



All Ireland Institute of
Hospice and Palliative Care

**Palliative and End of Life Research Priority
Setting Project for Northern Ireland and Republic
of Ireland**

*Putting patients, carers and clinicians at the heart of
palliative and end of life care research*

April 2015

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Acknowledgements

AIHPC would like to thank and acknowledge the following:

- Professor Sonja McIlfratrick, Senior Investigator in the Palliative Care Research Network and former Head of Research for AIHPC for leading this project.
- Dr Leanne Doherty , Post-doctoral research fellow for PCRN for work on the project and for undertaking data analysis
- Ms Cathleen Muholland, AIHPC Project Manager for policy and practice for facilitating and working on the project.
- Dr Katherine Cowan, Senior Advisor to the James Lind Alliance, for independently facilitating the final workshop partnership
- The patients, current and bereaved carers, health and social care professionals, organisations and patient /carer groups who disseminated and participated in the survey, prioritisation and workshop.

Supported and guided by James Lind Alliance



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Introduction

Palliative and end of life care is an under researched area. Therefore it is vital that the limited resources available are spent on research which is most relevant to patients, carers and clinicians – those who will benefit from and use the results of research. There is a dearth of evidence on the priorities for research in palliative and end of life care. Only two studies have specifically sought the views of palliative care patients on research priorities [Perkins et al, 2007 and 2008]. No studies have explicitly consulted carers. Furthermore, in recent years there has been an increased emphasis on the importance of not only involving patients and carers in research, but also in ensuring that the research undertaken clearly addresses their concerns. Chalmers et al (2014) highlighted the need to increase the value and reduce the ‘waste’ in research, proposing that research investment that does not address the needs and concerns of its end users is wasted.

A recent systematic review of published palliative care research in Ireland indicated that whilst there was an upward trend in the number of publications in palliative care research over the last ten years this has largely been needs-based and small scale studies (McIlpatrick & Murphy, 2013). Furthermore there appeared to be an absence of user/carer involvement in palliative care research in Ireland. Whilst this review was useful in providing baseline evidence of the nature and type of palliative care research undertaken within Ireland over the last decade, such an analysis only becomes meaningful whenever it contributes to the identification of areas for future research and research priorities. Therefore this paper clearly recommended the need for future strategic direction and collaboration for palliative care research in Ireland.

Background

This project was part of much larger UK wide and Ireland project entitled, “Palliative and end of life care Priority Setting Partnership” (PeolcPSP). This larger project, initiated by Marie Curie Cancer Care UK, brought together around 30 organisations and groups with an interest in palliative and end of life care research. The overall aim of the partnership was to bring patients, carers, volunteers, health and social care professionals together to identify and prioritise research questions in order to influence the prioritisation of future research. This project was undertaken in partnership with the James Lind Alliance (JLA). This is an organisation, funded by the National Institute of Health Research (UK), which provides an infrastructure and process to help patients and clinicians work together to agree the most important treatment uncertainties affecting their particular interest.

Further details on this large project can be found on www.palliativecarepsp.org.uk

All Ireland Institute of Hospice and Palliative Care (AIHPC) was one of the partner organisations in this larger study. This report will outline the aim, objectives and methodology for the wider study, concluding with the results obtained for Ireland.

Methodology

The PeolcPSP followed the methodology described in the JLA Guidebook jlaguidebook.org. The study comprised four stages.

Stage 1: Establishing the partnership

The PeolcPSP was initiated in 2013 by Marie Curie with the support of the JLA. In total, more than 30 organisations were involved either as co-funders or stakeholders. Stakeholders assisted in disseminating the survey, project updates, and results to their networks of patients, carers and professionals. Some stakeholder organisations sent representatives to the steering group. A project protocol was agreed (available online on the JLA website lindalliance.org/palliativecare.asp).

Stage 2: Identifying evidence uncertainties

Unanswered questions from patients, current and bereaved carers and health and social care professionals were collected via a public survey. The survey was launched on 9 December 2013 and remained open until 16 May 2014. The survey asked:

- What question(s) do you have about **care, support and treatment** for people who are in the last few years of their lives that could help them to live as well as possible? This could also include question(s) about care and support for current carers or families.
- What question(s) do you have about **care, support and treatment** for those rapidly approaching the end of their lives? This could also include question(s) about care and support for current or bereaved carers or families looking after someone at the end of their life.

The wording and design of the survey was piloted with a small group of current and bereaved carers, and patient representatives, adapted to incorporate feedback and then signed off by the JLA Steering Group. The survey was built using SurveyMonkey online survey software. This survey was distributed to various networks and organisations included in the AIHPC database (appendix 1).

Stage 3: Refining questions and uncertainties

This stage of the study was comprised of two main elements.

A – Identification of themes and questions

The steering group agreed that a separate data assessment group would be formed, comprising some members of the steering group, to oversee and validate the data management stage of the PeolcPSP. An initial coding framework based on the first 200 responses to the survey was created. This coding framework had six overarching themes:

- communication
- support
- service use
- managing symptoms and medications
- perceptions of palliative care, and
- understanding dying

B –Formation of interventional questions and searching for evidence

Each survey response was analysed and formed into an interventional research question, where possible, using the Patient/Population, Intervention, Comparator and Outcome (PICO) format.

Responses that were not within the scope of the project, including those pertaining to paediatric palliative care, non-terminal conditions, and questions that would be more appropriately addressed by other types of research, were removed and retained for separate analysis at a later stage.

From 1,403 survey responses 749 provisional PICO questions were formed. These questions were then reviewed, duplicates combined and checked again to make sure they were within scope.

