

A collaborative approach to patient involvement in health research: challenges and enablers

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Abstract

There is considerable concern that patient involvement within health care research is tokenistic in nature. This has led to an increasing interest in the quality of patient involvement in research with active collaboration with patients and carers encouraged. In this paper, with specific reference to renal disease, the aim was to identify and explore the possible challenges that may arise from academic researchers collaborating with clinicians, patients and carers as part of the same project panel. The project panel consisted of the principal investigator, senior research fellow, research practitioner, a nephrology consultant, a cultural liaison officer, pre-dialysis, dialysis and transplant patients and also a carer. Semi-structured qualitative interviews were conducted with members of the panel. The main challenges identified included: ensuring the panel included patients from different modalities of renal disease and different social and cultural backgrounds, managing member expectations, conducting meetings, communication, financial constraints and patient anxiety. Enablers of the collaborative process were found to be: relevance to the research project, early involvement, previous experience with research, panel composition and flexibility. The study has clear practical implications for collaborative involvement of patients and carers in social and health care research.

Keywords: patient involvement, collaboration, challenges, enablers

Introduction

There have been three main drivers for the involvement of patients within health care research (Wright *et al.*, 2010). Firstly, there is a general assumption that services will not be able to meet the needs of patients unless patients are involved in the design and development of the service (Miller *et al.*, 2006), which has led to a political imperative for the involvement of patients within research (Hunt, 2000; Department of Health, 2001). The second driver has been the growing movement of patient and carer advocacy groups; and finally the academic community itself has driven patient involvement, with academic researchers publishing anecdotal evidence of the benefits of involving patients (Wright *et al.*, 2010).

Despite increasing initiatives encouraging service user involvement, little was known about the practicalities of achieving patient involvement within the research setting. This led to the establishment of the group INVOLVE in 1996, with the remit of enabling researchers to embed patient and public involvement within their research. INVOLVE emphasise the role of patient involvement as a method of delivering safer health care and improving health care services (Ocloo & Fulop, 2012). Several systematic reviews for example, PIRICOM (Patient and Public Involvement in Research: Impact, Conceptualisation, Outcomes and Measurements), PAPIRIS (Patient and Public Involvement Review on the Impact of Health Care Services) and INVOLVE (Staniszewska *et al.*, 2011); have found a range of impacts on research that are attributable to patient

involvement (improved relevance of research questions, appropriate approaches to data collection and interpretation of results). Patient involvement in health care research is now being assessed and examined in all aspects of research, from peer review of funding bids to research ethics applications, to the dissemination of research findings and development of research training for service user researchers (Beresford, 2003; 2007).

Patient involvement in research is often compared with Arnstein's (1969) 'ladder of participation' with participation ranging from consultation (researchers seeking the views of lay people) to lay control (whereby lay people lead on the design, undertaking and dissemination of research). Oliver *et al.* (2008) have proposed a number of advantages and disadvantages for each level of patient involvement. For example, although the consultation approach is associated with being able to obtain the view of patients with ease and with the added bonus of having no commitment to act on these viewpoints; such top down approaches are criticised for involvement being 'an add on' and tokenistic. Collaborative approaches to patient involvement may be considered beneficial as access to research participants is improved, and patients are more likely to disseminate the findings of the research due to feelings of ownership (Oliver *et al.*, 2008).

Despite the benefits of utilising the collaborative approach to patient involvement within health care research, there are a number of challenges within this process that need to be addressed. For example, collaboration with patients and carers is considered time-consuming with further cost requirements. Furthermore, much of previous literature discussing the challenges associated with collaboration has been presented from the researchers' perspective. The aim of the current study is to explore the challenges faced by a diverse range of members of a research project panel (patients, carers, clinicians and health service researchers) and to identify the enablers of working collaboratively.

