

No. 18

Measuring patient experience

Evidence scan

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Health Foundation evidence scans provide information to help those involved in improving the quality of healthcare understand what research is available on particular topics.

Evidence scans provide a rapid collation of empirical research about a topic relevant to the Health Foundation's work. Although all of the evidence is sourced and compiled systematically, they are not systematic reviews. They do not seek to summarise theoretical literature or to explore in any depth the concepts covered by the scan or those arising from it.

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Key messages

Enhancing people’s experience of health services may be a key goal of improvement initiatives. There are many ways to assess patient expectations, experience and satisfaction. This evidence scan describes approaches to measuring patient and carer experiences of healthcare.

The evidence scan includes 328 empirical studies sourced from five bibliographic databases searched in April 2013. The most commonly researched approaches for measuring patient and carer experience include surveys, interviews and patient stories. There is little comparative information about the pros and cons of these approaches, but a number of studies have examined the properties of individual tools.

Approaches can be divided according to the depth of information they provide and the extent to which they collect information that may be generalisable to a wider population. In selecting an appropriate measurement approach, it may be necessary to weigh up the importance of depth versus generalisability, or to combine approaches to gain a mixture of both.

	Less descriptive	More descriptive
More generalisable	<ul style="list-style-type: none"> – Surveys – Comment cards – Kiosk questions 	<ul style="list-style-type: none"> – In-depth interviews – Focus groups – Patient panels
Less generalisable	<ul style="list-style-type: none"> – Online ratings – Public meetings 	<ul style="list-style-type: none"> – Patient stories – Ward rounds – Patient Advice and Liaison Services feedback – Complaints and compliments – Photographs

It is not possible to suggest that a certain approach or a particular tool is most effective for measuring people’s experience, but the evidence base suggests 10 things that need to be considered when planning how to measure changes in patient and carer experience over time.

1. Consider how patient experience is being defined to inform exactly what needs to be measured.
2. Think about why patient experience is being measured and how the information will be used.
3. Assess whether it would be useful to combine approaches so that both qualitative and more quantitative material is collected.
4. Consider whether to ask everyone using the services or only a sample to provide feedback.
5. Think about whether the best time to collect feedback is immediately after using the services, when experiences are fresh in people’s minds.
6. Allocate enough time at the outset to plan and test measurement methods, particularly if these will be used for many years to monitor change over time.
7. Think about how the end-result needs to be presented for various audiences as this may shape how data are collected. Potential outputs include statistical averages, in-depth quotes or graphs.
8. Make sure that there is appropriate infrastructure at an organisational level to analyse and use patient experience information.
9. Make sure that patients, carers, managers and health professionals are all comfortable with why feedback is being collected and how it will be used. Staff need to be on board as well as patients.
10. Ensure that patient experience measures are seen as one component of a broader framework of measurement and that all of the approaches work well together, without excessive burden for either staff or patients.

1. Scope

The way people experience health services is an important component of the quality of care. This evidence scan provides examples of common approaches for measuring patient experience that could be used to track changes due to improvement initiatives.

Purpose

Health services in the UK support more than one million people every day.¹ The experiences of patients and their family and friends are a key component of the quality of healthcare, and there is an increasing focus on improving patient experience.²⁻⁴

For example, Lord Darzi's 2008 review of the NHS, *High quality care for all*, highlighted the importance of ensuring that people are treated with compassion, dignity and respect⁵ and recommended developing the NHS Constitution, which describes the purpose, principles and values of the NHS.⁶ Since the Health Act came into force in January 2010, healthcare commissioners and service providers have had a legal obligation to take the Constitution into account in all their decisions and actions, including focusing on patient experience. The 2010 White Paper, *Equity and excellence: liberating the NHS*, suggested that more emphasis needs to be placed on improving people's experience of healthcare⁷ and the NHS Outcomes Framework makes clear that the provision of a 'good experience' of care for patients is a central goal for the NHS, making up one of the five core domains.^{8,9}

Patient experience is therefore seen as a central outcome for the NHS, alongside clinical effectiveness and safety. The NHS Patient Experience Framework includes an evidence-based definition of patient experience and considers how this concept should be measured.¹⁰ The government response to the NHS Future Forum emphasises the need for new metrics that bring together existing data on patient experience and steps have been taken towards this.¹¹ A quality standard for patient experience in adult NHS services has been developed by the National Institute for Health and Care Excellence (NICE)^{12,13} and the collection of patient-reported experience measures (PREMs) and patient-reported outcomes (PROMs) has been tested, with high response rates. PROMs are now mandatory practice in the NHS for elective procedures.¹⁴

All of these activities illustrate that patient and carer experience is the focus of much work and debate. Collecting information from patients can help organisations make better decisions about how to improve services and is even part of some service accreditation programmes.¹⁵

Measuring patient experience is important not only to guide service improvement, but also because people's experiences of care may be linked to clinical outcomes and costs.¹⁶ A systematic review of 55 studies in primary care and hospitals found consistent positive associations between patient experience, patient safety and clinical effectiveness for a wide range of disease areas, settings, outcome measures and study designs.¹⁷ This supports the case for including patient experience as one of the central pillars of quality in healthcare.

It supports the argument that the three dimensions of quality should be looked at as a group and not in isolation. Clinicians should resist side-lining patient experience as too subjective or mood-oriented, divorced from the 'real' clinical work of measuring safety and effectiveness.¹⁸

Many services routinely ask people for feedback about the care that they have received and improvement projects usually include patient expectations, satisfaction or experience as a core indicator. However, questions remain about the best way to understand and act on the experiences of patients and carers.

There are many approaches to measuring patient and carer experiences of health services. This evidence scan reviews published research about these approaches to help gain an understanding of the advantages and limitations of different methods.

The scan addresses the following questions:

- How has the experience of patients and carers been measured in healthcare?
- What are the pros and cons of different approaches for measuring improvement over time?

The scan provides a general overview of the **most commonly researched** approaches to measuring patient and carer experience reported in empirical literature. It summarises key themes from research about the strengths and weaknesses of various approaches and provides some descriptions of specific tools as examples.

The aim is to provide an accessible overview of the range of methods that have been used, in order to help practitioners, planners and researchers consider the best ways to measure patient experience in their own local improvement initiatives. However, the focus is on compiling broad themes from the literature, not providing summaries of individual studies or tools. In other words, the scan provides examples of different approaches and draws out potential pros and cons so that local teams can consider whether any of these approaches could be adapted to measure changes in people's experience of health services over time.

Scanning research

The scan focuses on readily available research published in journals in the UK and internationally. It was completed over a three-week period in April 2013.

To be eligible for inclusion in the scan, studies had to:

- explore the measurement of patient expectations, experience, perceptions or satisfaction
- be focused on healthcare in the UK or internationally
- include empirical data
- be published in a print or online journal
- be published in the English language or be readily available for translation within a short period of time
- be published between January 2000 and April 2013.

There were no geographic restrictions.

To identify relevant research, two reviewers independently searched five bibliographic databases for studies of any design published between January 2000 and April 2013. The databases comprised Medline, Embase, the Cochrane Library and Controlled Trials Register, Google Scholar and Web of Science.

Search terms included combinations of patient, carer, experience, satisfaction, perceptions, expectations, feedback, assessment, measurement, quality improvement, PROMs, PREMs, real time feedback, survey, focus group, online, patient stories, interviews, observation, complaints, photovoice and similes.

More than 10,000 articles were scanned and the full text of 3,453 studies was read. Information from 328 empirical articles met the inclusion criteria and additional contextual material was also summarised.

All of the evidence was sourced and compiled systematically, but the scan is not a systematic review and does not seek to summarise every study about measuring patient and carer experience.

Findings were extracted from all publications using a structured template and studies were grouped according to methodological types to provide a narrative summary of trends.

Scope

This evidence scan does not purport to be a practical manual or a step-by-step guide to measuring patient experience, nor does it contain information about the advantages and limitations of different research techniques more generally. The focus is on summarising empirical studies about approaches for measuring patient and carer experience.

For the purposes of the evidence scan, 'measuring patient and carer experience' relates to expectations, satisfaction or experience with healthcare services and staff (rather than patient feedback about clinical information, safety incidents or functional outcomes).

It could be argued that terms such as satisfaction and experience have distinct meanings. For instance, 'expectations' may refer to people's perceptions before receiving care, 'experience' may relate to what happens during care and 'satisfaction' may refer to information collected afterwards. Alternatively, 'experience' could be taken to describe things that happened and the extent to which people's needs are met whereas 'satisfaction' could relate more to how people feel about those things.

While there are some detailed theoretical and academic arguments about the difference between these terms, for simplicity, within this scan 'experience' is taken to mean any combination of satisfaction, expectations and experience, so long as it relates to feedback provided by people using health services or their family or carers. For consistency, the term 'experience' is used throughout

this scan, although terms such as ‘satisfaction’ and ‘expectations’ are used if an individual study focused on these particular concepts.

Feedback from real patients and carers rather than trainees, actors or ‘professional’ patients was the focus. Studies are available about simulated patients, ‘mystery shoppers’ and about professionals attempting to put themselves into the patient role and consider things from this point of view, but these were outside the scope of the scan.^{19–23}

For ease of summarising, approaches were divided into two categories: those where patients or carers provided descriptive feedback about their experiences, such as using interviews or patient stories (67 studies) and those where patients or carers were surveyed about their experiences (more than 250 studies). Although descriptive methods tend to provide more qualitative data and surveys tend to provide more quantitative information, these sections are not termed ‘qualitative’ and ‘quantitative’ because, in theory, it is possible for both types of data to be collected using most approaches. For instance, online approaches can be used to collect both numerical and more in-depth feedback, as can interviews and surveys.

General research about the extent to which patients and carers were satisfied with health services was not included because the focus of this scan was on **approaches** for measurement, rather than the findings of that measurement.

Things to bear in mind

When interpreting the findings of this evidence scan it is important to bear in mind several caveats.

Scope: Firstly, the scan is not exhaustive. Many tens of thousands of studies have measured patient experience. The scan presents examples of readily available and recently published empirical studies. It does not purport to represent every study about measuring patient and carer experience. The purpose is to give a flavour of available research, to signpost readers to interesting material and to highlight some of the key implications for measuring improvement rather than to summarise every study in detail.

Furthermore, only studies explicitly focused on issues relating to **measuring** patient or carer experience are included. Many studies have outlined the extent to which patients or carers are satisfied with health services, but unless the studies commented specifically about **measurement issues**, they were not the focus of the scan.

There are many descriptions of approaches for measuring patient experience, and a number of tools exist. Such descriptions were not eligible for inclusion in the evidence scan unless they were based on published research. This means that there may be many types of measurement taking place that are not included here, merely because there is little research published about them. An example of this is the NHS Institute for Innovation and Improvement’s toolkits, which are available online.^{24–26} NHS organisations are also using many tools and approaches which may not be detailed here, merely due to a lack of published research about them.

Quantity of research: Another important point to note is that there are relatively few studies providing detail about the exact approaches used to measure patient and carer experience. There is much research testing and validating individual survey tools, but the quantity of studies about other approaches such as interviews, online forums and more qualitative techniques is limited. The relative pros and cons of different approaches and the cost-effectiveness of various strategies is also uncertain. There is very little research focused on carers.

Quality of research: There are also issues with the quality of the studies included. Many of the studies are small, do not contain a lot of detail and are conducted in single sites, often outside the UK. This may mean that it is not possible to generalise about the applicability of the approaches or tools to the UK context.

Making comparisons: Finally, it is difficult to make comparisons between approaches or tools because the studies used different definitions of patient and carer experience and took place in widely varying contexts.

