Patient perspective

Assessing patient, carer and public involvement in health care

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ABSTRACT

Involving patients and carers aims to be empowering and broaden participation in decision making. However, creating adequate structures and processes for involvement is still in its infancy. Clarity of the meaning of involvement can help to move patient, carer and public involvement from rhetoric to reality. This paper presents a content analysis of NHS staff's, patients', carers' and the public's understanding of involvement. Six categories of involvement were identified (outcome-focused, patient-led, representative, variety of methods, feedback, those with power should be involved). The categories were used to pilot a questionnaire to measure involvement based on their understanding of involvement. A reliability analysis demonstrated good reliability. Further development is needed to assess construct validity. Feedback from those involved in piloting the questionnaire highlights that involvement is a complex process involving more than tangible outcomes. We recommend that further research is carried out to understand and assess the quality of the process of patient, carer and public involvement.

Keywords: meanings, measurement, patient involvement

How this fits in with quality in primary care

What do we know?
It is recognised that patient, carer and public involvement (PCPI) is complex. The gulf between rhetoric and reality has been debated. It is well documented that PCPI at the individual level has different meanings for different categories of people.

What does this paper add?
This paper provides an understanding of the meaning of PCPI at the collective level for different categories of people. The attempt to measure this meaning to provide a tool to develop and assess PCPI has further revealed the complexities of PCPI. The tool was a useful starting point to develop a PCPI strategy and to stimulate discussion. However, this paper has shown that the quality of the involvement process needs further scrutiny.

Introduction

Complexities of involvement

Involving patients and carers aims to be empowering and broaden participation in decision making. Other outcomes include creative problem solving and improvement of services in ways that meet patient and carer needs. Despite the legal obligation to involve

patients and carers,[1] creating adequate structures and processes for involvement is still in its infancy. Most people applaud the principle of involving patients and carers. Nevertheless, they are aware that it can be complex, especially during the early stages. Complexities such as representatives, time, energy and resources, conflicting agendas and perspectives and unequal distribution of discursive power can hinder success. The aim of this paper is to describe how a patient, carer and public involvement (PCPI) project aiming to improve services for coronary heart disease (CHD) patients and carers developed an assessment tool for the development of a PCPI strategy, and to share the lessons with others making similar attempts.

Power and involvement

Lennie evaluated the empowering and disempowering impacts of community information technology initiatives.[2] Four types of disempowerment were identified. Social disempowerment included not gaining sufficient knowledge or understanding about the project. Technological disempowerment included lack of local IT training and support. Some participants and project partners felt that certain activities had been controlled by particular participants. This was labelled political disempowerment. Some people reported a lack of confidence to participate, a type of psychological disempowerment.

Similar limitations have also been reported in patient, carer and public involvement projects in healthcare settings. For example, Telford Gold *et al* found a lack of clear direction regarding networks and patient participation, dominance of regional cancer centres in planning activities and competing provincial priorities.[3] Williamson discussed the concept of involving patients in health service by cogently arguing that professionals' and patients' or consumers' standards are often at a variance.[4] She highlighted that the two groups often have differences in interest, power and position. She explored these differences and provided an in-depth comparison of patient and professional values. An understanding and acceptance of these differences is needed to progress patient, carer and public involvement.

Wilcox (2005) stressed the need to understand power and provided a guide to effective participation.[5] He pointed out that there are many organisations that are unwilling to allow people to participate because they fear loss of control. He clearly distinguished the difference between 'power to ...' and 'power over', and highlighted that people are empowered when they have the power to achieve what they want for their purpose.

Levels of involvement

Involvement occurs at the individual level, as in the healthcare professional–patient consultation, or at the collective level such as policy making, service commissioning and resource allocation.[6] Within the different levels of involvement, the spectrum of involvement ranges from passive input through to active participation to partnership. An example of the individual level is the Expert Patients' Programme which is an NHS training programme that enables people living with a long-term chronic condition to develop skills to better manage their condition.[7] In this programme the individual is encouraged to become more active in the management and decision making related to their care needs.

