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Workshop Protocol

Identifying research themes for social sciences and humanities research into dying and palliative care: Secondary analysis of James Lind Alliance refresh

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Conflict of interest statement

The authors have no conflicts of interest to report

Background summary

The James Lind Alliance (JLA) is an initiative that brings patients, carers and clinicians together in Priority Setting Partnership (PSP) exercises to identify and prioritise research questions for a range of healthcare issues. In 2015 JLA and Marie Curie identified the [top research questions](#) for Palliative and End of Life Care (PEOLC) research. In 2023-24 they are undertaking a full 'refresh' of these research priorities, which includes a national survey and series of engagement events with public, clinicians and researchers. In 2015, the research priorities focused on care settings, access to care and care practices, training, and clinical outcomes. Whilst all useful to explore, these priorities were not immediately amenable to social science and/or humanities-oriented research, which is rich area of expertise for understanding and improving experiences of dying, palliative care and the aftermath.

Study aim, objective, and research questions

The aim of this project is to identify the issues for social sciences and humanities research into dying and palliative care.

The objective of this project is: Identify research themes for social sciences and the humanities.

The study research questions are:

1. What social science and humanities research issues can be identified in the data gathered by the JLA priority setting survey?
2. What social science and humanities research themes can be generated from these identified issues?
3. What exemplar research questions relevant to social science/humanities research can we identify for each theme?

Work we have undertaken so far: Secondary analysis and categorisation

The purpose of the initial coding was to make the data gathered by the JLA accessible to researchers from a wide variety of disciplines, whilst also preserving the integrity of the raw data as much as possible. The 1,032 responses received by the JLA were read and re-read by the research team (MG, JM, EB, BH), and were then subject to an initial coding using NVivo for issues relevant to any social science or humanities discipline. The initial codes were discussed and code names streamlined by the team, but further groupings were deliberately not undertaken, to avoid over analysis or the prioritising of the disciplinary backgrounds of the project team. This resulted in 37 relevant codes being produced. We also provided a short description of each issue, alongside exemplar quotes taken from the survey. For example, the code "home" might be accompanied by the quote, "How to make people who are cared at home at their families feel safe?" (see Appendix A).

Workshop aim and objectives

1. The aim of the workshop is to identify research themes and questions for social sciences and humanities research into dying, palliative care and the aftermath

based on the issues identified by the people affected by serious life-limiting illnesses in the JLA Survey.

To do this our objectives are:

1. Group issues from the JLA survey responses that can be related to each other as themes needing further research, and then name and describe these themes.
2. Provide contextualisation from the social sciences and/or humanities to what the ongoing or future research issues may be for the grouped issues.

Method

Design

We have taken the Evidence Café approach (Clough and Adams, 2017) as our starting point of our collaboration, bringing together research producers and users. The main activity in our event involves the co-production of analytical categories and their descriptions. We have modified the Evidence Cafe format to meet the needs of our task and the practicalities of our group.

Ethics

The workshop has received ethical approval on 8 April 2024 from The Open University Human Research Ethics Committee (Ref 2024-0397-2).

All discussions will be video recorded to ensure all issues and perspectives are documented. Any quotes used in publications will be pseudonymised.

Recruitment and participants

Securing the input of a wide range of social science and humanities researchers from a variety of disciplines will be crucial to the success of the project. We therefore undertook a multi-stranded strategy to identify UK-based social science and humanities experts in the field of death and dying was employed. This included using the mailing lists for the Association for the Study of Death and Society (ASDS), the British Sociological Association (BSA) Death, Dying and Bereavement, and the Social Science and End of Life Care email list, as well as snowball recruitment through the project teams and advisory group's networks of contacts. The researchers also identified individuals from relevant successful applications over the last five years to two Research Councils who have funded social science or humanities research in this area, the Economic and Social Research Council (ESRC) and the Arts and Humanities Research Council (AHRC).

