

## Knowledgeshare

# Web alert: involving patients and the public in health service development and research

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## Introduction

Evidence-based practice, as originally conceived, was intended as a methodology that would blend the best research evidence with clinical expertise and patient values.<sup>1</sup> But with the rise of guideline-driven health care, and an evidence-based movement that seems to focus almost exclusively on how to find and judge the quality of health research, the part that patient values play in decision making is at risk of being sidelined. Involving and engaging patients and the public in the design, evaluation and prioritisation of health services is hard to do well, but it is essential. After all, an important barrier to the implementation of guidelines is often that they fail to incorporate patient preferences, and that their development is not sufficiently responsive to patient needs.<sup>2</sup>

Consumer involvement in the National Health Service (NHS) has been on the Government agenda since the early 1990s,<sup>3</sup> thanks to the many benefits it can bring. In addition to developing more appropriate and accessible services, patient engagement can help to reduce health inequalities, encourage joined-up working between health care and social care, and restore public confidence in the NHS.<sup>3</sup> But how to go about implementing these ideals in practice remains contentious and complex. Real consultation involves a shift of power, and no one gives away power lightly, least of all highly experienced, well trained clinical experts. Variable levels of interest from patients in this engagement work have been shown, particularly if they are not convinced that their views will be acted upon, and staff often struggle to know when and how this public involvement should take place.<sup>4</sup> What is the most effective way to engage patients in the planning process? At what stage should views be sought, and from whom? These questions are exercising NHS management staff up and down the country, and the following resources will provide a number of useful starting points.

## Government initiatives

### Patient and public engagement

The Health and Social Care Act 2001 gave the NHS a statutory duty to involve patients in service planning and operation,<sup>5</sup> and to this end the Department of Health has set up a Patient and Public Engagement division ([www.dh.gov.uk/en/Managingyourorganisation/PatientAndPublicinvolvement](http://www.dh.gov.uk/en/Managingyourorganisation/PatientAndPublicinvolvement)). The creation of the division demonstrates that the NHS has come a long way in terms of public involvement, but to make this engagement 'mainstream in the commissioning of services' is an ongoing challenge. As part of this work each local council has been asked to set up a Local Improvement Network (or LINK), which will take its membership from individuals and community groups who are interested in monitoring health and social care services, and advising on what local people need. Authorised members of these networks must be allowed to observe the working practices of local NHS trusts, and trusts must respond to their recommendations. Information about LINKs, including a guide for health and social care staff, can be found via the Department of Health website at [www.dh.gov.uk/en/Managingyourorganisation/PatientAndPublicinvolvement/DH\\_076366](http://www.dh.gov.uk/en/Managingyourorganisation/PatientAndPublicinvolvement/DH_076366).

There is also an online LINKs Exchange ([www.lx.nhs.uk](http://www.lx.nhs.uk)) that is aimed at sharing best practice between those involved in running these local improvement networks. Once registered with the site (which is free) registrants will get access to the list of LINK leads as well as good practice examples, reports and research, a list of LINKs websites from around the country, and the opportunity to contribute their own information.

### Fontis

At the time of writing, the NHS Centre for Involvement, an organisation that was funded by the Department of Health to advise on the running of LINKs

(among other things), has recently closed down. Currently its site ([www.nhscentreforinvolvement.nhs.uk](http://www.nhscentreforinvolvement.nhs.uk)) can still be used to find the LINKs host for a particular geographical region and the relevant contact at the local authority, as well as a range of guides including: 'Making people aware of LINKs', 'The first ten things that LINKs should do' and 'Working with LINKs'. It is to be hoped that these resources will remain available for the foreseeable future.

Taking over some of the role of the Centre for Involvement is Fontis ([www.fontis.org.uk](http://www.fontis.org.uk)), a new independent social enterprise aiming to change the way that public services interact with the public. This organisation has only recently been launched, and so few details are available as how this work will develop. Its website currently includes a 'News' section, highlighting developments in the arena of public involvement, and a blog written by the directors of Fontis. They are actively seeking the membership of organisations and healthcare staff whose work involves engaging and collaborating with the public.

