

In their words
What patients think
about our NHS

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This report aims to uncover the **top issues** raised by **patients** and their carers on the Patient Opinion website



About Patient Opinion

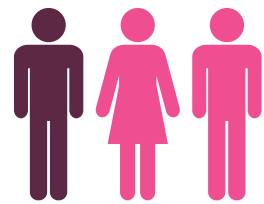
Patient Opinion was founded in 2005 by Dr. Paul Hodgkin. On the Patient Opinion website (www.patientopinion.org.uk), patients and carers share their experiences of health services. These comments are sent to the right staff member, who can respond to the patient and use feedback to improve services.

Executive summary

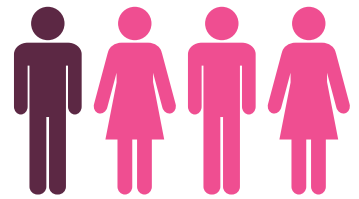
This report analyses a sample of critical patient comments posted on the Patient Opinion website over the past five years to find out their top issues with NHS healthcare services.

Key findings

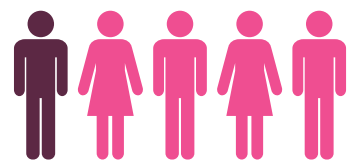
- **Staff attitudes** were perceived by patients and their carers to be the biggest problem within health services, with 33 per cent of postings raising it as a concern.
- Insufficient **care and compassion** was shown to almost 30 per cent of patients.
- **Poor or miscommunication between service and patient** was cited as a problem by 25 per cent of patients.
- **Responsiveness** was a concern to 22 per cent of patients.
- Over 40 per cent of the total number of concerns flagged by our research team fit into the top four categories above. These are, in essence, customer service issues that each member of health service staff could personally focus on and improve.
- **Choice of providers, dignity and inclusivity** – all at the heart of Government reforms – feature low, highlighting a potential mismatch between what matters most to patients and the decisions of policymakers.
- 79 per cent of the stories on Patient Opinion talk about a positive experience of the health service.
- **Staff attitudes** are also the most common aspect of the very best care experienced by patients and their carers, highlighting that patients' experiences are shaped by how staff treat them, and not just by medical outcomes.
- Of all patients who perceived a problem with **quality of care environment**, 46 per cent complained about nutrition.



1 in 3 patients perceived a problem with staff attitudes



1 in 4 patients perceived miscommunication between staff and patients



1 in 5 patients perceived a problem with waiting time



1 in 7 patients perceived a problem with cleanliness

Foreword

Fifteen years ago the only way to publicly raise concerns about local services was to get a letter or story published in a newspaper.



The web has changed all that. Everyone from the high street retailer to the local hospital can be held accountable in a public domain – on the internet.

Through social media anyone can blog, tweet or post a photo of a dirty ward on Flickr.

All this shifts power away from institutions and towards citizens – but having a voice is not the same as being heard. Unless you engage busy staff, the angry just shout louder while the quiet folk leave.

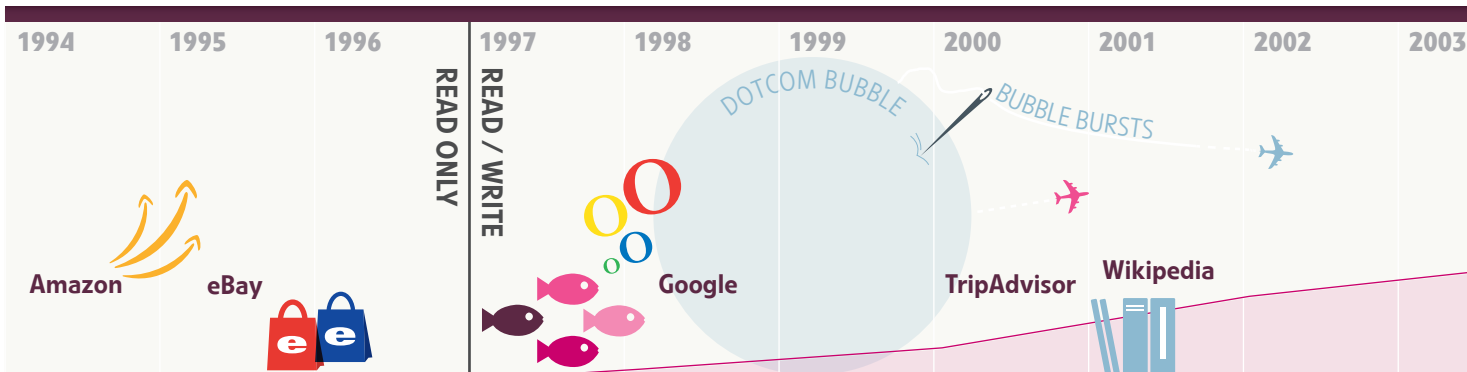
When I started Patient Opinion, I was determined to use these great new online tools to create conversations that made a real difference. So after we publish your comment anonymously online, we alert the right people at the hospital and in other organisations so that they can respond.

That way both sides can converse in safe but public ways.