Once a shortlist of relevant academics is compiled, we will send an email inviting potential participants to come to the workshop. The email will explain the purpose of the project and include a request to complete a short background questionnaire, if they are interested in attending. The purpose of the questionnaire is to help ensure we can purposefully invite a maximum variation sample i.e. so that we have a range of academic disciplines and career stages represented, from early career researchers to emeritus professors, as well as

ensuring we understand the demographic background of those who have attended. Demographic data and protected characteristics will not be used to determine if someone is invited. They will also be asked to return their consent form before the start of the workshop.

Those who agree to take part will be sent further information about the workshop timings, as well as a document containing the 37 codes with short descriptions and examples of data which has been ascribed to the code (see Appendix A).

Inclusion criteria are:

- Currently based at an academic at a UK HE institution (any contract) or independent scholars.
 - Self-described as working within a social science and/or humanities discipline or approach.
 - Ongoing research interest in dying, palliative care, or the aftermath.
- Representatives from UK bodies that fund research into social science and humanities research into dying, palliative care and the aftermath e.g. UKRI ESRC and AHRC, Marie Curie etc.

Exclusion criteria are:

- Undergraduate Students or on Taught courses.
- Researchers employed by Think Tanks, Market Research, or other third sector organisations.
- Researchers whose work prioritises a clinical approach or medicalised framing of dying, palliative care or the aftermath.

We will seek a sample of n=25 participants.

Data collection

The workshop will be held online on MS Teams. It is expected to last four hours, including breaks (see Appendix B: Timetable).

Phase One: Identify, name and group

Objective: Group issues from the JLA survey responses that can be related to each other as themes needing further research, and then name and describe these themes.

Ahead of the workshop we sent the participants the list of 37 descriptive codes, each with a short description. These descriptive codes are intended to help participants understand what is contained within the JLA survey responses, without having to read all of them.

However, many of the codes are similar and will generate more meaningful research issues when understood in relation to each other.

PART A: Allocating topics into five or six buckets

To help us organise the codes into more manageable groupings we would like our workshop participants to collate these codes together into “bucket” categories and provide a label that helps make sense of them. The bucket grouping and label can draw on the participant’s (inter)disciplinary background.

The activity will involve allocating each participant (including research team and facilitators) with one of the 37 codes. They will then be asked, in turn, to add their code into a bucket, while explaining their rationale. For example, a human geographer might add “home” to a bucket already containing “hospital” and “hospice”, explaining they are “locations of care and dying”. We will continue this activity until all issues have been added to buckets.

At the halfway point we will ask those participants who have submitted their code to a bucket if they would like to move it, in response to how other ‘buckets’ have developed. We will repeat this review at the end of the activity.

PART B: Review, name and describe the buckets

We will allocate the participants to one of five or six groups (depending upon the number of bucket themes identified). One or two members of the study team will facilitate each group to keep the participants on topic, manage timekeeping, and make notes.

In breakout rooms these smaller groups will discuss the contents of the bucket, deciding as a group whether they represent one theme or multiple themes. Participants will then asked to name at least one theme, and define their theme in 1-2 sentences.

PART C: Group feedback and discussion

In the main group each facilitator will share the name and description of their ‘bucket’. Participants will have the opportunity to comment in the Teams chat any thoughts or feedback they have. If any group feels a code might be better located in another bucket, this would be the time to share and discuss that.

Phase two: Contextualise the research issues

Objective: Provide contextualisation from the social sciences and/or humanities to what the ongoing or future research issues may be for the grouped issues.

In this phase of the workshop, we will seek to identify as many open, ongoing or potential future research issues for the social sciences and humanities.

PART A: Individual description of theme from a disciplinary perspective

Participants will be asked to return to their breakout room with their group. They will first be asked if, having heard how other groups named their theme, if they wish to refine the name and descriptor arrived at in the earlier exercise.

They will then be asked to discuss any potential research issues they are aware of for their theme. They will be asked to keep notes of their conversations, to share with the wider group later (Part C).

The participants will be asked to start by reflecting on their allocated theme in relation to their own research approach and interests. They will be free to use as much disciplinary, methodological, and/or technical language as they feel is necessary. The purpose is to share an understanding of the issue from their research perspective and drawing on their expertise.

