Results of a transparent expert consultation on patient and public involvement in palliative care research

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Abstract

Background: Support and evidence for patient, unpaid caregiver and public involvement in research (user involvement) are growing. Consensus on how best to involve users in palliative care research is lacking.

Aim: To determine an optimal user-involvement model for palliative care research.

Design: We hosted a consultation workshop using expert presentations, discussion and nominal group technique to generate recommendations and consensus on agreement of importance. A total of 35 users and 32 researchers were approached to attend the workshop, which included break-out groups and a ranking exercise. Descriptive statistical analysis to establish consensus and highlight divergence was applied. Qualitative analysis of discussions was completed to aid interpretation of findings.

Setting/participants: Participants involved in palliative care research were invited to a global research institute, UK.

Results: A total of 12 users and 5 researchers participated. Users wanted their involvement to be more visible, including during dissemination, with a greater emphasis on the difference their involvement makes. Researchers wanted to improve productivity, relevance and quality through involvement. Users and researchers agreed that an optimal model should consist of (a) early involvement to ensure meaningful involvement and impact and (b) diverse virtual and face-to-face involvement methods to ensure flexibility.

Conclusion: For involvement in palliative care research to succeed, early and flexible involvement is required. Researchers should advertise opportunities for involvement and promote impact of involvement via dissemination plans. Users should prioritise adding value to research through enhancing productivity, quality and relevance. More research is needed not only to inform implementation and ensure effectiveness but also to investigate the cost-effectiveness of involvement in palliative care research.

Keywords

Consumer participation, palliative care, research design, consumer-based participatory research, group processes, hospice care

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What is already known about the topic?

- User involvement (i.e. involvement of patients, their unpaid caregivers and the public) is increasingly seen as essential for all stages of high-quality research.
- User involvement in palliative care is limited by a lack of evidence on its goals and on the best models to implement.

What this paper adds?

- In palliative care research, patient and public involvement should occur early during the research process; it should be applied flexibly and offered both via virtual and face-to-face methods.

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- Researchers must promote the contribution that patients, their unpaid caregivers and the public deliver, emphasise the difference that they make and enable user dissemination.
- Patient and public involvement can help demystify palliative care and raise awareness about palliative care research.
- Patients, their unpaid caregivers and the public require guidance and encouragement from researchers on how to help improve research productivity, quality and relevance.

Implications for practice, theory or policy

- User-involvement practice in palliative care research should be characterised by early involvement facilitated by diverse virtual and face-to-face methods, and user visibility. User visibility should be stressed, especially in research dissemination. Patients, their unpaid caregivers and the public require guidance and encouragement from researchers on how to help improve research productivity, quality and relevance. Implementation, effectiveness and cost-effectiveness research is required to examine outcomes of user-involvement models.

Introduction

Patients, their unpaid caregivers and the public have a key role to play in improving research quality, relevance, funding and dissemination. National and international research authorities advocate patient and public involvement in research to increase research responsiveness and quality, and increase public engagement in research thereby creating research-active nations.[1–3] Patient and public involvement, which comprises active participation of patients, their unpaid caregivers and the public in research (e.g. in the design review and development of recruitment strategies), is increasingly seen as an essential component to 'good' research practice. Patient and public involvement is referred to in the literature in a number of different ways, including consumer involvement and user involvement.[4,5]

The evidence base for patient and public involvement in health research and within palliative and end-of-life care is expanding. Moderate quality trial evidence has shown that involvement can result in more relevant, readable and understandable patient information for research studies.[6] Qualitative research has identified user-involvement outcomes in palliative care research, including increased knowledge, skills, confidence, personal support, and emotional and practical demands. The need for users to cope with academic and clinical language has been highlighted as an issue to address. Heightened uncertainty regarding users' roles in being involved in influencing research and the value of their contribution also needs attention.[7] Differences between the views and experiences of users and healthcare professionals are beginning to emerge more generally in healthcare. Ethnographic research revealed that some staff view involvement as a stepwise event with measurable processes and outcomes, while patients view involvement as a dynamic, collective process enabled through collaborative relationships with the aim of rapidly improving services.[8]