## NHS Institute for Innovation and Improvement

The NHS Institute for Innovation and Improvement (NHS I<sup>2</sup>), which aims to transform health services by developing and spreading new ways of working, has produced a number of publications in relation to patient involvement (see [www.institute.nhs.uk](http://www.institute.nhs.uk)). Unfortunately, these do not seem to be gathered together in a single 'Patient involvement' section, and so a search on the site for the words 'involvement' and 'engagement' is recommended.

Resources to be aware of include 'What to look out for ... patient and public involvement', which is designed for those leading service change, and a module entitled 'Patient involvement' that will help readers to assess the current level of involvement, gives examples of information material and provides methods for evaluating any changes made. There is also a selection of engagement resources under the 'PCT portal' section of the site (this can be found under the 'Commissioning' heading) and a 'Patient and public engagement toolkit for world class commissioning'.

Finally, the NHS I<sup>2</sup> is supporting services to run a project called 'Armchair involvement', which is about using information technology to enable engagement with patients. This section of the site (to be found under the 'Building capacity' heading) includes a series of recommendations, an explanation of the different technologies that might be used and case studies from trusts that have been involved in the project.

## Care Quality Commission

Another Government body, the Care Quality Commission, has a number of pages on its website looking at how the Commission involves the public in its regulation of health and social care services. These can be found under the 'Get involved' tab at [www.cqc.org.uk](http://www.cqc.org.uk).

## Other sources of advice

### National Association for Patient Participation

Patient participation groups (PPGs) are groups run from with general practice and community health centres providing a forum for patients and healthcare staff to work together on the development of local services. Unlike LINKs, they are not mandated by the Government, but have grown up organically over time. Consequently their make-up and funding is very variable, but there are many of them, with around 40% of English practices supporting one (according to the National Association for Patient Participation (NAPP), which acts as an umbrella organisation for these groups). NAPP promotes the role of PPGs in decision making and aims to increase their numbers until every GP surgery has one.

The NAPP website ([www.napp.org.uk](http://www.napp.org.uk)) contains a step-by-step guide for setting up a patient participation group and has a small selection of the newsletters and web addresses of individual PPGs. NAPP is involved in consultancy and research, details of which can be seen under 'NAPP projects' along with a range of case studies of the ways in which patients have been able to influence the work of their primary care trusts. Finally, the association's 'Growing patient participation' initiative has a podcast which can be downloaded, a number of useful documents and a fund of money that PPGs can bid for in order to support a new patient involvement initiative.

### People and participation.net

This site ([www.peopleandparticipation.net/display/Involve/Home](http://www.peopleandparticipation.net/display/Involve/Home)) is for any organisation, from any sector, that is interested in increasing public involvement in its work. It is run by a not-for-profit company that provides support in a number of ways. The site has a 'Process planner', which staff can use when they are planning public engagement work as it helps in choosing participatory methods that are appropriate to the situation. The process planner asks users to consider the scope, purpose, participants, context and

follow-up of the project. The 'Methods' section of the site contains more detail on the different ways to get public engagement, and lists their strengths and weaknesses. There are currently about 55 different methods under discussion, from the use of online resources such as Twitter, to conversation cafes, community development and action learning.

People and participation.net also includes a large number of case studies of public participation, a library of websites and guides and the opportunity to post a question online for one of their experts to answer. This 'Ask an expert' area of the site includes an answer bank showing the responses to questions previously asked by users.

## Participation Works

Participation Works ([participationworks.org.uk](http://participationworks.org.uk)) is specifically aimed at involving children and young people in service level decision making. It runs training on how to involve 'hard to reach' children, how to build a culture of participation and how to use creative methods for improving engagement. This is a consortium that brings together expertise from a variety of organisations including the National Children's Bureau, the National Youth Agency and the British Youth Council. As with many of the other sites listed here, the Participation Works website includes dozens of reports, case studies and toolkits to help increase involvement of young people in public sector services.

