

Is the NHS getting better or worse?

**An in-depth look at the views
of nearly a million patients
between 1998 and 2004**

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Picker Institute Europe

The Picker Institute works with patients, professionals and policy makers to promote understanding of the patient's perspective at all levels of healthcare policy and practice. We undertake a unique combination of research, development and policy activities which together work to make patients' views count. There are three key strands to our work:

- Measurement - researching and evaluating patients' experience
- Improvement - leading initiatives that make improvements happen
- Policy - building evidence to inform health policy.

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Executive summary

1. The Picker Institute works with patients, professionals and policy makers to promote understanding of patients' needs at all levels of health care policy and practice. Since 1998 the Institute has been involved in running the national patient survey programme for the NHS in England, developing the survey methodology and questionnaires, implementing the surveys and analysing the results. The Institute currently coordinates the survey programme on behalf of the Healthcare Commission.
2. This report draws together key findings from 15 national (England only) patient surveys carried out between 1998 and 2005. The individual surveys were commissioned and published by the Department of Health, the Commission for Health Improvement, the Healthcare Commission and the National Audit Office. A total of 917,883 patients participated in these postal surveys and response rates ranged from 42% to 75%.
3. The findings of the surveys are summarised in this overview in relation to the eight aspects of health care that patients consider most important. These data enable an independent assessment of whether the quality of NHS care is getting better or worse from the patient's point of view.
4. Priority areas which have been the focus of co-ordinated action and investment, such as waiting times, cancer care and coronary heart disease, have seen major improvements. Levels of satisfaction with NHS care are high and improving, but these overall ratings mask some key problem areas.
5. The survey findings show that patients still want more information, more involvement in decisions about their care, more help when transferring from hospital to home, and easier access to their GP with appointments at more convenient times.
6. Hospital cleanliness is of increasing concern to many patients. Many patients need better help with pain relief and more information about medication side-effects.
7. The quality of patients' experience of the NHS in England is improving, but there's still a long way to go before the service can be said to be truly patient centred.

Introduction

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”.¹ 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 survey their patients on an annual basis, 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”.¹

The Picker Institute has been involved in running the national patient survey programme for the NHS in England since its inception in 1998, developing the survey methodology and questionnaires, implementing the surveys and analysing the results. The Institute currently coordinates the survey programme on behalf of the Healthcare Commission, but the programme was originally launched by the Department of Health, until it was taken over by the Commission of Health Improvement, the precursor of the Healthcare Commission. The Picker Institute has also carried out patient surveys for other national bodies, including the National Audit Office, and for individual hospital trusts in Scotland, Wales and Northern Ireland.

Fifteen national patient surveys have been carried out in England since 1998. Several of these have now been repeated with similar patient samples on at least two occasions, enabling an examination of trends. Just under one million patients (n=917,883) have participated in these postal surveys, with response rates ranging from 42% to 75%. These data provide the most reliable evidence available on the quality of care experienced by NHS patients in England.

This report draws together for the first time key findings from all fifteen surveys to assess progress on each of the eight dimensions of health care that patients say are most important to them.

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

What patients want

Extensive in-depth research carried out by the Picker Institute has distinguished eight aspects of healthcare that patients consider most important:

- **Fast access to health advice**
- **Effective treatment delivered by staff you can trust**
- **Involvement in decisions and respect for patients' preferences**
- **Clear, comprehensible information and support for self-care**
- **Physical comfort and clean, safe environment**
- **Emotional support and alleviation of anxiety**
- **Involvement of family and friends and support for carers**
- **Continuity of care and smooth transitions.**

Fast access to health advice

Hospital waiting times are getting shorter, but access times have not improved in primary care since 2003. Patients are less satisfied with consultation length in general practice than they were in earlier surveys, but Accident and Emergency (A&E) patients reported some improvement in the length of time with the doctor. While most patients said they had sufficient time to explain their symptoms or monitor their treatment, a significant minority would have liked more.

