring that palliative care be provided at different levels of expertise from specialist to basic, embedded in clinical practice. Perinatal palliative care is defined here as the planning and provision of supportive care during life and end-of-life care for a fetus, newborn infant or infant and their family in the management of an appropriate candidate condition. This proposal seeks to systematically review the literature to support the development of integrated care pathways for neonates with life limiting conditions in an Irish setting. It is anticipated that the review will inform a doctoral study undertaken by Denise.
Quality of Life assessment in palliative care day services

Dr Mary Armstrong, Physiotherapist, Marie Curie Hospice, Belfast.

The primary outcome from this research project is the identification of the most appropriate and acceptable method of assessing the impact of adult Palliative Care Day Services (PCDS) on the QoL of patients. The proposed research will be valuable to researchers engaged in designing assessments of QoL in palliative care. In palliative care research there is a dearth of good quality intervention studies and the proposed research will help ensure that rigorous evaluations are conducted in this area.

DR CATHY PAYNE RECEIVES THE FIRST AIIHPC PhD FUNDED BY THE PUBLIC HEALTH AGENCY (NORTHERN IRELAND) (OCT 2015)

AllHPC would like to congratulate Dr Cathy Payne who was recently awarded her PhD entitled “Rehabilitation in Palliative Care: A Novel Exploratory Study”. Her study focused on People with advanced inoperable non-small cell lung cancer (NSCLC) and the potential role of palliative rehabilitation in the symptom management of this condition. The PhD was funded by the Health & Social Care Research & Development Division of the Public Health Agency (Northern Ireland) in conjunction with AllHPC. Dr Payne is a registered Dietician with a Post Graduate Diploma in Health Sciences (Cancer Care) and M.Sc. in Nutrition. She is chair of the AllHPC/IAPC Early Career Researcher Forum and currently works as Palliative Care Educator in Our Lady’s Hospice & Care Services, Dublin.

AIIHPC/ IAPC EARLY CAREER RESEARCHER FORUM

The Early Career Researcher Forum Annual Seminar will take place on 24th November 2015. The seminar entitled “Adopting a mixed methods approach to evaluation in palliative and end of life care research” will be based on mixed methods research with a particular focus on different types of evaluation within the Medical Research Council’s (MRC) framework for evaluating complex interventions. Delivered by Dr Suzanne Guerin (AllHPC Interim Head of Research/ PCRN Senior Investigator/ Head of School, UCD School of Psychology), the seminar will examine the extent to which mixed methods can be applied to ensure rigorous and appropriate evaluations. The seminar will be of interest to those who are interested in and/or using this methodological approach in order to examine different aspects of service delivery and evaluation.

This is the first Early Career Researcher Forum Annual Seminar under the auspices of AllHPC’s Palliative Care Research Network (PCRN). The Forum was launched in 2013 in collaboration with the Irish Association for Palliative Care with the aim of offering early career researchers opportunities to share knowledge, skills and expertise; access peer support; develop links with senior researchers in palliative care; and benefit from participating in learning and knowledge transfer activities. The Forum is targeted at all those who consider themselves early on in their palliative care research career including clinical researchers, MSc/ PhD students and postdoctoral researchers. For further information visit www.aiihpc.org.
Highlights from 2014/15 - Knowledge Transfer & Dissemination

HRB AWARDS FUNDING TO AIIHPC FOR A ‘KNOWLEDGE EXCHANGE AND DISSEMINATION SCHEME (KEDS) RESEARCH PROJECT (NOV 2015)

AIIHPC was recently awarded significant funding from the Health Research Board to undertake a Knowledge Exchange and Dissemination research project entitled “Synthesising and Disseminating Key Lessons from the AIIHPC Palliative Care Research Network”. This project aims to further enhance knowledge transfer and exchange activities across the SRN/PCRN by conducting a higher level analysis of the dissemination products arising from each individual work project during the final year of the active grant. It is expected that dissemination products will include published papers, conference presentations, interim/final reports to AIIHPC and HRB, and documents relating to archived datasets. A secondary analysis of these dissemination products will be undertaken by identifying cross-cutting or high level messages from across all dissemination outputs including the final research reports.

This analysis represents significant added value to the SRN/PCRN as it will build on the learning from the individual work projects. Following the identification of these high level messages, the focus of the KEDS project will be the dynamic dissemination of these messages through the implementation of specific KTE activities and products including accessible and engaging video shorts, podcasts, policy briefs and newsletters. These activities will be designed with specialist input from key stakeholders representing researchers, practitioners, policy makers and users and carers of palliative care services to maximise the access and impact of the key messages. This project will be overseen by a working group co-led by Dr Suzanne Guerin (Interim Head of Research/AIIHPC PCRN Senior Investigator) and Dr Tara Murphy (Programme Manager Research).

LAUNCH OF FINAL REPORT FOR THE DIGNITY CARE INTERVENTION PROJECT

Co-leads: Professor Sonja McIlfatrick (Professor of Nursing, Ulster University)
Professor Phil Larkin & Professor Phil Larkin (Professor of Clinical Nursing – Palliative Care, University College Dublin and Our Lady’s Hospice and Care Services)

The overall aim of this service development initiative was to implement and evaluate an intervention delivered by community nurses to help conserve the dignity of people with advanced and life limiting conditions including the frail elderly in community settings. The Dignity Care Intervention – Ireland (DCI-Ireland) project involved a patient-centered assessment to identify and address key concerns in three main domains: (1) illness-related concerns; (2) dignity conserving repertoire; and (3) social dignity inventory. The intervention was intended to help nurses to identify what patients and carers consider most distressing for the patient and act as a guide in terms of how this distress may be addressed effectively. An evaluation of the intervention was undertaken to determine the relevance and acceptability of the DCI-Ireland to the local context. Overall, introducing the tool to patients required a level of confidence in the nurse that the tool was effective and that they had the skills to conduct discussions around the topics that could emerge from implementing the tool. The findings of the focus group interviews showed that the nurses were not confident in discussing death and dying, that time constraints were involved due to an ever increasing workload and organisational aspects related to their role and wider integration with other services. A number of recommendations are made in the final report which was launched on November 25th 2015.
LAUNCH OF CLINICAL GUIDELINES FOR CONSTIPATION CO-LED BY AIIHPC CLINICAL GUIDELINES SCHOLARS

Congratulations to the AIIHPC Guideline Scholars for Constipation (Dr Brenda O Connor, Dr Jodie Battley & Louise Duddy) who developed, under the supervision of Professor Phil Larkin, one of two new National Clinical Effectiveness Guidelines launched by Minister of State at the Department of Health, Kathleen Lynch. The guidelines are based on the best research evidence and on clinical expertise and aim to help health professionals with managing the symptoms of constipation in patients receiving palliative care. Dr Karen Ryan, Clinical Lead of the NCPPC acknowledged the commitment and expertise of the multi-disciplinary teams in developing the guidelines.(http://health.gov.ie/patient-safety/ncnc/national-clinical-guidelines-2/)

![Image of the launch event]
A new strategic vision for AIIHPC’s Palliative Care Research Network (PCRN)

Introduction
The following proposal sets out a clear plan and expectations for the strategic development of the Palliative Care Research Network (PCRN) over the next 15 months. This is described within the context of the future development of AIIHPC as it approaches its next phase. Under the terms of the previous Structured Research Network (SRN), which is funded by the Health Research Board, it was agreed that the SRN would evolve and expand to become a more inclusive and self-sustainable research network attracting and securing additional funding. This evolution requires changes to the structure and governance of the PCRN. The current proposal outlines how this might occur.