## Other organisations

There are also a number of organisations that can be commissioned to provide advice and support with public involvement. Two examples are Consulting Communities at the NHS Public Health Resource Unit ([www.phru.nhs.uk/pages/php/consulting\\_communities.htm](http://www.phru.nhs.uk/pages/php/consulting_communities.htm)) and the Moore Adamson Craig Partnership ([www.mooreadamsoncraig.co.uk](http://www.mooreadamsoncraig.co.uk)), which both help to put public consultation into practice.

## Research

As patients and service users become increasingly involved with advising on the delivery of health care, and evaluating the effectiveness of service models, it follows that they should also be drawn into the research agenda. No longer seen simply as research subjects, patients now often play a part in developing research questions, devising data collection methods and even instigating healthcare research. The NHS National Institute for Healthcare Research (NIHR) believes that 'involving patients and members of the

public leads to research that meets their needs, is more reliable and more likely to be put into practice',<sup>6</sup> and their *Research for Patient Benefit* programme looks most favourably on those projects with a significant component of public involvement.

As with public involvement in service improvement, there is a way to go before health researchers can be said to be adequately engaging with patients. There is some evidence that researchers overestimate the extent to which they involve consumers, and the proportion of UK projects that manage this successfully seems to be around 17%, according to a survey published in 2007.<sup>7</sup> There is no one method of involving patients in research that is better than any other, but the following resources can be used to gather ideas and make contacts, and to develop studies that more accurately address the needs of the public.

## INVOLVE

In order to support this agenda the NIHR funds a national advisory group called INVOLVE ([www.invo.org.uk](http://www.invo.org.uk)). Its aim is to create a research community that will be broader, more inclusive and more representative, by facilitating active partnership between researchers and the public. Researchers can use the INVOLVE website to find minutes of its meetings, reports of its work, and guidelines on involving patients at various different stages of the research process.

The 'Publications' section of the site includes reports commissioned by INVOLVE on such topics as training for service user involvement in research and the potential of user controlled research. Abstracts and presentations from INVOLVE conferences (held every two years) are also available, and there is a detailed 'Question and answer' section, which deals with such questions as: 'Why involve members of the public, who should I involve, and how?'

invoNET is a network of people whose aim is to build up knowledge and learning about public involvement in health and social care research, and the website gives details on who their current members are and how to join. Both invoNET and INVOLVE have online forums to which those interested can sign up, ask questions and share experiences. Finally, the 'Research database' section of the site contains details of hundreds of research projects (which can be browsed by disease area or research design), that have featured a high level of public involvement.

## People in Research

For public involvement in research to really take off, it must be made easy for researchers to identify those people interested in working with them, and for the

public to find out how to get involved. People in Research is a project set up by the UK Clinical Research Collaboration, a partnership bringing together the NHS, the academic world and organisations that fund health research.

The People in Research website ([www.peopleinresearch.org.uk](http://www.peopleinresearch.org.uk)) centres around a directory of organisations that offer opportunities for public involvement in research and give details of this collaborative work on their websites. This directory can be searched by location, by health topic, or by the aspect of research activity with which the reader would like to become involved. This might include instigating projects, collecting research data, analysing data, contributing to documents or communicating the results. The site seems primarily aimed at the public, and includes a 'jargon buster', which helps to explain the various stages of the research process. There is also a section of testimonials from members of the public who have become involved in research, reflecting on their experiences.

## Cochrane Collaboration Consumer Network

One of the most important organisations in world health care today is the Cochrane Collaboration. Inspired by Archie Cochrane, a doctor from the UK who raised awareness in the 1970s of the paucity of medical evidence, this collaboration of 10 000 people works systematically to review and synthesise the outcomes of clinical trials. The Cochrane Consumer Network is made up of patients and members of the public who wish to provide input into the development of these systematic reviews.

