Measuring patient experiences in Europe: what can we learn from the experiences in the USA and England?

Introduction

There is a growing interest in measuring patients’ experiences in health care. In several European countries, surveys are taking place to map the quality of care as perceived by patients. In a number of countries, this is part of a systematic programme of work that is undertaken at regular intervals. According to a review commissioned by the Organization for Economic Cooperation and Development (OECD), this is the case in Denmark, Norway, England and The Netherlands. Outside Europe, systematic evaluation of patients’ experiences takes place in Canada and the USA. In addition to these national programmes, the Commonwealth Fund, the Picker Institute Europe and the World Health Organization (WHO) have undertaken cross-national comparisons of patients’ experiences.1 The USA and England have by far the longest tradition of measuring patients’ experiences through, respectively, the American CAHPS (Consumer Assessment of Healthcare Providers and Systems) surveys and the surveys of the Picker Institute Europe for the English NHS. These programmes can serve as examples for European health care systems when it comes to measuring patients’ experiences. Countries that wish to embark on systematic and regular evaluations of quality of care from the perspective of patients can learn from the American and English experiences in this field. What are the main lessons learned in these countries?

Lessons learned

In the 1990s, patient satisfaction had become a widely accepted outcome measure in trials testing new drugs or interventions. In addition to that, patient satisfaction surveys were used to measure the quality of care from the perspective of the health care user. In the second half of the 1990s, however, it became clear that as a tool for quality improvement, patient satisfaction surveys were neither very sensitive nor very useful. One of the problems with patient or consumer satisfaction is its ambiguity. Satisfaction is a multidimensional concept, based on a relationship between experiences and expectations. It was argued that for continuous quality improvement it would be more fruitful to look at the underlying components of the concept: expectations and experiences.2 This led to the development of new ‘families’ of patient surveys, in which the emphasis is not on an evaluation of satisfaction but on collecting detailed reports of what actually happened to patients during a hospital stay or a visit to the doctor. The questionnaires used by the Commonwealth Fund, CAHPS and the Picker Institute Europe are the examples of those new types of surveys, that in turn have inspired the development of similar patient surveys in other countries, e.g. the Consumer Quality Index in The Netherlands.3

The reasons for studying patient experiences can differ between countries. The motives vary from external accountability of health care providers to enhancing patient choice, improving the quality of care or measuring the performance of the health care system as a whole. Often, patient experience surveys serve multiple purposes. For example, the work of the Picker Institute in the English NHS aims at providing comparative information for the Care Quality Commission (previously the Healthcare Commission) and the public. Therefore, they serve external accountability and consumer choice. However, at the same time, providers use the results for internal quality improvement. To that end, the Picker Institute offers ‘Guides to Improvement’.

If the goal is consumer choice, this requires a comparison of patient experiences across health care facilities. Comparison in turn asks for the standardization of questionnaires and methods. The development of the American CAHPS surveys was an explicit attempt to standardize patient surveys in order to make consumer report cards. In other words, the initial aim of CAHPS was to facilitate consumer choice. However, recently the CAHPS consortium too has put considerable effort into the development of the so-called ‘CAHPS Improvement Guide’: a guide for health plans and health care providers seeking to improve their performance in the domains of quality measured by CAHPS surveys.

How do surveys like these help to improve the quality of care? According to Berwick, measuring quality indicators can improve the quality of care along two routes: selection or change.4 Selection takes place if public reporting of quality indicators stimulates individual consumers or their agents to choose better performing providers over worse ones. Change takes place if (internal) feedback on performance stimulates providers to engage in quality improvement activities. Fung et al.5 have reviewed the American experiences with public reporting of performance indicators. She found that evidence for a relation between public reporting of performance indicators and the quality of patient care is scant. However, the little available evidence suggests that:

- No, individual consumers do not often use this information (yet) to select better performing providers over worse performing ones; but,
- Yes, publicly releasing performance data stimulates quality improvement activity at the hospital level.

If this holds true for comparative information about patient experiences, the publication of these data can trigger health care providers to initiate quality improvement projects, even if individual consumers do not use this information in the choice of providers. Given this link between publication and improvement, the instruments used for external accountability and consumer choice should also be useful for internal quality projects. Therefore, an integrated data system for quality measurement and reporting is required, as James6 already argued in 2003.

From the work conducted in the USA and England, European countries who wish to introduce similar programmes of measuring quality of care from the patient’s perspective can learn at least three things:

1. Measure detailed patient experiences instead of overall patient satisfaction;
(2) introduce an integrated system for:
   (a) internal quality measurement and improvement on the one hand, and
   (b) external reporting and accountability on the other hand; and
(3) standardize questionnaires and methods.

However, this is probably easier said than done. This goes particularly for the last two recommendations: the use of integrated systems and standardization.

### Integrated systems

The introduction of an integrated system for internal measurement and improvement and external accountability implies that all stakeholders involved have to agree on what is being measured, and how and when. This means that the researchers who develop patient experience questionnaires must work miracles. Their questionnaires should meet the information needs of individual patients, doctors and managers, health insurers and watchdogs such as the Care Quality Commission in England or the Inspectorate for Health Care in The Netherlands.