Origins of the PCRN
In September 2012, AIIHPC’s Structured Research Network was launched with an initial investment of €1.26million for palliative and end of life care research from the HRB in the Republic of Ireland and AIIHPC. This reflected a historical shift in research funding and policy development for palliative and end of life care on the island of Ireland. The SRN consists of two complementary research strands (including seven work projects) co-led by six academic institutions across the island of Ireland. An eighth work project overlaps both research strands and aims to develop and implement knowledge transfer activities. The SRN has now evolved attracting other researchers and projects to become the PCRN. A parallel contribution of two PhD Fellowships from the Research & Development Office of the Public Health Agency in Northern Ireland was made to AIIHPC which have been incorporated under the PCRN.

The overall aim of the PCRN 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 reflect, inform and contribute to AIIHPC’s programmes of work.

The strategic future of AIIHPC
As AIIHPC moves into its next phase, it seeks to develop and build on the achievements and outcomes from the previous five years. One of these achievements is the establishment of the PCRN. Three new strategic work programmes for the future have been identified by AIIHPC:

- **Work programme 1**: To integrate palliative care research, education and practice development in the health and social care systems across the island of Ireland.
- **Work programme 2**: To partner with users, carers and communities to ensure that palliative care provision meets their needs and continues to do so.
- **Work programme 3**: To support the development of specialist palliative care to meet the current and emerging demands of the health system.

The PCRN is envisaged to expand its remit across these three strategic work programmes.

What does the PCRN offer?
The Network aims to build on the work being conducted on the island of Ireland by research and clinical experts, bringing people together in a coherent network, encouraging the sharing of knowledge and collaboration across a broad range of areas. It has strategic links to the majority of major academic and research centre across Ireland and Northern Ireland. It also has strong links with key policy and practice stakeholders as part of AIIHPC.

Members of the Network have a wide variety of knowledge and experience, from early career researchers to more experienced researchers who are leaders in the field of palliative care research or associated fields. Three significant and cross-cutting activities within the Network are research promotion and development, dissemination and knowledge transfer, and research capacity building.
- **Promoting National and International Research Activity**
  The PCRN intends to establish clear links with international research networks working in the area of palliative care or other relevant fields through existing and other channels. These relationships will be formalised through Memorandums of Understanding.

- **Knowledge Transfer & Exchange**
  The Network's vision for knowledge transfer and exchange (KTE) is to translate research output for policy and practice in collaborative and innovative ways. Our plan for KTE includes, but should not be limited to, research outputs measured in peer reviewed publications, conference presentations as well as other outputs such as person and public involvement in research and knowledge exchange activities for policy and practice.

- **Research Capacity Building**
  A key aim of the Network is to enhance the research capacity of the palliative care community by delivering activities which are geared towards developing and enhancing multi-disciplinary research capability and output in palliative care. The Network adopts a multi-tiered approach to research capacity building through 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 and leadership opportunities for more advanced researchers.

What does the Network offer at an individual level?
At an individual level, the Network offers opportunities to recognise and promote individual researcher/teams of researchers’ acquired or developing expertise in the area of research in palliative and end of life care. Engagement and participation in the Network has the potential to expand the reach of a study nationally and internationally, opportunities to collaborate with other researchers, promote interdisciplinary research, maximise the impact of research findings beyond academia and promote research and clinical leadership. By joining the PCRN researchers will have access to a directory of people, their research, expertise and valuable KTE resources. The Network offers significant opportunities to build new relationships, extend existing capacity and act as a springboard to apply for European and international funding. The Network can help to disseminate research, supporting and promoting its impact on practice and policy.

**PCRN Governance and Membership Structure**
AllIHPc PRCN will be governed by two committees, as detailed below.

The PCRN will select from its membership a ‘Strategic Scientific Committee’ (SSC), which will be responsible for decisions regarding membership of the Network and will also manage proposals for activities and programmes of work in collaboration with AllIHPc. The SSC will also liaise with other research networks and groups nationally and internationally to promote research on the island of Ireland. The PCRN will select the SSC from its membership.

Within AllIHPc the PCRN will be governed by the ‘Research Governance Subcommittee’ (formerly known as the ‘Performance Management Committee’) which is responsible for the resourcing, operational and financial management of the Network. In addition, it is proposed that the Network would incorporate the PCRN Early Career Forum, which is central to the Network’s capacity building aims. The Irish Association of Palliative Care (IAPC) will be a key partner in the development of the Forum.
STRAND TITLE: ‘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.

Project Title: 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)

Postgraduate Scholar
• Sarah Walsh

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.

Progress
• Phase 1 – All Island survey of General Practitioners (n=3,900) has been completed and data analysis is currently being finalised. Initial results indicate that of GPs who responded, (n=567) approximately one third reported identifying patients with an existing mental illness as requiring palliative care. Of those with serious mental illness requiring palliative care, the primary diagnostic category was a cardiovascular disorder.
• Phase 2 – A survey of Psychiatrists (n=324) in the ROI is planned to proceed during November/December 2015 and into January 2016. The purpose of this survey is to identify if psychiatrists are identifying patients with serious mental illness who also have palliative care needs. Psychiatrists will be asked to identify patients and or their carers who may be willing to participate in interviews to examine their experiences of receiving palliative care.
• Phase 3 – This phase proposes to conduct interviews with clinical professionals who provide specialised palliative care services. The purpose of this phase is to explore the experiences of this group of providing care to people with serious mental illness and to identify any specific challenges in providing such care.
Key challenges

- Low response rate of general practitioners - Response rate in ROI was in line with previous Irish studies.
- Accessing and distribution of questionnaire’s to GP’s in Northern Ireland - Logistics of managing distribution of survey to NI GP’s was challenging in terms of costs and managing the process remotely. Response rate from NI GP’s was very low despite a robust system to boost response rates.
- Accessing patients/carers identified by GP’s to participate in qualitative component regarding their experiences of receiving palliative care.

Patient/ Public Involvement

The initial intention was to undertake qualitative interviews with patients and or their carers identified by GP’s. However, those who were identified by GP’s were unable to participate in interviews when approached to do so. Intentions is to access patients and or carers identified by psychiatrists who are in receipt of palliative care and invite them to participate in interviews relating to their experiences of receiving and or providing palliative care.

Selected Knowledge Transfer & Exchange Activities


Project Title: 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 Misericordia Hospital & St Francis Hospice & Clinical Lead for Palliative Care, HSE

PhD scholar

- Janet O’Farrell

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: A mixed methods approach.

Progress

- Pilot study completed
- Questionnaire and data collection method revised upon reflection on pilot study
- Data collected across 19 services in Ireland
- Data input and analysis ongoing

Key challenges

- Engaging with ethics boards across services
- Staff availability and resources in arranging interviews

Patient/ Public Involvement

Study participants are close caregivers of decedents who participated in the IDS-TILDA study, the Intellectual Disability Supplement to the Irish Longitudinal Study of Ageing. There is a strong keeping in touch strategy and input received around review and design of IDS-TILDA materials. This is ongoing and in keeping with the study’s values framework.

