



Research Article

Establishing palliative care research partnerships in Northern Ireland

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Abstract

Background: The National Institute for Health and Care Research call for research partnerships was designed to build research capacity in palliative and end-of-life care and to ensure that the research of the National Institute for Health and Care Research is conducted in areas of greatest need and where there are historically low levels of research. Northern Ireland has high levels of need, relatively underdeveloped services, and comparatively low levels of research.

Aims:

1. To build palliative care and end-of-life research capacity in Northern Ireland, with a specific focus on less experienced sites, so that strong applications could be submitted to Part 2 of the National Institute for Health and Care Research Commissioned Call: building the evidence base.
2. To create a sustained collaboration to support a programme of research focused on key areas of need in Northern Ireland that are also relevant to the rest of the United Kingdom.

Methods: The Partners were: Queen's, Ulster and Open Universities; All Ireland Institute of Hospice and Palliative Care; Marie Curie Hospice Care; Patient and Client Council; Kidney Care UK; the three Health and Social Care Trusts covering areas with greatest need; Northern Ireland Clinical Trials Unit; Palliative Care Research Forum Northern Ireland; Public Health Agency; Department of Health; Health and Social Care Board. The Partnership was co-led by Drs Peter O'Halloran and Clare McVeigh, senior lecturers at Queen's University Belfast. A post-doctoral research assistant was employed 3 days a week in a support role. The Partners agreed the terms of reference for the Partnership and met six times over the following year. An expression of interest form was distributed to potential investigators, producing 13 responses. The Partnership then offered networking opportunities for investigators with specific partners, facilitated by the research assistant. The Partnership hosted a palliative care research conference on 'Cross-sector Partnerships for Palliative and End-of-life Care Research'. This included presentations from the National Institute for Health and Care Research representatives on grant proposal preparation. A website and newsletter were published.

Results: Nine introductory meetings took place, mostly with early career researchers. Topics included symptom management, accessing palliative care for vulnerable groups, perinatal bereavement care and advanced care planning. Draft proposals were reviewed by the Partnership and one was prepared for submission to Part 2 of the National Institute for Health and Care Research Commissioned Call: an evaluation of an intervention to improve the readiness of people with end-stage kidney disease, healthcare professionals, and surrogate decision-makers to engage with advance care planning.

Conclusions: The Partnership took advantage of widespread interest and goodwill among the Partners and their organisations, and proved its usefulness by enabling one application to go forward under the Part 2 call, especially in facilitating patient and public involvement in the development of that application. However, the relatively small number of experienced researchers meant that few were placed to take full advantage of the opportunities offered during the funded lifetime of the Partnership. We believe that an investment over a longer period – for example, 3 years – combined with formal mentorship for potential principal and co-investigators, would be more likely to lead to the development of credible research proposals with a better chance of being funded by the National Institute for Health and Care Research.

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Background

The purpose of the National Institute for Health and Care Research (NIHR) call for Palliative and End-of-life Care Research Partnerships is to build research capacity in palliative and end-of-life care and to ensure that the NIHR research is conducted in the areas where the health and social care needs are the greatest, and where there are historically low levels of research. Northern Ireland (NI) fits this profile in the following ways:

