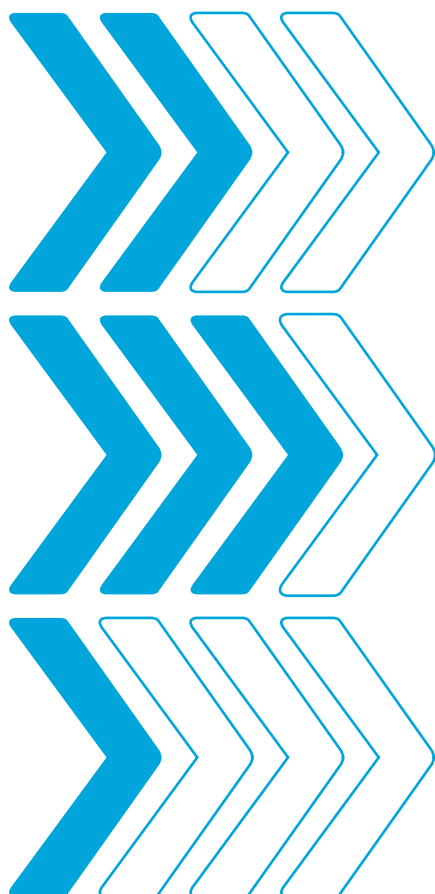Authors
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The Point of Care
Measures of patients' experience in hospital: purpose, methods and uses

Key points

- The King's Fund Point of Care programme aims to transform the quality of patients' experience in acute hospitals. This is against the background of the Department of Health's current range of policies designed to improve patients' experience of health care in England.

- Such an ambitious transformation requires the involvement of all frontline staff and will need first class leadership.

- Key to the strategy is robust evidence on the quality of patients' experience, and that of their families. While there is a range of indicators derived from various sources, direct feedback from patients is likely to remain the core method for measuring patients' experience.

- NHS trusts and commissioning bodies will need more detailed and more frequent forms of feedback if they are to meet the new requirements.

- Ensuring that you are measuring the things that matter most to patients is an essential component of a successful strategy for improving patients' experience. It is important to choose methods that are fit for purpose. This paper provides a brief guide to these to help trust boards and other interested parties decide which measurement and feedback tools are appropriate for their requirements.

- It is important to understand the difference between patient experience and patients' satisfaction, and to be clear about the distinction between patients' **experience of the care process** and **patient-reported outcome measures** (PROMs).

- Technologies and methodologies will be marketed vigorously over the coming months, and boards and senior managers need to be aware of the merits and drawbacks of the various alternatives.

- The starting point for measuring patients' experiences should be an agreed set of standards together with a set of measurable indicators. At the heart of this are patient-centred care and patients' priorities.

Introduction

The Point of Care programme aims to transform the quality of patients' experience in acute hospitals. Achieving this ambitious goal will depend on the active engagement of all staff who have direct contact with patients. They in turn will require strong support from their managers, trust boards and commissioners. All these interested parties need robust evidence on the quality of patients' experience, and that of their families. It is now widely recognised that the best source of this information is patients and families themselves.

Boards and executive teams will have to provide the leadership, drive and persistence to ensure that the necessary transformation takes place. They must make it clear to all employees that improving patients' experience is a priority and that feedback from patients is a crucial source of information about service quality. It must be carefully collected, the results must be taken seriously, and action taken whenever necessary. Similarly, criticisms and complaints from individual patients and their relatives must always receive due attention and a sympathetic response, no matter how justified or unjustified they are felt to be.

This paper provides a brief guide to the various methods for measuring patients' experience to help trust boards and other interested parties decide which measurement and feedback tools are appropriate for their requirements.

Policy context

The King's Fund project is being launched at a time when the Department of Health has announced various policy initiatives designed to strengthen the focus on improving patients' experience of health care in England.

In his introduction to the Next Stage Review, Lord Darzi said: 'High quality care should be as safe and effective as possible, with patients treated with compassion, dignity and respect. As well as clinical quality and safety, quality means care that is personal to each individual' (Department of Health 2008b).

The review defined quality as consisting of the following components:

- patient safety
- clinical effectiveness
- patients' experience.

The Department of Health has promised to strengthen and maintain the focus on quality by:

- establishing a National Quality Board
- requiring trusts to measure quality, including 'real-time' feedback to monitor patients' experience
- including data from patients' experience surveys in the 'vital signs' that comprise the NHS Operating Framework and National Indicator Set for national and local use
- publishing the results of national patient surveys on the NHS Choices website
- providing guidance on gathering and using regular patient feedback
- introducing routine application of patient-reported outcome measures (PROMs)
- establishing quality observatories in every NHS region
- publishing quality indicators (metrics) in the form of quality accounts
- rewarding high quality performance through Commissioning for Quality and Innovation (CQUIN).

In addition, the newly published NHS constitution includes several important commitments that have a bearing on patients' experience of hospital care. For example:

■ You have the right to be treated with a professional standard of care, by appropriately qualified and experienced staff, in a properly approved or registered organisation that meets required levels of safety and quality.

■ You have the right to expect NHS organisations to monitor, and make efforts to improve, the quality of health care they commission or provide.

■ You have the right to make choices about your NHS care and to information to support these choices.

■ The NHS commits to continuous improvement in the quality of services you receive, identifying and sharing best practice in quality of care and treatments.

Primary care trusts and strategic health authorities are required to check that providers meet the standards and to take action if standards fall below acceptable levels. PCT commissioners' decisions on contracts are routinely expected to take into account information about patients' experience. The Care Quality Commission will require frequent and regular use of information on the views and experiences of those using services, and those of their families and carers, as a condition of registration. The NHS Institute's experience-based design (EBD) programme aims to bring patients and staff together to improve care and redesign services.

Purpose of measurement

For the reasons outlined above there will be an increased focus on measuring patients' experience over the coming year. A great deal of work is under way to develop quality indicators, led by the Department of Health and the Information Centre for Health and Social Care.

A recent survey of staff views on the appropriateness and relevance of proposed indicators found support for indicators that were derived from various sources: questions in the national patient survey; formal complaints; staff surveys (eg, staff responses to whether they would recommend their own services to others, reports of errors, near misses or incidents that could have harmed patients or service users); surveys of cleanliness undertaken by the Patient Environment Action Team (PEAT); and routine data (eg, the proportion of patients seeing a relevant specialist nurse) (Information Centre for Health and Social Care 2009).

However, while routine data and staff surveys may contribute some useful and relevant information, direct feedback from patients is likely to remain the core method for measuring patients' experience. The Care Quality Commission has taken over responsibility for the series of national patient and staff surveys that have been annual requirements for each trust since 2002, but NHS trusts and commissioning bodies will need more detailed and more frequent forms of feedback if they are to meet the new requirements.