This left a total of 435 questions to be checked against relevant, reliable and up-to-date systematic reviews, to ascertain whether or not they were unanswered. Searches were limited to The Cochrane Library and the Database of Abstracts of Reviews of Effects (DARE). These databases cover systematic reviews of randomised controlled trials.

To ensure that the search terms created had not missed any key descriptors of the intervention or the disease in question, field experts were consulted. Once the relevance of

the search terms had been verified, the Cochrane and DARE databases were searched to confirm whether the questions were true research uncertainties. For many of the questions there were no systematic reviews identified. In some cases, the identified reviews only partly answered the question identified from the survey responses. This supports the widely accepted belief that there is limited definitive research in palliative and end of life care.

A final list of 100 questions was formulated, which was then reduced to 83 by combining similar questions. This long list was reviewed by the data assessment group and the project steering group to go forward for interim prioritisation (Appendix 4).

Stage 4: Prioritisation – interim and final stages

Interim Prioritisation

A second online survey was created that asked respondents to rate each of the 83 longlisted questions. The questions appeared in random order and respondents were asked to rate each from very low priority to very high priority or no opinion. The survey received 1,331 responses, of these 168 were completed on the Island of Ireland. For each of the 83 questions a “total” priority score was allocated. If a respondent indicated no opinion a score of 0 was allocated, very low priority= 1, low priority= 2, high priority= 3 and very high priority= 4. An average score was then calculated for each of the 83 longlist of questions and these were then ranked highest to lowest to identify the top 28 priorities.

Final Prioritisation

The final prioritisation workshop took place in Dublin on the 31 March 2015. The workshop was attended by a group of 16 participants, including current and bereaved carers, patients, nurses, palliative care consultants, social worker, district and public health nurse, among others. There were an additional 4 observers who attended on the day, but did not take part in discussions, including representative from Marie Curie, UK and representatives of funding partners for AIIHPC.

The workshop followed the JLA methodology, using the Nominal Group Technique to generate discussion, ranking and consensus agreement. The JLA sees value in providing this opportunity to reach the top 10 through discussion and the exchange of knowledge. The workshop was chaired and facilitated by Katherine Cowan with support from two co-facilitators from AIIHPC, Sonja McIlpatrick and Cathleen Mulholland. This process mirrored the Final Prioritisation workshop undertaken in London.

Participants were asked to complete a Declaration of Interest form and biographies of each participant were circulated to everyone attending in advance of the workshop to encourage

transparency and openness. Each participant was sent a ranking sheet listing the 28 shortlisted questions in a random order (Appendix 2) in advance of the workshop and asked to complete this beforehand so that there was a record of their initial thoughts and a basis for the discussions to start from.

The workshop agenda can be seen in Appendix 3. Participants worked in a series of small groups to rank the 28 questions. A final session was held where the aggregate ranking was presented and a consensus was reached by discussion. The interim rankings from the prioritisation survey were made available for reference during the discussions. This process was challenging, requiring discussion and consensus to be reached between diverse groups. Participants were pragmatic, respectful of others' views and open to compromise, which helped to make the workshop a success.

Results

The results will focus on the data obtained for Northern Ireland and the Republic of Ireland for Stage 4 of the project: interim and final prioritisation. In total 168 responses were obtained for Ireland (see Table 1).

Interim Prioritisation

Some 168 patients, carers, family members and professionals on the Island of Ireland provided ratings on the 83 “longlist” of questions (see Appendix 4). The majority of the respondents were identified as a professional working with people in the last few years of life (39%) (Figure 1). Of these, several different professions were represented. Of those who identified their profession, professionals allied to medicine, palliative care doctors, specialist palliative care nurses and nurses made up the highest proportion (see Table 2).

Bereaved carers, family members and friends made up 26% of respondents, whilst members of the public who had an interest comprised 17% of the respondents. Those who identified as being in the last few years of life comprised 1% of the sample. It was anticipated that this group would be the most difficult to access and so various measures were adopted to seek to address this.

A more detailed breakdown of the responses to the 83 questions is outlined in Appendix 4.

Table 1 The response rate for the Island of Ireland

	Population (UK – 63 million)	Total number completed
Northern Ireland	1.8 million	90
Republic of Ireland	4.6 million	78
Total		168