1. High levels of health and social care need: An estimated 11,300 people in need of palliative care die each year in NI,¹ yet recent research suggests that nearly 3000 of these people are not accessing palliative care.² There are five Local Commissioning Groups (LCGs) in NI, which share borders with the Health and Social Care Trusts. Those with the highest mean numbers of patients registered yearly as receiving palliative care 2015–20 are the Northern (1325), South Eastern (1037) and Belfast (1201) LCGs.³ The 2019–20 National Audit of Care at the End of Life^{4,5} reports a summary score of 7.4/10 (maximum score is 10) for the specialist palliative care workforce in England and Wales (E&W), compared to just 5.1/10 in NI. This reflects differences in services such as access to 7-days-a-week, face-to-face, specialist palliative care service (available in 36% of hospitals in E&W compared to none in NI); vacancy rates for medical staff (6% in E&W, 25% in NI); and inclusion of end-of-life care training in mandatory training programmes (46% in E&W, 25% in NI).
2. Low levels of research: A 2018 review of palliative and end-of-life care research on the island of Ireland noted that the vast majority of the research was observational (only one randomised controlled trial was reported), that funding in NI came from NI government sources, or charities, rather than research councils, and that 40% of the studies received no external funding.⁶ A search of the NIHR research portfolio on 13 August 2021 for funded research in palliative or end of-life care based in NI identified only one study (a systematic review).
3. Need and desire to build research capacity: The three universities in NI, Queen's University Belfast, Ulster University and the Open University are all seeking to strengthen their research themes in relation to palliative and end-of-life care.^{7,8} The

universities are affiliated with the All Ireland Institute of Hospice and Palliative Care (AIHPC), a collaboration of hospices, health and social care organisations and universities on the island of Ireland;⁹ and have a track record of conducting palliative care and end-of-life research in partnership with local Health and Social Care Trusts, and with the charitable and voluntary sectors. However, this portfolio of research needs to grow if it is to meet the needs of the NI population and provide opportunities for patients to join major studies.

To summarise: there is a high level of need for palliative and end-of-life care in NI, a relatively low level of research, and considerable potential for increased capacity. In recent years, researchers have established partnerships and conducted preliminary research which now puts them in a position to make applications to the NIHR, but such applications will be stronger and more likely to succeed with the support of the envisaged Partnership.

Aims and objectives of the Partnership

The twin aims of the Partnership were:

1. To build palliative care and end-of-life research capacity in NI, with a specific focus on less experienced sites, so that strong applications can be submitted to Part 2 of the NIHR Commissioned Call: building the evidence base.
2. To create a sustained collaboration that will support a further programme of research in the 5 years following the Commissioned Call, focused on key areas of need in NI that are also relevant to the rest of the UK.

Objectives

1. To form a Partnership to include the university researchers, health and social care practitioners, patient and public representatives, the charitable and voluntary sectors, and policy-makers and commissioners of services.
2. To identify and include Partners from geographical areas where there are the largest shortfalls in research activity compared to need and care capacity.
3. To work with Partners to develop several strong applications for submission under Part 2, that are co-produced with patients and the public, and address important and enduring evidence gaps for those

delivering and receiving personalised palliative and end-of-life care.

4. To optimise the policy and practice impact of the research funded under Part 2.
5. To establish an ongoing and expanding Partnership that will support the identification of palliative care and end-of-life care needs that are important in NI and the UK as a whole but have been under-researched, and to develop programmes of research to fill these gaps, thereby providing an evidence base to underpin policy, commissioning and practice.

Methods

Context

We have been working as part of a NIHR Partnership since January 2022. Our role has been to co-ordinate partnership and facilitate the development of research ideas for the Part 2 call. The Partnership consists of partners from many organisations with representation from those below:

- The AllHPC
- Belfast Health and Social Care Trust
- Northern Ireland Clinical Trials Unit (NICTU)
- Department of Health (DoH)
- Northern Health and Social Care Trust
- Kidney Care UK
- Marie Curie
- Queen's University Belfast
- Ulster University
- Open University
- South Eastern Health and Social Care Trust
- Palliative Care Research Forum Northern Ireland (PCRFNI)
- Public Health Agency – Research and Development Division
- Health and Social Care Board (HSCB)
- Patient and Client Council

Potential partner organisations were identified by the researchers and also through networked groups such as the Public Health Agency, the AllHPC and the PCRFNI. As Partners joined, they were asked to recommend other potential partners. Incorporating representation from both the Patient and Client Council and Voices for Care has been invaluable for ensuring that patient and public involvement (PPI) has been central to the research ideas from the initiation stages. Each partner provides a unique viewpoint and skill set which has been vital for those researchers interested in engaging with us. A post-doctoral

research assistant (PDRA) was employed 3 days a week in a support role to facilitate the work of the Partnership.

