

Patient and public involvement: in theory and in practice

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Abstract

Background: You've probably heard of patient and public involvement by now. You may even have 'involved' people in your research. But why involve patients, carers and members of the public at all? Is it just another hoop to jump through when preparing a research funding application for submission, or could it actually add something to your research? Could involving patients and members of the public even help you to design and deliver better research, with outcomes focused directly on the needs of your patient group?

Objective: This article aims to answer some of these questions. It considers the theory underpinning patient and public involvement. This is followed by practical suggestions and advice to help you develop (or further develop if you already involve people!) patient and public involvement within your own research. There is also a case study to illustrate some of the main points, and extracts written by members of Research Design Service North East Consumer Panels.

Key words: Patients; Carers; Patient And Public Involvement; Consultation; Collaboration; Community; Community Networks; Consumer Involvement

Patient and public involvement in theory

Before you read any further, stop for a minute and ask yourself the following questions. What is patient and public involvement? Why is patient and public involvement important? How can people be involved in research?

You may be thinking that these were some of the questions this article promised to answer. Indeed they were. However, it may be that you already know more about patient and public involvement than you thought you did. If you think about these questions, not only will it make you aware of what you already know, but it will help you realise more about what you don't know, and where you need to further develop your knowledge and practice.

Defining involvement

So what, exactly, is patient and public involvement? The answer is that there is no one, definitive definition of patient and public involvement. Active involvement can mean different things to different people. What is for sure is that patient and public involvement should not be a passive process – note the use of the word active above. Patients, carers and members of the public should be considered as equal members of the research team.

'Involve' is the national advisory group funded by the National Institute for Health Research to support greater involvement in National Health Service (NHS), public health and social care research.¹ It has described patient and public involvement as 'research being carried out "with" or "by" members of the public rather than "to", "about" or "for" them'.² This is a useful description that helps to contextualise the concept of patient and public involvement. It is also the description used across the National Institute for Health Research, and advocated through its research programmes and support organisations to health and social care researchers.³

Patient and public involvement isn't about 'involving' people as participants in research. It is about working in partnership with patients, carers and members of the public throughout the design, development, conduct and dissemination of research (Table I).⁴ Having said that, actively involving patients and members of the public in raising awareness of your research amongst their peers and the wider community, as well as involving them in the development of your recruitment strategy, is certainly likely to increase the number of participants in your study!

More detailed examples of how patients, carers and members of the public have been involved in specific

TABLE I
EXAMPLES OF INVOLVEMENT^{3,4}

Setting research priorities Identifying questions that health & social care research needs to answer Giving views on research proposals alongside clinicians, methodologists, scientists, & public health & other professionals Helping to assess proposals for funding Taking part in clinical trials, & other health & social care research studies, not just as participants but as active partners in research process Publicising results

projects can be found in the Involve ‘Research project database’.⁵

Approaches to involvement

There are three approaches to involving people in research: consultation, collaboration and user-led involvement.⁶ These are illustrated in Figure 1. Although each approach is distinct from the others, they can be used in any combination in the same or different parts of the research.

In a consultation, researchers ask patients, carers and members of the public for their views and comments, and use these to inform decision making. For example, you could ask a group of patients to look at your draft research proposal, and to give comments and feedback.

Consultation can be a one-off process, or can be repeated at different stages with the same or different groups of people. This means that it may not necessarily involve any on-going relationship or commitment with those consulted, and may be quicker and less complex than other levels of involvement. However, do remember that although consultation is a useful process which will help you to develop and refine your research, you may find that collaborative and user-led involvement will offer more to the research.

Collaboration is an active, on-going partnership between the researcher and the patients, carers and

members of the public. It results in a greater level of involvement in the decision making process. For example, you could work in collaboration with patients, carers and members of the public to develop your research question and research methods, as opposed to asking them to comment on a research proposal that you have already written.

Collaboration may require more time and commitment than consultation, but it is likely to add a great deal to the research. Another benefit of collaboration is that it helps to develop links and relationships not only with individuals but also, as will be discussed later, with relevant community groups and voluntary sector organisations that support patients, carers and members of the public in the wider community. When you have developed such links and relationships, you can then go back to these groups and organisations and involve them in subsequent research projects.

