

Online library of Quality,
Service Improvement
and Redesign tools

**Gaining insights from/
working in partnership
with health service users**



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What is it?

To design, re-design or improve services that are truly patient-centred, it is vital to gain insights from patients/health service users and understand their experience of using NHS services.

Service users and carers have a different perspective to staff and accessing their views alongside those of staff, opens up new ideas for improvement.

Involving service users and other key groups in service design or redesign, understanding their perspectives and acting on them will help to ensure that the changes you make in your improvement project are sustainable and will produce the best outcomes.

In addition, service users and carers are a vital resource and can help to provide insights. With support, they can also take responsibility for aspects of the improvement activity.

When to use it

Seek service user and carer perspectives and consider co-designing improvements in partnership with staff and patients any time you want to improve a service or process.

The investment of time will reward you with:

- a greater breadth of ideas
- an opportunity to involve more people in testing those ideas (see [PDSA](#)) and understanding the impact on services
- gaining buy-in from people who use services and their families and carers.

How to use it?

Define purpose

It is important to set out your reasons for wanting to understand the service user and carer experience at the start, as this will help with decisions about how and who to involve. Consider what changes might happen as a result of this participation activity, what resources you have and who the planned improvements/changes will impact on.

Decide on method

Thinking about what you are trying to achieve should help you decide what type of insight/ participation technique will be most effective.

There are many ways to gather insight into users' and carers' experience and to co-design with service users, ranging from the use of technology to face-to-face methods.

To do this well can take additional project time and resource, so ensure you plan for this to maximise the impact of gathering information in this way.

Recruit people to take part

It is important to seek insight from those for whom the changes will have the greatest impact. Consider the diversity of your service users and carers and identify how you can be as inclusive as possible – this might involve outreach activities or engaging the local voluntary sector to support service user-led involvement.

Decide what resource you have available and speak to the people in your organisation who might be able to support this activity, including existing service users groups and patient experience leads who can help you design participation from the perspective of the patient.

Decide how you will evaluate the process and communicate impact

One of the reasons that people get involved in helping health services to improve is to make a difference for others, so regular, clear communication and feedback on the impact are extremely important.

Engage other stakeholders and staff in this insight/participation process so that they too have an opportunity to understand the range of perspectives and their influence on the improvement decisions and activities.

Always feed back the improvements made to the people you have involved so that they know the difference their input has had.

The following qualitative approaches will help you gain staff and patient insights and enable you to work in partnership with people who use services:

- 1. Observation and feedback techniques** – provide insight into current experiences and are a way of testing new ideas. This might include patient shadowing and observing activity on wards, departments, etc.
- 2. Gathering individual perspectives** – gives valuable insight into people's experiences, attitudes and feelings. These include listening to patient stories, questionnaires and semi-structured interviews.
- 3. Participation and co-design techniques** – provide insight and help to design new ways of working. These include experience-based co-design, focus groups, patient panels and service user groups, open space, future search and asset-based community development.

You are likely to have a wide range of existing sources of data in your organisation, which may be of use as a starting point, including:

- Patient Advice and Liaison Service (PALS) data, incident reports, patient surveys (look at national surveys as well as those developed locally), Friends and Family Test
- real-time surveys, eg exit surveys
- patient diaries
- patient complaints, compliments and critical incident reviews
- websites offering opportunities for organisations to gather feedback from their patients, eg NHS Choices, Patient Opinion
- your organisation's Facebook page, Twitter feed and other social media.

Shadowing a patient, service user or staff member

This is when a member of staff or a volunteer accompanies a patient or service user on their journey or spends time shadowing a member of staff. Ideally, the shadower will be unfamiliar with the process. Shadowing provides observational feedback, which can helpfully be combined with other approaches, such as obtaining views of the service.

This technique gives you an insight into how people move through the service, what happens to them and their perceptions of the service.

While the patient is being shadowed, the shadower can use interview techniques and observation to gain more insights from the patient.

It is helpful to:

- Be clear about what you are trying to achieve, why shadowing is appropriate and how it will help you achieve your objectives.
- Clarify what aspect/touchpoint of the patient pathway you want to focus on (eg tracking the admission process – see experience-based co-design below for touchpoints).
- Write an information sheet about the aims, what is involved and the expected outcomes of the study, which can be given to the patient.
- Ensure the patient fully understands and is comfortable with their role; get their informed consent to participate. You may wish to take some photographs (include this in the consent process).
- Make it clear that the presence of the shadower will not influence the care the patient receives.
- Develop a template to capture key timings and moments in the patient journey.
- Ensure the shadower fully understands and is comfortable with their role and that the service is aware of this activity also.
- Observe how the patient is treated by members of staff.
- Observe how easy/difficult it is for the patient to find their way around the hospital. What goes smoothly for the patient? Are any tasks duplicated?
- Observe the environment and context.
- Provide support for the patient and shadower; acknowledge their time and effort.
- Feed back to the patient and the shadower on how their work has contributed to service improvement.

