



All Ireland Institute of
Hospice and Palliative Care



REPORT FROM
THE ALL IRELAND PALLIATIVE CARE
RESEARCH NETWORK

OCTOBER 2013

All Ireland Institute of Hospice & Palliative Care (AIHPC)

Background

AIHPC is an all island organisation, comprised of a Consortium of hospices and universities, all working to improve the experience of supportive, palliative and end-of-life care on the island of Ireland, by enhancing the capacity to develop knowledge, promote learning, influence policy and shape practice. The aim is to secure the best care for those approaching end-of-life.

AIHPC secured significant funding from Atlantic Philanthropies with additional funding commitments from the Irish Hospice Foundation, Irish Cancer Society, the Irish Health Research Board, and Research and Development Division of the Public Health Agency, Northern Ireland. The Management Consortium Partners also provide funding to AIHPC.

Mission & Values

AIHPC mission is to ensure a better experience for patients and their families across the island of Ireland.

Four values underpin AIHPC's approach and apply across all themes and activities as well as providing the basis for how the Consortium work together and with other stakeholders.

1. Social Justice
2. Inclusivity
3. Accountability
4. Evidence-base.

All Ireland Palliative Care Research Network (P.C.R.N.)

Launch

In September 2012, the All Ireland Palliative Care Research Network was launched. The Network offers the all-island palliative care research community significant opportunities to develop and enhance inter/multidisciplinary research collaboration, support research capacity building and leadership activities, promote availability, accessibility and transferability of learning, and to produce excellent, high quality, clinically-relevant, and innovative research. This network is the first of its kind for palliative care in Ireland.

Structure

The Network currently consists of two complementary Research Strands encompassing seven work projects.

A significant set of Network activities includes research capacity building, dissemination, policy engagement, development of new areas of research and other areas of work aligned to AIHPC's strategic objectives.

The Network received an initial investment of €1.26million (\$1,732,590) for palliative and end of life care research over four years from the Irish Health Research Board and AIHPC.

This reflects a historical shift in research funding and policy development for palliative and end of life care on the island of Ireland.

The following section provides a brief overview of the Research Strands, work projects and Principal Investigators.

Current Research Strands & Work Projects

Senior Principal Investigators and Early Career Researchers attending the P.C.R.N. National Research Symposium in Dublin, Ireland in September 2013).



Back row (l-r): Professor George Kernohan (University of Ulster), Professor Mary McCarron (Trinity College Dublin), Dr Tara Murphy (All Ireland Institute of Hospice & Palliative Care), Professor Phil Larkin (University College Dublin), Professor Donna Fitzsimmons (University of Ulster), Dr Janice Bailie (HSC Research & Development Division, Public Health Agency), Dr Gail Johnston (HSC Research & Development Division, Public Health Agency), Bridget Johnston (Trinity College Dublin), Professor Sam Porter (Queen's University Belfast), Dr Catherine Sweeney (University College Cork). **Middle row (l-r):** Helen Kerr (Queen's University Belfast), Professor Gerry Leavey (University of Ulster), Dr Suzanne Guerin (University College Dublin), Dr Leanne Breslin (University of Ulster), Sarah Walsh (University College Dublin), Janet O'Farrell (Trinity College Dublin), Dr Nicola Cornally (University College Cork), Dr Gemma Kiernan (Dublin City University). **Front row (l-r):** Professor Charles Normand (Trinity College Dublin), Dr Honor Nicholl (Trinity College Dublin), Dr Sonja McIlpatrick (University of Ulster), Dr Karen Ryan (Mater Misericordiae Hospital & St Francis Hospice), Fiona Hurley (Dublin City University), Professor Willie Molloy (University College Cork). Missing from the photo: Professor David Meagher (University of Limerick), Dr Suzanne Timmons (University College Cork), Professor Kevin Brazil (Queen's University Belfast), Professor Declan Walsh (Trinity College Dublin, University College Dublin & Our Lady's Hospice and Care Services, Dublin).

Research Strand 1

'Pathways toward Social Justice: Understanding Equality and Inclusion in Palliative Care' (SJS)

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

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 is examining 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 is intended that the evidence generated will be used 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.

There are currently four work projects under Research Strand 1:

Work Project 1

Identifying and Addressing the Needs of People with Serious Mental Illness.

Co-Investigators:

Dr Ann Sheridan, School of Nursing, Midwifery and Health Systems, University College Dublin

Professor Gerard Leavey, Director Bamford Centre for Mental Health & Wellbeing, University of Ulster (Magee Campus).

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.

