Author’s response to reviews

Title: Hearing the voices of older adult patients: processes and findings to inform health services research

Authors:

Sally Fowler Davis (s.fowler-davis@shu.ac.uk)
Anne Silvester (anne.silvester@sth.nhs.uk)
Deborah Barnett (deborah.barnett@sth.nhs.uk)
Lisa Farndon (Lisa.Farndon@sth.nhs.uk)
Mubarak Ismail (M.M.Ismail@shu.ac.uk)

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Author’s response to reviews:

Response to Reviewers

Reviewer #1: This paper describes an interesting process that has the potential to be useful to other researchers who want to involve and engage frail elderly people in their research. My comments mainly relate to where I think the article could provide greater clarity and detail.

Plain English Summary:

- I didn't understand the reference to 'reported priorities' in the first sentence.

Agreed, this has been removed as it was unclear

- Final two lines on page 1: this sentence implies that the priorities about independence were unexpected, but I don't think that was the case. Also, it isn't clear if you mean priorities for research or service delivery.
Older adults expressed a range of views about their experience of discharge planning and this provided an important perspective on patients' research priorities associated with their personal independence. Efforts were taken to ensure representative views across a cross section of the population.

Abstract:

- Under the objectives you don't mention anything about identifying priorities, so this feels disconnected from the results section.

Thanks - amended to align objectives and results

Introduction and background:

- Page 3: the aim is stated much more clearly here. Was the aim to influence research and service development at a national level (ie England)? I wasn't clear later on in the paper if it was more of a regional or perhaps city-based focus (see also page 5, final paragraph).

The scope of the initiative is now reported as 'community' as you suggest - with further detailed later on

Design:

- Are you able to give more detail on the 'established NHS PPIE group'? Were they from your area?

- How were the existing and known groups identified? I think some practical detail on how you went about identifying groups, would be useful for other researchers for whom this is a new challenge. (The detail on page 7 about the types of groups approached is great.)

Thanks - we have slightly amended to add detail

Participants and attention to diversity:
- Were the people that you engaged with older and frail? How did you define this? Had they been recently discharged from hospital? I'm wondering if people had to meet certain criteria for you to want to talk with them.

Frailty as a term is used to reflect the post-discharge state, not a formal syndrome. We have tried to clarify the criteria

Findings:

- I was quite confused about the priorities - it wasn't clear to me if they were all priorities for research (what kind of research?) or for service design/improvement (where?) The D2A is a national programme about discharge but the RDS funding was provided to do PPIE for the City. Also, are they in ranked order, and if so, how did you measure their relative importance? We did not rank the priorities The first line refers to the 'experiences of NHS patients' - do you mean 'frail older NHS patients'? yes this is added. How have you turned their experiences into priorities? I think the intro here needs more explanation and clearer parameters.

- Presumably the quotes have been taken from your notes (I don't think you recorded)? Yes

- Priority 5 - maybe rephrase to make it clear that it's about communication processes between hospital staff and patients/families. Done

- Priority 6 - 'research priorities' - again, I'm confused, were the previous priorities not research priorities? Did you specifically discuss research with the participants (it's not on your topic guide), or have you inferred where research can address the unmet needs they've expressed? I think this needs to be clearer.

Thanks for the comments- we have sought to clarify that these were topic areas for research and that 'maintaining research priorities is a better title. To clarify we have also added a section into Priority 3
The introduction to the finding now reads: "a series of topics to inform the continuing service improvements and to ensure that research planning was prioritised around patient experience." please see page 9

Discussion:

- page 12, para 2 - it might be worth being clear that the JLA Dementia Partnership priority on independence was the top priority identified by patients, carers and clinicians.

- I wondered what else you had learned from the process and what had been challenging. Some of the literature you've referenced about involving older people is quite dated, so this is an opportunity to share some fresh, practical intelligence.

Yes a short section is added on the particular important of experienced and well networked patient representatives in the first instance- see page 15

Conclusion:

- I noted that the first sentence is the first time you've directly articulated that the paper includes 3 examples of PPIE - I think this is a strength and could be mentioned earlier on to give a stronger sense of structure/progression to the reader.

Thanks- we have added small sections to the plain English Summary and to the introduction

- The final sentence is quite strident! The qualitative researcher in me is thinking you should couch it in 'having the potential to...'.

Thanks we agree and have amended
Reviewer #2: Hearing the voices of older adult patients: processes and findings to inform health services research

Reviewer comments - Janet Wale

Plain English summary and Abstract:

Good summaries of the paper

Use of terms:

These need to applicable to and recognised by a global audience

'frail elderly people' - via Google: frail elderly. 1. individuals over 65 years who have functional impairments. 2. sometimes used to describe any adult over 75 years.