Figure 1 Description of the respondents to the survey

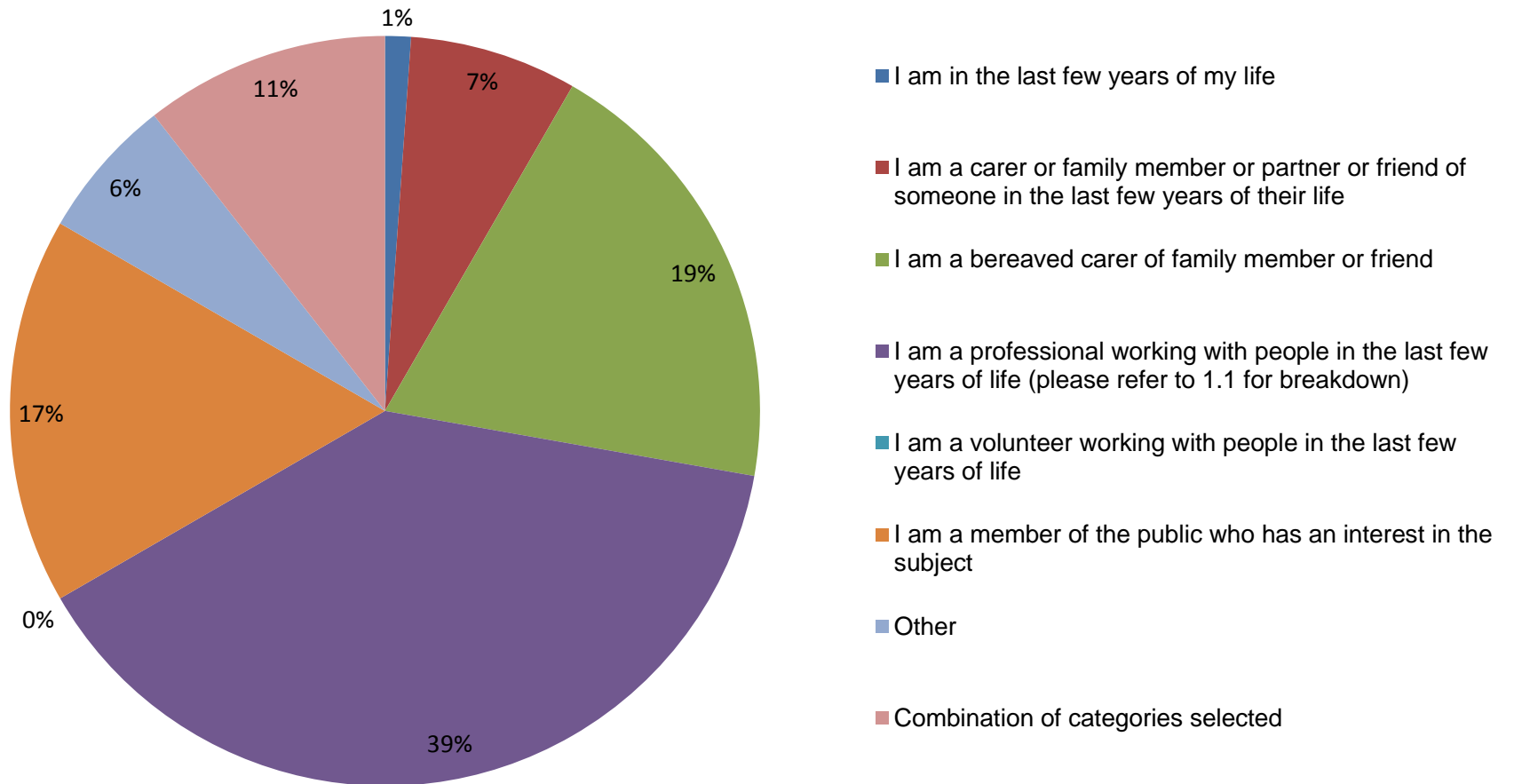


Table 2 The type of profession for those who completed the questionnaire and identified themselves as a professional

	Total number	Percentage of total completed
Specialist palliative care nurse	13	17
Nurse	12	15
Professional allied to medicine	23	29
Palliative care doctor	10	12
Occupational Therapist	2	2
Care home or home care staff	2	2
Clinical Researcher	3	4
Lecturer	3	4
Volunteer co-ordinator	1	1
Secretary	1	1
Geriatric medicine	1	1
Charity staff	1	1
Educator	1	1
Disability	1	1
Manager of PC services	1	1
Paediatrician with an interest in neurodisability & palliative care	1	1
Social worker	1	1
Other specialist doctor	1	1
SHCA	1	1
Senior health care assistant	1	1
GP	1	1
Dentist trained in HNC & PC	1	1
Prefer not to say	2	2

Final Prioritisation

A final prioritisation workshop was held on 31 March 2015 to identify the top 10 unanswered research questions, or evidence uncertainties, in palliative and end of life care in Ireland. The workshop participants ranked all 28 questions in order of priority. The full list can be found in Appendix 5.

16 participants attended:

- Nine professionals working with people in the last few years of life
- Four people who were bereaved carers as well as professionals working with people in the last few years of life
- One bereaved carer
- One person who was a patient representative as well as a professional working with people in the last few years of life
- One person who was a patient, a current carer and a bereaved carer.

Top 10 Priority Questions

The top 10 priorities for palliative and end of life care in order of priority, on the island of Ireland are:

1. What are the best ways of providing palliative care **outside of 'working hours'** to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families?
2. What are the benefits, and best ways, of **providing care in the patient's home** and how can home care be maintained as long as possible? Does good co-ordination of services affect this?
3. What are the best ways to make sure that palliative care patients receive adequate **pain and symptom relief** and which drugs for pain management are best in terms of side-effects, such as drowsiness?
4. What are the best ways for healthcare professionals to tell patients, carers and families that a patient's illness is terminal and also **explain the dying process compassionately and honestly**? Can literature, including leaflets, be helpful? Who is the best person to provide this information and communication?
5. What are the benefits of **Advance Care Planning** and other approaches to listening to and incorporating patients' preferences? Who should implement this and when?
6. What are the best ways to make sure there is **continuity for patients at the end of life**, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case-coordinator improve this process?
7. What are the best ways to **support children and young people** when someone close to them is dying or has died? This includes **communicating with them about the diagnosis and dying process**, enabling them to talk about their experience and providing bereavement support.
8. What **information and training do carers and families** need to provide the best care for their loved one who is dying?
9. What are the best ways to begin and deliver **palliative care for patients with non-cancer diseases** (such as COPD, heart failure, MND, AIDS, multiple sclerosis, Crohn's disease and stroke)?
10. Are hospices, hospitals and care homes providing adequate **staff training** to deliver specialist palliative care, and to what extent does funding affect this? How can high quality trained staff be ensured no matter where the care is being delivered?

