

○ Trends in patients' experience of the NHS

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The NHS patient survey programme

In 1997 the government launched its ambitious programme to improve the quality of health care, promising that “high quality health care should be a right for every patient in the NHS”. A new focus on patients’ experience was to be coupled with staff training and development to ensure that health care was truly patient-centred. At the same time they announced the new national patient survey programme, in which every NHS facility would be required to carry out regular surveys of a sample of their patients using standardised, validated postal questionnaires. The patient survey programme was designed to provide “systematic evidence to enable the health service to measure itself against the aspirations and experience of its users, to compare performance across the country, and to look at trends over time”.

The Picker Institute has been involved in running the national patient survey programme since its inception in 1998. Nineteen national patient surveys have been carried out in England since 1998, involving more than a million patients (n=1,186,277). Carried out for the Department of Health, the Commission for Health Improvement, the National Audit Office and the Healthcare Commission, these surveys have covered primary care, inpatients (adults and children), outpatients, emergency care, community mental health services, ambulance services, cancer, coronary heart disease and stroke. Instead of asking patients to indicate how satisfied they were with the care they received, the national surveys ask patients to provide factual reports on their experience.

Measuring patients’ experience

The main way in which patients’ views on healthcare performance have traditionally been sought is through the measurement of patient satisfaction. Satisfaction is an ill-defined concept which has been measured in many different ways. Generally recognised as multi-dimensional in nature, there is no consensus on which domains should be included or which are most important. Patient satisfaction is sometimes treated as an outcome measure, i.e. satisfaction with health status following treatment, and sometimes as a process measure, i.e. satisfaction with the way in which care was delivered.

Satisfaction ratings reflect three variables: the personal preferences of the patient, the patient’s expectations, and the realities of the care received. Public attitudes are influenced by many factors, including the media, commercial pressures and by patients’ interaction with health professionals. Expectations may also be influenced by cultural norms and by health status. Disentangling the effect of expectations, experience and satisfaction is a major problem when patients’ views are used to measure trends in performance in a particular hospital or other healthcare facility.

To help healthcare providers gain more reliable feedback from their patients, the Picker Institute has designed survey instruments to obtain detailed reports on their experience. Following qualitative research (interviews and focus groups) to find out what patients think are the most important features of their healthcare, fixed-response questionnaires

¹ Department of Health. The New NHS Modern Dependable. Cm. 3807, Dec 1997

are developed focusing on specific dimensions of patients' experience. Instead of asking patients to rate their care using general evaluation categories (e.g. excellent, very good, good, fair, poor), they are asked to report in detail about their recent experiences with a particular hospital, primary care organisation, or clinician. The questions ask respondents to say 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 occurred (experience), rather than the patient's evaluation of what occurred (satisfaction). In each case, the resulting data represent the perception of the patient. However, 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?"

This type of survey is generally more useful for helping providers to determine what action to take to address quality problems. Knowing that, say, 15% of patients rated their care as "fair" or "poor" doesn't give a manager or clinician a clear view of what they need to do to improve procedures and processes in their hospital. On the other hand, knowing more precise details of what went wrong, for example, the proportion of patients who felt they had to wait too long for the call button to be answered and monitoring trends over time in these indicators, can be much more useful. Focusing on the details of patients' experience can help to pinpoint the problems more precisely.

Our research has identified eight aspects of healthcare that patients consider most important:

- Fast access to reliable health advice
- Effective treatment delivered by trusted professionals
- Involvement in decisions and respect for preferences
- Clear, comprehensible information and support for self-care
- Attention to physical and environmental needs
- Emotional support, empathy and respect
- Involvement of, and support for, family and carers
- Continuity of care and smooth transitions.

Our studies for the national patient survey programme cover all aspects of health care, including primary care, emergency care and care for specific patient groups. Taking each of these dimensions in turn, and drawing on results from the national patient surveys², let's now examine whether patients think NHS care is improving or not.

² Not all of the surveys have been repeated every year, so the most recent results are reported in each case. Further information on the data sources can be found in the appendix.

Fast access to reliable health advice

Waiting times to see a GP or a consultant and to be admitted to hospital do seem to be improving quite dramatically according to respondents to the national patient surveys.

