Exploring patient and public involvement in stroke research: a qualitative study

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ABSTRACT

Purpose: To explore the experiences of patients and carers involved in patient and public involvement (PPI) activities for stroke research.

Method: Semi-structured interviews conducted with stroke survivors and carers (n=11) were analysed using thematic analysis.

Results: Four key themes emerged: impact of PPI on the individual and the research process, credibility and expertise, level of involvement, and barriers and facilitators to PPI for stroke survivors and carers. The perceived benefits to the research process included: asking questions, keeping researchers grounded and directing the research agenda. All participants drew upon their experiential expertise in their PPI role, but some also drew upon their professional expertise to provide additional credibility. Stroke survivors and carers can be involved in PPI at different levels of involvement simultaneously and the majority of participants wanted to be more involved. Barriers to involvement included: location, transport and stroke survivors capacity to concentrate and comprehend complex information. Facilitators included: reimbursement for travel and time and professionals effort to facilitate involvement.

Conclusions: PPI in stroke research benefits stroke survivors and carers and is perceived to benefit the research process. The barriers and facilitators should be considered by professionals intending to engage stroke survivors and carers collaboratively in research.

Implications for rehabilitation

- This study has implications for PPI in stroke rehabilitation research, which could also be extrapolated to stroke rehabilitation service development and evaluation.
- Professionals facilitating PPI need to invest in developing supportive relationships in order to maintain ongoing involvement.
- Professionals need to be aware of how the varied consequences of stroke might impede participation and strategies to facilitate involvement for all who wish to be involved.
- For each rehabilitation issue being considered professionals need to decide: (1) how representative of the specific rehabilitation population the PPI members need to be, (2) whether experience alone is sufficient or whether additional professional skills are required and (3) whether training is likely to assist involvement or potentially reduce the lay representation.

INTRODUCTION

The increase in patient and public involvement (PPI) in health research has been promoted by policies and guidelines in many developed countries (DH 2005; DH 2006; National Health and Medical Research Council, 2002; National Institute for Health, 2011). PPI in research is often defined as research carried out 'with' or 'by' members of the public, rather than the more traditional approach of carrying out research 'to', 'about' or 'for' them (Involve, 2012). In England the Department of Health has created an expectation that PPI will take place at one or more stages of the research process, including how health research is identified, prioritised, designed, conducted, interpreted and disseminated (DH, 2006). Research funding bodies have adopted this expectation and now require details of how patients and the public have been involved in the preparation of funding applications and how they will be involved in the research process if funding is received (O'Donnell, 2004). This political mandate is one reason for the rise of PPI in health research; other reasons include the consequentialist, epistemological and moral arguments (Boote, 2010). The consequentialist argument is outcome oriented and asserts that PPI in research improves the quality, credibility and relevance of the research design, process and findings (Hubbard, 2007; Lindenmayer, 2007; Sutton, 2008). The other arguments are process oriented with the epistemological argument emphasising the importance of experiential knowledge provided by patients and the public, and the moral argument highlighting the importance of democratic representation and the empowerment of disadvantaged groups (Boote, 2010).

In the UK the theoretical model of PPI most frequently employed is the 'level of involvement' model (INVOLVE 2004), derived from Arnstein's (1969) ladder of citizen participation. The model describes three discrete levels of public involvement: consultation, collaboration and user-control. *Consultation* refers to researchers asking lay people for their views and opinions about a research project or idea and deciding whether or not to act upon their suggestions. *Collaboration* refers to researchers and the public working together in equal partnership. Moreover, *user-controlled* research gives the patient or member of the public the power to set the research agenda and enrol researchers to work with them. INVOLVE, the national advisory group in England supporting PPI in health and social care research, established this model and encourages researchers toward collaboration or user-controlled research (Involve, 2004). The model's terminology has recently changed from 'level of involvement' to 'approaches to involvement', reflecting the realisation that projects may require the use of different approaches at different stages depending on the activity (INVOLVE, 2012).

The involvement of patients and the public in stroke research is promoted by the Stroke Research Network and the National Stroke Strategy for England (DH, 2007). The symptoms of stroke are many and varied, including motor, sensory, communication, cognitive and visual field impairment, as well emotional and behavioural problems. A qualitative study explored the consequences of stroke and how it affected stroke survivor's lives on a daily basis, this included: difficulty leaving the house, walking, talking, unhappiness, confusion and memory problems (Pound, 1998). All of the above could potentially impact upon people's involvement in PPI activities. The existing evidence base regarding PPI in stroke research is limited. Very few studies have reflected upon how the consequences of stroke influence involvement in stroke research. Hammel et al (2006) describe using a participatory action research approach with stroke survivors to identify barriers and supports to community participation at the individual, environmental and system level. The majority of barriers to community participation were identified at the environmental level. Similarly, a study that reflected upon the practices of involving stroke survivors in research discussed the need to allow more time to manage the logistic problems raised by involving stroke survivors with communication impairment and limited mobility (McKevitt, 2009). Extending this further Palmer et al (2013) describe a model of PPI suitable for people with communication difficulties and found their voice is stronger amongst an advisory group comprised of peers than individual representation on a research steering group of predominantly professional membership.

