# US-PEx

## Making better use of patient experience data for health service improvement



## Resource book for participating frontline medical ward teams

# Introduction

This booklet is intended to be a brief introduction to different types of patient experience data and how they can be used for quality improvement. It will signpost you to some further online resources and books/articles that can help. We hope it will be useful background reading before our first learning community meeting and also a continuing source of reference as you work on your quality improvement projects.

We are not expecting you to use everything included here or read it cover-to-cover; it is simply intended to be a source of ideas to dip into, to pick and choose and to help you design your own project.

We recognise that Trusts will already have a lot of data on patient experience. You may want to use these existing sources, or you may want to collect some new data – or do a mixture of both. What follows is intended to help you think through how you might use these different sources.

We would also like it to be a working document – if you identify things you would like us to add or change please let us know. It's important for us to understand what information frontline teams need to support them, so we can advise other Trusts in future.

If you have the printed version of this booklet, you can download the most current .pdf version from www.phc.ox.ac.uk/US-PEx. The digital version contains many links out to other useful sources of information or further reading.

*– Health Experiences Research Group (HERG), Nuffield Department of Primary Care Health Sciences, University of Oxford*

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# CONTACT DETAILS

Angela Martin,

HERG Research Operations Manager

**Telephone:** 01865 289373

**Email:** angela.martin@phc.ox.ac.uk

# WHAT DO WE KNOW ABOUT PATIENT EXPERIENCE?

Patient experience is one of the three main pillars of quality of care, alongside safety and effectiveness.

Not only this, but evidence suggests that good patient experience is associated with better clinical safety and effectiveness, as well as improved staff morale and retention, lower operating costs and lower lengths of stay ('organisational outcomes').

If we want to improve patient experience, it makes sense to find out what patients themselves think and use this information constructively. Staff assumptions about what needs to change may not match what matters most to patients.

Staff may have concerns that patients will come up with a list of expensive and unrealistic demands. But in fact, we already know a lot about what matters to patients, and much of it is around relationships, information and attitude, and small low-cost changes which can make a big difference.

A King's Fund and King's College London report summarised the most important themes for patient experience (across all settings) in the following table:

| Themes | Functional | Relational |
|---|:---:|:---:|
| Being treated as a person, not a number | | ✓ |
| Staff who listen and spend time with patient | | ✓ |
| Individualised treatment and no labelling | | ✓ |
| Using language that is easy to understand | | ✓ |
| Finding out about the latest technologies, innovations and medications | ✓ | |
| Feeling informed, receiving information and being given options | | ✓ |
| Patient involvement in care and being able to ask questions | | ✓ |
| More public awareness about condition | ✓ | |
| Efficient processes | ✓ | |
| Knowledgeable health professionals | | ✓ |
| Aftercare support | | ✓ |
| Positive outcomes | ✓ | |
| Continuity of care | | ✓ |
| Good relationships and positive attitudes among staff | | ✓ |
| The value of support services | | ✓ |

http://www.institute.nhs.uk/patient_experience/guide/the_patient_experience_research.html

The authors conclude that:

> *'Relational' aspects of care (like dignity, empathy, emotional support etc) are very significant in terms of overall patient experience alongside 'functional' aspects (access, waiting, food, noise etc).*

Yet, although we know a lot about patient priorities, translating this general knowledge into local action is still a challenge.

# HOW CAN WE USE PATIENT EXPERIENCE DATA FOR IMPROVEMENT?

There are several ways in which quantitative and qualitative patient experience data can support the change process:

1. It can assess what experience is currently like, and measure whether improvement activities have made any difference
2. It can help us understand why reported experience is sometimes not as good as we might hope, and generate ideas for change
3. It can tell us not just what is wrong, but what 'good' looks like and what could be better: patients often suggest better ways to do things, simple ideas
4. It can challenge our assumptions about what the problem areas are as far as patients are concerned; sometimes we assume something is more of an issue than patients think it is
5. It can be a powerful motivator for action and remind us what we're trying to achieve

Different types of data can contribute, more or less, to these purposes.

For example, to measure change, a patient reported experience survey is likely to be useful, or a numerical analysis of complaints received.

To generate ideas for changes, free text from surveys or the Friends and Family Test, interviews or observations may help us. Even a single patient story can create a 'lightbulb moment', making people think differently about the care they provide and prompt them to act.

Such 'soft intelligence' can bring a different kind of knowledge which challenges assumptions and changes perceptions. Even if it can't easily be captured and measured[1].

An important point to remember when collecting and using patient experience data is to work to include seldom heard voices – for example, people with learning disabilities, children and young people, and those from black and minority ethnic backgrounds.

All Trusts will already have a lot of data – survey findings, patient stories, NHS Choices and Patient Opinion postings – so we do not necessarily expect teams to collect new data for this project (though they may choose to).

Instead, our aim is rather to help you think through how you might use these different sources.

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[1] Martin G, McKee L, Dixon-Woods M. (2015) Beyond metrics? Utilizing soft intelligence for healthcare quality and safety. Social Science and Medicine 142: 19-26

# STAFF PARTNERSHIP WITH PATIENTS AND FAMILIES

People join the NHS because they care about providing good quality care. They come to work each day wanting patients and families to have the best possible experience.

But this doesn't always happen. There can be a range of reasons for this – some of them beyond the ward team's control.

Being empowered to engage with patient experience data and make change happen can help reconnect staff with their fundamental values.

Staff involved in co-design work with patients and family members directly involved in planning and implementing change, have reported that this has helped create and sustain momentum.

> *"Addressing the issue of values needs to be handled with care. It mustn't be experienced by those working in the service as an attack on their values, since this will be alienating. Rather it needs to be framed as an appeal to the values that brought them into health care in the first place, and a challenge to go further."*
>
> **Jeremy Taylor, National Voices**
>
> http://healthfdn.org.uk/4Y2-44Q91-83M3X0S793/cr.aspx

# SUPPORT AND GUIDANCE

In this resource book, we will summarise different sources and types of patient experience data, and some of the most successful techniques for using them.

Here are a few key points about how you will be supported:

- At the first learning community meeting, you will have a chance to talk to our research team experts and discuss how you might put together your own quality improvement (QI) ideas using patient experience data.
- What you choose to do locally will be entirely up to your team to decide; change shaped and led by frontline staff and local patients is more likely to succeed (and more motivating and rewarding for staff involved).
- We know that good facilitation and senior management commitment are helpful in supporting and empowering frontline staff to take action. We have asked Trusts to commit to this project and ensure local patient experience and quality leaders are ready to help you.
- Your local quality advisers can help you with particular QI methods, especially if your Trust has a preferred approach.
- We will offer ongoing support and reflect on the learning with you, so together we can offer guidance to the rest of the NHS. NHS England are partners in the study, so we will be well placed to share the learning across the NHS.
- NHS England will also be offering additional advice on improvement methods during the lifetime of the project.

# NUMBERS AND STORIES

A common question is whether quantitative or qualitative patient experience data is 'better'.

In a context such as the NHS, which rightly attaches great importance to evidence-based medicine, there can be a tendency to see evidence of different types in a hierarchy.

Quantitative evidence (especially from randomised controlled trials) is usually seen as best, with patient stories or narratives seen as 'anecdotal' or unreliable, because they do not represent a wide sample.

But we need to ask ourselves: 'better for what?'

Our team includes researchers who generate evidence on patient experience using a range of different methods. We have come together because we think both numbers and narratives have their strengths for particular purposes, and because we think NHS staff should be encouraged to use both.

'Dashboards' of different sources of patient experience evidence can be used to combine approaches, creating a more rounded picture than a single data source.

A dashboard is a visual representation of different aspects of patient experience. This might include, for example, different kinds of survey results, extracts from comments and complaints and Patient Opinion postings.
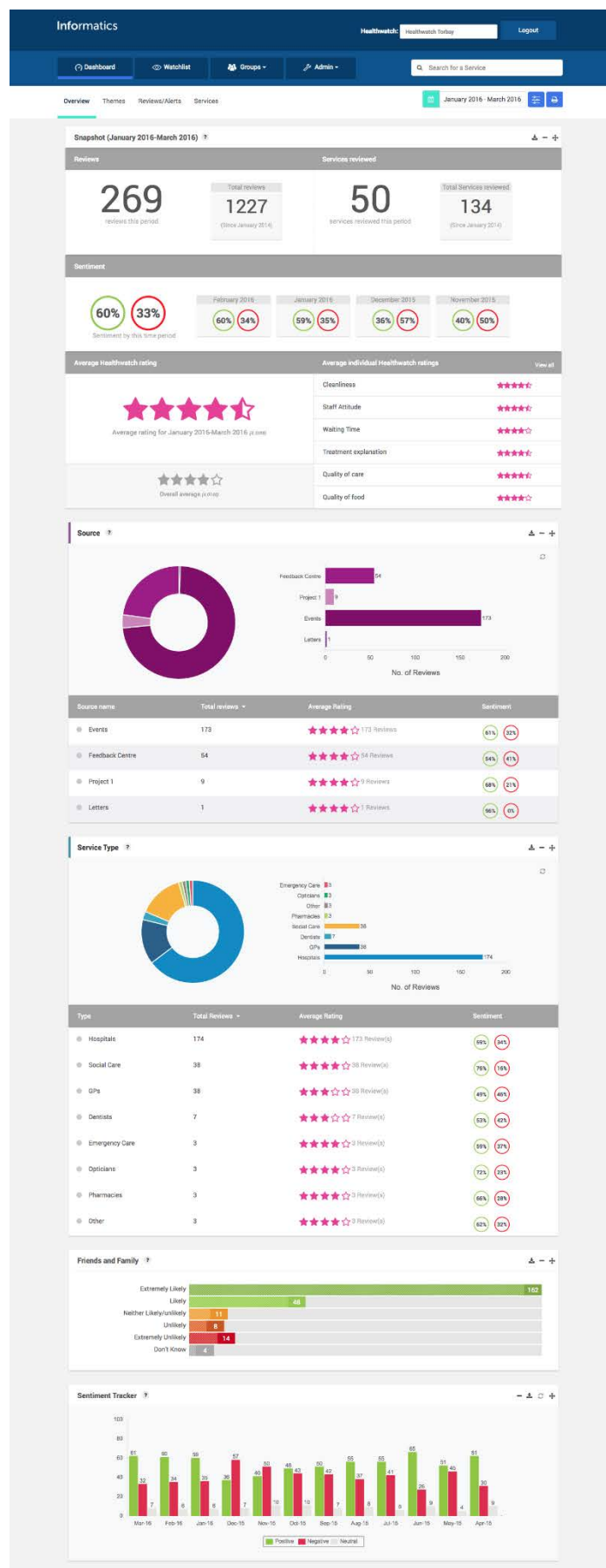
# SECTION 1: TYPES OF DATA AND HOW THEY CAN CONTRIBUTE



## SUMMARY OF DATA COLLECTION METHODS AND THEIR PROS AND CONS

There are many different ways of finding out about patients' experiences.