- In 2004 58% of primary care patients said they received a GP appointment as soon as they thought necessary; by 2005 the proportion had risen to 76%.
- In 2003, 75% of outpatients had their first appointment within three months of referral; by 2004 this had improved to 83%.
- In 2000, 70% of cancer patients saw a specialist within one month of referral; by 2004 this had improved to 80%.
- In 2002, 67% of patients undergoing emergency admission to hospital were allocated a bed within four hours of arrival; by 2004 this had improved to 74%.
- In 2005, 21% of primary care patients complained of inconvenient surgery opening hours; almost the same proportion as in 2004 (22%) and 2003 (20%).
- While most patients said they had sufficient time to explain their symptoms to the doctor or monitor their treatment, a significant minority would have liked more:
- In 2005 74% of primary care patients said they had sufficient time with the doctor; no change since 2004.
- In 2004, 75% of outpatients and 66% of A&E patients said they had sufficient time with the doctor or nurse. This represented no change since 2003 in outpatients, but an improvement of 4% in A&E.

Effective treatment delivered by trusted professionals

Most patients trust the doctors and nurses who treat them. The proportion expressing complete confidence and trust in health professionals is generally high and has remained stable:

- General practitioners – 76%
- Other primary care staff – 85%
- Hospital doctors – 80%
- Hospital nurses – 75%
- Psychiatrists – 59%
- Community psychiatric nurses – 73%
- Ambulance crew – 93%.

A minority of patients felt the staff they saw were insufficiently knowledgeable about their medical history or treatment:

- In 2004, 19% of outpatients said the specialist they saw did not seem fully aware of their medical history; the same proportion as in the previous year.
- In 2004, 17% of A&E patients felt that some of the staff they saw did not know enough about their condition and treatment; exactly the same proportion as in 2003.
- In 2005, 89% of stroke patients thought their stroke had been diagnosed quickly enough. Of those who did not receive a fast diagnosis, 33% felt their GP had not recognised that they had had a stroke and 40% blamed a hospital doctor.
- Pain relief for cancer patients appears to be handled relatively well and is improving, but some patients in other departments felt more could have been done to control their pain:
- In 2004, 85% of cancer patients said staff did all they could for their pain, an improvement on 2000 when the proportion was 81%.
- In 2004, 27% of inpatients and 44% of emergency department patients said they felt staff could have done more to ease their pain. This proportion had not improved since the previous surveys.
- Among children and teenagers in hospital, 23% said they were in pain all or most of the time and 31% felt that staff could have done more to help.

Involvement in decisions and respect for preferences

Many patients are not involved as much as they would like to be in decisions about their care and treatment. Expectations of involvement appear to be rising, but many health professionals are failing to make the necessary adjustments to their practice styles.

- In 2005, 69% of primary care patients said they were definitely involved as much as they wanted to be in decisions about their care; the same proportion as in 2004, but less than in 2003 when the proportion was 73%. Only 59% were involved as much as they wanted in medication decisions; and 17% of those referred to a specialist would have liked a choice about where to go but were not offered one.
- In 2005, 36% of respondents to the primary care survey had been referred to a specialist. Of this group, 26% were given a choice of which hospital they were referred to, 17% would have liked a choice but said they were not offered one (compared with 16% in 2004), and 57% were not given a choice but did not mind (compared with 58% in 2004).
- In 2004, 21% of outpatients and 26% of A&E patients said staff didn't always listen carefully to what they were saying; no improvement since the previous surveys.
- In 2004, only 53% of inpatients, 70% of outpatients, 64% of A&E patients and 61% of coronary heart disease patients said they definitely had a say in decisions about their treatment.

- In 2004, 32% of outpatients said they had not received a clear explanation of treatment risks, little improvement since 2003 when the proportion was 33%.
- In 2005, just over half of stroke patients (52%) said they had not been involved as much as they wanted in decisions about their care and treatment in hospital, including 19% who said they were not involved at all.

Patients with serious mental illness are supposed to be involved in determining their care plans, but many report shortcomings in this respect. However, there are signs that things are improving, albeit fairly slowly.

- In 2005, 40% of mental health patients said they definitely had enough say in decisions about their care and treatment; almost the same as in 2004 when the proportion was 41%. However, only 50% of these patients said they'd been given a written copy of their care plan, little improvement on 2004 when the proportion was 49%. More than half (58%) said they completely understood what was in their care plan, much better than in 2004 when only 47% said they completely understood it. There was also an improvement in the proportion indicating complete agreement with their care plan, from 55% in 2004 to 59% in 2005.