- **In 2003, 75% of outpatients had their first appointment within 3 months of referral; by 2004 this had improved to 83%.**
- **In 2002, 22% of patients waiting for elective admission had their admission date changed; in 2004 the proportion was 21%.**
- **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 4 hours of arrival; by 2004 this had improved to 74%.**
- **In 2004, 22% of primary care patients complained of inconvenient surgery opening hours, a slight deterioration since 2003 when the proportion making this complaint was 20%.**
- **In 2004, 23% of primary care patients said they had to wait more than 2 working days for an appointment; no change since 2003. The 1998 general practice survey asked a differently-worded question, but found that 19% of patients felt they had to wait too long for an appointment.**
- **In 2004, 74% of primary care patients, 75% of outpatients, and 66% of A&E patients said they had sufficient time with the doctor or nurse. This represented no change in outpatients since 2003, but an improvement of 4% in A&E. In 1998 87% of general practice patients said they had sufficient time with the doctor, suggesting that time pressures in primary care have increased over the six year period.**

Effective treatment delivered by staff you can trust

Most patients trust the doctors and nurses who treat them, but a significant minority said that staff could have done more to ease their pain.

- **In 2004, 76% of primary care patients said they definitely had confidence and trust in their GP, while 80% of inpatients and 81% of outpatients had confidence and trust in the hospital doctors they saw.**
- **In 2004, 75% of inpatients said they always had confidence and trust in the nurses and 73% of emergency department patients said the same of doctors and nurses.**
- **93% of patients who had used ambulance services said they had complete confidence in the crew's professional skills.**
- **Only 59% of mental health patients said they definitely had confidence and trust in their psychiatrist, but 73% had confidence in their community psychiatric nurse.**
- **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 department patients felt that some of the staff they saw did not know enough about their condition and treatment, exactly the same proportion as in the previous year.**
- **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 A&E 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 patients' 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 and dissatisfaction with this aspect of care is increasing. However, most patients report that staff treated them with respect and dignity most of the time.

- 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, 47% of inpatients, 30% of outpatients, 36% of A&E patients, 32% of primary care patients, 39% of coronary heart disease patients and 59% of mental health patients said they would have liked more involvement in decisions about their care.
- 51% of mental health patients said they had not been given a copy of their care plan and 24% said they did not understand what was in their plan.
- 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%.
- In 2004, 32% of outpatients said they had not received a clear explanation of treatment risks, no change since 2003 when the proportion was 33%.
- In 2004, 87% of cancer patients said they were always treated with respect and dignity, an improvement from 79% in 2000.
- In 2004, 79% of inpatients, 87% of outpatients and 79% of A&E patients said staff always treated them with respect and dignity.
- 79% of mental health patients said psychiatrists treated them with respect and dignity and 85% said the same of the community psychiatric nurses.
- 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.

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 their test results and their medicines and more help with looking after themselves when they leave hospital. There have been significant improvements in the provision of information to patients with cancer and coronary heart disease, but other patients report little improvement.

- **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 that 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.**
- **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 to 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 advice about physical exercise, up from 42% in 1999, and 54% were given dietary advice, up from 35%.**
- **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.**
- **In 2004, 43% of inpatients, 39% of outpatients, 49% of A&E patients and 35% of mental health patients said they were not given any information about possible side-effects of their medicines. This had not improved since the previous surveys.**
- **There has been no improvement in information or education for most patients in how to monitor their condition. 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.**

Physical comfort and a clean safe environment

Standards of cleanliness seem to have worsened (or patients' expectations have risen) and nearly half of inpatients are critical of hospital food. There has been a small reduction in the number of inpatients staying in mixed-sex wards. Some patients complain of insufficient 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%.**
- **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.**
- **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.**
- **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 it was 47%. Similarly, 48% of children and teenagers who had been admitted to hospital said the food was not good.**

Emotional support and alleviation of anxiety

Most patients are appreciative of 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 and 75% said primary care staff gave enough emotional support.**
- **Among those cancer patients with strong religious beliefs, 90% said they were taken into 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.**
- **Among children and young people in hospital, 60% were fully satisfied with the availability of toys and entertainment facilities.**

Involvement of family and friends and support for 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.**
- **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.**
- **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.**

Continuity of care and smooth transitions

Patients are still given insufficient information and support when moving between different care providers and care is not always well coordinated, particularly for mental health patients. Discharge planning has improved for cancer patients.

