Reviewer's report

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

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Reviewer: Janet Wale

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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

Use of 'the city' - an English provincial city?

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

Explain the "discharge to assess (D2A)" model (Page 5) as this is not a term recognised by a broad readership.

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. 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.

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.
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.

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 …

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.

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

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."

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?

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].

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'.

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…

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)?

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'

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.

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?

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….

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?

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?

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….
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

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

References:

Should be restricted to those references of value for informing the issues covered in this paper.

Level of interest
Please indicate how interesting you found the manuscript:

An article whose findings are important to those with closely related research interests

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