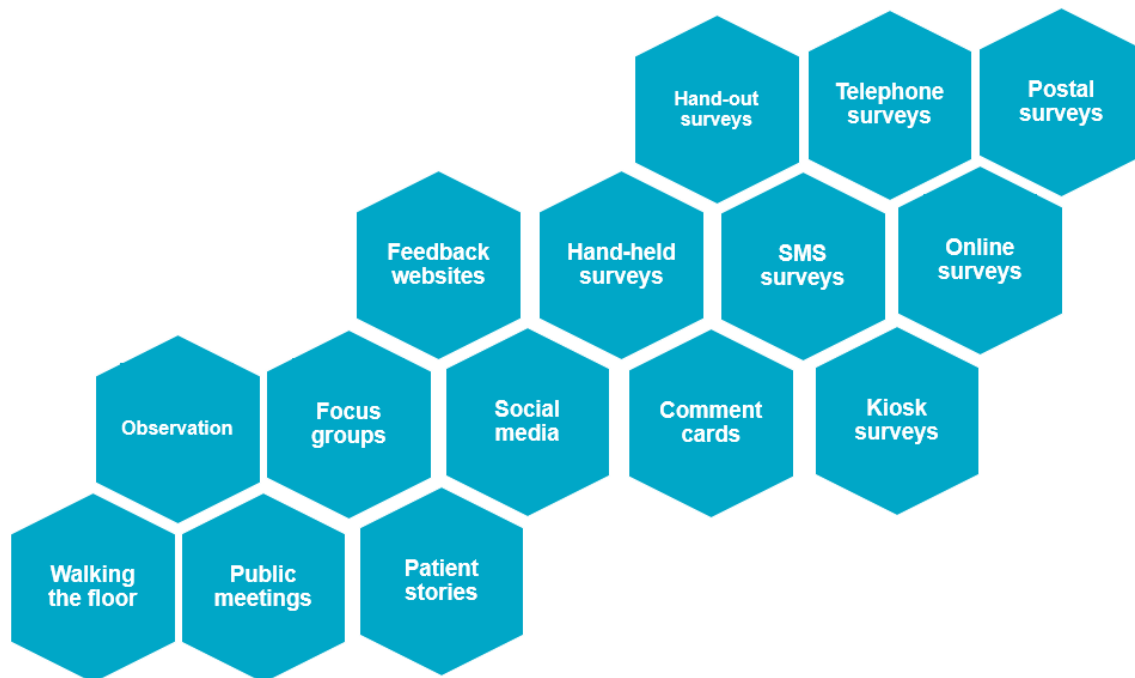In the following sections we will look in detail at the role of:

- Surveys
- Online feedback
- Local feedback and complaints
- Narratives and interviews
- Group discussions/focus groups
- Observation and shadowing

In each case we will examine what they can tell us, how easy or difficult they are to collect and analyse and how they may stimulate improvement work.

In Appendix One you can also find a summary table of the pros and cons of many different types of data collection for measuring patient experience.

# SURVEYS

Surveys are widespread in modern life, and healthcare is no exception.

Both in the NHS and internationally patient experience surveys are used to measure and understand the quality of service from the user's perspective. Surveys are a way of quantifying and generalising feedback or opinions for populations – e.g. hospital patients. As such, they explore collective experiences.

While surveys cannot tell individuals' stories, they do enable wide, representative groups to have a say, including people who might not otherwise volunteer their views.

Patient experience surveys ask people to report on what happened to them during their care. Questions focus on specific, reportable events reflecting important areas: whether things did or did not happen, rather than if things were satisfactory.

## DESIGNING YOUR OWN LOCAL PATIENT SURVEY

When thinking about designing your own local patient survey these are the things to consider:

- Question topics should be specific enough to be relevant, but not so specific that the questions become tedious to answer
- Avoid topics that are politically sensitive or might embarrass patients
- Phrase questions in simple and straightforward language
- Use single subject questions whenever possible
- Avoid leading or biased questions
- Limit the number of "open-ended" questions, e.g. 'How do you feel about the care your nurse gave you?' Vs 'Was the care you received from your nurse a) Good, b) Ok, c) Poor?'

Before launching a new survey, or new questions in a survey, at full-scale they should be discussed and tested face-to-face with a smaller group of patients first. This pre-testing is essential in order to:

- Discover parts of the questionnaire that do not work
- Identify questions that are unclear or difficult to answer
- Discover parts of the questionnaire that place an unacceptable burden on the respondent

Examples include asking people if they were involved as much as they wanted to be in decisions about care and treatment, or whether they got enough help from staff to eat meals.

Patient experience surveys can allow organisations to compare their performance with other similar organisations, track changes in experience over time and explore variations between different patient groups.

Surveys can be administered via various methods, or 'modes', from face-to-face interviews to online surveys. Survey modes differ in practical and theoretical characteristics, and there is no one 'best' method to use.

Each approach has its strengths and weaknesses, and the choice of survey mode for a project usually involves a cost-benefit trade off. For example, interview surveys typically yield higher response rates than self-administered surveys – but cost much more. Whereas postal surveys can be sent to large numbers of patients to collect high volumes of robust, standardised data at acceptable cost - but they take a fairly long time to produce results.

The best method for any particular application will be one that balances the strengths and costs of the available options.

## NATIONAL VERSUS LOCAL SURVEYS

In the NHS, patient experience surveys can be categorised into two groups; nationally administered or co-ordinated collections, and local collections.

### NATIONAL COLLECTIONS

Two examples of well-known national collections are the NHS Inpatient Survey, part of the national NHS survey programme, and the GP Patient Survey. Here we focus on the Inpatient Survey.

The NHS national survey programme, run by the Care Quality Commission (CQC) and its predecessors, has been in place for the last 15 years.

The programme uses robust, reliable measures to gather data on a variety of care settings (such as maternity care, community mental health care and inpatient care). One of these measures is the NHS Inpatient Survey.

The NHS Inpatient Survey is an annual postal survey of adult inpatients carried out by acute and specialist NHS Trusts. Each participating Trust is responsible for selecting their own patients and collecting data, carried out in strict compliance with instructions issued by a central co-ordination centre.

First carried out in 2002, the survey explores inpatients' experiences of care and treatment, aiming to provide key information which can be used to drive improvement. The survey achieves approximately 60,000 responses each year.

### LOCAL PATIENT SURVEYS

Local patient surveys are collections that individual NHS Trusts can undertake to explore specific areas of care or populations of interest to their organisation.

They can allow NHS Trusts to track the experience of their patients at more regular intervals than national mandated surveys, to survey different groups of patients, provide more detailed data at ward or department level, or ask about issues not covered in national surveys.

Data from these local surveys can then help provide evidence for bringing about and evaluating a range of local quality improvement initiatives.

To summarise, surveys can give us a broad sample and good high-level evidence of what people think. However, they may lack detailed nuance, and be less well suited for understanding why people feel the way they do and suggesting solutions.

## CASE STUDY

A study, led by Jill Maben and colleagues from King's College London, gathered both survey and interview data from the same patients.

In the box below, we compare responses from Betty, who was in her 80s:

| Patient survey data | Patient interview data |
|---|---|
| Q: Overall, did you feel you were treated with respect and dignity while you were in hospital?<br><br>A: Yes, always<br><br>Q: Overall, how do you rate the care you received?<br><br>A: Excellent | *The other thing I didn't raise, and I should have done, because it does annoy me intensely: the time you have to wait for a bedpan. Elderly people can't wait. If we want a bedpan, it's because we need it now. I just said to one of them, 'I need a bedpan please.' And it was so long bringing it out, it was too late.*<br>*It's a very embarrassing subject, although they don't make anything of it, they just say, 'Oh well, it can't be helped if you're not well.' And I thought, 'Well, if only you'd brought the bedpan you wouldn't have to strip the bed and I wouldn't be so embarrassed.'* |

*Maben J, Peccei R, Adams M, Robert G, Richardson A, Murrells T. and Morrow E. Patients' experiences of care and the influence of staff motivation, affect and wellbeing. Phase II case studies: Annexe to final report. NIHR Service Delivery and Organisation programme; 2012: pages 17-18. Granted permissions by lead author and NIHR (NETSCC).*

We cannot assume that one of Betty's answers is more 'true' than the other, or that her answers are inconsistent.

In answering overall ratings-style questions, people are weighing up the whole of their care experience. Overall, Betty felt well cared for.

However, she has one specific example where things could have been done better. Note that she says, 'I didn't raise [it], but I should have.' It can take some time and distance from the experience for people to reflect on possible improvement issues.

This is one reason why real-time feedback (useful though it is) may not always reflect what people really think about a service (see 'local feedback and complaints' below).

However, surveys usually invite people to add comments as 'free text' and these may provide a useful additional source of improvement ideas alongside numerical analysis.

*To summarise, surveys can give us a broad sample and good high-level evidence of what people think. However, they may lack detailed nuance, and be less well suited for understanding why people feel the way they do and suggesting solutions.*

## ONLINE FEEDBACK

While most improvement activities are based on patient experience data obtained through surveys, interviews and other feedback mechanisms, more and more people are now giving unsolicited feedback online.

Alongside blogs and social media, this includes more dedicated patient feedback sites, such as NHS Choices, Patient Opinion and IWantGreatCare. This online feedback is a rich but often under-used source of patient experience data.

However, this is changing. Patient Opinion, for example, invites Trusts to engage actively with patient feedback. In addition to monitoring what people are saying about their care, some Trusts also use it to:

- respond to comments, resolve concerns immediately and avoid complaints
- invite further involvement
- use the feedback to design and implement quality improvements.

Patient Opinion reports a steady increase in Trusts using it this way, though there is still disappointment at the defensive or dismissive tone of some Trust replies. For example those which say 'We're sorry you feel we did not provide a good experience' rather than 'we're sorry you did not have a good experience', and those which reply using the same wording every time or simply refer people to the local PALS service.

There is also more potential for thanking patients for positive feedback and passing it on to staff involved.

There are free and paid-for levels of engagement with Patient Opinion. Simple registration is free and gives two designated members of staff access to reply to comments. Subscription levels differ a little between CCGs and providers. The main features of paid-for levels are:

- More staff can use it to respond to postings about their own team or service
- More online features such as reporting, advanced alerts, blogging
- More support and training from Patient Opinion.

Despite this, some Trust managers may have concerns that giving many staff direct access to respond to comments might represent a worrying loss of control over corporate communications and cuts across the careful handling of complaints.

But Patient Opinion argues that Trusts which take this approach offer a more human face to patients, are more likely to make genuine changes and to make people feel reassured their comments have been acted on, reducing rather than escalating tension.

They also suggest that local ownership and responding to feedback is one part of creating the culture change needed to take patient experience seriously in every team. Many of the comments are positive and complementary, which can be

rewarding for staff, giving them pride in their team and reassurance they are getting things right for patients.

In the extract below, from Patient Opinion's 10th anniversary report, Dr Ben Mearns, Chief of Medicine, Surrey & Sussex Healthcare NHS Trust, explains how they have learned that letting staff engage directly with patient comments can enhance rather than damage the Trust's reputation. This is followed by an example of how one Trust has responded quickly to a patient comment.

**Was there an initial fear about using Patient Opinion?**

Yes, we felt exposed. No one likes to be criticised or feel judged. But it is like jumping into a cold swimming pool. You adjust and learn how to swim. We have found responding in human terms goes a long way.

A trust may feel it has a fragile reputation that needs to be protected, but that is the wrong way to view it. Reputation gets better when it lives and breathes its values of transparency and honesty. We have learned to trust our staff. We have learned trust is not brittle, it is a formed opinion of your community.

**Single biggest change using Patient Opinion has bought about?**

It has liberated our staff to be open and honest and to live their values. The relationship between our staff and patients is our biggest asset.

**What are the benefits of using Patient Opinion from a patient perspective?**

It helps build confidence in us. It empowers patients. They are reassured they have a level playing field there they can engage with us and help improve things.

**TOP TIPS ON USING PO FROM DR. BEN MEARNS**

Trust patients and carers

Trust staff to respond (clinical leadership)

Accept imperfection as normal

Solve each problem as it arises

Use positive feedback widely to empower staff and give confidence to patients/carers

Spot patterns and act to change the system

Remember the organisation's reputation will take care of itself

Executives have to let go and empower their team

Believe in patients and carers as our best cheerleaders and that they expect the best

Allow stories posted on Patient Opinion to help you work together to solve problems

Trusts may want to consider actively promoting sites such as NHS Choices and Patient Opinion to patients to gather qualitative feedback on specific services. This might be one way to monitor whether a recent change in service results in improved feedback.

Unlike trying to collect local interview data, which is time-consuming and expensive, online feedback has the potential to generate qualitative comment from a broad sample of people quickly and cheaply – though in either situation Trusts need some skilled capacity for qualitative analysis.

Patient Opinion Scotland are also working on numerical ways of expressing Patient Opinion data alongside stories, which may help improve its usefulness for improvement.

Of course, people who go online to report their experiences may not be

## COMPUTATIONAL ANALYSIS

**Text mining** – using a computer to extract and link together information from written feedback to reveal new facts, connections or ideas to explore; and

**Sentiment analysis** – where a learning computer program is taught how to identify and extract subjective information automatically from written feedback. This allows large amounts of text to be broadly categorised as good or bad.

representative of patients as a whole, so some caution is warranted.