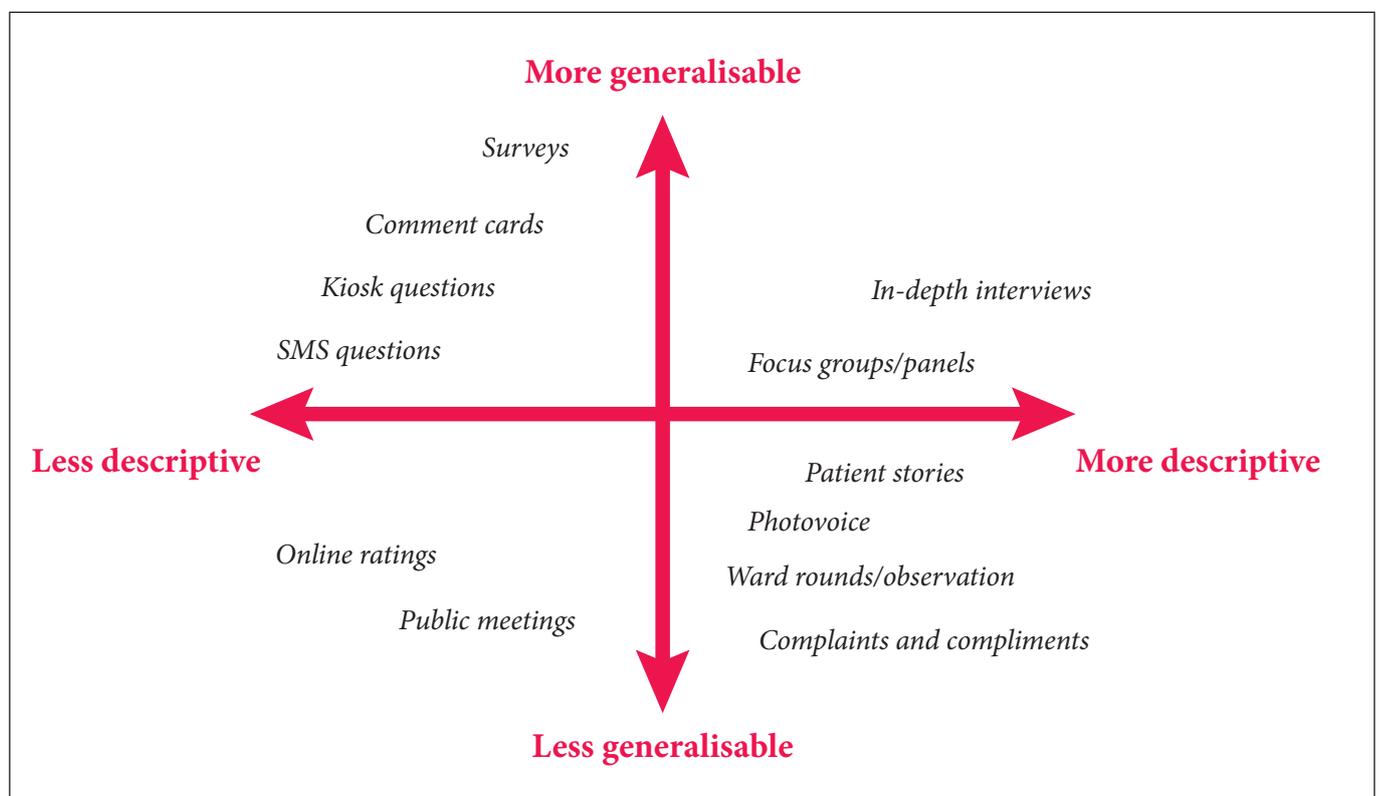
These methodological issues limit the extent to which we can suggest that some approaches are more effective or appropriate than others. Therefore, it is important to emphasise that the aim of the scan is not to draw conclusions about the most effective strategies for measuring patient and carer experience, but rather to summarise some of the main methods used and to highlight potential pros and cons for measuring change over time. The scan concentrates on giving examples of what has been done previously, to help researchers, managers and frontline staff plan what may work best in their own contexts.

2. Overview of approaches

Strategies for measuring patient experience can be viewed along a continuum, from those that collect detailed descriptive feedback to those that collate more numerical data.

Some of the key approaches that have been used to measure patient experience are listed in figure 1.

Figure 1: Examples of methods used to measure patient and carer experience of health services



These approaches are categorised according to the depth of information they provide and the extent to which they collect information that may be generalisable to a wider population. In selecting an appropriate approach, it may be necessary to weigh up the importance of depth versus generalisability, or to combine approaches to gain a mixture of both.

3. Descriptive feedback

This section gives examples of how patients and carers have provided descriptive feedback about their experiences using interviews, discussions and stories.

Interviews

We identified **18 studies** about methodological aspects of measuring patient or carer experience using in-depth interviews, either in person or by telephone. This refers to detailed discussions with probing and qualitative feedback, rather than merely asking structured survey questions verbally.

Interviews have been used to good effect to collect one-off information from patients or carers which is then fed into initiatives to improve quality or safety.²⁷⁻³³

For instance, researchers in England interviewed 14 patients in the community and in nursing homes to explore how their experiences and their perceptions could be used to reduce safety incidents during transfers between organisations. Patients said that good communication, responsiveness and avoiding risks were all important to them. This feedback was used to improve services.³⁴

Elsewhere in England, researchers examined patient perceptions of the quality and safety of care for people with long-term conditions. Interviews with 33 people with long-term conditions identified problems gaining access to primary care consultations, diagnostic tests and specialist care.³⁵

Very **in-depth interviews** are sometimes used as part of an 'experience-based co-design' approach whereby patients and carers are asked to comment on their experiences in order to shape improvements in care.³⁶

In Australia, five people who had suffered a stroke and their carers were interviewed about their experiences of care one month after discharge from stroke rehabilitation. Patients and carers emphasised slightly different things. This is an example of using a small number of interviews with families to develop a rounded picture of care experiences.³⁷

In Canada, **telephone interviews** were used to collate detailed feedback from people with cancer about their care journey. Interviews were transcribed verbatim and analysed using a grounded theory approach, which means that the words and content emphasised by participants themselves form the basis for the analysis. In this study, it emerged that there was no clear 'pathway' of care. Instead, there were difficulties obtaining a diagnosis; gaining appropriate information from health professionals; finding good treatment centres and finding disease-specific support. The depth of information in the interviews allowed managers and frontline staff to consider step-by-step changes to the care pathway which may not have been possible with more surface-level surveys.³⁸

Although interviews are a well-known technique, there is little empirical research evaluating their effectiveness for measuring patient experience, or monitoring changes over time. A limited number of studies have begun to draw conclusions about this, though. For instance, a team in Spain examined whether patients are a good information source about the occurrence of safety issues and adverse events. Twenty-eight patient interviews were combined with record reviews. The researchers concluded that patients can contribute to identifying adverse events affecting them with reasonable accuracy.³⁹

In the USA, **critical incident techniques** have been used to interview patients about their experience of primary care. In total, 168 patients were asked about behaviours that resulted in consultations being considered either good or poor quality. After the interviews, a taxonomy with nine key categories and more than 100 subcategories of important behaviours was developed. Clinical skill, rapport and health-related communication were thought to be essential for good quality experiences.⁴⁰

However, other studies have questioned the value of patient interviews for identifying issues related to quality and safety. One study compared four methods

of detecting medication errors at a US hospital: doctors' reports during their morning conference, nursing reports during shift changes, patient reports at **discharge interviews** and standardised medical record review. All methods were compared with the hospital's electronic medication misadventure reporting system. Forty-seven per cent of admissions experienced at least one medication misadventure. There was little overlap among the four reporting methods. No single method captured all incidents and only 20% were reported by more than one method. Fifty-one per cent of incidents were identified by medical record review, 11% by patient interview, 9% by doctor reports and 8% by nurse reports. Of five life-threatening adverse drug events, all were preventable, but only one was reported by a patient at discharge.⁴¹ This suggests that patient interviews may omit important aspects of the quality of care, particularly when looking for specific details.

Researchers from England compared the relative value of **detailed patient narratives** versus surveys for identifying priorities for improving breast cancer services as part of a quality improvement process. One set of data were collected using a narrative interview approach with 13 patients and this was compared with a postal survey of 82 patients. There were similarities and differences in the patient experiences and improvement priorities reported from each approach. The preferences identified in the narrative interviews commonly related to 'relational' aspects of patient experience whereas those identified by the survey tended to relate to more 'functional' aspects and were not always sufficiently detailed to identify specific improvement actions.

The researchers recommended that future improvement initiatives consider using an initial preliminary survey, with better use of open-ended comments, followed by an in-depth qualitative analysis of a small number of interviews.⁴²

Interviews may sometimes be supplemented with **observation** to help collate information about patient experience, although this is uncommon. Most studies using observation look at things from a professional or organisational perspective, rather than examining events explicitly from a patient's point of view. An example of more patient-centred observation comes from the USA, where one hospital combined patient interviews with observations of patients, family members and medical staff in a large hospital to assess patient perceptions of the quality of care. Observations were classified using a structured model focused on technical care, interpersonal care and amenities of care. Watching interactions with patients and then interviewing people

about their experiences helped the team collect very detailed information about patient satisfaction and underlying factors.⁴³

In Australia, interviews with patients were combined with observation to explore people's experience and dignity on hospital wards. Although observation suggested deviations to ideal practice in terms of maintaining the physical environment and communication styles of the nursing staff, when patients were interviewed they did not identify this as an issue or suggest that their dignity and privacy had been compromised. This may mean that patients have different priorities from those identified by independent observers – or it may signal that patients do not always feel comfortable detailing these types of concerns in interviews.⁴⁴

Overall, the evidence base suggests that interviews may be useful for providing in-depth information about patient experiences, but may not be the most appropriate method when trying to identify specific numerical information or safety concerns. Interviews also have significant resource implications (see box 1 on page 11).

A qualitative approach, centred on small stakeholder samples, is fairly effective at assessing service quality, yet demands a strong commitment from agencies in personnel time and resources, as well as the necessary skills.⁴⁵

Focus groups and panels

Another strategy is to engage patients or carers in discussion groups or 'group interviews'. We identified 10 studies about the methodological aspects of discussion groups or patient panels for measuring patient experience.

In the USA, a network of services provided through community-based clinics and small hospitals used **focus groups** to explore patient experience. Groups were run at clinics and at hospital sites, particularly targeting those who may not usually respond to surveys or those who may be most disadvantaged. Patients were willing to participate and the researchers found it easy to draw out themes and potential areas for improvement. Patients were most concerned about eligibility and enrolment policies, patient advocacy, access to primary care services and areas for improvement.⁴⁶

A number of other teams have used discussion groups to collate similar feedback about patient experience.⁴⁷⁻⁵⁰

Focus groups can be an excellent method for primary care practices to assess the complexities of patient satisfaction issues and engage patients in the continuous quality improvement process.

Focus groups can uncover unanticipated issues that surveys fail to identify.⁵¹

In Iran a '**voice of customer** (VOC) analysis' process was used to collate women's feedback about maternity services. VOC techniques are sometimes referred to in a business context and include both qualitative and quantitative methods for understanding demographics, people's expectations and needs, and satisfaction with services. Combining focus groups with other methods helped to provide an understanding of women's experiences and a grounding for further improvement.⁵²

As well as taking the form of one-off focus groups, discussion groups may also involve ongoing **patient panels**, committees or patient involvement groups. For instance, in Ireland seven patients from the haemophilia service at one hospital took part in a programme to improve quality and safety. Patients took part in discussion groups to identify issues of concern. A patient panel was developed so that there was an ongoing partnership.⁵³

While patient involvement groups are common in the UK, there are few empirical studies describing the pros and cons of this approach or the merits for measuring improvement over time.