Several studies describe individual examples of PPI in stroke research for specific research projects including examples of consultation (Boote, 2012; Ali, 2006; Koops, 2002), collaboration (Morgan, 2005; Hammel, 2006; Sims, 2013; Palmer, 2013) and one study that the authors categorise as both collaborative and user-controlled (McKevitt, 2009). In one of the studies in which researchers had engaged collaboratively with stroke survivors the authors described the difficulty of balancing scientific and ethical principles whilst allowing consumers to direct the research, reflecting that the increased researcher involvement might have professionalised the stroke survivors (Morgan, 2004). In addition, when differences of opinion are noted between researchers' and users' views they have in all cases been settled by the researcher adopting the suggestion of the stroke survivor or carer (Ali, 2006; Boote, 2012; Morgan, 2004) suggesting the balance of power lies with the stroke survivor. In contrast, McKevitt et al (2009) suggest that because stroke survivors do not perceive themselves to be an oppressed group they do not have a strong politicised desire to bring about social change, which the authors perceive to prevent stroke survivors from being more involved in user-controlled research. This is supported by a European survey which established that a large proportion of stroke survivors are not interested in being involved in

the research process and do not think that stroke survivors should be making decisions about stroke research (McKevitt, 2012). These studies present equivocal findings demonstrating the need for further research to explore stroke survivor's perceptions about their involvement in stroke research.

The current evidence base surrounding PPI in stroke research is ambiguous and primarily arises from context-specific examples, thus demonstrating the need to further explore the experiences of stroke survivors and their carers actively involved in the research process across England. In addition, there is further scope to identify the barriers and facilitators to stroke survivors' involvement in research. The present study aimed to explore stroke survivor's experience of involvement in the research process and how the consequences of stroke affect participation in PPI in research. The results may inform the practice of those researchers and clinicians endeavouring to collaborate with stroke survivors and carers in the research process.

METHODS

Design

Given the exploratory nature of the research and the limited existing evidence base a qualitative study design was adopted. Semi-structured interviews were used to elicit rich experiential data from lay people involved in PPI activities for stroke research (Mason, 2002).

Participant recruitment

Participants were recruited from PPI groups whose sole remit is to advise on stroke research or PPI groups that have a wider remit, but have previously been involved in stroke research and include at least one stroke survivor. The authors contacted professionals affiliated with PPI groups and asked them to share the study information sheet with lay people involved in stroke research. The information sheet invited people to contact the research team if they were interested in participating.

A purposive sampling strategy was used to ensure range and diversity in the experiences of participants (Ritchie et al, 2002). The first element of the sampling strategy, geographical diversity, was achieved by recruiting participants from a variety of PPI groups and networks throughout England. The second element of the strategy was to include people operating at different levels of involvement (consultation, collaboration and user-controlled). In order to establish the level of involvement the participant operated at the majority of the time a pre-

interview pro forma was developed. The INVOLVE (2004) descriptions of the three levels of involvement were re-worded into nine yes/ no answer questions (see figure 3). It was intended that three interviews would be conducted at each level of involvement to ensure a wide range of views and experiences were gathered. The pre-interview pro forma was delivered verbally over the telephone to each potential participant.

The only exclusion criteria related to participants ability to understand and process information because it was possible that some participants would have significant remaining cognitive and communication impairment. As such it was essential that the consent process was sensitive to the vulnerabilities of stroke survivors. For face-to-face interviews a Consent Support Tool (Palmer et al, 2011) was used and participants unable to comprehend three key words or more were excluded because it is unlikely that they would be able to contribute meaningfully to a semi-structured interview. For telephone interviews participants with communication or cognitive impairment were excluded because the Consent Support Tool cannot be used over the telephone.

Data collection

The study took place in England during 2012. Descriptive data about the individual and their involvement in PPI activities was systematically collected at the start of each interview (see table 1). The lead author (MH) who had received training in qualitative research methods conducted the semi-structured interviews, which lasted between 30 and 60 minutes, using a topic guide. Themes from the literature were taken into account in the development of the topic guide and an expert in the field was consulted before the topic guide was finalised to ensure all key topics were included and the language used was appropriate. The topic guide comprised twelve open-ended questions: e.g. “Could you describe the activities of the group that you are involved in?”; “What do you think is expected of you as a member of the group?”; “How do the consequences of your stroke affect your involvement in PPI activities?”. The study utilised both face-to-face and telephone interview methods. The choice of interview method was made pragmatically depending on the geographical location of the participant in England. The authors were mindful of the potential difficulties associated with telephone interviews and made greater effort to develop rapport and listened thoroughly for additional auditory cues to compensate (Carr, 2001). Face-to-face interviews took place at the participant’s home and telephone interviews were conducted if the participant lived more than 50 miles from the authors’ place of work. Joint interviews were offered to couples that attend a PPI group together. The interviews were recorded using a digital recording device and transcribed verbatim.

Data analysis

The data was analysed thematically, broadly following the guidelines described by Braun et al (2006). The first stage of the thematic analysis involved familiarisation with the data, this was achieved through repeated reading of the transcripts during which key ideas and patterns were noted (Braun et al, 2006). Secondly, three of the more diverse transcripts were analysed inductively to produce codes. The codes were then grouped according to higher order themes to develop an initial paper-based coding framework consisting of themes and sub-themes, in discussion with the second author (RP). At this stage the transcripts were imported into NVivo 9 (QSR International, 2011), which was subsequently used to manage the interview transcripts. The remaining transcripts were coded in NVivo and emerging codes were added to the coding framework where appropriate. When negative cases or patterns occurred that did not fit within the current thematic framework, the framework was reviewed and amended. The process of refining the framework ensured that the themes are both coherent and consistent.