Experience-based co-design

Experience-based co-design brings service users, carers and staff together to share the role of improving care and redesigning services. It was developed as a way of helping frontline NHS teams to co-design improvements in partnership with patients.

This method, which is based on person-centred design methods used across the world, focuses strongly on capturing and understanding patients', carers' and staff emotional experiences of services and deliberately draws out the subjective, personal feelings at crucial points in the care pathway. It does this by:

- Encouraging and supporting patients and carers to share their stories.
- Using the stories to pinpoint those parts of the care pathway where the user's experience is most powerfully shaped (the 'touch points').
- Working with patients, carers and frontline staff to redesign these experiences in partnership.

Patient questionnaires

This is a relatively straightforward way of getting information from large numbers of people. You can also use questionnaires to measure current experience, baseline information and evaluate change over time.

- Make sure you are aware of any information governance policies related to accessing patient information before you start.
- Be clear about what you are trying to accomplish, what you want the information for and how you will analyse, use and share the results.
- Involve service users in designing questions so that you find out what matters to them.
- Ask questions that only service users can answer, so that you make the most of the opportunity, ie don't ask people how long they had to wait, do ask about the experience/impact of waiting.
- Structure questions carefully: consider the balance between tick box (yes/no or Likert five-point scale – strongly agree through to strongly disagree) and free text questions. Multiple choice questions are quicker for the user to complete and for you to analyse. Free text questions often provide more valuable data, but take longer to analyse.
- Keep it short: it should take no more than 5–10 minutes to complete.
- Be aware of the language used; not all patients are likely to understand jargon, technical terms or abbreviations.
- Always test/pilot the questionnaire: try using small tests of change ([PDSA](#)) to refine and improve questions.
- Decide whether the questionnaire will be anonymous. If not, be mindful that this may affect how people respond to the questions.
- Think about how you will reach your target group. Leaving questionnaires in waiting rooms, day rooms or handing them out at reception is a good way to reach patients and carers. There are online survey tools available if your survey subjects have internet access and many NHS organisations now use survey kiosks for surveys such as the Friends and Family Test.
- Remember the small details such as providing contact details if they would like to talk to someone about their comments, pens to complete a paper survey and postal address/prepaid envelope for surveys to be mailed back to you.
- Snapshot audits are a good way to get a representative sample of views from patients using a specific service – this is a short questionnaire given to every patient who attends a particular clinic on a particular day, or over a particular week.

Friends and Family Test

The Friends and Family Test (FFT) was introduced in April 2013. It asks people if they would recommend the services they have used and offers a range of responses. This has given NHS patients attending any type of healthcare facility in England a way to report back on their experience. Real-time feedback, often gathered on-site using handheld electronic devices or feedback kiosks, has also been used to gather experience data in acute trusts.

When combined with supplementary follow-up questions, the FFT provides a mechanism to highlight both good and poor patient experience, which can be used to inform service improvement work.

The best time to collect feedback on an experience is immediately afterwards when it is fresh in the person's mind.

Focus groups

A focus group is a collection of people sharing common characteristics. Typically, focus groups meet to discuss and debate their experiences of a specific topic or problem, eg patients who have recently visited the accident and emergency department or received treatment for a specific condition.

Typically, focus groups will consist of 6–12 people who meet on one occasion only. They are a useful way of listening to a wide range of experiences of a single area and can give you rich in-depth feedback.

Holding a focus group:

- Establish how you will fund expenses before setting up the group. To be as inclusive as possible you may consider paying people to take part.
- Clarify the purpose, objectives and timings of the group.
- Send an invitation letter explaining the process, what is expected of the patients and what the expected outcomes are.
- The focus group should last between one and two hours.
- Make sure the venue is accessible to all participants.
- Be as inclusive as possible, this will inform where you hold the group, the timing, etc.
- Provide refreshments.
- Agree ground rules and an agenda for the group.
- Use prepared questions and themes relating to the topic for discussion.
- Have a skilled facilitator who will not seek to lead but has strategies to help the group if they get stuck.
- After the focus group, feedback outcomes/progress to the group.