Knowing how best to implement user involvement in palliative care research is impeded by limited evidence on the best ways to enable involvement, and uncertainty about the differences and similarities between the views of users and researchers. Therefore, research is required to identify optimal concepts or models of user involvement within institutes (not just individual research studies) to maximise benefits and to ensure that effective involvement models, which reflect the needs and expectations of those involved, are implemented. Ineffective models may increase role uncertainty and compromise intended involvement outcomes. Ineffective models may also increase emotional and practical demands unnecessarily on palliative care patients and their unpaid caregivers. Our research aims to determine an optimal user-involvement model through examining users' and researchers' priorities for user involvement in palliative care research. This study focuses on direct involvement of service users in palliative care research activities. The intended model seeks to identify characteristics of an optimal involvement model that fulfil the needs of both users and researchers while acknowledging any potential diversity between these groups.

Methods

Design

We used an abbreviated MORECare Transparent Expert Consultation approach consisting of only a modified nominal group technique in April 2014.[9–12] This approach involved three presentations given to individuals interested in palliative care research. This was followed by focus group discussions and a nominal group technique rating exercise to generate recommendations and form a consensus on priority order to inform the components of a model of user involvement in palliative care research. Areas of divergence between users and researchers were identified in this process. The three presentations provided were: (1) the value of user involvement in palliative care research (presented by an academic expert); (2) the

history of user involvement in the research setting (S.d.W.-L. and K.N.) and (3) the workshop rules, processes and purpose, which were to discuss and establish consensus regarding how user involvement might best be taken forward in palliative care research (C.M.). Participants were then split into smaller groups of three to five individuals with a facilitator to discuss three critical questions (Box 1). The questions had been circulated beforehand to ensure time for deliberation and consideration prior to the consultation.

Following this, seven consultative steps of the nominal group technique were facilitated, involving small and larger group discussions and individual priority setting (Box 2).

Box 1. Three critical questions answered by users and researchers.

1. How can patients, families and the public contribute to research in order to improve its quality and relevance?
2. How might patient, family and public involvement work best in the Cicely Saunders Institute?
3. How can researchers and patients, families and the public benefit from patient, family and public involvement?

The workshop was facilitated by experienced researchers (S.d.W.-L. and J.W.) and user advocates (K.N. and C.M.). Regular research supervision was provided (by B.A.D.) and all were trained in the study requirements.

Box 2. Seven steps completed in the consultation according to the nominal group technique.

1. In each small group, each participant silently wrote down their ideas in response to each of the three questions.
2. Each participant shared their ideas in a round-robin fashion, until all ideas for each question had been shared within the small group.
3. Participants were asked to discuss the ideas for clarity and overlaps. Duplicates were removed and similar ideas combined. Participants were encouraged to discuss and clarify each idea in relation to previous experiences of involvement.
4. Based on this smaller-group discussion, each small group produced a composite list of ideas for each question, ranked in order of importance.
5. Composite lists produced in the small groups were then shared with all participants, and all participants were encouraged to discuss each idea on each list to ensure every idea was understood from a common perspective.
6. Ideas from all small groups were collated to produce one manageable and comprehensive final list that outlined all ideas for the three questions. This involved deleting duplicates and merging similar suggestions into one idea, where feasible.
7. Each participant was asked to individually rank the five most important ideas for each question in order of one (most important) to five (least important) using a ranking sheet with the final ideas for each question included in the list.

The facilitators had no prior relationships with most participants. The researchers had existing professional relationships with most researcher participants. An active partnership approach between user representatives and researchers was used throughout the project.

Setting

The research was conducted at the Cicely Saunders Institute (CSI) at King's College London.

Consent

Potential participants were initially approached by familiar staff (already working in the research setting) with study information. If interested, further contact was made by phone or post, and then a formal workshop invitation was issued. Those interested then registered for the workshop and an information pack containing the three research questions was issued. In the interests of inclusive enquiry, the two service-user advocates who helped facilitate the consultation contributed their priorities. Written informed consent was obtained for all participants on the day of the workshop (by S.d.W.-L. and J.W.).

