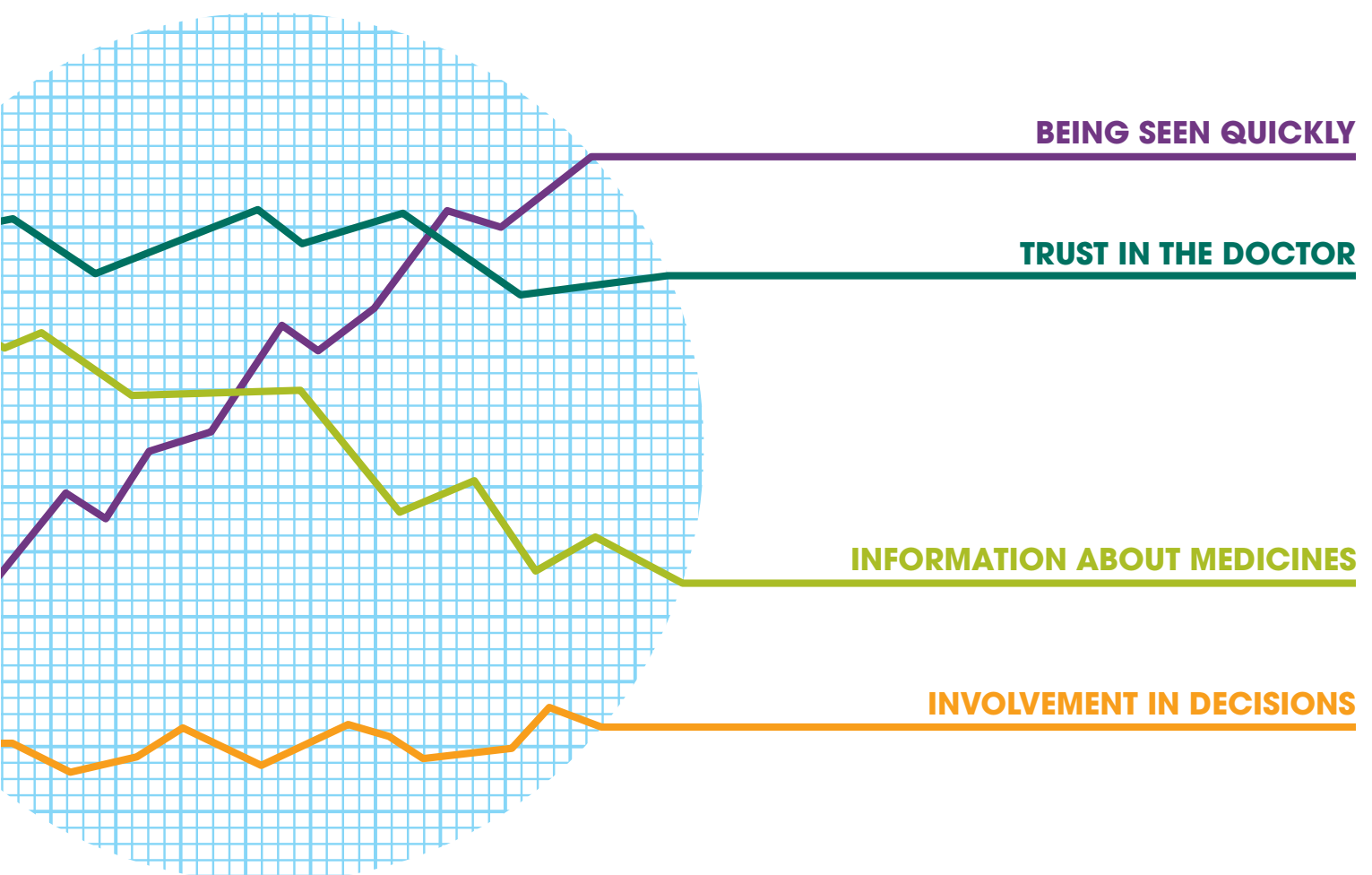


IS THE NHS BECOMING MORE PATIENT-CENTRED?

Trends from the national surveys of NHS patients in England 2002-07

NICK RICHARDS, ANGELA COULTER
SEPTEMBER 2007



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

This report draws on the results of 26 national patient surveys carried out under the auspices of the NHS patient survey programme in England to assess the quality of NHS care through patients' eyes.

These surveys have obtained detailed reports on the experience of care of nearly one and a half million NHS patients. In many cases it is now possible to compare results year-on-year since 2002, enabling examination of progress towards a more patient-centred service.

Key findings are as follows:

- waiting times have improved
- access to GP advice has become more difficult for some patients
- most patients trust health professionals
- hygiene and cleanliness shows some improvement but results are mixed
- hospital food is still disliked by many patients
- the hospital environment could be better
- community mental healthcare is improving in many aspects
- communication skills are mostly good....
-but information needs are not always met
- the availability of hospital staff has deteriorated
- many patients want more involvement in decisions
- patients want to be involved in medication choices too
- professionals are giving less information about side-effects
- shared decision-making isn't widely practised
- some patients don't receive enough help with self-care
- patients aren't actively encouraged to give their views
- information about patients isn't shared with them
- most patients give positive ratings of their overall care.

NHS care has improved significantly in some important respects and most patients are highly appreciative of the care they receive, but despite pockets of excellent practice the service as a whole is still far from patient-centred. The most significant problem is the failure of clinical staff to provide active support for patient engagement.

Some organisations achieve much better performance than others, demonstrating that excellence is possible. The challenge now is to encourage all organisations to strive to match the performance of the best.

Introduction

The question of how well the NHS is performing is on the daily agenda of politicians, the media, and the hundreds of thousands of people who work for the public purpose of keeping the nation healthy.

A litmus test of NHS performance must be to ask its users, not just what they 'think', but what is actually happening to them when they receive their care and treatment. A 'patient-centred NHS' must first and foremost know what impact it is having on patients.

This is what the national patient survey programme has been doing since 2002. From its results, we know what, *for patients*, have been the benefits of NHS expenditure and reform – and we know what, amongst the things that most affect patients' experience, has not improved or indeed may have worsened.

In some aspects of care, when patients tell the same story as the 'official' one we can be sure that the claimed improvements are real.

In other aspects, patients tell a different story – as when they recently reported that, contrary to what was being claimed, mixed sex accommodation was still a daily reality for tens of thousands of people in hospital.

Just as important is when patients' experience serves to highlight some of the weaknesses in health service quality that are not on anyone's radar but ought to be. Patients, if we will take note, are pointing us towards challenges for the future of the NHS.

Background

The Labour government came to power in 1997 promising to modernise the NHS. Ten years on there have been a number of attempts to assess the extent to which the Government's goals are being achieved. Most informed commentators agree that the latest round of reforms has led to some significant improvements, but many difficult challenges still need to be tackled.¹

A key goal of recent policy reforms, and of the current Darzi review, is to make the service more patient-centred.² This includes the enduring challenge of how to improve patients' experience of care.

Government targets can help. In 2005 a previous Picker Institute analysis of results from the national NHS patient surveys concluded that those areas that had been the subject of co-ordinated action, for example hospital

1 King's Fund: Health and ten years of Labour government (30-4-07) <http://www.number-10.gov.uk/output/Page11575.asp>

2 Shaping health care for the next decade, DH news release, 4th July 2007

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waiting times, cancer care, coronary heart disease and mental health, were showing encouraging signs of improvement.³

But centrally-imposed targets don't make much difference to those patients who don't happen to belong to a priority group. The Picker Institute report drew attention to worrying signs that care for the majority was still delivered in a paternalistic manner, with many patients given little opportunity to express their preferences or influence decisions.

Since that time, more national surveys have been carried out. We now have results from 26 surveys, giving reports on the experience of nearly one and a half million patients. This allows us to look at trends over a longer time period giving a better picture of the way things are progressing.

In this report we use the survey results to return to the question we grappled with two years ago: is the NHS getting better or worse as far as patients are concerned?

About patient experience surveys

Patient experience surveys were pioneered in the UK by the Picker Institute when the first national hospital survey was organised in 1994.⁴ The Department of Health commissioned a national survey of general practice patients in 1998; but a national programme was taken up from 2002, run first by the Commission for Health Improvement and now by its successor, the Healthcare Commission.⁵ The national programme – and the results included in this report – covers England only.

It is open to any NHS organisation at any time to conduct a survey of its patients. But the national patient survey programme requires at least one survey per NHS trust per year. These surveys can be used for the following purposes:

- each individual trust can see detailed patient feedback on its performance. It can benchmark this against its own previous results to see whether it is getting better or worse in particular aspects, and it can compare its results to national averages and to trusts of a similar type or location
- the regulator of healthcare organisations, the Healthcare Commission, can use the results as part of its annual health check of trusts' performance, its service reviews and investigations into service failings
- the trust-level results can build up a national picture of the NHS (in England) which is available to policy makers and researchers – and to the public, if they knew about it.