There are various reasons why feedback from patients may be considered useful. These include:

■ understanding current problems in care delivery

■ informing continuous improvement and redesign of services

■ helping professionals reflect on their own and their team's practice

■ monitoring the impact of any changes

■ facilitating benchmarking between services/organisations

■ comparing organisations for performance assessment purposes

- informing referring clinicians about the quality of services
- informing commissioners and patients about the quality of services
- informing patients about care pathways
- helping patients choose high quality providers
- enabling public accountability.

Patient feedback can make an important contribution to each of these objectives. Trust boards should be developing co-ordinated strategies for measuring quality in all its dimensions, including patients' experiences (*see* Some key concepts, below). Some may want to develop in-house capacity for measuring patients' experiences, while others will look to external providers. Companies selling technologies to obtain patient feedback offer a wide array of methodologies. These will be marketed vigorously over the coming months, and boards and senior managers need to be aware of the merits and drawbacks of the various alternatives. These are outlined in the section Designing a measurement programme.

Strategy for improving patients' experience

Despite long experience of gathering feedback from patients, there is little hard evidence on how best to use it to stimulate quality improvements. A number of studies have reported improvements following systematic gathering of patient feedback by hospitals (Draper *et al* 2001; Hildenhovi *et al* 2002; Crawford *et al* 2002; Gillies *et al* 2003; Reiber *et al* 2004; Sweeney *et al* 2005; Davies and Cleary 2004; Richards and Coulter 2007; Davies *et al* 2008; Bate and Robert 2006; Forbat *et al* 2009), but in general this has not been given high priority in NHS organisations. It is rare for patients to be asked routinely to comment on the quality of their care, and for the most part any quality improvements that have resulted from feedback have been small. Failure to listen to patients' and relatives' criticisms has been implicated in investigations as a key factor in failing hospitals (Department of Health 2001; Colin-Thomé 2009).

A recent study suggested that achieving and sustaining more substantial change is likely to require organisational strategies, engaged leadership, cultural change, and regular measurement and performance feedback (Davies *et al* 2008).

Most acute trusts collect a great deal of patient feedback in different ways, including:

- national patient surveys
- ward-level surveys
- interviews and focus groups
- patient forums
- informal feedback to PALs
- formal complaints
- comments on websites (eg, NHS Choices)
- feedback on the performance of individual clinicians for appraisal or revalidation purposes.

However, only a few organisations have adequate systems for co-ordinating data collection and assessing its quality, or for learning from and acting on the results in a systematic way.

Ideally what is needed is a co-ordinated strategy for improving patients' experience, with regular monitoring, clear reporting arrangements at all levels of the organisation, and an action planning process that closes the loop by reporting back up the line on changes and improvements.

A strategy for improving patients' experience in an acute hospital trust might look something like that outlined in Table 1, overleaf.

Table 1 Trust-wide strategy for measuring and improving patients' experience

Trust board and governance committee	■ Agrees patients' experience standards ■ Establishes patients' experience sub-committee ■ Reviews summaries of annual national patient surveys and external benchmarks ■ Reviews quarterly reports of headline results from rapid feedback surveys, supplemented by in-depth studies where relevant ■ Reviews complaints and critical comments ■ Reviews regular reports on quality improvement initiatives ■ Agrees dissemination/publication strategy
Executive board	■ Appoints senior patients' experience lead ■ Agrees set of indicators for measuring patients' experiences ■ Develops standards for robust, high-quality data collection and monitors these ■ Establishes rapid feedback system and monitors this ■ Reviews monthly trend reports ■ Reviews internal benchmarks, eg, comparisons between sites/directorates/wards ■ Reviews action plans and outcomes ■ Provides regular progress reports to board sub-committee
Clinical services, departments, directorates	■ Appoints patients' experience lead for each clinical service ■ Oversees data collection ■ Oversees action planning and quality improvement implementation ■ Identifies quick wins – things that can be tackled immediately (eg, patients not knowing which doctor is in charge of their care); short-term improvements requiring 1–3 months planning (eg, patients not receiving test results); medium-term improvements requiring 3–12 months planning (eg, patients wanting more say in decisions about their care) ■ Organises staff training where necessary ■ Provides regular progress reports to executive board

A comprehensive programme along these lines, with strong leadership and a carefully implemented approach to measurement, is the essential underpinning of a strategy to improve patients' experience of care.

Some key concepts

Most people working in health care are familiar with the notion of **patient satisfaction**, but there is often confusion between this and **patient experience**. In the past few years, patient-reported outcomes and real-time feedback have become much talked about but little understood. These concepts are described below.

Patient satisfaction

The main way in which patients' views on health care performance have traditionally been sought is through the measurement of what is termed 'patient satisfaction'. Satisfaction is a broad and often ill-defined concept that has been measured in many different ways (Carr-Hill 1992; Hall and Dorman 1988; Sitzia and Wood 1998; Fitzpatrick 1991; Fitzpatrick 2000; Fitzpatrick and Hopkins 2000; Edwards and Staniszewska 2000; Cleary and McNeil 1988; Cleary 1999). Generally recognised as multi-dimensional in nature, there is no consensus about exactly which domains should be included or which are most important. Patient satisfaction is sometimes treated as an outcome measure (satisfaction with health status following treatment) and sometimes as a process measure (satisfaction with the way in which care was delivered).

Satisfaction ratings reflect at least four factors:

- the personal preferences of the patient

- the patient's expectations

- response tendencies due to personal characteristics

- the quality of the care received (Sitzia and Wood 1998; Hargraves *et al* 2001; Zaslavsky *et al* 2000; Zaslavsky *et al* 2001; Staniszewska and Ahmed 1999; Staniszewska and Ahmed 2000; Jackson *et al* 2001).

Public attitudes towards health care are influenced by many factors, including personal accounts by patients of their own experiences, shared with their own informal networks; regulators' reports; the media; the organisations that lobby on behalf of patients, NHS organisations and health care professions; commercial suppliers to the health care industry. Expectations can also be influenced by cultural norms and by health status. Disentangling the effect of expectations, experience, and satisfaction can be problematic when patient or public views are used to compare the performance of health care organisations or clinicians. Studies have found systematic differences between the views of the public (healthy people/potential patients) and the views of current users of health services (Appleby and Rosete 2003; Edwards 2006). Patients may be further differentiated in terms of age, gender, ethnicity, disease severity, chronic versus acute, and so on. Expectations and concerns are likely to be affected by the user's experience of health care and their knowledge of/relation to/dependency on health care providers.

Health care providers have been measuring patient satisfaction for many years, but the value of such efforts has been limited (Cleary 1999). Surveys have tended to focus on managers' or clinicians' agendas rather than on the topics that are most important to patients, and they are frequently too broad to produce actionable results. Many researchers now believe that the complexities of modern health care and the diversity of patients' expectations and experiences cannot be reliably evaluated by asking general rating questions such as 'How satisfied were you with your care in hospital X?' or by focusing solely on food and amenities while ignoring patients' concerns about their illness and clinical care. Typically such surveys elicit overwhelmingly positive ratings that do not accurately reflect patients' experiences. Global satisfaction ratings such as this may have their place when monitoring trends over time, but they can be misleading if patients are not given the opportunity to comment on their care in more detail.

