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Research participation in palliative medicine—benefits and barriers for patients and families: rapid review and thematic synthesis

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► Additional supplemental material is published online only. To view, please visit the journal online (<http://dx.doi.org/10.1136/bmjspcare-2021-003093>).

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Received 1 April 2021

Accepted 16 June 2021

Published Online First

17 August 2021



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To cite: Chatland LE, Harvey C, Kelly K, et al. *BMJ Supportive & Palliative Care* 2023;**13**:35–44.

ABSTRACT

Background Research is essential for gathering evidence to inform best practice and clinical decision making, for developing and testing new treatments and services in palliative and end-of-life care (PEoLC). The participation of patients, carers and family members is essential, however, personal and ethical concerns are often cited by professionals as barriers to recruitment. There is evidence that patients and family members can benefit from participation in PEoLC research.

Aim To synthesise the evidence regarding patients', family members' and carers' experiences of participating in PEoLC research. To identify recommendations for enhancing the experience of participants.

Design A qualitative rapid review and thematic synthesis.

Data sources MEDLINE, PsycINFO and PubMed were searched from 2010 to 2020. Studies reporting patients', family members' or carers' experiences of participating in PEoLC research were included.

Results 4 studies were included and 7 themes identified relating to the benefits of, and barriers to, participation in PEoLC research. Both altruistic and personal benefits of participation were reported. Barriers (negative aspects) to participation included feeling overwhelmed, practical issues, reminders of being a patient, not seeing the research as relevant to them and unmet needs.

Conclusions A number of benefits (positive aspects) surround participation in PEoLC research. However, several barriers (negative aspects) can prevent or discourage participation. This review has identified recommendations for research teams to enhance the experience, and number of people who those participating in research in this field.

Key messages

What was already known?

⇒ Recruitment to palliative and end-of-life care (PEoLC) research is challenged by factors including ethical considerations, characteristics of the population and potential gatekeeping. There is limited evidence of the experience of participation from the perspective of patients and their family or carers.

What are the new findings?

⇒ A summary of the experience of participation in PEoLC research. An overview of the perceived benefits (positive aspects—altruism and benefits for themselves) and barriers (negative aspects—feeling overwhelmed by the situation, participation not being seen as relevant, practical barriers, reminded of being a patient and unmet needs).
⇒ This paper highlights the paucity of research into patient and family members experience of participating in PEoLC. This evidence is needed to ensure that research in this area is designed with the patient at its heart and to minimise burden on participants.

What is their significance?

Clinical

⇒ An enhanced experience of participation has the potential to increase the number of people engaging in research at the end of life, potentially reduce research attrition rates and ultimately improve future PEoLC services and intervention.

Research

⇒ Recommendations for research teams conducting PEoLC research are provided which could lead to improved engagement and experience of participants research and could assist in the design of future research.

INTRODUCTION

Research is essential for the gathering of evidence needed to inform best practice and clinical decision making, and to develop and evaluate new treatments and services.¹ For palliative end-of-life care (PEoLC) research, the participation of patients, carers and family members ensures the research provides meaningful insights into living with a terminal illness and opportunities for new treatments and interventions to be developed and evaluated. Yet, there can be resistance from individuals, including healthcare professionals,² to discuss and invite research participation as assumptions are held about patient and family members' vulnerability and associated burdens towards the end of life.³ The practical and ethical obstacles to research participation have been documented in the literature.⁴ Particular barriers include issues with gaining consent, additional burdens on patients and families (including distress and anxiety) and equipoise between care and research needs.⁴⁻⁶

However, the benefits of research participation have also been evidenced,^{7,8} including with vulnerable populations.⁹ Gaining a balanced and nuanced understanding of how adult patients, carers and family members *actually* feel about taking part in a research study at the end of life is important. Providing researchers with a better understanding of an individual's research experience could lead to enhanced patient participation in research, and patient-orientated methodologies and protocols.

Aims

The aim of this rapid review is to gain a deeper understanding of the experiences and perspectives of adult patients, carers and family members who have participated in a PEoLC research study.

METHODS

This rapid review was conducted between July 2020 and September 2020 and was informed by the guidelines put forward by the Palliative Care Evidence Review Service.¹⁰ A rapid review methodology was adopted due to time and resource constraints and to focus on the most recent research in this field. The review was reported according to Enhancing Transparency in Reporting the Synthesis of Qualitative Research guidelines.¹¹

Inclusion and exclusion criteria

Inclusion criteria

Included papers reported on primary, qualitative studies that enquired specifically about adult patients', carers' or family members' experiences of participating in PEoLC research, published between 2010 and 2020 in the English language and conducted in OECD (Organisation for Economic Co-operation and Development) countries.¹²

Exclusion criteria

Research exploring participants' experience of involvement roles in research as defined by the National Institute for Health Research Centre for Engagement and Dissemination were excluded.¹³ This rapid review was specifically interested in the participant, carer and family member perspective on participation. Research exploring the views of other stakeholders (such as researchers, clinicians, nurses) was excluded. Studies were excluded if they explored curative treatments and those involving children under the age of 18, as these areas of research have their own specific issues relating to gatekeeping and accessing this population for research and cannot be studied alongside an adult population.¹⁴⁻¹⁸

Search and selection strategy

The search was conducted across three online databases (MEDLINE, PsychInfo and PubMed) for studies published from 2010 to 2020.

A predefined search criterion was applied and was based on that used in a similar paper¹ with the removal of 'involvement'. The search terms used were as follows: (palliative or terminal or end-of-life, or hospice, or death or dying or bereave or supportive care) AND ((attitude or experience or perspective or challenge or benefit or burden) AND (research)).

Three independent reviewers (BFH, CH and LEC) screened titles and abstracts of citations for eligibility using Endnote X8.¹⁹ Full texts were consulted where necessary. Disagreement between reviewers was resolved through discussion with an additional reviewer (KK).

Data extraction and synthesis

The following data were extracted from each paper and entered into Excel: methodology including study aim, what participation entailed, duration of participation; setting; method of recruitment; participant characteristics, clinical information including diagnosis and stage of illness; participant reported benefits of, and barriers to, research participation participant retention and study conclusions.