Many policymakers, managers and practitioners espouse the value of involving patients in discussion groups of this nature, but the extent of engagement may be somewhat limited. There may be a number of barriers, as evidenced by one health centre in England that set up group discussions and patient panels to help people participate in developing better quality and safer services. Dilemmas surrounding patient participation included concerns about how to reward volunteers, how doctors and patients can share knowledge, how participation is affected by professional boundaries and whether or not a regular group meeting is the best way to involve patients in decision making.⁵⁴

Researchers in Canada concluded that variable patient interest and the attitudes of health professionals may act as barriers to patient involvement in discussion groups for improving services.⁵⁵

However, the more patients are engaged in planning and developing services, the more accepted this may become among both patients and professionals. Researchers from England examined whether engaging patients in service development impacted on healthcare professionals' and service users' attitudes toward engagement. Focus groups before and after lung cancer teams were supported to engage with patients and family members found that staff and patients who participated had more positive attitudes towards involvement than those who did not participate.⁵⁶

Having clear guidelines about the type of people who should participate and the level of feedback required, and providing support with practical issues, may help to motivate patients to take part and keep clinicians engaged too.⁵⁷

The main pros and cons of using discussion groups or panels for measuring patient experience are similar to those associated with in-depth interviews (see box 1).

Box 1: Key pros and cons of measuring patient experience using interviews and focus groups

Potential advantages	Potential limitations
Helps collect in-depth information	May not be able to collect data that readily translate into numerical findings
Can probe the reasons for people’s opinions and delve into depth about thoughts and feelings	May gloss over specifics if not conducted well
Can be useful when discussing sensitive topics	Depends on the skill of the interviewer or facilitator
Can incorporate visual aids	May be prone to facilitator bias
Can help people feel more engaged in improvement initiatives by giving a more personalised experience of providing feedback	Can be time-consuming for patients and carers
Can use telephone calls rather than solely relying on face-to-face discussions	Can be time-consuming for teams to organise, conduct and analyse
If using a group approach, feedback from other members can spark ideas	Requires effort to make sense of detailed qualitative data
Can explore unexpected responses immediately	Patients may lose interest in continuing to participate over time so it is essential to tailor participation requirements to people’s preferences ⁵⁸
	May be affected by social desirability bias
	If using a group format, may be affected by consensus bias
	Can be costly for the amount of output gained
	Can be difficult to replicate over time

Patient stories

Another approach is to collect patient stories about the care journey. We identified three studies about methodological aspects of using narrative stories to document patient experience.

Written or videoed patient stories have been used to encourage discussion in team meetings or board meetings, particularly regarding patient safety issues.⁵⁹ For instance, the US Institute for Healthcare Improvement's 'Boards on board' programme suggests that having written or videoed stories or asking patients to attend a board meeting to describe their experience can put a human face on safety issues and encourage healthcare managers to promote change.⁶⁰

There is a growing body of literature suggesting that storytelling is an effective strategy for learning and improvement. Researchers in the UK examined the process of learning from patients' stories during practice placements. In-depth interviews with 12 nursing, midwifery and social work students found that listening to patient stories helped students to gain valuable insights about patient experience. However, this tended to be done in a haphazard manner, rather than using a structured improvement process to actively facilitate reflection.⁶¹

Another trend is to invite patients and carers to provide their stories or reviews of services **online**.⁶² There are many mechanisms for collecting people's views, such as questionnaires and patient involvement groups.⁶³ However, formal research can be resource intensive, selective in the types of questions asked and the types of people who respond, and may take time to analyse and act upon. **Newer techniques** are being tested to augment traditional ways of understanding the opinions and experience of patients and family members. Social media, such as Twitter and Facebook, blogs, online forums and websites that encourage patients to share their views are increasingly popular.^{64,65}

*The advent of social media and new technology potentially opens a door to insights into care (both positive and negative) unfiltered by traditional methods of healthcare data capture and analysis. For the first time, the voice of the patient may be heard with clarity and immediacy.*⁶⁶

Examples of **websites** in the UK that encourage patients and family members to share their stories include NHS Choices, Patient Opinion and IWantGreatCare. These are part of a wider trend for using online information to understand people's views and predict trends that is sometimes known as the 'Big Data' revolution.⁶⁷

For example, analysis of social media posts and online content has been used to predict popular movies,⁶⁸ election results,⁶⁹ financial issues⁷⁰ and for disease surveillance.⁷¹⁻⁷⁴

To describe one example in more detail, Patient Opinion encourages people to provide short anonymous stories about the care that they have received. More than 45,000 stories have been submitted to the website. Patient Opinion publishes the stories online, contacts the relevant health organisation about the feedback and allows organisations to make a response online if they wish. The feedback comprises both positive and negative experiences and includes the geographic region and the name of the organisation involved. The website has been acknowledged in the Francis Report as a potentially useful tool for improving the quality of care.

*Publication of comments online, good and bad, is a powerful tool for patient choice and in forcing providers to address, in public, criticisms made. Encouragement should be offered to impressive contributions made in this field by organisations such as Patient Opinion.*⁷⁵

Similarly, the government-run website NHS Choices encourages patients to provide narrative feedback about services, particularly hospital services. In fact, NHS Choices stories now feed in to the Patient Opinion website. An analysis of 200 patients' feedback about 20 randomly selected hospitals found that the domains covered typically reflected those included in traditional satisfaction surveys. Comments about health professionals were common (90% of stories) and overwhelmingly positive. In two-thirds of the stories (62%), patients commented about technical aspects of hospital care, including quality of care, injuries, errors, and incorrect medical record or discharge documentation. Perceived medical errors were described in one quarter of the stories (26%). Hospitals replied to about half (56%) of the patient reviews.⁷⁶

*[Patient stories] appear to have similar domains to those covered in existing satisfaction surveys but also include detailed feedback that would be unlikely to be revealed by such surveys. Online narrative reviews can therefore provide useful and complementary information to consumers (patients) and hospitals, particularly when combined with systematically collected patient experience data.*⁷⁷

A major issue with such ‘open access’ websites is that there is uncertainty about the provenance of responses. Readers cannot be sure that stories originate from actual patients or that patients are attributing their experiences to the correct healthcare provider. ‘Closed access’ systems have been set up to counteract some of these issues, whereby only registered patients or those sent an email invitation are able to share their stories. However, this tends to take the form of surveys rather than free-text stories.

Box 2 summarises the advantages and limitations of using descriptive stories to measure patient experience. While this is becoming a more common practice, and has been tested in the UK, little published research is available evaluating the pros and cons of this approach for assessing patient experience.

Box 2: Key pros and cons of measuring patient experience using patient stories

Potential benefits	Potential limitations
Provides in-depth information	Can take time to collect, especially if videoing or audio-recording
Can personalise statistics and incidents so that the ‘human impact’ is at the forefront because stories involve real people talking about the things that they have experienced and how they feel, in their own words	Can be difficult to analyse and draw out themes from stories
Has been found to help managers and students learn rapidly about patient experiences ⁷⁸	Stories in isolation cannot be used to represent the views or experience of other patients
Can be combined with more quantitative surveys or other approaches to provide a well-rounded picture	Has a danger of focusing in on individual circumstances, rather than wider learning points for groups or organisations
Can draw on internet technology to collate stories and service reviews	Stories collected online may not include demographic information or other important contextual information
By providing an environment in which people can talk about their experiences in an unstructured way, it is possible to draw out the areas of greatest importance or interest to patients	Few people may provide stories, so this gives small numbers for an individual organisation to work with when considering change
	Relies on people being able to provide coherent feedback, which may not always be the case
	The nature of patient stories can make it difficult and expensive for individual teams or organisations to scale up their use

Complaints and compliments

Analysing the complaints or compliments that patients and families submit to health services can also be a source of feedback about patient experiences, especially when a systematic analysis approach is implemented.⁷⁹⁻⁸² We identified seven studies about this.

There are some formal systems to assist with this. For instance, the UK has a system that allows patients to make **official complaints** against general practitioners (GPs) without seeking compensation. The Netherlands uses a similar system. An analysis of 250 complaints from this Dutch system found that many related to a wrong diagnosis, insufficient care or a wrong treatment.⁸³ It was possible to use the complaints database to extract key trends, and there was potential to do this on a rolling basis to monitor changes over time.

One hospital in Taiwan tested the value of using **complaints** to measure patient experience and drive service improvement. Over the study period, 59 people registered 87 complaints, most commonly about the level of care, humaneness and communication. The majority of complaints were resolved within three days. The hospital explained the circumstances to complainants, investigated events and showed empathy.⁸⁴ However, there was a lack of any systematic use of complaints data to track changes over time or to plan improvement.⁸⁵

Instead of attempting to use such data as the basis for initiating quality improvement measures, complaints were consigned to a 'black hole' where their existence was conveniently forgotten.⁸⁶

In the USA, one hospital team developed a codebook to categorise and report on patient complaints, including those received from surveys and elsewhere. A database was set up to store all complaints, both verbatim and with numeric codes identifying the main issue. About 4,000 complaints were received each year. The team prepared department-specific, location-specific, and organisation-wide reports every quarter and these were analysed to identify trends in the incidence of complaint themes and specific locations where improvement was required. Most complaints were about one of five things: facilities/environment, quality of care, respect and caring, timeliness and communication. The patient complaint tracking system worked well to help managers and teams to develop improvement efforts based on quantitative and qualitative data. However, one of the limitations was that only one administrative department had exclusive access to the database, and other teams had to rely on the generated reports.⁸⁷

Formally using **compliments** is perhaps less common than analysing complaints. One service in England implemented a way of eliciting compliments about nursing care on a dementia assessment ward. This not only collated patient experience, but also changed staff attitudes to receiving feedback because most observations were couched in positive terms.⁸⁸ Box 3 lists some of the potential pros and cons of using complaints and compliments as a measure of patient experience.

Box 3: Key pros and cons of measuring patient experience using complaints or compliments

Potential benefits	Potential limitations
May provide in-depth information, particularly about things that need improvement	If using formal systems it may be more likely to elicit feedback from people who feel confident complaining, who may also be more literate
Can identify things that people feel particularly passionate or concerned about, since it relies on spontaneous reporting ⁸⁹	Biased towards the most serious (or most positive) aspects of care rather than acknowledging a continuum
	May not have large numbers of complaints or compliments to work from
	May be in danger of focusing upon individual issues rather than broader pathways of care or service redesign

Photovoice

Another novel method for documenting patient experience is ‘photovoice’. This is an emerging technique whereby people use photographs and captions to share their experiences, and changes can be monitored over time. We identified 23 studies about using this approach to explore patient experience.

*Photovoice is a community-based participatory research method that provides participants who traditionally have little voice in community policy decisions, with training in photography, ethics, critical dialogue, photo captioning, and policy advocacy. Photovoice has been used primarily as a needs assessment and advocacy tool and only rarely as a pre/post intervention evaluation method.*⁹⁰

In the USA, photovoice was used to help gain feedback about patient experiences as part of a six-year community obesity prevention initiative. Fifty community members used photos and captions to identify what they thought the most significant accomplishments of the initiative were at baseline and follow-up.⁹¹

Another example comes from Canada, where photovoice was used to collect the experiences of people taking part in community psychosocial rehabilitation.⁹²

Elsewhere in Canada, a neighbourhood with many immigrants and ethnic minorities used photovoice to engage and empower people to secure improved local services for promoting health and wellbeing. Twenty-seven residents used photography and storytelling to record neighbourhood characteristics and their impact on people’s health and service use. Eight participants presented actionable recommendations to the local councillor and worked with the council to carry out selected recommendations.⁹³ There are many similar studies suggesting that photovoice can be used to generate dialogue about people’s concerns and priorities and to promote action.^{94–99}

This is a relatively new technique and the pros and cons for monitoring patient experience have not been explored in any depth (see box 4). However, it highlights that visual media can be used, perhaps in conjunction with other techniques, to engage people in sharing their experiences. Photovoice has been found to be particularly useful with young people, ethnic minorities and less well educated or more deprived groups.^{100–113}

Box 4: Key pros and cons of measuring patient experience using photovoice

Potential advantages	Potential limitations
This method may engage both patients and staff due to novelty	Participants need to be trained in the approach and in writing captions
Has been used to good effect with less advantaged and hard-to-reach groups	Requires technology (cameras)
Gains unprompted feedback about issues that matter most to participants	May be difficult to draw out trends because the ‘output’ is in a novel format
Has benefits of being a visual medium, and thus is perhaps easy to understand and engage with	Does not always get behind the surface regarding the reasons that things are important to people
Has been used to create community involvement and motivate change	

4. Surveys

This section provides examples of how patients and carers have been surveyed about their experiences, including different survey administration methods, timeframes and question types.