However, digital skills are spreading rapidly across the population and in the future online feedback is likely to become the norm.

In fact, the data from these sources may be more representative than we think. Comparing NHS Choices ratings for particular services with the findings of the NHS Inpatient Survey (which draws on a more representative sample) shows a high degree of consistency between the two[2].

We are running another study looking specifically at the use of online feedback, including how we can use computational techniques (see box), to draw out important themes and patterns in the data.

There will be four case studies with Trusts looking at how they use such feedback, what motivates them to do so and what the pitfalls are. We will share learning across the two studies.

See appendix two for further reading.

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[2] For more details, see:
https://www.researchgate.net/publication/224811810_Associations_between_Internet-based_patient_ratings_and_conventional_surveys_of_patient_experience_in_the_English_NHS_an_observational_study

# LOCAL FEEDBACK AND COMPLAINTS

The Friends and Family Test (FFT) is a local feedback tool used widely across the NHS.

The FFT is not a survey in a conventional sense; it does not have a standardised methodology, sampling or administration approach, and asks only one question: How likely are you to recommend our service to friends and family if they needed similar care or treatment?

While the results will not be statistically comparable against other organisations due to the various data collection methods, FFT does give a broad measure of patient experience that can be used alongside other data to inform service improvement.

The FFT also offers patients the opportunity to explain their ranking by adding comments, and some follow-up questions may be asked. The 'free text' collected by the FFT may be especially useful at a local level in understanding what patient experience issues are being raised, and suggesting areas for improvement.

Much of the feedback through online sites and the FFT is positive praise and constructive ideas, not just complaints, as is sometimes assumed. Nonetheless, complaints – whether online or written direct to the Trust – can be a valuable source of patient experience evidence.

Wards can take a proactive approach to reviewing complaints and identifying possible improvements, and can use patterns in the number and type of complaints as a measure of performance.



**HAVE YOUR SAY TO IMPROVE YOUR CARE** NHS

We welcome patient feedback to tell us what we are doing right and what we can improve.

We would like you to think about your recent experience of our services. How likely are you to recommend our practice to friends and family if they needed similar care or treatment?

| Extremely Likely | Likely | Neither likely or unlikely | Unlikely | Extremely Unlikely | Don't Know |
|---|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| ☺ | ← | | → | ☹ | ? |

Thinking about your response to this question, what is the main reason why you feel this way?

Increasingly Trusts are concerned to stop incidents turning into complaints, by using real-time feedback mechanisms to alert staff to problems and taking action quickly to put things right.

While this is undoubtedly one useful strategy, there are caveats about relying on real-time feedback, for example:

1. We cannot assume that an absence of concerns raised means people are happy with their experience. There is evidence that people who are currently receiving care for themselves or a loved one may feel reluctant to voice even quite serious complaints, in case it adversely affects the care.

2. People may also need time and distance to process what has happened to them, and reflect on what could have been done better. For this reason, complementary strategies are needed, and may include both post-discharge surveys and interviews.

# PATIENT NARRATIVES AND INTERVIEWS

"People think that stories are shaped by people. In fact, it's the other way around."

*– Terry Pratchett, Witches Abroad*

The key point about patient narratives, or stories, is that they are told in a patient's own words. They show how patients are affected by the issues that are important to them.

Narratives can be a powerful way of understanding people's experiences and stimulating change. Yet, some are reluctant to use patient narratives as evidence for change. They voice concerns that narratives are anecdotal or aren't representative of patients more generally.

To a degree this is true. Patient stories can't tell you how many people think X or Y, or measure if improvements have taken place. But the real value of narratives (if carefully collected and analysed) lies in their ability to identify major themes - themes that matter most to patients.

### Sources of patient narratives

Patients can be invited to share their stories, for example by:

- interviews;
- speaking at board or education meetings;
- filming or audio recording;
- writing for newsletters or support group websites; or
- keeping a patient diary.

'Unsolicited' sources of patient narratives can include:

- complaints;
- comments on surveys and forms;
- online forums and feedback sites (e.g. patientopinion.org.uk); and
- personal blogs.

Narratives are a great source of ideas for improvements. They can highlight possible problem areas and examples of good practice.

There are many different ways to collect patient narratives. See box for examples.

Interviews are a good way to help people tell their story, with careful listening and prompting.

## INTERVIEWING FOR PATIENT NARRATIVES

Good interviewing can look easy – like having a conversation with someone. In reality, there are some important points to bear in mind if you want to do it well:

1. **Listen more than you talk**

   Allow silences and pauses for the person to think about what they really want to say.

2. **Follow the flow - let the person lead the direction**

   Careful prompting can help someone to tell their story, as well as give more detail on issues you're particularly interested in. But be careful not to switch the subject to your next question, or the things you think matter before they're finished.

3. **Try not to assume, or give the impression, that you understand what someone feels like or what they are trying to say**

   Saying things like 'I know just what you mean' may sound sympathetic, but it may frustrate the person being interviewed. Or even stop them from saying what they were about to, skipping something important.

| Themes from patient interviews | Functional | Relational |
|---|---|---|
| Being treated as a person, not a number | | ✔ |
| Staff who listen and spend time with patient | | ✔ |
| Individualised treatment and no labelling | | ✔ |
| Using language that is easy to understand | | ✔ |
| Finding out about the latest technologies and innovations medications | ✔ | |
| Feeling informed, receiving information and being given options | | ✔ |
| Patient involvement in care and being able to ask questions | | ✔ |
| More public awareness about condition | ✔ | |
| Efficient processes | ✔ | |
| Knowledgeable health professionals | | ✔ |
| Aftercare support | | ✔ |
| Positive outcomes | ✔ | |
| Continuity of care | | ✔ |
| Good relationships and positive attitudes among staff | | ✔ |
| The value of support services | | ✔ |

4. **Use open questions, while avoiding leading questions**

   Try to use more open-ended questions, like 'how did you feel about the nursing care?' or 'how did you feel the doctor treated you?', rather than 'were the nurses kind?' or 'was the doctor good?'

## DEALING WITH PATIENT NARRATIVES

It's easy – and often interesting – to collect more and more interviews. However, people often underestimate the amount of time, skills and money needed to analyse and understand what they have.

The King's Fund Experience-Based Co-Design toolkit has a helpful page on how to analyse video narratives which could be adapted for audio or written transcripts. http://www.kingsfund.org.uk/projects/ebcd/editing-film

One way to help analyse narratives for improvement is to think about whether the themes are functional (which might include noise, food and cleanliness), or relational (how people interact with staff and whether they feel listened to, involved and treated with kindness).

### EXISTING RESOURCES

Because collecting and analysing interviews is so labour intensive, it may difficult for each Trust to take this on. However, it can also be very effective to use existing contemporary interviews recorded at other organisations to support co-designing service improvement with patients and staff. And much cheaper, as we demonstrated in our 'accelerated experience-based co-design' research.

See the box for some ideas. With the help of our lay panel, we have produced a trigger film specifically on medical ward experiences which sites can use if they wish.

Another idea which may be useful is the development of 'personas' or 'vignettes' – fictionalised, but realistic accounts intended to prompt discussion about ideas for change.

These draw together several themes or points from different interviews into a story about a single, fictional, individual.

For example, 'John is an 87-year old man who came into the hospital with heart failure. He is hard of hearing and finds walking difficult…' The story might then go on to describe several experiences of ward care.

## Existing sources of patient stories for teaching and improvement:

### Healthtalk

Healthtalk features people sharing their experiences of cancer, autism, motor-neurone disease, pregnancy, drugs, depression and much more. Video and audio interviews were recorded across the UK and analysed by the Health Experiences Research Group at the University of Oxford.

Summaries of the findings, illustrated with video and audio clips, are available at www.healthtalk.org, as well as a series of pre-prepared trigger films for use in experience-based co-design.

### Patient Voices

Patient Voices contains around 250 short (2-3 minute) films about both patient and staff experiences, created using digital storytelling methods.

These are free to use as a reflective tool for any educational or quality improvement purpose.

### Patient Stories

Patient Stories is a not-for-profit social enterprise which provides films featuring individual experiences of safety issues in healthcare (including sepsis, birth trauma, and hospital-acquired infections).

Films can be used free for personal reflection, but for organisational use a license fee is requested.

# GROUP DISCUSSIONS/FOCUS GROUPS

Group discussions (or focus groups) are an established method to stimulate interactive discussion around a specific topic or experience.

The rationale for focus groups, rather than single interviews, is that interaction can help generate a different type of participation. Some people might feel more comfortable talking in a group setting than on their own. The group format can help to foster a supportive and non-threatening atmosphere, where people spark ideas off each other and value hearing each other's experiences.

However, how the group is composed must be carefully considered, to ensure people will feel comfortable with each other

- It is important not to see focus groups as simply a way of interviewing lots of people simultaneously. In sensitive areas such as illness, discussing feelings or experiences publicly can be challenging and upsetting.
- Sometimes one or two people may dominate making it harder for others to express their views, so skilled facilitation is essential.

As part of an improvement process, where the focus is more on people's ideas for improving services rather than exploring in-depth personal experiences, focus groups can contribute. In this sense, they can be more like a co-design workshop, inviting people to make suggestions for improvement and thinking about how these might work in practice.

It should be noted that focus groups may not always be the best place to come up with truly innovative ideas for change. Instead, they may be better used for exploring how to 'fine-tune' a proposed innovation, to make sure it will be embraced and used.

Focus groups normally have four to eight participants, and are usually led by at least one facilitator who will direct the conversation around the intended focus of the session. They will try to avoid silence within the group and, as mentioned above, simultaneously prevent more vocal individuals from dominating.

The facilitator will also need to ensure that a session does not simply spiral into a series of questions (asked by the researcher) and answers (provided by the group members), rather than a discussion. Additional supporting facilitator(s) may be involved in recording the views, comments and other non-verbal communication that emerge, using audio/video recording as well as writing notes (based on direct observation) to capture the discussion.

When used for research purposes, the analysis of focus group data would look not only at the content of what is said, but also at the nature of interactions between people and how they work together to make sense of the topic and develop a shared understanding. For improvement purposes this aspect is less relevant. Nonetheless, like qualitative interviews, the time and skills needed to collect and analyse focus group data are substantial.

# OBSERVATIONS AND SHADOWING
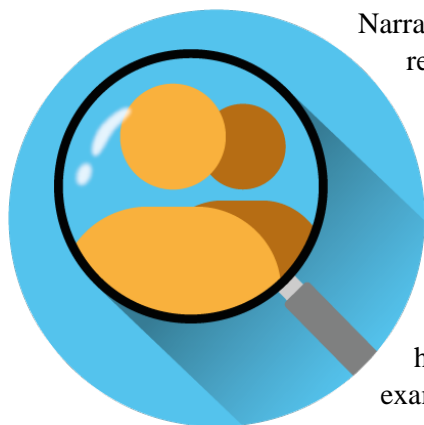
Narratives can only tell us what people think happened, or what they can remember.

Studies using observations, for example of doctor-patient consultations, have shown that both staff and patients can hold very different views of what happened, and observations can help us understand how this mismatch happens.

Observations can also be a useful way of accessing the experiences of people who might not otherwise be able to convey what has happened to them. Because they are unconscious or confused, for example.

There are many ways of collecting observations, and we explore a few of these below.

## PATIENTS AND FAMILY VISITORS

Patients and family visitors, who have time to sit and watch what goes on around them, and how staff interact with other patients and each other, are an untapped source of observations. These informal observations of care and the ward environment can be collected through interviews or conversations, or feedback surveys and comments cards.

Patients involved as partners in quality improvement work can also act as more formal observers, perhaps spending a few hours sitting on the ward and making notes of what they see.

## STAFF AND STUDENT OBSERVATIONS

Staff and students can also become observers, and may find this an eye-opening experience when they have time to stand back and realise what things may look like (and indeed sound or smell like) from a patient perspective.

That being said, it is important for staff to be alert to the fact that they may be so used to the ward environment they no longer notice things which matter a lot to patients – perhaps noise, or lack of privacy, or inconvenient routines. Interviews may be a useful complement to observations in this case.