PART B: Group discussion and identification of issues for future research and exemplar questions

Leading on from this discussion, participants will be asked to explain what they see as any ongoing or future research issues or questions that may need investigation. They will be asked to note all potential issues, with any caveats they may have e.g. “may need a literature review to establish just how much research there is on this issue”.

For example, a sociologist may suggest that the group of issues labelled “locations of care and dying” needs further work to problematise the ideal of “home” as the best place to die; that further research is needed to explore issues around socio-economic disparities of homes as suitable places; question the norms of homes as “safe” spaces; or, relate ideas of space to the gendered political-economy involved in (compassionate) communities of care. From this discussion, participants will produce a list of potential exemplar questions.

In the last 15 minutes of the breakout group, participants will be asked to share any research issues they may be aware of from outside of their expertise, methodological comfort-zone, or discipline. For example, “I believe health-economists may be exploring just what the cost savings are when ‘dying at home’ is properly resourced”.

PART C: Large group discussion

For the final session of the workshop we ask the participants to return to one large group to share their reflections on their theme, and a few exemplar questions. The other participants will be asked to provide any comments or reflections. The “chat” function will also be open to any comments, references or resources participants want to share.

WORKSHOP CLOSE

Participants will be reminded that the workshop was recorded and will be provided with a last opportunity for any brief comments, before being thanked for their attendance and contributions.

A short evaluation survey will be distributed at the end of the workshop. This will collect participants reflections upon on how it was to be involved, recognising that this is the first time the JLA Survey data has been used to generate research themes outside of a clinical context. This survey will also provide participants with the opportunity to add any further reflections on the themes they may have. At this stage, participants will also be offered the option to be named in the project report and/or be involved in future dissemination activities.

Analysis, outputs and dissemination

The theme names and descriptors produced within the workshop sessions will be collated and standardised by the study team, ensuring that each theme stands alone, but noting where there are any connections with other themes.

The exemplar questions produced will be refined by the Advisory Group, ensuring that the voices of both academics and PPI members contribute to the selection of questions. We will endeavour to provide similar numbers of exemplar questions for each theme.

We will generate a report to be published alongside the main JLA Priorities and made publicly available on Marie Curie's website.

Will share findings via a webinar. This will include a discussion of the issues as well as outline the process (as detailed in this protocol) for generating these issues and exemplar questions.

Afterword

Having conducted the workshop and drafted the report we wish to note two amendments.

First, we changed our terminology from identifying 'research themes' to 'research areas'. This is to disambiguate our approach from thematic research methods.

Second, we have not provided examples of research questions in our report. It became evident during discussions at the workshop and with Advisory Group members that generating and providing good quality research questions across multiple topics for a range of disciplines, even as examples, was unfortunately not feasible with the time and resources we had available. That is, we recognise that research questions and project design are situated in the contexts in which they are developed and will inevitably need to reflect, amongst many things: the funding call; the researcher(s)'s expertise; the wider collaborative and project environment including additional patient, public, carer or professional insights; and, be methodologically consistent connecting questions to data collection and analysis.

References

Clough G, Adams A. Evidence Cafes: A how-to guide. 61637, The Open University, <https://oro.open.ac.uk/61637/> (2017, accessed 6 November 2023).

Appendix A

JLA research suggestions for palliative and end of life care

Initial codes and descriptions for social sciences and humanities workshop

The [JLA Palliative and End of Life Care Priority Setting Partnership \(PEoLCPSP\) refresh in 2024](#) (run by Marie Curie) collected just over 1,000 responses to their survey. Survey participants included people living with a serious life-limiting illness (or caring for someone who is), bereaved carers/family/friends, health and social care professionals, volunteers supporting people with serious life-limiting illnesses, and members of the public.

We conducted an initial categorisation of the free-text survey responses, using NVivo to code them at ‘issue’ level. This has produced 37 initial codes, which are shown in the table below. We have created a short description of each issue, alongside exemplar unedited quotes from the survey data.