Ethical approval

Ethical permission was obtained from ScHARR Research Ethics Committee at the University of Sheffield.

RESULTS

Ten interviews were conducted with eleven participants, comprising nine individual interviews and one dyadic interview. Three interviews took place face-to-face at the participants' home and seven telephone interviews were conducted due to the participants' geographical location. The mean age of participants was 68 years old (ranging from 59 to 85). Male participants accounted for 46% (n=5) of the total sample. All participants were white British. The individual participant characteristics, presented in table 1, provide contextual information about each participant that can be linked to quotes via the participant's pseudonym.

Geographical diversity was achieved by recruiting participants from various organisations that engage patients and the public in stroke research across England. Nine organisations were contacted and agreed to forward information about the project to their members. The organisations included: stroke specific national organisations (n=2), stroke specific regional advisory groups (n=2), generic regional advisory groups (n=2), research project level communication impaired only groups (n=2) and a stroke support group for carers (n=1). Lay members from six of the nine organisations volunteered to participate in the study.

Participant pseudonym	Participant type	Age	Education	Self-reported post-stroke impairments	Number of years involved	Number of hours involved per month	Number of activities	Type of activity
Joyce	Carer	69	No qualifications	Not relevant	14	1	8	A,B,C,D,E,F,G,H
Simon	Carer	71	Diploma/ certificate in higher education	Not relevant	4	1	6	B,C,D,F,G,H
Berol	Stroke survivor	65	No qualifications	Aphasia	4	1	6	B,C,D,F,G,H
Stuart	Stroke survivor	60	Degree	Aphasia	5	22	5	A,B,C,D,G
Mary	Stroke survivor	64	Higher Degree	Hemiparesis	3	1	7	A,B,C,D,G,H,I
James	Stroke survivor	59	Higher degree	None remaining	5	3	5	A,B,D,H,I
Dorothy	Stroke survivor	85	No qualifications	Mild cognitive impairment	3	1	4	A,B,C,D
Mike	Stroke survivor	70	Higher degree	None remaining	4	2	3	A,D,I
Elizabeth	Spouse of stroke survivor*	61	Degree	Not relevant	3	5	2	A,C
Claire	Stroke survivor	76	Degree	Hemianopia	5	30	5	A,B,C,D,I
Walter	Stroke survivor	73	Degree	Personality change	4	30	9	A,B,C,D,E,F,G,H,I

Table 1. Individual participant characteristics. Activity key: A= helping to select research; B= helping researchers design projects; C= helping develop information sheets; D= joining an advisory group; E= carrying out some of the research; F= helping to interpret research results; G= ensuring understandable research reporting; H= helping disseminate findings; I=other activity.

** The participant rejected the label of carer, preferring instead to be referred to as the spouse of a stroke survivor, other carer participants were also the spouses of stroke survivors.*

Data collected about the participant's involvement in PPI activities demonstrated that the median amount of time spent engaged in PPI activities was 2 hours per month (range 1-30). The median length of time involved in PPI activities was 4 years (range 3-14). Participants were engaged in a median of 5 PPI activities (range 2-8). Figure 1 demonstrates that the most common activity was joining a research advisory group and the least common activity was carrying out research. The *other activities* that participants described were helping to organise research workshops and reviewing research proposals to contribute to funding decisions.