This programme should have a key role in service improvement. By enabling NHS organisations to see areas of weakness, it can enable them to focus their plans for improving quality.

3 Coulter A. Trends in patients' experience of the NHS. Oxford: Picker Institute Europe, 2005

4 Bruster S, Jarman B, Bosanquet N, Weston D, Erens B, Delbanco T L. National survey of hospital patients. British Medical Journal 1994; 309: 1542-9

5 In 2009 the Healthcare Commission will merge with the social care regulator, CSCI. A Bill to enact this has been promised in the November 2007 Queen's Speech

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The Picker Institute's approach to surveying patients

The Picker Institute is an approved provider of surveys for the national programme, and carries out surveys for individual trusts. On behalf of the Healthcare Commission it also acts as the national co-ordinator for the hospital and primary care surveys. The Picker Institute also provides bespoke survey services to NHS bodies and other organisations, including staff surveys and surveys of specific patient groups, for example those with particular diseases or conditions. In addition to its surveys for NHS trusts in England, the Picker Institute has also carried out patient surveys in Scotland, Wales, Northern Ireland and the Channel Islands.

On the basis of this evidence and its other independent research, the Picker Institute works to improve the quality of patient care with NHS staff and with a variety of other organisations involved in the NHS, in professional regulation and in representing patients' views. It is consulted frequently by government, the Department of Health, parliamentary groups and committees, and health professional bodies.

Central to the survey methodology developed by the Picker Institute and adopted for the national programme is to measure *actual experience* as opposed to 'satisfaction', although most surveys also include a question asking patients to say how satisfied they were with their overall care.

'Satisfaction' is an ill-defined concept and there is no agreement as to what it should include. It may be strongly affected by the patient's own preferences and expectations, or by prevailing public attitudes, among many other factors. That is significant because studies show that there are systematic differences between the views of the public as a whole, and the views of patients.

Moreover, 'satisfaction' ratings do not provide very useful results for the purposes of service quality improvement. Knowing that 75% of people were 'satisfied' with a service does not tell us anything about what is going wrong for a quarter of service users – so we do not know how to put it right.

Also, a patient may express 'satisfaction' with a consultation overall, while still being dissatisfied with one partial, but possibly significant, aspect of it. This is especially the case in the NHS where patients by and large trust, like and respect their health professionals and do not want them to be given bad ratings.

Patient experience surveys, by contrast, ask each recent patient to recall and report on what happened to them in each detailed aspect of their encounter with the service. This means that they can say, for example, that they were treated with dignity and respect by staff, while at the same time reporting that sometimes there was not a staff member to talk to, or that they did not always understand the information they were given.

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Patients are asked to report on their experience of specific episodes of care, for example a recent hospital stay, or, for services that are used on a continuous basis, for example GP care, over a specific time period such as the previous twelve months.

At trust or service level, the aggregation of this reported experience means that, while satisfying itself that quality is good in some aspects, an NHS organisation can also see specific areas that need further action.

The 2006 national survey of hospital inpatients, for example, showed that 90% said their care was “good”, “very good”, or “excellent” – which was taken as a vote of confidence in the NHS. But at the same time this was the survey that exposed the fact that patients were still sharing wards and sanitary facilities with patients of the opposite sex, triggering action from the Chief Nursing Officer.

Measuring what matters to patients

One could survey patients about anything. A national survey of patients’ experience of car parking at hospitals would tell us a great deal about how much they are paying and how easy it is to park. But does car parking really matter to patients?

Patients say no. Although car park charges can be an irritant, when asked to rank their importance against other factors, such as the quality of treatment provided by a doctor, or whether their consultation took place in privacy, car parking disappears down the ranking.

We have to make sure we measure what is important to patients themselves. Therefore the *methodology* of the patient experience surveys is important. Each time a new survey questionnaire is developed, patients are interviewed to find out what they think are the most important aspects of their healthcare. Specific questions are developed, but are then further tested to ensure that they do, indeed, cover the most important matters, and that their wording and the response options make sense to patients.

From its experience of talking to large numbers of patients in interviews, focus groups and surveys, the Picker Institute has identified eight aspects of care 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.

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If all these things are working well, care can be said to be truly patient-centred. So the results of the NHS patient surveys, which include questions about all the above topics, provide the best means of determining whether the government's goal of a patient-centred service is close to being achieved.

Interpreting the survey results

The national surveys involve mailing questionnaires to random samples of patients who have recently received care in an NHS trust in England (usually 850 patients per organisation). Up to two reminders are sent to non-respondents to encourage good response rates.

The differences between surveys over time commented on in this report may seem small (often only one or two percentage points), but because the size of the total sample is so large, any changes from previous surveys are almost certain to be real (and not a result of chance or the way the survey was conducted).

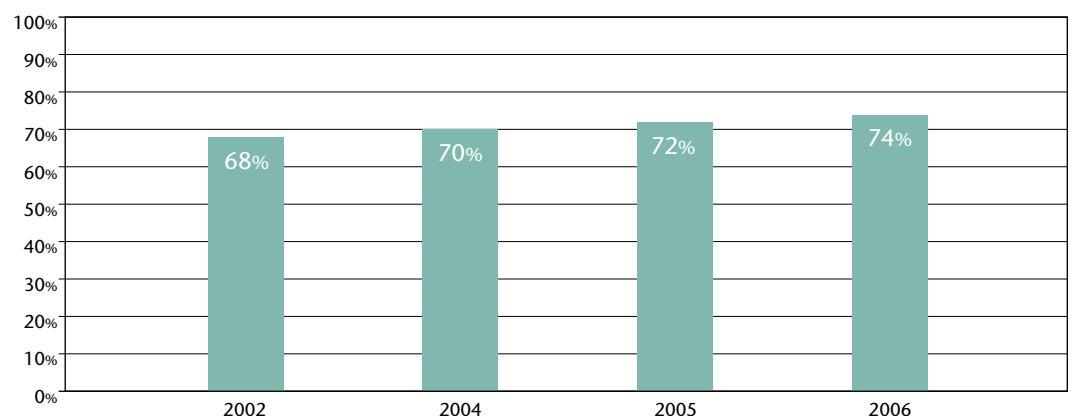
2 Review of progress

Waiting times have improved

Reports from patients sometimes conflict with the picture derived from official statistics, but when it comes to hospital waiting times both sources concur. The unacceptably long waits that many patients had to endure in the past are now much less of a problem.

- In 2006, 77% of primary care patients said they received a GP appointment as soon as they thought necessary, a slight improvement on 2005 when the proportion was 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 2006 74% of people who had planned admissions to hospital thought they were admitted “as soon as necessary”, a steadily improving trend (figure 1).⁶

Figure 1: Proportion of patients who were admitted to hospital “as soon as necessary”



Nevertheless some patients do still have to wait too long.

- 28% of patients undergoing emergency admission to hospital in 2006 said they had to wait more than four hours after arrival for allocation of a bed. This was worse than 2005 when the proportion was 25%, but better than 2002 when this problem was reported by a third of patients (33%).

⁶ Results for the inpatient surveys include patients aged 16+ for 2002, 2005 and 2006, but the 2004 survey includes those aged 18+ only

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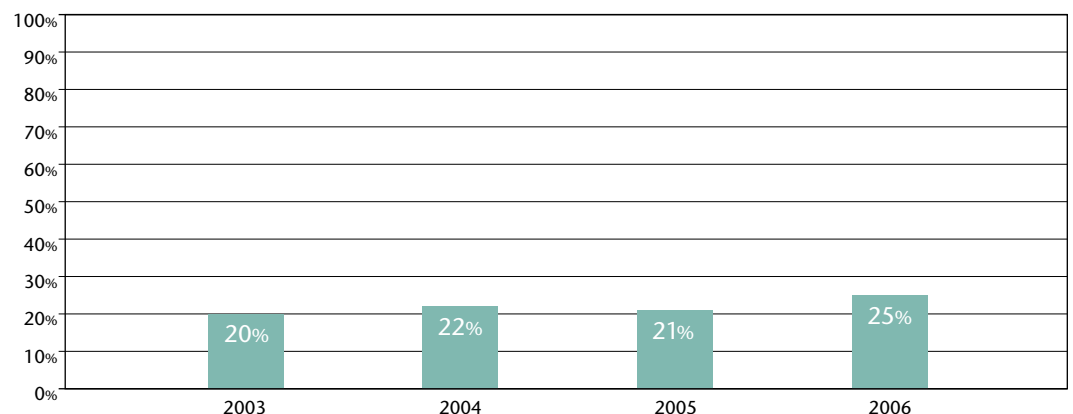
The steady reduction in waiting times is an impressive achievement, but the fact that some emergency patients have to face long waits for a bed is an indication of the pressure that hospitals are under.

Access to GP advice has become more difficult for some

Changing employment patterns and new contracts have encouraged many GPs to give up their 24-hour commitment, causing patients to rely on alternative arrangements for out-of-hours care, for example hospital emergency departments, minor injury units or walk-in centres. The most obvious manifestation of the change has been the closure of most general practice-based Saturday morning clinics.