Eligible papers were transferred into Nvivo V.11 for analysis.²⁰ Thomas and Harden's thematic synthesis method²¹ guided the data extraction and synthesis processes. This involved three stages: (i) line-by-line coding of extracted text, (ii) development of descriptive themes and (iii) generating analytical themes from the studies' data. The review was not registered on PROSPERO, as there are no direct health-related outcomes. Line-by-line coding of the findings of each study, including participant quotes was undertaken by reviewers. Through discussion between reviewers the codes were refined. Similarities and differences between codes were identified and clustered to inductively generate descriptive themes. Analytical themes

and subthemes were generated through additional discussion, reflection, and iteration.

Quality assessment

To assess the quality of the included research papers, Hawker's Risk of Bias tool²² was used and produced a score for each study of a minimum of 9 points and a maximum of 36 points. This assessment included scoring of the abstract, methodology, sampling, analysis, ethics and bias, generalisability, and implications. It should be noted that scores were not used to exclude studies but to provide an indication of the quality of each included paper. See online supplemental table 2 for individual scores.

Primary data collection

In addition to the rapid review, a survey and focus group was undertaken to explore the themes and recommendations identified in the review. A survey was developed using Microsoft Forms to gather information from attendees at the Marie Curie Palliative Care Virtual Research Conference in November 2020 (from 27.22 min), at which early findings of this review were presented. The survey (online supplemental appendix 1) was distributed electronically to attendees during and after the presentation. The audience were clinical professionals in PEOLC and responding to the survey was entirely optional indicating implied consent from those who chose to respond. No demographic information is available for survey respondents.

A virtual focus group was held with five Marie Curie Research Leads and Fellows who are academics with extensive experience in conducting PEOLC research. The same question format as the survey was applied to the discussions to explore feedback on the recommendations and whether the benefits and barriers in the review were reflective of their experience as researchers. The focus group discussions were recorded using Microsoft Teams.

Patient and public involvement

Three members of the Marie Curie Patient and Public Involvement (PPI) group, called Research Voices were involved throughout the process of this rapid review and two are coauthors on the paper (MB and SP). The Research Voices generated the analytical themes and subthemes with the remainder of the authors. They shared their experiences and expertise in PEOLC, and research which helped to clarify the themes, and to ensure that the recommendations that were drawn up were both practical and reasonable. The Research Voices challenged any assumptions held by the remainder of the authors and provided insight that helped shape the review. The Research Voices commented on each draft and any extra materials generated related to the work (eg, presentation materials for the Marie Curie Palliative Care Virtual Research Conference).

RESULTS

Search and selection strategy

Across the three databases, 3578 papers were identified, of which 157 were duplicates. An additional paper was identified by contacting experts in the field. Of the remaining 3423 studies, 3341 were excluded after screening the abstracts and titles.

The full texts of 41 papers were reviewed and a further 37 were excluded. Figure 1 presents the search and selection process.

Four papers were included in the final thematic analysis.^{23–26}

Characteristics of included studies

The characteristics of the four included studies are summarised in tables 1 and 2.

Two studies explored the views of patients participating in PEOLC,^{23 26} and two explored the views of family members or carers of a person with a terminal illness.^{24 25} In total, the papers represent the experiences of 70 patients and 347 family members. Patients who participated in the studies were those with cancer (n=52)²³ and severe Chronic Obstructive Pulmonary Disease (COPD) (n=18).²⁶ The majority of participants in included papers were white females.

Two studies were conducted in the USA, one in Switzerland and one in Australia. All studies explored the views of patients or carers who had participated in clinical trials.

All studies utilised retrospective interviews. Two studies conducted face to face interviews,^{25 26} two used telephone interviews^{24 25} and the method of interview was not reported in one study.²³

Three of the four included studies involved participation in hospital-based studies,^{23 25 26} and the other was home based.²⁴ Participants across the studies were in receipt of different interventions, see table 2.

Thematic synthesis

Seven high-level themes were identified from the four studies: benefits or positive aspects included altruism and perceived benefits for participants themselves. Feeling overwhelmed by the situation, participation not being seen as relevant, being reminded of being a patient. Unmet needs, practical issues, not seeing the research as relevant to them, being reminded of being a patient and feeling overwhelmed were identified as barriers or negative aspects of participation (table 3).

Benefits or positive aspects of participation

Two overarching themes encompassing the benefits participants reported in their experiences of PEOLC research—altruism and benefits for themselves—were identified.

Altruism

Improving things for other patients and carers

Altruistic factors were identified as motivators for research participation. Patients and carers described

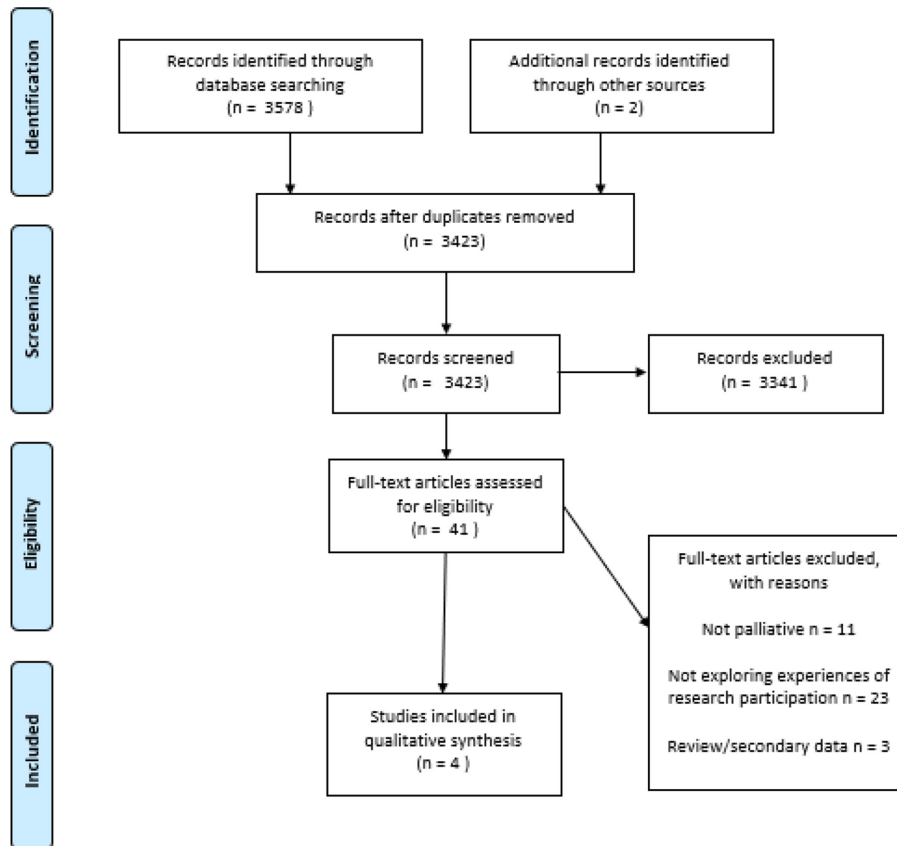


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram.