Key outcomes: A series of case note studies and vignettes to allow for the demonstration of best practice and will include barriers and facilitators impacting on diagnosis, referral, access and engagement with palliative care. These tools will then be re-introduced in workshops with clinicians and other professionals with the intent of designing a number of supports including algorithms for identification, diagnosis, referral, and supporting engagement of people with a diagnosis mental illness requiring palliative care services as well as educational programmes to support clinicians, service users and carers.

Work Project 2

Identifying and Addressing the Needs of People with Intellectual Disability.

Co-investigators:

Professor Mary McCarron, Dean of Health Sciences, School of Nursing and Midwifery, Trinity College

Dr Karen Ryan, Palliative Medicine Consultant, Mater Misericordiae Hospital and St Francis Hospice and Clinical Lead for Palliative Care, Irish Health Service Executive

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 five-step approach to include documentary analysis, database analysis, surveys, and case studies.

Key outcomes: Illustrative case studies demonstrating the personal, professional, organisational and policy-based determinants of access and lack of access to palliative care for persons with ID and terminal illness.

Work Project 3

An Exploration of Access, Decision Making and Experiences of Palliative Care Services for Families of Children with a Non Malignant Life-Limiting Condition.

Co-investigator:

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

Dr Honor Nicholl, Lecturer, School of Nursing and Midwifery, Trinity College

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 approach.

Key outcomes: An evidence- based model of palliative care in Ireland. This will incorporate the perspectives of children, parents and professionals, thereby ensuring the most comprehensive picture of current palliative care practice including access to services, decision making and service provision. Ultimately, the model will inform the development of a framework to enable efficient service provision to families.

Work Project 4

Exploring Dimensions of Inequality in Current Palliative Care Provision for Carers of People with Advanced Heart Failure in Ireland.

Co-investigator:

Professor Donna Fitzsimons, Belfast City Trust and University of Ulster (UU)

Dr Sonja McIlfatrick, Reader/ Head of Research, Institute of Nursing Research/AIIHPC, UU

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, and qualitative interviews.

Key outcomes: To provide important evidence that relates patients' symptoms, and support available to the psychosocial impact on carers. It is envisaged that this will lead to follow-up of this cohort of patients and carers undertaking an economic analyses of service use and moving into an experimental phase of developing psycho educational interventions for caregivers of patients with heart failure and potentially other chronic illnesses throughout the island of Ireland.

Research Strand 2

'MEASUREMENT AND EVALUATION OF OUTCOMES FOR PALLIATIVE CARE (MES)'

Led by Professor Charles Normand, Edward Kennedy Professor of Health Policy and Management, Centre for Health Policy and Management, Trinity College Dublin.

Background

The Measurement and Evaluation Strand (MES) explores methodological development for palliative care research with a focus on measurement of needs, measurement of impact and evaluation of service priority and delivery. MES intends to 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.

There are currently three work projects encompassed within this strand.

Work Project 5

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 (as before)

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.

Key outcomes: Development of simple assessment procedures that can be readily applied for more timely and consistent detection allowing more optimal treatment. Assist policy development by contributing key evidence regarding optimal approaches to assessment of cognition and mood in real-world practice and that can be incorporated into evidence based guidelines.

Work Project 6

Development and Evaluation of a Psycho-Educational Intervention for Patients with Refractory Cachexia and their Lay Carers

Co-investigators:

Professor Sam Porter, Chair in Nursing Research, School of Nursing and Midwifery, Queen's University Belfast (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.

Key outcomes: Ultimately a psychoeducational intervention that has a positive impact on patients' and carers' psychological wellbeing and is cost-effective.

Work Project 7

Eliciting Preferences for Complex Packages of Palliative Care – Extension of IARE study (International Access, Rights and Empowerment Programme).

Co-investigators:

Professor Charles Normand (as before)
and Dr Karen Ryan (as before)

Professor Irene Higginson, Cicely Saunders Institute, King's College London.

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.

Key outcomes: The study outcomes will be preferences as derived from the choice experiments, showing how these vary with age, primary diagnosis and location. This understanding will form a basis for work on development of measurement tools. A further outcome will be an analysis of how feasible it will be for care providers to shift towards more fully meeting the needs.