## SHADOWING

In shadowing, rather than observing the whole ward (as an outsider looking in), the observer is attached to one patient and stays alongside them to view the hospital through their eyes.

If the patient is conscious and well enough, this can become a paired activity, so the shadowing observer exchanges views with the person about what happens and finds out what they think and how they interpret staff words and actions.

## PHOTOGRAPHS

Photographs of what has been observed can be as powerful as narratives to identify a need for change; the examples below come from an Australian emergency department reception area.

No-one needs an elaborate research study to tell them this environment does not provide a good experience, either for patients or for receptionists. The redesign project working in this department ended up with this:
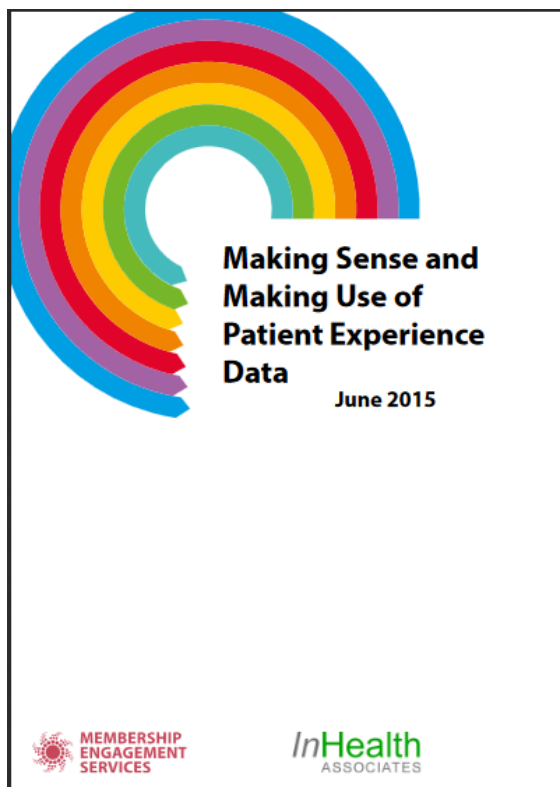
Video can also be used – an approach called 'video-reflexive ethnography' is described in this paper (bit.ly/1UakcLm).

Both experience-based co-design (EBCD) and the patient and family centred care (PFCC) method recommend using observations (see Section 2 below).

PFCC explicitly recommends shadowing. The King's Fund toolkits on both EBCD and PFCC have useful practical guides on what to do (see section 2).

## CASE EXAMPLES

A recent report by Nick Goodman and patient leader David Gilbert reports findings from interviews with 20 patient experience managers on how they are using patient experience data to improve services and shares a useful series good practice examples. (bit.ly/1RZ9jHG)



**Making Sense and Making Use of Patient Experience Data**

June 2015

MEMBERSHIP ENGAGEMENT SERVICES

InHealth ASSOCIATES

Reproduced from Piper *et al* (2010) Emergency Department Co-Design Program 1, Stage 2 evaluation report, University of Technology Sydney, with permission from the lead author and NSW Health.



Why observation – a picture tells a thousand words

And staff experience

# SECTION 2: QUALITY IMPROVEMENT (QI) APPROACHES

## WHAT DO WE MEAN BY 'QUALITY' AND 'QUALITY IMPROVEMENT'?

The Institute of Medicine[3] identify six dimensions of quality in healthcare:

- Safe
- Effective
- Patient-centred
- Timely
- Efficient
- Equitable

The Health Foundation's report "Quality Improvement Made Simple" (bit.ly/25PcCye) provides a useful overview of quality improvement approaches in healthcare.

This report highlights that these six dimensions are often complementary. However, the views of patients, families, ward staff and management of which aspects should be prioritised may differ, meaning that sometimes tensions between these groups may need to be balanced.

The report argues that quality improvement is more likely to be sustained if patients and staff are involved in developing, designing and implementing changes, rather than if it is imposed from the top down.

On page 11 the report sets out the following principles that underlie many quality improvement methodologies, approaches and tools:

- Understanding the problem, with a particular emphasis on what the data tell you.
- Understanding the processes and systems within the organisation – particularly the patient pathway – and whether these can be simplified.
- Analysing the demand, capacity and flow of the service.
- Choosing the tools to bring about change, including leadership and clinical engagement, skills development, and staff and patient participation.
- Evaluating and measuring the impact of a change.

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[3] Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington DC: National Academy Press, 1990, p244.

# PICKING AN APPROACH AND GETTING THE SKILLS IN PLACE

Improving healthcare services can all too easily become equated with the use of certain 'in vogue' tools for improving quality.

Advocates for different approaches often argue strongly that their way is the best (or even the only) way. Staff may feel overwhelmed by the array of methods promising a sure recipe for success, and concerned they can't live up to the examples set by leaders in the field.

Some concerns about this include:

- What if focusing so much on the tools is actually unhelpful?
- Do we become obsessed with getting the method right rather than doing something?
- Do approaches imported from manufacturing need more tailoring to healthcare?
- Could too much jargon and promotion of a particular method be putting off the very people at the frontline who are best placed to do this work?
- Might it lead people to see improvement as an event or a 'project' rather than as a way of working?

The Health Foundation report '*The habits of an improver*' suggests that what is needed is to get in 'the improvement habit' rather than becoming too focused on tools and techniques. It argues that:

> "[…] education for improvement practices can all too easily be reduced to, for example, 'how to use a driver diagram' or 'how to lead an improvement project'. Both of these are entirely worthwhile approaches to improvement and both are helpful to learn. The first enables structured logical thinking and decision making and the second equips managers with some useful operating principles. But without a clearer picture of what improvement really looks and feels like, the 'packaging' of improvement can end up becoming its lived reality."

By contrast "improvers are constantly curious, wondering if there is a better way of doing something." They use a kind of "smart common sense" to keep reflecting.

A recent King's Fund report suggests it is important for hospitals to adopt an established method for quality improvement, one that is 'modern and scientifically grounded', and ensure all leaders and staff are trained in it.

While using one consistent method certainly has advantages, the evidence behind most quality improvement approaches remains fairly weak. In a review for Healthcare Improvement Scotland, Powell and colleagues (2009) conclude that:

> "Importantly, there is no one right method or approach that emerges above the others as the most effective."

Most methods have something to offer and will work some of the time in some settings, but are also likely to fail if good conditions aren't in place.

Many evaluations have shown that contextual factors – such as skilled facilitation, time, senior management commitment, resources, and authority for staff to make change – are influential. Powell and colleagues identify the following as 'necessary but not sufficient conditions', regardless of what approach is adopted:

- provision of the practical and human resources to enable quality improvement;
- the active engagement of health professionals, especially doctors;
- sustained managerial focus and attention; the use of multi-faceted interventions;
- coordinated action at all levels of the health care system;
- substantial investment in training and development; and
- the availability of robust and timely data through supported IT systems.

As a result, there has been growing interest in assessing whether organisations or teams/wards are 'improvement ready' before starting any new quality process.

The 'Cancer Patient Experience Survey Buddy Programme' paired organisations with high patient experience ratings with organisations identified as having scope for improvement. The idea was for them to work together on improving experience using patient data. The evaluation findings identified several components of improvement readiness:
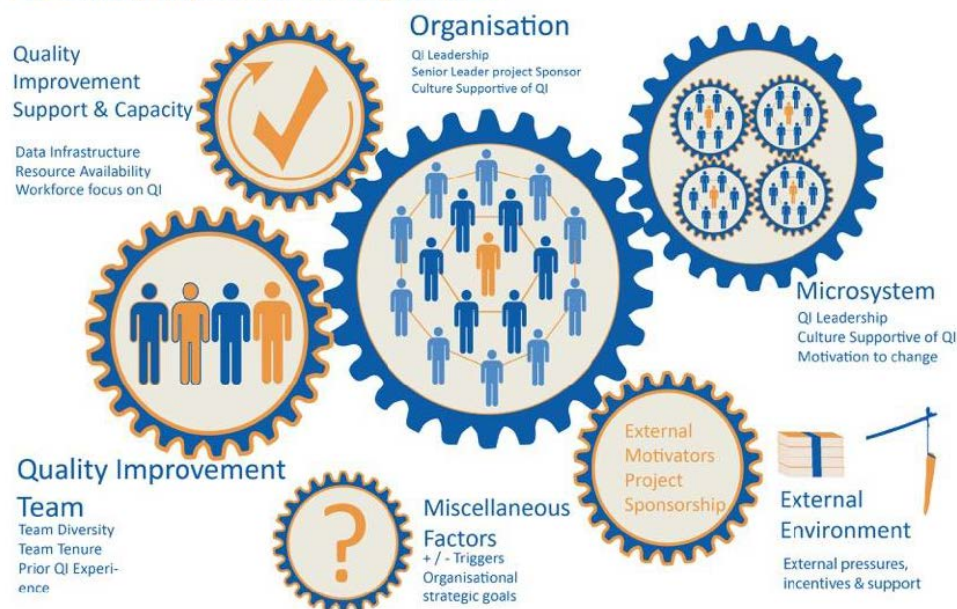


We agree it is important to pay attention to these organisational and cultural issues – but at the same time perhaps it is important in the real world to find ways to help those who are not so obviously 'improvement ready' and not deter

27

them from trying things out and learning. Overall, organisational culture may matter less at ward level than ward culture and enthusiasm.

Powell and colleagues (2009) conclude that a more pragmatic approach to selecting or blending approaches to suit local needs may be best.

> "Managers need to have a range of tools and approaches, and have to examine a range of staff, task, organisational and environmental characteristics before deciding on a course of action….the specific approach (or combination of approaches) may be less important than the thoughtful consideration of the match and 'best fit' (however imperfect) for the particular circumstances in the local organisations using it."

The Health Foundation report '*Skilled for Improvement*' argues that understanding recognised QI tools is important, but that 'applying the techniques of improvement science alone is unlikely to be sufficient to deliver sustained quality improvements in healthcare.'

The authors argue that as well as technical improvement skills, teams need to develop a culture of continuous learning and reflection, and a range of 'soft skills', including good communication, conflict management, assertiveness and negotiation, time management, stress management, leadership and team-working skills, and organisational and administrative skills.

They also identify the importance of:

- strong and sustained institutional support;
- the influence of key individuals who can either drive projects forward or hold them back;
- flexibility to adapt to changing realities; and
- linking the quality improvement into existing work streams rather than making it a stand-alone project.

The Cancer Patient Experience Survey Buddy Programme suggests that peer-to-peer learning – as we hope to offer through this project – can be a helpful way to develop these skills.

## EVALUATING QUALITY IMPROVEMENT INTERVENTIONS

Given the lack of evidence for the effectiveness of quality improvement interventions, an argument can be made for ongoing qualitative and quantitative evaluation to be built into all quality improvement interventions to contribute to the evidence base.

The Health Foundation's publication '*Evaluation: what to consider*' provides helpful guidance for those considering evaluating a quality improvement intervention.

# PATIENT-CENTRED QUALITY IMPROVEMENT METHODS

The evidence-base supporting specific patient-centred quality improvement methods is not especially strong at the moment, though efforts are being made to address this. Below we list a few of the best known approaches, starting with those for which there is most evidence.

## FACILITATED SURVEY FEEDBACK

There is some evidence for facilitated patient survey feedback at ward level.

A pilot trial showed that simply giving ward staff written findings from their patient experience survey did not result in any improvements in how patients rated the quality of nursing care. However, using the survey findings as the basis for a facilitated discussion did have an impact.

The finding that written feedback on its own has little effect is in line with wider evidence about behaviour change and effective learning methods.

## EXPERIENCE-BASED CO-DESIGN

Experience-based co-design (EBCD) is a participatory action research approach developed by UK researchers. It uses narrative video interviews with patients, staff interviews and observations of care to start a discussion between patients and staff about how to improve care.

The patient interviews are analysed for 'touchpoints' - moments of interaction between the patient and staff or between the patient and the organisation, either showing really good examples of care or instances where something could have been done better.

These touchpoints are made into a 'trigger film' which is shown first at a workshop with patients alongside a technique called 'emotional mapping' where patients identify particularly good or bad points on the care pathway, and how they felt.