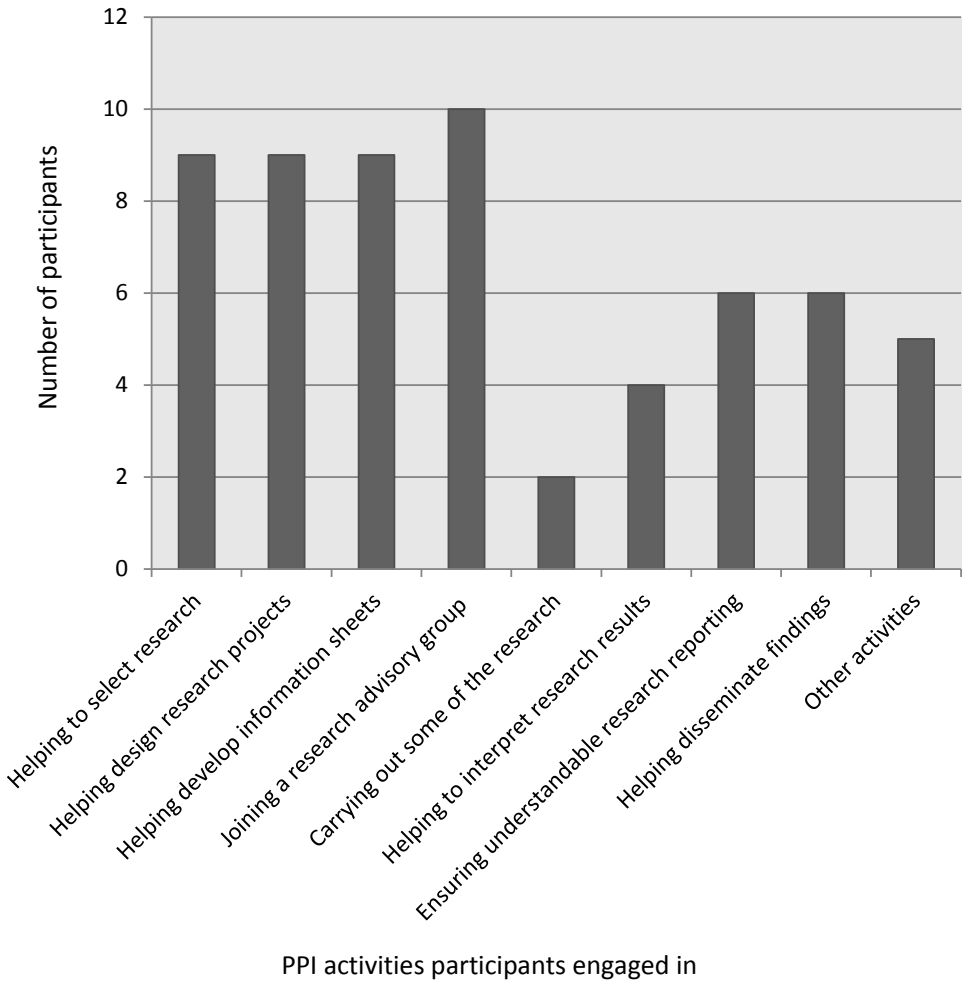

Figure 1. Bar graph showing which PPI activities were most prevalent amongst participants

It was anticipated that the pre-interview pro forma would ensure the sample included participants working at different levels of involvement. However, participant's responses did not allow them to be classified as functioning at one level of involvement (consultation, collaboration and user-controlled) instead the results demonstrated that all participants functioned at two or even all three levels of involvement. For that reason each participant has been represented in a section of a Venn diagram, which represents the complex interplay of the different levels (see figure 2). This was an interesting finding; however it prevented the application of the purposive sampling strategy.

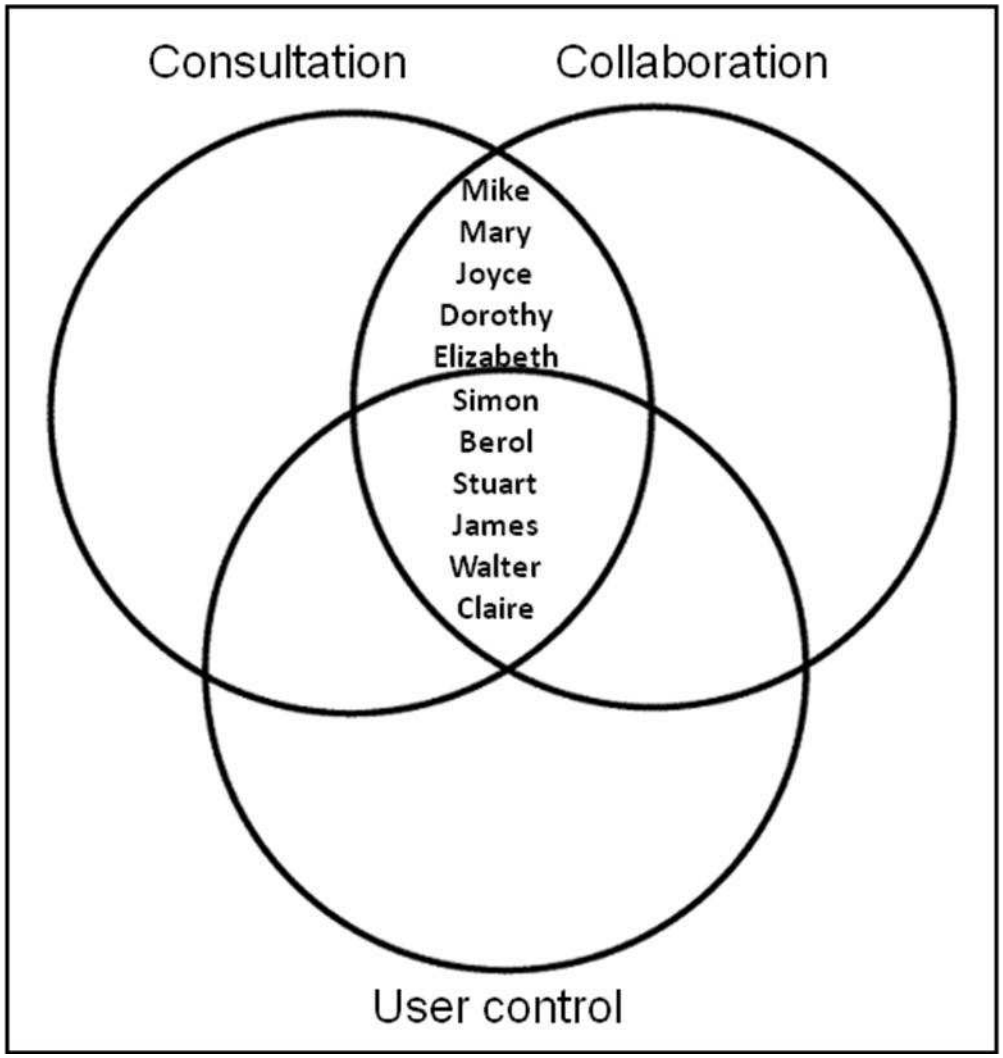

Figure 2. A Venn diagram demonstrating the level of involvement of the participants

On the pre-interview pro forma the majority of participants reported that they worked with the same researchers on a regular basis (n=8), rather than a one-off basis (n=3). Figure 3 shows that all participants thought researchers wanted their views and opinions about research, but no participants reported that a lay member ran the research advisory group they attended, despite recruiting participants from an organisation that stated their advisory group was chaired by a lay member.