Context of the project panel

The main objective of the research project (for which the project panel was established) was to address the research question as to whether an electronic reporting system such as Renal Patient View (RPV) can increase the amount of information available to improve the quality and safety of health care. RPV was established in 2005 as an electronic health record for renal patients (to include all modalities of treatment, from pre-dialysis through to transplant). Through the use of RPV, patients are able to check their blood test results, referral letters and other specific health care advice. As RPV does not provide a portal for patient feedback on quality or safety of health care, the research project aims to adapt existing RPV technology to accommodate a patient led feedback system.

Based on the findings of recent reviews of patient involvement in patient safety (Hall *et al.*, 2010; Catwell & Sheikh, 2009), which suggests that patient inclusive feedback schemes should be designed with patients; it was decided that the study would be grounded in patient involvement from the outset. Patients are considered active collaborators throughout the research project. They are named applicants on the funding bid and the intervention is co-designed with patients and the research project is co-steered with patients. A project panel was set up which met every two months during the duration of the project.

Method

Prior to commencement of the current study, full ethical approval was obtained from the South Yorkshire Ethics Committee (11/YH/0371). Independent researchers (who were not part of the research team) conducted semi-structured interviews with each member of the project panel. The panel includes the principal investigator, a senior research fellow, a research practitioner, a consultant nephrologist, an ethnic liaison support worker, four patients (transplant, dialysis and pre-dialysis) and a carer. Each session (lasting an average of one hour) was digitally recorded and fully transcribed.

The data were analysed using thematic analysis (Bryman, 2004). A series of codes were used to assign a conceptual label to sections of the transcripts. Research team (SP, SG and ID) discussions about code definitions and patterns in the thematic analysis facilitated the interpretation of the data. The reliability of the coding process was checked by the third author (ID) who reviewed the coding applied to four transcripts.

Findings

The findings will be discussed with regards to specific challenges experienced by the project panel followed by the enablers of the process.

Challenges

Panel composition

A key aim of the project was to set up a panel that included patients from all modalities of renal disease (i.e. pre-dialysis, dialysis (both Haemodialysis and Peritoneal Dialysis, and Transplant). They were also keen to recruit panel members from a wide range of age groups, ethnic and socioeconomic backgrounds. However, recruitment of patients was found to be difficult perhaps due to the severity of renal disease, particularly those undergoing dialysis were difficult to recruit due to the time commitment required by patients to attend meetings.

... it's quite hard to recruit your patients because they've got a Monday, Wednesday and Friday slot or a Tuesday, Thursday slot, yeah, so maybe that the meetings possibly look at alternating the dates so that they're not all, they don't always land on a Thursday coz then that will exclude 50% of the patients possibly. (Member 5)

A further challenge in recruiting patients related to the inclusion of non-English speaking patients, with an attempt to represent the local population in which the research project was taking place (Bradford, UK). A cultural liaison officer (who was also able to translate a number of languages) was

invited to participate in the panel, and also to recruit non-English speaking patients. Two non-English speaking South-Asian patients were asked to join the panel; however, these members only attended the first meeting of the project. The main reason for these patients opting out of the panel was proposed to be poor health but remaining members also perceived that language difficulties may have also been an important factor.

Well I think if you're coming to a meeting where you're not going to understand anything that's been said, and it's very difficult to have somebody there translating the whole time. I think in a meeting like that where you've got quite a big group of people or potentially sometimes we have a big group of people, and you've also got doctors, other health professionals who you might feel intimidated by, you don't know, from a patient's perspective. (Member 2)

I think if all the people we have on the panel would attend, we would have just been right because that has a nice number of patients we had there, but because some of the patients haven't been attending because of the medical issues, we've had a little bit of lack of patient involvement in it from a South Asian community, but that's something that circumstances outside of our control. (Member 10)

Interestingly, there appeared to be a tension between the desire to include a broad range of renal patients on the panel and the view that all panel members should be able to communicate adequately, as one patient member expressed:

You should have people that, I mean, I don't want to blow my own trumpet but you should have people like me, people who can put a viewpoint across, people that are actually concerned about what goes on there, because there are people there, Asian people, that are concerned about what goes on. Those are the kinds of people that you want to be getting, but at

the moment it seems the people that you tend to be picking on are the wrong ones unfortunately [laughs]. (Member 8)

Member expectations

One of the major challenges discussed by the panel members was the issue of managing expectations. Patients were found to be generally uncertain with regards to what was expected of them and were unsure of what they were able to contribute. Perhaps due to the lack of information provided to patients, one member was initially unaware he was part of a panel.