Inclusion or exclusion criteria

Inclusion criteria were the ability to provide informed consent to understand written and spoken English to a degree that allowed workshop participation and active involvement in CSI palliative care research. Travel expenses for user participants were reimbursed. A gift voucher (£15) was given to them at the end of the workshop. The users had no knowledge of this voucher before agreeing to participate in the workshop.

Sample size

In line with expert guidance, practical judgement and experience were used to determine a sample size that would enable deep and sufficient analysis of the questions.[13] A sample of between 6 and 10 has been recommended for focus group discussions as this allows for variation in views to be shared, facilitated and managed.[14] We aimed for this number as there are clear similarities between the processes of a nominal group technique discussion and focus group discussions. In order to achieve the sample size, we approached 35 service users and 32 researchers to participate in the study.

Analysis

Individual rankings were transferred into an Excel sheet for separate group analysis (J.W., S.d.W.-L. and B.A.D.). Consensus was defined as items ranked within the top five by ≥50% of the participants. These items were analysed (thus excluding items prioritised by the minority). The median and interquartile range (IQR) were calculated and compared for each of these items to produce a ranked list of recommendations for each question. Deductive content analysis[15] of the audio recordings enabled the following: (1) identification and comparison of reasons for involvement priorities, (2) identification of involvement methods for implementation and (3) interpretation of quantitative findings. Deductive analysis was done once the quantitative findings were established. This involved listening to the recording and searching deductively for statements for each question and for any mention of involvement methods. These data were typed verbatim into a word document. Illustrative statements were then presented alongside the quantitative findings in order to convey comprehensiveness and details.

Rigor and quality

Regular research meetings and user-representative involvement aided analysis and credibility. Data inputting and analysis were double checked. Agreement was established between authors to verify authenticity of the qualitative component.

Ethics

Ethical approval was obtained from the King's College London's Research Ethics Committee (BDM/13/14-97).

Results

A total of 12 users and 5 researchers were recruited. The two most common reasons for not participating were having little time and scheduling difficulties. User participants were four patients (two with cancer and two with a non-malignant condition); four unpaid caregivers; two user advocates and two members of the public involved in care provision, research governance and/or service commissioning. Research participants were a clinical research nurse, two research assistants, one clinical–academic PhD fellow and a senior scholar. Participants generated 47 recommendations across the three questions (Table 1).

Question 1: how can patients, families and the public contribute to research in order to improve its quality and relevance?

A total of 14 recommendations were generated (Table 1).

Users. The first consensus priority was widening the scope of palliative care research beyond cancer to ensure involvement of those with non-malignant conditions and the public (M=2, IQR=1–3, n=9; Table 2). The second priority was user involvement at each stage of the research (M=3, IQR=1.75–5, n=8), especially early on to influence idea generation and study design (M=3, IQR=3–4, n=7). Users clarified that researchers should come to them asking '"What should we be studying?" [not] "We are studying these"' (Public 1). Users wanted their involvement to be more visible with a greater emphasis on the difference their involvement makes (M=4, IQR=2.5–4.5, n=7). For example, they wanted to be more heavily involved in the dissemination of findings. They shared the importance of receiving meaningful feedback regarding whether and how their contribution helped, which necessarily involves feedback from researchers:

> [the researcher] sends an email and they say 'yes this is the situation, we've taken on board [what you've said] and we've changed this or that' … It makes you feel that this isn't in vain … It's worth continuing … makes you feel as though you want to come to the next one. (Patient 1)

Researchers. The first priority was that involvement can improve palliative care research by identifying research bias and ensuring quality (M=1, IQR=1–1, n=3): '… by making sure we haven't missed anything informed by our own experience … to help identify systematic biases that we are unable to see …' (Researcher 1). The second priority was involvement in idea generation and study design to aid research quality and relevance (M=2, IQR=1.75–2.25, n=4): '… having brought patients and the public into the research after the research has been designed is really unsatisfactory for everyone' (Researcher 2). The third priority was involvement can aid dissemination and increase impact (M=4, IQR=3.75–4.25, n=4; Table 2).

Question 2: how might patient, family and public involvement work best in the CSI?