In user-led involvement, individuals, groups or communities can be supported and equipped to undertake specific pieces of work themselves, and then come back to you with the results. This approach can prove particularly useful when engaging marginalised or disadvantaged groups or communities, where there may be cultural, religious or other barriers, or lack of trust. In this scenario, a member of the particular group or community can engage their peers, validate and promote the importance of the proposed research, and then feedback the views and opinions of that particular group or community. This approach can be used as part of the research design and development, or could be a user-led aspect of the research itself.

The user-led approach can also help to provide access to skills, perspectives and experiences that may be highly relevant to the research which might otherwise prove unavailable to researchers. This may be particularly relevant when engaging so-called ‘hard to reach groups’.

It is very important to think carefully about diversity and inclusion when planning patient and public involvement in research. Otherwise, those involved will not reflect the diverse make-up of the population

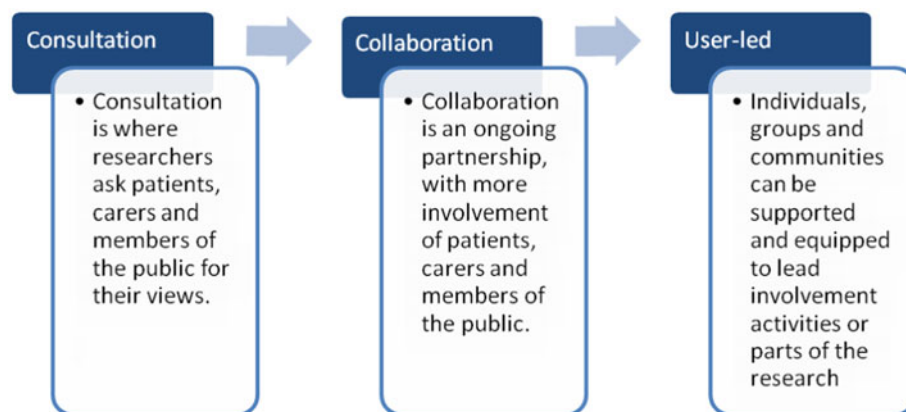


FIG. 1

The three approaches to involving people in research.⁶

to which the research relates. Although it may not be possible to get a complete representation of the population, it is still important to involve a cross-section of people from different groups and communities.⁷

Avoid the ‘easy option’ of only involving people who are easier to engage and may already have some knowledge of research. This tends to be older people from Caucasian ethnic groups and higher socio-economic backgrounds.⁸ Whereas there is no question as to the invaluable contribution such individuals may make to research, involving them alone may mean that the research does not benefit from the skills and experiences of those from the wider community.

More information about involvement approaches and how to involve people can be found in the Involve ‘Putting it into practice’ database.⁹

Benefits of involvement

At this point, you may be thinking that involving people in your research sounds like quite a bit of effort. So what’s in it for you? Quite simply, actively involving patients, carers and members of the public can help you to make sure your research is relevant, credible and offers the best possible outcomes to the patient group to which it relates.⁶ Remember that only patients have personal experience of what it’s like to live every day with a particular illness or condition. They know what is important to them, and they know what would improve their quality of life. Although you may think that your research question is important and that your outcomes will directly benefit people, the priorities and issues from a patient’s perspective may be very different.

Similarly, involving carers will help you to understand their issues and priorities, as well as their perception of the needs of the person they care for.

The researchers of one particular case study (‘John’s cheese sandwich’) worked in collaboration with survivors of head and neck cancer, and their partners, from the earliest stages of the project, even before a research question had been identified.¹⁰ Although the researchers knew that they wanted to improve the quality of life of head and neck cancer survivors in relation to the issues they face with food, they wanted to ensure that the research question and outcomes directly focused on the needs and priorities of the survivors, addressing the issues that were most important to them and offering them maximum benefit in terms of improved quality of life. The researchers ran a series of ‘food play’ workshops with head and neck cancer survivors, their partners and a local chef. During these workshops, they explored problems and issues related to food, and the chef used gastronomy techniques to change the texture and flavour of foods. It was during these workshops that the research question and outcomes were determined, and that John was able to eat his first cheese sandwich.