Well I didn't know I'd become part of a panel to be perfectly honest with you, erm, I just thought that I was going to be coming to these patient meetings giving my views and opinions on various issues, I had no idea I was going to be part of a panel. (Member 8)

A further challenge experienced by the panel members was managing the diverse range of ideas from panel members with some members considered to have 'personal agendas' that were perhaps beyond the scope of the research project.

We want to link up with other groups, I think as we're a patients' panel here we're the voice of the people, you want our voices for your research projects and everything, we should also link up with the hospital. (Member 7)

... so focused on a particular issue and what he wants to improve he drifts away from whatever we're talking about into that condition and what he wants to improve, and I think sometimes then things get lost with him because he's too focused on that, I think if especially someone has a particular issue and that's what they're focused on fixing... (Member 3)

Another challenge that emerged during discussions of expectations was the increasing emphasis (particularly from patients) on the outcomes of the research project. Patients appeared to be focused on

achieving positive changes (that were perhaps beyond the scope of the intervention being designed). There was some concern amongst the researchers that this would not be achievable and would potentially "unnerve" the patients.

I don't just want to sit on a panel and listen to Joe Blogs going on about something and then somebody else going on about something, what I want to see is I want to see results. I want to see action, I want to see things being done, I want to see change and I want to see that change. (Member 8)

... we wouldn't want the study to then fail because we're building up people's expectations and we can't offer that so we're trying to match what we'd like sometimes with what's realistic to offer, so for example some of the patients wanted that but then we've had to explain that that's not possible. (Member 3)

Meetings

One of the challenges experienced with respect to conducting the project meetings was maintaining the equilibrium of power between panel members. This was a particular challenge for researchers due to concerns that as patients became more confident they would gain more control over the research and the process would no longer be collaborative.

... when they get more confident and more kind of drive the project a bit more as it goes on but, then there is the danger that then they take over and actually it's meant to be more collaborative but we'll see how it goes. (Member 2)

Adhering to a democratic process was a further challenge for panel members, particularly for those who held strong views on the direction of the research.

... so the majority of rules and sometimes a patient, or for that matter a researcher, might have a particularly vehement view

about something and may not want to give in... we still have to remind them that they can't always have the casting view that they can't always get exactly what they want so that's a further challenge. (Member 1)

An additional challenge to the democratic process within meetings was the involvement of all members (a challenge experienced by the chairs of the meetings). As would be expected, some members of the panel were found to be more vocal than others, which required the chair to be diplomatic and actively encourage involvement from all members.

I think you also have to do that as the chair, you have to make sure people are saying things otherwise they're not really contributing and they should be doing in equal shares really, so I think it's one of those governance things – how to manage a meeting to make sure there's general participation. (Member 4)

One of the major concerns raised by panel members was the low attendance rate for meetings. This was a concern for all members as it had a significant impact on the running of meetings, for example, it shortened meetings and delayed decisions. The low attendance rate was thought to be due to the nature of renal disease that is patients had to attend three sessions of dialysis per week, attending hospital appointments, with fatigue also being common leading to patients not always able to attend meetings.

Another challenge is the nature of renal patients and they can be really quite sick and one of the problems is that they are often anaemic so fatigue is not uncommon, so that's something else that needs to be kept in mind alongside the fact that some of them die rather prematurely and we always have to be mindful and respectful of, the team of patients may reduce because patients have died along the way. (Member 1)

I think the only thing is, it's like I've mentioned, it's a lack of people attending that sort of shortens the meetings because they can't, they're unable to take anything further forward because that person isn't there to answer or question what it is that's being commented on. (Member 6)

Communication

A specific challenge related to communication was the use of clinical/research jargon within meetings and in written information. Although researchers made conscious efforts to avoid jargon, there was a fear that over-simplification of information might be patronising. Researchers had to achieve a balance between the two.