We believe that people have the right to be heard and the right to a fair response. We have also learnt that they want to help. After all, the person with the strongest incentive to get the best care for the patient in Bed 8 is the patient in Bed 8. They want the nurses to wash their hands. They want to help busy staff do a great job. Giving them a safe, independent and confidential way to do this opens up a whole new resource for a hard-pressed NHS.

This report is based on the thousands of stories shared on Patient Opinion by patients and staff over the past five years. The common themes that emerge offer a revealing insight into day-to-day life across the NHS and I hope that by publishing these we will encourage many others to tell their stories. ➡

Internet milestones




Trusts reviewed

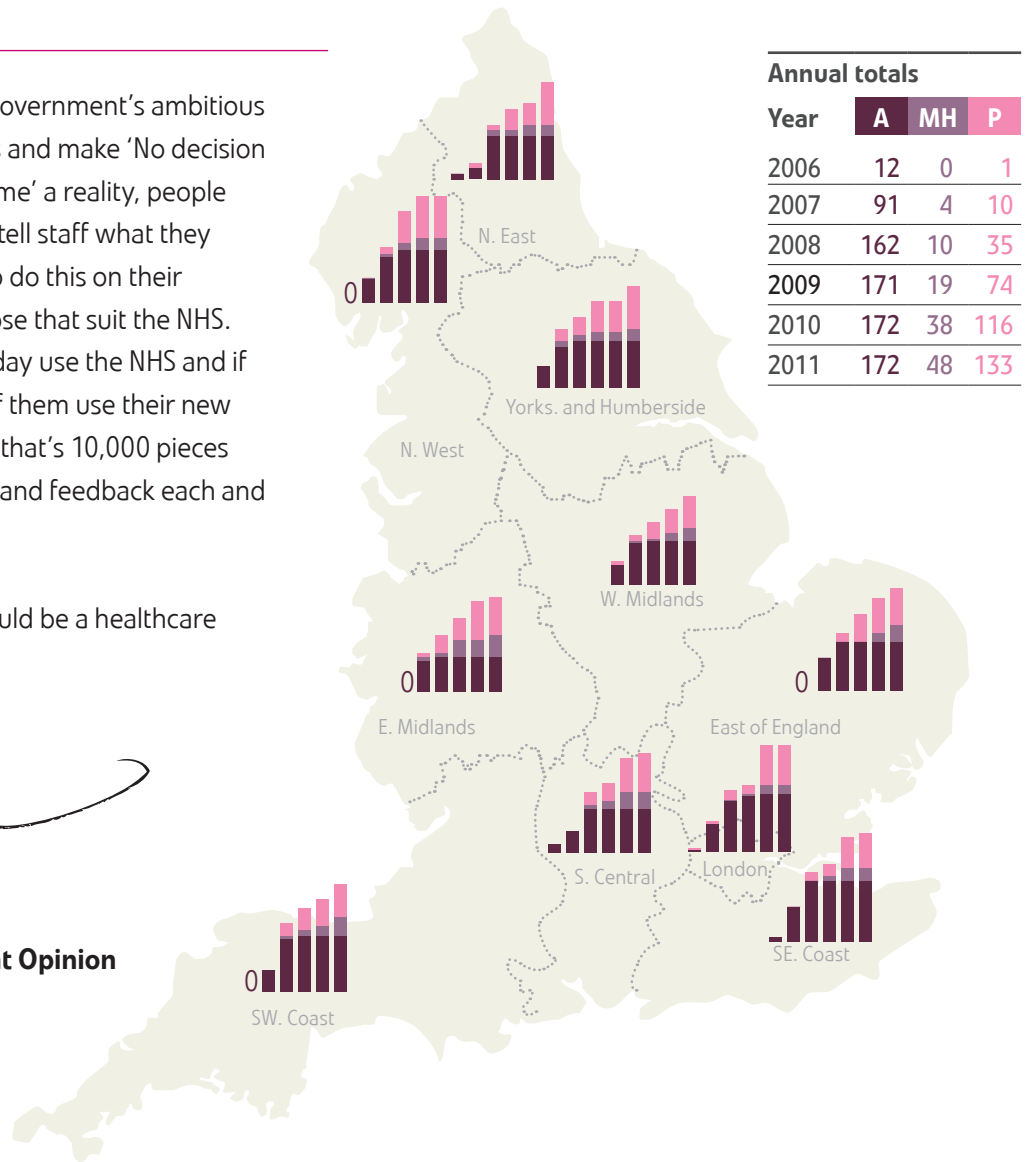
Number of trusts posted about on Patient Opinion, 2006–2011
(Acute, Mental Health, Primary care)

← To deliver the Government’s ambitious healthcare reforms and make ‘No decision about me without me’ a reality, people need new ways to tell staff what they want. They need to do this on their own terms, not those that suit the NHS. A million people a day use the NHS and if just one per cent of them use their new voice to comment, that’s 10,000 pieces of wisdom, insight and feedback each and every day.