The list shown in Table II provides a summary of the general benefits of involvement. This is not an exhaustive list, but illustrates some of the main points.

The importance of active involvement in health and social care research was emphasised by Professor Dame Sally Davies, Chief Medical Officer and Chief Scientific Adviser for the Department of Health. She stated that ‘people-focused research in the NHS simply cannot be delivered without the involvement of patients and the public. No matter how complicated the research or how brilliant the researcher, patients and the public always offer a unique, invaluable insight’.¹¹

Active involvement in research design and development can also potentially influence the outcomes of research funding applications. Funding bodies, including National Institute for Health Research related research programmes, increasingly recognise the importance of patient and public involvement, and the benefits it brings to research.¹² Although it is unlikely that patient and public involvement would determine the outcome of a funding application in its own right, it may certainly influence it. Applications demonstrating robust and effective involvement may certainly be strengthened. Nevertheless, it is important to involve patients, carers and members of the public in research for the right reason, not purely in an attempt to ‘tick the box’ and strengthen an application for funding.

TABLE II
INVOLVEMENT BENEFITS SUMMARY³

Identifying right research question Making research relevant & credible Focusing research directly on needs of patients & issues important to them Better recruitment strategies & information for potential participants Research methods that are more accessible & make it easier for people to take part Clearly defined outcomes more likely to directly benefit patients Improved dissemination of results & implementation of change

TABLE III
PPI IN RECRUITMENT¹¹

<i>PPI can help to:</i> Produce better patient information Make sure recruitment procedures are sensitive to needs of potential participants Enhance credibility of study to potential participants & encourage people to take part Explore & overcome barriers to recruitment Facilitate access to potential participants Create commitment, energy & enthusiasm amongst potential participants
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Recruitment rose from 18 to 38 per cent in a trial run by a mental health research network after a number of service users were brought together to redesign the recruitment leaflet to make it more relevant to potential participants. PPI = patient and public involvement

Who to involve

The sections above have provided a brief overview of patient and public involvement, and its levels and benefits. A further issue to consider is who you are actually going to involve and how you will find and engage them. This may seem like a straightforward question, with a relatively obvious answer. However, it does need careful consideration. The list shown in Table IV provides a summary of people you could involve in your research.

Involving the wider community is not always an option considered by researchers. If you are a clinician, for example, you may consider involving some of your patients, and their carers or families, in your research. However, it is important to remember that there is a whole range of skills, perspectives and experiences in the wider community. If you don't involve the wider community, your research won't benefit from these. As mentioned earlier, voluntary sector groups and organisations can contribute their own perspectives. They can also offer links to past and current patients, carers and members of the public. Voluntary sector organisations can also prove invaluable in areas such as raising the profile of research, recruiting their members as participants, facilitating focus groups and discussions with the people they support, and disseminating information through their networks at the end.

When thinking about who to involve, bear in mind the following factors. Don't expect people to come to you – they won't! Be proactive – find and approach relevant individuals, groups and communities. Talk to organisations like HealthWatch and Councils for Voluntary Service. Engage those you would like to be involved in a way that is accessible to them, in an environment in which they feel comfortable. Explain what you would like them to get involved in and exactly what you would like them to do. Build and maintain relationships. Finally, offer people support and regular feedback.

When to involve people

Where appropriate, and depending on the needs and context of the research, patients, carers and members of the public can be involved throughout the research cycle. The best time to involve people is right from the start of the research design. If possible, this could include the development of the research question

TABLE IV PEOPLE YOU COULD INVOLVE ⁶
Current, past & potential patients People who use health & social services Members of public Informal carers Parents & guardians People from marginalised & disadvantaged groups
You could also involve community groups, charities and voluntary sector organisations.

itself. It may not always be possible or appropriate to involve people in every stage of the research. It's important to think through each stage of the research cycle and think about what involvement could add. Figure 2 illustrates the different stages of the research cycle.