Key publications co-authored by PIs in 2013 (including but not limited to):

1. May, P., Hynes, G., McCallion, P., Payne, S., Larkin, P. & McCarron, M. (2013). Policy analysis: Palliative care in Ireland. *Health Policy*.
2. McIlfatrick, S. & Murphy, T. (2013). Palliative care research on the island of Ireland over the last decade: a systematic review and thematic analysis of peer reviewed publications. *BMC Pall Care*, 12: 33 (September 2013).
3. McIlfatrick, S. (2013) Raising Public Awareness of Palliative Care: Opinion. *Primary Health Care*, 23 (4). pp. 10.
4. McIlfatrick, S, Noble, H, McCorry, N, Roulston, A, Hasson, F, McLaughlin, D, Johnston, G, Rutherford, L, Payne, C, Kernohan, G, Kelly, S, Craig, A (2013). Exploring public awareness and perceptions of palliative care: A qualitative study. *Palliative Medicine*. DOI: 10.1177/0269216313502372
5. McIlfatrick, S, Hasson, F, McLaughlin, D, Johnston, G, Roulston, A, Rutherford, L, Noble, H, Kelly, S, Craig, A, Kernohan G (2013). Public awareness of and attitudes towards palliative care in Northern Ireland. *BMC Palliative Care*.
6. McVeigh C., Reid J., Hudson P., Larkin P., Porter S. & Marley A.M. (2013). The experiences of palliative care health service provision for people with non-malignant respiratory disease and their caregivers: an all-Ireland study. *Journal of Advanced Nursing*.
7. Millar, C., Reid, J. & Porter, S. (2013) Refractory cachexia and truth-telling about terminal prognosis: a qualitative study. *European Journal of Cancer Care*, DOI: 10.1111/ecc.12032.
8. Millar, C., Porter, S. & Reid, J. (2013) Healthcare professionals' response to cachexia in advanced cancer: a qualitative study, *Oncology Nursing Forum*, forthcoming.
9. Normand, C. Setting Priorities in and for End of Life Care. *Journal of Health Economics, Policy and Law*, 7, 2012, p431 – 439.
10. Reid, J., Noble, H.R., Porter, S., Shields, J.S. & Maxwell, A.P. (2013) A literature review of end-stage renal disease and cachexia: understanding experience to inform evidence-based healthcare. *Journal of Renal Care*, 39(1): 47-51
11. Ryan DJ, O'Regan NA, Caoimh RÓ, Clare J, O'Connor M, Leonard M, McFarland J, Tighe S, O'Sullivan K, Trzepacz PT, Meagher D, Timmons S. (2013). Delirium in an adult acute hospital population: predictors, prevalence and detection. *BMJ Open*.
12. Smith, S., Brick, A., O'Hara, S. & Normand, C. (2013). Evidence on the cost and cost effectiveness of palliative care: A literature review. *Palliative Medicine*, 0(0), 1-21.
13. van der Steen, J.T., Radbruch, L., Hertogh, MPM C., de Boer, M.E., Hughes, J.C., Larkin, P., Francke, A.L., Jünger, S., Gove, D., Firth, P., Koopmans, R. TCM, & Volicer, L. and on behalf of the European Association for Palliative Care (EAPC). (2013). White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* published online 4 July 2013.

Cross-Cutting Elements and Activities

Dissemination and Knowledge Transfer

The P.C.R.N.'s vision for knowledge exchange and engagement is to:

- Translate research output for policy and practice in collaborative and innovative ways.
- Develop comprehensive and coordinated dissemination plans for all research strands.
- Align dissemination plans to overall AIHPC dissemination and strategic plans.
- Ensure users, carers and other key stakeholders are engaged in meaningful ways. With this in mind, the following research projects specifically address dissemination and KT activities.

With this in mind the following two work projects are situated within the P.C.R.N. and focused on the dissemination and application of evidence-based research findings.

Work Project 8

Developing and Implementing a 'System' of Structured Network-Wide Dissemination and Knowledge Transfer Activities.

Co-investigators:

Professor W. George Kernohan, Institute of Nursing and Health Research, School of Nursing, UU

Dr Suzanne Guerin, Senior Lecturer, Centre for Disability Studies, School of Psychology, UCD

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

Methods: This will be a mixed methods study.

Key outcomes: 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. It is intended that a focus for dissemination and knowledge transfer, and research on knowledge transfer in palliative care will be provided.

Work Project 9

Implementing and Evaluation a Dignity Care Intervention in rural versus urban communities in Ireland

Background:

Dr Sonja McIlfratrick in collaboration with Professor Phil Larkin, the Institute of Community Health Nursing (ICHN) and Public Health Nursing were awarded funding in early 2013 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). 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.



P.C.R.N. Research Capacity Building Activities

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.

This approach is recognised but not limited to the development of a research career (outlined in the following table).