We identified more than 250 studies about methodological issues when using surveys to explore patient experience, and this is only a small proportion of the many thousands of studies that have used surveys to help assess patient expectations, experience and satisfaction.

Research about the value of surveys for measuring patient and carer experience can be divided into three broad categories, although these overlap: survey administration (the method used to collect survey data), survey content (the content of the questionnaire) and survey timeframe (the timing of data collection).

Survey administration

Handing out surveys

Approaches to collecting descriptive feedback from patients and carers are becoming more common, but surveys remain by far the most frequently researched approach for measuring patient experience. There are numerous examples of surveying patients and carers about their experiences and the quality and safety of care.¹¹⁴⁻¹¹⁶

In the published literature, surveys are common in both hospital and primary care contexts and are often undertaken as part of multi-faceted improvement programmes. One of the most frequent survey administration methods involves handing out surveys **during or immediately after service use**. This has been found to work well to gain people's immediate impressions of the care that they received. For example, a hospital in England used benchmarking, patient feedback and 'Lean' approaches to improve quality and safety. Gaining feedback from patients in a structured way and promoting staff ownership of quality improvement processes reportedly helped to raise standards of care.¹¹⁷

Short feedback postcards

As well as longer surveys, some organisations have tested simple methods for generating immediate feedback from patients about their ongoing care. This often takes the form of feedback postcards or comment cards.¹¹⁸

As an example, in Sweden a hospital used a **'tell us' card** to help patients report on quality and safety. Patients were asked to write what was most important for them on the cards during the day or just before discharge. This approach asked patients to provide immediate regular feedback about issues relating to their current care rather than merely reporting on incidents they had potentially experienced some time ago. The aim was more active participation in an ongoing manner. This provided a written alternative for people who may not feel confident raising an issue about their care verbally with staff. In wards using the cards, patients were more likely to think that they were involved in decisions about their nursing and medical care.¹¹⁹

A team in England used real-time patient feedback to improve safety and patient experience at one hospital. Short tools were used to collect immediate feedback while people were on one ward. Comments were then themed, which helped staff to use them to change services or rectify any problems. It was important to help staff adopt the tools into their routine working schedule.¹²⁰

Devices for real-time feedback

Another approach to gaining 'real-time' survey feedback is to use kiosks or electronic devices at the point of care. Real-time systems aim to capture and display patients' feedback about their experiences on a continuous basis. The 'Friends and families test' currently being rolled out in England is an example of this. **Electronic kiosks** are being set up in accident and emergency departments and on wards to help people give immediate feedback about

whether they would recommend the service to others. It is planned that this information will be regularly collated and disseminated to support improvement.

*In every hospital, patients are going to be able to answer a simple question, whether they'd want a friend or relative to be treated there in their hour of need. By making those answers public we're going to give everyone a really clear idea of where to get the best care – and drive other hospitals to raise their game.*¹²¹

There is some support for this approach in the literature. One primary care clinic in the USA used electronic touchscreen kiosks to obtain patient feedback. Staff asked patients to use a kiosk after their consultation. Half of all patients attending consultations during the trial period used a kiosk to provide feedback (50%). Women and men were equally likely to use the kiosks but older people and minority ethnic groups were less likely to use them. There was no negative impact on waiting time or other aspects of the practice routine. The researchers concluded that electronic kiosks might be a useful way to collate patient experience data in busy services.¹²²

However, safety and hygiene need to be considered when using kiosks or electronic devices to collect feedback in healthcare environments. Off-the-shelf devices such as those designed for commercial or retail applications may be unsuitable because they can be difficult to clean and present infection control challenges.¹²³

Some organisations have tried using devices such as hand-held bedside equipment, tablets, text messages, mobile apps or other novel approaches to collate short patient feedback, but there have been few empirical studies outlining methodological details or the relative pros and cons of these approaches. These approaches are much more likely to be used to provide information or self-management support than to collect feedback about patient or carer experience.¹²⁴

Postal surveys

There are many other ways to collect survey information. A number of studies have used **one-off postal surveys** to collect information about quality and safety issues which then feed into improvement initiatives. For example, a postal survey of more than 11,000 people from Australia, Canada, Germany, New Zealand, the Netherlands, the UK and the USA examined people's experience of health services and the extent of medication errors.¹²⁵

Postal surveys and short postcards can also be used to **collect information over time**, rather than on a one-off basis. A team in the USA tested the feasibility of using a short posted survey to collect feedback about patient satisfaction with emergency medical services (paramedics). Previously, patient satisfaction information had been collected using resource-intensive telephone follow-up, so the aim was to test whether a single mailing, anonymous postal survey would work just as well. Every patient transported over a four-year period was mailed a brief satisfaction questionnaire. Five Likert scale questions and three open-ended questions were printed on a pre-addressed, postage paid postcard. Including all administration and analysis, the survey required about six hours of time per month and cost about \$70 per month. The response rate was 32%. Open-ended questions suggested that interpersonal communication was the single most important contributor to patient satisfaction. The researchers concluded that this may be a feasible and cost-effective way of collecting feedback from patients on an ongoing basis.¹²⁶

Another team in the USA examined whether the administration method influences the results of patient experience surveys. Over a 17-month period, all families of babies discharged from the neonatal intensive care unit at one hospital were surveyed two to 42 days after discharge with two parallel surveys, one posted and one by telephone. The response rate was 94% for the telephone survey and 29% for the postal survey. Three out of the five questions yielded significantly different answers in posted and telephone responses. This related to the specific substantive content of the answers. For instance, telephone feedback tended to focus on process issues whereas postal feedback was more likely to cover interpersonal issues. Telephone feedback was also more likely to be positive. This illustrates that telephone and postal surveys with the same questions may gain very different feedback.¹²⁷ This may be a function of social desirability bias, whereby people try to fit in with what they think the person they are speaking with wants them to say.

Elsewhere in the USA, a randomised trial compared patient satisfaction results gained from a survey that was either handed out in primary care or posted. Surveys that were handed out at the practice yielded higher satisfaction scores than posted surveys. The response rate was higher with handed out surveys than with mailed surveys, but handed out surveys were returned with more questions left unanswered and fewer written comments.¹²⁸ Thus teams may need to weigh up the number of responses gained versus the quality of the feedback contained when selecting an appropriate method.

Online surveys and rating sites

An increasing number of people are using the internet as a platform to describe their healthcare in the UK.¹²⁹ Similarly, in the USA, more than eight out of 10 adults are using the internet regularly¹³⁰ and, of these, one-third say that they have read about someone else's health experience online and more than one in 10 have viewed online reviews of health services.¹³¹ Corresponding figures are not available for the UK, but these statistics suggest that websites may be an important way for people to gain information about healthcare and to provide feedback of their own.¹³²

Online surveys are becoming common.¹³³ For instance, in Taiwan, an online system was developed to collect people's feedback about consultations with doctors. The Patient Feedback Questionnaire (PFQ) designed by the Picker Institute was adapted for online use, with a lot of visual content. Doctors were emailed graphs of the results. Testing with 450 patients found that the system worked well. This is an example of how established and validated surveys can be adapted for use in new mediums.¹³⁴

In the UK, an electronic system has been set up to collect patient-reported outcomes from cancer survivors, including measures of experience. Patients are contacted primarily via email and invited to take part in online surveys repeatedly over time. The system is secure so that responses can be linked with clinical registry data. Patient monitoring and communication is semi-automated via a tracker database. Large-scale feasibility testing is underway.^{135,136}

There are few studies comparing the reliability and validity of online versus other survey approaches. An exception is a study in Scotland that compared online versus postal approaches for collecting PREMs among people with chronic heart failure. In total, 121 people in the community completed a bespoke online or postal survey. Almost twice as many people completed the postal version. There were differences in the type of people who chose to complete each type of survey. For instance, the online cohort was younger, in better health and seemed less satisfied with the quality of clinical services. Those completing the postal survey had less negative feedback. The researchers concluded that it may be important to offer a range of mechanisms to help patients to voice their opinions.¹³⁷

On the other hand, a study comparing online versus paper completion of the Service Satisfaction Scale for Cancer Care (SCA) found similar response rates and patient satisfaction levels with outcomes, practitioner manner and skill, information and waiting/access.¹³⁸

A number of **websites** invite patients to rate the quality of care that they receive from individual services or professionals. This is different from web surveys, which ask similar questions to paper surveys but in an online format. Instead, online rating sites tend to focus on gaining simple numeric feedback which is then collated to give an overall score for specific services or health professionals.¹³⁹ These rating sites are an online resource for peer-to-peer information about individual doctors or services. Typically such websites provide information about a doctor's address, opening hours and qualifications or specialisms. In addition to this factual information, the websites collect and present information about patient experience with individual services.

Research suggests that online ratings by patients can provide a good indication of the quality of health services, as measured by mortality and patient safety rates.^{140,141} Thus examining these websites in conjunction with other information may provide important indicators of the overall quality of care.

An analysis of all 146 acute general NHS hospital trusts in England compared data from 9,997 patient ratings posted on the *NHS Choices* website with indicators of patient experience from a paper-based survey. The online ratings correlated well with the national survey data.¹⁴² The researchers concluded that:

*Unsolicited web-based patient ratings of their care, though potentially prone to many biases, are correlated with survey measures of patient experience. They may be useful tools for patients when choosing healthcare providers and for clinicians to improve the quality of their services.*¹⁴³

Other online tools seek to draw quantitative material from more **descriptive feedback**. For example, in the USA, an online health assessment system for patients has been used to identify safety issues events. In total, 44,860 adults entered information online over a two-year period.¹⁴⁴

Researchers from the Netherlands also described the use of an online community to help understand patient safety issues. The online community had 82,000 members. Members entered demographic information and assessments of their treatment and care. These were then compiled into reports about various treatments.¹⁴⁵

Box 5: Key pros and cons of measuring patient experience using websites

Potential advantages	Potential limitations
Can gain unprompted feedback from a large number of people	Only certain types of people may comment online
May give an indication of what respondents feel most passionate or concerned about if feedback is unprompted	Cannot be sure of the provenance of comments
Can use a range of descriptive, visual and rating techniques	May only cover selected components of patient experience
May be correlated with other measures of patient experience	May give simplistic rating scores without exploring underlying issues
	May be prone to collating more negative feedback

However, there are a number of issues with these types of websites, not least in terms of how patient experience is defined. A review of 21 German- and English-language doctor-rating sites examined the included core domains of patient experience and satisfaction. The rating sites included only a small number of domains compared to structured questionnaires and theoretical frameworks about patient experience. The sites tended to ask patients to comment on professional competence and doctor-patient relationships, but there was less exploration of dimensions such as communication skills and information provision, especially on English-language websites.¹⁴⁶ Thus the content of these types of websites may not well represent the broad concept of patient experience (box 5).

Survey content

Research has investigated various survey content and question types. There are validated surveys about many different topics, from all over the world.

Box 6 signposts examples of studies that have tested surveys about specific topics within the broad field of patient experience. This is interesting for two reasons. First, it points to the wide range of tools already available, perhaps suggesting that local teams could use or adapt existing surveys for their own needs. Second, it illustrates areas where a significant number of tools are available and those where fewer tested surveys exist.