wanting to help improve matters for others in similar situations in the future. One patient described their reason for participating:

"A psychological benefit in knowing that someone is thinking about these issues actually helped me. At least someone is doing research in this area and may make some changes to help others in our situation". (Control 128)²⁴

Location of study	
USA	2
Switzerland	1
Australia	1
Study setting	
Hospital	3
Home	1
Participants	
Patients	2
Family members	1
Carers	1
Diagnosis	
General palliative	2
Cancer	1
Chronic Obstructive Pulmonary Disease (COPD)	1
Stage of illness	
Palliative	2
Advanced	1
Mixed (advanced or recurrent)	1

This often reflected less of an attempt to improve matters for themselves and more of an acceptance that changing the eventual outcome for themselves at this stage was not possible.

Raising awareness

Participants reported wanting to raise awareness, including making a difference for others by helping to shape government priorities and contributing to knowledge in the field to increase healthcare professionals' understanding of conditions and caring:

"I am happy to do whatever I can to help if it makes a difference for others. Unless the government knows the details of what we need they can't make a difference." (Control 77)²⁴

"Well, I guess my attitude is that, um, knowledge is power. The more that the scientists and the doctors know, the sooner there is going to be a cure, or there is going to be a treatment that is going to prolong somebody's life". (P3 Intervention; Breast)²³

Table 2 Study characteristics

Author(s)	Title	Setting	N	Participants	Study design	Trial intervention	Method of evaluation	Hawker's Risk of Bias score
Maloney <i>et al</i> ²³	Patient perspectives on participation in the ENABLE II randomized controlled trial of a concurrent oncology palliative care intervention: Benefits and burdens	Hospital	52	Patients	Randomised control trial	Four telephone-based educational sessions ran by advanced practice nurses with palliative care training, and monthly telephone contact. Participants completed questionnaires every 3 months until death or study completion	Retrospective interview	32
Aoun <i>et al</i> ²⁴	Family caregiver participation in palliative care research: Challenging the myth	Home	322	Family caregivers	Stepped-wedge cluster trial	The intervention groups received the Carer Support Needs Assessment Tool (CSNAT) vs a control group who received standard support. Intervention group received two visits from a nurse and telephone questionnaires were completed pre-intervention and postintervention .	Retrospective interview	31
Dotolo <i>et al</i> ²⁵	Strategies for enhancing family participation in research in the ICU: Findings from a qualitative study	Hospital	25	Family members	Randomised trial	A facilitator to improve clinician-family communication in the ICU vs usual care. Surveys assessing depression, anxiety and Post traumatic stress disorder were mailed to family members' homes 3 and 6 months after the patient's death or intensive care discharge.	Retrospective interview	32
Véron <i>et al</i> ²⁶	Recollection of participating in a trial: A qualitative study of patients with severe and very severe chronic obstructive pulmonary disease	Hospital	18	Patients	Randomised control trial	Intervention group received an early specialist palliative care intervention and standard care vs standard care. The intervention group received monthly visits for 12 months from nurses specialising in palliative care.	Retrospective interview	30

ICU, intensive care unit.

Benefits for themselves

Practical insight and access

In addition, participation in research in PEOLC provided benefits to the participant themselves, including gaining practical insights, for example, access to information. Patients and carers reported that having an increased number of contacts within the medical/research field provided further sources of information, which sometimes was not provided by their primary clinicians.

"I remember thinking that it could probably only be a positive thing to maybe get some extra information or some extra help with getting information. So I couldn't see any downside". (Group 1; ID# 2)²⁵

Emotional insight and support: feeling supported and reassured, giving a sense of hope

Patients and carers found that their participation also provided emotional insights and support, including feelings of reassurance, support and giving a sense of hope. The sense of hope was not hope for recovery or a cure but hope for receipt of extra support, information or improvement in quality of life.

The feelings of support and reassurance were particularly important and were achieved for some participants in simple ways, including having regular check-ins with researchers:

"... the phone calls. Especially in the beginning when I felt really lousy from the chemo ... I think

Table 3 Benefits and barriers to participation in palliative and end-of-life care research, and recommendations to facilitate participation

Benefits (positive aspects)	Barriers (negative aspects)	Recommendations
Altruism <ul style="list-style-type: none"> ▶ Improve things for other patients and carers ▶ Raising awareness ▶ Advocating for change ▶ Increasing healthcare professional understanding 	<ul style="list-style-type: none"> ▶ Feeling overwhelmed by the situationTaking the focus away from the patientParticipation not seen as relevant to self ▶ Practical barriers 	Communication <ul style="list-style-type: none"> ▶ Aim and requirements of the study are clear ▶ Offer a summary of the research findings ▶ Respect participants and listen to them (treat them as people, not participants) ▶ Be sensitive in tone and language used.
Benefits for themselves <ul style="list-style-type: none"> ▶ Emotional insight and support ▶ Feeling supported and reassured ▶ Gave a sense of hope ▶ Having someone independent to talk to ▶ Validation of the caring role ▶ Gaining practical insight and access 	<ul style="list-style-type: none"> ▶ Reminded of being a patient ▶ Unmet needsDisappointment ▶ Disappointment for self ▶ Participation of others 	Appreciating the researcher's role from the participants perspective <ul style="list-style-type: none"> ▶ If possible, provide additional information about local services available for them ▶ Where possible, be flexible in the timing and methods of data collection

it's kind of made everything just a little easier". (P4 Intervention; Breast)²³

Moreover, participants found that the research gave them further practical insights and access, including enhanced problem solving. A strong theme arising from the studies was that the research provided an opportunity for participants to gain a better understanding of their own condition:

"She [nurse] especially brought me practical elements that nobody else could give me, in fact. Doctors don't treat us like that. So she did the transition between the simply human side, and the doctor who never answers those questions: 'how should I eat' or 'what I could do to breathe better". (Participant 14, palliative care, female, 70 years old)²⁶

Having someone independent to talk to

Carers reported that research participation also provided an opportunity to speak to an independent person allowing an impartial space for them to express themselves in.