Level	Opportunities/ Activities
Clinical Masters	<ul style="list-style-type: none"> • 'Exposure' activities • Guidelines Adaptation Scholarships • Clinical Research Fellowships • International Travel Bursaries • Systematic Reviews
Doctoral	<ul style="list-style-type: none"> • PhD students; joint supervision • Doctoral Fellowships • Research Training Activities facilitated via P.C.R.N.
Postdoctoral	<ul style="list-style-type: none"> • Fellowships • Mentoring • Leadership
Independent Investigator	<ul style="list-style-type: none"> • Supervision; mentoring • Knowledge Translation

Recent RCB activities

AIHPC / HSC R&D Doctoral Fellowships

In late 2011 and 2012, AIHPC in conjunction with the Health and Social Care Research and Development Division of the Public Health Agency awarded two Doctoral Fellowships in hospice and palliative care. The first recipient was Cathy Payne (Dietician University of Ulster), who is currently undertaking research on the development and testing of a cancer cachexia rehabilitation intervention to reduce symptom burden and improve quality of life in individuals with non-small cell lung cancer (NSCLC).

The second fellowship was awarded to Helen Kerr (Teaching Fellow at the School of Nursing and Midwifery, Queen's University Belfast). Helen's research is focused on the transition of young people with life-limiting conditions to adult services in Dublin and Belfast.

AIHPC International Research Travel Bursaries

Five international travel bursaries were awarded in early 2013 to enable academic and clinical researchers working on the island of Ireland to attend the following research methods courses:

- *International Research Methods Summer Academy, International End of Life Observatory, Lancaster University (June 2013).*
- *International Palliative Care PhD programme, European Palliative Care Research Centre, Trondheim & University of Edinburgh (October & November 2013).*

Clinical Research Fellowships

As part of its drive to develop research capacity in palliative and end of life care, AIHPC 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).
- '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 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).
- ‘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).



Being awarded 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).



Dr Sonja McIlfattrick, Head of Research, All Ireland Institute of Hospice and Palliative Care (AllHPC) and Professor Dame Judith Hill, Chief Executive, Northern Ireland Hospice & Chair, AllHPC Management Committee with the recipients of Clinical Research Fellowships awarded by the AllHPC

Guidelines Adaptation for Constipation & Depression

Clinical guidelines aim to provide the best quality and standards for people requiring care and treatment. In December 2011, AIIHPC appointed four scholars to adapt international best practice clinical guidelines in depression and constipation for those with palliative care needs. Each guideline team is supported by an Expert Advisory Group. Members of the EAG include Professor Lukas Radbruch, Professor Mari Lloyd Williams (Honorary Consultant in Palliative Medicine, Health Services research, Institute of Psychology, Health & Society, University of Liverpool).



Recent work includes a presentation delivered by the guidelines scholars for constipation at the European Association of Palliative Care (EAPC) Congress in Prague in June 2013.

All Ireland Early Career Researcher Forum in association with AIIHPC and the Irish Association for Palliative Care (IAPC)

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. Links may also be established with significant others including EuroIMPACT and BuildCARE.

RCB activities for 2014-2015

Postdoctoral researcher

During 2014, AIIHPC will jointly appoint a Postdoctoral Fellow funded for two years via the Irish Cancer Society. To develop the priority areas for research, a systematic review of palliative care research in Ireland was undertaken, identifying gaps in the evidence base for palliative care research (McIlpatrick & Murphy, 2013).

EAPC Research Congress Travel Bursaries

Six international travel bursaries to attend the EAPC Research Congress, jointly funded by AIIHPC and the Irish Association of Palliative Care, will also be launched in 2014. The bursaries will specifically target members of the AIIHPC/IAPC Early Career Research Forum who do not have access to an additional source of funding i.e. PhD students, clinicians on studentships, and so on.

Four Clinical Research Fellowships

It is envisaged that AIIHPC will launch a further four Clinical Research Fellowships in 2015. The focus of these will be similar to the original call and will target clinicians working on the island of Ireland.

Recent Developments

New partners

University College Cork (UCC, Ireland) has officially become a consortium member of AllHPC. UCC has an expansive research programme relevant to palliative care. For example, it is co-lead on The COLLAGE (Collaboration on Ageing) consortium which is one of 13 sites to be awarded top 'three star' status from the EU. For further information visit <http://www.collage-ireland.eu/>

P.C.R.N. National Research Symposium

During September 2013, AllHPC held their annual research programme symposium for the All Ireland Palliative Care Research Network (P.C.R.N.) in Dublin. The purpose of the event was to review existing research projects, develop relationships with new and potential research partners, provide opportunities to progress future projects, and to develop targeted grant proposals for funding. The event was attended by over 30 researchers including all principal investigators, postgraduate and postdoctoral researchers currently in the Network.



User/Carer Involvement

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.