Prior to the first meeting of the Partners, the co-leads drafted the terms of reference for the Partnership (including the roles of the Chair; membership and membership roles; aims and objectives; frequency of meetings; decision-making; reporting processes, etc.) and a Project Initiation Document (PID), following an approach commonly used in the NHS.¹⁰ The PID set out key components of the Partnership process, such as project rationale, background, scope and exclusions, constraints and assumptions, project objectives, costs and benefits, project approach and work streams, project plan – indicative timescales, project management team structure and roles, and risk management. The terms of reference and PID were circulated to Partners, many of which have experience of project management (e.g. AllHPC, Marie Curie, NICTU, HSCB and DoH), before the first meeting. This allowed them to be discussed, developed and agreed at that meeting.

As a whole, NI has relatively high health and social care needs and historically low levels of funded research in palliative and end-of-life care. However, within NI, the Belfast, South-Eastern and Northern LCGs have larger numbers of patients registered with palliative care needs, in comparison to the South-Eastern and Northern Trusts who have historically lower levels of research activity. Consequently, we included representatives from these three trusts as partners and planned to involve colleagues from the trusts in the Part 2 studies as co-investigators.

A vital part of the Partnership's work has been to fully involve and support the principle investigators (PIs) by understanding the requirements of the Part 2 call and pooling resources to help them overcome obstacles and meet those requirements. We invited PIs to consider common challenges and also unique requirements of their projects and bring these to the Partners for consideration and support.

Planned activities

- Bi-monthly partner meetings.
- Agreeing terms of reference.
- Publishing a bi-monthly newsletter.
- Prioritising potential proposals.
- Working with co-investigators (CIs) to coproduce Part 2 proposals.
- Reviewing draft proposals prior to submission.
- Submitting Part 2 proposals.
- Planning the continued life and priorities of the Partnership.

Results

What we did

An expression of interest form was circulated (March 2022) among Queen's University Belfast and Ulster University colleagues to determine the level of interest in engaging with the Partnership. This was disseminated not only to those working in the health sciences but also to colleagues in psychology and social sciences. Information was requested as follows: name and contact e-mail, role in research (PI/CI), areas of interest, proposed title, type of research, stage of development and how the Partnership might help. Thirteen responses were received. Of these, seven respondents considered themselves to be principal investigators of their planned projects and six were interested in contributing as co-investigators. Following this, a meeting was held with respondents (end of April 2022). This meeting provided an initial introduction to the role of the Partnership and aimed to discover more about the respondents' backgrounds and research ideas. They were asked to provide a list of partners that they felt would be beneficial for them to connect with, and the PDRA for the Partnership then made introductions via e-mail and arranged an online meeting at their convenience

(see [Figure 1](#)). Nine introductory meetings took place in the months that followed. Topics included symptom management, accessing palliative care for vulnerable groups, perinatal bereavement care and advanced care planning ([Table 1](#)). Those involved were at various stages of their careers from early career researchers to those in lectureship positions. Ideas were developed and networks strengthened during these interactions. The proposed projects were at various stages of development.

Throughout all meetings, networking opportunities were discussed and links made to others to strengthen the proposed research.

Meetings using a hybrid approach have taken place at regular intervals over the 12-month funding period (March, May, June, September, November 2022 and January 2023). This has allowed the Partnership to plan support for the Part 2 studies and to monitor progress on their development and on the advancement of the Partnership. Partners have been updated on recent progress and plans made for subsequent stages. This pattern of meetings will continue for the duration of the funding.

We hosted a UK-wide meeting with the NIHR Partnership leaders (late March 2022) to share partnership processes. This was an opportunity for discussion about the development of the partnerships and the prospect of providing support to one another as research ideas develop. This opportunity helped to stimulate interest in the Partnership.