At the collective level, The National Institute for Health and Clinical Excellence (NICE) invites patients, their carers and the public to be involved in their work to improve the wider needs of patients such as producing guidance that addresses patient, carer and public issues.[8] Patients, carers and the public are also involved in NICE decision making such as deciding which treatments to recommend.

Being involved in the collective level is typically synonymous with inviting a patient, carer or a member of the public to attend meetings and be a member of a board. Often the roles and meaning of such involvement are poorly defined or not defined at all. This type of involvement has the potential to become a tokenistic gesture. Coulter noted that it is important to recognise the limitations of direct participation.[9] She pointed out that most patients are not members of organised groups and that patient members of such groups cannot be said to represent the views of the majority. Most patients would want providers to take account of their experiences and views, yet only a small unrepresentative minority would want to be actively involved in committees to achieve this. Those that do become actively involved may be people with a particular axe to grind.

As far back as 1969, Arnstein described eight rungs on a ladder of citizen participation.[10] At the bottom two rungs of the ladder, power holders strive to 'educate' or 'cure' participants. Rungs 3 and 4 progress to the levels of tokenism, in which participants hear and are heard but they lack the power to ensure that their views will be heeded by those with power. At rung 5, participants have some degree of influence though tokenism is still apparent. At rung 6, there is a higher level of tokenism because participants are allowed to advise but the power holders have the continued right to decide. At rung 7–8, participants have more decision-making power. A partnership enables participants to negotiate and engage with decision makers. At the top of the ladder, participants obtain the majority of decision making and managerial power.

Clarity of involvement as a way to move from rhetoric to reality

Dyer suggested that a lack of clarity about participation can dilute potential contributions.[11] With such a range of involvement opportunities, seeking a shared understanding about the meaning of involvement could help assess PCPI outcomes by measuring the indicators of involvement on a continuum at various stages of a project. Such an assessment tool could help those responsible for PCPI to assess baseline involvement (practice guidance one[1]), develop a PCPI strategy, monitor the strategy and quantify success. Finding a way to demonstrate the success of PCPI in way that is understandable to those who control resources and is user-friendly is needed to promote PCPI in the league of priorities.

A commitment to clarify and improve public involvement in social care and health care has been shown in the Department of Health publication of *A Stronger Local Voice*.[12] It recognises that there continues to be a lack of meaningful engagement when services are planned and commissioned, and that continuous dialogue with people and improvements are needed. A new framework for user and public involvement has been put forwarded with five key elements: local involvement networks, overview and scrutiny committees and commissioning, explicit duties to involve and consult, a stronger national voice and a stronger voice in regulation. However, the framework did not include an element for improving the evaluation of patient, carer and public involvement.

This paper describes how a project aiming to improve services for CHD patients and carers at the collective level developed a shared understanding of the criteria for PCPI, which were used to develop a PCPI assessment questionnaire. The assessment questionnaire was used to inform a PCPI strategy, and the usefulness is discussed.

Methods

Understanding involvement

Thirty members of an organisation concerned with improving services for CHD patients and their carers consisting of primary, secondary and tertiary care trusts were emailed asking them what patient, carer and public involvement means to them. They were also asked to ask patients and carers what being involved in decision making about NHS services means to them. All the responses from patients and carers were from white British individuals. As the project took place in an ethnically diverse area, an attempt was made to obtain a wider range of views.

Leaflets with reply slips asking for the same views were placed in a cultural centre attracting people from a range of ethnic backgrounds, for a period of one month.

Respondents' views were typed up. Two researchers carried out a content analysis. The responses were read independently, then categories were agreed. The researchers then re-read the responses and independently inserted quotes into the categories. The researchers then compared their findings and sought agreement in cases where there had been differences in classification.[13] The categories were used as a basis for a questionnaire to assess involvement before developing a PCPI strategy.

