

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