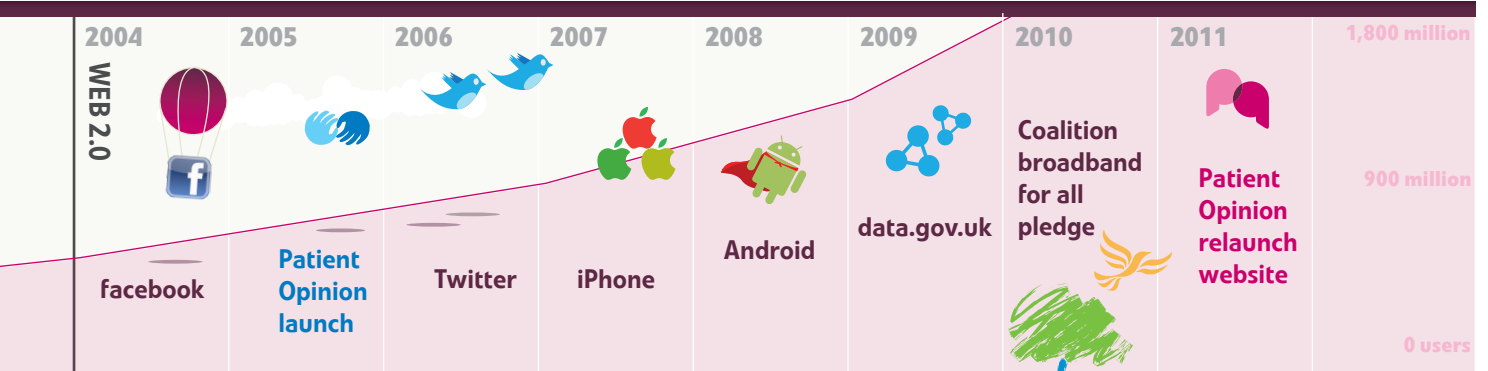
Now that really would be a healthcare revolution.



Paul Hodgkin
Founder of Patient Opinion



YEAR OF LAUNCH



Amount of users

Introduction

This report is a first in that it aims to quantify patient stories and opinions that have so far gone unheard or been dismissed as too anecdotal. It brings together five years' worth of patients' views on the treatment and service they have received at the hands of the health services.

We have analysed these stories and identified a number of common themes and calls to action.

Interestingly, all of the changes to health services suggested by the results of this report can be addressed on an individual level through changes in behaviour, culture and operating practices. All things that most NHS staff control on an individual level and could wake up and improve, themselves, tomorrow.

To address the top four issues that patients complain about most frequently requires no major investment or fundamental change in NHS structure or policy. This is an important point to make at a time of landmark changes to the NHS and the need to make big reductions in spend.

There is clearly no better time to analyse, use and act on the Patient Opinion data in this report.

The Coalition Government is committed to improving patient experience and involvement. "Ensuring that people have a positive experience of care" is one of the five domains in its recent Outcomes Framework.¹ As the authors of this Framework note: the approach to measurement here is evolutionary and there needs to be a move away from the reliance on national surveys with long lead-times and small samples.

The way the NHS responds to complaints is also being re-examined, with the Health Select Committee currently hearing evidence on the NHS complaints system². There is also increasing evidence of the effect that positive patient experiences have on the experience of staff.³

Measurement of patient experience is no longer a case of ticking boxes and fulfilling statutory requirements. Increasingly, NHS organisations want real-time and representative data to →



← use in their Care Quality Commission assessments, their board reports and their day-to-day management. Yet there is still work to be done here, with many trusts slow to pick up on patient involvement.

Data is no substitute for the patient voice, and we should be careful not to oversimplify messages and stories. That is why this report is so important. It aims to bridge that gap between data and stories by combining the useful pragmatism of quantifiable data with the colour and richness of personal patient accounts. The results have been both surprising and encouraging.

Later this year, the public inquiry into Mid Staffordshire NHS Foundation Trust will report its findings. The Trust's failings are already well documented, but the public, patients and taxpayers have a right to understand how and why such a failure in the duty of care was allowed to continue. For too long the trust board failed to listen to patients who were trying to let them, and others, know that the care given at this hospital was inadequate.

Patient feedback can act as an early warning system for issues as they arise, and we should be encouraged that many boards have started to take heed of this. It is a shame that it takes a scandal such as Mid Staffordshire to send a clear message that patients should be listened to. But, as consumers of healthcare, we should be encouraged that the Government, and its local providers, can and will listen to our views, and can and will act on them.

This is a point explored further in the Department of Health's information strategy consultation, where it is noted that *"patient and service user-generated information provides a rich source of intelligence that can be used to improve services... Service user feedback, when used effectively, also provides a basis for people to enter into a dialogue with their care providers, involving them squarely in decisions about their care and the way it is delivered."*⁴



The social web is a powerful and gripping development

This is the most explicit endorsement yet of the power of patient and public opinion and feedback in improving healthcare. The social web is a powerful and gripping development that has revolutionised transactions between the customer and the provider in almost all areas of life. With a national health service that we all contribute to and participate in, and with a Government focused on promoting a Big Society, the public could not be in a better position to use this opportunity to its advantage.

Change, however, can only happen when both parties are communicating and listening to each other. To this purpose, this report also outlines some practical tips that will help service users and those that run services maximise the gains that information posted on websites such as Patient Opinion can yield.