In the workshop, we discussed these codes, identifying potential groupings of the codes into wider categories, and discussed issues and exemplar questions that social science or humanities disciplines could investigate in relation to these categories.

Terminology

HCP	Health or care professional
P/EOLC	Palliative or end of life care
Patients and service users	We recognise that patient is not always an accurate term to describe those receiving non-medical palliative or end of life care. Our decision to use this term is influenced both by the data, where ‘patient’ is widely used, and to enable use to distinguish from ‘service users’ who are family or friends of those who are dying who are also accessing palliative care services (e.g. counselling).
MDT	Multidisciplinary Team
CNS	Clinical Nurse Specialist
GP	General Practitioner
HCA	Healthcare Assistant

Code		Description	Quotes
1	Communicating information	Discusses how information is communicated between patient/relatives and HCPs	<p>More openness and honesty between patients, families and carers and professionals.</p> <p>More information as to where to get aids to help the patient.</p> <p>There's little known about bone metastases. Consultants can't answer any questions on what you and can't do physically.</p> <p>In my experience communication with relatives and carers is so important and isn't always great. My husband had throat cancer and spent six weeks in an NHS hospital before being transferred to a hospice. It was immensely difficult juggling work, a young family, and visits and getting to talk to anyone about his care and plans was nigh impossible. I remember finally chatting to the MDT and they said "we have a plan" and I replied "how about you share it with me as the primary carer". Once he was transferred to the hospice it was so much easier. So, for me, clear communication with relatives and carers is absolutely key to improving the experience of the patient and relatives / carers at the end of life.</p>
2	Disjointed communication and/or services	Describes service conflicts or communication difficulties between different sectors of P/EOLC services	<p>Disjointed Care - Differing advice from Hospice CNS, Oncology CNS, GP, District Nurses</p> <p>how can information be shared across services. it is exhausting having to repeat information time and time again. Given our advances in technology, surely it must be possible for everyone involved in my care to have up to date information about whats going on.</p> <p>A single point of contact for all support needs - financial (benefits, welfare, grants, etc); occupational therapy (equipment like hoists, commodes, etc); care packages (home care); etc. There were so many different people that we had to reach out to, it was very confusing and added a lot of admin in an extremely stressful time. It also needs to happen quicker, particularly for people with a very short prognosis.</p>
3	Continence	Discusses continence and incontinence in P/EOLC	<p>Recommendations re incontinence problems and management of proactively to prevent urine and faecal scald and infected skin. Pain relief for skin infections/scald. Training of staff to recognise fistulas and understand importance of proactive care and counselling of patient as very distressing for them to experience and may not understand themselves. Also ensure doctors check this as a possibility when treating diarrhoea and examine or take adequate history as to where faeces/urine is passing. Recognise proactively consequences of this type of incontinence and alert staff.</p>

4	Withdrawal of care	Describes the difficulties of stopping types of care	<p>My father was on end of life care and was withdrawn from medication, food and water. I sadened me watching him die. It was very hot at the time and i asked could i get him an ice lolly. Reluctantly they agreed. My poop dad devoured thos he must have been so thirsty. They said unconscious.</p> <p>Dont let the end of life be so cruel</p>
5	Awareness and acceptance of dying in healthcare	HCPs reluctance to discuss P/EOLC	<p>Why health professionals are so blind to see dying.</p>
6	Care roles	Questions about who should do what, when	<p>Should not have to wait for a District nurse for break though medication why can't HCAs be trained to give injections</p> <p>The staff are the best, the compassion and care they give was greatly appreciated</p> <p>Some hospices allow only 1 family member to stay overnight at the hospices, whilst others allow 2. Needs consistency and at least 2 family members should be allowed to stay overnight with their loved in all hospices.</p> <p>When my dad was terminally ill, my mother found it difficult to focus on anything other than his terrible illness, the medication and hospital visits.. life became all consuming on the bleakness and stress for her, which consequently was mirrored then in the support and environment around my dad. I think the gap was no one reaching out to say to her, yes this is awful, but here's how you can help reduce the stress, create happier memories and times of comforting distraction. In addition, probably a generational thing, but both my parents seemed terrified of troubling doctors as they didn't want to be a burden.. this meant they underplayed serious issues which ultimately resulted in delayed treatment and prolonged suffering.</p>
7	Decision making	How people receiving P/EOLC make decisions	<p>Exploration of the psychological aspects of dealing with this decision. Why do some people "give in" and some don't are there ways of supporting those people and creating an appreciation of this stage of life rather than just waiting to die</p>