A website has been created for the Partnership (www.qub.ac.uk/schools/SchoolofNursingandMidwifery/Research/research-themes/chronic-illness-palliative-care/cipc-projects/NIHRPartnership/) which sits within the School of Nursing and Midwifery pages on the Queen's University Belfast site. The web page is updated regularly as the Partnership progresses and research ideas develop. This has been a useful platform not only for members of the



FIGURE 1 What we did.

TABLE 1 Possible projects discussed in the Partnership

May 22	June 22	July 22	August 22
Patient simulation	Policy planning	Using Virtual Reality as an educational tool	Ensuring that care is holistic
Family/staff perspectives on bereavement care	Refugees accessing end-of-life care	Terminology around palliative care	Symptom management
Importance of psychosocial factors as a midwife	Identifying the correct target group	Importance of identifying a research gap	Reaching out to industry
PPI			

Partnership but also a way to promote the Partnership and the support it can provide. The current content includes the aims and objectives of the Partnership, a short video providing a brief overview of what the Partnership is, a list of the Partners, PPI work within the team, a write-up of our recent conference (details below) and some useful contact details and websites. There is also a form for people to make contact with the Partnership should they feel their research could benefit from our support. The website was shared among the Partners networks during recent months.

Newsletters have been developed on a bi-monthly basis and are issued to all connected with the Partnership. This has been a convenient way to provide an update on what has been happening over the period since the last edition.

On 13 October 2022, we hosted a conference in collaboration with the PCRFNI in the Great Hall at Queen's University Belfast. The conference was entitled 'Cross-sector Partnerships for Palliative and End-of-life Care Research' (see [Appendix 1](#)) and was attended by more than 90 healthcare professionals, policy-makers, researchers and members of the public. It was opened by the NI Health Minister, Robin Swann, and provided an opportunity to promote the work of the Partnership and disseminate palliative research findings from within Queen's University Belfast and Ulster University. A poster competition took place at the event.

A Senior Research Manager and Consultant Advisor from the NIHR presented to attendees about how to prepare for grants and provided practical tips to increase their chances of success. Feedback was received from 27 attendees through a QR code on the conference programme with more than 90% agreeing that the conference was informative, relevant, interesting and worthwhile, and that they would seek to implement the knowledge or skills learnt into their research (see [Appendix 2](#)). Attendees also enjoyed the PPI aspect of the day and hearing stories from patients and those involved in research as PPI representatives, with members of Public Involvement Enhancing Research NI, and AllHPC Voices for Care, presenting on their roles. Attendees particularly welcomed the fact that this was an 'in-person' conference and therefore there was opportunity to network with many commenting on this in the evaluation particularly as this was the first opportunity many had had to meet in person since the pandemic.

This was an excellent conference which covered a wide variety of palliative care issues. Looking forward to the next conference.

Discussion

What we learnt

We have learnt much from the Partnership. A widely based Partnership for palliative care research, incorporating Health and Social Care Trusts, patients and the public, policy-makers, charities and universities, had not met on a regular basis prior to this initiative. However, we found that there was enthusiasm from relevant stakeholders, who were prepared to give time and energy to supporting the initiative. Among colleagues and wider members of the Partnership, there is a wealth of information and knowledge which must be shared regularly both in an informal and a formal basis. There is much to learn from one another and strengths to be gained from the synergies in our research. Too often, researchers work in isolation and are failing the benefit from the strength of collaboration.

Our conference event in October was a demonstration of the need for a return to face-to-face networking. Attendees commented specifically on the value to be gained from meeting in person and having a chance to speak with others who work in a similar field. The event also highlighted the importance of PPI work in research. By hearing from these individuals, it was clear that PPI should be central to our projects and showed the importance of their involvement.

In terms of our first aim – to build palliative care and end-of-life research capacity in NI, so that strong applications can be submitted to Part 2 of the NIHR Commissioned Call – we had limited success. Because there is a relatively small number of palliative care researchers who are at the career stage where submissions to the NIHR are feasible, and the timing fell at a time when a number of those researchers were in the midst of existing projects, proposals in very early development were not yet ready for submission. However, this serves to illustrate the need for ongoing support and collaboration in order to achieve a critical mass of researchers with the needed experience and expertise.

