

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).

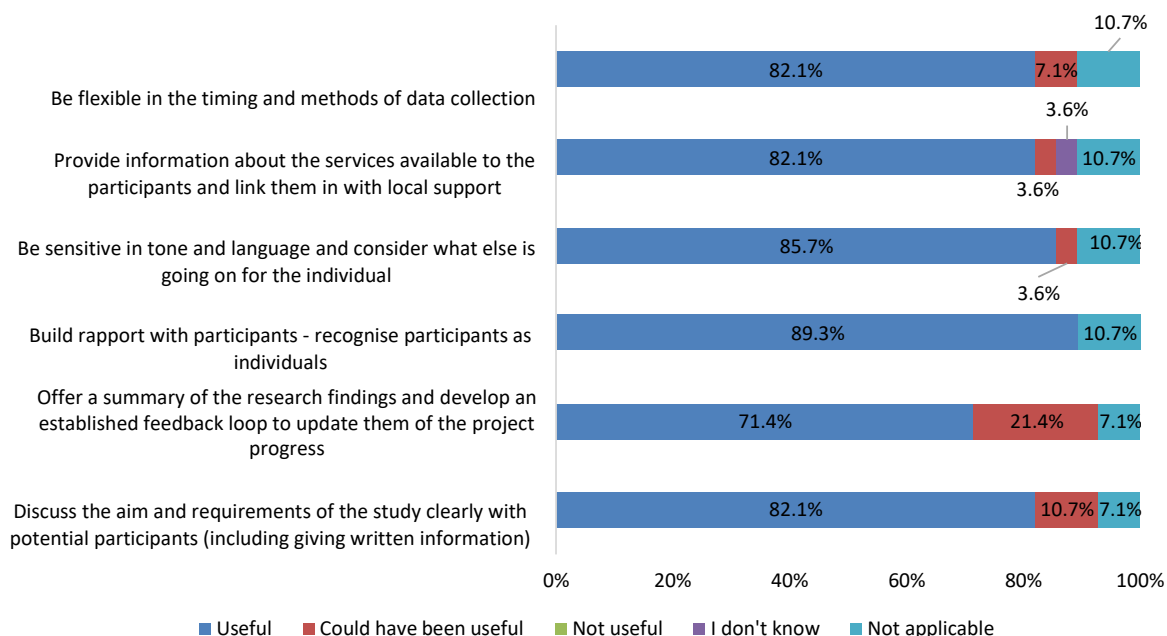
Occupation	N
Researcher	12
Palliative care doctor	3
Specialist palliative care nurse	2
Patient and public involvement representative	3
Various backgrounds	1
Nurse	2
Other specialist nurse	1
Professional allied to medicine	1
Clinical academic specialist palliative care nurse	1
Clinical research nurse	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?



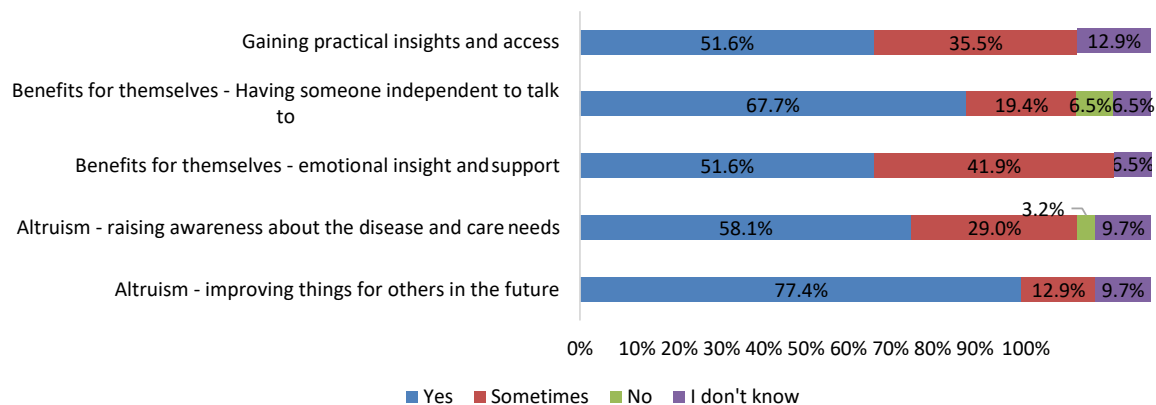
Supplementary Figure 1. Survey responses to whether the recommendations would have been useful for researchers in their most recent research project.

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).

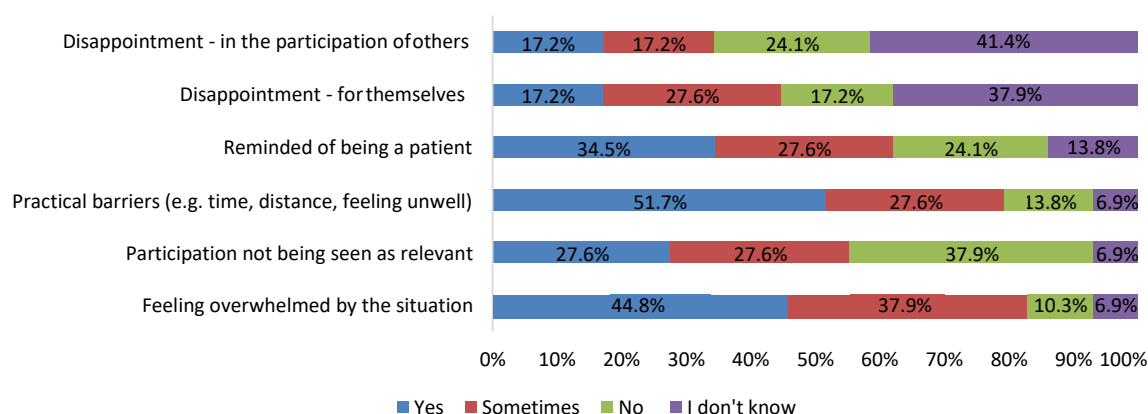
The feedback on the barriers to participation were more varied and were reflective of individual experiences. For example, disappointment in the participation of others showed variable response, with 24% reporting this was not something that was reflective of experience, and equal acknowledgement that 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.