The trigger film is then shown at a joint event between staff and patients as part of a facilitated discussion to generate ideas for improvement. Patients and staff work together as partners to identify priorities for improvement and form co-design groups to plan and implement specific changes.

EBCD has been tested in several qualitative evaluations (including by the King's Fund) and is currently being tested in a randomised controlled trial in Australia.

Evaluations so far have shown it to be an effective way of achieving both specific patient-centred improvements and also cultural, attitudinal change among staff, and staff report finding it highly motivating. But take-up has been limited by the cost and time it takes.

We have recently been involved in a study of an accelerated form of EBCD, which used a trigger film derived from nationally collected interviews we had already conducted and disseminated on www.healthtalk.org.

In this study we showed that using national rather than local patient interviews did not affect staff or patient engagement with the process, and the changes reported

were very similar to a standard EBCD process, but in half the time and at 40% of the cost.

We are making a trigger film available for any ward team which chooses to use it, either as part of an EBCD process or to weave into any other project they design.

- The King's Fund provides an excellent free online toolkit to support anyone wishing to use this approach.
- There is also a LinkedIn forum for EBCD facilitators to support each other and share learning.
- The Point of Care Foundation provides training courses in EBCD, the 'Patients as Partners' programme.

## PATIENT AND FAMILY-CENTRED CARE

The Point of Care Foundation is currently implementing and evaluating an improvement approach developed by the University of Pittsburgh Medical Center, called Patient and Family-Centred Care (PFCC).

PFCC aims to change the perspective of staff delivering care, and reconnect them with their values and motivation for working in healthcare. It approaches improvement through the lens of patients' experiences of care, but improvement activities can relate to both processes of care and staff-patient interactions.
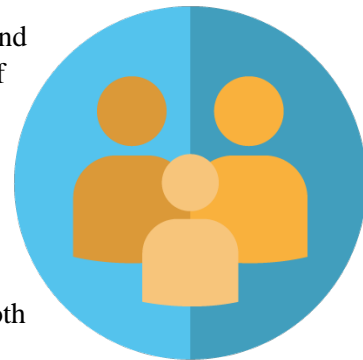
PFCC makes extensive use of patient shadowing (see observations and shadowing above), alongside other forms of data, such as patient interviews, to help staff redesign care to be more patient-centred. It places less emphasis on involving patients directly in the change process than EBCD, but encourages them to involve patient and family advisers on project working groups.

A key principle of PFCC is not to blame staff when things go wrong, but rather to understand where care systems and processes prevent staff from providing the kind of care they would wish for themselves or their families, and see where improvements are possible.

The process, as originally devised, consists of a simple low technology six step process, which guides improvement teams through:

- identifying the care experience;
- setting up a basic infrastructure to support improvement teams;
- seeing care through patients' eyes and creating urgency for change, through shadowing;
- visualising the ideal care experience, to help teams articulate their improvement goals; and
- identifying and supporting small project teams to take the improvement work forward and maintain momentum.

The application of the PFCC method in the UK by the Point of Care Foundation blends this approach with more traditional quality improvement approaches, by forming collaborative groups of participant teams modelled on the US Institute for Healthcare Improvement's "Breakthrough Series" collaborative. Teams come together to share learning, and are provided with teaching and support on traditional

QI approaches including measurement for improvement, using driver diagrams, and the 'Model for improvement' (see below), all within the context of improving patients' experiences of care.

A Health.org report describes the outcomes of the 2012-13 PFCC programme.

Again, there is a detailed online toolkit available free from the King's Fund:

The original US programme site (www.pfcc.org) includes extensive details of the methods alongside evaluation and research papers relating to its use particularly in the US context.

## 15 STEPS CHALLENGE

"I can tell what kind of care my daughter is going to get within 15 steps of walking on to a ward."
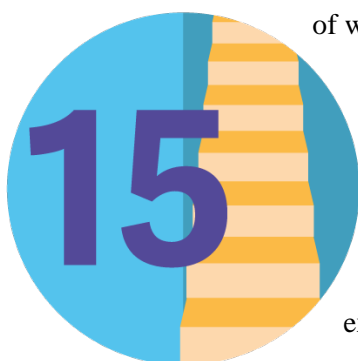
This comment from a mother sparked the development of "The 15 Steps Challenge", a toolkit to help look at hospital care through the eyes of patients and relatives, and get a sense of what good quality care looks and feels like.

Using the 15 Steps Challenge toolkit staff, patients and others can work together to identify improvements that will enhance the patient experience.

The Challenge is a ward walk-around, seeing the ward through a patient's eyes. The Challenge toolkit helps structure these observations, the guide is underpinned by the Care Quality Commission's essential standards.

A small 15 Steps Challenge team, consisting of a patient/carer, a staff member and a board member, walk onto the ward and take note of their first impressions.

After the ward walk around, the 15 Steps Challenge team feeds back to senior leaders in the Trust. Feedback focuses on good practice to share, and areas for improvement. The Challenge is repeated on a regular basis, to cover all ward areas and to ensure that improvements are being made.

## WHOSE SHOES?™

'Whose Shoes?' is an approach which has been developed by independent consultant Gill Phillips as a way of helping staff see care through the patient's eyes, using a series of thought-provoking exercises and scenarios.

The aim is to help staff share good practice and challenge attitudes and assumptions in a non-threatening way. It is founded on the principles of changing hearts as well as minds; creating equal partnerships and co-design; cutting through jargon; giving people space to share openly.

No formal evaluations have yet been published, but the University of Wolverhampton is currently preparing an evaluation report and the approach has been used successfully in many Trusts.

Organisations wishing to use Whose Shoes? can purchase a license from http://nutshellcomms.co.uk/buy/

# GENERAL QUALITY IMPROVEMENT APPROACHES

As well as these specific patient-centred approaches, patient experience data can be used as part of other more generic quality improvement methods which are used for improving safety and clinical effectiveness as well as experience.

Two of the most well-established are the Boston Institute for Healthcare Improvement's 'Model for Improvement', using Plan-Do-Study-Act cycles, and 'Lean' as practised by Virginia Mason Hospital in Seattle. Lean is a methodology derived from manufacturing that aims to eliminate waste and boost efficiency.

Many quality improvement approaches draw on the Japanese principle of Kaizen (continuous improvement) and use a technique called 'process mapping' to analyse bottlenecks or hand-offs (transition from one staff member or department to another) where problems arise.

These approaches commonly do not focus on patient experience data, but there is no reason why they should not. Indeed, attempts to improve patient experience without asking people themselves what that experience is are not likely to achieve their intended goal.

Useful overviews of quality improvement in healthcare include:

www.health.org.uk/publication/quality-improvement-made-simple

www.institute.nhs.uk/patient_experience/guide/how_to_improve_patient_experience_-_the_critical_list.html

## MODEL FOR IMPROVEMENT – INCLUDING 'PLAN, DO, STUDY, ACT' (PDSA)

The Model for Improvement is based on short cycles of small scale, incremental changes linked to reflection. Front line staff play a role in identifying problems and ideas for solutions, as well as in monitoring the impact of change.

It begins with three questions:

1. 'What are we trying to accomplish?'
2. 'How will we know that a change is an improvement?'
3. 'What changes can we make that will result in improvement?'

These questions are linked with small cycles of change:

- **Plan** - planning the change to be tested or implemented.
- **Do** – implementing the change.
- **Study** – compare the situation before and after the change and reflect on what was learned.
- **Act** – act on the information and plan the next PDSA cycle.

The diagrams below represent the PDSA cycle, and the potential to build from small-scale to larger scale change using a succession of PDSA cycles.

Proponents of the Model for Improvement approach argue that, because changes are introduced on a small scale, risk and disruption can be controlled and they require relatively little resource. Interventions are designed locally, so address the needs of a particular context. Where change is unsuccessful, it can be discarded, and successful cycles of change can be built upon and generate large scale improvement.

However, problems may arise where local teams want to make changes that conflict with an organisation's strategic objectives, and where data are not available to evaluate the impact of change within a cycle.

The Institute for Healthcare Improvement now offers a free online course in its approach: PH556x Practical Improvement Science in Health Care: A roadmap for getting results

(Image from The Scottish Government Health Delivery Directorate: Improvement and Support Team: The Scottish Primary Care Collaborative, http://www.gov.scot/Publications/2008/01/14161901/3)

## LEAN

The Lean approach focuses on five principles, as set out by the Health Foundation:

- customer (patient) value
- managing the value stream (the series of steps/events that take a patient through their care)
- regulating flow of production (to avoid quiet patches and bottlenecks)
- reducing waste
- using 'pull' mechanisms to support flow. Using 'pull' mechanisms means responding to actual demand, rather than allowing the organisational needs to determine production levels.

The idea is that by identifying what the customer values, and removing any activity that is not valued, waste is removed and experience is improved.



The Lean approach uses a range of tools to identify core processes and develop them to allow the system to run more efficiently. In a healthcare setting, Lean aims to improve processes, outcomes, and patient and staff experiences while minimising waste.

Its strengths are that it encourages staff to adopt a patient-centred view of the system and is seen as a bottom-up process. Amongst its challenges in a healthcare setting is the need to accurately predict demand, and identifying the needs of the "customer" when there may be a range of potentially conflicting interest groups. Staff may be concerned that "lean" implies cost-cutting and potentially staff reduction.

The Virginia Mason Institute in Seattle specialises in Lean and has supported a number of Trusts in the UK to apply the approach.

See: http://www.virginiamasoninstitute.org

# OTHER QUALITY IMPROVEMENT TOOLS
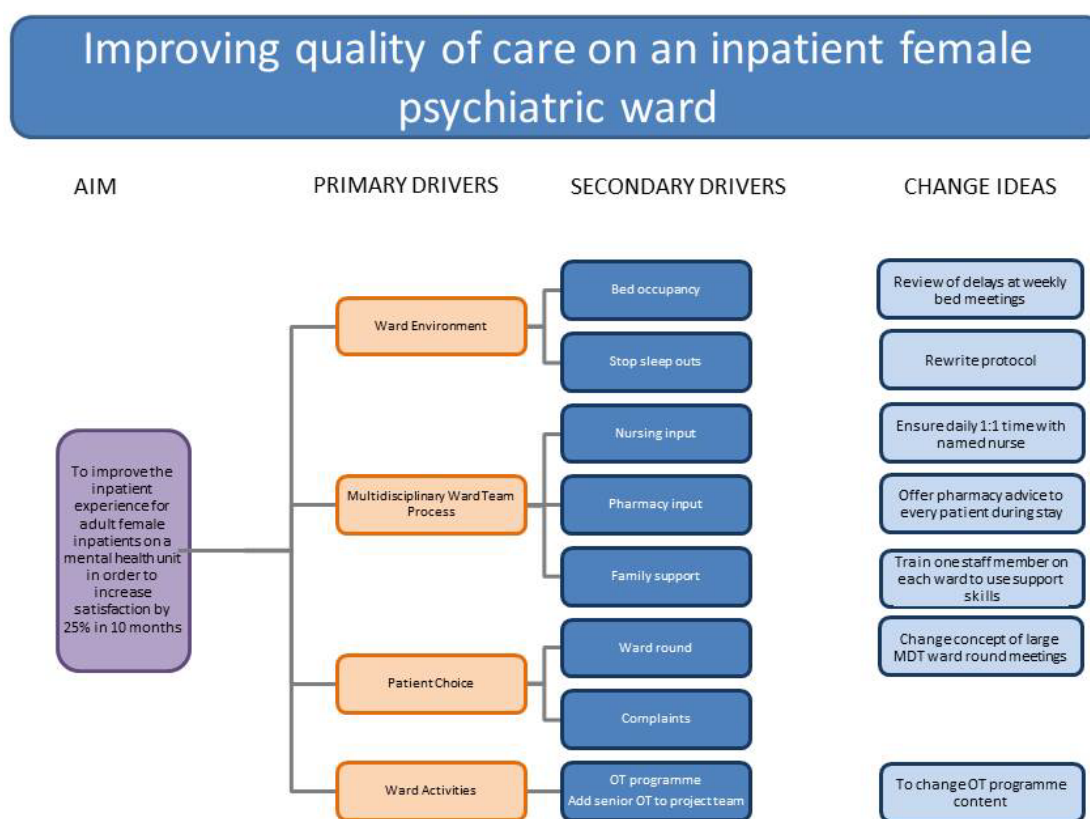
There are a range of quality improvement tools that can be used to support projects. Here we summarise a few key tools that are commonly used.