Involvement is much better in cancer care, but patients are becoming less satisfied, probably because expectations are rising.

- In 2000, 89% of cancer patients were satisfied with the extent to which they were involved in decisions about their care; by 2004 this had fallen to 85%.

Clear, comprehensible information and support for self-care

While most patients are positive about the way doctors and nurses communicate with them, they want more information about medicines, test results and referrals and more help with looking after themselves when they leave hospital.

- In 2005, only 22% of primary care patients had been given copies of all referral letters and other communications between their GP and the hospital and a further 8% said they'd received some but not all.
- In 2004, 80% of outpatients and 77% of A&E patients said they were given sufficient information about their condition and treatment.
- In 2004, 65% of inpatients said the doctors always gave clear explanations and comprehensible answers to their questions, no change since 2003, and 68% said the same of nurses, an improvement of 4% since the previous survey.
- In 2004, 38% of A&E patients, 32% of primary care patients and 35% of outpatients said the results of diagnostic tests had not been clearly explained to them.

Patients in primary care who receive prescriptions for new medicines are mostly satisfied with the information they receive, but there is a widespread failure to provide sufficient information on side-effects.

- In 2005, 80% said they were given sufficient information about the purpose of their medicine, and 86% said they were clearly told how to use the medicine, but only 61% said they received enough information about possible side-effects. These were exactly the same proportions as in 2004 and 2003.
- In 2004, 43% of inpatients, 39% of outpatients, and 49% of A&E patients said they were not given any information about possible side-effects of their medicines. This had not improved since the previous surveys.
- In 2005, only 37% of mental health patients said they were definitely told about possible side effects of their medicines, very little difference since 2004 when the proportion was 36%.

There have been significant improvements in the provision of information to patients with cancer and coronary heart disease, but many patients still do not receive sufficient information or education on how to look after themselves after leaving hospital.

- Cancer patients reported many improvements in the provision of information since 2000: in 2004, 61% were given written information about their diagnosis, up from 45% in 2000; 68% said they always received clear explanations about what was wrong with them, up from 62%; 76% said they were given understandable information about medicine side-effects, compared with 63% in 2000; and 70% said they understood doctors' answers to their questions, up from 88%.
- There has been an improvement since 1999 in the advice given to coronary heart disease patients on leaving hospital. In 2004, 25% said they were given no advice on when they could resume their normal activities, as compared to 35% in 1999; in 2004, 66% said they were given dietary advice, up from 35%.
- In 2005, 43% of stroke patients said they were not given information about dietary changes that might help prevent another stroke; 33% were not given information about physical exercise; and 62% said no one gave them information about possible side-effects of the medicines they had to take at home.
- In 2004, 40% of inpatients, 37% of outpatients, and 61% of A&E patients said they were not told about danger signals to watch out for, almost exactly the same proportions as in the previous surveys.

Attention to physical and environmental needs

Hospital patients are critical of standards of cleanliness and many complain about the food.

- In 2004, only 54% of inpatients said the ward they were in was very clean, slightly fewer than in 2002 when 56% responded positively. Only 48% said the toilets and bathrooms were very clean, down from 51% in 2002.
- In 2004, 46% of inpatients said the food was not good, very similar to 2002 when 47% said the same. Similarly, 48% of children and teenagers who had been admitted to hospital said the food was not good.
- There has been a slight downward trend in the proportion of primary care patients saying their local surgery or health centre is very clean, from 74% in 2003 to 73% in 2004 and 72% in 2005.

Slightly fewer patients are having to stay in mixed wards, but a substantial minority still complain about lack of privacy.

- In 2004, 22% of inpatients stayed in mixed wards, a reduction of 4% since 2002.
- There was evidence of some improvement in patient privacy in A&E departments: the proportion saying they had sufficient privacy for treatment discussions rose from 70% in 2002 to 72% in 2004, and for examinations from 78% to 80%.
- In 2004, 31% of inpatients complained of insufficient privacy for treatment discussions and 13% said that privacy was not good enough for physical examinations, exactly the same proportions as in 2002.
- Cancer patients were more satisfied with arrangements to protect their privacy, with 85% in 2004 saying they had sufficient privacy for treatment discussions and 97% saying the same for physical examinations, an improvement of 4% and 5% respectively since 2000.

Emotional support, empathy and respect

Most patients appreciate the emotional support they receive from staff when they have anxieties or fears, but there is still scope for improvement.

