# Involving patients in Quality Improvement Projects

## Why do it

There are lots of reasons to consult patients/service users/carers and ask for their advice in service delivery planning and research. One reason is that it simply makes the research better, and quality improvement interventions more relevant. People at the receiving end of healthcare services may challenge your assumptions about what needs to change, provide insight into areas you haven't yet considered, and help you design an intervention that targets the most appropriate outcomes.

### Case study example

An outpatient clinic had a problem with patients not turning up to appointments (it had a high 'Did Not Attend', or DNA rate). This wasted valuable consultant time and meant that it was hard for other patients to get appointments when they needed them. A project was identified to design an intervention to reduce DNAs.

***Without patient involvement:***
The clinicians targeted patient motivation and engagement as the key thing that would make a difference. They decided to educate patients about the problems of non-attendance (the waste of resources, the inconvenience to other patients, and the risks to longer-term health) using leaflets and posters in clinic.

***With patient involvement:***
When patients were consulted, they pointed out that motivational information in clinic would only be seen by those already at clinic, not by those who didn't attend appointments. They also suggested that there were other issues involved. Appointment letters were sent out with set times, and if these had to be changed, patients had to ring a central number to ask for a new appointment. Calls were not being picked up on this number and information was not being passed on. In fact, when a researcher looked into the reasons behind DNAs, 61% turned out to be down to communication breakdown within the hospital rather than patient motivation. An intervention was identified in which communication would be decentralised as far as possible, patients given the opportunity to choose their appointment time, and asked for landline and mobile contact details for additional reminders as well as postal address.

## How to do it

Asking patients' advice in designing your project should be approached like asking a specialist colleague (a nurse, a statistician, a medic with more experience than you) for advice. You are looking for people who can help you see issues you might not have spotted, advise you on areas you are unfamiliar with, and let you know if what you are researching is feasible, worth doing, and relevant. The earlier in the process you do this, the more useful the advice will be.

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***ETHICS*****:** If you are consulting patients on the design and outcomes of your project, and are not asking them to take part in any intervention or give data for analysis, they are an adviser rather than a research participant, and you do not need formal ethical approval to take their advice. See: http://www.invo.org.uk/posttypepublication/patient-and-public-involvement-in-research-and-research-ethics-committee-review/

## Finding the right people to help you

***DO***

Identify patients who have experience/expertise in using the services you want to improve. Be aware that people have different priorities depending on things like whether they work full-time or have other responsibilities. What range of experience do you want to tap into?

Ensure the patients you involve feel in control and respected when talking to you. Treat them as you would a senior colleague whom you have asked for advice; meet them on their terms, at times and places convenient for them.

***DON'T***

Make the mistake of thinking that you are trying to get a representative sample of all patients. You are looking for advisors with useful insights, not research participants.

Have a 'token' patient surrounded by healthcare professionals, or ask a patient for advice in inappropriate situations (such as during clinic where they are dependent on you for healthcare – make a separate time to talk about your project).

## Working with patients to improve your project

***DO***

Ask patients to suggest outcomes for the project; they may have insight into areas you have not thought about, and may challenge your assumptions about what is really important.

Consider what will happen if you don't agree with the patients you involve, or can't change what they suggest you change. Be very clear about the scope of your project from the start.

***DON'T***

Ask patients to approve something you've already decided to do; don't ask for help unless you are prepared to listen and allow yourself to be challenged.

Discard what patients say because it clashes with 'the way things are done around here'. Part of the point of a QIP is to challenge practice and change things for the better.

## Offering something in return

***DO***

Acknowledge the value of the work done by the patients you involve, and pay if you can. Patients may help without asking for anything, purely for the opportunity to make things better, but there's no reason why they should. As a minimum, always cover expenses. See FURTHER RESOURCES.

Keep everyone involved updated on how the project is going, including positive and negative outcomes and any posters or publications that come out of it. Consider getting your patient advisors to comment on these and perhaps co-author them.

***DON'T***

Assume that patients should or will help you. Never let them be out of pocket (for example, paying their own travel to get to a meeting).

Forget to tell those who have helped you what happened to their input and what changes are being made as a result of the project.

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***FURTHER RESOURCES:*** INVOLVE is funded by the NIHR to support public involvement; see www.invo.org.uk. For full research projects, your local Research Design Service can also help: http://www.rds-sc.nihr.ac.uk. National Institute for Health Research (NIHR) advice on how manage payment: https://nottingham.ac.uk/clahrc-ndl-nihr/documents/ppi/05-paymentratesatinvolve.pdf.