- In 2006 25% of primary care patients said they had been put off going to their GP because practice opening times were inconvenient. This was worse than in previous years (figure 2).

Figure 2: Proportion of patients who said general practice opening times were inconvenient



- The 2006 primary care survey asked patients about their preferences for general practice opening hours: 34% said they would like the surgery to stay open for longer in the evenings and 29% said they would like it to open on Saturdays.

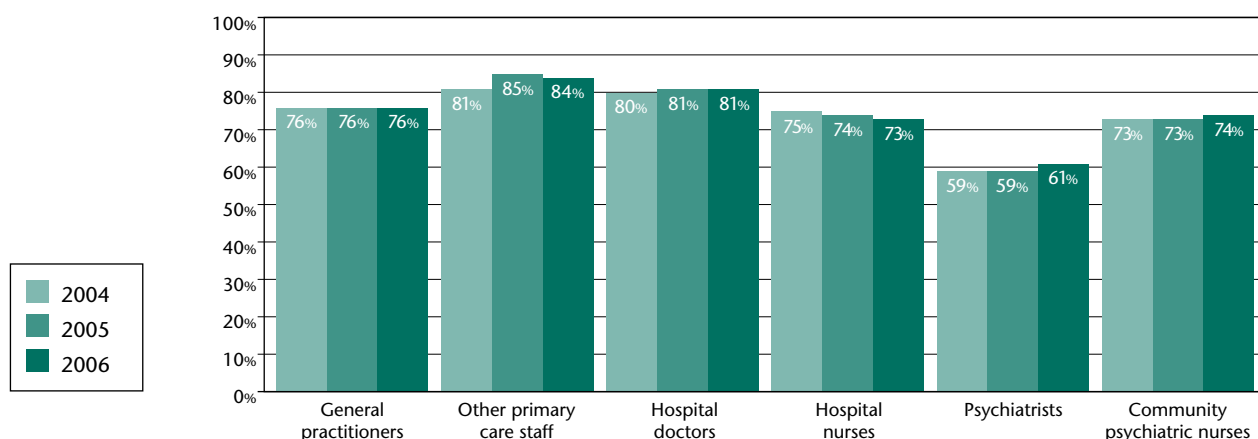
Most general practices used to open only for urgent cases on Saturday mornings, but these survey results suggest that some patients resent the loss of a familiar local service. In the 2006 survey, 69% of patients said it would be "acceptable" for surgeries to close for part of a weekday in order to open at a more convenient time.

Others may find it difficult to get time off work during the day, so evening clinics would suit them better. Walk-in clinics provide an alternative to general practice care in some places, but they are not available everywhere.

Most patients trust health professionals

Confidence and trust in healthcare professionals remains high, and in the case of psychiatrists, community psychiatric nurses and primary care nurses has improved. There has been a slight deterioration, however, in the number of patients expressing confidence and trust in hospital nurses. The proportion of patients expressing “complete” confidence and trust in healthcare professionals is shown in figure 3.

Figure 3: Proportion of patients who had complete confidence and trust in the healthcare professionals treating them (2004-6)



Patients have continued to give positive reports on the interpersonal skills of healthcare professionals. Most patients say they were treated in a respectful and dignified manner.

- In 2006, as in previous years, 92% of primary care patients said that the doctor always treated them with respect and dignity, while 7% said this only happened “some of the time” and only 1% stated that the doctors had not treated them with respect and dignity.
- In 2006, 78% of inpatients said they were “always” treated with respect and dignity while in hospital, as compared to 79% in 2005 and 2002.
- Overall, 79% of stroke patients said they were “always” treated with respect and dignity while they were in hospital in 2004. However, those on a specialist stroke unit (82%) responded more positively than those on other wards (74%).

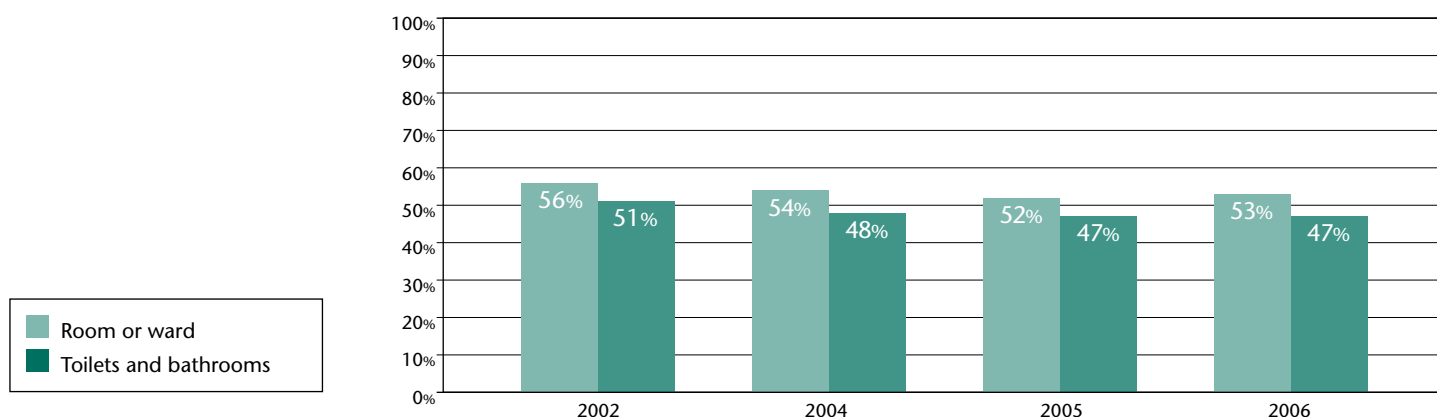
Trust in the health professionals advising or caring for them is an important ingredient in patients’ recovery, so these results are encouraging. However, trust is not equivalent to blind faith; it has to be earned. Failure to meet patients’ expectations in terms of providing safe, effective care, good communication skills, comprehensible information, respectful treatment, and empathy can undermine trust, and can potentially lead to worse health outcomes. Provider organisations should monitor these indicators very carefully and take swift action to deal with any problems if they wish to retain the trust and confidence of their patients.

Mixed results for hygiene and cleanliness

In 2006, patients reported some improvements in cleanliness and hand washing compared to the 2005 results, but reports of hospital cleanliness were worse than they had been in 2002.

- 75% of primary care patients said that the doctor’s surgery was “very clean”, up from 74% in 2003, 73% in 2004 and 72% in 2005.
- In hospitals there has been a downward trend in the proportion of patients rating their room/ward or the toilets and bathrooms as “very clean” (figure 4).

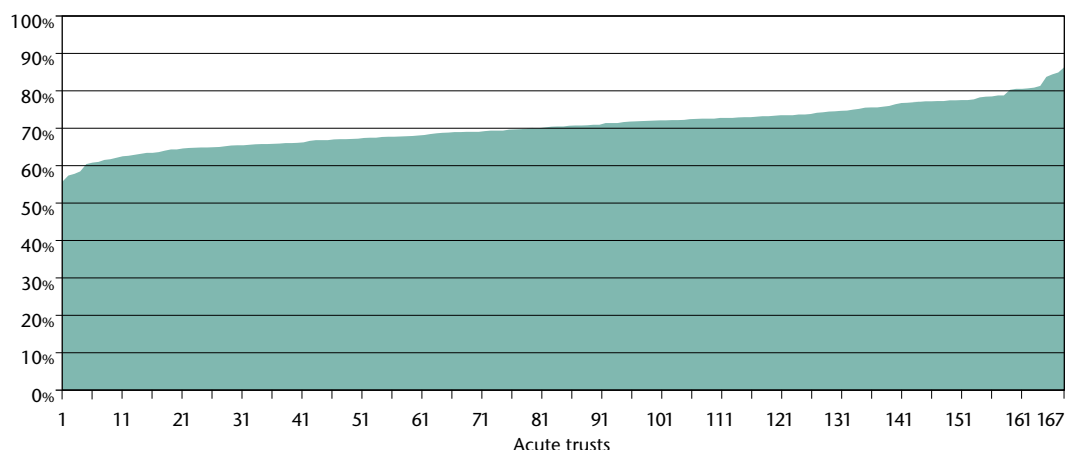
Figure 4: Proportion of inpatients who said facilities were “very clean”



Press coverage of hospital infection rates has caused a great deal of public concern. Most hospitals have made great efforts to raise staff awareness of the need for hand hygiene and many patients notice when standards fall below an acceptable level.

- A higher percentage of inpatients said doctors (69%) and nurses (71%) “always” washed or cleaned their hands in 2006 than in 2005 (doctors 67%; nurses 69%). There was some variation between acute trusts on this measure, for nurses it ranged from below 60% to more than 80% (figure 5).