8	Differences between palliative and EOLC	Exploring differences between EOLC and palliative care	<p>How to integrate End of Life care in through palliative care. Often people see these as the same things, but they are distinct and different - yet I can't find any research into how those of us currently in palliative care would like to see end of life care developed for our own needs/circumstances - or for those supporting our care currently (family, friends, other health care providers)</p> <p>Transition care from palliative to end of life</p>
9	Education for public	Calls for general or specific education around P/EOLC or death and dying for patients, family, friends or the general public	<p>More research on how best to educate the public about normal dying and the importance of anticipatory care planning, death literacy and dispelling myths about palliative care.</p> <p>More education on the difference between palliative and end of life. Education for everyone on what Dying looks like. Improved information for families on what JIC medications are and how they are used. Often as a Nurse families insist you give medication even when there is no clinical need just because they are uncomfortable</p> <p>Improved understanding of the trajectory of end of life for people with dementia. Impact of cancer treatments (especially chemo) on all organs of the body and the increased risk of premature death.</p>
10	Education for HCPs	Calls for general or specific education around P/EOLC for HCPs	<p>Investigating the best training for healthcare providers on early approach to palliative care</p> <p>More education delivered to registered nurses to recognise when patients are entering the end of life stage. More education on delivering 'bad news' to patients and to their families. More education on how to ensure patients and their families are receiving high effective end of life care</p>
11	Assisted Dying	Calls for assisted dying or assisted suicide to be legalised or otherwise made available	<p>When I had anxiety, I was prescribed some medication from the GP. I never needed to take the medication, but knowing it was available if I did need it was tremendously helpful. Similarly, when I am reaching the end of my life, I would like to have the option of ending my life at a time of my choosing. I may not take up that option, but I would like it to be there. I think it is inevitable that this option will happen at some point. I would therefore like some really excellent research now to prepare for this. I, and many others, see assisted dying as a component of end of life care, but others do not. Perhaps this could be a starting point for the research.</p> <p>From my own personal experiences losing both parents in the most horrific way..... I</p>

			<p>wholeheartedly believe, end of life options should be given to those sound of mind.</p> <p>End of life options should also be available for patients in a vegetative state or unable to verbally communicate, etc. obviously this would require next of kin involvement</p>
1 2	Forward planning	How patients, families and HCPs planning for EOL or palliative care can be supported/can happen better	<p>The need for advanced care planning to be integrated into the work that all health and social care professionals do with people with limiting illnesses at an earlier stage.</p> <p>When delivering a bed to a patients home. When they've been sent home on palliative care. Make sure a commode is delivered at the same time, not 2 days later.</p> <p>I feel really concerned about the care of people with dementia. The biggest killer in uk . There is no advanced care planning , no support for families and sadly often the person is sectioned (often involving police) for a proper assessment to meet the person and families needs . More care in the home particularly night care might enable carers to cope better and enable the person to be cared for at home .</p>
1 3	Place of death	General questions comparing places of death	<p>whether people are dying in their preferred place of death.</p> <p>If early intervention of palliative care makes difference to outcomes</p> <p>Cost-effectiveness of specialist support in different settings, e.g. hospital inpatient/outpatient, hospice inpatient/outpatient/daycare, other community settings, home</p> <p>-Models to provide a combination of basic/general support and specialist support/support to those with complex needs at a population level so that there is appropriate access to end-of-life care for everyone, just as there is access to antenatal care for every pregnant woman</p> <p>Options for patient - hospital, care at home, hospice</p>
1 4	Hospital	Questions about P/EOLC in hospitals	<p>In my experience communication with relatives and carers is so important and isn't always great. My husband had throat cancer and spent six weeks in an NHS hospital before being transferred to a hospice. It was immensely difficult juggling work, a young family, and visits and getting to talk to anyone about his care and plans was nigh impossible. I remember finally chatting to the MDT and they said "we have a plan" and I replied "how about you share it with me as the primary carer". Once he was transferred to the hospice it was so much easier. So, for me, clear communication with relatives and carers is absolutely key to improving the experience of the patient and relatives / carers at the end of life.</p>

