Greater patient involvement

Sir Robert Francis was unequivocal in his report that patients, not numbers, are what count and he commented that it is not the system that would ensure patients are put first day in, day out.

Quality of care is about patient experience as well as outcomes, and decisions made with an impact on quality need to consider the views of patients to understand this. Evidence shows that patients who have been able to develop care in partnership with clinicians can improve the benefits of the care provided and save money.

Patients also offer a non-institutional perspective that can test the assumptions of NHS organisations to see if they really are more convenient and better for patients, and not just simply for services themselves. This is one reason why the NHS recognises the need for greater patient engagement in decision-making, as demonstrated by 92 per cent of NHS leaders stating patient engagement as either very or fairly important for achieving change.

Three key messages

1. Quality is about patient experience as well as outcomes, and decisions made with an impact on quality will need to consider the views of patients to understand this.

2. NHS organisations are getting better at including patient views in their decision-making but more can be done to recognise the value of greater patient involvement.

3. Patient-reported feedback and complaints are invaluable ways of encouraging patients to get involved in changing and improving the care they receive.

How important is greater engagement with patients and the public on strategic decision-making for achieving change? (NHS leaders, Nr=547)

- Very important: 54%
- Fairly important: 38%
- Fairly unimportant: 7%
- Very unimportant: 1%
However, patients we spoke to do not feel it is yet the norm to involve them in many decisions about the NHS.

Patients often felt NHS organisations have paid ‘lip service’ to their views without actually allowing them the opportunity to influence decisions. As such, they found it difficult to recognise where they were influencing decisions. Many also believed there was sometimes a mindset that saw them as a hindrance and not constructive in contributing to decision-making.

There seems, however, to be little disagreement among staff in the NHS that patients should be involved in decisions, as part of a shift to deliver better value. Most of the people we spoke to thought their organisation was getting better at including the patient perspective, but that more could be done to improve this.

In particular, they demonstrated the importance attached to patient feedback and complaints as part of the decision-making process, although they admitted that this was not often apparent to patients. This would also be the case with using information from patient reported outcomes measures (PROMs) to help guide decisions and understand the effectiveness of current services. Most agreed that the approach for many organisations moving forward should focus on meaningful engagement with patients and transparent feedback on how information from them is being used.

Patient feedback should be fed into decisions, just as any other data – seamlessly.

Clinical director