Conclusions and Recommendations

AIHPC value the importance of this work in shaping the future development of the Palliative Care Research Network (PCRN) in Ireland. AIHPC will seek to address some of these priority areas by further engagement, seeking to increase awareness of these priority areas with the wider palliative care community and specifically with the palliative care researchers. Further discussion and consideration of the implications for key stakeholders, such as researchers; research funders; charities and policy makers is needed.

Recommendations for Key Stakeholders

Research Funders:

As funding for palliative and end of life care research is limited, the findings of this project will help to enable existing funders of palliative care research, to target their funding to address the priority areas that matter most to patients, carers and health care professionals. In seeking to address these priorities, the research funders should be able to co-ordinate their efforts and seek to address the highest priority areas together.

Research Community

The results of the project should enable researchers to demonstrate that their research is relevant and targeted to help ensure that the research that is undertaken will be valuable to the people who most need it. The results should assist in having research that is informed by and informing patients, carers and health care professionals. The results from this project will help to inform the future research strategy for the AIHPC Palliative Care Research Network (PCRN).

Policy Makers and Charities

It is anticipated that policy makers and other charitable funders in the area will be able to use this project to demonstrate the need for increased funding and focus in palliative and end of life care. It is hoped that this project will enable an increased awareness and interest in palliative care research for the public, health care professionals and research community on the island of Ireland.

References

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Appendix 1: Distribution list for questionnaire survey on the island of Ireland

AllHIPC Management Committee representatives at the following organisations:

Our Lady's Hospice and Care Services in Dublin

Northern Ireland Hospice

Milford Care Centre in Limerick

St Francis Hospice in Dublin

Marie Curie Hospice in Belfast

St James Hospital in Dublin

Trinity College Dublin

Queens University Belfast

Ulster University

University of Limerick

University College Dublin

Dublin Academic Medical Centre

University College Cork

Dublin City University

National University of Ireland Maynooth (NUIM)

Marymount University Hospital and Hospice, Cork

Members of the following committees:

Expert Advisory Board

AllHIPC Steering Committee

Palliative Care Research Network

Palliative Care Senior Nurse Network

Voices4Care

Palliative Care consultants Northern Ireland and Republic of Ireland

Irish Hospice Foundation

Patient and Client Council, N.I

Irish Association of Palliative Care

Care NI

Appendix 2: Palliative and end of life care Priority Setting Partnership (PeolcPSP) – Pre-Workshop Exercise

Individual ranking of questions for the workshop on 31st March 2015

PLEASE COMPLETE THIS AND BRING WITH YOU TO THE WORKSHOP

This is a list of 28 research questions about palliative and end of life care. They have come from a survey of people in the last few years of life, current and bereaved carers, family and friends, and health professionals on the Island of Ireland. **Please spend some time before the workshop reviewing this list of research questions.** Rank them from 1–28, 1 being the most important in your opinion and 28 being the least important, for research to address. Make a note of any comments in the right hand column.

Ref	Question	Your ranking (1-28)	Notes
A	What are the best ways to make sure that palliative care patients receive adequate pain and symptom relief and which drugs for pain management are best in terms of side-effects, such as drowsiness?		
B	What are the benefits, and best ways, of providing care in the patient's home and how can home care be maintained as long as possible? Does good co-ordination of services affect this?		
C	Are hospices, hospitals and care homes providing adequate staff training to deliver specialist palliative care, and to what extent does funding affect this? How can high quality trained staff be ensured no matter where the care is being delivered?		
D	What are the signs that a person will die in the next few days and how can detection of these signs be improved? How can families be made aware?		

Ref	Question	Your ranking (1-28)	Notes
E	What information and training do carers and families need to provide the best care for their loved one who is dying?		
F	How can patients, carers and families easily access care services, equipment and statutory welfare benefits? How can people learn what resources are available and limit the time it takes to access these?		
G	What are the benefits for patients, carers and families of day hospices and day therapies such as complementary therapies, rehabilitation and physical exercise? Do they help people stay more independent? When are the best times to refer palliative patients to these services and who benefits most?		
H	What are the benefits, and best ways, of ensuring patients, carers, families and friends are given privacy and not restricted in visiting hours when palliative care is given in a hospital, care home or hospice?		
I	What are the best ways to support children and young people when someone close to them is dying or has died? This includes communicating with them about the diagnosis and dying process, enabling them to talk about their experience and providing bereavement support.		
J	How can carers and families of people at the end of life be supported to communicate better with each other and their loved one?		
K	What are the best ways to diagnose and treat delirium, agitation, distress, and restlessness in people at the end of life?		
L	What are the best ways for healthcare professionals to tell patients, carers and families that a patient's illness is terminal and also explain the dying process compassionately and honestly? Can literature, including leaflets, be helpful? Who is the best person to provide this information and communication?		

Ref	Question	Your ranking (1-28)	Notes
M	What are the best ways to make sure there is continuity for patients at the end of life, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case-coordinator improve this process?		
N	Are outcomes (for example, symptom control and incidental prolonging of life) better for terminally ill patients the sooner palliative care is introduced and services are accessed?		
O	What are the best ways to recognise and treat depression, anxiety and low mood in people who are dying? What are the pros and cons of different psychotherapeutic interventions, including drug therapies, and when is the best time to provide them?		
P	What is the best way to give palliative care to patients with dementia and their carers and families? This includes communicating about their diagnosis when they are being cared for at home or elsewhere?		
Q	What are the benefits of, and best approaches to, providing palliative care in care homes, including symptom relief, emotional and spiritual support for patients, carers and families?		
R	What are the best ways of providing palliative care outside of 'working hours' to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families?		
S	How can we best determine a person's palliative care needs, particularly for patients with non-cancer diseases such as Motor Neurone Disease (MND), Parkinson's disease, Dementia and heart failure?		
T	What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients' preferences? Who should implement this and when?		
U	How can people who live alone and do not have friends or family nearby receive adequate palliative care, particularly if they wish to stay in their homes?		