Measuring involvement

Seventy healthcare professionals from primary, secondary and tertiary care, and patients and carers involved in providing or receiving CHD services in the same strategic health authority area were given the questionnaire at meetings or via email.

Results

What does involvement mean?

Eighteen healthcare professionals provided their views on involvement, a 60% response rate. Twenty views from white British patients and carers were collected, and ten people from a range of ethnic backgrounds provided their views on involvement.

Their views were classified into six categories (see Table 1).

Interestingly, quotes from patients, carers and the public and NHS staff fell into nearly all of the six categories. The only exception related to the 'those with power should be involved' category. None of the NHS staff mentioned that involvement should involve senior members of staff. Similarly, only one quote from a patient fell into the 'patient-led' category.

Is our measurement of involvement reliable?

A questionnaire with one question per theme was developed (see Appendix 1). Having one question per theme prevents an analysis of validity, however it was felt that the practical nature of a short questionnaire was more desirable.

Forty-one respondents returned the questionnaire, a 59% response rate. A reliability analysis was conducted, giving a Cronbach's alpha of 0.815 and a Cronbach alpha based on standardised items of

Table 1 Involvement categories and quotes

Category	Quotes
Outcome-focused	'People would want to know that they are not wasting their time, that someone is going to take the time to read and use the information.'* 'You need to know you can make a difference and that you are not wasting your time.'* 'I don't mind giving my opinion but you have to explain why you want it and how it will be used.'* 'I've never quite understood how outcomes of user involvement groups are fed back into the service to ensure that effective change occurs.'+ 'I don't think it really matters what PPI stands for, whether it involves the public or patients, because their say is never heard and if it is then it is not listened to.'+ 'People would want to know that they are not wasting their time, that someone is going to take the time to read and use the information.'* 'Questionnaires left on the ward would be a good way of getting feedback. They make you feel that someone is listening and interested in your opinion. I would also like to know what was done.'* **Total: * = 5, + = 2**
Patient-led	'Patients should be the ones driving the whole PPI agenda forward.'+ 'My view of PPI groups/reviews would be to ensure that service users are involved in the decision-making process relating to direct issues affecting their quality of care and services provided by an organisation.'+ 'Really patients should have the power in this.'+ 'It should be about patients'* **Total: * = 1, + = 3**
Representative (but not targeted)	'We need to make sure it is not just the patients who want to complain who we hear from.'+ 'There are plenty of ways to get our opinion. Just treat us like humans and not something special that has to be studied.'* 'You should try to obtain a range of views.'+ 'You need to ensure it is representative of all patients.'+ 'Is it purely about getting interested, articulate people to attend various meetings and giving input from a patient's persepective? Or is it about listening to the nitty gritty ordinary inarticulate people who nevertheless might have a lot to say?'+ **Total: * = 1, + = 4**
Variety of methods for understanding views needed	'Questionnaires would be good while you are sitting waiting for the doctor. However, what about the people who don't go to the doctors? It would have to be something on paper as it is cheap, not by telephone for example. Setting up a website for feedback and really publicise it, telling people to have their say, maybe with a count down of how many days they have to have their say.'* 'I like to give my views face-to-face. I like to see the person. It feels like a waste of time, writing on a form. Too many English forms are bad for my health.'* 'You need to have a combination of things so that young and old can have their say. I would log onto a website but I'd have to be told about it and encouraged to use it.'* 'Meetings and questionnaires.'+ 'I think that lots of people who have had recent experience of being a patient in hospital, or a carer of a person in hospital, would be more than happy to tell of their experiences, both good and bad. This could be by way of an open letter or wide-ranging questionnaire.'* 'People are often more articulate on paper than they would be if invited to attend a meeting and give their views – and they might not have time to attend meetings if they are working or still caring for someone.'+ 'Sitting in the café talking to someone is a good way, it's more comfortable than talking in front of lots of people.'* 'I am ready to tell about my experience but don't know how. You would have to do it with something important so that people don't forget, for example, send it out with the electoral roll with a space to write your opinion and experience.'* 'I don't mind talking to someone like you if it helps, but I would not want to talk in front of others.'* 'Posters, leaflets completed in hospital. Postal patient care questionnaires.'+ **Total: * = 7, + = 3**
Feedback	'I don't mind giving my opinion but you have to explain why you want it and how it will be used.'* 'I would want to know how I'd helped to improve something.'* 'You should keep us informed about progress.'* 'I've never quite understood how outcomes of user involvement groups are fed back into the service to ensure that effective change occurs.'+ 'Perhaps an open forum once a month for to enable us to air our views. It would also be nice to have someone to go to and have feedback from on how any grievances or suggestions are being dealt with.'+ **Total: * = 3, + = 2**
Those with power should be involved	'I hate when they come to festivals and ask you about health. Health is private and we have a right to privacy, just as much as anyone. Besides, why would you want to talk about health at a festival, it's the wrong vibe ... and the ones they send don't have any power anyway.'* 'I would write a letter to the top person.'* 'It needs initiative from politicians, unions and employers to raise the awareness of how the public can contribute.'* 'If I was going in for some kind of operation, I would like to have someone on the ward to comfort any worries about the procedures. It would have to be someone with some power who could act on my worries.'* 'I would want to talk to someone face-to-face. Someone in charge.'* **Total: * = 5, + = 0**