Primary care surveys

In England, an annual General Practice Patient Survey is undertaken to explore people's experience with primary care.¹⁴⁷ Around five million people are sampled each year. Existing information sources like this may be a useful way to track changes over time. Data can be collated at the level of individual practices or at broader local or regional

areas. However, an issue with large national surveys of this nature is that managers and practitioners may not believe that the questions are sufficiently tailored to local needs. For instance, interviews with 37 GPs, practice nurses and practice managers found that, although some reported making changes to their practice as a result of the survey data, many expressed doubts about the credibility of the findings. Key concerns included: thinking that the response rate and representativeness of the sample was inadequate; thinking that the survey provided insufficient detail to facilitate change or failed to address important issues; unease about potential political influences and rationales underpinning use of the tool. The annual General Practice Patient Survey and other similar large-scale surveys have the potential to act as a simple means of capturing and using feedback from patients, but studies such as this suggest a mismatch between the objectivity of the survey and the attitudes and experiences of the professionals receiving the data.¹⁴⁸

Originally the Quality and Outcomes Framework (QOF) awarded general practices points for measuring patient satisfaction with tools such as the Improving Practices Questionnaire (IPQ) or the General Practice Assessment Questionnaire (GPAQ). A review of literature about these tools found only one study purporting to measure the validity and reliability of the IPQ and no studies reporting the reliability and validity of the GPAQ (though three studies assessed an earlier version, the General Practice Assessment Survey (GPAS)). The reviewers concluded that there was no published evidence that the tools used in English general practice have been validated against external criteria.¹⁴⁹

The General Medical Council Patient Questionnaire (PQ) has been used to collect feedback about doctors for use in performance evaluation (both in primary care and

in hospital). A study in 11 UK healthcare organisations compared ratings of the professional performance of 1,065 doctors, using the PQ versus the Colleague Questionnaire (CQ). Both surveys had good reliability and validity, but at least 34 PQs and 15 CQs per doctor were required to achieve acceptable reliability. Patient and colleague ratings were both skewed towards favourable impressions of doctors' performance. The researchers concluded that surveys such as this may be useful for providing formative feedback about a doctor's professional practice within an appraisal process, but should not be used in isolation to monitor changes over time or to inform decisions about a doctor's fitness to practise medicine.¹⁵⁰

Another commonly written about survey is the Patient Satisfaction Questionnaire (PSQ). One study of 1,390 patients from five practices in the North of England, the Midlands and Scotland found that tool to be valid and reliable for measuring satisfaction with primary care.¹⁵¹

A widely used tool in the USA is the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey, which contains patient experience measures. This tool is used to provide ratings and rankings of health services and quite comprehensive reports are then collated to help patients to select between services. A version for primary care and another version for hospital services are also available.¹⁵² While the outputs contain detailed performance information, they have been criticised for unnecessary complexity that may make the information less easy for patients to understand.¹⁵³

However, this tool has been used to good effect to monitor changes in patient experience over time. In one US region, a quality improvement collaborative asked patients recently visiting services to complete a modified CAHPS survey before, after and continuously over a 12-month improvement project. Teams were encouraged to set goals for improvement using baseline data and used an online tool to view the monthly continuous data. There were small improvements in patient experience for some services, though overall results were mixed. Team leaders reported that frequent reports about survey findings were a powerful stimulus to improvement, but more time and support was needed to help professionals change their behaviour.¹⁵⁴

There are many other survey tools for measuring patient experience in primary care, or specific components of patient experience. One review of surveys for assessing patient perceptions of person-centred care in primary care identified 13 instruments. Two instruments were fully dedicated to patient-centred care (Patient Perception of Patient-Centeredness and the Consultation Care Measure) and 11 others included relevant subscales or items.

The reviewers concluded, however, that the measurement tools were limited because they were based on assessing individual visits, rather than studying care processes over time, such as in the case of long-term conditions.¹⁵⁵

Hospital surveys

There are also many surveys about patient experience in hospital. A review of tools used to collect data about patients' perceptions of hospital care identified hundreds of surveys across a wide range of institutional settings and patient groups. Most surveys were **administered by mail** and response rates varied widely, from very low to relatively high. Most studies provided limited information about the reliability and validity of the tools. This highlights that there is no standardised or commonly used instrument, sampling method or administration protocol.¹⁵⁶

In the UK various patient surveys are used to collect feedback about patient experience with hospital care,^{157,158} including inpatient,¹⁵⁹ outpatient,¹⁶⁰ accident and emergency,¹⁶¹ maternity services¹⁶² and ambulance¹⁶³ user surveys. In fact, the NHS led the way internationally in mandating a national patient survey programme in England in 2001. By contrast, the first public reporting of the US equivalent, the Hospital Consumer Assessment of Healthcare Provider and Systems surveys, was in 2008. Most European countries, apart from the Netherlands and Norway, do not have systematic arrangements for measuring and monitoring patient experience at a national level, although some countries have regional or state-level initiatives.¹⁶⁴

The National Adult Inpatient Survey has been reporting in England since 2002, gathering data from over 600,000 patients every year. An analysis of how the survey results have been used over the past decade found stable trends nationally over time. Improvements in patient experience have been found for topics where there have been coordinated government-led campaigns, targets and incentives. This may be an untapped resource for monitoring patient experience because most documents reviewed merely reported the findings of the survey, rather than using it for trend analysis or improvement initiatives.¹⁶⁵

*The national inpatient survey has been a useful resource for many authors and organisations but the full potential inherent in this large, longitudinal publicly available dataset about patients' experiences has not as yet been fully exploited.*¹⁶⁶

Other tools are also available. The Department of Health commissioned and tested a short general-purpose survey, the Outcomes and Experience Questionnaire

(OEQ), which combines feedback about patient outcomes and experiences. The survey invites patients to judge and report the outcomes of services used and has been tested with hospital patients.¹⁶⁷

The Picker Institute has a number of survey tools targeted towards patient experience, for use both within and outside hospitals.^{168,169} One tool that has been tested in the research literature is the Picker Patient Experience Questionnaire (PPE-15). The Picker Institute suggests that organisations follow a validated methodology when using their tools.

In Switzerland, 14,089 adult hospital patients from 24 hospitals provided feedback after discharge using the 'Picker Problem Score' and six domain scores (care, communication, respect, cooperation, organisation and discharge management). Reports of patient experience varied according to self-reported health, age and education. The researchers concluded that it is important to use statistical adjustment for patient mix and additional stratification for some hospital factors when comparing patient experience scores across organisations.¹⁷⁰

A comparison of the 15-item Picker Patient Experience Questionnaire with a 48-item tool developed in Australia, the Patient Evaluation of Emotional Care during Hospitalisation (PEECH) survey, sought to examine the strengths and weaknesses of these different tools in English hospitals. A combined survey was completed by 423 patients using four hospital services (emergency admissions, maternity, medicine for the elderly and haemato-oncology). The study found that having more detailed items such as in the PEECH survey can help to build an understanding of complex interpersonal aspects of quality of care, alongside the more transactional and functional aspects typically captured by the Picker Institute tool.¹⁷¹

Other examples are available from around the world.¹⁷²⁻¹⁷⁵ For example, the National Perception of Quality of Care Survey has been used in Ireland. During development and testing, 1,950 patients from 13 hospitals were surveyed three to six weeks after discharge using structured telephone calls (Computer Aided Telephone Interviews (CATI)). This approach resulted in a response rate of about 60%. Patients' perceptions about admission procedures, pain management, adherence to the patient charter, medication and overall satisfaction were examined. The main areas for improvement focused on information and communication.¹⁷⁶

In Hong Kong, a cross-sectional survey (one point in time) was completed to assess inpatient experience in 25 public hospitals. The survey contained 54 items designed

to measure patient experience of the process of admission to hospital, environment, food and facilities, hospital staff, patient care and treatment, the process of leaving hospital and the overall impression of hospital care. Most of the questions were closed-ended but free-text comments from respondents were also recorded. The survey was administered face-to-face using short interviews. Eight out of 10 patients thought that they received good care, but areas for improvement included waiting time for a ward bed for accident and emergency cases, food quality, infection control, information provision, and patient engagement in decisions about their treatment and care.¹⁷⁷

In Finland, one hospital developed a 12-item questionnaire based on issues that patients had identified as being most in need of improvement regarding outpatient services. The survey used a simple seven-point scale to rate aspects of care from 'extremely poor' to 'excellent'. Every year, patients were invited to complete the survey over a three-week period, with a total of 7,679 people taking part over a three-year period. The survey was useful for systematically collecting patient feedback. It helped the hospital to detect strengths and weaknesses and track changes over time. The poorest ratings related to access to information and adherence to appointment times.¹⁷⁸

A great deal of work has been done in this field in France. As one example, a generic postal questionnaire with 29 items and tested with large samples was found to be valid and reliable. Hospitals randomly sampled patients and sent them a survey within two to four weeks of discharge. Response rates were about 70%. The survey has been designed to allow changes to be tracked over time, following improvement efforts.¹⁷⁹

Other services

Surveys to measure other types of services are also available. As an illustration, a systematic review identified 24 studies of measuring patient satisfaction with **community pharmacy services**. Eleven of these measured patient satisfaction with general services, six measured satisfaction with pharmacy intervention services and seven measured satisfaction with cognitive services. Most studies measured satisfaction as a multidimensional construct, but none tested any theoretical models of satisfaction or used a framework to define patient experience. Most studies used self-developed, non-validated or ad hoc instruments, drawing items from previously published tools.¹⁸⁰

Box 6 on page 23 signposts many other examples of tools developed to assess patient experience with specific services.

Surveys about components of quality

While many surveys focus on assessing patient experience with a particular hospital or service, some tools examine transitions between services or the extent of **continuity of care**. In Canada, a generic measure of management continuity from the patient perspective has been developed. The tool includes questions about the main doctor, multiple clinicians, team relationships, coordination and gaps in information transfer and the patient's partnership in care. The tool has been found to be reliable and valid for assessing both positive and negative dimensions of continuity of care across the wider health system.¹⁸¹

Another group in Canada has developed the Patient Continuity of Care Questionnaire (PCCQ), which has six main topic areas: relationships with professionals in hospital; information transfer to patients; relationships with professionals in the community; management of written forms; management of follow-up; management of communication among providers.¹⁸²

Similarly, in the USA the Patient Perceptions of Integrated Care survey has been developed for use as a measure of the integration of care received by people with long-term conditions. The tool has been found to be valid and reliable as a research tool to compare interventions intended to improve the integration of care and as a quality improvement tool to support the refinement of service delivery.¹⁸³

Another component of experience that people are often surveyed about involves **safety issues**. For instance, in England 80 medical and surgical patients from one hospital were surveyed prior to discharge to assess reports of problems in their care. Patients' medical records were also reviewed. There were an average of three undesirable events reported per person. These included interpersonal problems, medical complications and healthcare process problems. Patients identified 83% of the safety events that were reported in the medical records. Patients also reported events that were not recorded in the medical records. This demonstrates that patient surveys can bring things to the attention of teams that they may otherwise be unaware of.¹⁸⁴

Safety surveys have also been undertaken with **families**. For instance, in Canada all families of children discharged from one hospital over a one-year period were asked to complete a survey about their experience and any safety issues during the hospital stay.¹⁸⁵

Work is underway to increase the robustness of systems to collate and use patient and carer feedback for safety improvement. For example, in the UK a team is developing a patient survey to measure organisational safety.

Researchers have reviewed literature and undertaken focus groups and interviews to develop a survey tool with about 60 items spread across 10 domains.¹⁸⁶

Surveys for specific subgroups

Some survey tools have been developed to capture the experiences of people with specific conditions, such as diabetes or cancer. For instance, a commonly researched survey in the USA is the validated Patient Assessment of Chronic Illness Care (PACIC).¹⁸⁷ This survey measures patient experience with aspects of care associated with the Chronic Care Model on a scale of 1 to 5, with 5 being highest, and has been used to collect feedback from people with many types of **long-term conditions**. The tool has shown that people tend to have more positive experiences of care and better quality of life when they have more direct contact with primary care and integrated systems of care.¹⁸⁸ This may therefore be a useful tool for linking people's experiences of care with wider structural and staffing issues.

