

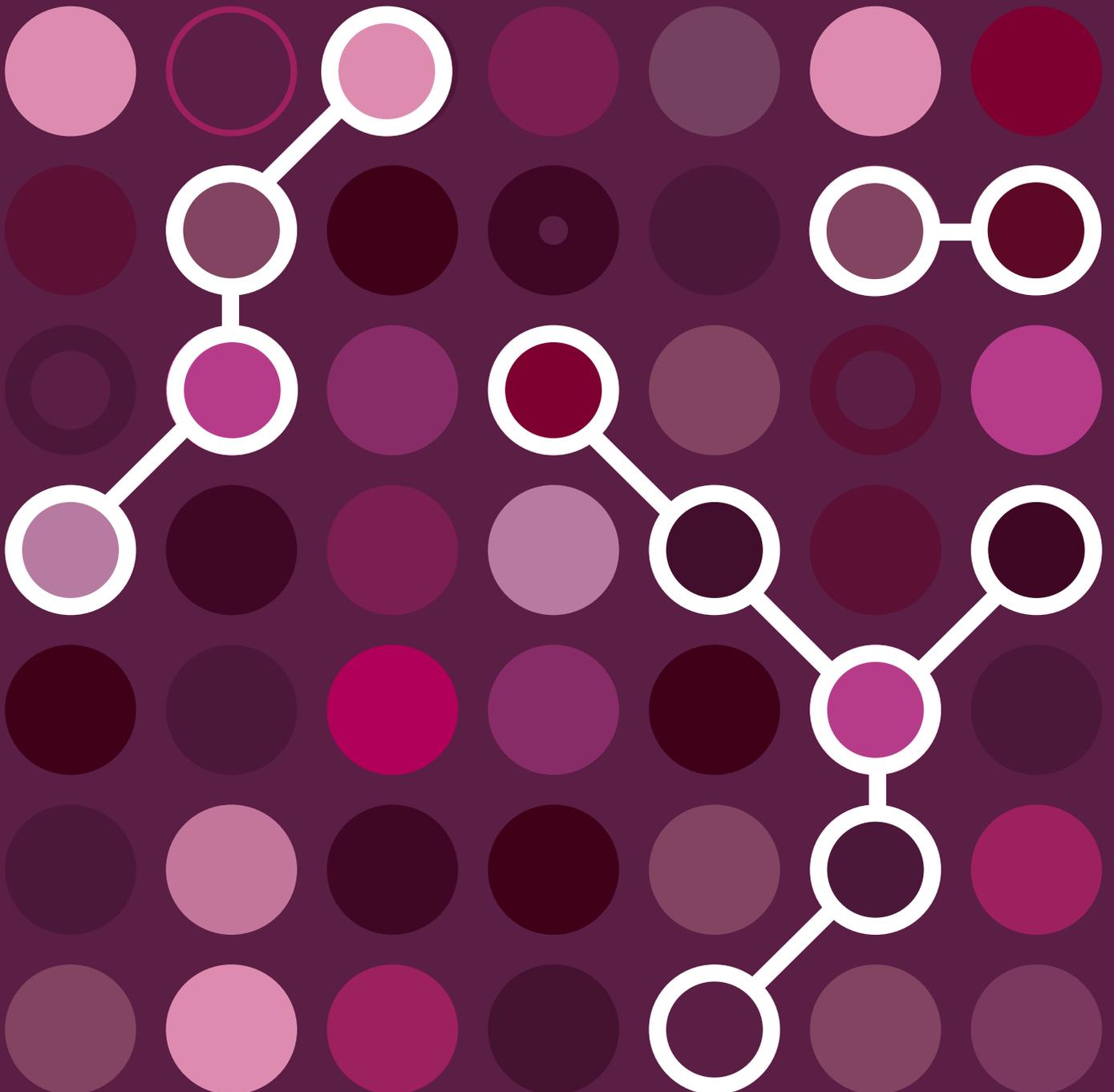


**Patient
Opinion**
Every voice matters

THE POWER OF CONNECTION

How networked citizen voice is changing
health and social care

10TH ANNIVERSARY REPORT



Patient Opinion is an independent, not-for-profit, social enterprise which runs an award winning website, harnessing the power of the web to carry the voices of patients and carers into the heart of health and care services.