## DRIVER DIAGRAMS

A driver diagram can be used to plan improvement project activities. It offers a way of systematically displaying the different aspects of an improvement project, showing how we think particular actions will lead to the change we want. It has three columns: Outcome, Primary Drivers and Secondary Drivers.

Primary Drivers are a set of factors that we believe must be addressed to achieve the desired outcome. Secondary Drivers are specific areas where we plan changes or interventions. Each Secondary Driver will contribute to at least one Primary Driver.

This is what a driver diagram looks like (shared by East London NHS Foundation Trust QI Programme):

## Improving quality of care on an inpatient female psychiatric ward

| AIM | PRIMARY DRIVERS | SECONDARY DRIVERS | CHANGE IDEAS |
|---|---|---|---|
| To improve the inpatient experience for adult female inpatients on a mental health unit in order to increase satisfaction by 25% in 10 months | Ward Environment | Bed occupancy | Review of delays at weekly bed meetings |
| | | Stop sleep outs | Rewrite protocol |
| | Multidisciplinary Ward Team Process | Nursing input | Ensure daily 1:1 time with named nurse |
| | | Pharmacy input | Offer pharmacy advice to every patient during stay |
| | | Family support | Train one staff member on each ward to use support skills |
| | Patient Choice | Ward round | Change concept of large MDT ward round meetings |
| | | Complaints | |
| | Ward Activities | OT programme Add senior OT to project team | To change OT programme content |

Some good sources of advice on designing and using driver diagrams can be found at:

- elft.nhs.uk
- institute.nhs.uk
- qihub.scoy.nhs.uk

## RUN CHARTS

A run chart is simply a graph which shows performance on a particular measure (on the y axis) over time (on the x axis). It can be annotated with actions at a particular time point to help understand what difference these actions have made. They can look like this:
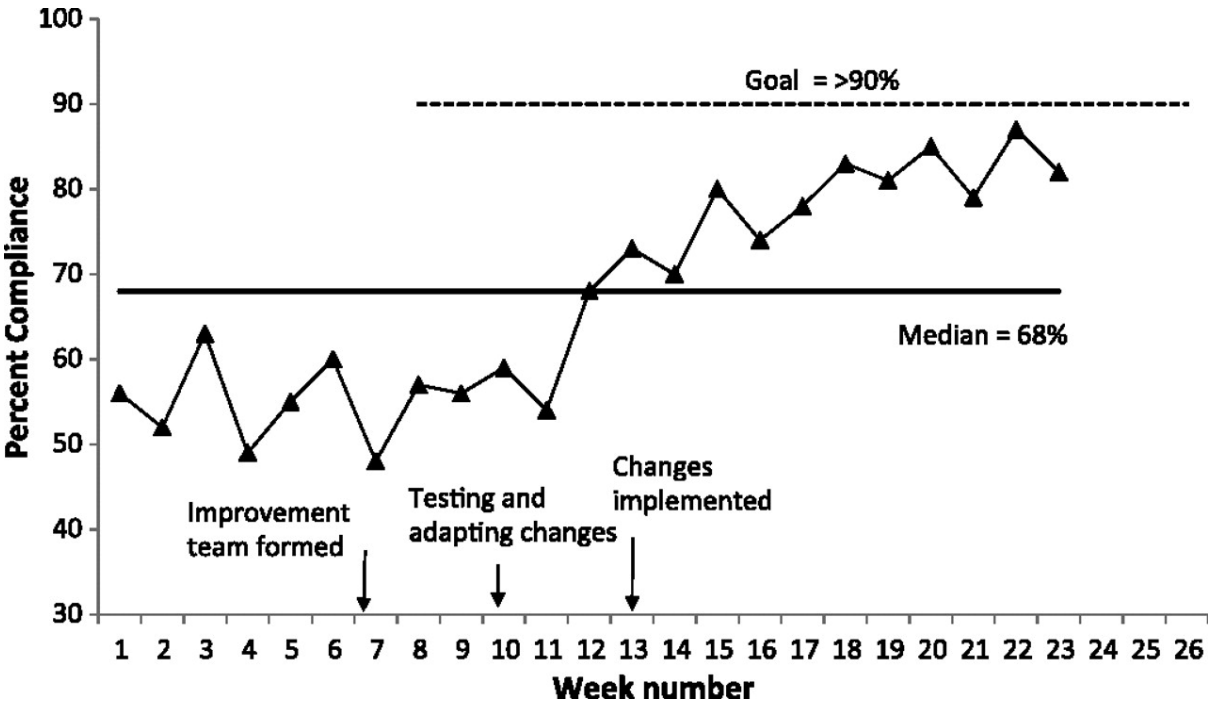


Run
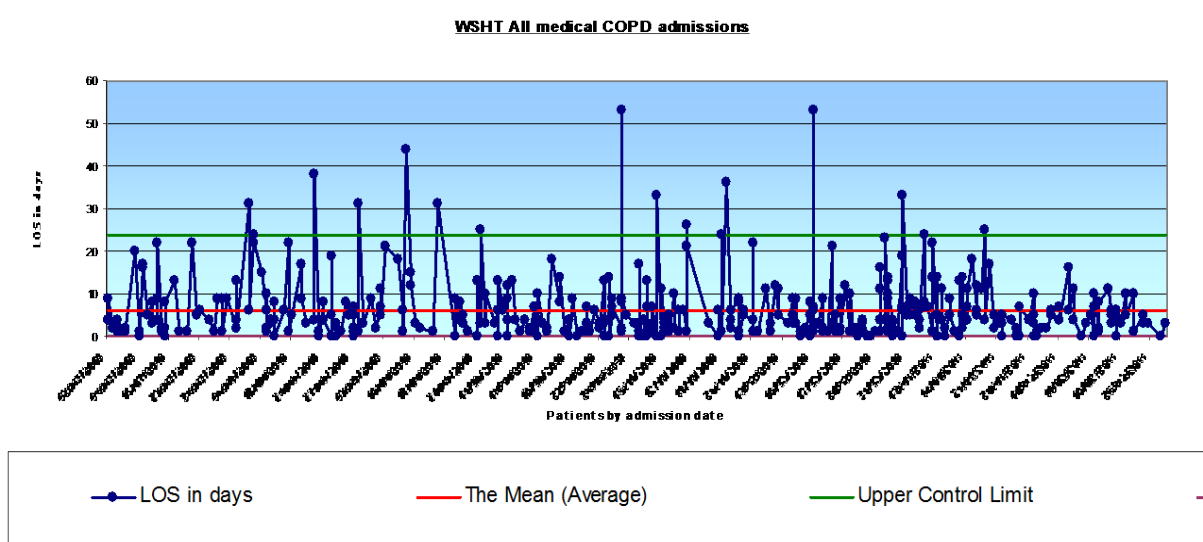


This run chart shows us the length of stay of all patients admitted to a hospital over a 6 month period. It shows the mean at about 7.5 days and demonstrates significant variation in length of stay between patients. This chart helps to make meaning from length of stay data.

**End to End TAT - Sept 2008 to Jan 2009**
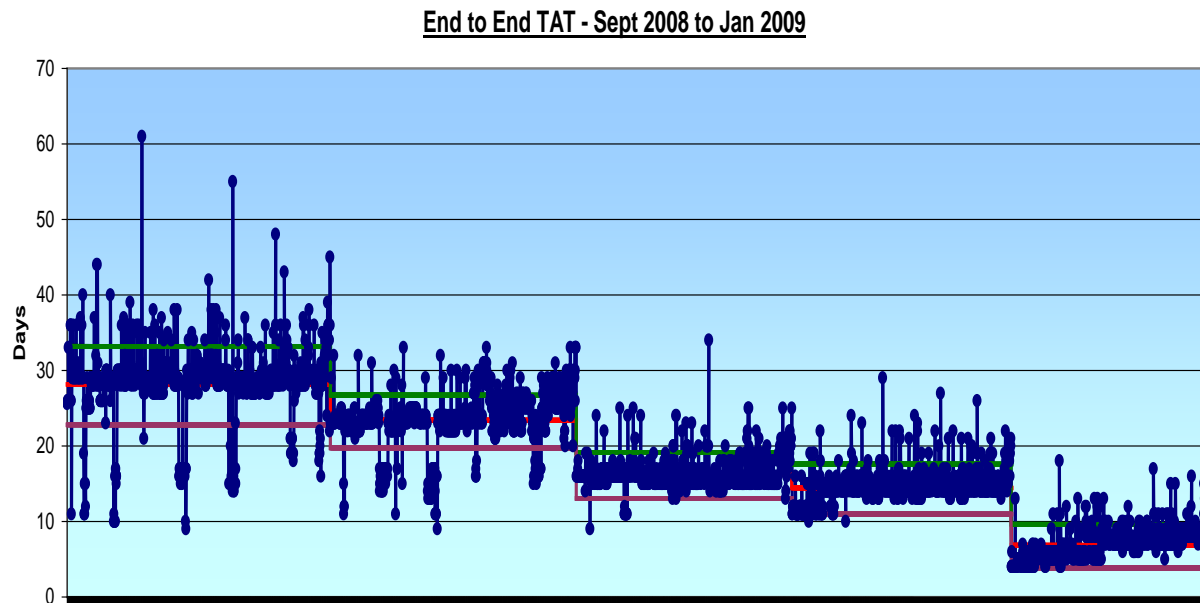


This run chart shows the times taken to process test results in a lab. The series of 'steps' helps to illustrate how the average 'turn-around-time' (TAT) has reduced as a result of a series of improvement interventions.

Run charts help us:
- Monitor performance over time to detect trends, shifts or cycles
- Compare a performance measure before and after implementation of a solution to measure its impact.
- Assess whether improved performance has been sustained.

Sources of advice on run charts and how to interpret what they show include:
- qi.elft.nhs.uk/run-charts (including a short video explanation)
- www.qihub.scot.nhs.uk/knowledge-centre/quality-improvement-tools/run-chart.aspx
- www.rcgp.org.uk/~/media/Files/CIRC/Quality-Improvement/RCGP-A-practical-guide-on-how-to-build-a-run-chart.ashx

The Institute for Health Improvement in the US offers an easy to use template spreadsheet to help you create run charts automatically (free registration required).

## PROCESS MAPPING

Process maps – a type of flow chart – are a visual way of representing all the steps in a healthcare process or patient pathway.

A process map can help teams to understand what the patient experience is and where problems or poor experience are happening.

A process map may use different shaped symbols or images, and may be annotated with times to show how long each stage takes. Staff from different disciplines may only ever see a part of the process; bringing staff together to share their understanding of the process can be very revealing.

Getting patients and families involved can be even more powerful, as they may be the only people who see the full process and they may see it very differently to staff. Using observations can also help demonstrate that we think happens isn't necessarily what actually happens.