¹ www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_123138.pdf

² www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/news/compllit1-news/

³ See for example http://www.nursingtimes.net/Journals/1/Files/2010/2/12/dh_111827.pdf

⁴ www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_120598.pdf

Our reasoning

Qualitative accounts, such as the descriptions of people's NHS experiences posted on Patient Opinion, provide a fascinating insight into how patients perceive the NHS.

However, they only reveal an individual's experience, rather than capturing the types of quantitative data analysis that has traditionally provided the strongest calls to action within the NHS. As trend analysis is so powerful, there are many quantitative data capturing devices in play in the NHS today. Yet all too often, these datasets or trend analyses fail to capture the essence of patients' experience.

By taking the qualitative sample of patients' opinions and analysing it for trends, we have made a first attempt get the best of both worlds. We intend to show that trends can be identified without losing the patient voice. We hope this will encourage other organisations to follow suit and contribute to the discussion.

The sample

Since February 2008, Patient Opinion has categorised all posts made on a scale of zero to five, with five being the most severe. For this report, the research team selected stories with a severity threshold of three or more, to ensure that the most serious concerns were prioritised. For concerns submitted prior to February 2008, they included entries longer than 500 characters. This gave a dataset of 1,790 stories, with a 30 per cent sample size of 537 stories (from the overall total of 15,605 posted on Patient Opinion in this time period).

The analysis

Distinct themes and categories started to emerge as the research team read the postings. From these 537 stories, they flagged



This report is intended to prompt change and drive improvements

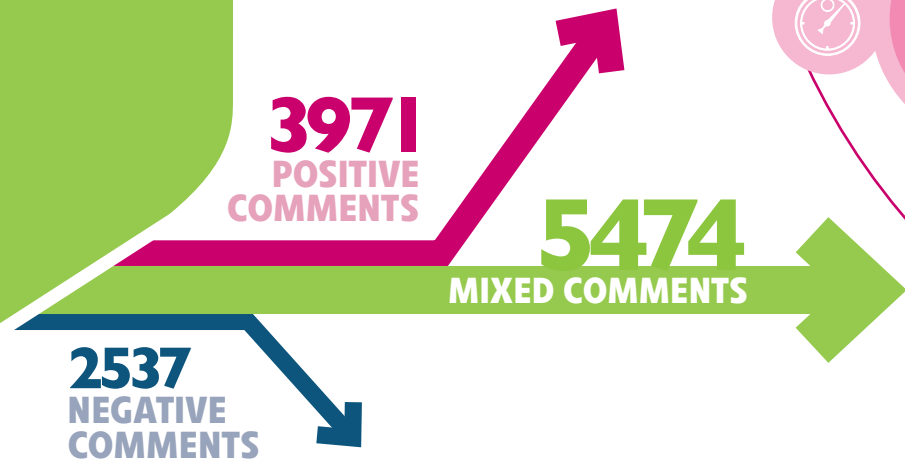
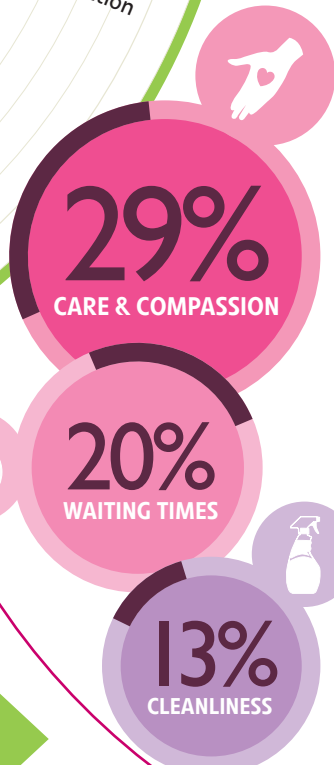
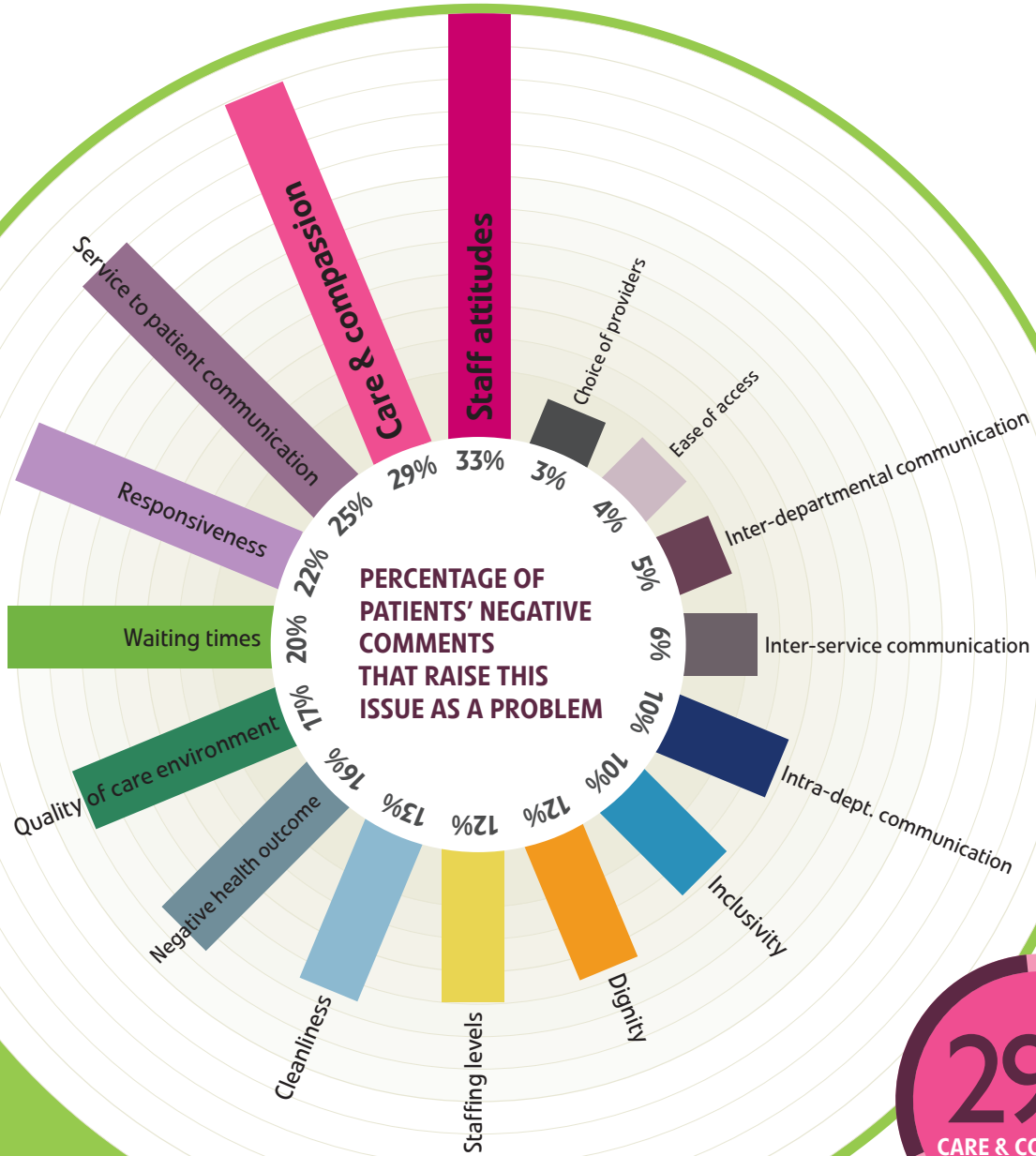
a total of 1,298 issues, which were in turn categorised into 16 themes (see page 16–17). A full methodology can be found on page 18 or visit www.patientopinion.org.uk/info/reportmethodology.