Selected Knowledge Transfer & Exchange Activities


• Ryan, K., (2015) Palliative Care Role Delineation Framework. On behalf of the National Clinical Programme for Palliative Care Working Group Dublin: HSE


Other significant events and/or activities

New funding

• 2015- (end date 30.9.17): “What are the clinical effectiveness and cost-effectiveness of different organizational models of community specialist palliative care (CSPC) provision in Ireland?” Lead co-applicants: Professor Charles Normand and Dr Karen Ryan, Co-applicant: Professor Sonja McIlfatrick. Source of Funding: Health Research Board. Grant amount: €280,000

• 2015- (end date 2017): Palliative Care Cluster: International Access, Rights and Empowerment Study II (IARE II): An international mixed methods study to compare palliative care experiences among older people affected by cancer and non-cancer populations. Principle investigator: Professor Irene Higginson. Lead investigators: Dr Barb Daveson (UK); Professor Diane Meier, Professor Sean Morrison (US); Professor Charles Normand, Dr Karen Ryan, Dr Regina McQuillan (Ireland). Grant reference: 24609. Source of Funding: Atlantic Philanthropies. Grant amount: €740,000

Project Title: 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

PhD scholar
• Fiona Hurley

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.

Progress:
Data-collection is almost complete. Five research sites were included in the study. These were:
• University complex in Limerick.
• Children’s University Hospital in Temple Street.
• Northern Ireland Children’s Hospice.
• Suzanne House.
• Letterkenny General Hospital.

The following is an emerging profile of participants:
• Parents- A total of 22 interviews have been completed (5 fathers) (17 mothers) with parents of children with
non-malignant life-limiting conditions. These interviews were conducted throughout Ireland with parents from a wide socio-demographic spread.

- Healthcare Professionals- Thus far, 8 interviews with health care professionals working in paediatric palliative care throughout Ireland have been completed. A wide variety of healthcare professionals have been interviewed including a paediatrician, a social worker and an Outreach nurse.
- Children-One child with a non-malignant life limiting condition has been interviewed. Data collection with children is on-going.

Data-analysis is currently underway with a preliminary analysis of parent interviews almost complete.

**Key highlights & challenges**

- The process of obtaining Ethical approval for this study through the Office of Research Ethics in Northern Ireland (ORECNI) was more challenging and time-consuming than previously anticipated.
- Recruitment was more challenging than had been initially envisaged. In order to reach sample size, recruitment was extended to additional sites (i.e. Suzanne House, under the auspices of Saint John of Gods Dublin) and active engagement with Gatekeepers at all sites pursued. As geographical location emerged from the interviews as an influence on palliative care service provision recruitment was also extended to include Letterkenny General Hospital.
- The process of recruiting children has posed many challenges. The major challenge is due to the fact that the majority of children with non-malignant life-limiting conditions have severe developmental delay and are non-verbal. It has only been possible thus far to recruit one child, but there is a commitment to recruiting more.

Advice has been sought from (1) a Speech and Language therapist based in the National University of Ireland in Galway regarding optimal methods of engaging with children who are cognitively impaired was valuable; (2) a Lecturer in Queen's University Belfast with experience of interviewing children with disabilities with regard to their participation in health and social care decisions.

**Activities involving patient/public involvement**

Advice was sought regarding acceptable terminology for use in the Letters of Invitation and Information sheets from parent representatives and from an organisation which supports parents who are bereaved was hugely beneficial. Although some of the Gatekeepers were concerned with the terminology used such as ‘palliative care’ and ‘life-limiting’ it was ascertained that parents freely use these terms. A number of parents spoke of their willingness to use these terms.

**Selected Knowledge Transfer & Exchange Activities**


**Other significant events/activities**

Dr Gemma Kiernan, on behalf of the project, will take part in a study supported by AIHPC re Implementing and Evaluating a Knowledge Transfer Exchange Model for Palliative Care (WP8: Kernohan, Guerin & Brown). It is anticipated that this will assist in implementing the findings of our research, as well as aiding in the validation of a KTE model to support palliative care research.

**Evidence of collaborations**

Collaboration with Dr Aidan Mc Kiernan (Clinical Psychologist Laura Lynn Hospice) and Dr Suzanne Guerin to support hospice related service development and evaluation in paediatric palliative care services in Ireland.
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Project Title: Exploring Dimensions of Inequality in Current Palliative Care Provision for Carers of People with Advanced Heart Failure in Ireland

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

PhD scholar
• Dr Leanne Doherty (nee Breslin)

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

Progress
Data collection for Phase 1 of the project has been slow for reasons outlined in previous updates. These are linked with a) incomplete databases from which to access possible sample; b) rigorous inclusion criteria previously agreed with clinical colleagues and c) a level of gate keeping applied by clinical teams. In order to seek to address this following was undertaken:
• A minor amendment was submitted to both ethics committee to extend data collection until November 2015.
• The research team decided to add an additional qualitative element to Phase 2 of the project to also recruit bereaved carers for interview alongside current carers recruited (n=20). Ethical approval for this additional phase has been obtained.
• To date the overall numbers of patients and carers who have returned packs are 115 patients and 90 carers, respectively and 20 current carer interviews (both North and South of Ireland) have been completed.

Key highlights & challenges
The Research Associate for this project, Dr Leanne Doherty, has been on maternity leave from June 2015. It was planned to recruit a replacement for maternity leave cover, and approvals gained for this, but owing to the requirements of the project it was decided to recruitment research assistance on a consultancy basis for 2 specific elements of the study.
• Dr Kate Thompson- has agreed to undertake data analysis and write up of quantitative data analysis.
• Dr Mary Murphy- has agreed to undertake bereaved carers Phase.
• Both these people have been recruited since October 2015. The research team need to acknowledge that 3 months of the project were lost owing to seeking maternity leave cover and the challenges over the summer period.
• A reviewed timeline has been developed for the project with an expected completed date of June 2016.

Activities involving patient/public involvement
The Post doc researcher attended meetings to update re ensuring PPI involvement in research. We did identify a service user who currently sits on steering committee and commented on all documentation as part of ethics application and continues to provide guidance to the project. Nothing additional to report for this time period.

Selected Knowledge Transfer & Exchange Activities
• European Association for Palliative Care 14th World Congress 8-10th May, Copenhagen 2015 Poster Presentation

Conference presentations:
• European Association for Palliative Care 14th World Congress 8-10th May, Copenhagen 2015 Poster Presentation

Other palliative care publications
• Beck, ER, McIlfatrick, SJ, Hasson F & Leavey G (2015) Health care professionals’ perspectives of advance care planning for people with dementia living in long-term care settings: A narrative review of the literature Dementia 1471301215604997,

Grant Information
• Health Research Board: Research Collaborative for Quality and Patient Safety Clinical and Cost Effectiveness of Specialist Palliative Care in the community. Normand (PI); McIlfatrick (Co-I); Ryan (Co-I) (2015-2018) €280,000
• NI Hospice ENRICH –IN support of research evidence based practice and clinical practice development, Kernohan, Hasson (PI), McIlfatrick, Martin £31,733 (2015-2017)
• McIlfatrick & Hasson (2015) Evaluation of Palliative Care Senior Nurse Network (PCSNN) and Voices 4 Care Initiatives. All Ireland Institute of Hospice and Palliative Care €16720

Evidence of Collaborations
This study has been adopted by the NI Cardiovascular Network enabling clinical collaborations across Ireland. These clinical collaborations can be evidenced by inclusion of clinical colleagues on the submitted Chest, Heart and Stroke grant application. Professor Debra Moser, University of Kentucky, USA is an advisor to the project, alongside Professor Peter Hudson, Australia.
STRAND TITLE: MEASUREMENT AND EVALUATION OF OUTCOMES FOR PALLIATIVE CARE

Led by
Professor Charles Normand, Edward Kennedy Professor of Health Policy & Management, Centre for Health Policy & Management, TCD

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.