Patients' experience

Concern about the problems with patient satisfaction surveys has led to an emphasis on measuring patients' experience rather than satisfaction (Cleary *et al* 1992; Cleary 1998). Instead of asking patients to rate their care using general evaluation categories (eg, excellent, very good, good, fair, poor), they are asked to report in detail about their experiences of a particular service, hospital episode, general practice, or clinician. Such questions ask respondents to report whether or not certain processes or events occurred during a particular visit, a specific episode of care, or over a specified period. These types of questions are intended to elicit reports on what actually occurred, rather than the patient's evaluation of what occurred. In each case, the resulting data represent the perception of the patient, but the response task is different in the two cases. The first asks, 'What was your experience?'. The second asks, 'How would you evaluate that experience?'.

There are several potential advantages to using more direct report, rather than evaluative, questions. First, questions that ask patients to provide a general rating of their care tend to elicit more positive responses than factual questions about events and occurrences. This often results in 'ceiling' effects where surveys about satisfaction yield uniformly high ratings that do not differentiate between different facilities. A second advantage is that report questions, because they are less subjective, are less susceptible to the effects of expectations and response tendencies(Cleary *et al* 1992). However, this can be overstated – a person's response to his or her hospital experience is necessarily subjective, and it may be impossible to eliminate the effect of differential expectations. A third advantage is that the responses to report questions are usually easier to interpret and respond to than the responses to evaluative questions.

Knowing, for example, that 15 per cent of patients rated their care as 'fair' or 'poor' doesn't give managers or clinicians a clear view of what they need to do to improve the quality of care in their hospital. On the other hand, knowing more precise details of what went wrong, such as the proportion of patients who had to wait more than 15 minutes for the call button to be answered, can be much more useful. Focusing on the details of patients' experience can help to pinpoint the problems more precisely.

The NHS national patient survey programme uses this approach to obtain data from samples of patients in each NHS trust for the purpose of annual performance monitoring (Richards and Coulter 2007). The questionnaires include mainly report-style questions (*see* Appendix 1 for examples), and these surveys have been used to gather information about experiences of NHS care from more than 1.5 million respondents.

The national surveys include fairly detailed questions on most aspects of patients' experience:

■ choice of provider

■ access and waiting times

■ confidence and trust in health professionals

■ information and communication

■ involvement in treatment decisions

■ availability of staff when needed

■ hygiene, cleanliness and hand-washing

■ food and physical environment

■ access to records and medical communications

■ being treated with dignity and respect

■ overall satisfaction.

Findings from the regular surveys can be found on the Care Quality Commission's website, which includes results for each individual NHS trust. (*See* www.cqc.org.uk/usingcareservices/healthcare/patientsurveys/aboutpatientsurveys.cfm)

This programme is now being supplemented by even larger surveys of patients' experience of general practice care. General practitioners can earn extra contractual points and more money if they achieve satisfactory scores on the Department of Health's newly launched general practice patient survey (GPPS). Questionnaires are being mailed to more than 5 million general practice patients to produce a detailed picture of patients' experience of primary care. (*See* www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_092085)

Patient-reported outcome measures (PROMs)

It is important to be clear about the distinction between questions about patients' experience of the care process and patient-reported outcomes measures (PROMs). PROMs are standardised validated instruments (question sets) to measure patients' perceptions of their health status (impairment), their functional status (disability), and their health-related quality of life (well-being). There are many such instruments available, some focusing on specific diseases or conditions, while others are designed to obtain a generic measure of health outcome. PROMs are usually applied before and after a course of treatment to measure any changes due to the treatment and to assess whether the outcome is beneficial. It is usually necessary to collect detailed information about the patient's clinical status alongside the subjective measures in order to assess the full range of factors that may affect outcome. Quite often, patients' experience measures are used alongside PROMs to produce a more rounded picture of patients' views on both the process and the outcome of care.

PROMs can also be used as a general measure of health status for inclusion in cross-sectional surveys. Some of the former Healthcare Commission's national patient surveys include the EQ-5D, a utility measure or PROM, alongside the measures of patients' experience. The SF-12, another PROM, has also been used in this way.

The Department of Health has launched a new programme to introduce routine PROMs measurement throughout the NHS, starting with hip and knee replacements, hernia repair and varicose vein surgery (Department of Health 2008a). All hospitals treating patients with these procedures are required to ask them to complete a PROMs questionnaire before and after surgery. The Department of Health hopes this will provide a reliable measure of the clinical quality of care as perceived by patients themselves to complement other routinely collected statistics. Plans are under way to extend data collection to other conditions, including long-term conditions, and to link this to financial incentives to encourage providers to improve the quality of care.

'Real-time' or rapid feedback

There are three options when considering when to measure patients' experiences:

- point-of-contact/on-site feedback
- post-treatment/post-episode feedback
- continuous feedback/regular monitoring.

The Department of Health has announced that it will shortly require every hospital trust to collect 'real-time' feedback from its patients. This will involve the use of various technologies to collect data on patients' experiences during or immediately after their treatment (Department of Health 2009b). In fact 'real-time' is a misnomer, since it is rarely appropriate to ask patients to comment on the quality of their care while they

are receiving it. The intention, however, is to encourage trusts to obtain more regular and more detailed feedback with faster turnaround of results than is currently possible from the annual national patient surveys. For the purposes of the discussion here, this is referred to as 'rapid feedback'.

Exit surveys take place when a patient is leaving the hospital after a period of inpatient care. On-site or exit surveys can be carried out using pen and paper, hand-held devices, kiosks, bedside terminals, video boxes, or comment cards. Patients can be handed a questionnaire to take home and mail back or to complete before leaving. There are pros and cons to each of these methods (see below), but data collected from inpatients while they are still in hospital has a number of important limitations. On-site surveys cannot be used to obtain feedback about discharge arrangements or recovery periods, and a significant proportion of patients may be too ill to complete them while they are in hospital. Also, such surveys often rely on staff inviting patients to respond, running the risk that they will elicit only favourable comments. Many patients may be reluctant to comment critically for fear of antagonising the staff looking after them. For a truer picture it is often better if data collection can be organised by a non-staff member – some trusts have successfully engaged lay volunteers in this role – and it is always important to guarantee anonymity for participants.

Continuous feedback methods such as patient diaries may give a more complete picture, but they place a considerable burden on respondents as well as on those who have to analyse the results. Diaries are not appropriate for patients with limited literacy skills. To obtain a picture of the whole patient journey it may be better to use a brief survey to gather feedback from groups of patients at different points along the care pathway.