Room for improvement

This report is intended to prompt change and drive improvements. We have therefore focused on examples where improvements can be made within the NHS. The majority of patients and carers who posted their comments on Patient Opinion did not have such a negative experience of care.

In fact, 79 per cent of all postings on Patient Opinion refer to some kind of positive experience, indicating that the NHS continues to provide excellent care to patients and their families all over the country. There will always be room for improvement though, and this analysis exposes these areas. Our analysis shows that the attitude of staff makes the biggest impact. Most of the stories and responses on Patient Opinion reveal that this was the deciding factor between poor care, good care and exceptional care. It is clear that for the majority of patients and carers, staff attitudes play a vital role in shaping the final perception of their care experience.

Results



Full results

Our analysis shows that the biggest concern for patients and carers on Patient Opinion is the **staff attitude**, with one in three of critical postings raising this as an issue.

Alongside this, almost 30 per cent of patients and carers said they experienced an insufficient level of **care and compassion**; 25 per cent said there was a problem with **poor or miscommunication between service and patient**; and 22 per cent commented on a disappointing lack of **responsiveness** from staff.

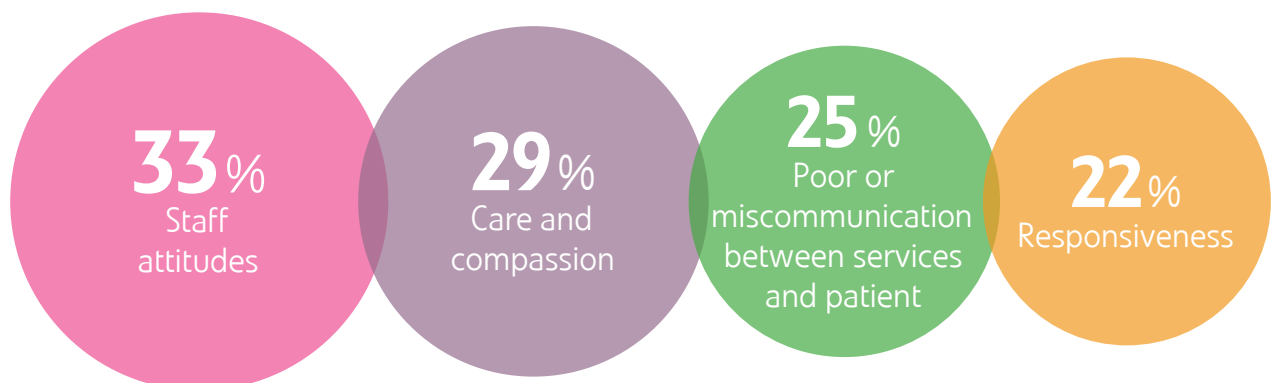
These top four concerns all share one quality; they happen at a one-to-one, staff to patient level and can all be remedied quickly and cheaply. Recent cuts in resources, such as staffing levels and managerial support, may affect staff attitude and behaviour. But ultimately, the way a doctor or nurse interacts with a patient is something that can easily change themselves today.