"I can tell you and you are impartial with my answers. I think it was very beneficial". (Control 8)²⁴

Validation of the caring role

A carer explained how the research had offered time for reflection on their role as a carer and validated their caring role:

"It makes you think a little, made me realise the emotional side of caring and how [with] a lot of those issues you tend to 'soldier on'" (Intervention 115).

Moreover, as caregivers we're prompted to reflect about the issues at hand, they developed greater insight into both their own need for support and the services available to them.²⁴

Barriers or negative aspects to participation

While positive aspects of participating in palliative care research were described, several barriers or negative aspects to participation were also reported by participants.

Feeling overwhelmed by the situation

One identified barrier to participating in PEOLC research was that potential participants could feel overwhelmed by the situation, leaving little capacity for participating in research.

"When your mind is in shock, it is really hard to turn the emotional side off and turn the analytical research side on and say, "Yeah, this is an okay thing". For me, I just didn't even want to deal with it". (Group 2; ID# 14).²⁵

Participation not seen as relevant

For some patients, they assumed research was not relevant to them, whether that was because of their stage of disease, or in relation to symptom manifestation:

"Actually, up until a couple of months ago, a lot of the stuff that was in the book that I was given, it wasn't even appropriate. I mean, it wasn't necessary for me ... at first I couldn't relate to a lot of the stuff". (P17 Intervention; GI)²³

Reminded of being a patient

Patients also explained that being invited to participate in research emphasised their identity as a patient and reminded them of their disease. Palliative or end of life patients are already surrounded by discussions about their disease and/or health and expressed that sometimes they just wanted to be seen as a person, rather than a patient:

"I don't want to be a patient every day of my life". (P14, Intervention; GI)²³

"And it's a way for me to evacuate basically. And that's what saves me a bit. (...). If we think about it, we keep talking about it, it becomes burdensome. Yes. Too burdensome. (Participant 7, palliative care, male, 71 years old)"²⁶

Practical barriers

Practical barriers, for example, feeling too unwell, travel distance, clash with medical appointments and time required to dedicate to research were noted as reasons to deter participation in PEOLC research. Two participants in the studies considered within the scope of this review reported practical barriers including time, travel distance and being too sick.^{23 26}

Unmet needs: disappointment for self and disappointment for others

Another overarching theme identified as a barrier or negative aspect to participation was unmet needs, which was expressed in terms of disappointment for the individual themselves and disappointment surrounding the participation of others.

For the individual, there was commonly disappointment when participants were randomised to a control group as they did not receive the intervention and the support they were expecting from the trial.²³ Even individuals who were randomised to the intervention arm in one study expressed disappointment at the limited interaction with the researcher, and some were of the opinion that 'nothing was done' as there was no tangible change to medication or treatment.²⁶

Participation and engagement of others were noted as disappointing for participants, with an expectation that everyone else would be as motivated to participate as themselves:

"The biggest disappointment was going into the group meetings and feeling as if ... the energy wasn't there ... So, I didn't feel like it was as helpful as it could have been". (P14 Intervention; GI.)²³

Recommendations for research teams

Based on the perceived positive and negative aspects of participation in PEOLC research described by

participants, recommendations for research teams have been developed to facilitate participation, enhance the positive aspects and potentially minimise the negative aspects of research participation. See [table 3](#) for a summary of the recommendations.

Communication

- ▶ Ensure that the aim and requirements of the study are discussed clearly with potential participants (many participants in the reviewed studies could not remember the aim of the research):

"But I can't remember, I can't remember, you can't remove it from me. I don't want to talk nonsense to say, because I don't know, so, honestly. I can't even tell you how those ladies [the nurses] were. Probably nice, but ... "(Participant 10, palliative care, male, 73 years old)²⁶

Consider the format of written information given to participants to read at a later date which includes the contact details of the research team.

- ▶ Participants should be offered a summary of the research findings or have access to updates on the project and findings for example, through a website. This approach will enable support through an established feedback loop where participants, where possible, are kept up to date with the project progress until publication (those that are more research aware may be more likely to participate in future studies).

"I'm very familiar with how you do research ... I'm sure if [people] were more familiar with it, they would be more prone to do it" (Group 3; ID# 21)²⁵

- ▶ Build rapport with participants—recognise participants as individuals and that data collection is only part of the interaction.

"[The researchers] were really aware [of the stressful circumstances] and acted accordingly. I think that sometimes it helps the stress to talk about why you're there and what's going on in your life. So, I think that's kind of a natural benefit just to get you to open up and not hold it all inside". (Group 1; ID# 17)²⁵

- ▶ Be sensitive in tone and language used (consider what else is going on for the participant) and ensure communication is personal and appropriate:

"When you are talking to the carer, your disposition and tone of voice is important, the caring tone shows genuine interest and is a good thing for the caregiver, they pick up on this. "(Intervention 605)²⁴

Appreciating the researcher's role from the participants' perspective

- ▶ If possible, provide information about the services available to participants and link them in (participants described seeing research as a source of local information):

"Well, the actual [study enrollment] was just maybe five minutes' worth of time, but she spent at least another 20 minutes with me ... kind of her own personal things about best time to go down to the cafeteria, when it's not so crowded and ... you know, little things like that." (Group 1; ID# 5)²⁵

- ▶ Where possible, be flexible in the timing and methods of data collection used (participants described good days and bad days):

Similarly, participants who were feeling relatively well or preferred to use denial or avoidance to cope with their illness didn't want to feel like "... a patient every day" (P14 Intervention; GI) and preferred to have less contact with medical professionals.²³

Strengthening the recommendations

Survey and focus group

To explore the acceptability of the recommendations generated, feedback was sought from a range of clinicians, researchers and people with lived experience in the field of PEoLC research in the form of a survey and focus group (see methods and online supplemental appendix 1).