A total of 18 recommendations were generated (Table 1).

Users. The top priority was involvement would work best if researchers could establish and lead on providing and

Table 1. A total of 47 recommendations generated by all participants for ranking.

Research questions	Recommendations generated for ranking
Question 1: how can patients, families and the public contribute to research in order to improve its quality and relevance?	1. Dissemination and increasing impact 2. Early involvement in idea generation and study design, before the idea is thought of ask patients/families/the public 3. Flexible and responsive research templates 4. Making involvement visible beforehand, during and after research (what difference did it make?) 5. Listen, respond and act continuously at all stages of research 6. Involvement in the complete research continuum (from start to finish) 7. Widen to public and other illnesses (not just cancer) 8. Partnerships (e.g. with other societies and organisations) 9. Need to be involved/access for everyone 10. Define terms/avoid jargon 11. Engagement 12. Communication and advertising to get as many people as possible involved 13. Helping to identify researcher bias and ensuring quality 14. Providing specific feedback (e.g. on grant applications, outputs and study materials)
Question 2: how might patient, family and public involvement work best at the CSI?	1. Wide access, ensuring diversity (aiming for representativeness) and have the facilities to support diversity 2. 'Pick and mix', that is, wide variety of ways to get engaged, flexibility in engagement and different levels of engagement 3. Collaboration with other organisations and charities, reaching out to people and wide advertising 4. Make it visible, show its value (and make people feel valued) and show its impact (i.e. actions taken in response to patient/family/public involvement and their feedback) 5. Access to palliative care for everyone 6. CSI takes the lead role in implementing understanding of palliative care for lay people, ensure people understand the same thing by 'palliative care' and get people talking about it 7. CSI looking outwards and tells the world about involvement and get people talking about it 8. User champions embedded within the CSI to lead, facilitate and ensure true engagement and involvement happens 9. Ensure people understand what research takes place currently 10. Rewards and thank you token for participants 11. Personalise involvement and make appropriate for lay people (avoid jargon) 12. Ensure user voice is equal and everyone feels safe and able to share their expertise 13. User involvement from the start (early involvement) 14. Shared learning from other research user-involvement initiatives 15. Well-planned and properly funded (potential guidelines for researchers on patient/family and public involvement) 16. Support and training for researchers, organisational recognition and shared learning 17. Support and training for patients/families/public members of research partnership team and clear communications from CSI 18. Regular monitoring evaluation and feedback on impact of involvement
Question 3: how can researchers and patients, families and the public benefit from patient/family and public involvement?	1. Mutual understanding and benefit for both researchers and patients/family/public 2. Practical impact through feedback mechanisms 3. Creation of a wider network due to knowledge gained 4. Intrinsic and truthfulness (not tokenism involvement) 5. Use social networking and coordinate across platforms

(Continued)

Table 1. (Continued)

Research questions	Recommendations generated for ranking
	6. Take lead in coordinated communications (talking and listening) and tell people why it is important to get patients/families/the public involved
	7. Demystify perceptions of palliative care and raise awareness of palliative care and research
	8. Shared understanding
	9. Teamwork
	10. Improved confidence in knowledge and research (truthfulness)
	11. Influencing the agenda
	12. Sharing more widely, even if negative
	13. Reduce research wastage and increase relevance (improve future care)
	14. Opportunity to share experience (among researchers and patients/family/public)
	15. Empowerment, recognition and contribution of patient/family/public contributions

CSI: Cicely Saunders Institute.

implementing a shared understanding of what palliative care is (M = 1.5, IQR = 1–3.5, n = 6) as this would help advance the field of palliative care (Table 3). The second priority was the need for a flexible involvement model with a wide variety of ways to become and remain engaged with various levels of intensity to accommodate individuals' competing demands (M = 3, IQR = 1.5–3, n = 7):

> It's a matter of timing when you work with family members and carers because going through the process of supporting somebody with fighting whatever condition they have and possibly looking at the end of their life they [the patient] are your sole concern … research doesn't matter when you're just trying to get through chemo or get the district nurse in. (Caregiver 3)

Methods to implement were shared:

> Be a member of a network, which responds to requests for ideas, comments, etcetera by post and online, and be available to take part in focus groups … have a wide offering to people so that they can pick and mix what they want to do. (Caregiver 1)

The importance of using different platforms was recommended: 'Twitter is a start but it needs to be coordinated across all of the platforms' (Patient 2).