Yeah, because you can get stuck, can't you and fill it with medical jargon and you sort of, oh what's that all about, I know that because from when I was on the bench on the family panel they would put in the medical reports about these children and you'd think what on earth does that mean! So it's good to have it in plain English. (Member 9)

Well, if there's some bit of NHS jargon or something I don't understand, I usually ask, it's the nature of these things, you can't simplify everything, and a) it's patronising and b) some things just can't be like that, can they? (Member 6)

Establishing a preferred method of communication was also a challenge. Some members preferred receiving updates by email, whereas others found this impersonal and perceived the minutiae of the members' comments were being lost in emails.

I think it's good to pick up the phone and have a chat coz you can explain things better and you can have a more in-depth conversation, in email you just want to put bullet points down and what we need, but to actually discuss it in person or over the phone is better coz you can't pick up

everything from an email whereas if you're speaking to somebody there's so many questions that come out of a question so I think it's better to just pick up the phone and have a chat. (Member 10)

Financial

One practical challenge that emerged was related to financial concerns amongst the panel members. Although the panel was set up to be collaborative with each member's contribution considered equally important, members were not paid to attend meetings (only travel expenses were covered). This caused some anger with one patient who felt his contribution was devalued due to his misconception that the consultant was paid to attend the meetings.

But the thing is if these guys get paid for it why can't we? Because obviously it's my time as well, my time is as important as a doctor's time is. When I was working I used to get paid £50 an hour. You know what I mean and so if you add the maths together if you've got a doctor there at a meeting you'll be paying them at least £250 to be there because they're not going to be there for free, no-one does anything for free these days. (Member 8)

Patient specific challenges

Patients were found to experience specific challenges related to their involvement in the project. Some patients felt intimidated during the meetings due to considering clinicians and researchers as 'more qualified' and therefore more capable. Anxiety was also caused by patients believing they were representing an entire patient population and therefore were wary of making 'an incorrect' decision which would impact other patients negatively.

*It's nice to have a couple of patients there for moral support because when you're sat round a table with some quite high people you know, commissioners or people like ***** that have been in renal for years and years and years and researchers like yourself that are quite experienced and knowledgeable in their sort of field, you*

can sort of feel a bit intimidated sometimes. (Member 5)

Enablers

Relevance to research

The key enabler to the collaborative process was found to be the relevance of the research project to patient involvement. The intervention (an electronic feedback system) being designed was to be used by patients. Through collaboration with patients, the researchers hoped to design a system that would be relevant to patients and additionally patients would raise awareness of the system.

Well for this project I suppose it was, it is appropriate to have a patient panel because we're looking at something an intervention that's going to be a patient-led thing so it's very much centred around patients and their involvement and also the method that we're using this sort of very much linked to close collaboration with patients so really it's very appropriate for this project. (Member 2)

Early involvement

The setting up of a collaborative panel was significantly facilitated by early involvement from patients and clinicians. It was hoped by involving a patient advocate from a national organisation and a consultant in the write up of the research funding bid, the project would be more relevant to patients. Additionally the patient representative would provide links with the patient population and enable collaboration between the groups.

I think, I would hope that for this project the way it's set up that it will work more effectively because we've involved patients right from the start I hope. (Member 1)

Previous experience

Previous experience with patient involvement was also found to be beneficial within the current research project. Researchers had been involved with a number of research projects previously which had used patient panels, and they perceived this previous

experience had taught them how to work more effectively with patients. Patients and carers also considered their previous experience with research as beneficial as it aided them in understanding the process of the current study more clearly.

That's because I've learnt from experiences on the other study – the study where there have been some tensions, a better way of proceeding. (Member 1)

Clinician involvement

The panel consisted of a diverse range of individuals and many members felt the inclusion of a clinician on the panel was an enabler of the collaborative research process. The clinician's involvement was perceived positively by all members perhaps due to his willingness to collaborate with patients and as a direct channel to services.