PROJECT TITLE: 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

PhD scholars
• Mas Mohamed & Brid Davis

Aim: 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.

Progress
The project is progressing well and is fast approaching the conclusion of data collection which requires n=100 palliative care admissions assessed serially. At present, almost 150 patients have been assessed cross-sectionally of which 85 have undergone repeated (serial) assessment. This should be complete by end of year 2015.

The cross-sectional data has allowed for some preliminary reports in terms of patterns of neuropsychiatric symptoms, cognitive profile and physical wellbeing and these have been the subject of scientific presentations at a variety of conferences (see below).

The New Year will see the commencement of detailed statistical analysis of the longitudinal data which will be directed at identifying novel approaches to the assessment of cognition and mood. This will be followed by preparation of scientific reports.

Key highlights & challenges
The project is progressing on schedule and has received very positive feedback at the various forums where initial/preliminary findings have been presented. The principal challenge will be to progress the longitudinal analyses and commence the preparation of data reports from the project.

Activities involving patient/public involvement
Milford Lunch and Learn’ Presentation – 2014 - ‘Depression and Delirium in the palliative care setting: a longitudinal study of its severity, frequency and relationship with pain, fatigue and cachexia’ Oral Presentation
Selected Knowledge Transfer & Exchange Activities


New collaborations

We have ongoing collaborations relevant to the Milford project with the psychiatry for later life services in Limerick, Galway, Cork and Sligo as well as internationally with elderly medical (Boston), palliative geriatric (Italy) and psycho-oncology (Japan) services (see publications). Also closely linked to our work, Dr Martina O’Reilly completed a PhD entitled ’Development and validation of an assessment tool for palliative care inpatients’ through GEMS and the Faculty of Education and Health Sciences at UL.
Project Title: 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

Post-Doctoral Scholar
• Dr David Scott

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.

Progress: The study remains open for data collection.

Key highlights and challenges
Recruitment into the study has been extremely slow. In consultation with our steering group, we have gained ethical approval to open in the Cancer centre and all satellite units across NI. This has commenced in October 2015. We are also in the process of applying for ethical approval for additional qualitative work with health care professionals.

Patient & Public Involvement
Updates on study progress provided to NI cancer consumer forum at regular meetings.

Selected Knowledge Transfer & Exchange Activities
• O’Halloran, P, Scott, D, Reid, J & Porter, S 2015, ‘Multimedia psycho-educational interventions to support patient self-care in degenerative conditions: a realist review’ Palliative and Supportive Care., 10.1017/S1478951514001229
• Royal College of Nursing, End of Life eResource, launched October 2015 – this resource features cachexia and Dr Reid’s work on the experience of cachexia has been included in this resource.
• Presentation on trial accepted at the 8th International Cachexia conference in Paris (December 2015)
• Dr Reid provided an invited presentation on the trial at the European School of Oncology, Cachexia and nutrition in advanced cancer patients: a multidisciplinary approach conference (March 2015)

Other Activities & collaborations
• Dr Reid had been invited to join a Cancer Anorexia Cachexia Syndrome expert panel chaired by Professor Ken Fearon to develop a new medical education programme for Cancer Anorexia Cachexia Syndrome.
• Dr Reid provided a masterclass in palliative care at the NI Hospice with H Noble and P O’Halloran (June 2015).
• We have completed data collection and analysis comparing the cultural variation of cachexia management and applicability of the DVD intervention in an Australian context – final draft of peer review paper completed. We have secured funding to collaborate with the Mayo Clinic to replicate this work in the American context. The ethical application is currently in IRB review to permit this research to commence.
**Project Title: Eliciting preferences for complex packages of palliative care – extension of IARE**

**Co-Investigator**
Professor Charles Normand, Edward Kennedy Professor of Health Policy and Management, Centre for Health Policy and Management, TCD

**PhD scholar**
Bridget Johnson

**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.

**Progress**
- Applications for the IARE+ study have been submitted and approved by Research Ethics Committees at: Health Policy and Management/Centre for Global Health REC, Trinity College Dublin; HSE Mid-Western Regional Hospital, Limerick; Mater Misericordiae University Hospital, Dublin; Mayo Regional Hospital, Castlebar.
- Analysis of existing data sets for development of pilot DCE during Phase 1
- Development of pilot patient and caregiver questionnaires for Phase 1
- Phase 1 interviews were conducted with patients and caregivers at Mater Misericordiae University Hospital between June and July 2015.
- Analysis of Phase 1 data and completion of Phase 2 interview questionnaires and DCE
- Phase 2 interviews began at Milford Care Centre (Limerick) in September 2015. More than 40% of recruitment has been completed and data collection at this site is on schedule to be completed by mid-December.
- PhD Continuation Report submitted to the School of Medicine in August 2015. The Continuation presentation was given in St. James’ in October, followed by an interview with the examiners. The Transfer Panel recommended continuation subject to amendment of the continuation report.

**Key highlights and challenges**
- Being awarded an oral presentation at EAPC 2015 for findings from the qualitative component of the IARE study.
- The process of receiving ethics approval at all study sites was challenging, but helped guide the development of the IARE+ study.
- Bridget Johnston has successfully completed the PhD continuation process
- Collecting data and meeting the recruitment targets
- Bridget Johnston has become a member of the Committee for the AllHPC’s Early Career Researcher Forum

**Activities involving patient/public involvement**
Phase 1 and Phase 2 interviews involve direct contact with patients and their caregivers

**Selected Knowledge Transfer & Exchange Activities**
- Oral presentation at EAPC 2015 on IARE qualitative findings
- Poster presentation on IARE qualitative findings at the SPHeRE conference (Dublin) in January and Marymount (Cork) in October.
- Abstract submitted for EAPC 2016 on DCE data from the IARE study

**Grants**
- IARE 2, GBP£108,305, funded by Cicely Saunders International via Atlantic Philanthropies, a collaboration with King’s College London and Ichan School of Medicine at Mount Sinai. Pls: Professor Charles Normand, Dr Karen Ryan, Dr Regina McQuillan, dates 1/10/2014 - 30/9/2017
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- IARE Fellowships, GB£270, 360, funded by Cicely Saunders International via Atlantic Philanthropies, a collaboration with King’s College London and Ichan School of Medicine at Mount Sinai. PIs: Professor Charles Normand, Dr Karen Ryan, Dr Regina McQuillan, Professor Declan Walsh, dates 1/10/2014 -30/9/2017
- RCQPS/HRB, €280,000, PIs: Professor Charles Normand, Dr Karen Ryan, Professor Sonja McIlfatrick, dates 1/10/2015 – 30/9/2017

Evidence of collaborations
Continued collaborations with the BuildCARE team on analysis of the IARE data sets and attendance of an All-Assembly meeting held in October 2015.