Post-discharge feedback using mail, telephone or online surveys, face-to-face interviews, focus groups or patient panels, can often give a more reliable picture of the quality of care because respondents have had time to reflect on their experiences, although in some cases their recollection might be poor or affected by subsequent events. In any event, the timing of data collection requires careful thought. Two weeks may be too short a period in which to obtain useful data. For example, some patients might not feel well enough to respond to surveys within two weeks of discharge and such surveys need time for reminders to ensure a good response rate. It is now considered standard good practice to send at least two reminders to non-respondents in a self-completion (mail or online) survey. Allowing at least two weeks between mailings plus time for data entry and analysis means it takes a minimum of six weeks to obtain a reasonable response rate (ie, more than 40 per cent) to a postal survey.

The internet offers the potential to obtain rapid feedback from patients who want to comment on their care outside of a formally organised survey or focus group. A number of websites now offers this facility, including NHS Choices (www.nhs.uk), Patient Opinion (www.patientopinion.org.uk), and iWantGreatCare (www.iwantgreatcare.org). This form of feedback can be a useful source of intelligence, and responses can be provided via the websites too, so users can see what the trust is doing to address any problems. However, there is no way of knowing how representative the comments are, so this web-based feedback cannot be used for benchmarking or monitoring trends.

For a more detailed discussion of the use of rapid feedback methods, *see* Brown *et al* 2009.

Routine data sources

For the most part, measuring patients' experience demands specially designed data collection exercises, but it is sometimes possible to derive insight from administrative data that may have been collected for a different purpose. For example, we know that most people with a terminal illness prefer to die at home but this does not happen as often as it should. Trusts that routinely record reason for discharge as 'to die' could monitor

this indicator to see how far deaths in hospital had been successfully avoided. Similarly, keeping a close eye on 'did not attend' rates might give an indication of the convenience or otherwise of clinic times or booking arrangements.

There is almost certainly more potential to use routine data to derive useful information about patients' experiences, especially if the analysis focuses on individual cases or services. Looking at, for example, the number of times a patient is moved between wards during an inpatient stay, the number of different staff involved in an individual's care and the specialties to which they belong, or the proportion of notes that are missing when patients arrive at a clinic, could point to problems that need to be tackled. Like many of the other feedback methods, analysis of routine data will not usually provide a definitive picture, but it can point to issues that require more detailed investigation.

Practical considerations

Resources

Many NHS organisations spend a great deal of time and effort gathering feedback from patients in an uncoordinated manner. Individual staff design and implement surveys that managers may not be aware of for use in their ward or department. Too often, surveys are poorly designed, implemented or analysed. Data are sometimes collected but not used, and in some trusts the absence of a strategy results in duplication and confusion.

Sometimes survey work does lead to significant change, but often the results are disappointing. Gathering reliable feedback from patients is a sophisticated research task, for which most clinical staff lack the skills and support to do it properly. Significantly greater value for money could be obtained if the resources devoted to these exercises were pooled and co-ordinated.

Ideally each NHS trust needs an executive director to take charge of the measurement of patients' experience, with delegated responsibility for designing and leading a data collection and improvement strategy. The postholder would need an annual budget and the support of the board to co-ordinate efforts across the trust.

Staff and their representatives should be engaged in the planning process because ownership of the feedback results is important for stimulating change. Staff may also need to be involved in encouraging patients to provide feedback, and in some cases may play an active role in data collection.

Responsibility for data collection can also be given to lay volunteers. Several trusts now involve lay volunteers in carrying out on-site patient surveys using questionnaires on hand-held computers, often with excellent results. The volunteers enjoy the opportunity to talk to patients, and patients often prefer to give feedback to someone who is independent and has not been involved in their care.

Clarity of purpose

Before making any decisions about what type of feedback to collect and the resources required, it is critically important to be clear about the purpose of the feedback and how it will be used. For example, if the main purpose is comparison (over time and with others) then feedback needs to be obtained from representative groups of patients. If the main aim is to obtain insight into the relationship between particular service attributes and patients' experience, or to motivate staff and catalyse change, then qualitative methods and stories are valuable. If the purpose is to check that a quality improvement initiative or a service redesign is achieving its goals, then regular and frequent feedback from small numbers of patients may be sufficient; if it is to monitor what is happening to specific groups of patients then routine data or observation may be appropriate. Decisions must also take account of issues such as availability of budgets and staff resources to carry out the work and act on the findings.

Attention to sample and the representativeness of comments received is important for comparisons between hospitals, sites, departments or wards, for benchmarking, for monitoring trends and for publishing in quality accounts. But that does not mean that one-off or non-representative comments should be ignored. Some things that happen to only a few people can be very important (eg, patients left on trolleys without being kept warm; insufficient attention paid to pain relief; a person left in a soiled bed for hours, and so on). These situations are 'never events' that should never be allowed to happen, so it is not necessary to know whether they are representative (of events or social groups). If they occur – even on only one occasion – they must be investigated, reported and an explanation and apology provided, and action taken to prevent a recurrence.

Sampling

For those purposes for which feedback from a representative group of patients is required, then it is important to take account of:

- the survey population – that is, the totality of patients using the trust or the particular department or ward that is the object of interest

- the sampling frame – the list from which the sample is to be drawn

- the sample – the group of people who will be invited to give their feedback

- the achieved sample – those who complete the questionnaire

- the response rate – the number who responded as a proportion of those invited to respond

- coverage error – when some groups of people are excluded from the sampling frame

- sampling error – problems when the characteristics of the achieved sample differ in some systematic way from the population of interest.

Sometimes people not trained in statistical methods or probability sampling make the mistake of assuming that obtaining the views of a large number people is enough, no matter how many were invited to give feedback in the first place. In fact it is often better to start with a smaller sample and make considerable efforts to encourage all of them to respond to reduce the risk of non-representativeness leading to biased results. This is why so much attention is paid to response rates, and why it is important to gather data on demographic characteristics to check how representative the sample is.

Patient samples may be drawn randomly from, say, a list of all those discharged over a three-month period, or they may be systematic, eg consecutive admissions or discharges during a single month.

Qualitative research (see below) does not aim to produce results that can be generalised in the same way, so probability sampling is less of an issue. But it is still important to try to ensure that those involved are representative of the spread of views in the patient population.

Ethics, data protection and screening

All research with patients in the NHS is subject to research and ethics committee approval. The National Research Ethics Service (NRES) (www.nres.npsa.nhs.uk/applicants/apply/research-in-the-nhs/) oversees the process. It is likely that research of the type described here will be classed as audit or service evaluation rather than research and therefore not subject to ethical review, but local research and development officers can provide guidance on this.

The National Information Governance Board for Health and Social Care (NIGB) is the guardian of patient confidentiality (*see* www.nigb.nhs.uk). Research using information that could identify patients without their consent must obtain approval from the NIGB.