It's also important to talk to people about their skills and experiences, about how they think they could bring these to the research, and which stages they would like to be involved in. For example, some people may want to be involved in the design stage, but may not be interested in being involved in the conduct or management of the research.

Evidence and impact

As described above, patient and public involvement has the potential to add a great deal to health and social care research. But where is the evidence showing that patient and public involvement actually does make research better? How can the impact of involvement be measured and reported?

The process of finding answers to these questions, and of developing methods and tools to measure the impact of patient and public involvement in research, has proved challenging. A review of impact conducted by Staley *et al.* in 2009 concluded that it was '...difficult to assess the impact of involvement or to predict where involvement would have the greatest impact'.¹¹ In 2010, Brett *et al.* highlighted the '...clear need to develop a much more consistent and robust evidence base by enhancing the quality of reporting to enable impact to be fully identified and evaluated'.¹³ However, as Mockford *et al.* argued, lack of evidence does not necessarily reflect a lack of impact.¹⁴ Their



FIG. 2

Different stages of the research cycle.⁶

research did, nevertheless, highlight the need for the development of an effective method of impact measurement.

Guides and tools to identify and measure patient and public involvement impact have now been developed. In 2011, Staniszewska *et al.* developed Guidance for Reporting Involvement of Patients and the Public to help researchers focus on specific issues and impacts of involvement in their research.¹⁵ More recently, Popay *et al.* developed a Public Involvement Impact Assessment Framework.¹⁶

Evidence of patient and public involvement impact also continues to grow. In September 2013, for example, a review of mental health studies by Ennis and Wykes concluded that studies with robust patient and public involvement were four times more likely to recruit to time and target than those where patients and members of the public had not been actively involved.¹⁷

There is information about, and further examples of, patient and public involvement impact in the Involve 'Evidence library'.¹⁸

Barriers and challenges

Barriers and challenges may arise that, in some circumstances, make it more difficult to involve people effectively.⁶ These may occur from the perspective of the researcher, the people involved in the research or from within the research process itself.

For example, some researchers may consider patients' knowledge of research to be too limited, or they may not know where to find people to involve or how to engage them. There may also be a perception that involving patients, carers and members of the public in research may be time consuming, expensive and will achieve little else than create another hoop through which to jump.

Some patients may see their involvement as a token gesture. They may feel that they aren't clever enough to get involved in research or may have personal circumstances that make it difficult to get involved. For example, when those involved are single parents or carers.

There may also be barriers to involvement within the research process itself. For example, there may be no funds available to involve people in the research design prior to the awarding of the main research grant. Effective involvement may make the process longer and more complex, and there may be a lack of learning and development opportunities to fully support those involved to effectively undertake their roles.

However, where problems and challenges do arise, there is normally a solution. Often the issues can be explored and solutions found, in collaboration with those affected by them. Whatever the problems and challenges, the benefits of actively involving patients, carers and members of the public in research are likely to outweigh these.

Another potential barrier to effective involvement has been confusion over whether or not involvement activities require approval from an ethics committee prior to the activity taking place, and whether involvement activities are subject to the same governance requirements as the research itself. Involve and the National Research Ethics Service issued a joint statement in 2009 to clarify this issue. This makes it clear that:

...the active involvement of patients or members of the public does not generally raise any ethical concerns for the people who are actively involved, even where those people are recruited for this role via the NHS. This is because they are not acting in the same way as research participants. They are acting as specialist advisors, providing valuable knowledge and expertise based on their experience of a health condition or public health concern.

Therefore ethical approval is not needed for the active involvement element of the research, even where people are recruited via the NHS, where people are involved in planning or advising on research e.g. helping to develop a protocol, questionnaire or information sheet, member of advisory group or co-applicant.¹⁹

Patient and public involvement in practice

Ok, so that's the theory. But how, you may wonder, do I go about involving people in my own research? This may seem a daunting prospect if you have never involved people in research before.