Patient Opinion makes it safe, simple and effective for patients and carers to give feedback about their health care, and for health service providers to respond to and make use of feedback for service improvement.

The result is issues resolved, relationships restored, complaints avoided and services improved, all in real-time and at low cost, right across the UK.

“Well done Patient Opinion for providing the catalyst to enable change without the need for formal complaints/ correspondence.”

(from “Safety”,
story no 141088)

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An independent platform generating visible change

DR PAUL HODGKIN

PATIENT OPINION FOUNDER

Patient Opinion launched in 2005, a month before YouTube went live and the same year that News Corp bought Myspace for \$580m. The Social Age was new and Twitter was something that the birds did.

Having toiled away at the coal face of PCTs and Health Authorities, I was tired of the multiple conflicting accountabilities that bedevil health services the world over. Tired of always finding that we just needed to wait for another committee, in another room, in another two weeks, to decide whether B could follow A. So the shiny new world of 'web 2.0' looked good to me. Suddenly we could collectivise the wisdom of patients and turn these insights into better services, at scale. No more pilots, no more permissions. Just patients sharing their stories publicly on a platform built for them and their needs.

Well, we didn't make it to YouTube or Facebook status. But Patient Opinion survived and flourished, spreading to Australia and Ireland, and along the way building a great team and having a lot of fun. Today Patient Opinion is that rare thing: an independent social media platform generating direct, countable improvements. It is financially independent of state, industry, foundations and venture capitalists - and all without carrying any advertising.

So what lessons do the first 10 years of Patient Opinion hold for today? Two come to mind. First, it is worth asking why Patient Opinion hasn't become a "must-have app". Put another way: why has something like Facebook not yet arisen for health? One answer is that network effects are relatively rare in digital health platforms. On Twitter or YouTube re-posting drives more and more use - but sharing health-related content on public platforms is intrinsically hard. Tweeting from the colorectal ward takes more bravery than telling everyone you're in the Maldives and 'liking' a picture



of your friend's colostomy is more problematic than 'liking' a picture of their kitten. This is why neither Patient Opinion nor the feedback channel of NHS Choices have hit the "winner takes all" status of the massive social media platforms. This lack of network effects is bad news for all those digital health start-ups currently chasing venture capital around Shoreditch.

But – the second lesson for today – PO is living proof that it is possible to build a platform which avoids the trolls, is not unremittingly negative, and really does create concrete improvements, changing how busy, stressed staff think about patients. Wonderfully intimate conversations abound on PO. Not only that: people are measured, courteous and thoughtful. I am always amazed and humbled by the fact that swearing in stories submitted to Patient Opinion is vanishingly rare. Even when people are justifiably angry they mostly still want to help.

This is important for all of us because "voice" - the ability of users to influence services by giving feedback – has been transformed by social media. "Exit" – the ability to use the market and choose a different provider – may have been the health policy darling of the last 30 years but in the 21st century it is voice that will dominate. This is not just because Exit, in the form of markets and choice, has largely failed in health (after all "having" a Mercedes really is very different to "having" a heart attack). It is because the transaction costs of running markets in healthcare are high and rising, while the cost of having an effective public voice are dropping like a stone.

Patient Opinion remains an important part of this story. Patients, their insights, generosity and forgiveness, are at the heart of all that we have achieved. It is patients and carers who have shown that public feedback can be so much more positive than cynicism, moaning or trolling. And the ruffled, crumpled, over-stressed staff of the NHS – whenever they have been allowed – have been there too, responding with humanity and understanding.

