

## Quality improvement science

# Patient perspectives on quality

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### ABSTRACT

The patient perspective is central to quality improvement. This article describes how health services are involving individuals and the public in improving healthcare. It describes the importance and different methods of accessing patient and carer feedback on satisfaction, experience and outcomes, and explores current thinking on individual in-

volvement, engagement in commissioning, and the role of the public in redesigning health services.

**Keywords:** focus groups, general practice, interviews, patient perspectives, primary care, quality improvement, regulation

## Introduction

This, the sixth in our series of articles on quality improvement tools and techniques, focuses on patient perspectives on healthcare quality improvement and how we might involve patients, carers and the public in developing our notions of quality and in monitoring and regulation. Previous articles in the series have considered: frameworks for improvement,<sup>1</sup> understanding processes and how to improve them,<sup>2</sup> leadership and management,<sup>3</sup> measurement,<sup>4</sup> commissioning for quality<sup>5</sup> and systems and spread.<sup>6</sup>

Previous articles have emphasised the primary importance of patients' perspectives on quality. Indeed, it could be reasonably asked, what perspective of quality is there other than the viewpoint of the patient, whether this relates to the care that they receive or the clinical outcomes that they experience? Understanding what service users value is usually the key to knowing where we should focus quality improvement and, just as importantly, how we should bring about improvement or judge whether it has been achieved. This requires a major shift in our thinking from patients being (passive) recipients of care to being (actively) involved in informing and improving services.

Unfortunately, in the past, quality and improvement in healthcare have focused on what professionals think should be valued and have been less interested in what service users felt was important or have failed to

elicit patients' views directly. Professional perspectives are a proxy for that of the patient, but there may be occasions where the two diverge and the reasons for this need to be understood.

Recent major failures in health services, for example, those described in the Francis Report, have reiterated the importance of the patient perspective.<sup>7</sup> To quote Robert Francis: 'individual experiences that lie behind statistics and benchmarks and action plans that really matter, and that is what must never be forgotten when policies are being made and implemented.'<sup>7</sup>

Academics, clinicians, managers and commissioners of services may all try to see issues from the patient perspective and claim to represent patients, but the involvement of patients themselves and their representatives in measuring satisfaction, experience and outcomes, in designing improvements in care and in making judgements about the quality of services, are the focus of this article.

## Quality frameworks and patient perspectives

Key quality frameworks have highlighted the importance of patient experience. For example, in the USA,

the Institute of Medicine in their landmark monograph, *Crossing the Quality Chasm: a new health system for the 21st century*, referred to patient centredness, together with safety, timeliness, effectiveness, efficiency and equity, as the fundamental components of quality. 'Patient centredness' is a complex term that means different things to different people, but in this context refers to respect for an individual patient's culture, social context and specific needs, and the patient being active in decisions about his or her own care.<sup>8</sup>

In the UK Lord Darzi, in his report *High Quality Care for All*, sought to identify and address the key quality issues for health systems of safety, effectiveness and experience.<sup>9</sup> This led to the development of the UK government white paper *Equity and Excellence*, which focuses on improving patient outcomes,<sup>10</sup> the *NHS Outcomes Framework* which has 'ensuring people have a positive experience of care' as one of five outcome domains,<sup>11</sup> and *The NHS Constitution*, which lays down the rights (and responsibilities) of patients and staff in order to achieve this.<sup>12</sup> Recent studies have suggested that there is a consistent positive relationship between patient experience, effectiveness and safety,<sup>13</sup> reinforcing experience as part of the quality triad.

More recently, in response to the review of failures at Mid-Staffordshire NHS Trust, Don Berwick and the National Advisory Group, in their publication *Improving the Safety of Patients in England*, expressed their view that patients and carers should be present, powerful and involved at all levels of healthcare organisations.<sup>14</sup>

Finally, Bruce Keogh's *Review into the Quality of Care and Treatment Provided by 14 Hospital Trusts in England* stated that we should involve patients, carers and members of the public as vital and equal partners in the design of services, and involve patients and clinicians as active participants in regulatory inspections.<sup>15</sup>

## Patient satisfaction, experience, outcomes and involvement

Patient satisfaction, experience, outcomes and involvement are overlapping, but not identical, concepts. Satisfaction and experience are both expressions of 'utility' or 'happiness' with services provided, which, of course, many people might prefer not to use.