See [table 4](#) for an outline of the main feedback points from the survey respondents and focus group participants. Further detail on the results can be found in online supplemental file 1.

Table 4 Summary of the key points identified from the survey and focus group

Survey	Focus group
Benefits (positive aspects)	The benefits were reflective of the respondents' experience of why people had participated in their most recent studies (all of the benefits were reported by more than 50% of respondents).
Barriers (negative aspects)	These were reflective of their experience of why patients and carers had participated in research. Focus group participants also reported that qualitative research can also have a cathartic benefit and that the researcher can also act as a proxy for feeding back to clinical team on the patient or carer well-being.
Recommendations	<ul style="list-style-type: none"> ▶ Practical barriers can also be considered as specific physical, mental and conditional barriers. Contextual barriers are also important to acknowledge. ▶ Distress is also a barrier but can often be a motivator for gaining altruistic benefits and improving things for other people in the future. ▶ Establishing consent is a particular difficulty in this field of research
	<ul style="list-style-type: none"> ▶ More than 70% of respondents reported that each recommendation could have improved the experiences of people in their studies. ▶ No respondent reported that any of the recommendations would not have been useful.
	<ul style="list-style-type: none"> ▶ Importance of clear and concise aims and requirements—participants just want to 'get on with it'. ▶ Distress protocols should be in place for safeguarding. ▶ Benefits, barriers and recommendations are applicable to most types of research, not specifically always PEoLC.

PEoLC, palliative and end-of-life care.

DISCUSSION

This review has identified the benefits or positive aspects of participation in PEOLC research and barriers, or negative aspects of participation, as described by patients, family members and carers. Despite participants often reporting altruistic benefits to participation, this review identified a number of ways in which participants themselves can benefit, including gaining access to services, receiving additional support and validation of their caregiving role. This finding indicates that participants often have their own personal reasons for taking part in research and that they do not always necessarily share the ethical, concerns of clinicians and healthcare professionals. These concerns can lead to gatekeeping, and may reflect a more paternalistic style of medicine, both of which have been reported elsewhere.^{7 27}

Despite these reported benefits in the considered studies, the review also identified barriers or negative aspects to participation in PEOLC research, which included feeling overwhelmed, practical barriers (such as feeling too unwell and travel distance) and the reminder of being a patient. This review has considered these negative aspects and developed recommendations for researchers, clinicians and wider research teams, in an attempt to negate these barriers and support and encourage participation in research.

There was a strong sense that the participants within the included research studies, wanted to be recognised as individuals, rather than another unwell person nearing the end of their lives. Participating in research has the potential to provide psychosocial benefits to participants, as ongoing interactions with healthcare professionals and researchers can help to guide participants through uncertainties faced. It has been reported that in these interactions, it is essential that participants' personal identity is acknowledged, and their role is seen as the 'patient as person' rather than the 'person as patient'.²⁸ The survey results further support the idea that participants have personal reasons for both choosing to participate and varying barriers to participation (see online supplemental file 1).

Strengths and limitations of the review

This review used a rapid review methodology which has enabled a rapid literature search to identify studies published within the last 10 years related to the research question, providing up to date and relevant research within the field of PEOLC. However, this method does not consider all research in the field and has strict inclusion/exclusion criteria.

The review benefited from the involvement of PPI representatives as part of the research team. The representatives provided insights from their own experiences of being approached to participate in PEOLC as former carers for those at the end of life which strengthened the development of the recommendations. In addition, feedback was sought from a range

of PEOLC clinicians and researchers which has resulted in the development of practical and achievable recommendations for researchers within the field.

Despite including research from OECD countries, no papers exploring the experience of participation in UK-based studies were included, as none were identified in the literature search. Those included were in the USA, Australia and Switzerland, and although parallels in research approaches can be drawn to the UK, specific UK-based studies would be an interesting avenue for future research, as there may be some cultural differences between nations as well as different health system funding models.

Three of the four included papers explored the experiences of participation in research-based in a hospital setting. The setting in which the research is conducted may influence the experience of participants. For example, participants in hospital-based studies where they are an inpatient or visit on a regular basis may be less burdensome than someone who must travel to the hospital as an outpatient for the purposes of research.

In addition, all included studies involved relatively low commitment levels, for example, completion of questionnaires, monthly nurse visits, which could be viewed as less burdensome. Further exploration of the experiences of participation in other types of studies which may involve more invasive interventions or more time commitment and potentially more barriers or negative aspects for participants, is an avenue for future research.

The quality of the included research papers was assessed using the Hawkers Risk of Bias scores. There was a variation in quality of the included studies, however, the decision was taken to include all studies and not use a score cut-off, as only four studies were eligible for inclusion. The bias scores can be seen in online supplemental table 2.

Practical barriers were identified but to a lesser extent than was expected, being reported in only two studies. This suggests that participants in PEOLC research may not be deterred by practical barriers such as travel distance, and time commitments. However, this may also have been influenced by the type of study and participation requirements of included studies, . Therefore, these studies may not be representative of studies which require more time commitment or need for additional travel. Further exploration of the impact of practical barriers on research participation would be of interest, particularly given the necessary and rapid uptake of digital solutions due to the COVID-19 pandemic as face-to-face interactions have been either limited or impossible.

Furthermore, the authors were unable to explore other characteristics of participants which may influence their experience of participation, their perceived levels of social support, their living arrangements or the presence or absence of a carer. This would be particularly interesting in those who reported that

participation benefited them in terms of emotional insight and support, making them feel more reassured, and whether this was confined to those who were missing emotional support outside of their interactions with the researcher(s).

Within the recommendations, the development of an established feedback loop to provide participants with ongoing updates until the point of publication of the research findings has been suggested. It is acknowledged there is some potential difficulty in applying this practically within PEOLC research. It is not uncommon for patients to die during the study or shortly after due to the prognosis of terminal diseases. Combined with this, it can often take many months or years for a publication to be released, however, we suggest that it may still be possible for the carers or family members of the participant to be offered the opportunity to be informed of the research findings, should they wish to.

The survey and focus group provided an opportunity to gain feedback on the relevance of the recommendations from professionals within the field. However, small sample sizes were limited.