- In 2000 and in 2004, 94% of cancer patients said staff had told them their diagnosis with sufficient sensitivity and care. In 2004, 10% of patients were told the bad news by a nurse, compared to 6% in 2000.
- In 2004, 80% of cancer patients said hospital staff did everything they could to relieve their anxiety or depression while in hospital. Many (75%) also received emotional support from primary care staff.

- Among those cancer patients with strong religious beliefs, 90% said these were given due consideration by hospital staff.
- Children and young people who had been inpatients mostly felt able to discuss their fears and anxieties with staff: 60% said that nurses gave them emotional support and comfort whenever needed, but 10% felt they did not get any such support. 13% said they did not have an opportunity to discuss their fears about having an operation with doctors or nurses.
- Almost half (48%) of stroke patients said they had experienced emotional problems, such as confusion or depression, in hospital. Of these people, 40% said they had definitely received enough help and support with their emotional problems and 36% said they had received it only to some extent. Those in specialist units reported better support than those in other wards. After leaving hospital, 41% said they would have liked more support of this type.

Most patients say NHS staff always treat them with dignity and respect, but some complain that staff sometimes talk in front of them as if they weren't there.

- The proportion of primary care patients saying doctors always treat them with respect and dignity has remained very high at 92% in 2005, 92% in 2004, and 93% in 2003. The vast majority of patients treated by other primary care professionals also said they were always treated with respect: 95% in 2005 and 94% in 2004.
- In 2004, 79% of inpatients, 87% of outpatients and 79% of A&E patients said staff always treated them with respect and dignity.
- In 2004, 17% of A&E patients and 12% of cancer patients said doctors and nurses sometimes talked in front of them as if they weren't there. Among hospital inpatients, 28% said doctors did this and 20% said the same of nurses.
- In 2004, 87% of cancer patients said they were always treated with respect and dignity, an improvement from 79% in 2000.
- In 2005, 80% of mental health patients said psychiatrists treated them with respect and dignity and 85% said the same of community psychiatric nurses, little change since 2004.

Involvement of, and support for, family and carers

Support for carers shows signs of improvement, but there is still a long way to go.

- In 2004, 45% of inpatients said staff were always available when needed to talk to their family or carers, a slight improvement since 2002 when the proportion was 42%.
- In 2004, 67% of inpatients said their family or carers were given sufficient information about how to help with their convalescence and recovery on leaving hospital, exactly the same proportion as in 2002.

- 93% of young people were satisfied with the visiting hours in hospital and 78% said they felt their friends and relatives were definitely welcome.
- 95% of parents of sick children said they could stay overnight in the hospital when necessary, but 31% said the facilities for parents were only fair or poor.
- In 2004, 70% of coronary heart disease patients said their family was given sufficient opportunity to be involved in their treatment and care, a considerable improvement since 1999 when only 60% said this.
- In 2004, 71% of cancer patients said that family and friends were involved as much as they desired, a slight improvement over 2000 when 69% said this.

Continuity of care and smooth transitions

Care is not always well coordinated and some patients are still given insufficient information and support when moving between different care providers.

- In 2004, 31% of inpatients, 12% of outpatients and 16% of A&E patients said they were given conflicting information by staff, no change since the previous surveys.
- In 2004, 32% of inpatients said their diagnostic tests were not always performed on time, a deterioration since 2002 when the proportion was 29%.

Patients sometimes need help from statutory or voluntary services with sorting out crises, but many patients are not given information about how to access such help.

- In 2005, less than half (48%) of mental health patients had been given the phone number of a mental health professional if they needed help out-of-hours, no better than in 2004 when the proportion who'd been given a crisis line number was 49%.
- There has been an improvement in the proportion of mental health patients who have been given information about local support groups, from 53% in 2004 to 57% in 2005.
- Among cancer patients, in 2004 40% said they had not been given information about relevant support groups, no improvement since 2000 when the proportion was 39%.
- Only 36% of stroke patients said hospital staff had given them information about national stroke organisations or useful websites.

Long-term illness can have a serious impact on patients' employment and financial situation. Many patients would like help in dealing with these problems, but this is often not forthcoming from the health services.

- In 2004, 77% of cancer patients said they were not given any advice on financial or other benefits, but 48% said they would have liked some.