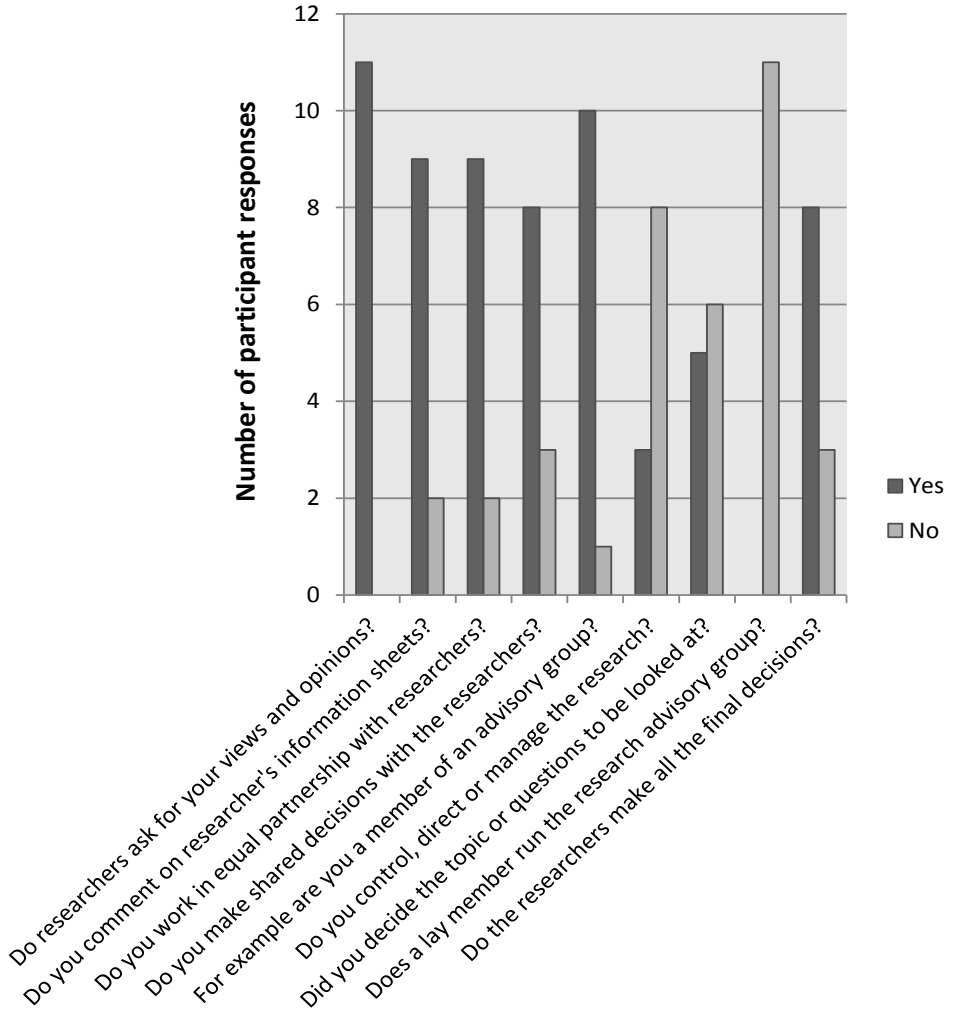

Figure 3. A bar graph showing the participants responses to the questions from the pre-interview pro forma

Four themes were identified: impact of PPI, credibility and expertise, level of involvement, and how the consequences of stroke influence involvement.

Impact of PPI

This theme was divided into three sub-themes: beneficial impacts of PPI for the individual, negative impacts of PPI for the individual and beneficial impacts of PPI to the research process.

Beneficial impacts of PPI for the individual

Seven benefits were identified, the two key benefits, developing supportive relationships and intellectual stimulation, are discussed in detail and the remaining benefits are shown in table 2. *Supportive relationships* were developed with other lay members, group leaders and other researchers and clinicians. Shared experiences of stroke were perceived to strengthen the relationships between lay members.

> Yeah, the social side is very good. Everybody is very friendly and everybody has a common cause and I think that binds people together. (Elizabeth)

Participants spoke with equal warmth about the professionals that lead the different advisory groups, describing them as *'very good acquaintances'* or '*friends*'. The relationships participants developed with other researchers and clinicians were held in high regard because they allowed them to associate with an intellectual and professional elite.

> Meeting, you know highly qualified researching people and making sort of friends with them and that was nice. (Stuart)

The benefits of *intellectual stimulation* were divided into those who wanted to keep learning for self-empowerment, as one participant said '*knowledge is power'*, and those who wanted to continue challenging themselves intellectually to aid their recovery from their stroke.