I think the important thing is it's no good just listening and promising to have a look at something and not getting back, you need a framework really to say these issues have been raised in a formal way and there will be evidence of a response to it so we're just tightening up on that promise I suppose to listen but also to act as a result of that. (Member 4)

Proactive members

The panel membership included a group of proactive patients who were very willing to be involved with all aspects of the research process which was a significant enabler of collaboration.

I've been very proactive with the researchers, I've tried to get involved in any research that they need us on as a patient, so I've been involved in SAVVI (an interactive situational awareness tool), I've been in the renal project, I've been involved in testing the tablets, I'm very proactive, I must say there were about four or five members were always there and proactively involved. (Member 7)

Flexibility

Flexibility was highlighted as a key factor which enabled collaboration between members.

I think it's very much a developmental thing where you have to change according to the needs of the group; otherwise it's not going to work. (Member 2)

The authors were approached by the study research team to undertake an evaluation of the project panel. This clearly demonstrates the willingness of the researchers to be flexible in their approach to patient involvement.

Communication

Communication between members was aided by provision of clear contact details. In addition, patients were able to contact a patient representative if they had any anxieties or queries. This was set up as an additional support point for patients. Communication between members was encouraged beyond meetings, thus allowing members to keep up to date if they were unable to attend a meeting.

I think the meetings have to be the hub for what goes on coz of what they offer but the other side of that is that we make sure there's engagement through other means and whether that's just email communication or whether it means arranging meetings with the patients. (Member 4)

Discussion

A collaborative approach with patients within health care research is increasingly encouraged (Hunt, 2000), however little is known about the process. The aim of the current study was to explore the potential challenges that may arise from collaboration between researchers, clinicians, patients and carers whilst designing an intervention for renal patients. More importantly, the study has also identified a number of enablers for working collaboratively which has implications for future researchers who wish to set up a collaborative research panel with members from diverse backgrounds.

The findings of the study indicate that involvement of patients and carers in health care research is a dynamic process. The project was set up to be in collaboration between health care researchers, clinicians, patients and carers (that is in line with the 'partnership' rung of Arnstein's ladder of citizen engagement). It was found that during the various stages of the project, the level of involvement was found to either drop down the ladder to targeted consultation (i.e. panel style method of involvement) and also move up to 'placation' and collaboration. It was found to be a challenge to maintain the 'collaborative' status of the project with researchers concerned that as patients became more confident, this would lead to level of involvement becoming more user led. Tritter and McCallum (2006) highlight that engagement of service users is a complex phenomenon that requires dynamic processes legitimised by both parties, therefore models of participation should not be based on constrained conceptualisations of activism as is Arnstein's (1969) model.

A number of studies have identified challenges related to involving patients in health care research, for example, Clark *et al.* (2004) report that a significant challenge of involving patients is the attrition rate. Patients are likely to drop out of projects and panels due to hospital appointments, fatigue and illness. This was found to be a challenge

within the current study whereby all members of the project panel were concerned about the low attendance rate at meetings. The researchers sought to overcome this challenge by ensuring over-representation of patient panel members thus guaranteeing some level of patient involvement, despite not all patients being able to attend meetings. It is worth noting that patient 'drop out' due to fatigue/illness is a common phenomenon and therefore it is important that the involvement process be flexible and based on the patient/carers pace.

Further challenges identified include ensuring a representative panel was set up. Interestingly, the views of what the composition of the panel should be differed between patients and researchers. Researchers were focused on including a diverse range of people on the panel, however, some patients believed that only specific individuals should be invited to join the panel that is members should be able to speak English and be proactive. This suggests that perhaps when setting up project panels, patients and researchers should identify a recruitment criteria checklist when recruiting additional members to ensure there is no conflict. Surprisingly, one patient was not actually aware he was part of a project panel, suggesting that only limited information was provided to patients. The misunderstanding from patients in relation to what was expected of them may also be due to the various people recruiting members for the panel. For example, some members were recruited by researchers and others were recruited by other patients thus not all members would necessarily have received the same information. Further challenges included managing expectations of members that were beyond the scope of the project (for example, patients wanting quick action and change), actively involving all members during meetings and financial constraints.