How the term is being used in this paper needs to be defined up front

Thank you we have added a generic descriptor into the for the benefit of the international readership

Use of 'the city' - an English provincial city? On page 3 we have replace northern with provincial as suggested

The term 'gatekeeper' when referring to "local clinicians or community leaders", that is two very different 'types of people'.

We agree and have used these two examples however adding 'and/or ' acknowledge the difference
Explain the "discharge to assess (D2A)" model (Page 5) as this is not a term recognised by a broad readership.

We feel that we have explained sufficiently in the last paragraph on page 5

Background/Introduction:

Page 3, starting line 49. In delivery of services, patient experience of health care is not referred to yet this is an important element that is referred to in the discussion section of the paper. It would be helpful to separate service delivery models and research goals of patient and public engagement so the distinction is clearer.

Thanks for identifying a problematic sentence, we have amend the paragraph on P3

The concept of an academic positioned within a hospital environment may be new for readers from a range of countries (presumably to inform new service delivery models) and so a brief explanation would be very helpful.

Whilst we would like to include more detail there is a limit to the word count that prevented us from adding further detail

A definition of what the authors mean by 'frail older people' would be helpful here. Also, there is no mention of cognitive impairment and dementia in this population, and how that is taken into account in this work.

We have amended and added a descriptor as suggested and in this project no-one was recruited or not recruited because of cognitive impairment and dementia- this covered under the definition of 'frailty as referring to over 75, with some mobility issues and a wide range of health conditions and care needs.

Page 5: the planning for the timely application of the "discharge to assess (D2A)" model needs to be explained, and whether it is in place at time of discharge to avoid any deterioration in health and functional ability….

We have explained the nature of the community care with a small addition to the last para on page 5
By placing the PPIE heading at the end of this section it comes across that the service received some funding and so applied the engagement without any clear objectives in mind - rather than to address serious issues about older frail people in hospital and in planning their discharge, and involving the people concerned.

Rather, state at end of the intro that this paper is to describe how you went about directly involving frail older people in discussions about discharge from hospital and identified issues and concerns, and out of that experience how you have set up a Community Elders Panel …

Yes we see your point and have added a sentence at the end of Introduction and also changed the header on page 6

Methods:

This section is informative.

I do not see that the last sentence (and presenting stakeholder involvement) on page 8 (Collated findings) is relevant to this paper.

We have accepted this advice and removed the sentence referring to the research that followed on from this activity

Findings:

Good summary

Does not demonstrate clear differences between the various groups involved in the PPIE State at bottom of Page 11 that a Community Elders Panel was not set up until 3 years later ie put statement into context

There is reference to this in the first para on page 16 to provide context
Discussion:

The opening sentence talks about 'a range of views' across different participants (strongly influenced by their social and family context or by the presence or absence of a social and family network) - yet this is not evident from the quotes used in the Results section…. Also, line 57 on same page states: "Other findings from the project revealed few differences in the responses of the participants regardless of socio-economic status, ethnicity or gender."

We have deleted the earlier point that could appear contradictory

1st para message: returning 'home' clearly has strong associations with being independent

Page 12, line 21/22: talks about 'patient and public' - needs more explanation about how 'public' involved. Is this through the original PPIE group/and how many of these were 'public'/where do carers sit? That is, do you need to refer to 'public' here as is confusing?

We agree and have stated carer which is actually more accurate

Line 26/27: A key finding was the wish to remain independent throughout their care, which aligns to the research priority identified by people with dementia from the James Lind Alliance26. What it means to 'remain independent throughout care' is obscure to me; and how this connects to the reference is also unclear and would need explanation [if it is relevant to this paper].

we have removed 'throughout their care' but have retained the JLA reference to demonstrate an alignment to this work and organisation

2nd para message: most people wish to be discharged home as soon as possible (priority 1), but the quality of the discharge is equally as important. Ref 30 is a relatively old reference and more recent references/reviews could also be quoted here, from your existing references that provide very clear messages about the need for consultation with the older patients themselves and their families, and preparations for their care 'at home'.

Thank you we have updated the reference
Page 13, top of page: this seems to be the key message from this paper - from research in this area and confirmed by the present work where patients (frail elderly) were themselves asked.

Line 23: "The findings have been reported to the clinicians involved in D2A within the Trust enabling positive changes to be made to some of the processes…” - it would be good to include some examples…

We feel this is included by referring to the priorities in feedback to service

Page 14, reference to the Community Elders Panel (CEP) - surely this is about improvements to services and not just research (as referred to in opening pages of this paper)?

We agree but we are using research to drive service improvement but we have removed the reference to research so this is not seen to only be about research infrastructure

There seems to be a tendency for the authors to 'hang on to the current 'jargon' within UK rather than to the essence of what is happening within health services generally.