Figure 5: Proportion of inpatients in each trust saying nurses always cleaned their hands (2006)



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These differences between hospital trusts need careful interpretation. Since we have no reliable independent source against which to compare them, we cannot judge whether they reflect real differences in hand-washing practices, or simply differences in patients' perceptions. Also, some variations might be due to differences in patient characteristics or response rates. Nevertheless, now that patients can choose which hospital to go to, perceptions of cleanliness are likely to be an important influence on their choice.

Hospital food is still disliked by many patients

Despite various attempts to introduce new menus and better cooking and serving practices, many patients still do not like hospital food.

- Since 2002 there has been little change in how inpatients have rated hospital food with only just over half saying it was good. In 2006 (54%), 2005 (54%), 2004 (54%) and 2002 (53%) rated the food as "very good" or "good".

A majority of those with special dietary requirements said their needs were well served, but a significant minority did not.

- In 2006, 66% of the diabetes patients who had been admitted to hospital as an inpatient in the last 12 months, for any reason (not just diabetes) said the food was "always or almost always" suitable for them, with 11% answering "rarely or never". Sixty nine percent said that the timing of meals was "always" or "almost always" suitable for them, in terms of their diabetes, while 9% said the timing was "rarely or never" suitable.
- In 2004, 60% of stroke patients said they were "always" able to get healthy meals from the hospital menu, and 30% said "sometimes". Only 7% said they could not get healthy meals from the hospital menu.
- Among the patients who needed help to eat their meals, only 58% of those surveyed in 2006 said they always received it – down from 62% in 2005.

It is dispiriting that efforts to improve hospital food appear to have had little impact. Food choice and quality is important, but ensuring that adequate help is available for those who have difficulty eating is equally, if not more so. The fact that a large proportion of those who need help are not getting it merits urgent attention.

The hospital environment could be better

Living in close proximity with others in hospital can be difficult if facilities are cramped.

- Nearly one in three patients (30%) who had undergone an emergency admission in 2006 said they had to share a sleeping area (room or bay)

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with a member of the opposite sex. For respondents who were moved to another ward during their stay this percentage then fell to 16%.

- Of those admitted for elective or planned care in 2006, 11% said they had shared a room or bay with a member of the opposite sex when first admitted.

Having to share a room and toilet facilities with members of the opposite sex is unacceptable to many patients and the government is committed to stamping out this practice wherever possible. In some cases it is unavoidable, for example in intensive care units and some admissions units, but the fact that a significant minority of patients stayed in mixed sex rooms in 2006 shows there is still some way to go.

Having sufficient privacy and the ability to sleep undisturbed is also crucially important. The latest results suggest there is plenty of room for improvement.

- Fewer patients entering hospital as an emergency in 2006 (77%) said they were given enough privacy during examinations or treatment in the emergency department, than in 2005 (79%).
- 70% of inpatients said they “always” had enough privacy when discussing their condition or treatment on the ward, as compared with 71% in 2005. Most patients (88%) said they had enough privacy when being examined or treated, which was the same as in 2005.
- Compared to 2005, a greater percentage of inpatients reported being bothered by noise at night in 2006: 38% were bothered by noise made by other patients (37% in 2005); 19% were bothered by noise from hospital staff (18% in 2005).

Community mental healthcare is improving in many aspects

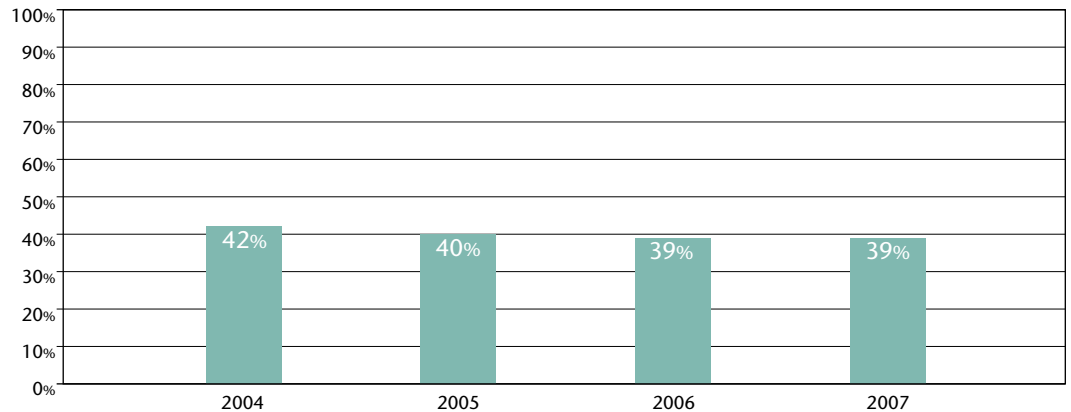
The Picker Institute’s previous report flagged up mental health care as a special problem because patients were more critical of these services, but there are now encouraging signs of improvement in the services provided in the community:

- in 2007, 82% of mental health patients said they had definitely been treated with dignity and respect by psychiatrists, an improving trend, better than 2006 (81%), 2005 (80%) and 2004 (79%)
- there were similar improvements in mental health patients’ views of treatment from community psychiatric nurses, up from 85% in 2005 to 86% in 2007
- 65% of mental health patients who had seen a psychiatrist in 2007 reported that they were definitely given enough time to discuss their condition and treatment, an improvement on 2006 (64%), 2005 (63%) and 2004 (60%).

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However, despite a policy commitment to provide ‘talking’ therapies, there has been a downward trend in the percentage of mental health service users saying they had received counselling sessions (figure 6).

Figure 6: Proportion of mental health service users who received counselling in the previous 12 months



- Of those respondents who had not received counselling sessions, in 2007 over a third (35%) said they would have liked them, no change from 2006.

The problem seems to be a lack of access to sufficient people trained in the provision of talking therapies – a classic example of the gap between the policy rhetoric and the capacity to deliver it on the ground. Worryingly these results suggest the situation has become worse not better.

Communication skills are mostly good

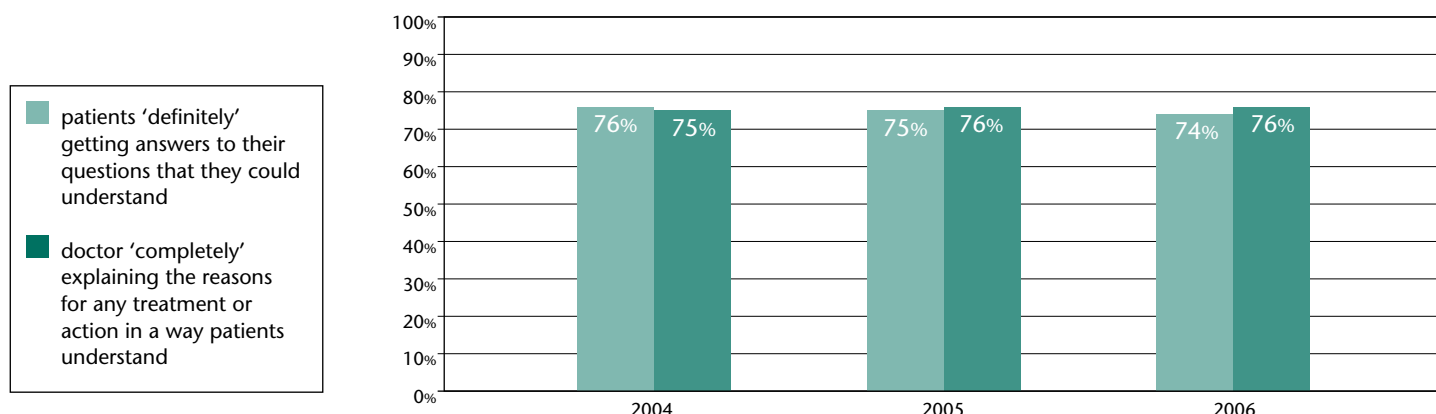
The majority of patients answer positively when asked general questions about the information they were given, in both primary and secondary care.

Patients want to be listened to and to understand what is happening to them. Health professionals’ communication skills appear to be good, on the whole. For example, in the 2006 primary care survey:

- 82% of respondents said their GPs “definitely” listened carefully to what they had to say, while a further 16% said that they did “to some extent”. In 2005 these figures were 82% and 17%
- And 76% felt that their doctor “completely” explained the reasons for a particular course of care or treatment, a figure unchanged from 2005
- 74% said that doctors in primary care “definitely” provided clear answers to their questions, but this was fewer than in 2005 (75%) and 2004 (76%) (figure 7).

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Figure 7: GP gave clear comprehensible answers and explanations



Information and good communication is equally important for patients undergoing treatment in secondary care. This appears to be working well in many cases. Among hospital inpatients in 2006:

- 79% said they were given the right amount of information about their condition and treatment (unchanged from 2005)
- 81% of inpatients undergoing an operation or procedure said that a member of staff explained the risks and benefits to them “completely” beforehand (unchanged from 2005)
- 76% said they had their questions answered in a way they could “completely” understand before the operation or procedure (unchanged from 2005)
- of those who received some form of anaesthetic, 84% said they received complete explanations from the anaesthetist about what would happen (up from 83% in 2005)
- 84% reported that their family and friends had an opportunity to talk to a doctor if they wanted to (unchanged from 2005).