It was an honour and a privilege to be part of the first generation of health-related platforms in this new Social Age. The next 10 years will bring yet more change but I know that the team at PO are better equipped and better led than they have ever been and I look forward to following their progress with pride as they navigate this new world.

Connecting people to create change

MY STORY

A patient, service user or carer shares their story of care, on their own terms. The story may be about a number of services across both health and social care. Patient Opinion moderates and publishes the story.

RESPONSE FROM STAFF

On publication, Patient Opinion sends alerts to relevant staff in the care providers, commissioner or health board, regulator, patient organisations, and other local or national bodies. Staff are able to respond to the story without knowing who the author is. Everyone can read the responses.

RESPONSE FROM PATIENT

The story author may reply back to staff, and may mark responses as helpful or not. Staff may respond in turn, so that concerns can be clarified, information provided, issues resolved, and relationships restored. Staff and students in many places can learn from this open exchange.

CHANGE MADE

Staff can show when a story leads to change, and everyone – patients and staff – can see this. The story author will know their story made a difference. Other patients, users and carers can see that concerns are heard and acted on. Staff feel confident in their service and empowered to act on feedback. Trust and understanding grows. An open, learning culture develops.

www.patientopinion.org.uk

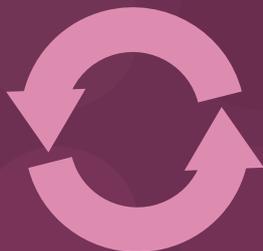
My story



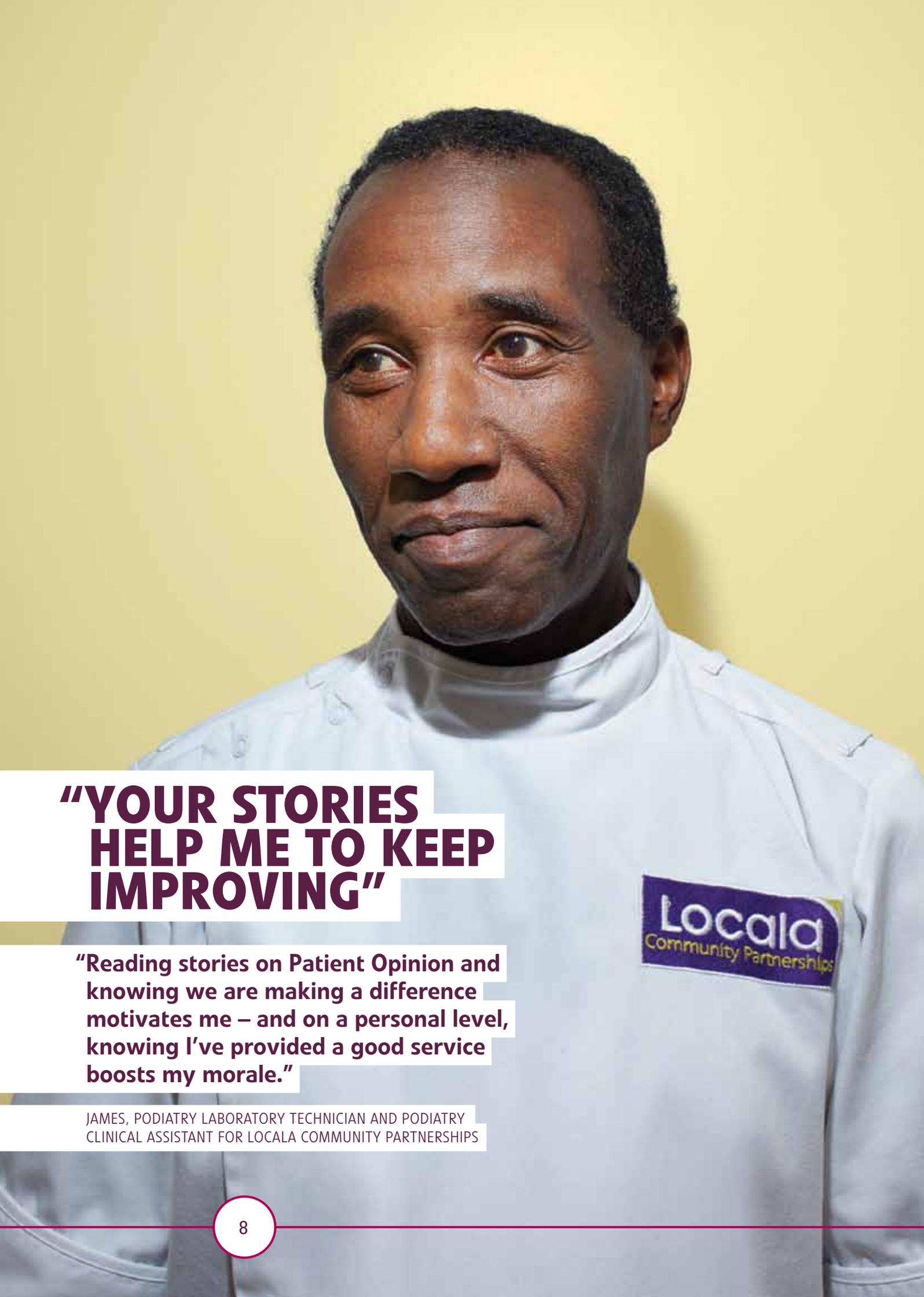
**Response
from staff**



**Response
from patient**



Change made



**“YOUR STORIES
HELP ME TO KEEP
IMPROVING”**

“Reading stories on Patient Opinion and knowing we are making a difference motivates me – and on a personal level, knowing I’ve provided a good service boosts my morale.”

JAMES, PODIATRY LABORATORY TECHNICIAN AND PODIATRY CLINICAL ASSISTANT FOR LOCALA COMMUNITY PARTNERSHIPS

JANE DANFORTH

INVOLVEMENT AND EXPERIENCE OFFICER,
NOTTINGHAMSHIRE HEALTHCARE NHS FOUNDATION TRUST



How do you use Patient Opinion at Nottinghamshire Healthcare NHS Foundation Trust?