			NHS in my opinion does not offer the level of support & understanding that Hospices & Charities do. They need better training & resources.
1 5	Care home	Questions about P/EOLC in Care Homes	More research on the palliative care needs of people living and dying in care homes who are 85+, have multimorbidity and dementia and the skills, resources and systems that are required to meet these needs effectively and equitably. What are the criteria for specialist palliative care input for the care home population? What percentage of people dying in care homes need specialist palliative care input and what percentage receive specialist palliative care input when it is needed? What are the medication needs of people at the end of life in care homes e.g. care homes cannot legally hold a stock of drugs including morphine but to what extent is this a problem? When JIC meds are prescribed, are they used or is there a lot of wastage? More research on who is (or should be) responsible for funding palliative care in care homes, including equipment. Also more research, or putting into practice research that has already been done, on how best to equip, empower and sustain the care home workforce and the social care workforce who support people dying at home. More research on the extent to which undergraduate curricula in all health and social care disciplines include palliative care in all settings and
1 6	Hospice	Questions or comments about P/EOLC in hospices	Accessing hospice care and support. How to fund hospice care
1 7	Home	Questions about P/EOLC at home	Better pain management from home, when your loved one doesn't wish to be in a hospice. I was trained to use a PICC line to feed my husband and give him fluids, but he was at times in excruciating pain waiting for district nurses to turn up to administer opioid pain relief. I had it right there and could have given it to him safely to save his screaming pain, but it is against the law. So much suffering for no good reason The length of time you can be waiting for pain relief if dying at home. We waited for hours with my dad only to then have the nurse refuse to give what he was written up for. Resulted in us having to film him the next time he was in pain for fear of not being helped. Promised him he wouldn't be in pain. Massively traumatic I would like to see more overnight respite for families, xxx sit with tge patient and it allows family to sleep and allows patients to spend there last months,weeks or days in there own home

			option for more care at home . limited sources in community . should be hospice like support at home
18	General inequalities	Undefined inequalities	<p>Inequities in access and provision of palliative care</p> <p>1. Inclusion and acknowledgment of the diversity of our community that ALL should have access to EOLC- homeless, learning disability and deprived communities are just some examples.</p> <p>2. Improving access for ALL to 24hr palliative care support that is consistent and UK wide.</p>
19	Age inequality	Age-based inequalities in P/EOLC	<p>To me it seems that access to palliative care is inequitable. Both my mother and mother-in-law died with dementia, but neither woman received, or was offered, specialist care of any kind. One was in her 80s, the other in her 90s. I have talked to many people and the impression I get is that age can be a barrier to receiving palliative care.</p>
20	Ethnicity or language inequalities	Ethnicity or language-based inequalities in P/EOLC	<p>Health inequalities for ethnically diverse families - specifically including after death care processing for Muslim families</p> <p>those where english isn't a first language and those people who are of different faiths - what are their health beliefs around death and dying? is there any support for staff having conversations with diverse populations</p> <p>I have continued to see preferential treatment in Hospices where people or families who are able to advocate for themselves get an improved service when compared to someone who is less likely or unable to challenge the medical model. This has happened in my experience with someone who had a tracheostomy, someone from the Roma-Gypsy Traveller Community and someone who followed the Muslim faith. Not all Hospices have family support or social work professionals as part of their MDT and I think this is a missing perspective.</p>
21	Financial inequality	Inequalities faced by those in different financial situations, and the financial inequality created by providing P/EOLC	<p>The huge impact of caring for people with life limiting illnesses on informal, unpaid carers (often partners and family members), which often results in exhaustion and burn out as well as having a significant financial impact on many.</p> <p>Link between poverty and life limiting conditions And up take in service provision</p> <p>A functioning health service</p>