However, there is still scope for improving patients’ understanding of the process of hospital treatment and surgical outcomes.

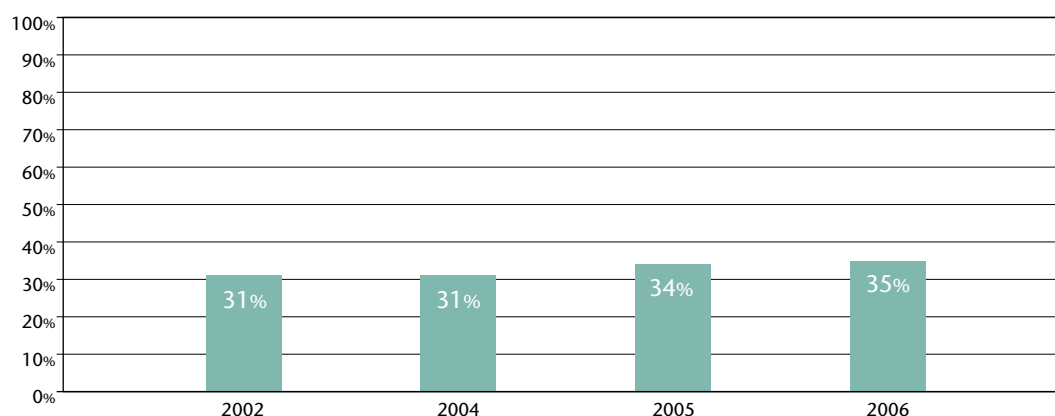
- 68% said that doctors “always” replied to their questions with answers that they could understand, an improvement on 2005 (67%) and 2002 (65%).
- 65% of patients said that nurses “always” gave answers that they could understand (unchanged from 2005).
- Only 56% of inpatients having an operation or procedure said they were told “completely” beforehand how they could expect to feel afterwards, compared to 55% in 2005.
- 64% said they were fully informed about how their operation or procedure had gone, an improvement since 2005 when the figure was 63%.

But information needs are not always met

While several of the above questions showed some improvement in information provision in hospitals, particularly around the nature of specific procedures, on other questions there was a decline, or at best a failure to improve. In 2006:

- 35% of inpatients reported that staff “sometimes or often” gave conflicting information, a worsening trend since 2002 (figure 8)

Figure 8: Proportion of inpatients saying staff gave conflicting information



- only 39% of inpatients said that staff informed them “completely” of any danger signs they should watch for after they went home, a decline from 40% in 2005
- 24% of inpatients said they were not told who to contact if they were worried about their condition after leaving hospital
- only 42% of inpatients said that, when leaving hospital, their family or someone else close to them “definitely” got all the information they needed to help them recover, down from 43% in 2002 and 2005.

Patients and their carers need information to help them look after themselves – yet many say they haven’t received it. This is a clear communication failure.

Communication skills can be improved with good training – there is research evidence to support this⁷ – but good communication is impossible if staff don’t have sufficient time to talk to patients. This is sometimes difficult to achieve in the busy hospital environment and the omens are not good (see overleaf), but managers and clinical leaders should do their best to ensure that sufficient time is made available for this important activity.

If patients do not know what to expect, how to care for themselves, or when to call for help, it can lead to an increased anxiety, disappointment and ultimately, worse outcomes and more complaints.

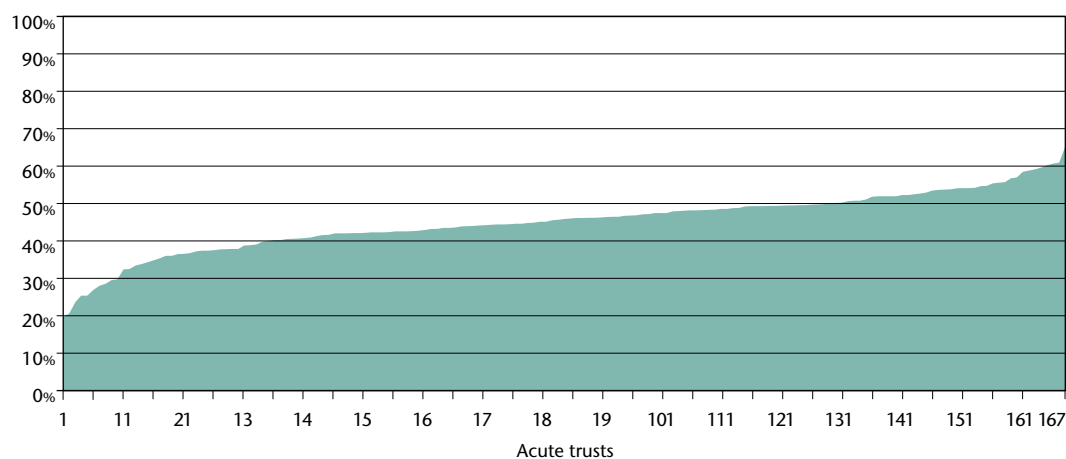
7 Coulter A. and Ellins J. Patient-focused interventions: a review of the evidence. Picker Institute Europe for the Health Foundation’s QQUIP programme, 2006

Availability of hospital staff has deteriorated

The 2006 inpatient survey uncovered a general problem of the *availability* of healthcare staff to patients, when they needed either information or personal help:

- 22% of inpatients reported being unable to find a member of hospital staff to talk to about their worries or fears, up from 17% in 2002 and 21% in 2005
- 15% said that it took more than *five* minutes for a member of staff to answer the call button, a decline in service since 2005 when it was 13%
- responses from hospital staff to the call button within *two* minutes fell, from 59% in 2005 to 57% in 2006
- 44% of inpatients in 2006 said there were not always enough nurses on duty to care for them, a decline in service since 2005 (42%)
- the proportion of inpatients who felt there were too few nurses on duty, ranged from 19% to 64%, with a mean of 44% (figure 9).

Figure 9: Proportion of inpatients in each trust saying there were not enough nurses on duty (2006)



So nearly half of all hospital patients surveyed felt there weren't enough nurses to care for them properly. In the hospitals that performed best on this indicator the proportion of patients who felt this way was less than 20%, but in the worst it was reported by nearly two out of every three patients.

The availability of good quality care provided by committed, well trained nurses makes an enormous difference to hospital patients. These results suggest that such care is only patchily available in English hospitals. And this is despite the fact that the total number of hospital nurses employed has increased by 25% over the past ten years.⁸

⁸ NHS staff 1996-2006 shows the number of qualified hospital nurses rose from 318, 856 in 1997 to 398, 335 in 2006: www.ic.nhs.uk/pubs/obcensus

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It is hard to know what lies beneath these figures. It may reflect real staffing shortages, but it could also be an indication that nurses are deployed on tasks that take them away from direct contact with patients. Whatever the reason, the fact that this particular quality indicator appears to be getting worse is not good news for those who hope to see a more patient-centred hospital service.

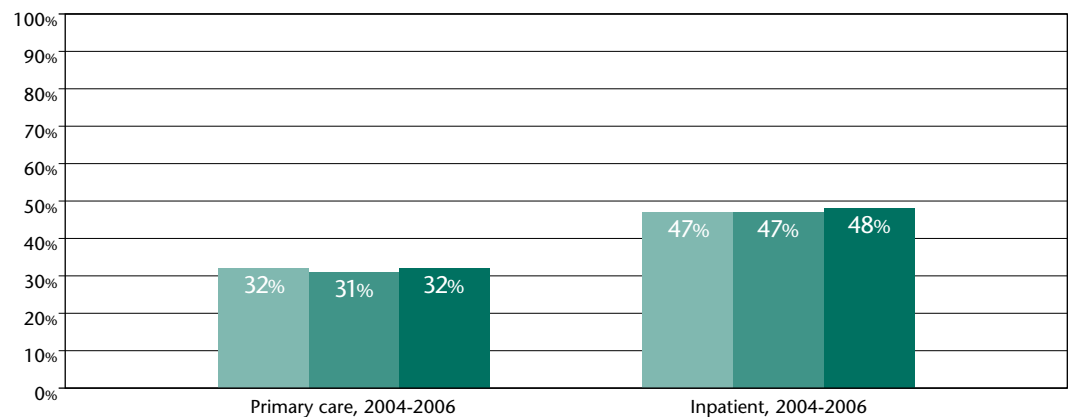
Many patients want more involvement in decisions

When asked whether they had been involved in decisions about their care as much as they wanted to be, in 2006:

- 32% of primary care patients and 48% of hospital patients said they had not been sufficiently involved.

These figures have stayed at similar levels since 2004 in both primary and secondary care (figure 10).