In addition, the authors acknowledge that the research considered within this review explores the experiences of those who can consent for themselves and does not specifically address those participants who have lost or diminished capacity for example. However, the recommendations put forward in this report provide useful learning for all 1 participant groups, including carers if they are involved in proxy consent.

Avenues for future research

There is a need for further research into the particular experiences of participation within UK-based research studies. It is noted that all the included papers explore the participants' experience of research retrospectively and this has its limitations, including recollecting the experience accurately. Participants may exhibit recall bias dependent on their perceived experience and only report either the good or the bad aspects of participation. It would also be interesting to explore the impact of the setting and methodologies used by researchers on likely uptake of the recommendations.

When considering the demographic features of participants in the included studies, it was clear that there was very limited evidence exploring the experiences of participants from diverse backgrounds and marginalised groups. This is an important area for future research as the benefits and barriers to participation in PEOLC research are likely to be culturally sensitive.

Qualitative studies exploring the participant experience embedded within trials may be better able to capture patient experience alongside the impact or outcomes of interventions. This would enable a more rounded

assessment of the interventions being assessed which could be useful for future development and implementation.

Further consideration of the specific terminal condition being experienced and the relevance of these benefits, barriers and recommendations would also be useful. Patients, carers and family members are likely to have very different needs depending on the condition or disease and this may also affect their ability or willingness to participate.

Further evaluation of the recommendations in practice is required.

Recommendations for practice

Overall, areas have been identified within research and research delivery that can be improved to encourage participation or improve experiences of participants in PEOLC research. These recommendations are practical and achievable and could be implemented by research teams in the field relatively easily. Moreover, these recommendations align with those identified in a project undertaken by versus Arthritis.²⁹ Similarly, they found that, within their community, individuals need to understand and feel connected to research to enable a high-quality experience, and to increase the likelihood of participation in the future. This shows that while the recommendations in this review are aimed at PEOLC researchers specifically, the underlying principles of improving communication and empathising with the patient role and journey are more universal and are paramount in research in other areas.

Researchers are encouraged to adopt these recommendations, as they have been developed from the experiences of participants within the included studies and in collaboration with members of Marie Curie Research Voices Patient and Public Involvement group, who are former carers and have had experience participating in PEOLC research. These recommendations can be implemented for general best practice within research.

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Acknowledgements The authors would like to acknowledge the Motor Neuron Disease Association for allowing Dr Kirsten Kelly to work on this review alongside Marie Curie. The authors would also like to acknowledge the contributions of Diana Robinson, Marie Curie Research Voices member.

Collaborators NA.

Contributors BFH, LEC, CH and KK conducted the literature screening and selection, data analysis and interpretation, drafting and revision of the article. MB and SP contributed to the development of the qualitative themes, data analysis and interpretation and reviewing article drafts. All authors were involved in final approval of the version of the publication.

Funding This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors. BFH, LEC and CH's posts were funded by Marie Curie. KK's post was funded by the Motor Neurone Disease Association.

Competing interests None declared.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

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Appendix 1

The development of recommendations for researchers conducting PEOLC research.

Thank you for listening to our talk at the Marie Curie virtual research conference 2020.

Members of the Marie Curie Research Management Team and the Research Voices Group have conducted a rapid review to explore the benefits and barriers to participation in palliative and end of life care (PEoLC) research for patients, carers and family members described in the literature.

As part of this review we have identified some recommendations for researchers, which may be helpful in minimising some of the challenges described. We presented these recommendations at the Marie Curie virtual research conference.

We would value your input and feedback on these recommendations as a professional in the palliative and end of life care field, or as someone with personal experience.

This survey should take no longer than 10 - 15 minutes to complete.

* Required

1. Please select from the below which best describes your occupation *

Palliative care doctor
Other specialist doctor
General Practitioner
Specialist palliative care nurse
Other specialist nurse
Nurse
Professional allied to medicine
Social worker
Care home, or home care, staff
Chaplain
Researcher
Patient and public involvement representative
Other

2. What setting do you primarily work in? *

Community
Hospice
Hospital
Primary care
University
Care home
Other

3. Which of these would best describe the most recent piece of research you completed?

Trials
Epidemiological studies
Qualitative
Quantitative
Mixed methods
Other

4. We outlined 6 recommendations for researchers which may minimize the barriers to participation in palliative and end of life care research. Thinking about your most recent piece of research, to what extent did you do the following things? *

	I did this	I sometimes did this	I did not do this
Discuss the aim and requirements of the study clearly with potential participants (including giving written information)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Offer a summary of the research findings and develop an established feedback loop to update them of the project progress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Build rapport with participants - recognise participants as individuals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Be sensitive in tone and language and consider what else is going on for the individual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide information about the services available to the participants and link them in with local support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Be flexible in the timing and methods of data collection	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5. Thinking about your most recent piece of research, how useful do you think these recommendations would be in improving patient/carers' experiences of participating in palliative and end of life care research? *

	Useful	Could have been useful	Not useful	I don't know	Not applicable
Discuss requirements of the study clearly with potential participants (including giving written information)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Offer a summary of the research findings and develop an established feedback loop to update them of the project progress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Build rapport with participants - recognise participants as individuals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Be sensitive in tone and language and consider what else is going on for the individual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide information about the services available to the participants and link them in with local support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Be flexible in the timing and methods of data collection	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. Are any of these recommendations something you might implement in the future? *

	Yes	No	Maybe	Not applicable
Discuss the aim and requirements of the study clearly with potential participants (including giving written information)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Offer a summary of the research findings and develop an established feedback loop to update them of the project progress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Build rapport with participants - recognise participants as individuals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Be sensitive in tone and language and consider what else is going on for the individual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provide information about the services available to the participants and link them in with local support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Be flexible in the timing and methods of data collection	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

7. Any further comments?

8. Thinking about your most recent piece of research you have been involved in, do you think the benefits of participating in palliative and end of life care research outlined in the presentation were reflective of participation in the study? *

	Yes	Sometimes	No	I don't know
Altruism - improving things for others in the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Altruism - raising awareness about the disease and care needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Benefits for themselves - emotional insight and support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Benefits for themselves - Having someone independent to talk to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Gaining practical insights and access	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

9. Any further comments?

10. Thinking about your most recent piece of research you have been involved in, do you think the barriers of participating in palliative and end of life care research outlined in the presentation are reflective of participation in the study?