			<p>Financial support to help in accessing health services. Policy change to make life limiting illness treatment subsidized</p> <p>Support to all involved more resources so charity can give adequate support</p>
2 2	Learning disability inequalities	Differences in needs/inequalities faced by people with learning disabilities accessing P/EOLC	Community and hospice options and support required for people with learning disabilities at the end of their life.
2 3	Geographical inequalities	Comments about rural versus urban inequality of P/EOLC, or references to postcode lotteries	<p>identify areas (regions) where Palliative and End of Life Care is being delivered most effectively and how these can be implemented across</p> <p>Lack of palliative care services in remote & rural parts of UK Local teams being disempowered to deliver care by the specialist - palliative care should be in the skill set</p>
2 4	Mental health and substance misuse and P/EOLC	The difficulties faced by those with pre-existing substance misuse and their families when accessing P/EOLC	<p>Understanding and acknowledgement of the stigma families carry when a relative has co-existing substance use/mental health problems. Supporting them and their grieving process.</p> <p>Outreach to people who are insecurely housed and who may be using substances and/or mh problems</p> <p>how to deal with EOL medications for someone already addicted to either drugs or alcohol, how does it affect the medications normally</p>
2 5	Cancer v non-cancer	Questions about the perceived lack of aspects of P/EOLC without a cancer diagnosis	<p>Access for patients with non-cancer diagnoses, eg lower limb ischaemia - Pathways to access good symptom relief for pain, dressings for wounds based on good evidence. Psychological support for patients with non-cancer diagnoses</p> <p>Access to hospice services for people who don't have cancer - particularly inpatient services</p> <p>My mother is living with a life limiting condition not cancer and on discharge from hospital was given very little support from any services. I see people with a diagnosis of cancer receiving lots of support and feel this needs explored in other areas for peopl living with life limiting conditions</p>

2 6	Pain	Questions or comments about pain and pain management	<p>Planning and knowing my end will be managed in terms of pain and emotional support</p> <p>The length of time you can be waiting for pain relief if dying at home. We waited for hours with my dad only to then have the nurse refuse to give what he was written up for. Resulted in us having to film him the next time he was in pain for fear of not being helped. Promised him he wouldn't be in pain. Massively traumatic</p> <p>Pain management regarding end of life care</p>
2 7	Support for carers/family	Suggestions that unpaid carers or close family members need additional support	<p>Physical and social support for close family members</p> <p>Psychological support early in the process</p> <p>Our experience was excellent, the care our loved one received and the support given to the family could not have been better. Wakefield Hospice is a place of calm and reflection.</p> <p>Time to talk to carers</p> <p>Building knowledge and awareness for family and friends about symptoms of actively dying. As this can be frightening for people they don't always know what's "normal" or to be expected</p> <p>There is quite a lot of support available if you know how to find it. A carer can feel very alone when there is a crisis. You are responsible but you have no idea where to turn. It would really help if there was one allocated contact who could help find and coordinate</p>
2 8	Support for HCPs	Suggestions that HCPs and paid carers need additional support	<p>We were promised support, but never got it. Our local palliative care team were too busy. So I would say supporting the Palliative Care teams - making finance available, so that there are more trained staff.</p> <p>I think more research needs to be done into the coping strategies of the doctors and nurses who work with palliative patients</p>
2 9	Support for patient	Suggestions that those who are receiving P/EOLC	<p>Psychological support for patients receiving palliative and end-of-life care at home.</p> <p>As you know it's a difficult question to answer to chose one aspect as each person is different. From my experience with my brothers last few months in hospice care it is the whole person</p>