We have partnered with Patient Opinion since 2008. I use 'partnered' consciously as we have worked together to develop the service Patient Opinion provides to NHS organisations.

We committed early on in our Trust to reply to stories in an informal way and this has revolutionised how we communicate with patients. It has removed a barrier; it allows staff to talk to patients compassionately, using everyday language, one to one.

We use feedback daily. Every team within the Trust is encouraged to tell patients, service user and volunteers that this is one of the ways they can feedback to us.

If someone leaves their feedback on Patient Opinion, they are guaranteed a response within two days. This has the backing of our Directors.

What makes PO different from traditional approaches to feedback?

It is about choice. It is direct and reaches the teams who deliver the services and resolves problems or concerns quickly. We get the feedback and can make changes quickly. We publish what happened in a public forum for others to see.

As the stories are told from the patient/service user point of view they often cross departments. This allows us to see how our services work alongside each other and gives us a chance to work more closely together.

Patient stories can bring about changes. What changes are you most proud of?

One of the first changes was in response to a story titled 'No more jacket potatoes' which pointed to the need for better menu planning. We were able to improve communication between the kitchen and catering with this feedback which directly impacted on patients, who went from dreading meals to looking forward to them; important for our long stay patients.

A young mother who used our Sure Start service was left upset after a taxi failed to arrive to take her to her IT course. She told her story on Patient Opinion. We were able say sorry and as a result review our contract with the taxi provider.

In our mental health services for older people, inpatients were given general time slots when the consultant would see them. The slots spanned several hours. By the time the consultant got to see them, people were often agitated and anxious and the consultant was met with hostility. A patient told this story on Patient Opinion and the consultant listened. She visited the ward to talk to patients and agreed to change the appointments system, with obvious benefits on both sides.