If patients are to be sent a survey questionnaire after discharge, it is important to screen the sample to ensure that recently deceased patients are excluded. It can be very distressing for relatives to receive a questionnaire addressed to a patient who died in hospital or shortly after discharge. The Demographics Batch Service provides this screening service for NHS trusts.

Designing a measurement programme

As mentioned above, direct feedback is not the only way of gathering information about patients' experiences. Routine data and staff observations also have a part to play, but feedback from patients and their families remains the main way in which trusts can assess this aspect of the quality of care. This section describes the various ways in which patient feedback can be obtained.

Qualitative and quantitative approaches

In thinking about approaches to measurement it is helpful to make a distinction between quantitative and qualitative methods. Surveys using structured questionnaires are the most common form of quantitative measures of patients' experience. These are designed to produce numerical data that can be analysed statistically and used to describe and compare results from the sample population as a whole and specific sub-groups. The emphasis is on examining patterns and trends from a large sample, providing breadth and the ability to compare, but often lacking depth because questions and response options are predetermined.

The following are examples of quantitative methods and technologies for obtaining patient feedback:

- self-completion postal surveys
- interviewer-administered face-to-face surveys
- telephone surveys using live interviewers
- automated telephone surveys (interactive voice response – IVR)
- online surveys using web-based or email questionnaires
- surveys using hand-held portable devices (PDAs or tablets) (on-site)
- surveys on touch-screen kiosks (on-site)
- surveys on bedside consoles (on-site)
- administrative data/routine statistics.

Qualitative methods are different in that the focus is on obtaining an in-depth understanding of people's experiences and the way they explain or interpret these. Qualitative data are usually reported using words, not numbers, and it is harder to use the evidence to make comparisons or generalisations.

Some commonly-used qualitative methods are:

- in-depth face-to-face interviews (may be audio- or video-taped)
- discovery interviews carried out by clinical staff
- focus groups
- web-based free text comments
- comment cards or suggestion boxes (on-site)
- video boxes (on-site)
- complaints and compliments
- patient diaries
- mystery shopping and observation
- customer journey mapping.

More details on each of these methods are provided in Appendix 2.

People often make the mistake of assuming that surveys are simple to design and carry out. In fact, well conducted survey research is quite complex, involving a number of steps (*see* Appendix 1). Important decisions must be made about the scope of the survey and what questions should be included or excluded. Survey questions are usually 'closed', in that they offer a specific set of response options, and pre-coded, but it is also possible to include open-ended questions that can be coded at the data entry stage. Indeed, it is considered good practice to include a space for comments at the end of any questionnaire as a check that all issues of importance to the respondent have been covered. Pre-selection of questions and response options necessarily imposes restrictions, so understanding the process of selection is crucial for interpreting the findings. It is also important to assess the validity of the sampling strategy and the reliability of the achieved sample.

Qualitative methods are used to address somewhat different questions from quantitative surveys. For example, if you have a reasonably good idea of what is important to patients and what the problems might be, you could use a survey to learn more about the prevalence of these or to benchmark performance against other departments or hospitals. On the other hand, if you are not sure about patients' priorities, or you want to explore the experiences of specific groups in greater depth, then you should consider using qualitative methods such as in-depth interviews or focus groups. These methods are very useful for gaining a deeper understanding of the local context, but it is not usually appropriate to use the findings for wider generalisations or benchmarking against the performance of other organisations. As with surveys, qualitative research must be done well if it is to produce useful results. Any method that involves face-to-face contact is particularly susceptible to bias, and qualitative data can be difficult to summarise and make sense of.

Selecting an approach

When measuring patients' experience it is important to choose methods that are fit for purpose. There are various issues that must be considered:

- What is the specific purpose of measurement?
- What standards and indicators have been agreed for achieving high quality patient-centred care?
- Do you want to monitor trends and benchmark against comparators (internal or external)?
- Do you want to generate quick results that will engage the interest of staff?
- Which is more important, depth or breadth?
- How important is it to produce valid, reliable, unbiased and representative results?
- Which topics/clinical areas should be priorities for measurement?
- At what point on the care pathway will the measurement be carried out?
- What budget is available for the work?
- Will the data be collected in-house or should external contractors be commissioned to carry out the work?
- How will patient/family participants be identified and recruited?
- Are there any ethical/confidentiality/data protection issues that need to be considered?
- What do you intend to do with the results?
- How will the results be summarised and presented to board/senior managers/staff/external stakeholders (eg, Local Involvement Networks [LINks])?

- Who will be responsible for taking action on any problems identified?

- Will the results be published and, if so, where?

Appendix 2 describes the methods that have been used for obtaining patient feedback. Their main strengths and limitations are summarised in Table 2.

Table 2 Strengths and limitations of feedback methods

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

Feedback method	Strengths	Limitations
Quantitative		
Survey using bedside media consoles	▪ Can be completed by patients while in bed ▪ Reminders and incentives (eg, reduced cost phone calls) are possible ▪ Automatic data entry ▪ Rapid turnaround of results	▪ Some patients don't want to use bedside consoles because they are expensive ▪ No control over timing of survey ▪ Difficult to calculate response rates
Routine statistics	▪ Using routine or administrative data can be cost-effective ▪ Utilisation patterns may be indicative of underlying problems	▪ An indirect measure of patients' experiences
Qualitative		
In-depth interviews	▪ Can produce richer, more detailed data ▪ Allows respondents to express themselves in their own words	▪ Expensive ▪ Interviewers must be trained ▪ Problem of interviewer bias ▪ Transcribing and data analysis is time-consuming
Discovery interviews	▪ Means of recording patient stories, which may increase staff understanding	▪ Interviewers must be trained ▪ Problem of interviewer bias ▪ Patients may be unwilling to be critical when interviewed by staff ▪ Transcribing and data analysis is time-consuming
Focus groups	▪ Rich source of data on experiences and their impact on patients ▪ Groups often 'spark' off each other to produce less predictable responses	▪ Moderators need training ▪ Responses can be influenced by dominant individuals ▪ Transcribing and data analysis is time-consuming
Web-based comments (free text)	▪ Allows people to make any comments they want to about the care they've received ▪ Respondents can be asked to give their views on specific topics ▪ Responses are available for others to read	▪ Not suitable for people who do not have internet access ▪ Sites must be moderated to avoid malicious comments
Comment cards, exit surveys, suggestion boxes, video boxes (on-site)	▪ Can be used to collect on-site feedback, usually unstructured ▪ Feedback can be analysed quickly	▪ Likely to be completed by a small minority unless specifically invited to respond
Complaints and compliments	▪ All trusts receive some of these so they can be analysed for identifying specific incidents and general trends	▪ Most people don't make formal complaints even when things go wrong ▪ Compliments are often made but not often in writing
Patient diaries	▪ Can be used to gather continuous feedback on patient journey ▪ Allows for unstructured feedback	▪ Places a considerable burden on patients to record relevant information ▪ Can produce voluminous data that is difficult to analyse ▪ Not suitable for those with low literacy
Mystery shopping and observation	▪ A useful way of testing services from patient's perspective if service users are involved ▪ Staff can observe patient's journey through the system	▪ Involves an element of deception – must comply with ethical guidelines ▪ Some aspects of experience are impossible to replicate ▪ If staff are observing their presence this may influence what happens
Customer journey mapping	▪ A mixed methods approach that involves staff and patients in mapping care pathways	▪ Requires careful co-ordination and training ▪ Time-consuming and resource-intensive

* CAPI, computer-aided personal interviews
† CATI, computer-aided telephone interviews

There is no such thing as a perfect method for obtaining feedback. In many cases triangulation will be desirable, ie, using several different data collection methods to produce a rounded picture. Table 3 compares the approaches according to their relative cost and other criteria.