Patient and public involvement

Two service users/members of the public (PPI members) nominated by the Patient and Client Council, NI, an independent voice for patients, clients, carers and communities, and Voices4Care which represents patients with palliative care needs and their relatives, reviewed and gave feedback on the Partnership plan and the plain language summary, leading to significant changes in the application for funding. Subsequently, representatives from Voices4Care, Kidney Care UK (the UK's leading

kidney patient support charity), and the Patient and Client Council, which represents and advocates for service users in NI were included as full members of the Partnership. These members were involved in agreeing terms of reference for the Partnership, participated in partnership meetings, contributing to and reviewing all partnership documents and decisions, setting priorities for the Partnership in terms of the supported studies, and reviewing progress towards partnership goals.

What we are taking forward

One proposal based in NI is being prepared for the Part 2 call, entitled 'Nurse-led advance care planning with people who have end-stage kidney disease: a cluster randomised controlled trial of a co-designed intervention incorporating an economic evaluation and mixed methods process evaluation'.

Patient and public involvement representation has been central from the beginning of this proposal and was accessed initially through members of the Partnership. In all, 10 patients and members of the public were involved in the preparation of this proposal on four occasions, helping to develop the different parts of the intervention and in deciding how the research should be done. The strengths and skills of those in the Partnership have helped to shape and improve the protocol, and members have also agreed to be part of the research steering committee if the research is funded. This proposal is being developed in collaboration with another NIHR Partnership, The Yorkshire and Humber Palliative Care Research Network.

Although other potential applications were identified, unfortunately most of these are not at the necessary stage of development to be submitted to the Part 2 call. However, the Partnership has played a role in developing these ideas and providing networking opportunities which have strengthened the ideas being developed.

In relation to our second aim – to create a sustained collaboration that will support a further programme of research focused on key areas of need in NI that are also relevant to the rest of the UK – we have made slow progress. The formal meetings of the Partnership ended with the funding, although relationships formed have persisted, and informal collaboration continues largely through the AllHPC and the Northern Ireland Palliative Care Research Forum.

Reflecting on the Partnership

Our plan for the Partnership envisaged up to five projects going forward to application under Part 2 of the palliative care research call. However, in the

event, only one project was submitted to that call. Our experience in leading the Partnership showed us that there is a core cadre of colleagues with the necessary experience and track record to mount a credible bid for research council funding for palliative care research, but that this is a relatively small group. Aside from this group of potential PIs, there were several colleagues who considered themselves early career researchers and who were interested in joining projects as co-investigators, but who would not consider themselves able to lead a project. These colleagues would have benefited from more formal mentorship to help develop their research ideas, but this was beyond the resources and scope of the Partnership. Consequently, a single year of funding to promote partnerships risks finding those researchers at very different stages in the development of potential projects, so that the opportunities provided by the Partnership can arrive at the wrong time in their research cycle. This appeared to be the case for us, as some researchers with the capacity to be PIs reported that, although they had plans for studies that might be submitted to the NIHR, those plans were not sufficiently mature to allow application under the Part 2 call. One of the projects identified in our plan (Integrated palliative care in oncology: a realist synthesis, NIHR152115) was funded but this was through the Health and Social Care Delivery Research Programme researcher led scheme, and the preliminary work for this project had been done prior to the creation of the Partnership.

Ongoing collaboration between researchers continues informally through existing networks but has not been significantly affected by the Partnership. Early career researchers, especially those outside the health sciences, appear to lack the necessary infrastructure and mentoring from experienced researchers that would enable them to develop their ideas.

Conclusions

The Partnership was able to take advantage of widespread interest and goodwill among Partners and their organisations, and was able to engage with a significant number of researchers. It has demonstrated the ability of researchers to work together across sectors and with colleagues in other universities. It proved its usefulness by enabling one application to go forward under the Part 2 call, especially in facilitating PPI in the development of that application.