One patient said she felt staff lacked compassion empathy and care. A project to improve the ward round experience for all was launched and information regarding ward rounds is now given out within the welcome packs for patients and carers.

We have noticed an overall culture change in how we talk to patients online. We are generally more responsive and informal. Staff that join us from other Trusts are often surprised and take time to adjust. We are used to our feedback being online. Now it feels natural.

Was there an initial fear about using Patient Opinion?

Yes! People were scared that criticism would be shared and 'go viral.' But we have learnt that a problem can be addressed in an open and authentic way and this goes a long way in rebuilding trust. In the early days it would take us much longer to respond to a patient than it does now, with better results.

Staff are more confident now. We collect good feedback about staff and pass it on directly, which has an obvious effect on morale. We have a more balanced view of how we are doing as a Trust.

Overall, Patient Opinion has changed the way we work. It has stopped us being internally focused and supported a culture which is now more open and transparent. It helps us live our values. It helps us to innovate.

The most valuable aspect of the partnership is that we can say to people: leave your feedback, it is independent of the NHS. Patients are happier to share their stories knowing this.

TOP TIPS

We discourage stock replies. It is a conversation.

We are not afraid to say we are sorry.

Our staff are encouraged to be empathetic.

We try to explain ourselves or say why a situation is the way it is. This can help a problem escalating and being filed as a complaint.

We reply to every story, good or bad.



Change made possible through connection

PROFESSOR CRAIG WHITE

HEALTHCARE QUALITY AND STRATEGY DIRECTORATE, SCOTTISH GOVERNMENT

Mindsets are so often vital in all domains of our lives – determining the way we feel emotionally, the responses that we have to events in our lives and ultimately the approach taken when ‘something new’ comes along.

Patient Opinion can act as a window into an organisation, showing how people think feedback and ‘lived experience’ might be used to inform learning and improvement. It also provides some clues as to how far along the road an organisation might be in becoming a learning organisation – one that uses every source of data (yes, even “an anonymous story”) as a potential source of learning about how to improve the quality of care and service.

Organisations that value relationships with the people who use services and support staff to develop positive relationships with people they work with (including colleagues) are the ones who seem to embrace Patient Opinion – seeing it as an opportunity to celebrate positive feedback and, through their responses, take action in respect of less positive experiences. Expressing concern, offering support and ensuring that is linked with a clear and publically made commitment to change that shows a personal engagement with the meaning and impact of the care experience.

Patient Opinion provides us with the means to capture feedback, to demonstrate through actions how important it is to continuous quality improvement and – ultimately to ‘connect’ health and care professionals with the values.

Patient Opinion has, through its work with hundreds of organisations, shown us the way in which mindsets can be changed, approaches can be refined and cultures transformed – changes made possible through powerful connections with experience, respect for individuality and commitment to continuous improvement.



Open channels for feedback are essential

ANNE COOPER

DEPUTY PROFESSIONAL LEAD, PROFESSIONAL LEADERSHIP GROUP,
HEALTH AND SOCIAL CARE INFORMATION CENTRE

I am a senior nurse, now working in informatics at the Health and Social Care Information Centre. During my career I have always had an interest in the experience of service users and carers. I led the establishment of a complaints function in a large trust back in the 1990s. I believe that open channels for feedback are essential for healthcare to improve.

During my career I have found myself wearing lots of different hats: nurse, manager, complaints investigator and responder, user of services. I have a long-term condition and have had lots of contact with various services over decades. I have praised when services are great and given feedback when they could have been better. Despite all of this, I think we have some way to go to have our ears tuned in to the experiences of people who use health services.