Ref	Question	Your ranking (1-28)	Notes
V	What are the best approaches to providing pain relief for people who have communication difficulties, perhaps as a result of their disease such as Motor Neurone Disease (MND), dementia, brain tumour (including Glioblastoma) or head and neck cancer?		
W	What are the core palliative care services that should be provided no matter what the patients' diagnosis is?		
X	What are the benefits of increasing the number palliative clinical nurses/nurse specialists in hospitals, GP surgeries, nursing homes and other settings?		
Y	What are the best ways to begin and deliver palliative care for patients with non-cancer diseases (such as COPD, heart failure, MND, AIDS, multiple sclerosis, Crohn's disease and stroke)?		
Z	What are the best ways to assess and treat pain and discomfort in people at the end of life with advanced dementia, Parkinson's disease and other diseases that affect cognition and communication?		
AA	How can distress that is not related to pain be best assessed and managed in palliative patients with Dementia, Parkinson's disease and other diseases that affect communication?		
BB	What are the best ways to facilitate communication across services and between healthcare professionals, including effective IT systems, team meetings and remote technology?		

Appendix 3: Workshop Agenda



AIIHPC

All Ireland Institute of
Hospice and Palliative Care

Palliative and End of Life Research Priority Setting Project for Northern Ireland and Republic of Ireland Workshop Agenda

31st March 2015, Clarion Hotel, Liffey Valley, Dublin

Time	Topic	Facilitator(s)
9.30 – 10.00 am	Registration & refreshments	
10.00 – 10.30 am	Introduction	Katherine /Sonja
10.30 - 11.25 am	Commence priority setting: small group discussion	Cathleen / Katherine Sonja
11.25 - 11.40 am	Refreshments	
11.40 - 12.40 pm	Round 1: small group discussion	Cathleen / Katherine / Sonja
12.40 - 1.30 pm	Lunch	
1.30 - 1.45 pm	Plenary session: review of progress so far	Katherine
1.45 - 2.30 pm	Round 2: different small group discussion	Cathleen / Katherine / Sonja
2.30 - 2.45 pm	Refreshments	
2.45 - 3.30 pm	Final plenary	Katherine
3.30 - 4.00 pm	Summing up & next steps	Sonja

Appendix 4: Priority rating for the 83 questions

Priority rating for the 83 questions	No opinion		Very low priority		Low priority		High priority		Very high priority	
	n	%	n	%	n	%	n	%	n	%
How can patients, carers and families easily access care services, equipment and statutory welfare benefits? How can people learn what resources are available and limit the time it takes to access these?	2	2	-	-	32	29	44	39	33	30
How can the spiritual support needs of palliative care patients and their carers and families best be met in a way that is appropriate for people of different religions and people who are not religious?	8	7	5	5	34	31	42	39	20	18
How can palliative care information and services be made more accessible to people whose first language is not English?	10	9	3	3	28	26	54	50	13	12
How can access to palliative care services be improved for everyone regardless of where they are in the UK?	14	13	2	2	12	11	42	39	38	35
What are the best ways of providing palliative care outside of 'working hours' to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families?	2	2	-	-	7	7	36	33	63	58
What are the core palliative care services that should be provided no matter what the patients' diagnosis is?	1	1	2	2	14	13	41	38	50	46
What are the best models of palliative care in an acute setting, such as a hospital?	11	10	-	-	18	16	48	43	34	31
What are the benefits of, and best approaches to, providing palliative care in care homes, including symptom relief, emotional and spiritual support for patients, carers and families?	2	2	2	2	15	13	45	41	46	42

Priority rating for the 83 questions	No opinion		Very low priority		Low priority		High priority		Very high priority	
	n	%	n	%	n	%	n	%	n	%
What are the benefits for patients, carers and families of day hospices and day therapies such as complementary therapies, rehabilitation and physical exercise? Do they help people stay more independent? When are the best times to refer palliative patients to these services and who benefits most?	6	5	3	3	22	20	43	39	37	33
What are the best approaches to giving medicines, such as morphine, in a patient's home, for example using different cannulas such as BD-saf-T-intima? What are the pros and cons of training carers, families and non-palliative professionals, such as healthcare assistants, to give these medicines?	15	14	5	5	19	17	43	39	27	25
What are the benefits, and best ways, of providing care in the patient's home and how can home care be maintained as long as possible? Does good co-ordination of services affect this?	1	1	-	-	12	11	39	35	60	53
Are hospices, hospitals and care homes providing adequate staff training to deliver specialist palliative care, and to what extent does funding affect this? How can high quality trained staff be ensured no matter where the care is being delivered?	5	5	-	-	8	7	51	47	45	41
What are the benefits, and best ways, of ensuring patients, carers, families and friends are given privacy and not restricted in visiting hours when palliative care is given in a hospital, care home or hospice?	1	1	3	3	34	31	34	31	38	34
What are the pros and cons of receiving palliative care in different environments, including at home, in a hospice, hospital or care home? Are there certain people and conditions that each are best for?	7	6	-	-	19	18	51	47	31	29
Are some palliative care approaches better than others (e.g. holistic support, co-ordinated care, nurse-led care, early intervention) and for whom?	7	6	1	1	28	26	50	46	23	21