Knowing that, irrespective of political, financial or managerial constraints, what really matters to patients is something that is within their immediate control should empower and inspire frontline staff.

According to these results, every NHS staff member has it in their power to personally improve the experience of their patients – at no extra cost.

Small changes would make the biggest difference to patients

Of the total number of concerns sampled in our report, over 40 per cent fell into the four categories listed above. This means that over 40 per cent of patients' concerns could be solved if staff were better supported and ➔



These four concerns all share one quality: they happen at a one-to-one, staff-to-patient level

← enabled to exhibit a positive and helpful attitude, show care and compassion towards patients, communicate facts accurately and be more responsive to patients' needs.

Of all the 15,000 postings on Patient Opinion, over the past five years, 79 per cent include at least one positive aspect of their experience. Similarly to the critical postings, staff attitudes was the most commonly raised topic.

This further reinforces the fact that staff behaviour has the biggest immense impact on patients and their carers' experience.

What does this mean?

The results reveal a potential mismatch between the main concerns of patients and the key reforms being undertaken by the Coalition Government's Health and Social Care Bill.

The Bill rightly emphasises the importance of putting patients' needs and views at the heart of delivering care, but reforms in areas such as **choice of providers**, hotel aspects (such as food) and **inclusivity** may not significantly improve the experience of patients. Analysis shows that these issues rarely motivate patients and their carers to raise concerns about the quality of their care.

While other sectors have become increasingly accountable to consumers and members of the public, the lack of consumer insight in healthcare has led to a growing gulf between policy and patient experience that needs addressing urgently.

For a full table of results, including yearly trend data, visit www.patientopinion.org.uk/info/reportresults



Staff can now understand more immediately the needs of patients

Case studies

Both **patients and staff can play an equally vital role in improving the standard of care within the NHS**. Below are three examples of patients posting a comment and receiving a full and helpful response from the service that treated them. The process empowers patients and allows NHS staff to hear what their patients are saying and adapt accordingly. When NHS departments truly listen to patient feedback, change happens.

POSTED BY SADMOTHER
JULY 2010

Upset by lack of care in St Thomas' post-natal ward

I underwent an emergency C-section at St Thomas' last year. My experience of post-natal care was so bad I had to undergo counselling and am reluctant to try for another baby. It took me 10 months to bond with my daughter.

I was given a sponge bath by two women who did not introduce themselves or explain what they were doing. I was so roughly handled I felt like an animal. I had to beg for pain relief – at one stage I went six hours before someone brought me some paracetamol.

When I asked for help breastfeeding, the midwife shrugged and said “try whatever you like” and walked away. It was the worst experience of my life and it devastates me that the rude and uncaring staff I met have left me resentful towards my daughter and reluctant to set foot in an NHS maternity ward ever again.

Response from St Thomas' Hospital

It is very disappointing that our unit let you down so badly. Over the past year, as a result of feedback, we have implemented a series of initiatives that are beginning to have a positive impact on the main areas of concern.

All staff on the post-natal ward are undergoing customer care and communication skills training to address issues related to attitude, behaviour and interpersonal skills.

We're improving the ward environment to reduce midwife time spent away from the bedside and installing individual drug cabinets to eliminate waiting times for pain relief.

We're also increasing the number of maternity support workers, who are fully trained in breastfeeding and provide additional bedside support, for which we have received very favourable feedback. It is with regret that all of these actions are too late for you and we are so sorry that you have had such a terrible experience.

NHS RESPONSE

POSTED BY TRACY1
NOVEMBER 2010

Treatment of my daughter's depression highlights the need for change **My daughter was 17 when we first had concerns over her depression.**

In January 2010 she was taken to our GP, who felt that she was suffering from more than clinical depression. She had made a suicide attempt by this point. Due to her age, this problem has taken a year to resolve. The system needs to be changed. Mature adolescents are different to adults and should be treated accordingly. I really do not want another teenager to go through the experience my daughter has endured over the past 12 months due to the system not being able to cope.

Response from Leeds Partnerships NHS Foundation Trust **We have changed our referral criteria for Adult Services. From now on, our Adult Directorate will provide mental health services for people aged 18–65.**

This will mean that anyone under 18 referred to our Trust will instead be redirected to the more specialist and age-appropriate Child and Adolescent Services provided by NHS Leeds.

I appreciate that this does not re-write your daughter's story, but I hope it is an important step towards ensuring that people at this often difficult and vulnerable stage in their lives receive age-appropriate mental health services.

NHS RESPONSE

POSTED BY WATERBOY

Why change how I get my repeat prescription?

I have Cauda Equina Syndrome and have to catheterise myself five times a day. I was quite content with my repeat prescription and felt that, because my doctor is quite near, should I require the catheters earlier it wasn't a problem.