AIIHPC FUNDED WORK PROJECT

**Project Title:** 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

**Postdoctoral Scholars**
- Dr Lucia Prihodova and Dr Mary Jane Brown

**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.

Dr 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 (AIIHPC) research project aimed at developing and implementing a system of structured based at the School of Psychology, University College Dublin.

**Progress**
2014/15 has been a busy year for Work Package 8, with the completion of Phase 1 – the Systematic Review – overlapping with the first half of Phase 2 – the KTE Case Studies.

Dr Lucia Prihodova completed work on the project in July 2015, moving to a position with the Royal College of Physicians (RCPI). Lucia had led the systematic review of models of knowledge transfer in health settings. In line with PRISMA guidelines, a systematic scoping review was conducted to search articles included in six electronic databases (including MEDLINE, EMBASE, CINAHL and PsycINFO) for four terms (knowledge, transfer, framework, healthcare) and their variations. The search identified 4288 abstracts, with 294 eligible for full-text screening, resulting in 79 papers analysed. With additional support from Conall Tunney (UCD School of Psychology) analysis has been completed on the main elements of KTE models and features of the publications. Studies were published between 1985 and 2014 (two thirds since 2006); the majority was conducted in North America. In total 87 models were indicated, with the Promoting Action on Research Implementation in Health Services Framework (PARIHS) being the most common (n = 15). The key components of the models include a partnership or collaborative approach to KTE, focus on the needs of the audience, and an awareness of different modes of communication. The papers were appraised for relevance to the palliative care and it was found that the study or the target population were relevant.
in many of the papers. The components most relevant to palliative care were used to establish a proposed model of KTE for palliative care, which will inform the case studies completed in Phase 2 of this project. Lucia continues to serve as a member of the research team and is currently leading on the first article from the systematic review. The model will be presented to members of the AllIHP Palliative Care Research Network (PCRN) at the Annual Symposium on 25 November 2015.

Dr Mary Jane Brown began work on the project in April 2015. Jane is leading the case studies of the KTE model developed in Phase 1. Jane began by developing a programme of activities which would underpin the proposed case studies. Having secured ethical approval she began a series of qualitative interviews with researchers involved in the PCRN. The interviews examined planned knowledge transfer activities including questions on knowledge generated by the research, any potential plans for implementation, barriers to implementation and identifying the target audience. Jane completed nine interviews with researchers and is currently analysing these interviews, with a focus on key information for the development of the Phase 2 case studies. Interviews with representatives of target audiences identified by the PCRN researchers are planned, again to inform the development of the case studies. Five case studies have been proposed in collaboration with the AllIHP. These case studies include transfer activities to a number of key stakeholders including PC researchers, healthcare practitioners, policy makers and advocacy organisations. The case studies will be completed between November 2015 and April 2016.

**Key Highlights & Challenges**

A key highlight of the year has been the successful programme of dissemination activities, with publication of the Phase 1 study protocol and presentation at several national and international conferences (detailed below). In addition the appointment of Mary Jane Brown to Phase 2 has ensured continued progress on Work Package 8.

Key challenges have included the sheer volume of analysis to be completed as part of Phase 1. The knock on effect has been delays in progress with [phase 2. However we are confident that the work will be completed, including final reports to AllIHP by July 2016.

**Activities involving patient/public involvement**

Given the nature of Work Package 8 public/patient involvement has been limited. However, as part of Phase 2 representatives of target audiences to be interviewed will include users of palliative care services and a number of the planned case studies include a focus on dissemination to users of services.

**Selected Knowledge Transfer & Exchange Activities**

- **Prihodova, L., Guerin, S., & Kernohan, W.G.** (2015). *Identification of knowledge transfer and exchange frameworks for palliative care: Findings from a scoping review. Poster presented at the 14th World Congress of the European Association for Palliative Care, Copenhagen, Denmark. Thanks to AllIHP for the award of a bursary to support this presentation.*
- **Brown, M. J., Kernohan, W. G., & Guerin, S.** (2016). *The transfer of new knowledge into practice: Exploration of implementation plans in palliative care research. Submitted for presentation at the 9th World Research Congress of the European Association for Palliative Care, Dublin, Ireland, 9-11 June 2016.*
Other significant events/activities

- **Lunchtime series, School of Psychology, UCD, (2014.)** The lunchtime series of seminars at School of Psychology, UCD are hour-long presentations aimed at staff and post-graduate students of the school. To highlight the research activities funded by AIIHPC, Lucia Prihodova delivered a seminar presentation entitled ‘Palliative Care Knowledge Utilisation Project (PiCKUP): Update on scoping review of frameworks addressing the research into practice gap’.

- **Universitas 21 Early Career Researchers (ECR) Innovation and Entrepreneurship Workshop hosted by UCD, (2015.)** The key objective of the Universitas 21 Early Career Researchers workshop is to increase ECRs’ research capabilities and enhance skills associated with career development in academia. As a part of this workshop, Lucia Prihodova presented a poster entitled ‘Development and Implementation of a Knowledge Transfer Model for Palliative Care: An All-Ireland Collaborative Project’.

- **Professor Kernohan** participated in the WHO/AIIHPC Global Colloquium on Palliative Care, (2015.)

New grants applied for or grants obtained

Co Principle Investigator Dr Suzanne Guerin was a named partner on AIIHPC’s successful application for funding under the HRB’s Knowledge Education and Dissemination call.

Evidence of collaborations

KTE is inherently a collaborative endeavour and the grant awarded reflects this in the ongoing collaboration between Ulster University and University College Dublin. Additional collaborations include those with AIIHPC (for case study selection), collaboration with other research teams in phase two (including lead PIs in the SRN) and the team’s contribution to the development of KTE workshop to be delivered at the AIIHPC PCRN Annual Symposium.

**PCRN ALIGNED PROJECTS**

**Project Title: General practitioners’ perceptions on palliative care for individuals with Alzheimer’s disease and other progressive dementias**

**Co-investigators:** Professor Kevin Brazil, Professor of Palliative Care, School of Nursing & Midwifery, QUB & Department of Clinical Epidemiology & Biostatistics, McMaster University, Dr Karen Galway, Lecturer in Mental Health, QUB, Dr Jenny van der Steen, Senior Researcher, VU University Medical Centre Amsterdam, The Netherlands & Professor Max Watson, Visiting Professor University of Ulster, Acting Medical Director Northern Ireland Hospice, Honorary Consultant Princess Alice Hospice, Esher

**Abstract**

Neurodegenerative disease mortality is projected to increase by 119% - 231% between 1990 and 2040, with the greatest proportion of this increase being attributed to dementia. However, despite the increasing numbers of dementia diagnosis and the poor prognosis of persons living with dementia, it is not always recognised as a terminal disease leading to inappropriate palliation and difficult decision-making for family members.