	Yes	Sometimes	NO	I don't know
Feeling overwhelmed by the situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Participation not being seen as relevant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Practical barriers (e.g. time, distance, feeling unwell)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Reminded of being a patient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Disappointment - for themselves	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Disappointment - in the participation of others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

11. Any further comments?

12. Do you have any further comments on the recommendations? (Is there anything we have missed, or anything we should add or remove?)
13. If you have any specific questions to ask the research team or would like to be kept updated with the progress of the review, please leave your email address in the box so we can contact you in the future

Supplementary material: Research Participation in Palliative Medicine - Benefits and Barriers for Patients and Families: Rapid Review and Thematic Synthesis - survey and focus group results

Survey

Thirty-three people responded to the survey and the breakdown of their occupation can be seen in Supplementary Table 1 below. For the purpose of his analysis 31 responses were included. Two responses were excluded from the analysis as the respondents reported that they were not research active in their role. Patient and Public Involvement representatives were only included in the analysis of the 'usefulness of the recommendations' section, as they were not required to complete questions 2 to 8 (See appendix 1).

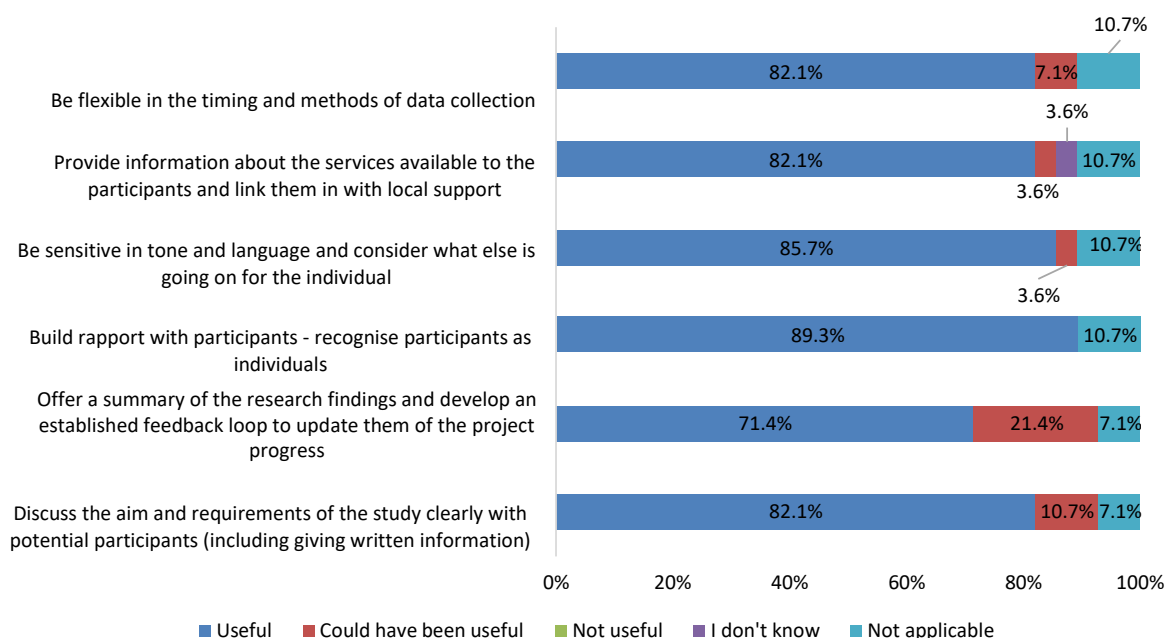
Occupation	N
Researcher	12
Palliative care doctor	3
Specialist palliative care nurse	2
Patient and public involvement representative	3
Various backgrounds	1
Nurse	2
Other specialist nurse	1
Professional allied to medicine	1
Clinical academic specialist palliative care nurse	1
Clinical research nurse	1
Founder of a children's hospice in Indonesia	1
CEO cancer charity	1
Student	1
PQL	1

Supplementary Table 1. Occupation of respondents to feedback survey

Respondents reported the setting in which they worked, and their research methods used in their most recent research. 43% of respondents worked in universities, followed by 30% in hospices. 39% of respondents reported using qualitative methods and 24% mixed methods.

More than 70% of respondents reported that each recommendation could have improved the experiences of people in their studies. No respondents reported that any of the recommendations would not have been useful, with the large majority rating the recommendations as being useful or could have been useful (see Supplementary Figure 1).

Would the recommendations be useful in improving participant experiences in their most recent research projects?



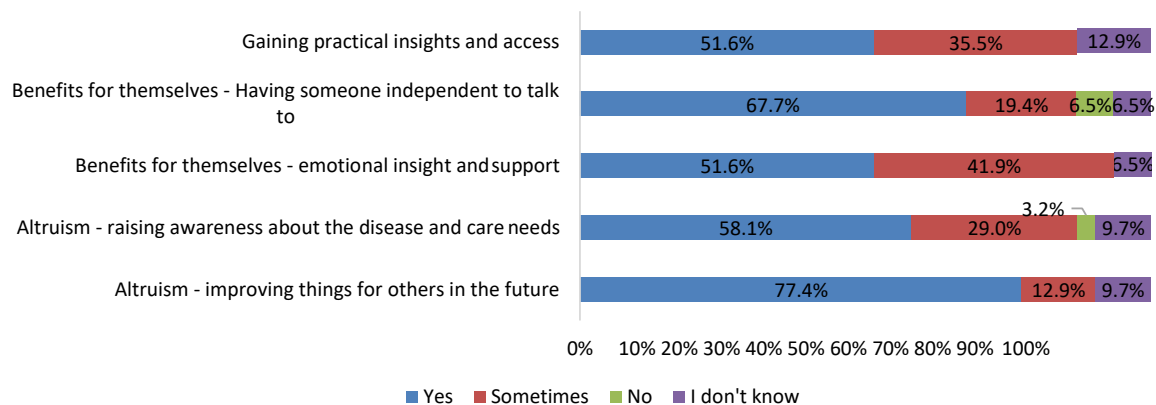
Supplementary Figure 1. Survey responses to whether the recommendations would have been useful for researchers in their most recent research project.

The respondents also provided feedback about whether the benefits and barriers identified from the included studies in the review were reflective of their experience with participants in their most recent studies.