* Patients, carers, public; +NHS staff.

0.823. The means and item discrimination are presented in Table 2. Table 3 shows the frequency scores for each question on the questionnaire.

Thirteen months into the project, ten healthcare managers and seven patient representatives were asked to look back and rate the usefulness of the questionnaire in designing the PCPI strategy. They were asked to rate the usefulness of the questionnaire on a scale of 0–10 (0 = not useful at all, 10 = extremely useful). The average score was 8 with a range of 7–10. There was also a space for comments. Five patients provided the following comments:

'It is useful but does not pick up on the fact that we do not have the power to change things. On one hand, we are seen to be leading, on the other, we don't have any power at all.'

'At the moment I don't think we are taking full advantage of the opportunity that is in front of us.'

'I think that they are carrying on the way they were before but just we're then tagging on.'

'It does not show how extremely slow it is.'

'This helps us to see some progress, and look back and think actually we are making a difference. However this is more useful to bureaucrats than patients.'

Three managers provided the following comments:

'This is excellent. It gives us evidence that we have made improvements.'

'Very useful. It helped us focus on involving more patients in the beginning.'

'I found it difficult to answer question 4.'

Discussion

Satisfaction with the assessment of involvement

This questionnaire was simple to administer and has demonstrated good reliability (a Cronbach's alpha score over 0.7 and item discrimination score above 0.3 is considered good).

Table 2 Means and item statistics

Question	Mean	Corrected item – total correlation	Cronbach's alpha if item deleted	SD
1	4.03	0.634	0.773	1.66
2	2.91	0.630	0.773	1.85
3	2.18	0.621	0.776	1.66
4	4.62	0.397	0.823	1.74
5	3.85	0.646	0.780	1.26
6	3.59	0.607	0.782	2.12

SD, standard deviation.

Table 3 Frequency scores for each question on the questionnaire

Question number	Scale value						
	1	2	3	4	5	6	7
1	5	4	7	11	5	5	4
2	4	9	7	4	8	1	2
3	11	10	4	4	4	1	
4	2	5	5	12	7	5	
5	3	5	7	7	15	1	1
6	5	7	2	8	3	7	4

Ideally, the mean scores would be between 3.5 and 5.5. Two items fall outside this range. Question 4 was raised as causing some confusion by one participant. The term 'a variety of methods' may be confusing and more appropriate for those familiar with research methods discourse than those familiar with using tools to assess or those asked to give views. This question may need rephrasing.