Table 3 Comparison of costs and other criteria relevant to methods for measuring patients' experience

	Cost	Comprehensive coverage of care pathway	Suitable for rapid feedback	Appropriate for low literacy groups	Suitable for internal/ external benchmarking or monitoring trends	Suitable for checking performance against	Purpose
Quantitative							
Postal surveys	££	X	X	X	✓	✓	1, 2, 3, 4, 5, 6, 7, 8, 10, 11
Face-to-face surveys	££££	X	X	✓	✓	✓	1, 2, 3, 4, 5, 6, 7, 8, 10, 11
Telephone surveys	£££	X	✓	✓	✓	✓	1, 2, 3, 4, 5, 6, 7, 8, 10, 11
Automated phone surveys (IVR)	££	X	✓	✓	✓	✓	4, 5, 6, 7, 8, 10, 11
Online surveys	£	X	✓	X	✓	✓	1, 2, 3, 4, 5, 6, 7, 8, 10, 11
Hand-held device surveys	££	X	✓	✓	✓	✓	1, 2, 3, 4,
Touch-screen kiosk surveys	££	X	✓	X	X	X	1, 2, 3, 4
Bedside console surveys	£	X	✓	X	X	✓	1, 2, 3, 4
Routine statistics	£	X	X	N/A	✓	✓	1, 2, 4, 5, 6, 7, 8, 9, 10, 11
Qualitative							
In-depth interviews	££££	✓	X	✓	X	X	1, 2, 3
Discovery interviews	£	✓	X	✓	X	X	1, 2, 3
Focus groups	££	X	X	✓	X	X	1, 2, 3
Web-based free text comment	£	X	✓	X	X	X	1, 2, 3
Suggestions, video boxes	£	X	✓	✓	X	X	2, 3, 4
Complaints, compliments	£	X	✓	X	X	X	1, 3, 4
Patient diaries	£££	✓	X	X	X	X	1, 2, 3
Mystery shopping and observation	££	✓	X	✓	N/A	✓	1, 2, 3, 4, 7, 8, 10
Customer journey mapping	££	✓	X	✓	X	✓	1, 2, 4

Purpose of measurement
1.   Understand current problems in care delivery.
2.   Inform continuous improvement and redesign of services.
3.   Help professionals reflect on their own and their team's practice.
4.   Monitor the impact of any changes.
5.   Facilitate benchmarking between services/organisations.
6.   Compare organisations for performance assessment purposes.
7.   Inform referring clinicians about the quality of services.
8.   Inform commissioners about the quality of services.
9.   Inform patients about care pathways.
10. Help patients choose high quality providers.
11. Enable public accountability.

What to measure

The starting point for measuring patients' experiences ought to be an agreed set of standards together with a set of measurable indicators. The Point of Care programme has adopted the Institute of Medicine's definition of patient-centred care:

■ compassion, empathy and responsiveness to needs, values and expressed preferences

■ co-ordination and integration

■ information, communication and education

■ physical comfort

■ emotional support, relieving fear and anxiety

■ involvement of family and friends.

(Committee on Quality of Health Care in America 2001).

Local knowledge and awareness of the service context are essential in deciding what to focus on, but it is also important to consult service users before selecting questions and indicators. Although there is often considerable overlap between patients' and staff perceptions of services, it is not sufficient to rely solely on staff views of what is important to patients as their assumptions may be incorrect.

Published studies can be another good starting point for determining patients' priorities. For example, a qualitative study carried out as part of the development of the national inpatient survey in 2002 (Reeves *et al* 2002) used a card sort exercise to rank the items that patients considered most important (*see* Appendix 3). The most important factors were:

■ having confidence in staff

■ clear information and communication

■ staff knowledge and experience

■ clean facilities

■ being treated with dignity and respect.

Similar results were obtained in a later survey carried out in 2006 to determine the issues of most importance to hospital patients (Acute Co-ordination Centre for the NHS Patient Survey Programme 2007), suggesting these features are of enduring priority.

Ensuring that you are measuring the things that matter most to patients is an essential component of a successful strategy for improving patients' experience. Measuring things because they are easy to measure even if not really relevant or useful breeds cynicism and resentment among staff. Clinicians will be much more likely to take account of any problems identified if they know these are important priorities for their patients.

Appendix 1

Survey design

Survey design and development can be complex and time-consuming. For example, the box below summarises the steps that the Picker Institute goes through when designing a national patient survey for the Care Quality Commission.

Steps in designing and implementing a national patient survey

1. Consult relevant stakeholders to define the scope of the survey.

2. Review relevant literature to inform content.

3. Obtain ethics committee approval.

4. Consult Patient Information Advisory Group (PIAG) and data protection authorities.

5. Organise focus groups with patients/families and professionals to determine their priorities.

6. Draft questionnaire.

7. Design sampling strategy in liaison with trusts.

8. Design mode of administration.

9. Test questionnaire in cognitive interviews with patients.

10. Redraft questionnaire and retest.

11. Where appropriate, organise 'importance' survey to check patients' priorities.

12. Pilot survey to check response rates and test sampling strategy.

13. Where appropriate, carry out psychometric tests of validity and reliability.

14. Write guidance and timetable for survey implementation.

15. Co-ordinate implementation of survey (if devolved).

16. Use tracing service to ensure that deceased patients are removed from sample.

17. Check samples from all trusts.

18. Monitor fieldwork, including response rates and calls to helplines.

19. Co-ordinate data entry and collate data.

20. Check and 'clean' all data.

21. Analyse data and write reports.

22. Present key findings to trust boards, national bodies and NHS staff.

23. Provide advice on action planning to determine priorities for quality improvement.

Sample questions

The questionnaires used in the national patient survey programme include mostly 'report' style questions as in the following example:

C3. If you had any anxieties or fears about your condition or treatment, did a doctor discuss them with you?

　　1 ☐ Yes, completely

　　2 ☐ Yes, to some extent

　　3 ☐ No

　　4 ☐ I didn't have anxieties or fears

The surveys also include a few general questions to elicit patients' overall ratings of their care, for example:

J4. Would you recommend this hospital to your family and friends?