Priority rating for the 83 questions	No opinion		Very low priority		Low priority		High priority		Very high priority	
	n	%	n	%	n	%	n	%	n	%
When is it appropriate to receive care virtually (such as via Skype or video-phone calls)? What are the benefits and potential harms for patients, carers and families?	12	11	10	9	56	51	19	17	13	12
What are the benefits of occupational, beauty, diversion therapies (such as mindfulness, meditation, art, dance and gardening) for palliative care patients? How and where are these best provided?	4	4	8	7	30	28	45	41	22	20
What are the benefits of alternative therapies (such as homeopathy) or complementary therapies (such as acupuncture) for palliative care patients? How and where are these best provided?	8	7	10	9	46	42	32	30	13	12
When is the best time to introduce bereavement support, and for how long? Should it be offered before the death of a loved one? How can this support be catered to individual needs, including access to 24-hour support?	5	5	1	1	36	32	47	42	22	20
Should bereavement support be made available to all bereaved people and, if so, how? Should GPs or other professionals provide bereavement visits?	6	6	4	4	47	43	37	34	14	13
How can the risk of intense and long-lasting grief best be assessed and treated? Can this be prevented through early bereavement support?	7	6	3	3	32	29	51	47	16	15
What are the benefits of bereavement support, including preventing depression and other illness?	3	3	3	3	28	25	50	45	26	24
What are the benefits of all health and social care staff having training in bereavement awareness and support? Is this possible?	8	7	7	7	32	29	32	29	31	28
What are the best ways to make sure there is continuity for patients at the end of life, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case-coordinator improve this process?	2	1.8	3	2.7	17	15.5	49	44.5	39	35.5

Priority rating for the 83 questions	No opinion		Very low priority		Low priority		High priority		Very high priority	
	n	%	n	%	n	%	n	%	n	%
What are the best ways to facilitate communication across services and between healthcare professionals, including effective IT systems, team meetings and remote technology?	6	6			23	21	38	35	41	38
Since patients are often seen by a variety of professionals and services, would care improve if patients carried their own medical notes?	2	1.9	6	5.6	41	38.3	36	33.6	22	20.6
What are the benefits of increasing the number palliative clinical nurses/nurse specialists in hospitals, GP surgeries, nursing homes and other settings?	5	4.6	2	1.9	19	17.6	50	46.3	32	29.6
What are the best care packages for patients, carers, family and staff which combine health care and social care and take individual prognosis into consideration?	10	9	1	1	24	22	40	36	35	32
Who should be part of the care team (such as chaplains, occupational therapists, GPs, etc)?	3	3	6	6	36	33	36	33	28	2
Are outcomes (for example, symptom control and incidental prolonging of life) better for terminally ill patients the sooner palliative care is introduced and services are accessed?	9	8	1	1	15	14	50	45	35	32
Much palliative and end of life care is provided by charities. What are the benefits and risks of this and is it sustainable and efficient?	7	7	2	2	29	27	44	41	25	23
What are the best ways and times to meet the emotional support needs of patients, carers and families, including one-on-one peer support, support groups and professional counselling?	5	5	2	2	30	27	47	43	25	23

Priority rating for the 83 questions	No opinion		Very low priority		Low priority		High priority		Very high priority	
	n	%	n	%	n	%	n	%	n	%
What are the best ways for healthcare professionals to tell patients, carers and families that a patient's illness is terminal and also explain the dying process compassionately and honestly? Can literature, including leaflets, be helpful? Who is the best person to provide this information and communication?	2	2	2	2	21	19	35	31	51	46
How can carers and families of people at the end of life be supported to communicate better with each other and their loved one?	2	2	-	-	20	19	48	46	35	33
How can patients, carers and families be supported when the patient does not want their carers and families to know their prognosis?	8	7.4	2	1.9	37	34.3	39	36.1	22	20.4
What are the best approaches to providing pain relief for people who have communication difficulties, perhaps as a result of their disease such as Motor Neurone Disease (MND), dementia, brain tumour (including Glioblastoma) or head and neck cancer?	12	11	1	1	11	10	39	36	45	42
What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients' preferences? Who should implement this and when?	8	7	1	1	15	14	43	40	41	38
What is the best way to give palliative care to patients with dementia and their carers and families? This includes communicating about their diagnosis when they are being cared for at home or elsewhere?	11	10	-	-	10	9	50	46	38	35
What are the best ways to ensure that people with Motor Neurone Disease (MND) receive essential care promptly on diagnosis, when is the best stage to transition to palliative care and when should a "just in case kit" be considered?	17	16	3	3	16	15	47	43	25	23

Priority rating for the 83 questions	No opinion		Very low priority		Low priority		High priority		Very high priority	
	n	%	n	%	n	%	n	%	n	%
What are the best ways to begin and deliver palliative care for patients with non-cancer diseases (such as COPD, heart failure, MND, AIDS, multiple sclerosis, Crohn's disease and stroke)?	7	6	1	1	12	11	47	43	43	39
How can we best determine a person's palliative care needs, particularly for patients with non-cancer diseases such as Motor Neurone Disease (MND), Parkinson's disease, Dementia and heart failure?	6	6	2	2	9	8	49	46	40	38
Does earlier palliative intervention for patients with Chronic Obstructive Pulmonary Disease (COPD) improve quality of life? When is the right time to intervene to improve understanding of prognosis, exercise tolerance, overall progression and access to pulmonary rehabilitation?	23	21	2	2	25	23	42	38	18	16
Do people with various types of terminal cancer have different palliative care needs? If so, what are the best ways of managing their symptoms?	7	6	5	5	21	19	51	47	25	23
What information and training do carers and families need to provide the best care for their loved one who is dying?	-	-	2	2	12	11	52	48	43	39
Does respite for people caring for a family member or friend who is dying benefit the patient's care and the quality of life for both the patient and carer? What is the best way to provide respite?	4	4	5	5	30	27	45	40	27	24
Do people who are dying and their carers and families fare better if domestic support with shopping, washing up, laundry, etc, is provided?	9	8	6	6	48	45	35	32	10	9
Does practical advice for concerns about housing, finance and transport, etc, reduce anxiety for carers and families and increase their wellbeing?	6	6	1	1	26	24	50	47	24	22
How can carers and families be encouraged to seek support for themselves at the right time?	4	4	3	3	33	30	42	38	28	25