Then I had to start phoning a clinic further away every time I need a prescription, which was very stressful. I have to have the prescription at least three days before I need it so that the chemist can get what I need.

My concern now is holidays – Christmas, New Year or any bank holiday is when I believe things could go wrong. I need these things and without them I would be in dire trouble.

Response from NHS Rotherham

Your comments encouraged the staff in the Continence Service to think about how the service would work over holiday periods.

Now, staff are currently preparing for the Christmas period, and are sending out a letter to all service users detailing delivery options. One of these is through a pharmacy which opens every day of the year until 10pm and can make home deliveries.

We sincerely hope that the options given will ensure the service works well for everyone over bank holidays.

NHS RESPONSE

Tips for the NHS

Every NHS department can make great changes to the care they provide by simply listening to their patients and acting on the feedback they receive

1

Join the conversation.

Patients are talking about their experiences online every day. They have a unique insight into your service so use them as your ears and eyes. The web makes it so much easier and cheaper for you to listen to patients and carers, to let them know that they have been heard, and to keep them informed about your services.

2

Meet people on their terms.

This kind of feedback is here to stay, and it's increasingly the way most people want to communicate. Independent sites such as Patient Opinion are your chance to meet people on their terms, to hear exactly what they think and to show the wider world that you're listening.

3

Really listen.

In a conversation, you can tell when someone isn't really listening to what you've got to say. The same is true online. When you're honestly listening and engaging with the public, they will know. The results will show in your services, and how patients feel about them. Use these comments as a chance to start a two-way conversation.

5

Be yourself.

The language of the web is relaxed and conversational. When you talk to patients online they want to know who is speaking to them – they want to know the 'real' person behind the NHS comments. It's not enough to post a standard response to each story. That can come across as insincere and uncaring. The web is your chance to show the human faces behind your service and that personal touch in your responses.

4

Do something, and make it stick.

Online feedback shouldn't simply be left online: it should be used to change services for the better. Ensure your staff see feedback about their services, and can act on it. With the web, patient and carer experience can inform every part of your service provision.

Every patient can play an active role in improving their local NHS services by telling their story and ensuring their voice is heard

Tips for patients

1

Be heard. Your voice can make a huge difference to health services. Whether your experience was wonderful, disappointing or a bit of both, health service staff need to know. Your voice matters, and by sharing your experiences online, you are helping to improve services for everyone.

2

Remember: it's your NHS. When you share your experience, you let health services know what works well and what needs to change. The NHS belongs to all of us and this is a simple way of improving services for everyone. Health services need your regular feedback to know whether the changes they are making are right, and are genuinely improving the care you receive.

3

Be constructive. Say what happened and how it made you feel. This is your chance to have an impact. When you are constructive and fair in your feedback, staff will find it easier to identify ways to improve services.

4

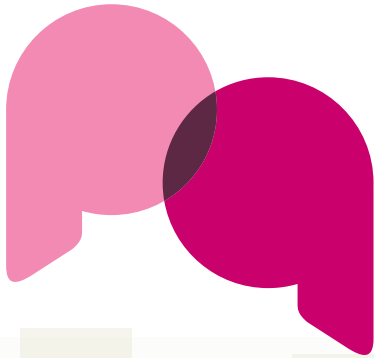
Spread the word. You've written about your experience online, or read one that really affected you. What now? Share it with your friends and family, so that they can comment too. The more people who join the conversation, the more power it will have.

5

Complete the loop. When a health service responds to your feedback, you are able to reply online to their comments. Let them know what you think of their response. Ask them what they are doing about the problem, tell them what you thought of their response, and congratulate them when they make a change. At every stage, your feedback is vital.

The categories

This report analysed 537 postings, placing the issues raised in them into 16 categories. These are the 16 categories defined, complete with real examples from patients in our sample.



Inter-service communication

Patient perceived a problem with poor communication or lack of integration between different services such as GP clinic, hospital or police.

"There was no hand-over to local psychiatric services, despite asking for this." Sussex Partnership NHS Trust, 2009

Staff attitudes

Patient perceived staff as rude, arrogant, lazy or having a negative attitude.

"Unfortunately, I found the neurologists who cared for me at Treliske to be incredibly arrogant, unapproachable and happy to make (incorrect) assumptions." Royal Cornwall Hospital (Treliske), 2008

Care and compassion

Patient perceived staff did not do enough to ensure the patient was comfortable or in a condition conducive to recovery.

"My mother's hair had never been washed and she was wearing soiled clothing." Northern General Hospital, 2007

Quality of the care environment

Patient perceived a problem with their care environment including poor food/nutrition, noise at night, a lack of physical resources, degraded buildings or a lack of capacity in areas such as waiting rooms.

"I'd only had two slices of toast and one sandwich in four days [...] the meals from Saturday were both disgusting." Royal Derby Hospital, 2010

Responsiveness

Patient perceived their requests or complaints were not adequately responded to.

"I have spoken to Patient Advice and Liason Services (PALS) and found them to be of no use whatsoever in this case. According to them this is an ongoing issue so they won't deal with my concerns." Greater Manchester West Mental Health NHS Foundation Trust, 2009

Dignity

Patient perceived they were not treated with sufficient dignity or afforded enough privacy. This includes being made to feel embarrassed, humiliated or dehumanised by staff.