The benefits of participation resonated with the researchers' experiences, with at least 50% of respondents reporting that each identified benefit was a reason people had participated in their most recent research. For example, altruism (improving things for the future) and altruism (raising awareness) were benefits reported by 58% and 77% of researchers respectively (see Supplementary Figure 2).

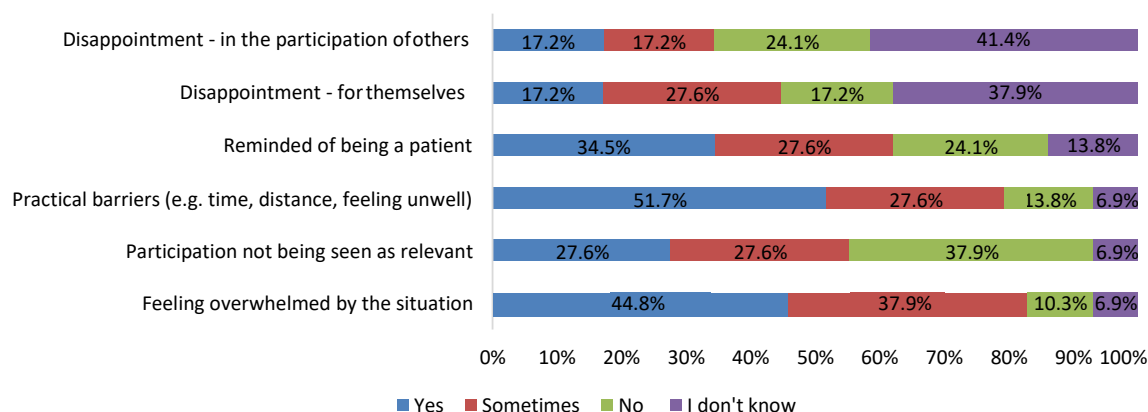
The feedback on the barriers to participation were more varied and were reflective of individual experiences. For example, disappointment in the participation of others showed variable response, with 24% reporting this was not something that was reflective of experience, and equal acknowledgement that this was and was sometimes a barrier (17.2%) (See Supplementary Figure 3). There was a higher percentage of respondents who were not sure whether these barriers existed in their recent research, when compared to the benefits.

Were the benefits outlined reflective of respondents experiences in their most recent research?



Supplementary Figure 2. Survey responses to whether the benefits outlined in the research were reflective of respondents experience in their most recent research

Were the barriers outlined reflective of respondents experiences in their most recent research?



Supplementary Figure 3. Survey responses to whether the barriers outlined in the research were reflective of respondents' experience in their most recent research

Focus group

A 1-hour focus group was held on 25th November 2020 with 5 Marie Curie Research Leads and Fellows, who are all experienced PEOLC researchers. The aim of the focus group was to further explore the benefits, barriers and recommendations and how these resonated with their experiences as researchers.

Overall, it was reported that the identified benefits and barriers were generally reflective of their experiences, however the Research Leads and Fellows fed back that the relevance of the benefits and barriers is dependent on the type of research methodology used. Focus group participants indicated that the recommendations are all things that they hope are

already being done by most researchers in the field but having them clearly defined is helpful. The ability to implement some of them, however, might be constrained by ethics, data protection and practical difficulties. Some of the issues highlighted include participants dying before the research findings are published, issues around data sharing and keeping contact details. The focus group also queried the feasibility of providing additional information about local services in nationwide studies and whose responsibility this should be.

<p>Benefits</p> <ul style="list-style-type: none"> • Having someone independent to talk to is a common benefit that participants in the focus group agreed upon. This could go even further in that the literature has found qualitative research in particular can have a cathartic benefit for people as an unintended effect of being interviewed (25), by giving an opportunity to tell their story. • Discussing their condition in more depth can also happen with quantitative research and patients can feel that research participation is providing them with better care. This is consistent with literature that suggests research active organisations have better outcomes for patients and staff. (26, 27) • Another benefit reported by the researchers in the focus group was that they can often be a proxy for feeding back the patient or carers' wellbeing to their clinical team. Particularly if someone is not opening up to clinicians, the researcher can feed back on how the person was during their interaction.
<p>Barriers</p> <ul style="list-style-type: none"> • Practical barriers can also be considered as contextual barriers from a research team perspective for example, fitting in research around other appointments, tiredness, symptom fluctuation. Requires flexibility from the research team. • The focus group suggested there are specific physical, mental and conditional barriers which may not have been captured in 'practical barriers' • The potential for distress to arise while participating in research can lead to adversity to participation which this review did not identify. Distress can be a barrier, but sometimes also a motivator. One participant in the focus group recalled a research participant being interviewed who was very upset and distressed but wished to continue to help others in the future (altruism). • Establishing ongoing consent is often difficult and very important due to nature of illness trajectory and fluctuation of symptoms. The potential difficulty to take in and retain information at the end of life was highlighted. • In the current pandemic, comfort with using technology to be involved in research remotely is an additional barrier which has arisen more recently.
<p>Recommendations</p> <ul style="list-style-type: none"> • Aims and requirements should be clear <i>and concise</i> – researchers reported that participants often just 'want to get on with it' and may not want to read lengthy documents about the study.

- Consideration of other disparities is required e.g. illiteracy and language barriers
- Providing a summary of the research findings can be problematic due to illness trajectory as by the time this is available the patient is likely to have died. This should be considered on an individual basis and information should be reframed dependent on the individual patient and family preferences including around how/whether they would prefer to be contacted, e.g. providing contact details for the research team, blogs, Twitter and study websites.
- Distress protocols should be in place to manage distress events in patients' best interests and alleviate some of the concerns of gatekeepers (28, 29) .
- Longitudinal consent is something from a researcher perspective that is important to gain due to trajectory of disease, and the fluctuation of symptoms across the disease course. The ability to retain and recall information and consent to research can change in the space of days and weeks for some.
- Provision of local information can be difficult if the study is nationwide. Information should be relevant to the context and given if someone expresses an interest.
- The benefits and barriers, and recommendations, appear applicable to most types of research (particularly qualitative) not specifically always for just PEoLC research where the main challenge is gatekeeping.

Supplementary Table 2. Summary of the focus group discussions on benefits, barriers and recommendations.