However, the very conditions that made NI a candidate for investment in the Partnership – a weak track record

of palliative and end-of-life care research funded by the NIHR or other research councils, and a relatively small number of experienced researchers in these areas – meant that few researchers were in a position to take full advantage of the opportunities offered during the funded lifetime of the Partnership.

We believe that an investment over a longer period – for example, 3 years – combined with formal mentorship for potential principal and co-investigators would be more likely to lead to the development of credible research proposals with a better chance of being funded by the NIHR.

Additional information

CRediT contribution statement

Julie McMullan (<https://orcid.org/0000-0001-8566-4807>): Methodology (supporting), Project administration (supporting), Writing – original draft.

Clare McVeigh (<https://orcid.org/0000-0001-9691-6766>): Conceptualisation (supporting), Funding acquisition (supporting), Methodology (supporting), Project administration (supporting), Supervision (supporting), Writing – editing and reviewing (supporting).

Peter O'Halloran (<https://orcid.org/0000-0002-0022-7331>): Conceptualisation, Funding acquisition, Methodology, Project administration, Supervision, Writing – editing and reviewing (supporting).

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Professor Sonja McIlpatrick, Professor in Nursing and Palliative Care, Ulster University.

Dr Joanne Jordan, Research Fellow, School of Health, Wellbeing and Social Care, The Open University.

Mr Paul Turley, Regional Palliative Care Programme Lead, Commissioning Lead SE LCG, Health and Social Care Board (Northern Ireland).

Miss Lynn Murphy, Manager, Northern Ireland Clinical Trials Unit.

Dr Mary Rabbitte, Research Programme Manager, All Ireland Institute of Hospice and Palliative Care.

Professor Joanne Reid, Professor of Cancer and Palliative Care, School of Nursing and Midwifery, The Queen's University of Belfast.

Dr Carol Stone, Consultant in Palliative Medicine/Specialty Lead for Palliative Medicine, Belfast Health and Social Care Trust/The Queen's University of Belfast.

Mrs Fiona Loud, Policy Director, Kidney Care UK.

Mrs Corrina Grimes, Advance Care Planning Lead, Department of Health, Northern Ireland.

Dr Tracey McConnell, Marie Curie Senior Research Fellow, School of Nursing and Midwifery, The Queen's University of Belfast.

Professor Helen Noble, Professor of Nursing, School of Nursing and Midwifery, The Queen's University of Belfast.

Mr Craig Harrison, Policy and Public Affairs Manager, Marie Curie Cancer Care.

Mrs Vivian McConvey, Chief Executive Officer, The Patient and Client Council, Health and Social Care Board (Northern Ireland).

Mr Ray Elder, Strategic Lead for Palliative Care, Community Palliative Care Team South Eastern Health and Social Care Trust.

Data-sharing statement

No research data were collected as part of this project.

Ethics statement

No research was planned as part of the project, so ethical approval was not required.

Information governance statement

No personal information was handled as part of the project.

Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at <https://doi.org/10.3310/QUTP1946>.

Primary conflicts of interest: Peter O'Halloran – member of the HS&DR Associate Board from 2016 to 2020.

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List of abbreviations

AIHPC	All Ireland Institute of Hospice and Palliative Care
DoH	Department of Health
E&W	England and Wales
HSCB	Health and Social Care Board
LCGs	Local Commissioning Groups
NI	Northern Ireland
NICTU	Northern Ireland Clinical Trials Unit
NIHR	National Institute for Health and Care Research
PCRfNI	Palliative Care Research Forum Northern Ireland
PDRA	post-doctoral research assistant
PID	Project Initiation Document
PPI	patient and public involvement

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Appendix 1 Conference programme