Researchers. Researchers also prioritised a flexible involvement approach as their top priority (M = 1, IQR = 1–2, n = 3) and acknowledged that this requires effort (Table 3):

> … allowing for people to dip in and out depending on how their disease progresses or how their caring responsibilities

progress … so to take on lighter tasks or more intense involvement at times … there's also an element of making an effort to find out what people prefer. (Researcher 5)

Researchers prioritised diverse involvement (M = 2, IQR = 2–3, n = 5) as this helps extend the research focus and responsiveness:

> Our questions might become focussed on the people that we have got in the groups … maybe we are always focussing on areas that we have always focussed on … to bring new voices and new experiences into that group. (Researcher 4)

Researchers recommended instituting adequate facilities and funding for involvement, especially to support diverse involvement (M = 2, IQR = 1.5–2.5, n = 3):

> If it's not properly funded and we're not really given the time to do it properly or adequately that's when it becomes very unsatisfying for the people you are engaging as well as for the researchers themselves. (Researcher 1)

Researchers indicated that involvement would work best if a collaborative approach with other organisations and charities was taken – reaching out to people and using wide advertising (M = 5, IQR = 5–5, n = 5):

> Helping us translate the research that we do into patient-, family- and also policy-relevant findings. Sometimes we have patients and families living with a particular condition … they have very good links with support groups for people with that condition and they have a good understanding of what other organisations might be relevant in terms of disseminating findings. (Researcher 1)

Table 2. User and researcher results for question 1: how can patients, families and the public contribute to research in order to improve its quality and relevance?

Order of priority (for users)	Recommendations	Users (n = 12)			Researchers (n = 5)		
		Median[a]	Quartile (1st–3rd)	Number that ranked this item in their top five	Median[a]	Quartile (1st–3rd)	Number that ranked this item in their top five
Most important	Widen palliative care research to the public and other illnesses, that is, not just cancer	2	(1–3)	9	N/A	N/A	2
	Involvement in the complete research continuum (i.e. from start to finish)	3	(1.75–5)	8	N/A	N/A	0
	Early involvement in idea generation and study design, before the idea is thought of ask patients and/or families and/or the public	3	(3–4)	7	2	(1.75–2.25)	4
	Make involvement visible beforehand, during and after the research (e.g. what difference did it make?)	4	(2.5–4.5)	7	N/A	N/A	2
	It can help identify researcher bias and ensure quality	N/A	N/A	0	1	(1–1)	3
Least important	It can aid dissemination and increase the impact of the research	N/A	N/A	2	4	(3.75–4.25)	4

N/A: not applicable.

[a]Scores are only shown if an item was ranked within the top five by ⩾50% of the respondents. A higher median indicates a more important item.

Table 3. User and researcher results for question 2: how might patient, family and public involvement work best in the Cicely Saunders Institute?

Order of priority (for users)	Recommendations	Users (n = 12)			Researchers (n = 5)		
		Median[a]	Quartile (1st–3rd)	Number that ranked this item in their top five	Median[a]	Quartile (1st–3rd)	Number that ranked this item in their top five
Most important	CSI takes the lead role in implementing understanding of palliative care for lay people, ensure people understand the same thing by 'palliative care' and get people talking about it	1.5	(1–3.5)	6	N/A	N/A	2
	Flexible and varied ways to get engaged, flexibility in engagement and different levels of engagement	3	(1.5–3)	7	1	(1–2)	3
	Well-planned and properly funded (potential guidelines for researchers on patient/family and public involvement)	N/A	N/A	1	2	(1.5–2.5)	3
	Wide access, ensuring diversity (aiming for representativeness) and have the facilities to support diversity	N/A	N/A	5	2	(2–3)	5
Least important	Collaboration with other organisations and charities, reaching out to people and wide advertising	N/A	N/A	5	5	(5–5)	3

N/A: not applicable.

