Exploring patient and family members’ views and experiences of involvement in critical care research and quality improvement: a qualitative study

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Introduction and background

- Importance of Public and Patient Involvement (PPI) in healthcare research widely acknowledged (Denegri, 2015)
- Impact on individuals, service delivery and health outcomes within critical care remains unclear, as does the best way to involve people who have experienced critical illness
- Most published studies describe case examples with little discussion of the method of involvement or impact (Bench et al., 2018; Domecq et al., 2014).
- Where experiences are reported, these tend to focus on those of clinical staff and/or researchers as opposed to service users (Bench et al., 2018).

Study Aim and Design

- To explore former patients' and family members' views and experiences of involvement in critical care research and/or quality improvement
- Qualitative methodology using semi-structured telephone interviews
- Ethical approval granted by King's College, London (LRS-16/17-4217)
- Funding through NIHR CLAHRC south London
- Informed consent obtained from all participants prior to data collection
- Anonymised data subjected to a standard process of inductive thematic analysis (Newell and Burnard, 2011)

Participant	Gender	Age	Type	Marital status	Ethnicity	Employment status	Highest Qual	Location
1	Female	45	Family member	Married	White British	Housewife	GCSE	Staffordshire
2	Male	39	Patient	Married	White British	Full time	Post grad	Staffordshire
3	Female	53	Family member	Married	White British	Full time carer	Post grad	Middlesborough
4	Male	47	Patient	Married	White British	Full time	A levels	Milton Keynes
5	Female	50	Patient	Single	White British	Full time	A levels	Liverpool
6	Male	UK	Patient	Married	White British	Full time	Post grad	Liverpool
7	Male	59	Family member	Single	White British	Self employed	Doctorate	Liverpool
8	Male	70	Patient	Married	White British	Retired	Degree	Surrey
9	Male	78	Patient	Married	White British	Retired	Masters	Berkshire
10	Female	60	Patient	UK	White British	Unknown	None	Newcastle

Themes

Making it happen	Overcoming hurdles	It helps	Respect and value
Nature of involvement	Meeting logistics	Personal Benefits	Support, encouragement and feedback
Inclusivity	Health status	Wider impact	Training needs
Providing opportunity			Shared language

Making it happen: Nature of involvement

"We started initially…helping to contribute towards research and also the process of improvement…then we're going to move from there into the trauma research… and I've also explored communication with patients who have got tracheostomies"
(Interviewee 2)

"I would be concerned…somebody without a clinical background managing my personal details about what happened in ICU, I probably wouldn't give the information, to be honest"
(Interviewee 5)

"If you read that article…they were my comments on there"
(Interviewee 8)

Making it happen: Inclusivity and providing opportunity

"You don't want to have the same people constantly at all these different research projects, you want to kind of, make sure you get a broader patient view rather than just one individual" (Interviewee 4)

"I would hate to exclude people who haven't had the advantage of education…or if somebody is not very articulate" (Interviewee 7)

"everybody's different…some people will be ready to share six months after they've come out of ICU, somebody will be several years down the line" (Interviewee 3)

"A lot of people like to come through me…there's no pressure…you would sort of be the intermediary between the research team and the group" (Interviewee 3)

"Aren't they of a greater asset because they lost loved ones?" (Interviewee 5)

Overcoming hurdles: meeting logistics

“You don’t want people to lose interest halfway through the study…Of all the people that must have attended in the beginning and who applied to do the study, there’s only actually two of us who go” (Interviewee 5)

“I find it easier to talk and discuss things with other people in a meeting...Anything that involves dealing with people, I find it much better to do it face-to-face” (Interviewee 9)

“It all worked quite well in those small working groups, and when the bigger group came together you were already into it and so it was perfectly reasonable to participate in the bigger meeting as well at that stage” (Interviewee 9)

“The more constraints you put in...then they drop out” (Interviewee 5)

Overcoming hurdles: Health status

“I was on walking sticks for a while and then crutches…it was quite a military ordeal for them to get me into car and get me into the seat and, you know, on the train, that kind of thing” (Interviewee 2)

“I suppose the difficulty is constantly kind of, facing the emotional impact of the trauma…we’re sort of finding it difficult to keep going over that if you like…I sort of went through post-traumatic stress and everything and I had to be counselled as well” (Interviewee 2)

“People have such a desire to help, that they will put themselves forward and they will volunteer before they’re ready to and that could potentially end up damaging the research…potentially the person himself” (Interviewee 4)

It helps: Personal benefits and wider impact

"I would say, 'Try it because it helps your recovery. I think it helps you mentally… It feels good to help others" (Interviewee 5).

"There's one gentleman that's lost his wife and he's very grateful and happy to be part of the group actually because he, for one thing, it gets him out, he's socialising…so he's happy to be there too, for the social side" (Interviewee 1)

"Quite often when we're in these meetings with the professionals, they'll turn around and say, 'I've never thought of that before, I haven't been a patient'" (Interviewee 8)

"If somebody gave me a million pounds, it wouldn't be enough for what, you know, they saved xxx's life and his life is so precious, so anything I can do that will make a difference" (Interviewee 3)

"When you've been through something so life altering, life threatening, it's the desire to do something to repay what you feel is a debt of gratitude" (Interviewee 4)

Respect and Value: Support, encouragement and feedback

"You find that those people who are patronising you soon listen when you start to put your ideas forward and so they start to respect you" (Interviewee 8)

"make them feel an equal part of the team" (Interviewee 4)

"I was a little bit nervous at first but then they put us quite at ease and it was fine. No problem at all" (Interviewee 5)

Respect and value: Training and shared language

"As a patient you sort of want to know what your areas of responsibility are" (Interviewee 2)

I don't understand at least 50% of this'…somebody like myself who can't understand the medical terms and phraseology, it would put people off"
(Interviewee 5)

"almost a kind of, underground map of the different stages explaining…where we're at, where you'll be involved, where you get on, where you get off…just help visualise the view from the patient's involvement"
(Interviewee 4)

Study limitations

- Small sample of exclusively white British participants and reports only the experiences of people located within a single geographically defined healthcare system
- Clear sense of data saturation, supporting that these findings may have wider resonance

Conclusions and Implications for practice

- Critical illness survivors and their families want to be involved in research/QI
- Individual and wider benefits of involvement
- PPI arrangements should be considered early in project development
- Flexible and individualised approach
- Offering opportunity-it is "*ok to ask*" (NIHR, 2014)
- Representation?
- Gatekeepers and protectors
- Clarification of roles and responsibilities +/- training
- Value: language, payment and respect

Questions?

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