In Norway, the Cancer Patient Experiences Questionnaire (CPEQ) has been developed and validated nationally. Like most large-scale surveys, the tool was developed based on a literature review of existing concepts and questionnaires, patient interviews, expert-group consultations, pretesting of questionnaire items and then full survey implementation with 7,212 **cancer patients** attending 54 hospitals. The survey was designed as a self-complete postal questionnaire, with questions about people's experiences of nurse contact, doctor contact, information, organisation, patient safety, contact with next of kin, and outpatient and inpatient experiences.¹⁸⁹

Few validated tools exist to directly gather information about **children's perceptions** of their own healthcare. Surveys of parents tend to be used as proxies. In the USA, the Children's Perceptions of Healthcare Survey has been developed to fill this gap. The tool can be used with inpatients or outpatients and has been found to have good reliability and validity. A study comparing the feedback of parents and their children found that parents tended to report more positive views than their children. This suggests that involving children in care assessment is worthwhile and may capture things that would be missed if only parents were surveyed.¹⁹⁰

Surveys for carers

The experience of carers, such as partners, relatives and friends, is rarely monitored even though their role can be substantial. In order for carers to sustain their support, it may be important to address their needs. Thus, understanding the experience of carers may be important.

In the UK, a survey tool has been developed to assess the carers of men with prostate cancer (the Prostate Care Questionnaire for Carers (PCQ-C)). A test with 514 carers found the survey to be well completed, with good reliability and validity. Follow-up interviews found that the tool was acceptable to carers and feedback from hospital teams suggested that they found the questionnaire useful for highlighting areas for improvement.¹⁹¹

In Wales, the Stroke Carer Experience Questionnaire (SCEQ) was developed to measure the experience of

informal carers of patients with stroke through acute and rehabilitation hospital treatment. Six stroke units in the UK posted the survey to carers. There was a response rate of 49% and the tool appeared valid and reliable. It was more likely to elicit negative feedback than the Carer Hospital Satisfaction Questionnaire (Carer HospSat). The researchers concluded that this is a promising tool for identifying service strengths and unmet needs because it identifies experiences that elude global satisfaction ratings.¹⁹²

Box 6: Examples of surveys measuring patient or carer experience

<p>Primary care</p> <ul style="list-style-type: none"> – Annual General Practice Patient Survey in England¹⁹³ – Consultation Satisfaction Questionnaire (CSQ)¹⁹⁴ – Consumer Assessment of Healthcare Providers and Systems (CAHPS)^{195–197} – Dialogue – consultation satisfaction questionnaire¹⁹⁸ – General Practice Assessment Survey (GPAS / GPAQ)^{199,200} – Improving Practice Questionnaire (IPQ)²⁰¹ – Medical Interview Satisfaction Scale (MISS-21)²⁰² – Patient–Doctor Interaction Scale (PDIS)²⁰³ – Patient Feedback on Consultation Skills (PFC)^{204,205} – Patient Satisfaction Questionnaire (PSQ)²⁰⁶ – Picker Patient Experience Questionnaire (PEQ)²⁰⁷ – Other primary and community care surveys^{208–233} <p>Hospital care</p> <ul style="list-style-type: none"> – American Board of Internal Medicine (ABIM-10)²³⁴ – Consumer Assessment of Healthcare Providers and Systems Hospital Survey (CAHPS Hospital)^{235,236} – Hong Kong Inpatient Experience Questionnaire²³⁷ – Irish National Perception of Quality of Care Survey²³⁸ – Newcastle Satisfaction with Nursing Scale^{239,240} – NHS National Adult Inpatient Survey^{241,242} – Patient Evaluation of Emotional Care during Hospitalisation (PEECH)²⁴³ – Picker Patient Experience Questionnaire (PPE-15)^{244,245} – Quality of Discharge Teaching Scale (QDTS)²⁴⁶ – Questionnaire for satisfaction of hospitalised (QSH) patients²⁴⁷ – Other hospital surveys^{248–276} 	<p>Broad communication and continuity surveys</p> <ul style="list-style-type: none"> – Communication Assessment Tool (CAT)^{277,278} – Consultation Satisfaction Questionnaire²⁷⁹ – Doctors’ Interpersonal Skills Questionnaire (DISQ)^{280–282} – Partners for Change Outcome Management System (PCOMS)²⁸³ – Patient Perception of Patient-Centredness (PPPC)^{284,285} – UK General Medical Council Patient Questionnaire²⁸⁶ – Other broad experience and ‘consumer quality’ measures^{287–291} – Other surveys about continuity of care^{292–296} <p>Specific services</p> <ul style="list-style-type: none"> – Anticoagulant services,²⁹⁷ chiropractic care,²⁹⁸ dentistry,^{299–301} genetic counselling,³⁰² long-term care,³⁰³ mental health,^{304–306} nursing,^{307–310} occupational health,^{311,312} out of hours,^{313,314} outpatient services,³¹⁵ pain management,^{316,317} pharmacy,^{318–327} physical therapy,^{328–335} prison health services,³³⁶ radiotherapy,³³⁷ rheumatology,³³⁸ screening and tests,^{339–342} sexual health,^{343–345} substance abuse services,³⁴⁶ surgery,^{347–359} telecare,^{360,361} transgender services,³⁶² women’s services and maternity.^{363–365} <p>Specific conditions</p> <ul style="list-style-type: none"> – Arthritis,^{366,367} cancer,^{368–380} diabetes,^{381–385} end-of-life/palliative care,^{386–388} gastro-oesophageal reflux disease,³⁸⁹ glaucoma,^{390,391} inflammatory bowel disease,³⁹² migraine,³⁹³ Parkinson’s disease,³⁹⁴ Patient Assessment of Chronic Illness Care (PACIC),^{395,396} sickle cell disease,³⁹⁷ stroke³⁹⁸ <p>Carers</p> <ul style="list-style-type: none"> – Carer Experience Scale³⁹⁹ – Carer Hospital Satisfaction Questionnaire (Carer HospSat)⁴⁰⁰ – Stroke Carer Experience Questionnaire (SCEQ)⁴⁰¹ – Other surveys for carers of people with cancer⁴⁰² or in the neonatal unit⁴⁰³
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Note: The examples above are not exhaustive. They merely provide illustrations of the wide range of surveys available that have been tested in published research. Some of the references are prior to 2000 in recognition that the survey tool may have been developed earlier, even though it also featured in studies published more recently.

Question types

Another area of research regarding survey content is whether patients prefer **open- or closed-ended questions**. Open-ended questions are where people are free to provide responses using their own words and format. Closed-ended questions include multiple-choice responses, Likert scales, visual analogue scales and other questions where there is a fixed set of answers to choose from.^{404–406} Some closed-ended questions are designed to create a 'scale' that can be added up to create a total score. Others use labels such as 'agree' or 'disagree' and count the proportion of responses that fall into each category. Still others are very complex and require special computer packages for analysis.

In England, there is a formal PROMs survey programme for cancer care. Researchers tested the benefit of adding one open-ended free-text question to the end of the structured survey. In total, 3,300 cancer survivors were surveyed and one-third of these chose to complete the open-ended question (32%). This suggests a significant desire to provide written feedback about patient experience. The researchers found that these open-ended comments helped to illuminate relationships between factors that impact on people's experiences of care and their clinical outcomes and quality of life. They concluded that it was important to include space for qualitative feedback alongside quantitative questions in surveys about patient experience.⁴⁰⁷

An analysis of four years' worth of patient satisfaction surveys in eight public hospitals in Denmark examined the usefulness of adding open-ended questions. Data from 75,769 patients were available and feedback about the data was gathered using surveys and interviews with health professionals and hospital managers.

Three-quarters of patients chose to add one or more open-ended comment to their questionnaires. The most and the least satisfied patients were most likely to comment. Eight out of 10 department management teams said that they found the open-ended feedback useful (81%).

The wording of the open-ended questions, the number of questions asked and having an appeal in the covering letter all appear important in encouraging people to comment.⁴⁰⁸

Research suggests that question format can significantly impact on the answers received. Responses to closed-ended questions are usually positive, while responses to open-ended questions are more likely to be negative. This is sometimes known as the 'leniency effect'. A study with 560 primary care patients in Poland compared people's answers to a five-point scale and an open-ended question on the same postal survey. They found that even

when patients gave high ratings using the closed-ended question, they were more likely to provide negative feedback in the free-text box. The researchers concluded:

*Questionnaires are not sufficiently precise tools in a complex evaluation of doctors' care by their patients. In practice this may mean that questionnaire surveys, which are often used because of the ease of administration, may require to be complemented or replaced by other more qualitative research tools, such as in-depth interviews and open questions.*⁴⁰⁹

Survey timeframe

The best time at which to conduct surveys of patient experience has not been well researched. Most studies provide surveys immediately or shortly after service use (within one to three weeks), but we identified no studies formally comparing different timing schedules. For some services it may be best to assess experience some time later, especially where satisfaction measures are combined with feedback about physical outcomes or quality of life. One example is the case of surgery patients, whose experiences may differ depending how promptly after surgery they are surveyed.⁴¹⁰ The best timing of survey administration also depends on the scope of services to be examined (eg hospital services alone or including transitional and aftercare) and on the extent to which completing surveys may be emotionally or physically burdensome for patients.⁴¹¹

Researchers from England asked people with cancer and clinicians about the best time to approach patients about taking part in **longitudinal surveys** (repeated over time). Patients said that they did not want to be approached about taking part early on in the care pathway, near to the time of diagnosis and treatment planning or before any surgery and its results. They thought that it would be more appropriate to approach people to take part in improvement studies when patients were more 'settled' on (post-surgical) treatment regimens, provided that they were coping well physically and emotionally. Clinicians also advised against approaching people for feedback around the time of diagnosis, but wanted to initiate recruitment to surveys or patient panels much sooner than the patients did.⁴¹²

Some attempts have been made to move away from surveys conducted at one point in time, towards more regular feedback as part of ongoing improvement processes.^{413–417} For instance, in Switzerland a survey has been developed to help collect feedback routinely from hospital patients, particularly about negative experiences of care. During trialling, patients were surveyed and then a sample of those who experienced negative

incidents were interviewed to gain further detail.⁴¹⁸ It is now hoped that the survey will be incorporated into routine data collection after hospital discharge.⁴¹⁹

In Australia, the Patient Participation Program (PPP) was a patient satisfaction survey endorsed by the Royal Australian College of General Practitioners to support continuous quality improvement. Between 1994 and 2003 the survey was completed by more than one million patients from 3,500 practices. It was possible to analyse trends over the decade, however the very high level of satisfaction with GP services made it difficult to demonstrate change. High initial satisfaction levels

and the way in which the results were presented made it difficult for GPs to use the survey to improve their practices. It was concluded that a more useful survey could be designed to detect negative patient experiences and provide integrated feedback to GPs.⁴²⁰

It is much less common for the same patients to be surveyed at several time points to track changes in individual responses. This could work well for people with long-term conditions who may have ongoing contact with health services, but would be less relevant for those undergoing one-off or emergency care.

Box 7 provides a summary of the key pros and cons.

Box 7: Key pros and cons of measuring patient experience using surveys

Potential advantages	Potential limitations
Can use visual tools and scales	May not be able to delve in-depth/tends to give surface level picture
Can easily include numerical questions/scales	May not cover sensitive issues well
There are many existing validated tools that can be used as is or adapted for the local context, perhaps using a modular system of core questions plus optional local additions ^{421,422}	People may have 'survey overload' since the method is used very commonly
Allows for standardisation (and thus comparability) of the questions, process and analysis method ⁴²³	There may be non-response and selection bias ⁴²⁴
Can be anonymous	Can exclude those who do not have good literacy and more deprived or unwell groups ⁴²⁵⁻⁴²⁷
People may feel more comfortable when they do not need to speak directly to a health professional about their experience. Patients may not want to appear to be challenging professionals or to be seen as difficult	May be more likely to gain negative comments from some groups
Can be quick to implement	May be difficult to explore the reasons for any differences between groups, such as the experience of patients from minority ethnic groups ⁴²⁸
May be easy to analyse, especially if predominantly closed-ended questions are used	Most validated tools focus on patient experience, rather than gaining feedback from carers
Can reach large numbers of people	Some surveys may focus on satisfaction and positive outcomes, whereas a metric for patient 'dissatisfaction' may be more useful ⁴²⁹
Can be undertaken relatively inexpensively	Results from patient experience surveys do not necessarily match with other data sources about service quality and safety, so the data cannot be used alone as a quality indicator ⁴³⁰
Possible to administer in a variety of ways for example online, using kiosks, handing out hard copies or by post	Surveys developed for one context may be inappropriately applied to others ⁴³¹
Can easily combine and correlate questions about experience/satisfaction with questions about clinical outcomes ⁴³²	Clinicians sometimes report that survey findings are difficult to interpret ⁴³³
	It may be essential to consider patient-mix and organisational issues when interpreting the results, particularly when making comparisons between organisations or over time ⁴³⁴⁻⁴³⁸

5. Summary

Knowing what patients and carers think of the care that they receive can be an important component of improving services. There are many approaches for measuring patient experience, each with pros and cons.