The most important thing is to make sure you don't become a patient and public involvement child catcher! There is an analogy to be made between the character from the Chitty Chitty Bang Bang film and some of the above-mentioned 'box-ticking' researchers. The latter often rush out and grab the first patients they see to be involved in their research.

The first stage of any patient and public involvement should be thinking and planning. Before you do anything, it's important to develop a patient and public involvement plan. Figure 3 shows a simple planning cycle that will help you to develop this plan.

Developing a patient and public involvement plan will help you to consolidate your thoughts, so that you know exactly what patient and public involvement will add to your research, who you want to involve to achieve this, and how you will identify and engage them. This will also help you to explain to people exactly what it is they would be expected to do if they get involved. This is one of the first things people will ask about when you approach them. If you don't know, people are less likely to engage and want to be involved. It may sometimes help people if you develop a role description outlining exactly what will be expected of them. Examples of role descriptions can be found in the Involve 'Briefing notes for researchers' publication.⁶

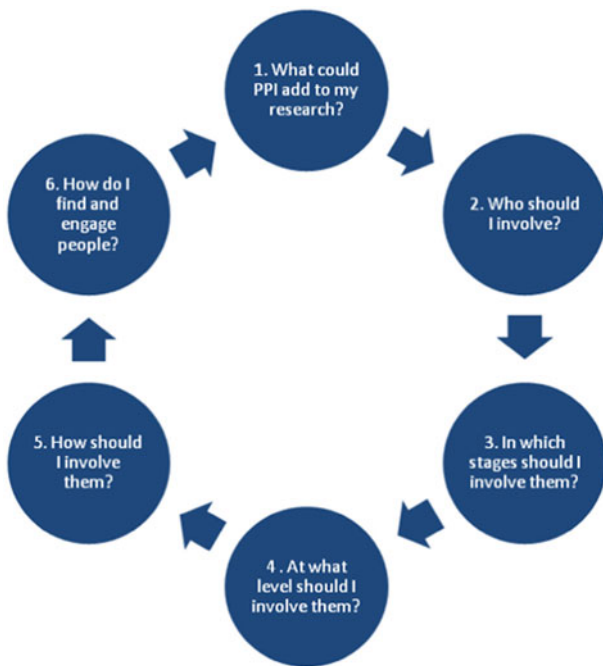


FIG. 3

Simple patient and public involvement (PPI) planning cycle.

Developing a patient and public involvement plan will also help when you come to complete your grant application form. If you have such a plan, you can summarise this in the relevant section of the application form and, where possible, mention patient and public involvement in other sections of the form. This demonstrates that you have thought carefully about patient and public involvement, and developed a robust and effective strategy that is woven throughout the research, as opposed to being confined to the patient and public involvement section of the application.

It's also important to project a patient and public involvement budget, and a plan will help you to do this. You may have developed a brilliant plan, but if you have no funds available to support the proposed involvement, the patient and public involvement is unlikely to evolve in the way described in your plan! Funding panels will also recognise this, and will be looking for an adequate budget within your grant application to support the involvement.

As well as paying travelling expenses to people involved, it is also considered good practice to pay them for their time and expertise, in the same way you would any other members of the research team. If you have a patient and public involvement plan, this will give you an idea of how many people will be involved, and how many meetings or activities they will be involved in over the course of the research. You can then project a budget to support this. Involve has produced guidance about payments and expenses for patients and members of the public, along with an online Involvement Cost Calculator tool.^{20,21}

Finally, you should talk to the people you involve about their learning and development needs, to help

them to carry out their role effectively.²² Remember that a blanket approach to learning and development is unlikely to prove successful, as different people with different skills, experience and backgrounds are likely to have different learning and development needs. Indeed, to some people, formal training may act as a barrier to involvement. Don't forget that patient and public involvement is about the expertise and experience people have in relation to living with, or caring for someone living with, a particular illness or condition. Patients, carers and members of the public don't necessarily need to have an in-depth knowledge of the research process itself to make an invaluable contribution. Don't forget to include a learning and development budget in your funding application.