　　1 ☐ Yes, definitely

　　2 ☐ Yes, probably

　　3 ☐ No

Appendix 2

Feedback methods

Surveys

Postal surveys are the most commonly-used method for getting feedback from large samples of patients. They are usually mailed shortly after an episode of care, and an up-to-date sampling frame (list of names and addresses) is essential. This should be checked for accuracy, and the names of patients who have died must be removed. Reasonable attempts must be made to achieve a good response rate. This usually involves sending up to two reminders to non-respondents, including duplicate copies of the questionnaire and pre-paid return envelopes. Many factors influence the likelihood that people will respond, but the salience of the questionnaire is particularly important (Edwards *et al* 2002). Well conducted postal surveys asking patients about the quality of care experienced typically achieve response rates of 40–70 per cent, but response rates from badly designed surveys are often much lower than this.

An important drawback of self-administered questionnaires is that they rely on respondents having sufficiently high literacy skills to comprehend the questions. If there is reason to doubt this, **interviewer-administered face-to-face surveys** are preferable. They do not rely on the respondents' literacy skills and they can be used to collect more detailed and complex data. However, they are resource-intensive and interviewers need training to conduct a survey satisfactorily, so they are much more costly than self-administered surveys.

Telephone surveys fall between postal surveys and face-to-face interviews in terms of cost. These are often used for population surveys, when sampling is usually done using random digit dialling, but they can also be used with defined samples if phone numbers are available. The most common method, computer-aided telephone interviews (CATI), ensures that interviewers stick to the script and record responses on the computer as they go along. Telephone surveys typically achieve lower response rates than postal surveys or interview surveys, and it is sometimes necessary to make a large number of callbacks to obtain a reasonable response rate. There is a limit to the amount of time people will be willing to spend answering questions on the phone, so telephone surveys are usually quite short – 20 minutes is probably the maximum time and many are considerably shorter than this.

Surveys using **interactive voice response** (IVR) technology or recorded questions that require respondents to press keys on their phone, also known as **automated telephone interviews**, are quite often used in health care research in the United States, but less often in the United Kingdom (Brodey *et al* 2005). The systems can be set to make outbound calls automatically, or respondents can be given a freephone number to call that connects them to a machine – often sounding surprisingly human – that asks the questions. These are much cheaper to run than CATI surveys, but they may achieve even lower response rates. They have one important advantage over interviewer-administered surveys in that multiple-language versions can be made available relatively easily.

As internet use becomes more widespread, **online surveys** are becoming more common. These can be web-based, when respondents are invited to go to a website to complete the survey, or email-based, when they are sent directly to a list of email addresses. They have some advantages over postal surveys in that they are cheaper to administer, data entry can be done automatically, and 'skips' directing respondents to appropriate questions following an introductory 'filter' question are hidden from the respondent, making them simpler to use. However, there is still a substantial proportion of the population without regular access to the internet, in particular older people who are the heaviest users of health services.

Several other means of gathering data electronically have been developed to facilitate 'on-site surveys' or 'real-time feedback', in other words, surveys carried out in hospital or other health care facilities to capture patients' experience of care while they are receiving it. These include questionnaires on **hand-held portable devices** (tablets or personal digital assistants [PDAs]), **touch-screen kiosks** and **bedside media consoles**. There are a number of practical considerations that must be addressed when using these, including infection control and how respondents will access them. Bedside terminals provide a range of media and telephone services, including facilities for providing feedback in response to survey questions. They are readily accessible to inpatients but not always used – the cost of phone calls has been shown to be an inhibiting factor. Hand-held devices or kiosks can be placed somewhere where patients can use them, for example, in a waiting room or day room, but unless patients are actively invited to complete the surveys and monitored while doing so, it can be impossible to know what proportion responded or to gauge the representativeness of the self-selected sample. Consideration must also be given to controlling the risk of spreading infection. An alternative method, which has been used with some success in several hospitals, is to recruit lay volunteers to act as interviewers using hand-held devices that store the questionnaires and responses, with the data being sent wirelessly to a computer for data analysis on a daily basis.

Staff surveys may be a useful additional source of information on problems in patients' experience of care. The national staff survey, a postal survey organised for the Healthcare Commission, tends to focus on traditional human resource issues, but it is possible to design questionnaires to learn about the challenges faced by staff in striving to provide a patient-centred service (Reeves *et al* 2005; West *et al* 2005). These focus on issues previously identified as of importance to patients, and ask respondents to report on the extent to which they are willing and able to adapt their routines to match patients' needs and expectations.

A great deal of administrative and clinical data is recorded routinely in the NHS. Much of it has little direct relevance to patients' experience of the care process, but some **routine statistics** may be useful indicators; for example, waiting times, prevalence of mixed sex accommodation, and statistics on usage rates of specific services. Routine statistics are readily available but not always completely reliable.

In-depth interviews

In order to overcome the limitations of the structured or fixed-response questions that are commonly used in surveys, in-depth interviews use open-ended questions to elicit a deeper understanding of why people behave as they do and the meanings they attach to social phenomena. Respondents are encouraged to describe their experiences and perceptions in their own words, and these are usually recorded for later analysis. Sometimes referred to as unstructured interviews, this is actually a misnomer. **In-depth interviews** may be wide-ranging but they are different from free conversation because they are led by an interviewer who always starts with some sort of structure in mind. Sometimes this may take the form of a topic guide, used as a prompt for the issues he or she intends to explore, and sometimes it will be a semi-structured questionnaire, with the questions set out in some detail but allowing time for the respondent to answer them as he or she sees fit.

Qualitative interviewing requires considerable skill to avoid interviewer bias, to encourage interviewees to open up, and to keep the interview on track (Britten 1995). Analysing and reporting the data can also be a challenge, although there are numerous guides available on how it should be done (Mays and Pope 2000; Pope *et al* 2000). It is important not to underestimate the time and skills required to do this well.

In-depth interviews are often audio-taped or video-taped. Video-taped examples of in-depth interviews are available on the web to provide visual records of patients' experience

for the benefit of staff, trainees and other patients. Examples include those carried out by the Dipex group (*see* www.healthtalkonline.org) and Pilgrim Project's Patient Voices digital stories (*see* www.patientvoices.org.uk). These can provide very useful examples of patients' reactions to the way they are treated.

Discovery interviews are a type of in-depth interview that was promoted by the NHS Modernisation Agency as part of its Collaborative Programmes. The Royal College of Nursing advocates a similar method, which it refers to as patient stories. Patients are encouraged to talk about their experience of receiving care to help staff review the quality of their service from the patient's perspective (NHS Modernisation Agency 2009). Small numbers of patients are interviewed, usually by members of staff, and their stories are recorded and used as part of a quality improvement programme. A version of this in the form of a questionnaire with open-ended questions to elicit information about patients' feelings and emotions during their care has been designed by the NHS Institute for use in its experience-based design programme. (*See* www.institute.nhs. uk/index.php?option=com_joomcart&Itemid=194&main_page=document_product_ info&cPath=84&products_id=550&Joomcartid=ui6ldomu9conmlj8kfkupeu2i0)

While encouraging staff to interview patients can be illuminating, it is important to remember that many patients are unwilling to give critical comments directly to the staff involved in their care, or their colleagues.