As much of previous research exploring the challenges involved in patient involvement in research has focused on the researcher's perspective, it was of interest to explore the

challenges perceived specifically by patients. Patients were found to experience anxiety due to the perceived burden of representing the renal patient population. In particular, they were concerned that if an incorrect decision was made it would have significant consequences on fellow patients. In addition, patients were found to feel intimidated when working closely with clinicians and researchers whom they perceived to be more qualified for the job. This finding has clear implications for involvement of patients in research; it is to be recommended that researchers set up panels with a number of patients that are able to provide support for one another. If possible it may also be of benefit to set up additional support services/mentoring for patients.

The current study goes beyond discussing the challenges and also identifies factors that may enable the collaborative process. Significant enablers of the process were found to be the relevance of the research project to patient involvement. As the intervention being developed by the research project was a feedback system for renal patients, it was assumed that through active collaboration with patients, carers and clinicians, the intervention designed would be more relevant for users.

Interestingly, previous experience with patient involvement from the researcher's perspective was important as it was considered as a learning process through which methods/processes of patient involvement could be improved. Previous experience with research involvement was also a facilitator for patients as it enabled them to understand the research process and be more confident in their involvement. This suggests that support should be provided (that is, an induction process) for patients who do not have prior experience with research projects. As mentioned earlier, flexibility from all members was significant in enabling a more collaborative process which was also related to previous experience with conducting research. An obvious facilitator of the collaborative process was clear

communication. By selecting 'a patient representative' the communication process between researchers and patients was greatly aided. The patient representative also provided additional support for patients and encouraged communication outside meetings to keep all members up to date.

There are clear benefits of collaboration that are apparent from the interviews with the panel members. For example, all members felt they had gained information from participating in the panel, this was found to be particularly important for patients who were able to increase their knowledge about their illness. Further benefits included the networking opportunities provided by the collaborative panel: patients discussed how building new contacts was important in gaining new information. Patients also believed that their self-confidence had increased as a result of participating on the panel. Furthermore the findings suggest that patients and carers had a clear impact on the intervention designed. The conception of the intervention designed within the project was attributed to patients by the principal investigator who then developed the project proposal with a lead patient and clinician. The project adopted a bottom-up approach to ensure the intervention was relevant to the wider renal population. The involvement of patients led to ensuring the design of the system and language used was appropriate. For example, patients on the panel were keen that the system be labelled 'feedback system' as opposed to 'reporting system'. The patients were also involved in recruiting renal patients to test the system in a 'real world setting'.

The current study has a number of strengths and builds on previous research exploring patient involvement in health care research. It also goes beyond presenting the researcher's perspective on collaboration in research and focuses on the views of a diverse range of members, including clinicians and patients. Furthermore, by identifying the enablers of the collaborative process, there is potential to improve the quality of patient involvement in research and thus the impact of such

involvement on research outcomes. The identification of challenges within a collaborative research project will also facilitate other researchers to overcome these early on in the process. Recommendations to aid collaboration between academic researchers, clinicians, patients and carers include the following:

1. Provision of clear information regarding the likely outcomes and timescales of the research project to limit unrealistic expectations from panel members.
2. Provision of regular updates of progress to maintain interest, using a variety of communication methods for example, newsletters, study website and social media.
3. That existing social benefits experienced by patients through involvement with research should be developed further, perhaps through interactions outside meetings (coffee mornings) and involvement in the activities of the wider department.
4. Using mentorship to improve patient and carer understanding of research to enable patients and carers to make a more meaningful contribution to research through their participation/collaboration.
5. Develop collaboration by involving all members in establishing meeting agendas and writing up minutes from meetings thereby avoiding researchers always leading meeting agendas.
6. Set up advisory groups specifically for non-English speakers to ensure a culturally diverse range of people are involved in the research.

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