- In 2005 and 2004, 71% of mental health patients who responded to the surveys had no paid employment. More than half of all mental health patients said they would have liked help with finding work: 52% in 2005 and 53% in 2004.
- In 2005, nearly half of all mental health patients (48%) said they did not receive any help with accommodation, but they would have liked some.

Conclusions

In general most patients are very appreciative of the care they receive from NHS staff and there are some encouraging signs that patients' experience is improving.

Improvements have been most dramatic in those areas that have been the subject of coordinated action, e.g. hospital waiting times, cancer care, coronary heart disease and mental health, although there is still room for more improvement, particularly in care of mental health patients. Pain relief is another area where care could be better. Standards in primary care are high on the whole, leaving less scope for improvement, but many patients want more information, especially about their medicines.

The news is not all good. Many patients want more involvement in decisions that affect them, and better support for self-care. Although most patients are treated with dignity and respect by NHS staff, there are signs that care is still too often delivered in a paternalistic manner, with many patients given little opportunity to express their preferences or influence decisions about their care. Transitions between different health care providers, and between hospital and home, are not as well-coordinated as they should be. Many patients need better help with recovery and rehabilitation, including financial and employment advice and information about relevant support services. This need is especially acute for those with long-term problems, such as cancer and mental illness.

Nevertheless, the patient survey results show that the quality of NHS care is improving, albeit not always as quickly and as comprehensively as many of us would like. This is encouraging because it demonstrates that improvement is possible when awareness of the patient's perspective is increased. The Picker Institute's work with health care staff, particularly through our Patients Accelerating Change programme, demonstrates that making the effort to understand and accommodate to patients' needs can lead to improvements that patients notice³.

However, there's still more work to be done. The survey results reveal considerable variations in the quality of care in different sectors and institutions, suggesting that some need to pull their socks up quite significantly to match standards of care provided by the best. Health care staff working in busy facilities face considerable pressures, but if some can deliver truly patient-centred care there's no reason why it should not be possible for all. The key is to make use of patient feedback to monitor service quality and to act promptly whenever problems are revealed.

³ Patients Accelerating Change. NHS Clinical Governance Support Team and Picker Institute Europe, 2005

Appendix: National patient survey programme for England

Primary care

1998: general practice (n=61,426, response rate 64%), NHS Executive, 1999 ^{4*}
2003: primary care (n=123,833, response rate 49%), Commission for Health Improvement, 2004
2004: primary care (n=122,113, response rate 49%), Healthcare Commission, 2004
2004: ambulance services (n=12,282, response rate 51%), Healthcare Commission, 2004
2005: primary care (n=116,939, response rate 47%), Healthcare Commission, 2005

Hospital care

2002: inpatients (n=95,280, response rate 64%), Department of Health, 2002
2003: outpatients (n=90,552, response rate 63%), Commission for Health Improvement, 2004
2003: emergency (n=59,155, response rate 46%), Commission for Health Improvement, 2004
2004: adult inpatients (n=88,308, response rate 63%), Healthcare Commission, 2004
2004: young patients (n=62,277, response rate 50%), Healthcare Commission, 2004
2004: outpatients (n=84,280, response rate 59%), Healthcare Commission, 2005
2004: emergency (n=55,339, response rate 44%), Healthcare Commission, 2005

Patient groups

1999: coronary heart disease (n=84,310, response rate 74%), Department of Health, 2001
2000: cancer (n=65,337, response rate 74%), Department of Health, 2002
2004: mental health (n=27,398, response rate 42%), Healthcare Commission, 2004
2004: cancer (n=4,323, response rate 55%), National Audit Office, 2005
2004: coronary heart disease (n=3,784, response rate 75%), Healthcare Commission, 2005
2005: stroke (n=2,786, response rate 65%), Healthcare Commission, 2005
2005: mental health (n=26,555, response rate 41%), Healthcare Commission, 2005

To date, a total of 1,186,277 NHS patients have participated in the national patient survey programme.

Notes

The Picker Institute was involved in designing and coordinating all the above surveys. The organisations responsible for commissioning the patient surveys have changed frequently (NHS Executive, Department of Health, Commission for Health Improvement, Healthcare Commission and National Audit Office) reflecting wider organisational changes affecting the NHS in recent years.

The Picker Institute has carried out patient surveys in selected trusts in Scotland, Wales, Northern Ireland and the Channel Islands, but the national programme relates to England only.

⁴ In this case the sampling frame was the electoral register. For all other surveys names were drawn from trust records.

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