Figure 10: Proportion of patients not involved in decisions as much as they wanted to be



In mental health, despite recent improvements in information, communication and trust and confidence in the health staff, there has been a *decline* in service users' experience of involvement. In 2007:

- of those who wanted to be involved in drawing up their care plan only 40% said they "definitely" had been, down from 42% in 2005
- 25% of service users said that they had not been involved at all in drawing up their care plan.

High proportions of stroke patients were not involved in decisions as much as they wanted to be. For those who had recently been hospital inpatients, surveyed in 2004, 52% said this. This rose to 59% in the 2005 survey which asked about their experiences of care and treatment since leaving hospital.

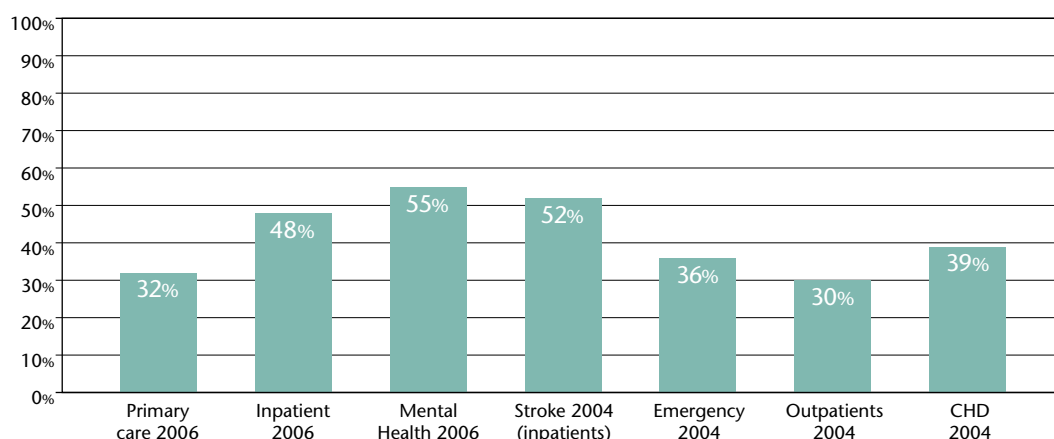
By contrast, 82% of patients with diabetes surveyed in 2006 said they had

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been involved as much as they wanted to be in decisions made about their care and treatment (not just for diabetes) at their GP surgery.

Taking the most recent figure from each of the main types of survey conducted since 2002, it is clear that across the health service a significant lack of patient engagement is experienced by one third of patients in all surveys, rising to half or more in some areas of care (figure 11).

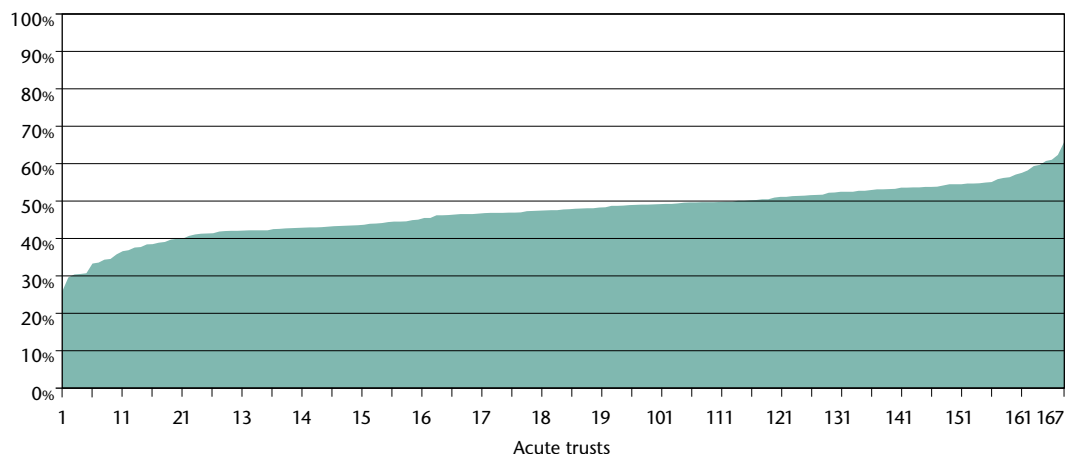
Figure 11: Proportion of patients not involved in decisions as much as they wanted to be



It is apparent that GPs, and presumably other primary care professionals too, are better at involving patients and sharing decisions than those working in secondary care. But if the service as a whole was really moving in a more patient-centred direction, we would have expected to see improvements over time in the proportion of patients feeling involved in both primary *and* secondary care. Sadly these figures show no improvement.

The situation was much worse in some hospital trusts than in others (figure 12).

Figure 12: Proportion of inpatients in each trust not involved in decisions as much as they wanted to be (2006)



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- In the best-performing trust only one quarter (26%) of patients said they had insufficient say in decisions about their care, whereas the proportion was two-thirds (67%) in the worst performing trust.

The good news is that two-thirds of patients in the best-performing acute trusts *did* feel involved, showing that it is possible to do well on this indicator. The challenge now is for all trusts to aim to do as well as the best.

Patients want to be involved in medication choices too

Choosing a new medicine is one of the most common decisions made, whether in primary or secondary care, and across all disease and patient groups.

In primary care, for example, the 2006 survey found that more than half the respondents had been given new prescriptions in the past 12 months.

Medicines therefore serve as a key indicator for the extent to which patients are helped to understand, question, and take decisions about their care and treatment:

- in 2006, 79% of primary care patients prescribed new medicines by a GP or nurse practitioner felt they had been given enough information about its purpose, down from 80% in 2005
- 76% of hospital patients taking medicines home after discharge were told “completely” about the purposes of the medicine in a way they could understand, worse than 2002 when the proportion was 79%
- 85% of primary care patients in 2006 said they were given enough information about how to use new medicines, down from 86% in 2004 and 2005
- however, mental health patients reported an improving trend: in 2007 65% of mental health patients said they had definitely been told about the purposes of their new medication, up from 60% in 2004, 62% in 2005, and 63% in 2006.

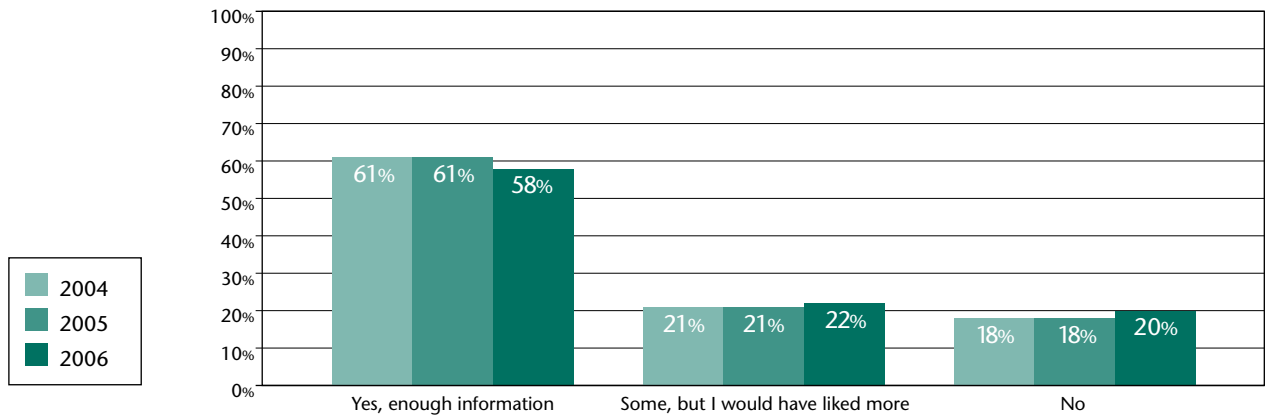
Professionals are giving less information about side-effects

If they are to be fully involved in decisions about the best medicine for them, patients need reliable information on any harmful side-effects as well as the benefits of each option. But they report that health professionals are becoming less likely to give them this type of information (figure 13).

- Only 58% of primary care patients who were prescribed new medicines in 2006 said that they were given enough information about the side-effects, down from 61% in previous surveys.