> So I'm trying to keep involved in something intellectually interesting and demanding. And of course, given I had a stroke I can quite literally try and get my grey matter to work again. (Stuart)

Beneficial impacts of PPI to the individual	Supporting quote
Giving something back	I had great treatment [...] I'm trying to give something back. (Stuart)
Doing something useful	It is just something interesting and useful to do, you know, I hope it's a bit useful. (Mike)
Gaining confidence	It gave Berol the confidence to be able to sit there and to be able to talk in front of all these people, she never would have done that before. (Simon)
Others valuing your opinion	And that value is both from colleagues and crucially from professionals. (Walter)
Provides respite for carers	But also it's the just getting away from it, you know and having a piece of cake and a cup of tea! (Joyce)

Table 2. Additional beneficial impacts of PPI to the individual and supporting *quotes*

Negative impact of PPI for the individual

Only one participant reported a negative impact of PPI. The participant felt that he was objectifying himself by '*displaying [his] handicap'* when giving a talk in support of the organisation in which he was involved. The participant subsequently resigned from this group after joining a different advisory group.

> I gave a talk, along with a colleague to a large group and I found myself, when I was reflecting on my experience it was very emotional, I realised I was objectifying myself and I found that a very strange thing to do in front of others. (Walter)

Beneficial impacts of PPI to the research process

The most frequently described beneficial impact of PPI to the research process was bringing a different perspective. Participants thought the synergy of the experiential expertise of stroke survivors with the professional expertise of researchers and clinicians benefitted the research process.

> We have a very individual perspective, it's certainly different to what the researchers can bring. And so, but what research requires is bringing together those different perspectives. (James)

Participants described asking questions to challenge the researcher's assumptions; some participants described this resulting in changes to the design of the research or the abandonment of a proposal.

> Well sometimes people can have an idea for a research and it sounds very good on paper and then they'll bring it to a group like ours and we'll say 'well, what really are you intending?' and almost take the wind out of their sails sometimes! [laughing] And we will say 'well how will it benefit, what will it do?' and when it comes down to it, it doesn't really, it just sounded a good idea. (Elizabeth)

Some lay members had their own research agendas that they were trying to put forward.

> I've been banging on quite a lot about the fact that in the [name] group all the research is aimed on the clotting and no research whatsoever about the haemorrhage type [...] and I think something is coming in the Summer, but that's making – having an impact, very, very small but it's there. (Stuart)

Participants amended lay summaries and study documents to ensure the public could understand the research. Participants did not, however, perceive themselves to be the 'public' instead they appeared to be acting as intermediaries between the researchers and the wider public.

> We get sent lay summaries to go through to make sure that the genuine Joe Public would understand what they're consenting to. And they frequently are badly written and not really understandable even if you are fairly academic or scientific. (Claire)

Credibility and expertise

A division was noted between participants primary source of credibility; some drew chiefly upon their experiential expertise, whereas others drew upon their professional expertise as well as their experiential expertise. Participants who focussed on their professional expertise as a source of credibility wanted professionals to recognise their wider knowledge and skills and seldom perceived themselves to be representing the stroke community.

> Well we're there to bring the patient perspective, aren't we? I think I do that, but for me it doesn't stop there because it's also bringing into play the experience I have got of both doing research and spending many years as a commissioner in social services and [...] it's about bringing all of that to bear. I think all of that experience is relevant and I would hope that my colleagues on the [group name] do see that as being relevant. (James)

Whereas, those participants that concentrated on their experiential expertise more often perceived themselves to be representative of the stroke community.

> Yeah, I hope [they are representative], yes I think so. I mean, obviously they're very personal but also they're, I mean, talking to other people who've had strokes, you know, there's often great -, a common area. (Mike)

Representativeness was thought to be increased through the incorporation of a wide range of diverse perspectives within an advisory group. The process of interviewing for lay members of advisory groups was perceived to reduce the ability of the group to be representative of the public, because it encouraged more affluent, educated people to apply.

> One would hope that the members of it would be Joe Public... in [name of organisation] they are, but in the [name of second organisation], they're all middle class and fairly academic. (Claire)

Those participants that placed greatest value on their experiential knowledge did not want training or even felt that training might detract from their lay role.

> Everybody there had experience of a stroke or being a carer for somebody, so in a way, that was the training you could say, yes. (Mike)

> If we had training in research skills I think that would detract from why we're in the group because we would no longer be lay members. (Elizabeth)

In contrast, users of professional expertise felt training was needed to allow for the greater involvement of lay persons in research activities.

> If you really want people to be more informed and hence more involved you do need to try and inform or educate [...] that group of people. (James)

Exploring the differences between the accounts of individuals who drew upon their professional expertise and comparing them to those who utilise their experiential expertise highlighted a typology based on the differences in the organisational structure of the groups, see table 3.

Experiential expertise valued and used to provide credibility	Professional expertise valued and used to provide credibility
Group comprised of a majority of lay members	Group comprised of a majority of professionals
Narrower local function	Wider regional or national function
Informal process of becoming involved	Formal process of becoming involved
No training and education provided	Training and education provided

Table 3. Features of group structure associated with the type of expertise used to provide credibility

Level of involvement

Many participants expressed a wish to be more involved in research activities than they were currently; two participants discussed this in relation to empowerment.

> The perceptions from some people are that they are just content to be invited along to meetings to contribute if they can, whereas I have a view that we should be more pro-actively or actively involved. (James)

Speaking to and observing other lay members caused some participants to feel somewhat intimidated by the level of involvement of other lay people, however, this only strengthened their own desire to become more involved.

> When us lay members get round the table I sit and I think 'cor, they can do that, why don't I do that?' I think they must find my experience very lightweight. (Stuart)

Other participants felt that their level of involvement was appropriate at that time and stated barriers to becoming more involved, including: time demand, lack of computer skills and internet, and age. Furthermore one participant suggested that greater involvement would make it feel like a job.