There are many ways of eliciting patient views, ranging from those such as surveys or questionnaires that attempt to provide a broader more representative assessment from the population being sampled, to interviews, focus groups and patient stories that try to gain a more in-depth understanding. Other methods

that provide lesser degrees of breadth and depth of views include online ratings, complaints and compliments, feedback from patient liaison services or participation groups and public meetings.<sup>16</sup>

Patient satisfaction surveys are regularly undertaken in most health settings and are intended to provide a quantitative (and often representative) assessment of satisfaction with services in a number of domains. For example, the general practice patient survey linked to the Quality and Outcomes Framework<sup>17</sup> covers areas such as access (telephone, face-to-face, in-hours, out-of-hours), continuity, communication, care (from the general practitioner, nurse or receptionist), support for self-care, and overall satisfaction.<sup>18</sup> The questions and response formats are constrained by particular areas and issues which are considered to be important for service provision and patient satisfaction. Satisfaction levels with general practice are often high, but this does not necessarily mean that users' experiences of services are good. This is partly because what health professionals think constitutes a good experience is not necessarily the same as what patients say.

For example, a focus group study showed how the complexities of patients' wants and needs from a consultation for insomnia differed from what doctors thought patients wanted or needed. Patients wanted to be shown understanding, listened to and taken seriously. What they initially saw as a lifestyle problem had become medicalised, often leading to a request for a hypnotic prescription. Doctors felt that patients might not take non-drug treatments seriously and expected patients to be resistant to stopping drugs they were already taking or reluctant to explore alternatives, whereas patients, often deriving little benefit from drugs, were open to alternatives, such as psychological therapies.<sup>19</sup> This understanding has been translated into an e-learning program for doctors, nurses and other health professionals.<sup>20</sup>

To understand patients' experiences implies seeking to see things from the patients' perspective. This requires us to work with patients to gather information on what constitutes a good or a poor experience and this may vary by person and by setting. In the UK the Department of Health has tried to address what domains of experience might look like through a patient experience framework derived from those developed by the Institute of Medicine and the Picker Institute (Box 1).<sup>21</sup>

Over the past few years, psychologists have begun to distinguish between the memory of an experience, and the experience as it happens, since what we usually refer to as experience is what we remember. This might seem an artificial distinction until we appreciate that our memory of an experience is affected not only by what happens during it, but by the peak experience (of pleasure or pain) and how the experience ends. If the

### Box 1 NHS patient experience framework<sup>21</sup>

- **Respect for patient-centred values, preferences and expressed needs**, including: cultural issues; the dignity, privacy and independence of patients and service users; an awareness of quality-of-life issues; and shared decision-making.
- **Co-ordination and integration of care** across the health and social care system.
- **Information, communication and education** on clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care and health promotion.
- **Physical comfort** including pain management, help with activities of daily living, and clean and comfortable surroundings.
- **Emotional support** and alleviation of fear and anxiety about such issues as clinical status, prognosis and the impact of illness on patients, their families and their finances.
- **Welcoming the involvement of family and friends**, on whom patients and service users rely, in decision-making and demonstrating awareness and accommodation of their needs as care-givers.
- **Transition and continuity** as regards information that will help patients care for themselves away from a clinical setting, and co-ordination, planning and support to ease transitions.
- **Access to care** with attention, for example, to time spent waiting for admission or time between admission and placement in a room in an inpatient setting, and waiting time for an appointment or visit in the outpatient, primary care or social care setting.

peak is highly positive and ends well, this increases our likelihood of recollecting this as a good experience.<sup>22</sup>

Patient-related experience measures (PREMs) and patient-reported outcome measures (PROMs) are increasingly seen as important tools by healthcare providers, commissioners, regulators and service users.<sup>23</sup> PREMs are brief questionnaires developed to measure people's experiences of services, whereas PROMs are short, self-completion patient questionnaires, which measure health status, health-related quality of life or experience of care at a point in time and change over time (pre and post intervention), from which the impact of healthcare interventions can be assessed.<sup>23</sup> Outcomes have been found to be correlated with, but not distinct from, experience.<sup>24</sup> The National Institute of Health and Clinical Excellence (NICE) has also developed statements on what constitutes good experience in adult services (Box 2).<sup>25</sup>

The various methods for accessing patient views have different pros and cons. These include issues of selection and reporting bias, representativeness, depth, complexity of analysis, and level of expertise, analysis and time required.<sup>16</sup> Qualitative feedback is often more valuable than exhaustive quantitative surveys, but often a combination of both is required to understand experiences in depth and to compare and improve services.