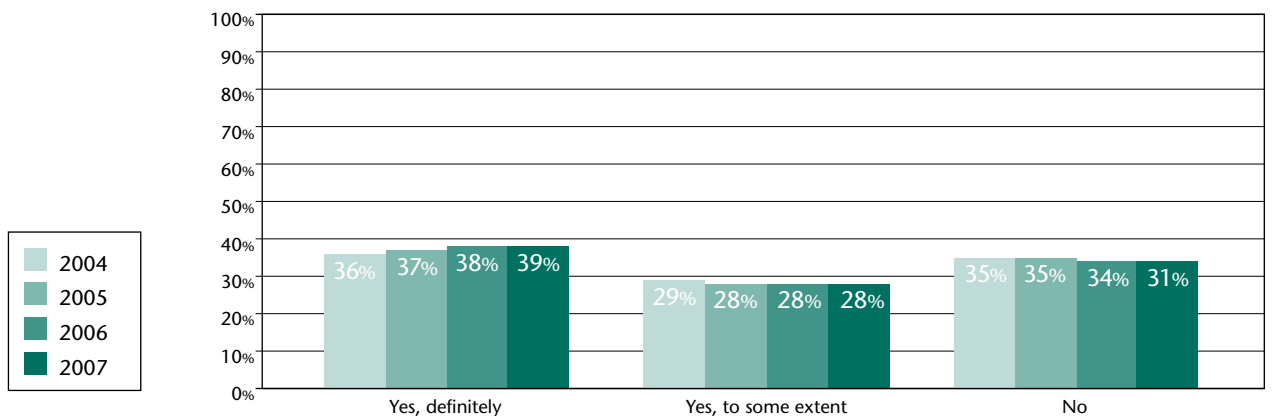
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Figure 13: Amount of information given to primary care patients on medication side-effects



- Only 37% of hospital patients who took new medicines home in 2006 were told “completely” about any side effects, down 3% since 2005.
- In mental health, again there was a gradual improvement but from very low levels: only 39% of patients in 2007 said that they were definitely told about possible side effects of their new medication, up from 36% in 2004, 37% in 2005, and 38% in 2006 (figure 14).

Figure 14: Proportion of mental health service users told about medication side-effects



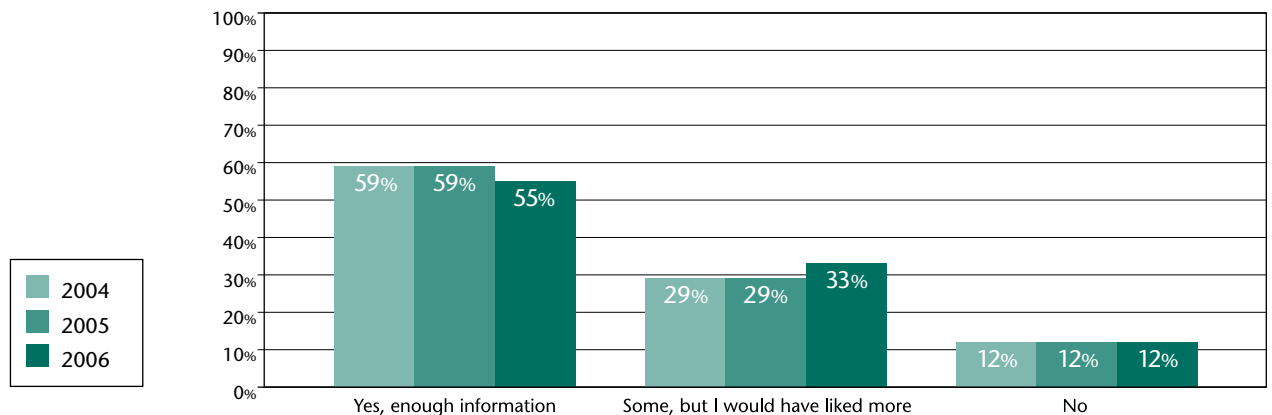
Shared decision-making isn't widely practised

Levels of involvement in shared decision-making about medicine choices are low.

- In 2006, only 55% of primary care patients who were prescribed new medicines said they had “definitely” been involved as much as they wanted to be in decisions about which medicines would be best for them, substantially less than the proportion in 2004 and 2005 (59%) (figure 15).

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Figure 15: Involvement of primary care patients in medication decisions



- 43% of mental health service users in 2007 said they had “definitely” been involved in decisions about medication, up from 39% in 2005; but 15% said they were not involved at all.
- Only 46% of stroke patients said that since leaving hospital they had “definitely” been involved as much as they wanted to be in decisions about the best medicine for them.

The litmus test of patient engagement is the degree to which shared decision-making is practised. Central to sharing is a two-way exchange between the patient and the professional.

The health professional acts as the expert on the effectiveness, probable benefits, and potential harms of the treatment options, and shares information with the patient. The patient acts as an expert on themselves, and shares information about their social circumstances, attitudes to illness and risk, values and preferences. These factors have a strong influence on weighing the appropriateness of any treatment and should be accepted as legitimate in the decision-making. Also accepted is the patient’s shared responsibility for the decision and for any risks taken.

Health professionals must recognise that paternalistic ways of making decisions *for*, or *about* patients instead of *with* them are outmoded. Patients nowadays expect to be treated as equal partners in their care. They want to understand the nature of their illness and to receive full information about the treatment options, including the opportunity to have a say in choosing the most appropriate treatment or management option for them. Failure to understand and respond to patients’ expectations of involvement will lead to increased dissatisfaction with the quality of healthcare services and a greater likelihood that treatment will be inappropriate and ineffective.

Some patients don’t receive enough help with self-care

Patients with chronic conditions have to live with their symptoms and manage their own care day in and day out. For this they need supportive

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help from health professionals, but this isn't always forthcoming:

- in 2006, 73% of patients with diabetes said they were given sufficient verbal information at the time of diagnosis, but only 57% reported receiving the right amount of written information
- only 11% of people with diabetes had participated in a course to help manage their diabetes; of those who had not participated about a quarter (26%) said they wanted to
- 48% said they had discussed their ideas about the best way to manage their diabetes with a health professional, but 27% said they were not asked about their goals for managing their condition.

There is good evidence that health outcomes improve if patients with chronic conditions are given appropriate education and support, so these results suggest that care for these patients is sub-optimal.

Patients aren't actively encouraged to give their views

Another way of testing the degree to which services want and enable patients to be engaged is to see whether it encourages them to give feedback. This question was only asked in the 2006 inpatient survey:

- only 7% of patients said they were asked to give their views on the quality of care they received while in hospital, and in some trusts the figure was as low as 2%
- only 18% recalled being given information about how they could complain about their care if they felt this was necessary, and in some trusts this was as low as 6%.

Anyone who has stayed in a hotel recently or travelled on an aeroplane will know that it is standard practice to seek customer feedback. Yet NHS organisations have been slow to catch on to the need to ask for regular feedback on the quality of their services.

Information about patients isn't shared with them

Similarly, a service which wants to encourage patient engagement would be as open as possible about sharing information. The Department of Health's guidance says that patients should see copies of letters between their GP and the hospital "as of right".

The recent figures show some improvement in this, while remaining so low as to have caused the former health minister Rosie Winterton to write to all

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health professional groups reminding them to follow the guidance. In 2006:

- only 37% of inpatients reported receiving copies of letters between their hospital doctors and their family doctor, an increase from 35% in 2005
- only 25% of primary care patients referred to a specialist thought they had received copies of all letters between their GP and the specialist, up from 22% in 2005
- in community mental health, where all service users are supposed to have a care plan, in 2007 45% said they had not received a copy of it.

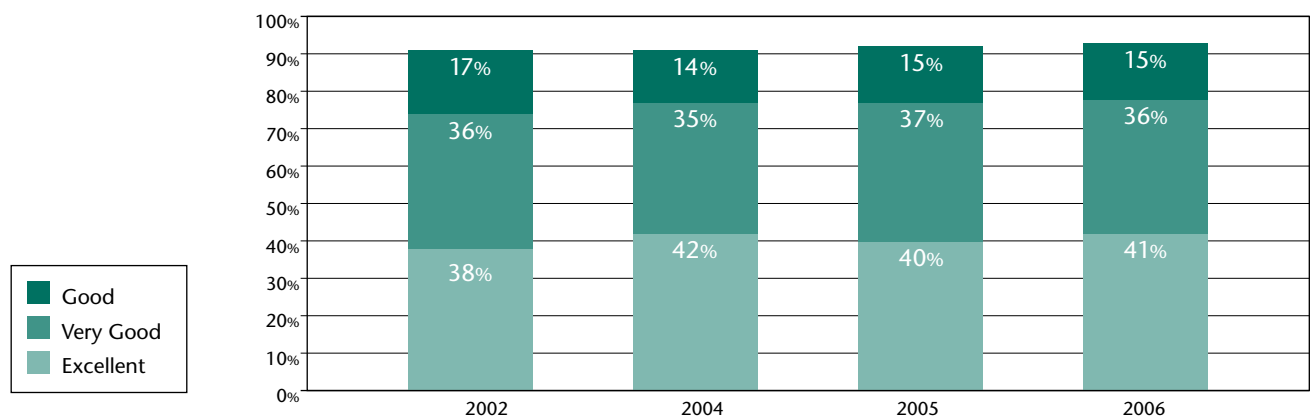
Failure to comply with the guidance means missing an opportunity not only to inform and engage patients, but also to improve safety, because patients have an important role to play in checking that their medical records are correct.

Most patients give positive ratings of their care

Despite the problems identified in response to questions about specific points, most patients are satisfied with their care overall.

- In 2006 41% of hospital patients rated their care as “excellent”, 36% said it was “very good” and 15% rated it as “good”. These overall ratings have remained consistently high (figure 16).