For example, patients and members of the public (page 15, line 19) could be replaced by 'people'

We have decided not to amend this for consistency but take your point

Page 15: "It was hoped some of those who participated in the D2A engagement would join the CEP but this did not occur. The time frame from the initial project to the start of CEP recruitment was over 3 years" - so perfectly understandable, especially for older people whose circumstances may have changed. It is good that the contacts and venues were able to be used.

yes we refer to this

I note that no mention of cognitive ability/memory is made yet this must be an important consideration in people who are older and frail. How much does this come into play when looking for people to be part of this work and for sustainability of the panel?

We have not mentioned cognitive impairment other than now, in a definition of frailty in the introduction- 'significant functional impairment'- it may be that some of the people we contacted or currently contact have impairment to memory but we do not ask and unless this information is offered or is evidently limiting the PPIE process we think it is more important to get a range of opinion
Line 19: patients and members of the public/people who are over 75 years of age, with some mobility issues and a wide range of health conditions and care needs - is this your working definition of 'frail elderly'? If so, use it in the introduction to the paper….

yes this was a good idea and we have added a definition to the introduction

Under 'Impact' - how important is the factor that many of these people state that loneliness is a problem [when discharged from hospital]. Is having a visitor who wants to talk to them the 'return' that the people get back? Does this need to be discussed?

We think it may be but need to evaluate whether this is the case for our CEP group? The CEP has a continuous recruitment so it is a plan we have for the future - the informal evaluation undertaken by AS is in first para on page 17

Page 16, 'Limitations' - why would these findings NOT be generalizable to other populations when using similar methodologies? You have covered focus groups in venues that people are comfortable with and where they have support; and at home visits. What other factors limit the generalizability?

We think the main reason is in the following sentence " The PPIE and follow-on activity benefitted from an institutional commitment to the formation and maintaince of formal panel activity"- we are often ask how we managed to fund the co-ordinator and allow them to sustain recruitment and relationship building

NOTE. This PPIE clearly identifies the issues and concerns of this group of patients; but does not address what the service is going to do about it, other than prioritise research…. We had to limit the remit of the paper but it is an interesting question- DB was part of the D2A team and so the feedback from the study was undertaken via the planning group

Conclusions:

Clearly stated. Important to emphasise at start this is in relation to care of the 'frail elderly'

Two important outcomes - confirms research around concerns about discharge from hospital - preparation and timing

- importance of learning directly from older people themselves
Thanks for this point -We have added this emphasis

Appendix A: Information sheet:
Was this prepared with input from PPIE group, and how much notice was taken of that input in terms of use of plain language?
Is this about research to inform service design? -Service design may be of more interest to people who participated
We are clear that this used interviews and focus group in the PPIE and was not research - otherwise we would have needed to undertake more thorough ethics and governance. That is also why we limited the conclusion to the findings in relation to research planning. In line with suggestion from another reviewer we have reduced the words around the bids that have been submitted since

References:
Should be restricted to those references of value for informing the issues covered in this paper.
All checked and relevant

Reviewer #3:
1) It seems strange that no Ethics Approval of the project was obtained since patients are vulnerable and their rights should be protected. No explanation was given why it was not sought or why it was excluded. Was it for time constraints? or for other reasons? If so, these should be listed.
This project was not undertaken as a qualitative research or study but rather a PPIE process. We think this is covered on page 6
"As a PPIE initiative, this project was deemed to be exempt from ethics by the clinical research office in the sponsoring NHS Trust. The work was registered as a service review and carried out by clinical academics working within the Trust, seeking the views on elder research and furthering the development of a sustainable PPIE infrastructure. The funders who are Regional Design Service of the NIHR in Yorkshire and Humber (RDS Y&H) recognised PPIE as service review activity. "
2) Although in the preliminary investigations the patient suggested that face2face was the best preference for this study. Contrary to this most interviews were conducted through focus groups. In my opinion, if this study was carried out face2face, a more honest set of replies would have been obtained since the patients would have been more at ease during to answer confidential questions.

Thanks for the comment- we think that we cover this issue on page 7 under recruitment:

" Volunteers who agreed to take part were given an appointment to talk individually or be part of a focus group in a place of their choice. Most preferred to be visited at a community venue but not a hospital site with just two preferring to be in their own home. Individuals and groups were invited to participate with support for travel, refreshments and any untoward costs associated with room hire. This enabled small organisations to facilitate by inviting members and potential participants and offering hospitality on behalf of the PPIE initiative."

Also the discussion (please see last para page 14) about the choices people made about venue and face2face individual or group

EDITORS' COMMENTS:

Overall the structure may need some tightening and some additional practical detail, for example to be clear to our international readership as to who does what in an UK hospital regarding research vs service delivery improvement.

This has been undertaken

Please also take a moment to check our website at https://www.editorialmanager.com/riae/l.asp?i=12162&l=36JRGAA3W for any additional comments that were saved as attachments. Please note that as Research Involvement and Engagement has a policy of open peer review, you will be able to see the names of the reviewers.