The provision of palliative care for end-stage dementia presents unique challenges. Specifically, the inability to hold meaningful communication with the patient in the terminal and most significant stages of the disease is exceptionally difficult. Consequently, due to the absence of constructive decision-making processes family members have to make uninformed decisions on behalf of the individual with dementia. Therefore, if Advanced Care Planning (ACP) is established, such family members would be in a position to make well-informed decisions regarding their loved one’s preference of future care. Consequently, good communication is at the heart of good dementia care, however, the completion of ACP in the primary care setting by patients with dementia is low.

The purpose of the study is to report attitudes and practice preferences of general practitioners (GPs) regarding communication, and decision-making for patients with dementia and their families. This was addressed by carrying out a cross-sectional postal survey of GPs located across Northern Ireland with responsibility for patients with
dementia. The ‘Care for Dementia Patients at the End of Life’ survey used explores GPs’ perceptions on palliative care for individuals living with dementia, with a focus on communication, decision-making and advance care planning. It is anticipated that this will help to identify barriers to the provision of palliative care in dementia and potential solutions.

**Selected Knowledge Transfer & Exchange Activities**


**Project Title:** Promoting informed decision-making and effective communication through advance care planning for people living with dementia and their family carers.

**Co-investigators:** Professor Kevin Brazil (QUB), Professor Mike Clarke, Director of the All-Ireland Hub for Trials Methodology Research (QUB), Professor Katherine Froggatt, Senior Lecturer, International Observatory on End of Life Care, Lancaster University, Professor Peter Hudson, Director, Centre for Palliative Care (QUB), Professor George Kernohan, Professor of Health Research, (UU), Dr Dorry McLaughlin, Lecturer in Palliative Care and Chronic Illness (QUB) & Professor Peter Passmore, Professor of Ageing and Geriatric Medicine (QUB)

**Other research team members**
- Research Fellow Dr Gillian Carter & ACP Nurse Facilitator Violet Graham

**Abstract**

The patient’s right to self-determination has become a key ethical principle in dementia care. Advance Care Planning (ACP) is in line with the principle of self-determination where an ACP document is a written or verbal record of a person’s choices about their future medical care. Regrettably, given the relative importance of ACP for people living with dementia, the available research demonstrates that the provision of ACP for persons living with dementia is poor.

In Western countries a substantial number of individuals living with dementia are admitted to a Nursing Home before death and are often transferred to hospitals were aggressive and overly burdensome treatments are provided. In this situation family carers are often required to make many difficult and emotionally burdensome decisions about whether or not to proceed with life sustaining treatments which may lead to death when they are not prepared to make such decisions.

The purpose of this study is to evaluate the application of a best-practice ACP model for individuals living with dementia in a sample of nursing homes in Northern Ireland. Twenty-five nursing homes were randomly assigned to...
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ACP with usual care to usual care alone. Specific outcomes examined included family carer satisfaction in decision making regarding options for care; family carer’s overall satisfaction with nursing home care; assessment of comfort care in nursing homes for persons living with dementia; and, impact the ACP model has on the use of acute care services. As part of this study, the lived experience of family carers required to make treatment decisions on behalf of a family member living with dementia will be explored.

It is anticipated that this study will provide evidence towards the development of practice in nursing home that will support family carers in decisions that will promote person-centred care for individuals living with dementia.

Selected Knowledge Transfer & Exchange Activities


- **Carter, G., McLaughlin, D., Kernohan, G., Hudson, P., Clarke, M., Froggatt, K., Passmore, P, and Brazil, K.** Recognising the transitions experienced by carers within the living–dying journey of a relative with dementia. Abstract submitted to EAPC June 2016

- **Brazil K. Carter, G., McLaughlin, D., Hudson, P., Clarke, M., Froggatt, K., Passmore, P, Kernohan, G.** Presentation to family carer participants from 25 care homes providing feedback and findings from the ACP study. March/April 2016

- **Brazil K. Carter, G., McLaughlin, D., Hudson, P., Clarke, M., Froggatt, K., Passmore, P, Kernohan, G.** Presentation to Four Season Health Care care home managers and senior management providing feedback and findings from the ACP study. March/April 2016

Project Title: **Consensus project on quality in palliative care day services**

**Co-investigators:** Dr Noleen McCorry, Research Lead, Marie Curie Hospice Belfast & Dr Martin Dempster, Director of Education, School of Psychology (QUB)

**Progress**

The Consensus Project on Quality in Palliative Care Day Services is being carried out in collaboration with a number of academic institutions and key stakeholder organizations. Its outcomes will be relevant to patients, family members, palliative care professionals, and policy makers. The aims of the project are: 1) to use an expert consensus process to develop a set of quality indicators for assessment of all aspects [structure, process and outcomes] of quality of care and 2) to test the suitability of a toolkit used to measure these indicators.

Progress to date is in line with the targets set out in the project protocol. An initial meeting of the project team was held in May 2015 at which the planned structure of the project was agreed upon. The meeting was also used to identify the requirements and roles of expert panel members who would be invited to join the consensus project and the methods used to identify them. Following an initial scoping exercise, a full systematic review has been completed following the PRISMA guidelines. The aim of the review was to identify existing quality indicators relevant to evaluation of palliative care day services and examine the evidence base in support of their use. This work formed an important part of the development work of the project. Five databases (Ovid MEDLINE, Ovid EMBASE, CINAHL, PsycINFO, Cochrane Central Register of Controlled Trials) were searched from January 2000 to June 2015. Grey literature sources were also searched for unindexed technical reports and practice guidelines. Development of the quality indicators was evaluated using the Appraisal of Indicators through Research and Evaluation (AIRE) Instrument. The GRADE approach was used to assess overall quality of the included evidence. Ninety six papers were included. Following removal of duplicates and grouping of similar indicators, 185 unique quality indicators were identified and classified into 17 separate domains. The majority related to physical and psychological care and support or co-ordination of care. Quality varied considerably but AIRE scores were typically low to moderate while overall methodological quality was also moderate. A substantial number of quality indicators for evaluating palliative care
day services are available, but evidence supporting their use, particularly in terms of outcomes after implementation is limited.

In addition, we have set up a wider stakeholder group and an expert panel, including 15 people from all over the United Kingdom who work in, or have experience of day services. Using the RAND/UCLA Appropriateness Method, these experts will attend a face to face panel meeting where they will rate the appropriateness of the potential indicators using their own experience and knowledge, as well as evidence summary tables provided by the project team based on the above review.

**Key highlights & challenges**

A key focus of the project in its early phase was to use an established scoping review methodology to identify existing quality indicators. This identified clear gaps in the existing evidence and highlighted the need for a full systematic review to be carried out. The inclusion of specific research questions and a broad search strategy was a particular strength of the review which has allowed the project to consider a wider body of evidence and reflect the diverse population attending palliative care day services.

Successful implementation of the projects findings is an expected challenge. To aid implementation, a draft toolkit will be produced incorporating an instruction manual, definitions, data forms, as well as instructions on how to treat missing data and analyse results in a way that adjusts for variation in demographic factors and settings. With the assistance of the expert panel and wider stakeholder group, we are seeking support from palliative care providers and umbrella organisations for adoption of the toolkit in practice. We anticipate that on completion of the implementation phase of the project, there will be sufficient information with which to amend and adjust the draft toolkit to provide an indication of those indicators that are core and others that could be considered supplementary to care quality.