A typical example from the NHS looks like this, with both a high level and more detailed map:



**THE ANTICOAGULANT BLOOD TESTING PROCESS**
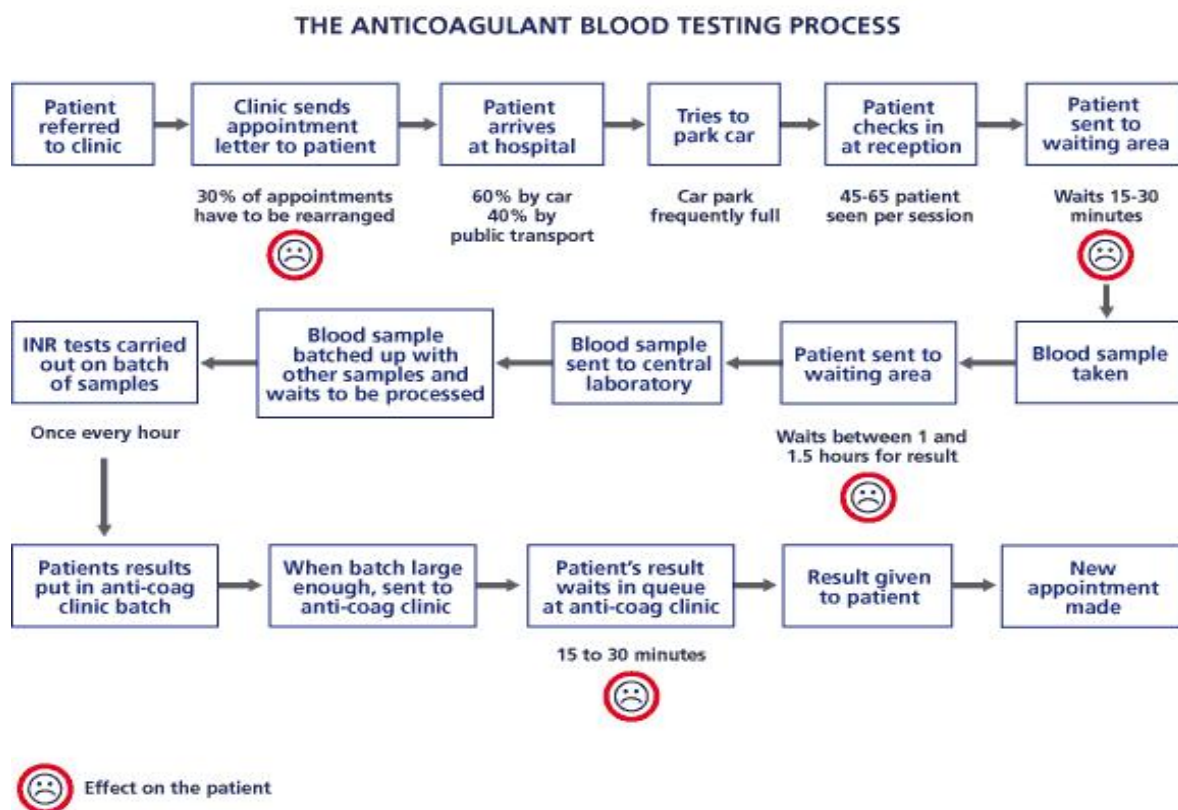
In this example images are used to help show the effect of delays on the patient. Another approach is to use post-it notes on a long flipchart both to create the process map and write positive or negative comments about particular points in the process. It does not have to be a high-tech exercise.

In experience-based co-design, the technique is adapted as 'emotional mapping', encouraging people to annotate feelings on the map of 'touchpoints' or key moments along the patient journey. See the Kings Fund for more information.

### 5Ys OR FIVE WHYS

Asking 'why?' is a simple way of undertaking a root cause analysis. By using a range of QI tools a range of causes or contributing factors can be identified, but sometimes it is necessary to understand 'why things are done that way'.
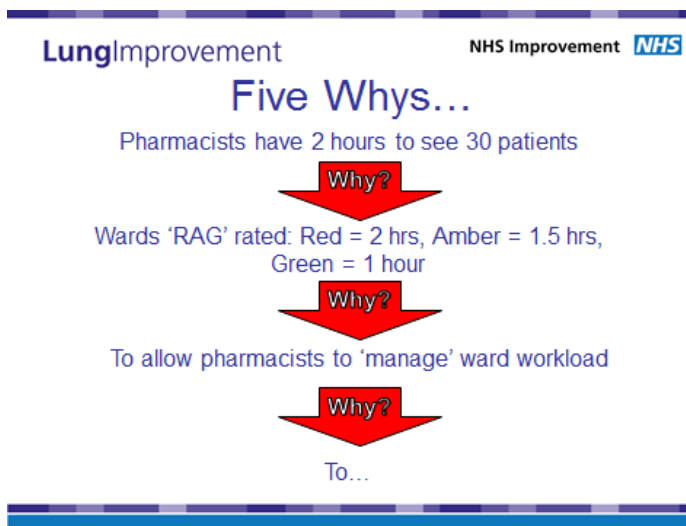


The diagram opposite demonstrates how a cause is explored by asking 'why?' and then when the answer is given, again asking 'why?'. 'Why?' usually needs to be asked about five times to really understand the reasons why things happen the way they do. The reasons that are identified can then be considered (a fishbone diagram can help with this).

*Other sources of help for root cause analysis are:*

http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/identifying_problems_-_root_cause_analysis_using5_whys.html

## FISH BONE DIAGRAMS

A fish bone or cause/effect diagrams is a tool to help understand or 'diagnose' what is causing the problem.

They provide a framework of questions or factors to consider e.g. is there anything in our policies that makes this happen? What is it about our people that makes this happen? Potential causes and contributing factors can then be identified and this information will help to identify some of the interventions and ideas that might be tested in PDSA cycles.

The first diagram below is a real example from an improvement project that explores some of the factors causing patients to be discharged from a ward late in the day rather than in the morning.
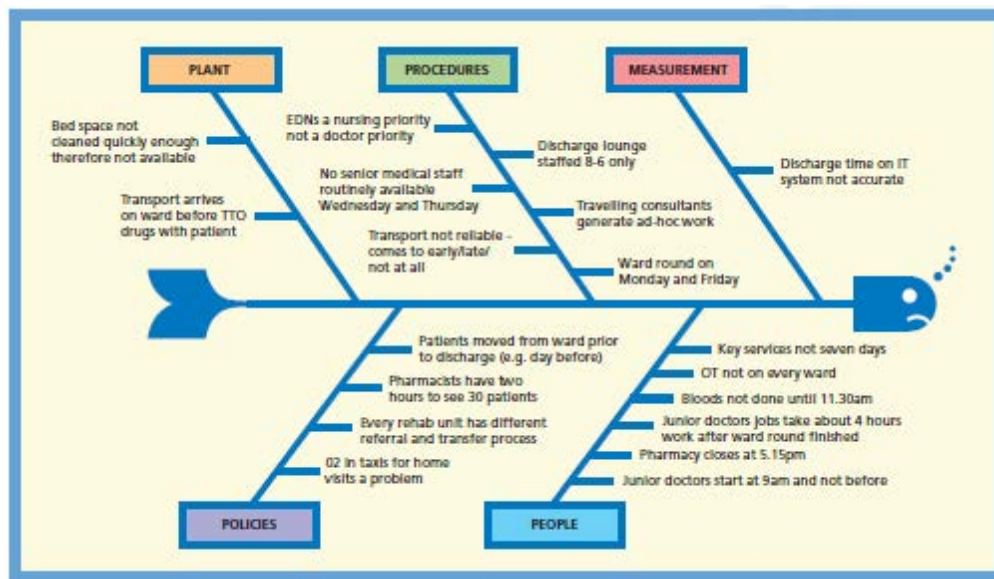


The second diagram demonstrates some alternative categories and factors that could be explored.
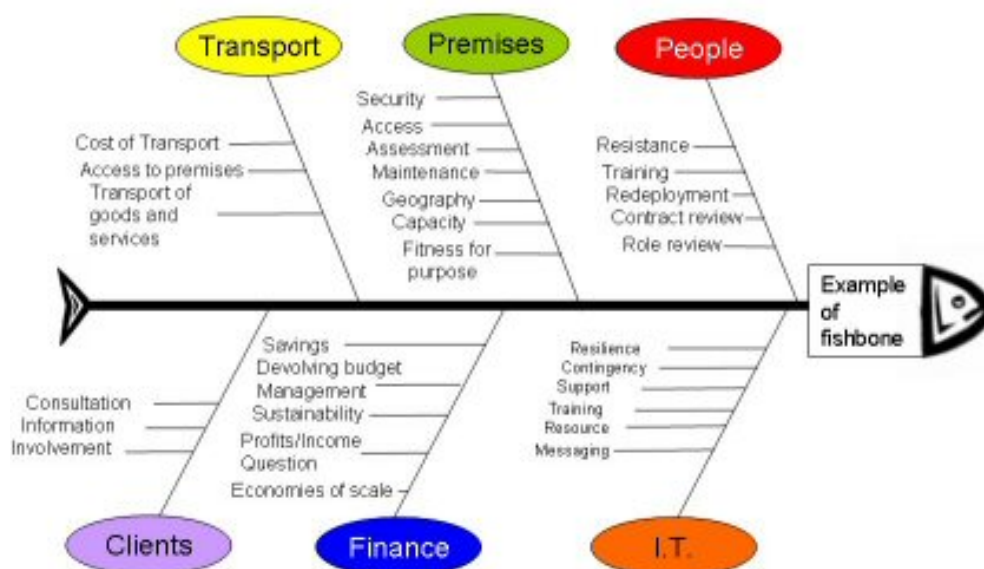
## DRIVER DIAGRAMS

A driver diagram or action /effect diagram can be used to plan improvement project activities.

It offers a way of systematically laying out aspects of an improvement project, showing how we think particular actions will lead to the change we want. It has three columns: Outcome, Primary Drivers and Secondary Drivers.

Primary Drivers are a set of factors that we believe must be addressed to achieve the desired outcome.

Secondary Drivers are specific areas where we plan changes or interventions. Each secondary driver will contribute to at least one primary driver.
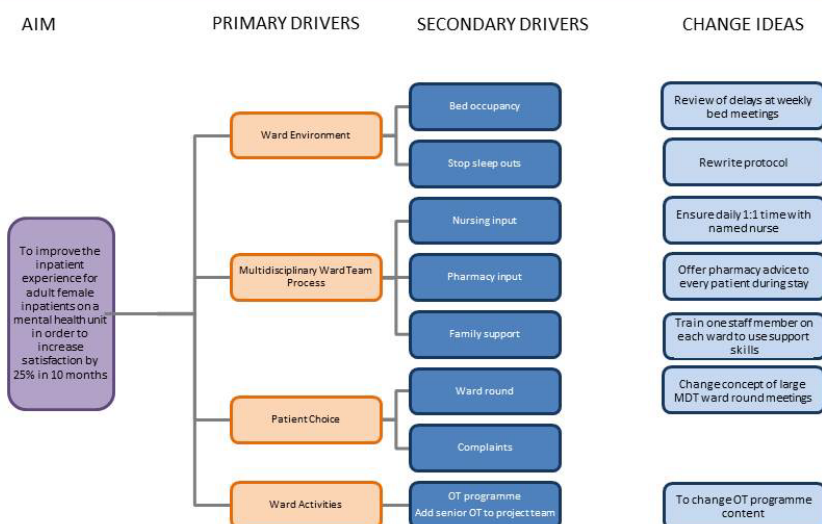


This is what a driver diagram looks like (left - shared by East London NHS Foundation Trust QI Programme).

This driver diagram (below left) show drivers and change ideas to improve self-management in COPD.
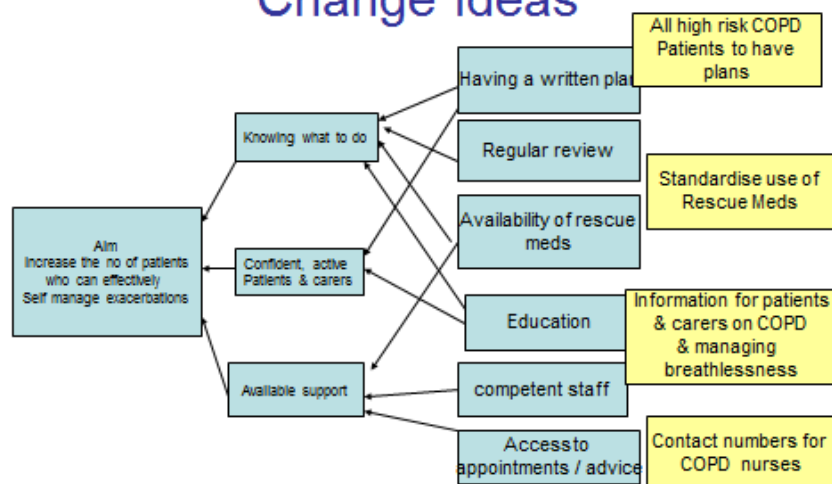
## MORE USEFUL PLACES FOR IMPROVEMENT IDEAS AND HELP WITH METHODS
NHS QI archived resources: www.nhsiq.nhs.uk

NHS change model

Patient experience is widely regarded as a fundamental component of quality, alongside factors such as effectiveness and safety, and is included in all leading global definitions of high quality health and care.