"In spite of all promises, the ward I was in was mixed." Nottingham Queens Medical Centre, 2009

Waiting times

Patient perceived a problem with waiting times before or between appointments, including delays being moved between departments.

"It's unacceptable that I have to wait 19 months for diagnosis and treatment of a painful and worrying condition." Calderdale Royal Hospital, 2010

Service to patient communication

Patient perceived a problem with staff communicating information effectively and keeping them sufficiently informed.

"No one is telling [my daughter] what the problem is and who to talk to." Bradford Royal Infirmary, 2009

Inclusivity

Patient perceived that staff made decisions about their care without consulting them or taking their opinions into account.

"You're made to feel that you're not allowed to ask the doctors any questions to do with yourself." Doncaster Royal Infirmary, 2007

Intra-departmental communications

Patient perceived a problem with poor communication between staff within a department.

"Instructions given by physicians were not carried out, nurses' notes didn't reach doctors, notes would go missing or were sent to surgeons not even involved in my case." Derriford Hospital, 2008

Lack of perceived positive health outcome

Patient perceived a problem with a medical procedure, diagnosis or treatment that delayed recovery or resulted in new or worsened conditions. This includes perceived neglect or a lack of procedure.

"The neurologist at Queen's got my diagnosis completely wrong, which meant I had two strokes." Queen's Hospital, 2009

Staffing levels

Patient perceived a problem with insufficient levels of staff, or lack of funding for staff.

"There were only two nurses on duty to cover 28 patients." Royal Hampshire County Hospital, 2007

Ease of access

Patient perceived a problem getting to and from their appointment. This includes travel, transport, parking and disability access, including once inside the hospital.

"I have to pay £7.20 per day to park at the hospital – money I can ill-afford as I am on benefits." Royal Hallamshire Hospital, 2008

Inter-departmental communication

Patient perceived a problem with poor communication between different departments in the same service.

"Outpatient clinics are consistently running late. This makes me miss my X-ray. Why [not] synchronise with the X-ray department so they both end at the same time?" Tiverton & District Hospital, 2010

Choice of providers

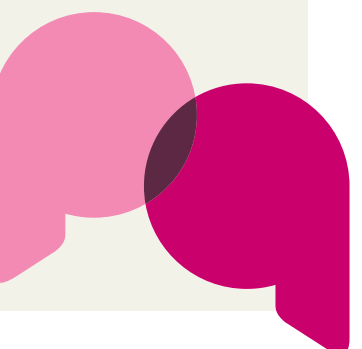
Patient perceived a problem with a lack of choice of providers. This includes lack of choice over when to use the service.

"I asked to be referred to the Stanmore Hospital. 14 weeks later I get a letter saying they can't see me and I've been referred to my local hospital." NHS Surrey, 2009

Cleanliness

Patient perceived a problem with cleanliness, hygiene or Hospital Acquired Infections.

"I was left with blood on my arm and on the sheets all night – and still in the same clothes as when I was admitted." Rotherham District General Hospital, 2010



Methodology

Aim of the analysis

The analysis aimed to highlight the top issues that patients and carers perceive to be a problem within the NHS. The research produced a table of the most common complaints, taken from a sample of patients' comments on the Patient Opinion website since its launch in 2006.

The sample included comments on GP clinics, acute hospitals, mental health trusts and outpatient services and clinics.

The subjective nature of patients' accounts means the report can only measure patient perceptions, and should not be stated as fact. Therefore all conclusions drawn should focus on the areas where patients and carers perceive a need for the NHS to improve.

Selecting the sample

The analysis used a sample of 537 accounts from patients and carers.

The analysed data was sampled by initially collating:

- All public postings made on Patient Opinion since February 2008 that had a criticality score of three, four or five.
- All concerns received prior to February 2008 that were over 500 characters in length, to give the fullest example of patient feedback in this period.

This gave us 1,790 accounts, of which 30 per cent were randomly selected, creating a final sample total of 537 accounts. These contain a wide variety of geographic locations and NHS services.

Analysing the sample

The 537 accounts were sorted into 16 categories and labelled using the language commonly used by patients. Definitions of these categories, along with examples, can be found on pages 16 and 17.

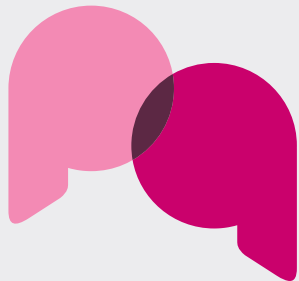
The research team counted multiple concerns within a single comment if the patient highlighted a perceived problem with more than one issue or topic during their experience. From the 537 accounts, 1,298 concerns were counted, creating an average of 2.4 concerns per patient comment.

Particular care was taken to not infer problems or draw assumptions from the data and comments. A category was only noted if the patient explicitly mentioned a concern.

The analysis presented the total number of postings per category as actual numbers and percentages.

NB: Criticality scoring is a rating mechanism used to score patients' comments on their severity, with zero being the mildest concern and five the greatest. This scoring system has been used by Patient Opinion's editorial team since February 2008.

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