Figure 16: Proportion of inpatients rating their hospital care as “excellent”, “very good”, or “good”



- In primary care in 2006, 74% of patients said the main reason for their visit to the surgery was dealt with to their satisfaction, up from 73% in 2005.

Ratings of other types of care were also overwhelmingly positive:

- almost all (98%) of those who had used NHS ambulances in 2004 said the service they received was “excellent”, “very good”, or “good”
- in 2004, 93% of children, young people and their parents said the hospital

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care they received was “excellent”, “very good”, or “good”

- in 2005, 34% of patients using hospital emergency departments said their care was “excellent”, 36% said it was “very good” and 18% said it was “good”, an overall satisfaction rating of 88%, up from 85% in 2003
- in the 2007 mental health survey more than a quarter (26%) described their care as “excellent”, 29% said it was “very good”, and 22% “good”. In total 77% of respondents reported their care as at least good, the same figure as in 2006 and 2005.

These ratings help to place the survey findings in context. When asked specific questions, patients identify many areas for improvement. But it is important to remember that most people are very appreciative of the care they receive in NHS facilities.

Staff should not feel defensive, therefore, in response to the criticisms. Instead they should view patient feedback as offering helpful suggestions from critical friends, giving them a valuable opportunity to view their services through patients’ eyes and helping them to raise their game where necessary.

3 Weighing the balance

Having reviewed the detailed evidence from patients' reports on their experiences, we can now return to our original question: is NHS patient care improving?

The answer is not as clear cut as we might want it to be. There is both good news and bad.

There have been some significant improvements

Patients now have better access to both primary and secondary care than at any time since national patient surveys began. Waiting times are fast-reducing and there is much greater diversity of sources of medical advice for those who know where to find them.

Patients are reporting good experiences in many respects – they continue to trust and have confidence in health professionals, and feel they are treated with dignity and respect.

Most patients give very positive reports on their interactions with clinical staff, receiving helpful answers to their questions and clear explanations.

Care is considerably better than it used to be for some priority groups, for example those with cancer and coronary heart disease; and mental health care has improved significantly from its previous low base.

Patient satisfaction with all types of NHS care is high. It is clear that many aspects of care targeted by the government have improved significantly.

But several important challenges remain

Primary care is mostly very good, but access to out-of-hours GP advice has deteriorated and support for self-care is patchy to say the least. Referral letters are infrequently copied to patients and they are not encouraged to access and check their medical records.

Hospital care still falls short of ideal in several respects. For instance, standards of cleanliness and infection control measures are not always optimal; hospital food is still disliked in many cases and some patients don't get the help they need to eat it; some patients are still treated in mixed sex wards; and noise levels and standards of privacy still leave something to be desired.

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Most staff have reasonably good communication skills, but time pressures get in the way. Availability of hospital staff who can help patients, especially nurses, seems to have got worse. Likewise the availability of therapists for community mental health service users has declined.

Patients' information needs are not always well met, especially in respect of surgical outcomes, recovery processes, the side-effects of treatment and what they can do to help themselves.

Above all, NHS clinicians have been slow to move away from paternalistic approaches to care. Opportunities to engage patients in their own care and treatment are frequently missed. Patients in all surveys say they are not involved in decisions as much as they want to be, and support for self-care is weak. The 'doctor/nurse knows best' culture is still alive and kicking.

Transformation is possible

From this analysis it appears that the most significant challenge for the NHS is to tackle the failure of clinical staff to provide active support for patient engagement.

The potential benefits of a transformation in patient engagement are huge. International evidence shows that involving patients in their care and treatment improves their health outcomes, their experience of the service, their knowledge and understanding of their health status, and their adherence to chosen treatment.⁹

It also leads in many cases to more appropriate and cost-effective use of healthcare resources, supporting the conclusions of the Treasury's Wanless review that patient engagement is a vital part of the future sustainability of the NHS.¹⁰

Are we expecting too much of a public service in assuming that high quality personalised care is achievable for everyone? If not, what can be done to speed up the improvement process?

Change is possible. The wide variations between trusts on some of these measures give good grounds for hope. Some organisations are doing really well and there are pockets of truly excellent patient-centred care which provide a beacon for raising standards everywhere else. The challenge is to harness the knowledge and experience of the best and encourage others to learn from them. Imaginative clinical leadership will be essential. Patients' relationships with health professionals are highly valued. Almost all health professionals would like to do an excellent job for their patients. Improving patients' experience relies on their active engagement. Clinicians need to be persuaded to take note of patient feedback and use it to develop action plans to address any problems. If organisational barriers get in the way, the evidence from patient surveys can be used to argue for change.

9 Coulter A. and Ellins J. Patient-focused interventions: a review of the evidence. Picker Institute Europe for the Health Foundation's QQUIP programme, 2006

10 Wanless D. Securing Our Future Health: Taking a Long Term View, HM Treasury, 2002

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The Picker Institute has worked with many NHS staff to develop quality improvement programmes. We know it can be done. Once the problems have been clearly identified, there is no shortage of good ideas on how to improve things. Groups of staff working together and learning from patient feedback have developed many creative solutions. Some organisations have found that patients or ex-patients are very willing to help with the improvement process. Their direct involvement can provide a powerful stimulus to action.

Listening to what patients say is the first step on the way to a truly patient-centred standard of care.

Appendix

National surveys of NHS patients in England

Primary care

1998: general practice (n=61,426, response rate 64%), NHS Executive, 1999¹²
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
2005: primary care (n=116,939, response rate 47%), Healthcare Commission, 2005
2006: primary care (n=10,008, response rate 43%), Department of Health, 2007

Ambulance services

2004: ambulance services (n=12,282, response rate 51%), Healthcare Commission, 2004

Inpatients

2002: inpatients (n=95,280, response rate 64%), Department of Health, 2002
2004: inpatients (n=88,308, response rate 63%), Healthcare Commission, 2004
2005: inpatients (n=80,793, response rate 59%), Healthcare Commission, 2006
2006: inpatients (n=81,000, response rate 59%), Healthcare Commission, 2007

Children's inpatients

2004: young patients (n=62,277, response rate 50%), Healthcare Commission, 2004

Outpatients

2003: outpatients (n=90,552, response rate 63%), Commission for Health Improvement, 2004
2004: outpatients (n=84,280, response rate 59%), Healthcare Commission, 2005

Emergency departments

2003: emergency (n=59,155, response rate 46%), Commission for Health Improvement, 2004
2004: emergency (n=55,339, response rate 44%), Healthcare Commission, 2005

Community mental health

2004: mental health (n=27,398, response rate 42%), Healthcare Commission, 2004
2005: mental health (n=26,555, response rate 41%), Healthcare Commission, 2005
2006: mental health (n=24,796, response rate 38%), Healthcare Commission, 2006
2007: mental health (n=15,9000, response rate 38%), Healthcare Commission, 2007

Cancer

2000: cancer (n=65,337, response rate 74%), Department of Health, 2002
2004: cancer (n=4,323, response rate 55%), National Audit Office, 2005

Coronary heart disease

1999: coronary heart disease (n=84,310, response rate 74%), Department of Health, 2001
2004: coronary heart disease (n=3,784, response rate 75%), Healthcare Commission, 2005

11 'n' represents the number of completed questionnaires received ie the achieved sample

12 In this case the sampling frame was the electoral register. Diabetes patients were sampled from practice records. For all other surveys names were drawn from trust records

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Stroke

2004: stroke (n=1,713, response rate 65%), Healthcare Commission, 2005

2005: stroke rehabilitation (n=875, response rate 75%), Healthcare Commission, 2006

Diabetes

2006: diabetes (n=68,500, response rate 55%). Healthcare Commission, 2007

To date, a total of 1,465,884 NHS patients have participated in these national patient surveys.

Detailed results from many of the surveys, including results for individual trusts, can be found on the Healthcare Commission's website: www.healthcarecommission.org.uk/nationalfindings/surveys/healthcareprofessionals.cfm

Note

The Picker Institute was involved in designing, coordinating and/or implementing all the above surveys. Other organisations have contributed to the design and development of the surveys, in particular the National Centre for Social Research. A number of different organisations have been responsible for commissioning the patient surveys, including the Department of Health, the Commission for Health Improvement, the Healthcare Commission and the National Audit Office.

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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.

What we do

- **Researching and evaluating patients' experience**
We measure patients' experiences using surveys and other methods to gain systematic feedback on the quality of healthcare. Original research is complemented by a suite of patient, staff, and public surveys to provide in-depth insights.
- **Leading initiatives that make improvements happen**
We work with healthcare providers to use patient feedback to improve services. Our educational and development work encourages and supports health professionals in implementing change.
- **Building evidence to inform health policy**
We use our research evidence to promote innovative, intelligent approaches to meeting patients' needs. We aim to make the views of patients and citizens count throughout health policy and practice.



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