[a]Scores are only shown if an item was ranked within the top five by ⩾50% of the respondents. A higher median indicates a more important item.

Question 3: how can researchers and patients, unpaid caregivers and the public benefit from patient, unpaid caregiver and public involvement?

A total of 15 recommendations were generated (Table 1).

Users. The highest level of agreement for question 3 was demystifying perceptions of palliative care and raising awareness of palliative care and research (M = 2, IQR = 1–2.5, n = 8; Table 4). Users suggested methods to achieve involvement diversity, suggesting early recruitment via general practitioner (GP) surgeries, via different social media platforms (such as Facebook) and through proactive personal contact in the community:

> Rather than waiting for the patients to come to you … You're not just a patient when you're in hospital are you?! You're a patient when you're at home … when you're doing your shopping … You can ignore telephone calls … posters … emails but you can't ignore a person. Whatever type of engagement it's just better to have that personal [approach] … (Public 1)

Users wanted to take a lead in coordinated communications and let people know why involvement is important in research (M = 2, IQR = 2–2, n = 9): 'The power is in the personal voice of implementation' (User-advocate 1). The third priority was wide dissemination of research findings, even if the results were negative (M = 3.5, IQR = 2.25–4.75, n = 6): 'because it all influences care' (Public 1). For users, dissemination was inextricably linked with impact and benefit: 'There are only three words [that matter]: contribute, involve and benefit' (Caregiver 5). Practical methods to evaluate impact were shared:

> You put in your ideas about what's important to you as a person with [a type of condition] or as a carer of someone with [a type of condition] and then the priorities are chosen and then the next stage is proposals that have been put in for funding. You grade them on a smiley-face scale from one to 10 … then the results of our assessment plus the results of the scientists' assessment who have seen whether the research is good science or not, come together. (Caregiver 1)

Researchers. Researchers' top priority was research efficiency and relevance to improve care (M = 1, IQR = 1–4, n = 4): '… it has really helped that there are some people [users] who bring us back to what we were actually trying to find out, bringing us back to our research question and objective and making us stick to that agenda' (Researcher 5; Table 4). Another clarified that 'At the end of the day it's [involvement] going to reduce research wastage as you're not answering pointless questions' (Researcher 2). The second priority was demystifying palliative care and raising awareness (M = 3, IQR = 2–3, n = 5). The third priority was

users taking a lead in coordinated communications and sharing the importance of involvement (M = 4, IQR = 3–4, n = 3), ensuring that people understand the research.

Discussion

Our study identifies four key elements essential for an optimal model of involvement and corresponding methods for palliative care research. First, researchers must promote the contribution that users deliver and emphasise the difference that they make. This sustains engagement and aids user satisfaction. To help achieve this, researchers need to clearly define palliative care and communicate clearly about it. Clear agreement about what constitutes palliative care will help users demystify palliative care and disseminate findings to others. Second, early involvement (i.e. getting people involved as close to or even before the start of a project) is fundamental to improving research productivity, quality and relevance. Third, a model that involves a high degree of flexibility is essential. Diverse virtual and face-to-face methods are needed because of disease fluctuation and progression, and unpaid caregiver priorities and responsibilities. Suitable methods include the following: proactive community engagement strategies, letters via generalist providers, focus groups, face-to-face meetings, online forums, tools to measure impact and social media platforms. Fourth, users should be encouraged to add value through enhancing productivity, and improving quality and relevance, as this is prioritised by researchers.

Users and researchers were clear that early involvement is essential. However, research has shown that when users first become involved in research, they may not be entirely sure about their roles and what they might hope to achieve.[4] Therefore, we recommend that time be devoted to clarifying roles early on. There also needs to be scope to develop roles throughout projects. We suggest that an initial relationship- and knowledge-building phase be considered to induct new users. This recommendation corresponds with ethnographic data that has shown that collaborative relationships are important to service users.[8] This phase can be facilitated through flexible, needs-based, face-to-face training programmes coupled with remote learning opportunities.[4] Good national, pump-primed, capacity-building demonstration projects have been implemented in palliative care and these can be used as examples to develop future work (such as the Complex Interventions: Assessment, Trials and Implementation of Services (COMPASS) collaborative[16]).