This questionnaire has not measured involvement. It is a measure of NHS staff's, patients' and the public's understanding of the tangible characteristics of involvement. It is well documented that involvement at the individual level usually has different meanings for different categories of people. For example, it has been found that patients' assessment of the quality of their care can be different from objective clinical measurements.[14] This research has shown that at the collective level, there may not be a great difference in the expectations of PCPI between different categories of people; however, it suggests that for the people in this study, there was a key difference of opinion in the responsibility for PCPI. This requires further exploration on a wider scale.

The comments from the patient representatives demonstrate that the process, quality and dynamics of involvement require further investigation and a different type of evaluation method. These aspects of involvement are crucial to the ongoing learning that needs to take place in our striving to improve patient and public involvement. At the moment, the tangible characteristics of patient and public involvement are important to ensure continued commitment and motivation as well as a starting point and a direction. As more and more PCPI projects are being set up, we will need to turn our focus to assessing the quality of the process of involvement.

Training needed to make the measurement more useful in practice

Construct validity of the questionnaire has not been shown. Patients involved in this project wanted a short questionnaire. In retrospect, the value of having several questions to measure constructs should have been further negotiated with patients. This pilot, however, has demonstrated that with further development it could provide useful baseline data to develop a PCPI strategy and then monitor it. Using such a tool can be visually powerful in decision-making meetings, especially when patient participants are familiar with the tool and are able to use an evaluation language to negotiate with decision makers. It is well documented that training is crucial for the success of PCPI.[15] From our experience, training in research and evaluation methods for those patients, carers and the public who want to enter into a dialogue with decision makers would facilitate their empowerment.

Moving away from a need to barter for PCPI resources

Making PCPI a legal requirement has shifted PCPI higher up the decision makers' agenda. The quality of involvement needs further scrutiny. For example, we found that an evaluation of the readiness to seize opportunities when patients, carers and the public demonstrate a readiness to commit to and be accountable for planning and decision making needs to be assessed. Such a readiness should be seen as a success of PCPI, that trust has been gained. This would require further qualitative research into the meaning of 'patient-led' among patients, carers and the public who have had experience of involvement projects. Understanding the quality of the PCPI process would help move away from the risk of tokenism. A measurement of involvement can be useful when you have to demonstrate success in a fight for resources. However, ultimately, we should be moving towards a situation where bartering for PCPI resources is no longer necessary and we are equally concerned with the quality of the process of involvement.

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CONFLICTS OF INTEREST

None.

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Appendix 1: Patient and public involvement assessment questionnaire

This questionnaire is designed to assess NHS staff's, the public's and patients' views on (insert name of trust or organisation) current efforts to involve patients and the public in the improvement of coronary heart disease (CHD) services. Please could you underline the number on the scale that corresponds to your views and return it to ....

THANK YOU

1 There is a link between the patients' and the public's views on CHD services in your area and improvement to services

0	1	2	3	4	5	6	7
Don't agree at all							Fully agree

2 Efforts to involve the public and patients in seeking their views reach all relevant people. In other words, efforts to involve are representative

0	1	2	3	4	5	6	7
Don't agree at all							Fully agree

3 It is the patients and the public who lead on improvement to CHD services in your area

0	1	2	3	4	5	6	7
Don't agree at all							Fully agree

4 A variety of methods are used to involve patients and the public in the improvement of CHD services in your area

0	1	2	3	4	5	6	7
Don't agree at all							Fully agree

5 Those with the power to make changes in CHD services are actively involved in acting upon improvement suggestions made by patients and the public

0	1	2	3	4	5	6	7
Don't agree at all							Fully agree

6 Improvements based on ideas from patients and the public are fed back to the relevant people

0	1	2	3	4	5	6	7
Don't agree at all							Fully agree