Bringing together collective improvement knowledge and experience from across health and care into eight components. The Change Model provides a useful organising framework for sustainable quality improvements, change and transformation that delivers real benefits for patients and the public.

The eight components provide a valuable lens that enables a better understanding of how to create an improvement environment and approach in a way that enables change.

- Our shared purpose
- Leadership by all
- Spread and adoption
- Improvement tools
- Project and performance management
- Measurement
- Influencing factors

East London Foundation Trust QI programme: qi.elft.nhs.uk

NW London CLAHRC e-learning modules: clahrc-northwestlondon.nihr.ac.uk/what-we-do/learning-and-development/elearning

Academy of Fabulous NHS Stuff: www.fabnhsstuff.net

Scotland's QI Hub: www.qihub.scot.nhs.uk/knowledge-centre/quality-improvement-topics/measurement-for-improvement/analysing-data.aspx

# APPENDIX ONE – STRENGTHS AND LIMITATIONS OF DIFFERENT FEEDBACK METHODS AS MEASURES

| Feedback method | Strengths | Limitations |
|---|---|---|
| **Quantitative** | | |
| Postal survey (self-completion) | ■ Can reach large numbers<br>■ Less intrusive than other methods<br>■ No interviewer bias<br>■ Questionnaires can be fairly long and detailed<br>■ Can collect demographic data<br>■ Possible to achieve high response rates if reminders are sent<br>■ Relatively cheap | ■ Not suitable for those with very low literacy<br>■ Not suitable for non-English speakers unless language known in advance or translation service available<br>■ Requires careful administration<br>■ Data entry (manual or scanned) takes time<br>■ Requires expertise in use of statistical package for analysis |
| Face-to-face survey | ■ Suitable for low literacy groups<br>■ Can include more detailed/complex questions<br>■ Can collect demographic data<br>■ Can enter data during interview (CAPI)* | ■ Training required for interviewers<br>■ Similar problems as for postal surveys re other languages, data entry (without CAPI)* and analysis<br>■ Time-consuming and expensive |
| Telephone survey | ■ Suitable for low literacy groups<br>■ Can enter data while conducting interview (CATI)†<br>■ Results can be available quickly | ■ Requires list of phone numbers<br>■ Response rates often low<br>■ Requires frequent callbacks at different times of day to get representative sample<br>■ Questionnaire needs to be brief<br>■ Interviewers must be trained |
| Automated telephone survey (IVR) | ■ Suitable for low literacy groups<br>■ Data entered automatically<br>■ Can be produced in multiple languages | ■ Requires list of phone numbers<br>■ Acceptability can be low, leading to low response rates<br>■ Questionnaire needs to be very brief |
| Online survey (email or web-based) | ■ User-friendly design – questions can be tailored to respondent and 'skips' avoided leading to better item-response completeness<br>■ Reminders are easy to send<br>■ Data entry is automatic allowing for rapid turnaround of results | ■ Requires list of email addresses or invitation to go to a website<br>■ Not suitable for people who do not have internet access, so representative coverage usually impossible<br>■ Questionnaire needs to be brief<br>■ Must take account of differences in computer systems and browsers |
| Survey using hand-held portable devices | ■ Used for on-site data collection<br>■ Questionnaires easily tailored to local setting<br>■ Automatic data entry<br>■ Rapid turnaround of results possible | ■ Questionnaires must be brief<br>■ Attention must be paid to infection control if patients are to handle devices<br>■ Someone must take responsibility for the PDA devices and monitoring use<br>■ May be difficult to calculate response rates |
| Survey using touch-screen kiosks | ■ Used for on-site data collection<br>■ Can be sited in waiting rooms or clinics<br>■ Automatic data entry<br>■ Rapid turnaround of results possible | ■ Questionnaires must be brief<br>■ Attention must be paid to infection control if patients are to handle devices<br>■ Impossible to calculate response rates because denominator is unknown<br>■ Hard to prevent multiple responses or staff masquerading as patients |
| **Feedback method** | **Strengths** | **Limitations** |

**Quantitative**

| | | |
|---|---|---|
| Survey using bedside media consoles | ■ Can be completed by patients while in bed<br>■ Reminders and incentives (eg, reduced cost phone calls) are possible<br>■ Automatic data entry<br>■ Rapid turnaround of results | ■ Some patients don't want to use bedside consoles because they are expensive<br>■ No control over timing of survey<br>■ Difficult to calculate response rates |
| Routine statistics | ■ Using routine or administrative data can be cost-effective<br>■ Utilisation patterns may be indicative of underlying problems | ■ An indirect measure of patients' experiences |

**Qualitative**

| | | |
|---|---|---|
| In-depth interviews | ■ Can produce richer, more detailed data<br>■ Allows respondents to express themselves in their own words | ■ Expensive<br>■ Interviewers must be trained<br>■ Problem of interviewer bias<br>■ Transcribing and data analysis is time-consuming |
| Discovery interviews | ■ Means of recording patient stories, which may increase staff understanding | ■ Interviewers must be trained<br>■ Problem of interviewer bias<br>■ Patients may be unwilling to be critical when interviewed by staff<br>■ Transcribing and data analysis is time-consuming |
| Focus groups | ■ Rich source of data on experiences and their impact on patients<br>■ Groups often 'spark' off each other to produce less predictable responses | ■ Moderators need training<br>■ Responses can be influenced by dominant individuals<br>■ Transcribing and data analysis is time-consuming |
| Web-based comments (free text) | ■ Allows people to make any comments they want to about the care they've received<br>■ Respondents can be asked to give their views on specific topics<br>■ Responses are available for others to read | ■ Not suitable for people who do not have internet access<br>■ Sites must be moderated to avoid malicious comments |
| Comment cards, exit surveys, suggestion boxes, video boxes (on-site) | ■ Can be used to collect on-site feedback, usually unstructured<br>■ Feedback can be analysed quickly | ■ Likely to be completed by a small minority unless specifically invited to respond |
| Complaints and compliments | ■ All Trusts receive some of these so they can be analysed for identifying specific incidents and general trends | ■ Most people don't make formal complaints even when things go wrong<br>■ Compliments are often made but not often in writing |
| Patient diaries | ■ Can be used to gather continuous feedback on patient journey<br>■ Allows for unstructured feedback | ■ Places a considerable burden on patients to record relevant information<br>■ Can produce voluminous data that is difficult to analyse<br>■ Not suitable for those with low literacy |
| Mystery shopping and observation | ■ A useful way of testing services from patient's perspective if service users are involved<br>■ Staff can observe patient's journey through the system | ■ Involves an element of deception – must comply with ethical guidelines<br>■ Some aspects of experience are impossible to replicate<br>■ If staff are observing their presence this may influence what happens |
| Customer journey mapping | ■ A mixed methods approach that involves staff and patients in mapping care pathways | ■ Requires careful co-ordination and training<br>■ Time-consuming and resource-intensive |

Coulter A, Fitzpatrick R, Cornwell J. (2009) Measures of Patients' Experience in Hospital. King's Fund.

# APPENDIX TWO: FURTHER USEFUL LINKS

## FURTHER INFORMATION ON SURVEYS:

For more information on designing and implementing surveys see:

Dillman, Don A., Smyth, Jolene D., Christian, Leah M. 2014. Internet, Phone, Mail and Mixed-Mode Surveys: The Tailored Design Method, 4th edition. John Wiley: Hoboken, NJ

Willis, G. (2005), Cognitive Interviewing: A Tool for Improving Questionnaire Design, Thousand Oaks, CA: Sage. A shorter 'how to' guide by the same author is available on the website of the US National Cancer Institute at appliedresearch.cancer.gov/archive/cognitive/interview.pdf

## ONLINE FEEDBACK

Some useful references for those interested in reading more include:

http://www.researchgate.net/publication/224811810_Associations_between_Internet-based_patient_ratings_and_conventional_surveys_of_patient_experience_in_the_English_NHS_an_observational_study

Using thematic analysis of online narrative comment about hospitals:

qualitysafety.bmj.com/content/early/2015/12/13/bmjqs-2015-004515.full#ref-32

Describes analysis of comments specifically about emergency departments, but may be more generally useful:

http://qualitysafety.bmj.com/content/25/1/14.abstract

'Social media and healthcare quality improvement: a nascent field', an editorial on two papers covering Twitter analysis of patient comments about hospital quality, and ED staff accessing individual Twitter and Facebook data as part of health record:

http://qualitysafety.bmj.com/content/early/2015/12/11/bmjqs-2015-004827.extract?papetoc

## LOCAL FEEDBACK AND COMPLAINTS

A recent article reports on a tool (the Healthcare Complaints Analysis tool) which can be used to identify themes in complaints:

http://qualitysafety.bmj.com/content/early/2015/12/13/bmjqs-2015-004515.full#ref-32

## SHADOWING

A useful summary of the role of shadowing is available here:

http://m.qualitysafety.bmj.com/content/early/2016/05/10/bmjqs-2016-005308.full?view=full&uritype=cgi

Process Mapping

Other sources of help with process mapping are:

http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/process_mapping_-_an_overview.html

http://qi.elft.nhs.uk/flow-diagram/

http://www.qihub.scot.nhs.uk/knowledge-centre/quality-improvement-tools/process-mapping.aspx

# ROOT CAUSE ANALYSIS

http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/identifying_problems_-_root_cause_analysis_using5_whys.html

# FISH BONE DIAGRAMS

Other sources of help for fish bone diagrams are:

http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/cause_and_effect.html

https://qi.elft.nhs.uk/cause-and-effect-diagram-fish-bone

# DRIVER DIAGRAMS

Some good sources of advice on designing and using driver diagrams are:

http://qi.elft.nhs.uk/driver-diagrams

http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/driver_diagrams.html

http://www.qihub.scot.nhs.uk/knowledge-centre/quality-improvement-tools/driver-diagram.aspx

# APPENDIX THREE – MEET THE TEAM

Listed below are the co-investigators on the grant, other members of the project team and the lay panel

## NUFFIELD DEPARTMENT OF PRIMARY CARE HEALTH SCIENCES

Louise Locock, Principal Investigator and Director of Applied Research, Health Experiences Research Group

Sue Ziebland, Director of the Health Experiences Research Group

Trish Greenhalgh, Professor of Primary Care Health Sciences

John Powell, Associate Professor and Consultant Clinical Adviser, NICE

Sian Rees, Director for Patient and Public Involvement, Engagement and Experience, Oxford AHSN

Angela Martin, Programme Co-ordinator

Stephen Parkin, study researcher

Catherine Montgomery, study researcher

Alison Chisholm, study researcher

## PICKER INSTITUTE

Chris Graham, Director of Research and Policy, Picker Institute Europe

Jenny King, Associate Director of Research, Picker Institute Europe

## NUFFIELD DEPARTMENT OF POPULATION HEALTH

Ray Fitzpatrick, Professor of Public Health and Primary Care

Crispin Jenkinson, Professor of Health Services Research and Director, Health Services Research Unit

Elizabeth Gibbons, Senior Research Scientist, Health Services Research Unit

Angela Coulter, Senior Research Scientist, Health Services Research Unit

## SAÏD BUSINESS SCHOOL

Sue Dopson, Rhodes Trust Professor of Organisational Behaviour

## NHS ENGLAND

Neil Churchill, Director for Improving Patient Experience

Catherine Thompson, Experience of Care Lead, Patient Experience Team

Rachel White, Experience of Care Team, NHS England

## ROYAL BERKSHIRE

Melanie Gager – Sister, Project Clinical Advisor

## LAY CO-INVESTIGATOR

Jennifer Bostock

## LAY PANEL

Ten lay people (picked for having inpatient/carer and/or service improvement experience, with varying degrees of previous patient involvement work).

Ann Tomline

Barbara Bass

Carol Munt

Georgina McMasters

Gillian Richards

Gordon Sturmey

Karen Swaffield

Paul Whitehouse

Tina Longhurst

Tracey Richards

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