> I've enjoyed doing what I've done but if it was anything more it would become a job and it would become stressful. (Joyce)

Only those involved in more than one group wanted to be less involved in research activities. One participant had addressed this by resigning from one of the groups and another

participant would have liked to have left the group she initially joined, but felt obliged to continue.

> One thing I wouldn't mind giving up is the [group name], but everything stems from that and I feel I owe it to that to continue. (Claire)

Researchers treated lay members with respect and many members felt that they had equal relationships with the professionals. However, some participants were sceptical about whether researchers truly valued their involvement. Most participants expressing this view worked at all three levels of involvement, potentially suggesting that professional's scepticism increases when lay members play a role in controlling the research.

> I think there's probably quite a lot of paying lip service to PPI because I think these days you can't get funding unless you're involved with the public. (Stuart)

> You're never quite sure whether they really want your input. (Claire)

How the consequences of stroke influence involvement

Barriers and facilitators to the involvement of stroke survivors and carers have been identified and are presented in tables 4 and 5. One additional sub-theme emerged that did not fit discretely into either category; participants recognised the multi-faceted consequences of stroke and recognised the importance of matching the stroke survivor's symptoms with the research topic. Therefore the varied consequences of stroke need to be taken into account by those intending to engage stroke survivors in PPI activities.

> Some people have different experiences, so if somebody for example is doing research on dysphasia and somebody's had a problem with that, they've got more to offer than say somebody who's just had more problems with mobility. (Mary)

Barriers to participation

Barrier to participation	Supporting quote
Location and transport	Where I live I'm quite remote from the major hospitals…if I were much more close to them I might be much more [involved], but I'm so far away I can't, which is very frustrating. Yeah, and plus I can no longer drive because of my stroke. (Stuart)
Ability and concentration to comprehend complex information	I tend to speak a bit less because the really technical subjects are more tricky so I'm listening very hard to think what they're actually talking about…sometimes at those meetings I feel rather out of my depth. (Stuart)
Fatigue	Not tiring for me, it's tiring for such as Berol or [name of other stroke survivor], they get tired after 2 hours. (Simon)
Communication impairment	You have a problem of, if somebody's had a difficulty with speech and it's harder for them to put their point across. (Mary)

Table 4. Barriers to participation and supporting quotes

Furthermore the following barriers were raised by individual respondents: physical limitation of dealing with paperwork with one hand, carers unable to leave the patient unattended, and the consequences of age coupled with stroke.

Facilitators of participation

Facilitator of participation	Supporting quote
Provision of transport	And I think one lady is provided with a taxi to get there because she can't drive. (Elizabeth)
Supportive group facilitators with awareness of the needs of stroke survivors	The facilitators are usually very good and well trained in how to facilitate these sorts of groups. And they go out of their way to facilitate our involvement. (Mary)
Supportive group in-tune with one another	Because of the friendship yes you can be more open. (Simon) There is more intense concentration when you are in a group like that. (Dorothy)

Table 5. Facilitators of participation and supporting quotes

In addition the following factors facilitated participation for individual respondents: holding meetings in disabled-friendly environments, giving time for people with aphasia to speak, carer participating facilitates stroke survivor's participation, and reimbursement for their time.

DISCUSSION

This exploration of the experiences of stroke survivors and carers actively involved in research activities identified a rich diversity of themes relevant to researchers and clinicians attempting to engage stroke survivors in PPI. Participants recognised personal benefits of taking part in PPI for stroke research, including developing supportive relationships, giving something back, gaining confidence and others valuing your opinion. Similar beneficial impacts were found in a study describing stroke survivor involvement in service development (Fudge et al, 2008). However, one benefit specific to this study was intellectual stimulation, suggesting that people involved in PPI in research might have different motivations compared to those taking part in PPI for service development purposes. The beneficial impacts of PPI to the individual could be used as an incentive to encourage people to participate in PPI activities.

The findings demonstrate that stroke survivors and carers can be involved in PPI at different levels of involvement simultaneously and the majority of participants wanted to be more involved. The 'level of involvement' theme and data from the pre-interview pro forma supports INVOLVE's recent transition toward 'approaches to involvement', rather than 'levels of involvement', because the levels do not operate in silos, but instead have complex interlinking relationships that fluctuate with time (INVOLVE 2004; 2012). This suggests that guidance is evolving to reflect reality. However, participants own conceptualisation of involvement in PPI activities were more compatible with a model that places PPI activities on a spectrum of involvement from more-collaborative to less-collaborative (Robinson et al, 2012). Furthermore, although participants in this study were already involved in PPI activities the majority stated that they would like to be more involved in research, particularly if they were only involved with one organisation at the time, which contradicts McKevitt et al's (2012) assertions that stroke survivors do not have a strong desire to be actively involved in research.

