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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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 a similar ‘buffered’ location to manage and defend the research. An academic institution may suffice, but its funding would need to be agreed at one remove from government to prevent it being unduly influenced to betray the principles and methods of rigorous measurement.

A further lesson from England is that surveys alone will not necessarily change provider behaviour (especially in the middle group of organizations receiving average scores). It is only during the last year, since the government made quality the ‘organizing principle’ of the NHS and identified patient experience as a key component, that the majority of organizations are beginning to take an active interest in what their patients report.

Other countries/regions will need to consider how best to align their incentives and ‘drivers’ so that the top tier of managers in healthcare organizations will take notice of their patient experience scores and actively respond, as with clinical and financial information. It may be best to organize incentives at ‘board’ or organizational level rather than at the level of the clinician or clinical team, as in our experience the latter display strong resistance to being judged by patient reports.

In some places in Europe, we see the beginnings of experimentation with systems that learn from the English experience. The National Health Service in Scotland—where health is devolved to the Scottish National Assembly—is preparing to start a national programme that will integrate qualitative methods with the quantitative surveys, and bind the NHS organizations into accountability for their improvement action plans.

In the Veneto region of Italy, the regional agency for social and health care (ARSS) commissioned Picker Institute Europe to provide methodological and technical support in order to develop a regional hospital survey closely following the English model. This experience has given us some insight into the problems 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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