Our findings demonstrated that users and researchers believe that involvement can demystify palliative care and raise awareness within the general public – helping to move palliative care beyond cancer. Participants agreed on the need for palliative care to focus more solidly on those living with non-malignant conditions. Therefore, through

Table 4. User and researcher results for question 3: how can researchers and patients, families and the public benefit from patient/family and public involvement?

Order of priority (for users)	Recommendations	Users (n = 12)			Researchers (n = 5)		
		Median[a]	Quartile (1st–3rd)	Number that ranked this item in their top five	Median[a]	IQR (1st–3rd)	Number that ranked this item in their top five
Most important	Demystify perceptions of palliative care and raise awareness of palliative care and research	2	(1–2.5)	8	3	(2–3)	5
	Take lead in coordinated communications (talking and listening) and tell people why it is important to get patients, families and/or the public involved	2	(2–2)	9	4	(3–4)	3
	Sharing more widely, even if negative	3.5	(2.25–4.75)	6	N/A	N/A	0
Least important	Reduce research wastage and increase relevance (improve future care)	N/A	N/A	3	1	(1–2)	4

N/A: not applicable.
[a]Scores are only shown if an item was ranked within the top five by ≥50% of the respondents. A higher median indicates a more important item.

public involvement, death and dying in society may be more frequently discussed. The denial of death and dying in society has been identified as a major barrier to achieving high-quality palliative care research.[17] User involvement may therefore have far-reaching benefits, and it may help address an intractable problem for the field.

Although both users and researchers prioritised the need for early involvement, only the users prioritised involvement throughout the entire research continuum (i.e. from start to finish). This result is similar to findings from a study that inolved cancer patients in commissioning services.[18] (Table 2). But many patients involved in the planning phases of a palliative care research project may die by the time the study has been completed. They will therefore miss out on being involved in disseminating findings. Many patients involved in palliative care research will also experience disease fluctuation which may compromise involvement. Similarly, demands on unpaid caregivers will fluctuate according to the needs of their beloved ones. Our findings therefore suggest that different users may be need to be involved in different stages of a palliative care research project. Plus, different involvement methods may need to be used at different stages. For example, a focus group with many may be facilitated initially to generate research ideas. This might be followed by email communication with key individuals to help refine a grant proposal and then another focus group with different users to aid interpretation of the research findings.

In our study, it was also shown that researchers are acutely aware of and prioritise user involvement to improve productivity and therefore reduce waste, for example, by avoiding researching an irrelevant need to the population. Researchers agreed on the importance of this. The IQR for this item for researchers was nil (i.e. IQR 1-1). But this was not a priority for the users (Table 4). Users may therefore need guidance and encouragement from researchers to deliver this priority. Billions of dollars of research investment are wasted every year because of correctable problems with research. Having users shape the healthcare research agenda is one way to help address these types of inefficiencies.[19] Our study highlights potential savings that can be made in palliative care research because of patient and public involvement. Therefore, investing in palliative care involvement infrastructure may produce a substantial return on investment.

Strengths and limitations

A limitation of this research is the study sample. Only users already involved in research and known to the CSI participated in this study. They were all English speakers. One of the findings from our project was the need to increase involvement diversity in future work. Achieving the right mix for research into the development of an involvement model such as ours is a significant challenge.

Another limitation was that very senior investigators, for example, those who lead on large programme grants, were missing from the consultation. Also, we used an ordinal ranking scale for our nominal group work rather than an interval scale. An interval scale would have allowed for a more thorough examination and understanding of the differences between the individual rankings.

Conclusion

Researchers should ensure visibility of involvement, stress its impact and provide clarity regarding the definition of palliative care. Users are to be encouraged to remain focussed on adding value to research through concentrating on improving research productivity (efficiency), quality and relevance. Implementation, effectiveness and cost-effectiveness research is required to examine the outcomes of this involvement model. Early and flexible involvement opportunities need to be offered for involvement in palliative care research to succeed. Involvement in dissemination should also be encouraged.

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