Approaches

The past decade has brought an increasing focus on understanding how people experience health services. People are perhaps more likely to expect to be involved in their care and want to be sure that the services they receive are of the highest quality and safety.⁴³⁹ There has been a corresponding drive to understand the best way to measure people's expectations, experiences and satisfaction with healthcare. Developing a comprehensive strategy for measuring patient experience requires decisions about what should be measured and how.⁴⁴⁰ A number of approaches and specific tools have been used to measure patient and carer experience, but there is no 'best' or most effective strategy – all have pros and cons (see box 8). The tools and techniques used need to be adapted for the context, patients and staff with which they are used.

There are some important gaps in the evidence base. There is little **comparative evidence** available to suggest whether some of these strategies are more effective for measuring experience or indeed for monitoring changes over time.

Individual initiatives have had some success – for example, specific surveys have been validated in many contexts. However, the extent to which this ultimately results in **improved patient and carer experience** has not been well quantified. Merely measuring patient and carer experience does not necessarily lead to improvements in staff behaviour or service delivery.⁴⁴¹ Thus measurement should not be seen as an end in itself, but rather one tool to help assess reported experience at a certain point in time and to track changes over time.

Another major gap in the evidence is how to measure **carer experience** and whether the same tools as used for patients are equally acceptable for assessing carers' views. Almost all of the empirical research about measurement techniques focuses on patient experience rather than carers. As family members and friends often spend a lot of time with people who are unwell, understanding their experiences may be an untapped resource for ongoing improvement.

Box 8: Potential pros and cons if measuring changes in patient experience over time

Approach	Main advantages	Main limitations
In-depth interviews	<p>In-depth information</p> <p>Can probe reasons</p> <p>Can handle sensitive topics</p>	<p>Resource intensive</p> <p>May have difficulty interviewing same people over time</p> <p>Generalisability issues with small samples</p>
Focus groups and panels	<p>In-depth information</p> <p>Can reconvene same group over time</p> <p>Group dynamic can spark ideas</p>	<p>Generalisability issues/selection bias</p> <p>Resource intensive</p> <p>May experience high rates of drop out over time</p>
Narrative stories	<p>In-depth information</p> <p>Puts 'human face' on issues</p> <p>Focuses on what is most important to patients and carers</p>	<p>Generalisability issues</p> <p>Can be difficult to draw out key themes</p> <p>Difficult to track changes in the same group of people over time</p>
Complaints and compliments	<p>Can signal areas in need of improvement</p> <p>Can identify things that people feel particularly passionate about</p>	<p>Biased towards the most serious (or most positive) aspects of care</p> <p>May not have large numbers to work from</p> <p>May focus upon individualised issues</p>
Photovoice	<p>Gains unprompted feedback about issues that matter most to participants</p> <p>Helps to engage disadvantaged and hard to reach groups</p> <p>Visual medium so may be more engaging</p>	<p>Participants need to be trained in the approach and in writing captions</p> <p>Requires technology (cameras)</p> <p>May be difficult to draw out trends because the 'output' is in a novel format</p>
Surveys	<p>Can gain large amount of feedback</p> <p>Can use multiple administration methods (post, kiosks, online, text messages, comment cards, telephone, in-person)</p> <p>Wide range of validated surveys available</p>	<p>May collect only a surface level picture, rather than understanding why people feel a certain way</p> <p>Subject to self-selection and literacy bias</p> <p>Closed-ended questions may be more likely to gain positive feedback</p>
Online rating tools	<p>Increasingly promoted and available to many people, so can get ratings from large numbers</p>	<p>Only those who use websites provide feedback</p> <p>Surface-level information only</p> <p>Only cover selected components of patient experience</p>

Ten things to consider

The evidence base cannot prescribe the best approaches for measuring patient experience, but it does highlight some key learning points to consider when planning how to monitor changes over time. According to the research evidence, the top 10 things to consider when selecting how to measure patient experience are as follows.

1. Consider exactly how patient experience is being defined as this will impact on how it is measured.
2. Think about why patient experience is being measured and the uses to which the information will be put.
3. Consider whether it will be useful to combine approaches so both qualitative and more quantitative material is collected.
4. Consider whether to ask everyone using services or only a sample to provide feedback. The approach should be guided by what the data collection aims to achieve.
5. Think about when people may provide the most useful feedback. The best time to collect feedback may be immediately after using services, when experiences are fresh in people's minds, but this does not allow time for reflection.
6. Allocate enough time at the outset to plan and test measurement methods, particularly if these will be used for many years to monitor change over time.
7. Think about the way the end-result needs to be presented for various audiences as this may shape how the information is collected. Outputs may include detailed reports, simple indicator scorecards, in-depth quotes, statistics and averages and graphs.
8. Make sure that there is appropriate infrastructure at an organisational level to analyse and use the information. There may be little point in measuring patient experience if the information will not be used robustly.
9. Make sure that patients, carers, managers and health professionals are comfortable with why feedback is being collected and how it will be used. Patients and carers are more likely to provide useful feedback if this is encouraged by staff.
10. Patient experience is only one indicator of the quality of healthcare. It is important that patient experience measures are seen as one component of a broader framework of measurement and that all of the approaches work well together, without excessive burden for either staff or patients.

1. What needs to be measured?

The topic of patient experience is complex, especially when being used to measure improvement over time. People can report high levels of satisfaction, for example, at the same time as describing experiences that are less than optimal.⁴⁴² When selecting measurement approaches, it is therefore important to define carefully what needs to be measured and to recognise different aspects of experience, expectations and satisfaction.^{443–445}

The concept of patient experience has many domains. A systematic review of instruments for measuring patient experience identified 13 core components being measured:⁴⁴⁶

Characteristics of interactions

- Patient–professional relationship
- Professional care
- Information and advice
- Communication skills
- Trust

Organisational aspects

- Accessibility/availability
- Medical and technical facilities
- Office characteristics
- Office organisation/waiting time
- Office staff

Overarching assessments

- Success of outcome
- General satisfaction
- Willingness to recommend service

It may be useful to consider which of these domains (or others) are the highest priority for measurement locally.⁴⁴⁷ Being clear about what needs to be measured will help to select appropriate approaches and tools. Using a theoretical framework can help guide measurement approaches.⁴⁴⁸

The differences between the types of measure and reasons for collecting data on them are not semantic, they are real and important. For instance, measures of satisfaction have a common-sense and political appeal, but they are the measures that experts, including experts in quality improvement, consider the least useful on their own for improving patient experiences locally.⁴⁴⁹

Patient experience can be considered in terms of:

- the determinants of experience
- the components of experience and/or
- the outcomes of experience.

Bearing this in mind, it may be worthwhile asking people the reasons behind their levels of experience/satisfaction and what they want to see improved rather than solely focusing on what they have experienced.⁴⁵⁰

*The traditionally used instruments also have limitations based on the relevance of the questionnaire items, sensitivity to change in longitudinal observational studies, and intraindividual variations over time. Patient priorities or preferences for improvement in health may be an alternative for the assessment of important patient outcomes.*⁴⁵¹

Finding out what patients and carers perceive to be important in terms of outcome may be a useful part of this process, otherwise there is a danger that measurement approaches may only incorporate the perspectives of clinicians and researchers, rather than the types of experience that patients prioritise.^{452,453}

Measurement approaches will provide information only about what patients and carers are asked, therefore when developing questions or topics to cover, care must be taken to reflect all aspects that patients consider to be important. Involving patients and carers in developing the strategies to measure patient experience may help to ensure that they are meaningful.

*[We] should embrace more collaborative forms of patient and public involvement with patients as research partners in the research process, not just as those individuals who are consulted or as subjects, from whom data are sourced, to ensure the acceptability, relevance, and quality of research.*⁴⁵⁴

To date, patient involvement in developing ways to measure patient experience has been cursory at best, so this is a potential area of innovation.⁴⁵⁵

2. Why does it need to be measured?

Similarly, it is important to think about why patient experience is being measured and to choose a method that meets those specific needs.⁴⁵⁶ For instance, one method may be useful if the goal is to collect detailed feedback to identify gaps in services, whereas other methods may be more appropriate if the goal is to monitor broad changes in satisfaction over time or to collect specific details about safety issues.

*The identification of methods for assessing the views of patients on healthcare has only developed over the last decade or so. The use of patients' views to improve healthcare delivery requires valid and reliable measurement methods. Four approaches are recognised: inclusion of patients' views in the information to those seeking health care, identification of patient preferences in episodes of care, patient feedback on delivery of health care, and patients' views in decision making on healthcare systems. Outcome measures for the evaluation of the use of patients' views should reflect the aims in terms of processes or outcomes of care.*⁴⁵⁷

Often, teams may select a survey approach due to ease or familiarity without considering whether this is really the best way to collect the type of information needed. Thinking back to the original goals of data collection may help to decide on more effective methods.

If it is important to track changes over time, as in the case of monitoring the outcomes of improvement initiatives, then there are some further factors to consider. The methods and samples used must be comparable over time. This may mean that if methods such as discussion groups or interviews are used, some thought is given to whether the same people will be able to be followed up over several periods, or whether it will be possible to match the characteristics of participants according to age, gender, ethnicity and other patient-mix characteristics.

3. Can approaches be combined?

It is unlikely that just one approach to measuring patient experience will provide the balance of detail and specificity that many improvement initiatives require. Combining different methods may be a good way forward.⁴⁵⁸ For instance, a short survey may help to gain feedback about general trends that can be quantified and tracked over time, supplemented with a small number of in-depth interviews or a patient panel to gain a more detailed understanding of why people feel a certain way.

As outlined in previous sections, there are a wide variety of existing survey tools available for use. Some suggest that it is important to use well-known validated tools for measurement, whereas others argue that it is important to tailor tools to the local context.⁴⁵⁹ A good compromise may be to use some existing validated tools and to supplement these with bespoke methods tailored to local concerns. An example would be to use a national survey dataset or a tool from the Picker Institute, combined with a patient panel or a small number of interviews asking about localised issues.

However, the importance and usefulness of patient experience measures also need to be considered, because combining data from multiple approaches will add to the time and cost involved. The advantage of a triangulative approach seems to be that it provides a fairly accurate description of patient satisfaction. However, the problem of this method is that it doubles the amount of work needed and is slow to use which is worth considering as patient satisfaction should be followed on a regular basis and the results reported without delay.⁴⁶⁰

4. Who should be asked for feedback?

Other points to consider include the most appropriate people to ask for feedback – and when people are asked.⁴⁶¹ The answers to these issues will depend on why patient or carer experience is being measured in the first place.

In some cases, it may be useful to invite everyone who uses a service to share their views, perhaps over a set period of time, such as a one-week or one-month period. In other instances, it may be more worthwhile to select a sample of patients, especially when the number of potential respondents is large. However, in this case, it is important to make sure that the sample does not systematically exclude some types of people, such as those who are particularly young or elderly or those from certain ethnic groups.