Involving patients to access their views and implement improvements is something that health services are at an early stage of addressing. Users may be individual patients, patient group members or patient representatives with different levels and types of knowledge, experience or approach, which might

lead to conflicting views.<sup>26</sup> There are demands from government and health organisations to increase patient involvement and – despite validated tools and much accumulated experience – tools, structures, strategies and methods for involving patients are still being developed.<sup>27</sup>

For example, *Transforming Participation in Health and Care* sets out a grand vision for participation in the UK National Health Service (NHS) which provides a framework for commissioners of services to promote individual participation in care and treatment, to engage the public in commissioning, to listen and act upon patient and carer feedback at all stages of the commissioning cycle, to engage with patients, carers and the public when redesigning health services, and to publish evidence of these activities and their impact on services (Box 3).<sup>28</sup>

Another area in which the public are increasingly involved is regulation. For example, there is now greater lay and patient involvement in regulatory bodies (such as the Care Quality Commission, Monitor and professional bodies), regulatory inspections and appraisal of health workers, and this is likely to increase in future.

This greater level of patient and public involvement will require further research into what outcomes matter to patients and action on how best to meaningfully involve patients and carers. It will also require new structures at national and local levels of provider and commissioning organisations. Finally, it will also require training and resources for patients, carers and public representatives.<sup>28</sup>

**Box 2 NICE quality statements on adult patient experience<sup>25</sup>**

- Patients are treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty.
- Patients experience effective interactions with staff who have demonstrated competency in relevant communication skills.
- Patients are introduced to all healthcare professionals involved in their care and are made aware of the roles and responsibilities of the members of the healthcare team.
- Patients have opportunities to discuss their health beliefs, concerns and preferences to inform their individualised care.
- Patients are supported by healthcare professionals to understand relevant treatment options, including benefits, risks and potential consequences.
- Patients are actively involved in shared decision-making and supported by healthcare professionals to make fully informed choices about investigations, treatment and care that reflect what is important to them.
- Patients are made aware that they have the right to choose, accept or decline treatment and these decisions are respected and supported.
- Patients are made aware that they can ask for a second opinion.
- Patients experience care that is tailored to their needs and personal preferences, taking into account their circumstances, their ability to access services and their co-existing conditions.
- Patients have their physical and psychological needs regularly assessed and addressed, including nutrition, hydration, pain relief, personal hygiene and anxiety.
- Patients experience continuity of care delivered, whenever possible, by the same healthcare professional or team throughout a single episode of care.
- Patients experience co-ordinated care with clear and accurate information exchange between relevant health and social care professionals.
- Patients' preferences for sharing information with their partner, family members and/or carers are established, respected and reviewed throughout their care.
- Patients are made aware of who to contact, how to contact them and when to make contact about their ongoing healthcare needs.

**Box 3 Case study: pre-hospital emergency pain management<sup>29</sup>**

- Pain management in emergency care is an important aspect of quality. A qualitative study with interviews and focus groups of patients, ambulance and emergency department staff helped us to understand their experiences during the patient pathway for emergency management of pain and how this could be improved.
- Although patients and healthcare staff expected pain to be relieved in the ambulance, refusal of analgesia or acceptance of inadequate analgesia occurred because patients feared adverse drug effects, were loath to be transported or were concerned that pain relief (e.g. with drugs like morphine) would interfere with subsequent hospital assessment. Patients and practitioners found pain scores confusing. When clinical observations of staff disagreed with patient-reported pain scores, practitioners often responded according to presumed diagnosis rather than the patient's pain severity leading to over- or under-treatment.
- Barriers to assessment of pain included communication difficulties or lack of co-operation due to the influence of alcohol or drugs. Morphine and Entonox were commonly used to treat pain, but reassurance, positioning and immobilisation were often used as alternatives to drugs.
- Suggestions to improve pre-hospital pain management included addressing identified barriers, increasing drug options and developing agreed multi-organisational pain management protocols with appropriate training for staff.
- This has led to further work to develop a patient reported outcome measure for pre-hospital pain management.

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## PEER REVIEW

Commissioned; not externally peer reviewed.

## CONFLICTS OF INTEREST

None declared.

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