Cross-sector Partnerships for Palliative and End-of-life Care Research

Conference Programme





Thursday 13 October, 09:30–16:30

Queen's University Belfast, Lanyon Building: The Great Hall

Time	Topic	Speaker
9:30	Registration and refreshments	
Morning session chaired by Dr Clare Mc Veigh (Queen's University Belfast)		
10:00	Conference welcome	Professor Donna Fitzsimons Queen's University Belfast
10:05	Opening address	Robin Swann Health Minister
10:15	Welcome and overview of the conference	Dr Peter O'Halloran Queen's University Belfast
10:30	HTA Programme – What is it and how to make a good application	Karen Williams and Jason Horsley NIHR
11:00	Applying for NIHR funding	Catherine Evans King's College London
11:30	Successful funding applications: round table discussion	Dr Pete O'Halloran to chair: Catherine Evans, Margaret Grayson, Jason Horsley, Sonja McIlfratrick, Lynn Murphy, Karen Williams
12:00 Session close <i>Networking, poster viewing and lunch</i>		
Afternoon session chaired by Dr Esther Beck (Ulster University)		
13:00	EAPC future directions for palliative care research	Professor Sonja McIlfratrick Ulster University
13:30	Voices4Care AIHPC	Clodagh O'Donovan AIHPC Monica Burns PPI group member Voices4Care
14:00	PPI in palliative care research: Challenges and opportunities	Sonia Patton and Margaret Grayson MBE Public Involvement Enhancing Research NI and the NI Cancer Research Consumer Forum
14:30	Refreshment break	

Time	Topic	Speaker
15:00	Family bereavement and its impacts during the pandemic	Dr Kelly Norwood <i>Ulster University</i>
15:30	Working in palliative care during the pandemic	Janet Kilfedder and Lynda Bell <i>Palliative Care Nurse Specialists (NIH)</i>
16:00	Poster prize and conference close	Dr Esther Ruth Beck <i>PCRFNI</i> Professor Joanne Reid <i>Queen's University Belfast</i>



QR codes	
Padlet 	Conference evaluation 
Partnership webpage 	Partnership newsletter 

Appendix 2 Conference evaluation

Cross-sector Partnerships for Palliative and End-of-life Care Research

Conference Evaluation Report

A conference evaluation form was distributed at the event on 13 October 2022 via a QR code on the programme. More than 90 individuals attended the conference, and 27 individuals completed the form. The results of this are displayed below.

- 96% agreed that the conference was well organised.
- 96% agreed that overall the speakers were informative, prepared and understandable.
- 92% agreed the material presented was relevant and helpful.
- 95% agreed the material was presented in an interesting manner.
- 81% agreed the questions and discussion were handled to their satisfaction.
- 85% agreed the conference food was good.
- 96% agreed the facilities were appropriate.

- 93% agreed that the purpose of the conference was met.
- 93% agreed that overall it was a worthwhile conference.
- 97% said they will try to implement the knowledge or skills learnt in this conference into their research.
- 96% said they would attend additional conferences on this subject area if offered.

Attendees were asked what one thing from the conference will help them the most. Various answers were given but a common response was 'networking'. Many individuals commented on the opportunity to be together in person and the value they drew from this.

'Networking with new people and meeting others for the first time in 3 years'.

Another common answer was around the PPI element of the day and the opportunity to hear patient stories. Attendees appreciated the information provided on incorporating PPI in research and felt that the patient stories were a good learning resource.

'This conference gave me some ideas for a small research project within my own workplace. I found the patient experiences very beneficial'.

The administration, EAPC awareness, advice on funding applications, the research proposal process and the session on how COVID deaths have affected relatives were also highlighted as helpful aspects of the conference.

A few suggestions were made by the attendees for improvements should a similar event be held in the future:

- More engaging interactive sessions.
- A future topic to consider would be how to approach a small-scale study – from an initial idea that you have into an actual study if you don't initially have access to research staff/grants.
- More space for poster presentations.

In addition to the formal evaluations, the conference also received positive feedback on the day of the event. There was a great 'buzz' and it was evident that people were delighted to be there and gained much from both the informative presentations and the opportunity to network.