Group interviews

When groups of people are interviewed together, the resulting interactions can provide interesting insights into people's knowledge and attitudes that are sometimes richer than those obtained in one-to-one interviews. **Focus groups** typically involve six to ten participants in a guided discussion lasting about two hours. They require expert moderation to ensure that everyone has a chance to speak and no individual is allowed to dominate the discussion. Selection of participants needs to be done with care. It is usual to aim for relative homogeneity within the groups as this is felt to facilitate better group dynamics. A topic guide is usually used, including prompts to persuade people to open up, and the resulting discussion is recorded and transcribed. Specific exercises, such as card sorts or trigger pictures, are often used to encourage people to think through their preferences and priorities. When carefully analysed, data from focus groups can be particularly useful for identifying the cultural norms of specific sub-groups, such as people from minority ethnic groups (Kitzinger 1995). However, it may be difficult for people with dissenting views to express these in a group, so this method is not as sensitive to variations in opinion as one-to-one interviews.

Web-based feedback

Wider availability of internet access and Web 2.0 allowing greater interactivity has led to the development of **websites** designed specifically to encourage health service users to provide free text comments on their experiences. Some of these websites also solicit responses to more structured survey-type questions. Examples include Patient Opinion (www.patientopinion.org.uk), which collects feedback on provider organisations and shares the service with NHS Choices (www.nhs.uk), and iWantGreatCare (www. iwantgreatcare.org), which invites users to record their views about care provided by individual doctors. These websites, which allow patients to record both positive and negative comments on any aspect of care, are modelled on travel websites such as TripAdvisor (www.tripadvisor.co.uk). They are moderated to ensure that comments comply with legal restrictions, but essentially people are free to write what they want.

Other feedback

Comment cards, suggestion boxes and video boxes have been used in hospitals to get comments from patients and help staff identify any problems that need rectifying. In common with other forms of unstructured feedback, these will not produce a representative picture of patients' experiences.

Complaints and compliments are another important source of unstructured comments. Complaints have often been badly handled by the NHS so the Department of Health has recently instituted a new, more streamlined approach covering all health and social care services (Department of Health 2009a). As well as handling individual complaints sensitively, health care providers can learn much from analysing them collectively to identify the most common types of complaint.

Observational techniques

Various forms of observation can be used for monitoring patients' experience, including participant and non-participant observation.

Non-participant observation can be used to report on patients' experience of using a particular service. There are various means of making systematic observations, ranging from sitting in a waiting room or clinic and taking notes about people's behaviour as unobtrusively as possible, to using video to record events (with the permission of those involved). Video is often used in GP training to record consultations for later review by trainers and trainees.

In **participant observation** the researcher or service user records his or her own experiences of using a service. Examples include managers working on the 'shop floor' to learn about the experiences of staff or patients, able-bodied or disabled people navigating through facilities in a wheelchair to check on accessibility, users recording events using diaries or disposable cameras, and mystery shopping.

Patient diaries have been designed to encourage patients to record their feelings and experiences as they go through an episode of care, for example, outpatients' experience, admission to the ward, going to and from the operating theatre, post-operative recovery and going home. These are another means of mapping the patient journey, but they can produce a large amount of data that is not very easy to analyse or interpret. Also this method cannot be used with low literacy groups.

Mystery shopping is a form of participant observation involving trained volunteers who act as undercover service users to audit service quality.

'Shoppers', who should be actual users or potential users of the service under review, are given a task or scenario and asked to record their experiences of carrying it out. Volunteers, who are usually paid a small amount for their services, may help develop the scenarios, which should be realistic and based on their prior experience. The collective experience of the 'shoppers' is collated and used to report on the quality of the service. Since mystery shopping involves observation of people who do not know they are being observed, the Market Research Society's code of conduct insists that employees should receive prior warning that this may happen. (*See* www.mrs.org.uk/standards/downloads/code2005.pdf)

Customer journey mapping is being promoted by the Cabinet Office to all government departments as a means of tracking and describing users' experiences. (*See* www.cabinetoffice.gov.uk/public_service_reform/delivery_council/cjm.aspx). The aim is to encourage providers to visualise how people experience their services and use this knowledge to review and improve them. It provides a map of the interactions and emotions that take place during a typical journey or pathway. There are three types

of journey mapping that can be used, either singly or in combination. For example, customer experience mapping can be used to understand the steps leading to diagnosis and treatment and the opportunities to engage patients in their health care; system mapping can be used to identify 'baton-changing' points on the patient pathway where there is potential for poor information or co-ordination; satisfaction mapping is the process of setting appropriate measurements, including emotional highs and lows. The overall aim is to start from a deep understanding of what service users really think and feel, moving through to taking action and evaluating the results.

Appendix 3

Patients' priorities

Patients' ratings of 30 aspects of inpatient care

Aspect of care	Mean rating	Percentage who rated issue 'Most important'
Confidence and trust in doctors and nurses treating me	1.05	93.1
Clear explanations of my condition or treatment	1.10	88.0
Staff knowing enough about my condition and treatment	1.13	85.2
Cleanliness of hospital	1.15	84.1
Getting clear answers to my questions	1.15	83.7
Being treated with dignity and respect	1.18	79.7
Pain relief	1.22	77.4
Operations or procedures being performed on time	1.24	74.6
Opportunity to talk to a doctor	1.27	72.4
Staff being open with me	1.27	71.3
Privacy when being examined or treated	1.30	70.1
Prompt help from hospital staff when I need it	1.33	65.9
Enough notice of operation or treatment cancellation	1.34	64.6
Being involved in decisions about my care	1.36	64.6
Information about medication	1.36	63.4
Not being discharged from hospital too early	1.37	65.2
Not waiting too long on a trolley or a chair before getting to ward	1.37	65.9
Short time on the waiting list before admission	1.43	57.5
Staff who understand my anxieties and fears	1.46	54.5
Information about my recovery at home	1.48	53.3
Being given an explanation about why I have to wait	1.49	54.5
Good quality food	1.64	43.5
Information about what to expect before admission to hospital	1.64	41.5
Not having to share a ward or room with patients of opposite sex	1.73	50.8
Not being moved around from ward to ward within the hospital	1.81	35.0
Low noise levels	1.82	32.5
Knowing the names of the staff in charge of my care	1.86	30.9
Having access to my medical records	1.98	28.9
Clear information about ward routines	2.00	22.6
Invitation to visit the hospital and meet staff before admission	2.39	11.0

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