		need additional support	<p>that is important and not just one aspect.</p> <p>I don't think my dad received the psychological support he needed to come to terms with what was happening to him. I think looking into the ways professionals and family members can support those with terminal illnesses and conveying that information in a comprehensible and actionable way would be beneficial. A lot of the ways family members are told to support maybe does not go far enough</p> <p>The physical, psychological and social support that my father received from the xxxxxxx charity was appalling and I was deeply distressed at how he was treated in the last 2 weeks of his life. When I voiced my concerns I was told that it was 'standard practice', but I felt that it was an awful way to treat a human being. So, I guess you could say that I feel there is a great deal that needs to be done.</p>
30	Paediatric palliative care	Specific suggestions for sibling support when a child is receiving P/EOLC	Psychological support for the unwell child but also the siblings. Siblings need an increased level of support both before and after the death of the unwell child.
31	Spiritual support	Suggestions for greater spiritual support for patients and carers	<p>Spiritual help should also be offered and inquired about as this is very poorly done now - in the past it was important and still is important to lots of people but secular society has encouraged ignoring of this aspect of care - which discriminates against those who wish spiritual support</p> <p>more training on spiritual support for patient and family</p> <p>Spiritual support is rarely touched on. It tends to be assumed that most people have no faith.</p>
32	Symptom management	Questions relating to the management of specific or general symptoms experienced during P/EOLC	Evidence for symptom control is so poor - this is an ongoing issues but trying to undertake studies in this is so challenging; RCTs may just not be feasible; but even starting to establish large data-bases of clinical practice on a national level could help understanding and practice.
33	Tension between	Suggestions about situations where the needs of a	Advice and assistance on how to get your affairs in order and the repercussions on family if this is not in place.

	patient and family	patient and the needs of their family may not align	<p>Increasing focus on bereavement at the expense of psychosocial care.</p> <p>meeting the needs of carers and supporting those who care for each other - both partners have care needs met by the other</p>
3 4	Lone patients	Situations where a patient may not have family or friends available to provide care	<p>What support / assistance is available to people who have no close family to help and guide through practical matters like managing finances, preparing for own funeral emptying property</p> <p>How to best support people who have no family.</p>
3 5	Timing	Questions about when P/EOLC should begin	<p>The difficulty identifying when palliative care should begin. I have found that there is difficulty and hesitancy in identifying when palliative care/ and comfort care should begin.</p> <p>Research into understanding when on the pathway introducing palliative care is the most effective and useful. I think much earlier than we do!</p>
3 6	Life pro-longing treatment versus comfort	Questions about what P/EOLC should prioritise	<p>There is too much emphasis on treatment and less on comfort care which is having a negative impact on the dying process. I feel people are generally not dying peacefully.</p> <p>I feel like a lot of hospices now focus on prolonging end of life instead of comfort. If that is what the patient wants then that is fine but if not then that should also be fine instead of pushing IV antibiotics and fluids onto them</p> <p>To reduce the number of unnecessary investigations people go through when admitted to hospital at the end of life</p>
3 7	Lifestyle as treatment/care	Questions about lifestyle changes as part of P/EOLC	<p>access to aerobic exercise; there is always hope and our endocannabinoid system is ever ready to rebalance systems.</p> <p>oxygen management that ensures cutting edge treatment and razor sharp management including free electricity bills, to ensure gentle times for the person requiring this.</p> <p>Provision of occupational therapy in palliative and end of life care, the impact of hospices and difference it can make, transition of care</p> <p>Use of Cognitive Behaviour Therapy in hospice day centres</p>

Appendix B
Workshop Outline (indicative timings)

9.30 - 10.00	Welcome, introductions to the research team and facilitators, and outline for the session. Including overview of the JLA process and purposes
10.00 - 10.30	1A: Allocating topics into five or six buckets
10.30 - 10:50	1B: Breakout rooms - Review, name and describe the buckets
10:50 - 11.10	1C: Group feedback and discussion Set up the next activity
11:10 - 11.25	Comfort break
11.25 - 11.50	2A: Breakout rooms - Individual description of theme from a disciplinary perspective
11.50 - 12.30	2B: Breakout rooms - Group discussion and identification of issues for future research and exemplar questions
12:30 - 12.45	Comfort break
12.45- 13.15	2C: Large group discussion
13:15-13:30	Thanks and close