Semi-structured patient interviews

Semi-structured one-to-one interviews are used to collect qualitative data. They aim to understand the respondent's point of view, rather than make generalisations.

They enable you to delve more deeply and ask 'why?' This often yields more information, depth and emotional response than a questionnaire. The patient also has the opportunity to ask for clarification. However, these interviews are more time consuming to conduct and analyse.

Conducting an interview:

- Gain each person's consent; discuss confidentiality and its limits and anonymity.
- If you are asking about potentially emotional information, think in advance how you might manage that or what support you can provide to the person – eg signposting support services, arranging a debrief, etc.
- Think about how you will gain perspectives from the diverse population who use services; you may need an interpreter. Contact your PALS Team for help if necessary.
- Consider using an interviewer who is independent from the topic being discussed, eg from another department or an external organisation.
- Explain the purpose of the interview.
- Use open-ended questions. Some will be planned ('Tell me about...') and some will arise naturally during the interview ('You said a moment ago...', 'Can you tell me more...?').
- Make sure you are clear about what the person is saying.
- Aim for a conversational feel: questions should be asked when it feels appropriate; they may be planned or spontaneous. The wording of the questions may vary in different interviews.
- Keep the number of interviews manageable; many improvement ideas can come from just a few interviews.
- Typically, these interviews are conducted face to face, but could be done using Skype or over the phone to avoid people making a special journey to be interviewed.

Consider asking your service users group or local voluntary sector to carry out the interviews.

Patient panels, service user groups

Patient panels are typically set up to gain insights on how services are meeting patient needs and to understand the patient perspective on how NHS organisations are delivering their services and care. They are often set up in relation to a specific service or condition and can be useful to gain patients' advice on making improvements to patient experience and redesigning services, improve communication with specific patient groups and act as a source of patient input to staff education and training.

Service user groups have often been set up to offer support to patients and their families and carers, but they are also a helpful resource to inform service improvement work. They are well used in the NHS to ask people for their views and to make decisions on changes in the organisation.

Patient stories

See the [patient stories](#) tool.

Open Space, Future Search and asset-based community development

If you are looking at a large scale challenge that affects a whole system or community you may consider Open Space, Future Search and asset-based community development methods, all of which require some experienced design and facilitation.

Open Space is a meeting framework that allows an unlimited number of participants to form their own discussions around a central theme. Open Space might be used at an early stage in a project, to understand and frame the relevant issues. It has the advantage that you can engage a large and diverse group of people; it is a very flexible and creative process and can support relationship building. Because of its open nature, it is less suitable if you have specific outcomes in mind.

A Future Search conference is a way for a community or organisation to create a shared vision for its future. It engages a large group of stakeholders who take part in a highly structured process. This kind of session often raises commitment levels and enables a deep level of understanding by participants of the challenge and the needs of all participants. It does however require longer commitment from participants.

Asset-based community development is a growing movement that considers local assets as the primary building blocks of sustainable community development. Building on the skills of local residents, the power of local associations and the supportive functions of local institutions, asset-based community development draws on existing community strengths to build stronger, more sustainable communities for the future.

What next?

Make sure you feed back to the patients involved how their information and insights are being used/leading to improvements.

Tools that may be useful once you have gathered patient perspectives include:

- [Using an affinity diagram](#) to enable you to theme and sort all the potential areas for improvement that you have identified.
- [PDSA](#) cycles provide a framework for developing, testing and implementing changes that lead to improvement.
- [Project management](#) can help you make larger, more formal changes.

Background

Combining patient and staff experiences gives a powerful insight into services. There is a strong relationship between patient experience and clinical outcomes. This is reflected in national and local policy, which makes the case to raise the profile and improve the way the NHS involves its patients in developing services and delivering care. Understanding what is working well for patients and what needs more improvement is an essential element of caring for vulnerable, sick people. This is recognised in policy developments such as the Five Year Forward View and documents produced by the National Institute for Health and Care Excellence (NICE).

Additional resources

Green, GP and Haines, A (2015) *Asset Building and Community Development*, Los Angeles: Sage

Weisbord, M and Janoff, S (2010) *Future Search: Getting the Whole System in the Room for Vision, Commitment and Action*, Berrett-Koehler, third edition

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Acknowledgements

Improvement Leaders' Guide: Involving Patients and Carers, NHS Institute for Innovation and Improvement