Priority rating for the 83 questions	No opinion		Very low priority		Low priority		High priority		Very high priority	
	n	%	n	%	n	%	n	%	n	%
What are the best approaches to support carers and families of people at the end of life where there are substance and/or alcohol addiction and/or domestic violence issues?	15	13.6	3	2.7	35	31.8	37	33.6	20	18.2
What are the best ways to support children and young people when someone close to them is dying or has died? This includes communicating with them about the diagnosis and dying process, enabling them to talk about their experience and providing bereavement support.	2	2	1	1	11	10	44	40	51	47
What are the best ways to manage the problems associated with difficulty in swallowing, including for patients with Parkinson's disease, Motor Neurone Disease (MND) and dementia who are at the end of their life?	12	11	1	1	8	7	54	50	33	31
What are the best ways to manage drooling and excessive salivation in patients with diseases such as Motor Neurone Disease (MND) who are approaching the end of their life?	12	11	2	2	31	28	47	43	18	16
What are the best ways to manage respiratory secretions (death rattle) in patients at the end of life?	18	17	3	3	26	24	42	39	19	17
What are the best ways to manage acute and/or chronic breathlessness in patients with cancer and non-cancer terminal illnesses?	12	11	-	-	16	14	45	41	37	34
What are the best ways to assess and treat pain and discomfort in people at the end of life with advanced dementia, Parkinson's disease and other diseases that affect cognition and communication?	8	7	-	-	6	6	50	47	43	40
What are the best ways to make sure that palliative care patients receive adequate pain and symptom relief and which drugs for pain management are best in terms of side-effects, such as drowsiness?	7	7	-	-	11	10	27	25	63	58
What are the pros and cons of withdrawing MST (morphine sulphate) in people at the end of life?	29	26	8	7	29	26	27	24	19	17

Priority rating for the 83 questions	No opinion		Very low priority		Low priority		High priority		Very high priority	
	n	%	n	%	n	%	n	%	n	%
Which sedative drugs (such as midazolam, haloperidol and levomepromazine) are most beneficial for managing agitation at the end of life and which are best in terms of side-effects? Do these drugs have an effect on other symptoms?	20	18	-	-	13	12	44	40	34	30
What are the best ways to diagnose and treat delirium, agitation, distress, and restlessness in people at the end of life?	10	9	-	-	14	13	44	40	42	38
How can distress that is not related to pain be best assessed and managed in palliative patients with Dementia, Parkinson's disease and other diseases that affect communication?	5	5	1	1	12	11	48	44	43	39
What are the benefits and limitations (physical, social, psychological) of providing artificial hydration and nutrition (for example, a drip) to patients at the end of life, including those with bowel obstruction? When should this be done?	16	14	2	2	26	23	46	42	21	19
What are the best ways of managing cachexia (weight loss) in palliative care patients, including people with cancer or Motor Neurone Disease (MND)?	12	11	1	1	30	27	52	47	16	14
Is it ever necessary to withdraw food and water (non-artificial hydration/nutrition)?	22	20.2	8	7.3	34	31.2	24	22	21	19.3
Is there an appropriate time to withdraw artificial hydration and nutrition (for example, a drip) and how can this be done sensitively and consensually? What is the best way to communicate with the carers and family about this process?	12	10.8	2	1.8	18	16.2	42	37.8	37	33.3
What is the best diet for palliative care patients? For example can maintaining a healthy weight and eating fatty or protein-rich foods have an impact on their disease progression?	9	8	6	6	36	33	43	40	15	14

Priority rating for the 83 questions	No opinion		Very low priority		Low priority		High priority		Very high priority	
	n	%	n	%	n	%	n	%	n	%
When should patients be (deeply) sedated? What are the benefits and limitations of sedation and what are the best ways of consulting patients, carers and families?	8	7.1	5	4.5	18	16.1	49	43.8	32	28.6
What are the best treatments for nausea and vomiting (including for people with bowel obstruction and those having palliative chemotherapy)?	14	13	1	1	12	11	40	36	43	39
How is incontinence best managed in people who are approaching the end of life (including those with Parkinson's disease)?	11	10	4	4	31	28	44	40	20	18
What are the best treatments for fluid retention in patients approaching the end of life?	24	22.2	8	7.4	28	25.9	37	34.3	11	10.2
What are the best ways to prevent blood clots, deep vein thrombosis and pulmonary embolism for patients at the end of life? What is the role of low molecular weight heparin (LMWH)?	28	25.7	5	4.6	37	33.9	26	23.9	13	11.9
How are steroids best used in palliative care (dose, duration, etc) for patients with different conditions, including those with brain tumours?	20	18	2	2	23	21	49	45	15	14
What are the benefits and limitations of chemotherapy and radiotherapy for patients approaching the end of life, including those with brain tumours? How can health care professionals best communicate this?	14	13	1	1	25	23	41	37	29	26
What are the best ways of managing constipation, including when caused by medication, such as opioids?	14	13	1	1	21	20	53	49	18	17
What are the benefits and limitations (physical, social, psychological) of blood transfusions at the end of life?	21	19	11	10	42	39	28	26	7	6
What are the best ways to recognise and treat depression, anxiety and low mood in people who are dying? What are the pros and cons of different psychotherapeutic interventions, including drug therapies, and when is the best time to provide them?	7	6	-	-	17	16	53	49	31	29