- **Among cancer patients there was an improvement in the proportion saying that their family and home situation was taken into account in discharge planning, from 74% in 2000 to 82% in 2004.**
- **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%.**
- **51% of mental health patients said they had not been given a number to call if they needed help out of office hours.**
- **71% of mental health patients had no paid or voluntary work, and 53% said they had not received any help with finding work although they would have liked it. 31% would have liked more help with getting benefits.**
- **47% of mental health patients received no information about local support groups.**
- **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 2004 40% of cancer patients said they were not given information about relevant cancer support groups, no improvement since 2000 when the proportion was 39%.**

Overall satisfaction with care

Most patients are very appreciative of their care and there are signs of improvement, particularly for inpatients and those using A&E services.

- **In 2004, 77% of inpatients rated their care as excellent or very good, compared to 74% in 2002.**
- **In 2004, 78% of outpatients rated their care as excellent or very good, exactly the same proportion as in 2003.**
- **In 2004, 70% of emergency department patients rated their care as excellent or very good, compared to 66% in 2003.**

The Picker Institute's assessment

- **The government's targets are having an effect. Patients' experience has improved significantly in those areas that have been the subject of coordinated action, e.g. hospital waiting times, cancer care and coronary heart disease.**
- **Access to primary care has not improved and there are signs that it may be getting worse. The timing of the surveys did not allow an assessment of the impact of the new GP contract, but anecdotal reports from patients indicate increasing difficulties with getting an appointment at a convenient time.**
- **Patients want more information, more involvement in decisions that affect them, and more support for self-care. Although most patients are treated with dignity and respect by NHS staff, there are signs that care is still delivered in an overly paternalistic manner.**
- **Hospital patients are becoming increasingly concerned about hospital cleanliness. This may be the result of greater media coverage of MRSA and other superbugs, rather than any deterioration in cleanliness per se, but standards of cleanliness are still poor in many NHS facilities.**
- **Many patients need more help with pain relief.**
- **Many patients want more information about their medicines, especially information about side-effects.**
- **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.**
- **Levels of satisfaction with NHS care among those using the service are high and improving, but these overall ratings mask some key problem areas.**
- **The quality of patients' experience of the NHS in England is improving, but there's still a long way to go before the service can be said to be truly patient centred.**

National Patient Survey Programme for England

To date **917,883** NHS patients have participated in the National Patient Survey Programme which consists of the following surveys:

General practice 1998 (n=61,426, response rate 64%), NHS Executive, 1999*

Coronary heart disease 1999 (n=84,310, response rate 74%), Department of Health, 2001⁺

Cancer 2000 (n=65,337, response rate 55%), Department of Health, 2002⁺

Inpatients 2002 (n=95,280, response rate 64%), Department of Health, 2002⁺

Outpatients 2003 (n=90,552, response rate 63%), Commission for Health Improvement, 2004⁺

Accident and emergency 2003 (n=59,155, response rate 46%), Commission for Health Improvement, 2004⁺

Local health services (primary care) 2003 (n=123,833, response rate 49%), Commission for Health Improvement, 2004⁺

Adult inpatients 2004 (n=88,308, response rate 63%), Healthcare Commission, 2004⁺

Mental health 2004 (n=27,398, response rate 42%), Healthcare Commission, 2004⁺

Ambulance services 2004 (n=12,282, response rate 51%), Healthcare Commission, 2004⁺

Young patients 2004 (n=62,277, response rate 50%), Healthcare Commission, 2004⁺

Outpatients 2004 (n=84,280, response rate 59%), Healthcare Commission, 2005⁺

Emergency department 2004 (n=55,339, response rate 44%), Healthcare Commission, 2005⁺

Cancer 2004 (n=4,323, response rate 55%), National Audit Office, 2005⁺

Coronary heart disease 2004 (n=3,784, response rate 75%), Healthcare Commission, 2005⁺

* Sampling frame was electoral register

⁺ Sampling frame was trust records

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. The Picker Institute is also coordinating this year's surveys due to be published by the Healthcare Commission later in 2005. These include primary care, inpatients, outpatients, A&E patients, mental health and stroke patients.

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