The public perspective

The above has focused on how patient and public involvement can help researchers to design, develop and undertake research that will concentrate directly on the needs of the population the research relates to, offering maximum benefit that may ultimately improve quality of life. But what do the patients and members of the public think about it? Do they think patient and public involvement is important? What do they think it achieves? Most importantly, do they actually want to get involved in the first place?

Research Design Service North East has developed a small network of Consumer Panels. The members of these panels are patients, carers, members of the public, and representatives of voluntary sector groups and organisations. They are from a variety of backgrounds, with a cross-section of skills and experiences. These Consumer Panels work with researchers to help them design and develop their research proposals and funding applications. The following extracts were written by three Research Design Service North East Consumer Panel members. These members were asked about their experience of, and views relating to, patient and public involvement in health and social care research.

Extract one

It wasn't until my family was affected by a chronic condition that was very poorly understood, with no proven known cause, no cure, and with limited on-going research, that I really started to appreciate not only the value of research, but more importantly, the enormous benefit of 'getting it right'. Research which is poorly targeted, answers the wrong questions, or is of little benefit to patients is simply not hitting the mark. Not every piece of health or social research will improve the lives of patients. Sometimes the outcome will be the first step on a very long road, sometimes the outcome might simply be that the hypothesis was wrong; but every research project should be aiming towards easing the problems faced by patients, their carers and their

wider group of friends and family, and be targeted at the things that matter most to those people. Patient Public Involvement (PPI) helps achieve this. Through feedback, the PPI panel helps ensure that the focus is on the issues that are important to people and improves the way in which research participants are included, thereby improving the overall quality, value and benefit. My appreciation of research is greater these days, and, through PPI, so is my support. The PPI panel doesn't always give researchers an easy ride, but researchers I have met have been unanimous in their praise and appreciation of PPI feedback; thoughts have been reviewed and changed, new ideas have been considered, and some researchers even come back for more. PPI makes a positive difference.

Extract two

As a carer of my daughter with a severe and enduring mental health problem, being involved in research is something I feel very passionate about ... I think it is a two way process as the research is of a better quality and the researcher has the benefit of multiple perspectives.

Doing research is also a part of my recovery and focuses some time of my day on a meaningful activity. This gives me a sense of purpose and a new energy and enthusiasm learning how to do good research, understand ethics and problem solve ... all to help others and improve life ... I think this is the main reason why many SU [service users] and carers become involved ... to make things better and improve understanding and reduce stigma. All these aspects improve services.

I have written poems on data analysis. Something I had not expected to do and am now published in journals writing on mental health issues ... this is a direct result of being involved in research. It has enriched my lifelong learning and I would encourage more SU and carers to become involved as it is not just a tick box exercise. And you will find your expertise and experience is greatly valued.

Extract three

[Since] initially being invited to local carers groups, I have gained opportunities and knowledge over the past seven years. I became a member of Tees, Esk and Wear Valleys NHS Foundation Trust through being a service user, and also being a carer for my wife who has Alzheimer's.

This has allowed me to be involved in many ways over a very wide area and, on many occasions, I have been involved with many other Trusts and health projects, including numerous research

projects. Lately I have been involved with Research Design Service North East Consumer Panels. This directs my views in yet another direction and gives another way of expressing a layman's point of view. This helps professionals to appraise other approaches to their projects, to clarify their proposals to others more effectively and efficiently towards the wellbeing of patients, and a better understanding for carers and family members.

PPI [Patient and Public Involvement] also offered me opportunities to attain confidence and how to deal with emotions by offering leadership and 'train the trainer' courses. This gave me confidence to be a presenter and I learnt the conduct and procedures to chair meetings.

Help and support

Help and support to develop patient and public involvement in your own research is available from various sources. If you are in the process of designing and developing a research proposal and funding application, you can get help and support from your local National Institute for Health Research, Research Design Service.²³

You may also be able to get help and support from your Local Clinical Research Network.²⁴ There are also new Academic Health Science Networks.²⁵ All these new networks will continue to provide advice and support relating to patient and public involvement.

More information and resources about patient and public involvement are also available on the Involve website.²⁶

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