Priority rating for the 83 questions	No opinion		Very low priority		Low priority		High priority		Very high priority	
	n	%	n	%	n	%	n	%	n	%
What are the best models of palliative care for people who have learning difficulties?	11	10	3	3	22	20	50	46	23	21
What are the best models of palliative care for people who have mental health issues?	15	14	1	1	15	14	53	49	24	22
What are the best ways to treat dry mouth in patients at the end of life, including medications and foods, such as pineapple?	14	13	1	1	31	28	41	38	22	20
What are the benefits of setting up universal training courses for volunteers, carers, families and complementary therapists who have regular contact with palliative care patients?	3	3	2	2	39	35	44	40	22	20
Is there evidence that some volunteer services that provide support for patients, carers and families reduce the need for paid trained staff?	13	12	9	8	51	47	26	24	10	9
Do people at the end of life who receive support from volunteers, carers, family or friends, have better end of life experiences than those who do not?	9	8	7	6	34	31	35	32	25	23
How can people who live alone and do not have friends or family nearby receive adequate palliative care, particularly if they wish to stay in their homes?	1	1	1	1	13	12.4	34	32.4	56	53.3
What are the signs that a person will die in the next few days and how can detection of these signs be improved? How can families be made aware?	5	4.5	1	0.9	15	13.4	42	37.5	49	43.8

Appendix 5 Final ranking order of the 28 priorities

1. What are the best ways of providing palliative care outside of 'working hours' to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families?
2. What are the benefits, and best ways, of providing care in the patient's home and how can home care be maintained as long as possible? Does good co-ordination of services affect this?
3. What are the best ways to make sure that palliative care patients receive adequate pain and symptom relief and which drugs for pain management are best in terms of side-effects, such as drowsiness?
4. What are the best ways for healthcare professionals to tell patients, carers and families that a patient's illness is terminal and also explain the dying process compassionately and honestly? Can literature, including leaflets, be helpful? Who is the best person to provide this information and communication?
5. What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients' preferences? Who should implement this and when?
6. What are the best ways to make sure there is continuity for patients at the end of life, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case-coordinator improve this process?
7. What are the best ways to support children and young people when someone close to them is dying or has died? This includes communicating with them about the diagnosis and dying process, enabling them to talk about their experience and providing bereavement support.
8. What information and training do carers and families need to provide the best care for their loved one who is dying?
9. What are the best ways to begin and deliver palliative care for patients with non-cancer diseases (such as COPD, heart failure, MND, AIDS, multiple sclerosis, Crohn's disease and stroke)?
10. Are hospices, hospitals and care homes providing adequate staff training to deliver specialist palliative care, and to what extent does funding affect this? How can high quality trained staff be ensured no matter where the care is being delivered?
11. How can people who live alone and do not have friends or family nearby receive adequate palliative care, particularly if they wish to stay in their homes?
12. What are the core palliative care services that should be provided no matter what the patients' diagnosis is?
13. How can patients, carers and families easily access care services, equipment and statutory welfare benefits? How can people learn what resources are available and limit the time it takes to access these?
14. How can carers and families of people at the end of life be supported to communicate better with each other and their loved one?

15. What is the best way to give palliative care to patients with dementia and their carers and families? This includes communicating about their diagnosis when they are being cared for at home or elsewhere?
16. What are the benefits of, and best approaches to, providing palliative care in care homes, including symptom relief, emotional and spiritual support for patients, carers and families?
17. What are the best ways to assess and treat pain and discomfort in people at the end of life with advanced dementia, Parkinson's disease and other diseases that affect cognition and communication?
18. Are outcomes (for example, symptom control and incidental prolonging of life) better for terminally ill patients the sooner palliative care is introduced and services are accessed?
19. What are the signs that a person will die in the next few days and how can detection of these signs be improved? How can families be made aware?
20. How can we best determine a person's palliative care needs, particularly for patients with non-cancer diseases such as Motor Neurone Disease (MND), Parkinson's disease, Dementia and heart failure?
21. What are the best approaches to providing pain relief for people who have communication difficulties, perhaps as a result of their disease such as Motor Neurone Disease (MND), dementia, brain tumour (including Glioblastoma) or head and neck cancer?
22. What are the best ways to facilitate communication across services and between healthcare professionals, including effective IT systems, team meetings and remote technology?
23. How can distress that is not related to pain be best assessed and managed in palliative patients with Dementia, Parkinson's disease and other diseases that affect communication?
24. What are the best ways to diagnose and treat delirium, agitation, distress, and restlessness in people at the end of life?
25. What are the benefits for patients, carers and families of day hospices and day therapies such as complementary therapies, rehabilitation and physical exercise? Do they help people stay more independent? When are the best times to refer palliative patients to these services and who benefits most?
26. What are the best ways to recognise and treat depression, anxiety and low mood in people who are dying? What are the pros and cons of different psychotherapeutic interventions, including drug therapies, and when is the best time to provide them?
27. What are the benefits of increasing the number palliative clinical nurses/nurse specialists in hospitals, GP surgeries, nursing homes and other settings?
28. What are the benefits, and best ways, of ensuring patients, carers, families and friends are given privacy and not restricted in visiting hours when palliative care is given in a hospital, care home or hospice?