**Activities involving patient/public involvement**

Two individuals with experience of attending day services as a patient are included on the expert panel. In addition we have set up a wider stakeholder group consisting of individuals and organizations representing patients, carers and family members who have expressed an interest in the project and who will provide informal feedback on project documentation and on the draft list of quality indicators. All materials, including the evidence summaries used to help rate the appropriateness of the quality indicators have been reviewed by an expert patient group prior to the project commencing. In addition we have set up a freely accessible project website to provide information on the project and an active twitter feed which is being used to more widely publicise the project and communicate with those interested in palliative care day services. The project has also adhered to the guidelines set out by INVOLVE.

**Selected Knowledge Transfer & Exchange Activities**

At this stage in the project, we have identified a clear dissemination plan. In addition to the main project outcomes, the following publications based on the initial development work of the project are in preparation for submission and appropriate target journals have been identified.

- Identifying Models of Delivery, Care Domains, Outcomes and Quality Indicators Relevant to Palliative Care Day Services: A Scoping Review Protocol
- Quality Indicators for Evaluating Palliative Care Day Services: Systematic Review
- Abstracts for these papers have also been submitted to the International Forum on Quality and Safety in Healthcare Conference, Gotenburg [April, 2016] and the 9th World Research Congress of the European Association for Palliative Care, Dublin [June, 2016]

**Evidence of collaborations**

As part of the project, we have established and initiated communication with a wider stakeholder group and developed further networks with individuals and key organisations with an interest in palliative care day services. These links will be critical to the successful implementation and development of the project through further research.
Project Title: Costs and effectiveness of UK palliative care day services: a three-centre mixed methods study of impact upon patients and family carers

Co-investigators: Professor George Kernohan & Dr Joanne Jordan, Research Fellows (UU)

Progress

This study aims to provide evidence of the cost-effectiveness of palliative care day services in improving quality of life. It comprises three related components. Firstly, a systematic review of the evidence on the clinical and cost effectiveness of interventions delivered in a day care setting. Second, using the Donabedian framework, a mapping exercise to deliver baseline information on the structure (organisation) and process (content) of day care service provision at three Marie Curie hospices (Edinburgh, West Midlands and Belfast). Finally, completing the Donabedian framework, a prospective cohort study of the outcomes of interventions offered in a day care setting on patients and their families’ quality of life.

Since the appointment of the study Research Fellow (Dr Joanne Jordan) in November 2014, the major focus of work has been on the systematic review of the literature and mapping exercise. A detailed protocol to guide the systematic review has been developed and registered on Prospero (International Prospective Register of Systematic Reviews), held at the Centre for Research and Dissemination, University of York. The review is ongoing. Initial searches of a comprehensive range of databases have been completed; these are currently being reviewed to identify studies for inclusion.

The mapping exercise involves three activities. Firstly, a review of Marie Curie policy and operational documents. Second a retrospective review of patient records, randomly sampled at each site using a proportionate regime, to deliver a total of 100 records. Finally, focus groups with clinicians and managers involved in Marie Curie day care services, as well as local-level referrers (primarily GPs) to these services. A detailed protocol guiding the mapping exercise, along with relevant supporting documentation, has been developed.

Key highlights & challenges

A key highlight has been the opportunity to work collaboratively with three Marie Curie Hospice staff in all aspects of research design and delivery. A valuable early outcome of this collaboration has been the development of the templates to guide data extraction during the mapping exercise, particularly those concerning the extraction of data from patient records. Sharing of relevant activities and processes underpinning data recording, storage and retrieval, including identified ‘best practice’, means that the mapping exercise is already delivering evidence capable of being used by Marie Curie for service development in two respects:

• To refine or enhance systems of data recording, storage and retrieval
• Patient population data (e.g. concerning socio-demographic, diagnoses, morbidity, care received, referral and discharge etc.) may be of value to each of the sites as they consider the appropriateness of current service design and delivery.

This key highlight also reflects a challenge. Given the variation in how patient data is recorded, stored and retrieved at each of the three sites, it has taken time to develop a system of and tool for data collection that ensures we generate a consistent and adequately comprehensive body of data.

Activities involving patient/public involvement

Two publicly available videos, in which the study is presented have been developed and posted on You Tube.

• Short version here at https://youtu.be/YWpBSt3JYYI
• Longer version here at https://youtu.be/DRacY3PzOwQ

The study is supported by a Steering Group. We are in the process of recruiting a member of the Marie Curie Expert Voices group at each of the three sites to ensure that the views and experiences of patients and their carers are represented on the Steering Group.
Selected Knowledge Transfer & Exchange Activities

• Kernohan, G. & Jordan, J. (2014) *An examination of the impact of palliative care day services upon patients and family carers*, presented to Ulster University, Institute of Nursing and Health Research, Managing Chronic Illness Group Meeting.

• Kernohan, G. *An examination of the impact of palliative care day services*, presented at the “Palliative care in the community - making a difference in practice” Annual Research Conference of Marie Curie Cancer Care at The Royal Society of Medicine, London.

Evidence of collaborations

A formal collaboration has been agreed with a closely related project on quality indicators suitable for palliative care day services. The title is “UK Consensus Project on Quality in Palliative Care Day Services”, led by Dr Martin Dempster (Queen’s University Belfast). Professor Kernohan has accepted an invitation to sit on the Steering Group for this project. Follow-up meetings have been held to ensure effective collaboration, in May ‘15 at Solihull and June ‘15 at Queen’s University Belfast. Meetings between the appointed Research Fellows on each study are also planned.

**Project Title: Pain assessment and management for patients with advanced dementia nearing the end of life**

**Co-investigator(s):** Dr Carole Parsons, Lecturer in Pharmacy Practice, School of Pharmacy (QUB)

**Aims**

This a three-year, multi-phase study investigating the clinical and professional issues in pain recognition, assessment and management. The outcome of this research is the development of an intervention to improve the way that pain is assessed and managed for people dying with dementia in primary, secondary, hospice and nursing home care settings. The multiple phases of the study are illustrated in Figure 1.

**Progress**

Data collection for Phase 1 commenced in May 2014 and concluded in July 2015 with a total of 61 interviews (23 doctors; 24 nurses and 14 healthcare assistants) across primary, secondary, hospice and nursing home care settings. Interviews were conducted face-to-face in healthcare professionals’ care settings and digitally recorded. Interview questions covered three core areas: (1) clinical and professional issues in pain recognition, assessment and management; (2) use and/or non-use of pain assessment tools and (3) training, education and public health awareness. Three bereaved carer interviews were conducted. Carer interviews covered three topics: (1) recognising signs of pain; (2) experiences of the way pain was managed for a family member with advanced dementia at end of life and (3) training, education and public health awareness. Phase 2, a systematic review of pain management interventions used in people dying with advanced dementia, is in progress, with expected completion in December 2015.

**Key highlights & challenges**

The Project Management Group (PMG) brings together academic and clinical expertise to inform research progress and intervention development. This collaboration has enriched the research experience by providing critical clinical
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insight and perspectives on study design, implementation and data interpretation and has enabled the expansion of palliative care and dementia networks. The research focus, pain assessment and management in advanced dementia in end of life care, is both timely and topical resulting in excellent participation rates of healthcare professionals in the first phase of the study and expressions of continued interest in future phases. There is much potential for future knowledge exchange and scope for further collaboration beyond the present study.