Stakeholder involvement is a prerequisite for collecting information once and then using it for multiple purposes. Through stakeholder involvement, researchers must try to incorporate the needs of all the potential users of the information. In this process, they should pay specific attention to the involvement of patients and patient organizations. Because if public reporting of patient experiences can trigger doctors and managers to improve care delivery, it is essential that reporting takes place about those quality domains that matter most to patients. If reporting takes place only about topics such as parking lots or interior design, than those are the kinds of things that health care managers will worry about. If we want them to worry about core domains care managers will worry about. If we do not or cannot pay attention, or are they not told at all? Do they get an information leaflet? Is that written in a language they can understand? How exactly do doctors and nurses have to change their behaviour or their routines in order to improve this outcome?

### Standardization

Often, patient experiences are measured with the purpose of comparing the performance of different health care facilities. This is relevant both for consumer choice or selective contracting by insurers as well as for quality improvement through benchmarking. The wish to compare the performance of providers calls for standardization of questionnaires and methods. After all, we want to measure differences in performance, not differences in the wording of questions or in the composition of study samples.

For practical reasons, standardization—if at all—takes place on the national level. And even at this level, it is difficult enough to get national stakeholders to agree on what should be measured and how. Nevertheless, there are at least two reasons why international standardization might be relevant. First, there is an interest in comparing the performance of health care systems. Ever since the WHO published its World Health Report 2000, the quality of care as perceived by patients (the so-called ‘responsiveness’) has been seen as an integral part of the performance of systems. Therefore, in November 2007 OECD Member Countries endorsed plans to develop internationally comparable measures of responsiveness or patient experiences under the auspice of the Health Care Quality Indicators Project.

Secondly, there is the issue of consumer choice. In border regions in particular, citizens of the EU are becoming increasingly aware of the possibilities of cross-border health care consumption. Comparative information about the quality of care on both sides of the border should therefore be available. Last year, the European Commission proposed a directive of the European Parliament and of the Council on the application of patients’ rights in cross-border healthcare. In the draft text of this proposal, the Commission argues: ‘If patients cannot have access to the key medical, financial and practical information relevant to the healthcare that they are seeking, this clearly would constitute an obstacle to their freedom to receive health services in another Member State by making it difficult for patients to make a rational and informed choice between different providers including providers in other Member States’. Information about the experiences that previous patients had with certain providers is relevant for patient choice. In other words, patient experiences form part of the ‘key medical, financial and practical information’ that the Commission mentions. Therefore, the question of standardization of patient surveys needs to be addressed in a European context.

### References


Neutrality and translation problems in measuring patient experience

Picker Institute Europe develops and co-ordinates large parts of the national patient survey programme in the English National Health Service. We are in strong agreement with much of Diana Delnoij’s article, so it may be most useful to add some further learning from our experience, and to identify outstanding problems in harmonizing patient experience measurement in Europe.

Delnoij’s contention that ‘researchers who develop patient experience questionnaires must work miracles’ is apt. The stakeholder involvement she describes is prone to many tensions. A crucial lesson from England is that the survey programme needs a ‘buffer’ from undue stakeholder pressure if it is to remain intact, based on what patients value, and objective and reliable in its findings. Here, this ‘buffer’ was created by placing the survey programme under the independent healthcare regulator (now the Care Quality Commission).

Pressure on the survey methods can come from:

- healthcare organizations that score poorly for patient experience and wish to locate the fault with the survey method;
- healthcare organizations that score highly, or that wish to introduce more tailored or detailed local measurement, who may criticize the national survey as irrelevant;
- patient or consumer organizations for whom survey results do not always back their own assumptions or alternative evidence of poor performance;
- clinicians who are antipathetic to the use of patient views as a measure of their quality; and
- government, which is the ultimate funder, and which may wish to use the surveys to gather evidence for its own policy development, or to monitor the effects of its policies.

An independent regulator is accustomed to sit amid and to manage these diverse stakeholders. Thus, where countries are introducing systematic measurement, they will need to identify performance indicators in different patient groups. PhD Thesis, Rotterdam, Erasmus University, 2008.

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associated with translating survey instruments across borders.

While the care settings and general patient experiences of them may be similar, questionnaire design may encounter various problems related to cultural context and expectations, affecting the design of questions and response options. Careful development of the question areas using research with recent patients can help to mitigate these effects. Even clearly worded questions translated into another language may start to mean something different. Questions such as ‘were you treated with respect and dignity?’ could well be culturally dependent. Similarly, rating scales may need to be adapted according to regional/national expectations of what a particular ‘rating’ denotes—thus, in Veneto, we found far fewer patients willing to rate their overall care as ‘excellent’ compared with English patients, even when their responses to other questions suggested similar levels of satisfaction with the care they received.

Aside from the questionnaire itself, local considerations might suggest alternative methodologies (e.g. telephone rather than postal) or necessitate different sampling approaches. This highlights the need for rigorous development and piloting so that differences can be at best minimized or at least understood.

All these learning points suggest a graduated, developmental approach to establishing patient experience measurement in each European country, using experienced researchers, rather than governments signing up to an international standard and expecting their systems rapidly to deliver it.

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