In this study none of the participants met all of the criteria for user-controlled research, even though participants were recruited from groups that professionals perceived to be user-controlled. This incongruence between the perception of the researchers and lay members suggests a lack of mutual understanding about the function of the group and the lay members' role within it. There are two potential reasons for the difficulties identifying an

example of user-controlled stroke research. Potentially the barriers to participation identified in this study might preclude user-controlled stroke research (e.g. reduced ability and concentration to comprehend complex information may make leadership difficult) or it could be seen to support McKevitt et al's (2009; 2012) supposition that stroke survivors do not perceive themselves to be an oppressed group and therefore do not have a strong politicised desire to bring about social change and lead research themselves. This refers to the moral justification for PPI that most strongly advocates for user-controlled research, and it is interesting to note that this argument was incited by a minority of participants (n=2). In contrast, the majority of participants focused on the consequentialist and epistemological arguments as the reason for their involvement in the research process (Boote, 2010). The participants perceived that they brought a different perspective to the research process through their experiential expertise, which improved the quality and relevance of the research being conducted.

The political mandate for PPI in health research is evident in Department of Health policy, which recommends that service users and carers should be involved in all stages of the research process (DH, 2005; DH, 2006). The data collected about what activities participants were involved in suggests that this is occurring within the field of stroke, although more participants were involved in activities at the selection and design stage of the research process. The policies make reference to the importance of INVOLVE, which supports users to play an 'active role in research' (DH 2005; 2006). Some participants in this study suggested that more training was needed to help them to play a more active role in research. The Research Governance Framework (DH, 2005) refers to the involvement of 'relevant service users', this bears similarities to participants recognition of the importance of matching the stroke survivor's symptoms with the research topic. It would appear that on the whole, within the field of stroke, lay members' experiences of PPI and the PPI agenda are congruent, and the policy recommendations are being implemented.

The theme of credibility and expertise was unanticipated by the authors, but emerged strongly from the data. Experiential expertise formed part of the rationale for all lay members' involvement, but some participants used their professional expertise as a further source of credibility. The typology of expertise and credibility describes the differences in the group structure which appear to influence whether participants used their professional expertise. Professional expertise was more often drawn upon when a formal recruitment process was used to identify lay members to join a group comprised mainly of professionals, which operated at a regional or national level and provided training and education. In contrast, experiential expertise was concentrated upon when an informal process led stroke survivors and carers to join a group with a majority of lay members, which operated at a local level and

did not provide training or education. The distinction between professional and experiential expertise has been described previously in the context of PPI in cancer research (Thompson, 2012) and lay participation on a research ethics committee (Dyer, 2004). The recruitment of participants from a variety of organisations and PPI groups in this study allowed this to be explored in the context of different group structures. The relationship identified between group structure and the type of expertise drawn upon warrants further investigation. More information about the context and process of PPI activities would have provided more rigorous evidence for the group structure typology.

Training was one component of group structure that appeared to be associated with whether the participants drew upon professional expertise or not. Opinion was divided between participants with some wanting more training, typically those who drew upon professional expertise, whilst others suggested that training would prevent them from being lay members. The latter suggestion is consistent with the 'professionalisation paradox' described by Ives et al (2012) which asserts that if participants receive training and become familiar with the research process they will achieve a level of 'professional socialisation' and their status as a 'lay' person is compromised.

Barriers and facilitators to the involvement of stroke survivors in research activities were identified. The barriers were location and transport, the ability and concentration to comprehend complex information, fatigue and communication impairment. The facilitators were the provision of transport, supportive group facilitators with awareness of the needs of stroke survivors, and supportive group which is in-tune with one another. The barriers and facilitators identified are similar to those for community participation as identified by Hammel et al (2006) at the individual and environmental level, although being specific to PPI fewer factors were identified. Furthermore the barriers bore similarities to those identified in a study exploring stroke survivors return to paid employment (Alaszewski, 2007), which found that for some participants the barriers were too great to overcome. McKevitt et al (2009) advised that more time and support needs to be afforded to involve people with communication and mobility difficulties and this was recognised as a facilitator of participation. In addition, the benefit of having an advisory group consisting of peers, as highlighted by Palmer et al (2013), was reflected in the facilitative elements of having a supportive group that is in tune with one another, which was discussed by stroke survivors with and without aphasia.

Study limitations

In this study the sample was small and the purposive sample became a convenience sample due to the inability of the pre-interview pro forma to categorise participants at discreet levels of involvement. The authors sought to recruit from groups that operated at all levels of involvement, however despite recruiting participants from organisations that stated they were user-controlled, this was not reflected in the data. All participants were white British, this is not representative of the UK stroke population, particularly as the African-Caribbean population have a higher incidence of stroke compared to other ethnicities (Wolfe et al, 2002). This limitation might have arisen due to the small sample or, as suggested elsewhere, it might be symptomatic of the lack of ethnic diversity of those involved in PPI activities in England (Beresford, 2007). The majority of participants were educated to degree level or higher, therefore findings may not be generalisable to the wider stroke patient and carer population, however this is consistent with the finding that those involved in PPI are highly educated (Sykes, 2003). It is also important to note there was no PPI involvement in this study, an insider perspective during the interpretation of results would have been interesting.

Conclusions

Stroke survivors and carers can be involved in PPI at different levels of involvement simultaneously and many would like to be more involved. The beneficial impacts of PPI to both the individual and the research process were recognised. In the field of stroke research lay members' experiences of PPI are congruent with the PPI agenda in England and guidance has evolved to better reflect reality. The relationship identified between group structure and the type of expertise drawn upon to demonstrate credibility has implications for the way in which PPI groups are structured and this theory warrants further investigation. The study also contributes to the understanding of the barriers and facilitators to the involvement of stroke survivors in PPI for research, which should be taken into consideration by professionals attempting to engage in such activities.

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