Bereaved carer recruitment has been a challenge in Phase 1. Bereaved participant sampling, recruitment and retention in research are well recognised to be methodologically challenging, with high rates of decline and attrition commonly reported. In this study thirteen carers were approached; eight declined at initial contact and two were lost to pre-interview attrition. These figures are not atypical for bereavement studies of this nature; however, in spite of multiple changes to recruitment methodology and sampling strategy, carer participation has remained below original estimations. The research team is reviewing the role of bereaved persons as research participants in this study with consideration given to inviting former carers to become involved in research design and implementation. This is described in more detail below.

Activities involving patient and public involvement
The PMG membership includes a PPI representative who has worked with the research team on the development of the grant proposal, with reviewing and providing feedback on interview questions for healthcare professional and bereaved carer interviews and verifying the accuracy of the transcripts produced from the digital recordings of participant interviews. Increased PPI has been planned for future phases particularly in regard to the involvement of former carers in the development and dissemination of the proposed intervention and in the design and implementation of the pilot study.

Selected Knowledge Transfer & Exchange Activities
- Two manuscripts discussing findings relating to the clinical and professional challenges in pain management (data from Phase 1) are currently being drafted, with submission expected in November 2015.
- Two abstracts presenting findings regarding pain assessment from Phase 1 have been submitted for consideration by the European Association for Palliative Care (EPAC) for presentation at the 9th World Research Congress of the European Association for Palliative Care in Dublin in June 2016.
- Data analysis for Phase 1 was completed in September 2015 therefore no conferences have been attended to date. Abstracts have been submitted for forthcoming conferences as detailed above.

Other significant events and activities
A lecture presenting the rationale for the research focus of this study and the research method was delivered as part of the Queen’s University Belfast School of Pharmacy Lecture Series in April 2015. An informal presentation on the project and interactive learning session for hospice staff has been scheduled to be held at the Marie Curie Hospice Belfast in November 2015.
AIIHPC/ IRISH CANCER SOCIETY POSTDOCTORAL FELLOWSHIP

**Project Title:** Delayed intervention randomised controlled trial to assess the effectiveness of a new model of social and practical support for community dwelling adults living with advanced life-limiting illness in Limerick, Ireland

**Lead:** Dr Kathy McLoughlin, AIIHPC/ ICS Research Fellow (NUI Maynooth)

**Progress**

This study seeks to evaluate Milford Care Centre’s Compassionate Communities Good Neighbour Partnership, a volunteer led initiative that seeks to meet the practical and social needs of people living at home, with advanced illness in their last year of life. The evaluation is guided by the MRC Framework for Complex Interventions. The study is progressing well in line with the project budget and agreed timeframes.

The acronym INSPIRE for the study has been agreed - INvestigating Social and Practical suppoRts at the End of life - as a short title for the study. The study has been allocated an ISCTRN number and the protocol for the study accepted for publication in BMC Palliative Care. A website www.inspirestudy.ie and associated social media feeds have been developed and are live. Briefing sessions with service providers and community organisations in Limerick are ongoing. The initiative has been well received to date.

The study comprises of three phases. Phase 0 includes: a number of scoping reviews; a Campbell registered systematic review; focus groups with healthcare professionals in palliative and primary care; and interviews with patient and families, all with a view to understanding the experience and impact of unmet social and practice needs at end of life, from a range of perspectives. Phase 1 of the study (now complete) involves the recruitment, delivery and evaluation of a 7-week training programme for 12 volunteers, together with the development of the documentation, policies and procedures to support the intervention. Phase 2 of the study is a Randomised Controlled Trial (n=80). Three patients have been referred since the trial commenced in September 2015. The trial will determine the impact of the intervention on social and practical need, loneliness, wellbeing, quality of life, social network and social capital.

**Highlights and Challenges**

The Good Neighbour Partnership has been very well received. The volunteers recruited to deliver the intervention fit well with the person specification developed for the role. The training was very successful, and the manner in which it was developed enabled volunteers to shape the sessions and the final policies and procedures for the intervention. The pre-pilot was successful in that it enabled people’s unmet social and practical needs to be addressed. In the first phase referrals came from Primary Care, and this resulted in somewhat inappropriate referrals, since the people did not appear to be in their last year of life. This has been addressed with the inclusion of the SPICT™ tool as part of the screening process for the study. A second challenge was the lack of social network that could be mobilisation for two patients, who were socially isolated by choice. This resulted in the need to recruit a pool of “Good Neighbour Volunteers” that brought with them logistical challenges in terms of insurance, supervision and support. In the next phase of the study, we anticipate that this pool will not be required, since further partnerships within existing community structures have been developed.

**Patient / Public Involvement**

The project has attracted 12 volunteers, all members of the public to deliver the intervention, all of who have now been trained. An additional 10 volunteers are in the process of recruitment. To date, the project has supported 3 patients as part of the pre-pilot and 3 patients are currently receiving the intervention. Patients, carers and health professionals have been involved in interviews and focus groups exploring their experience of social and practical need in the last year of life. The project is promoted through the community Limerick City and County via The Compassionate Communities Project.
Selected Knowledge Transfer & Exchange Activities

- The Campbell TRF form was submitted in June 2015 entitled: *Community-led practical and/or social support interventions for adults living at home with palliative and end of life care needs*. McLoughlin, K., McGilloway, S., Furlong, M. Callinan, J. & Rhatigan, J.

Other publications regarding the wider Compassionate Communities Project, from which the Good Neighbour Partnership stems and is referred to, have been successful - including a Chapter in an edited book: McLoughlin, K. & Rhatigan, J. (2015).

Abstracts have been submitted to the 9th World Research Congress of the EAPC 2016:
- The Development and Impact of a Training Programme for Volunteers Supporting People Living at Home with Advanced Life Limiting Illness: A Pilot Study.
- “There’s a spring in her step that just wasn’t there before”. The experience of volunteers delivering an intervention to meet the social and practical needs of people with advanced illness.

Collaborations

Milford Care Centre’s Compassionate Communities Project has signed a MoU with The NewHealth Foundation in Spain and we recently facilitated a visit from the Foyle Hospice Compassionate Communities Project who have a particular interest in The Good Neighbour Partnership. As part of the development and delivery of the intervention, partnerships have been made with Primary Care Teams, DCU, the OPRAH project, Serve the City Limerick, ALONE, Carer’s Ireland and The Alzheimer’s Society of Ireland.
Calendar of key events & activities for PCRN 2016

Key activities
- Recruit & appoint KEDS Project Manager (Jan / Feb)
- Develop & launch PCRN marketing material for national & international profiling
- Identify, establish & build on formal links with other research networks (from Jan)
- Identify & explore capacity building opportunities for AIIHPC/IAPC Early Career Research Forum
- Submission of HRB Penultimate SRN/PCRN Annual Report (Feb)
- HRB Evaluation Review meeting (Apr 2016)
- Review and explore funding opportunities in partnership with PCRN members/teams

Key events
- Launch of AIIHPC Palliative Hub including the Research Zone (early 2016)
- Palliative Care Congress UK (Mar 2016)
- EAPC Research Congress (Jun 2016)
- Other conferences and network events in 2016 as appropriate
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