Their website ([www.cochrane.org/consumers](http://www.cochrane.org/consumers)) acts as a means of connecting people interested in health research with the Cochrane groups that will be most relevant to them. It includes a large number of documents that guide members of the public as to how to comment on Cochrane reviews and to help in the writing of plain language summaries. There is a newsletter covering the activities of the group, and an email list keeping list members up-to-date with opportunities for collaboration.

## James Lind Alliance

Another central figure in the development of evidence-based practice is James Lind, who in 1747 conducted one of the first randomised trials. The James Lind Alliance (JLA) is a non-profit organisation set up to ensure that medical research is directed towards questions that affect and concern patients and clinicians, rather than those of interest only to scientists and pharmaceutical companies. It believes that

'patients and clinicians should work together to agree which, among [the many medical] uncertainties, matter most and thus deserve priority attention'.

The alliance works by facilitating the development of priority setting partnerships, which cover a range of different health topics from asthma to prostate cancer. It also works with Patient View ([www.patient-view.com](http://www.patient-view.com)) to survey the opinions of patients and patient advocacy groups to identify issues of importance for future research. The website ([www.lindalliance.org](http://www.lindalliance.org)) also contains a list of publications explaining the activity and ethos behind the alliance, and details of a programme of JLA sponsored events.

## Giving a voice to patients

### Health Talk Online

The Database of Individual Patients' Experience, or DIPEX, is a result of an extensive programme of qualitative research into patient experiences of illness. Now made available through the Health Talk Online website ([www.healthtalkonline.org](http://www.healthtalkonline.org)), this database provides high-quality evidence that can be used by patients to make decisions about treatment, and by NHS staff to make decisions about service delivery. The website contains the results of patient interviews, presented as video, audio and text pieces, which can be searched or browsed by disease area. Under 'Chronic pain', for example, there are lists of support groups, questions and answers and academic publications, as well as a huge subject list containing detailed patient responses to questions about topics from activities of daily living and acupuncture to x-rays and yoga. There is also a selection of online forums, which can be used to ask questions and share advice.

### Patient Opinion

Whereas DIPEX (above) is a managed project aiming to gather comprehensive real-life experiences of health care, Patient Opinion is more about giving the public a platform to express their views on the care they have received. A not-for-profit social enterprise that was set up by a general practitioner, Patient Opinion allows anyone to upload their compliments, complaints or comments about a particular hospital or trust. These comments are then forwarded to relevant managers for their response.

Staff wishing to learn from patient experiences and engage the public in service delivery may find the site ([www.patientopinion.org.uk](http://www.patientopinion.org.uk)) useful in identifying the problems that matter to patients. The site presents a selection of NHS service improvements that have happened as a result of feedback on the site.

## Other bodies

There are of course many patients' associations, organisations and advocacy groups that NHS staff should work with when attempting to bring the patient perspective into service improvement and research. These groups work to give patients a stronger voice in policy making and to link patients with the people who plan the delivery of health and social care. Umbrella organisations include National Voices ([www.nationalvoices.org.uk](http://www.nationalvoices.org.uk)) and the International Alliance of Patients' Organizations ([www.patientsorganizations.org](http://www.patientsorganizations.org)).

## Conclusion

Primary care trusts (PCTs) will need to win the commitment of their staff in order to establish a genuine culture of patient involvement – one that avoids tokenistic consultation but brings patient viewpoints into discussions in the right way and at the most appropriate time. They will also need to understand how to encourage patients, carers and service users to come into this process and what support they will need in order to contribute constructively to service planning. The sites listed above should help to begin these processes; further resources and ideas can be found at the Patient and Public Involvement Specialist Collection from NHS Evidence ([www.library.nhs.uk/ppi](http://www.library.nhs.uk/ppi)).

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## PEER REVIEW

Commissioned; not externally peer reviewed.

## CONFLICTS OF INTEREST

None.

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