It may be difficult and perhaps unethical to ask people who are very unwell to provide immediate feedback about their experiences. On the other hand, gaining feedback only from those who are reasonably healthy may not provide a comprehensive picture. It is always important to weigh up the benefits of the data collection with the imposition or burden placed on those being asked to provide feedback.

Measurement approaches must also take care not to exclude some subgroups, such as those who do not read or speak English well. Using simple wording and visuals in short surveys can help to overcome these issues.⁴⁶² However, no matter how carefully surveys are designed, some data collection methods will be more likely to exclude certain groups. For example, the very elderly or housebound may find it difficult to get to a letterbox to post back a questionnaire. Questionnaires, whether handed out or posted, are also not feasible for collecting the views of those who do not read or write well. Having someone sit and ask people questions can be a good compromise, but this requires additional resources.

While carers contribute significantly to informal care and support, little research has investigated how best to ascertain their views or, importantly, what can be achieved by measuring carer experience. Unless there is a specific reason to speak to carers, such as establishing their needs for ongoing support, the value of this type of information is not clear from the published research.

5. When should feedback be gathered?

Appropriately timing data collection is important.⁴⁶³ Asking patients questions when they are in the middle of receiving care has the benefit of gaining real-time insight, but may mean that people are too unwell, stressed or distracted to provide detailed opinions. On the other hand, asking for feedback too long after a care episode means that people may not remember pertinent points. In other words, during appointments patients may feel anxious but gaining feedback one to two weeks after appointments may mean important things are forgotten. Whether immediate feedback or more considered responses are needed will guide the data collection timeframe.

In published research, the two most common approaches are to hand out a survey immediately after services have been used or to conduct interviews, surveys or discussion groups shortly after service use (such as within one to two weeks). However, just because these are the most common timings does not mean that they are the most effective. We identified little research comparing the benefits of different timeframes for eliciting feedback about patient or carer experience.

6. Is there enough time to test?

Another learning point is the need to allow plenty of time at the outset to plan and test data collection methods. This is particularly important where changes will be monitored over time. The act of collecting information may itself impact on patient feedback, so spending time testing the tools and analysis approaches to be used may be a worthwhile investment.⁴⁶⁴

Having consistent tools is essential when seeking to measure change. Teams should spend time thinking through all of the possible things that information could be collected about at the beginning, rather than being tempted to add additional topics or questions at subsequent measurement points.

The tools used must not only be acceptable to patients and carers, but also to frontline staff who will need to promote them. It can be helpful to spend time testing the protocol and tools with clinicians and administrative staff so everyone is clear about their purpose and

comfortable with their use. Testing can establish how long tools take to use and whether they fit into routine practice. It can also illustrate the potential benefits to staff, to generate greater buy-in.

Testing is important both when using 'tried and tested' approaches and when developing bespoke tools. If new tools are being used, teams will want to ensure that the information collected meets their needs and that the questions are easily understood and not burdensome. If implementing validated tools, such as pre-existing surveys, testing remains important to account for cultural and linguistic issues. For instance, surveys developed in the USA may contain words such as cookies (instead of biscuits), chips (rather than crisps), gas (rather than petrol), chores and yard work (rather than housework) and so on.

7. Will the outputs be practical?

The methods used to collect information about patient experience will influence the type of outputs that can be created from the results. It may be useful to consider whether the target audience requires detailed quotes, simple statistics or graphical representations of findings. If simple statistics or graphs are needed for online displays, for example, then conducting one or two in-depth interviews will not provide information that can be displayed in this format.

Some studies suggest that health professionals find quick summaries of patient experience data useful, especially when this is broken down to the level of individual services or wards/departments.⁴⁶⁵

Researchers in Denmark investigated whether collecting patient experience information was seen as useful by hospital management. They found that approaches such as patient surveys were widely accepted as a tool for change. Negative results may be an incentive for improvement, but acceptance of surveys as a way to generate change diminished over time, as managers got more used to seeing survey findings. The researchers concluded that approaches for measuring patient experience may only be an incentive for change if: (1) the techniques are seen to have sufficient validity; (2) feedback is detailed on an organisational level and broken down by department so it is easy to identify poorer performing services; and (3) there are obvious actions to address the problems.⁴⁶⁶ Having some variety in the way that results are presented may also help to keep interest high.

This is supported by research about the national patient surveys used in the UK. Interviews with staff responsible for implementing these patient experience surveys in 24 hospitals in England found that staff perceptions of the

surveys were mainly positive. Staff welcomed the regular repetition of surveys and thought the questionnaires and reporting of results, particularly inter-organisational benchmarking charts, were of a good standard. Staff reported that the survey results were widely used in action planning. However, there was variation in the extent to which hospitals disseminated survey findings to patients, the public, staff and board members. The most commonly reported barrier to using results was difficulty engaging clinicians because the survey findings were not sufficiently specific to specialties, departments or wards. A lack of statistical interpretation and analysis skills was also a barrier.⁴⁶⁷

One way of presenting information about patient experience is to create hierarchies – with summary indicators for use by higher-level management and more detailed indicators and information available for use at the frontline level of service delivery.⁴⁶⁸ When planning measurement approaches, it may be useful to think through the extent to which the proposed methods will allow tailoring for different audiences.

8. Is there appropriate infrastructure?

Using patient experience information requires organisations to have the capacity to collate and analyse data and have good systems for managing and tracking the data collected.⁴⁶⁹

Reviewers from England examined factors that could affect patient participation in quality and safety initiatives and these issues may apply equally to engaging people in sharing their experiences. Five categories of factors could affect patient involvement: patient factors, illness (eg severity), health professional factors (eg professionals' knowledge and beliefs), healthcare setting (eg primary or secondary care) and task-related issues.⁴⁷⁰ Other research into the broader area of patient involvement suggests that in order to engage people effectively there is a need for strong leadership, changing patient and professional roles, motivated and informed patients and professionals and appropriate infrastructure.^{471–482} Thus, measuring patient experience is not solely about which questionnaire to use or what questions to ask, but also the **culture and infrastructure** of the health services and the motivation, attitudes and involvement of patients and professionals.

Research reinforces the importance of setting up easy-to-use analysis tools and upskilling managers and practitioners in how to interpret and use patient experience data.⁴⁸³ The measurement of patient experience may work best if it is viewed as a routine part of clinical practice, with every person being invited to provide comments, for example.⁴⁸⁴

Part of the required infrastructure involves having a consistent approach to collecting feedback.⁴⁸⁵ This may include setting up a protocol to ensure that patients and carers are asked for feedback at a set time (eg when leaving an appointment), having clear guidance for staff and patients about the information required and having an established and consistent process for analysing information and circulating the results regularly.

9. Are health staff on board?

An important learning point is that measuring patient and carer experience is not solely about patients themselves, but also depends on the attitudes and behaviours of health professionals and managers, and the extent to which the organisational climate and infrastructure is supportive.^{486–488}

Patients, carers, managers and health professionals need to be comfortable with why feedback is being collected and how it will be used. People are more likely to provide useful feedback if the purpose for this has been adequately communicated to them.

Even when health professionals express positive opinions about using patient feedback, this does not necessarily translate into changing practice. A randomised trial of giving GPs feedback from patient surveys in the Netherlands found:

*Compared to the control group, the practitioners in the intervention group had less favourable views of the relevance of patient feedback for their practice after the receipt of such feedback. Furthermore, these practitioners felt that a patient survey required considerable time and energy and saw little reason for change. Although patient feedback can help identify areas for improvement, specific barriers must be addressed before such feedback can be put to more widespread use.*⁴⁸⁹

Patients and carers may be wary about providing feedback, so educating health professionals to be encouraging may be essential. Studies have found that patients are more likely to be involved when they are invited or encouraged by professionals and when their concerns are then taken seriously and acted upon.⁴⁹⁰ Professionals need to be convinced that the advantages of seeking feedback from patients outweigh any perceived disadvantages such as ‘wasted time’. This includes advantages for patients, for professionals and for wider systems.⁴⁹¹

Generating positive views among staff may be an area in need of improvement. A survey of representatives from 159 different organisations from the higher education

and healthcare sectors in England said that training health professionals about relationships was important but there was little focus on how to measure and improve patient and carer experience.⁴⁹² Furthermore, of the 148,657 staff who responded to the NHS Staff Survey in 2010, 41% said that they had not received patient experience training and 22% said it was not applicable to them. The researchers concluded:

*While some relevant education courses are in place in England, the results suggest that specific training with regard to the physical needs and comfort of patients, and how patient experiences can be measured and used to improve services, should be introduced.*⁴⁹³

Some suggest that managers and health professionals may encourage and respond more appropriately to patient experience feedback when they know these data will be reported publicly.^{494,495}

10. Is there a balanced scorecard?

It is useful to collect information about patient experience, because measures of processes, clinical outcomes or cost only provide part of the story.

*Patient reported experience measures (PREMS) are used to understand patients’ views on their experience while receiving care, rather than the outcome of that care. Using information on both patient experience and outcomes enables us to have a broader understanding of service quality from patients’ viewpoint. It may be possible to have a service which provides good outcomes but a poor experience, or a good experience but poor outcomes.*⁴⁹⁶

However, the effectiveness of patient experience as a performance measure is not well researched. A systematic review of the impact of providing health professionals with feedback about patient-reported outcome measures, including satisfaction, found little evidence that seeing patient feedback influenced professional- or patient-level outcomes. The studies that did suggest a positive trend tended to use patient-reported feedback as a management tool in an outpatient setting on a specialised patient population.⁴⁹⁷

Thus, measuring patient experience is only one component of understanding changes in the quality of health services over time.^{498,499} Any approaches selected for measuring patient experience must also fit in with other methods being used to assess quality more broadly.⁵⁰⁰ Organisations need a mixture of measures that give them immediate and recent data that are

sufficiently detailed and meaningful to influence staff, managers and executives. A balanced scorecard with a mixture of measures about processes, clinical outcomes, patient experience and resource use may be worthwhile (figure 2). Care needs to be taken to consider the five domains of the NHS Outcomes Framework.

Figure 2: Balanced scorecard approach

Patient and carer experience measures	Clinical outcomes
Process measures	Resource use measures

In fact, some have argued that people’s satisfaction with the healthcare system depends more on factors external to health services than on the experience of care as a patient. Broader social factors, patient expectations and health status have all been found to impact on patient experience feedback, so it is important to account for this within measurement systems.⁵⁰¹

The World Health Organization’s Performance Evaluation Systems are a multidimensional approach to quality measurement with several categories, each with different indicators.⁵⁰² Patient satisfaction/experience is included among non-clinical indicators of performance. The indicators of patient experience include overall perceived quality, accessibility, humanisation and patient involvement, communication and trust in healthcare providers. This is merely one example of a measurement framework that includes multiple measures of patient experience alongside many other clinical and non-clinical indicators of quality.

To conclude, this evidence scan suggests that there are many different approaches for measuring patient experience, and a single approach is not likely to meet all needs and contexts. Combining approaches is likely to be most effective for measuring changes in patient experience over time within improvement initiatives.

A large number of survey tools have been validated for use in primary and secondary care and with people with specific conditions, therefore local practitioners need not start from scratch when selecting measurement tools. While it may not be appropriate to apply tools to local contexts without adaptation, there is no need to develop completely bespoke materials.

There is a wealth of evidence available about measuring patient experience. For example, the NHS Institute’s Transforming Patient Experience toolkit contains background information about measuring experience to improve services, feedback methods and examples of reporting systems.⁵⁰³ The NHS Operating Framework states that local organisations must supplement national patient surveys with local surveys and ‘real-time’ feedback techniques to fully understand the experiences of their patients, and publish and act upon the results. There are therefore many activities underway that local teams could draw upon. The challenge for planners and practitioners is to build on this knowledge rather than attempting to ‘reinvent the wheel.’ Put another way, the central challenge facing teams wanting to measure patient experience may involve a cultural shift from concentrating predominantly on gathering feedback towards using it effectively.

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