Most of the channels we have are what I call 'thin' channels. They lead people to a particular way of behaving. We tick boxes and fill in forms. In response

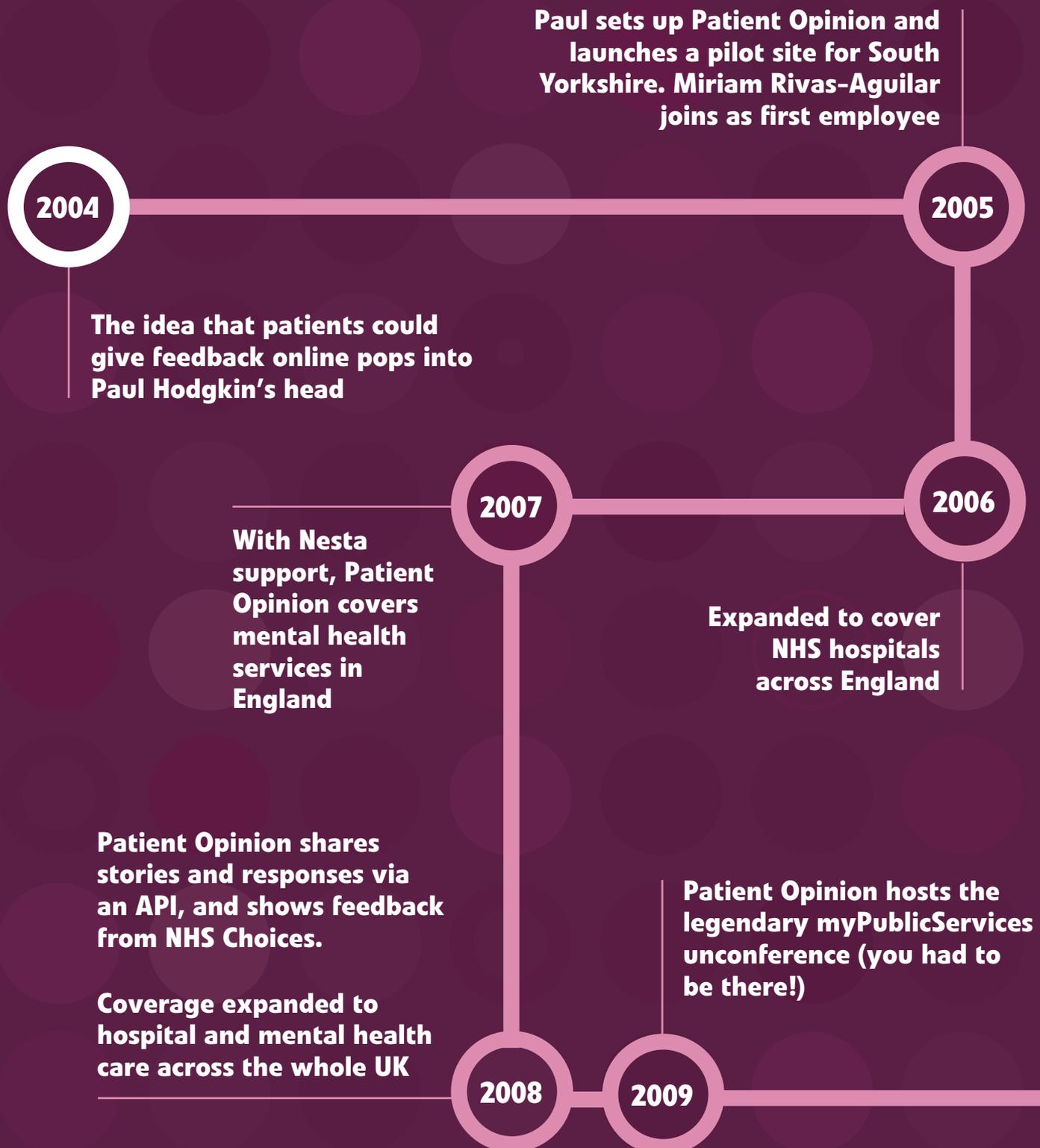
people process what we say: they count, create bar charts, send formal responses that reflect bureaucracy rather than emotions, and worry more about how quickly they respond than about what they actually say.

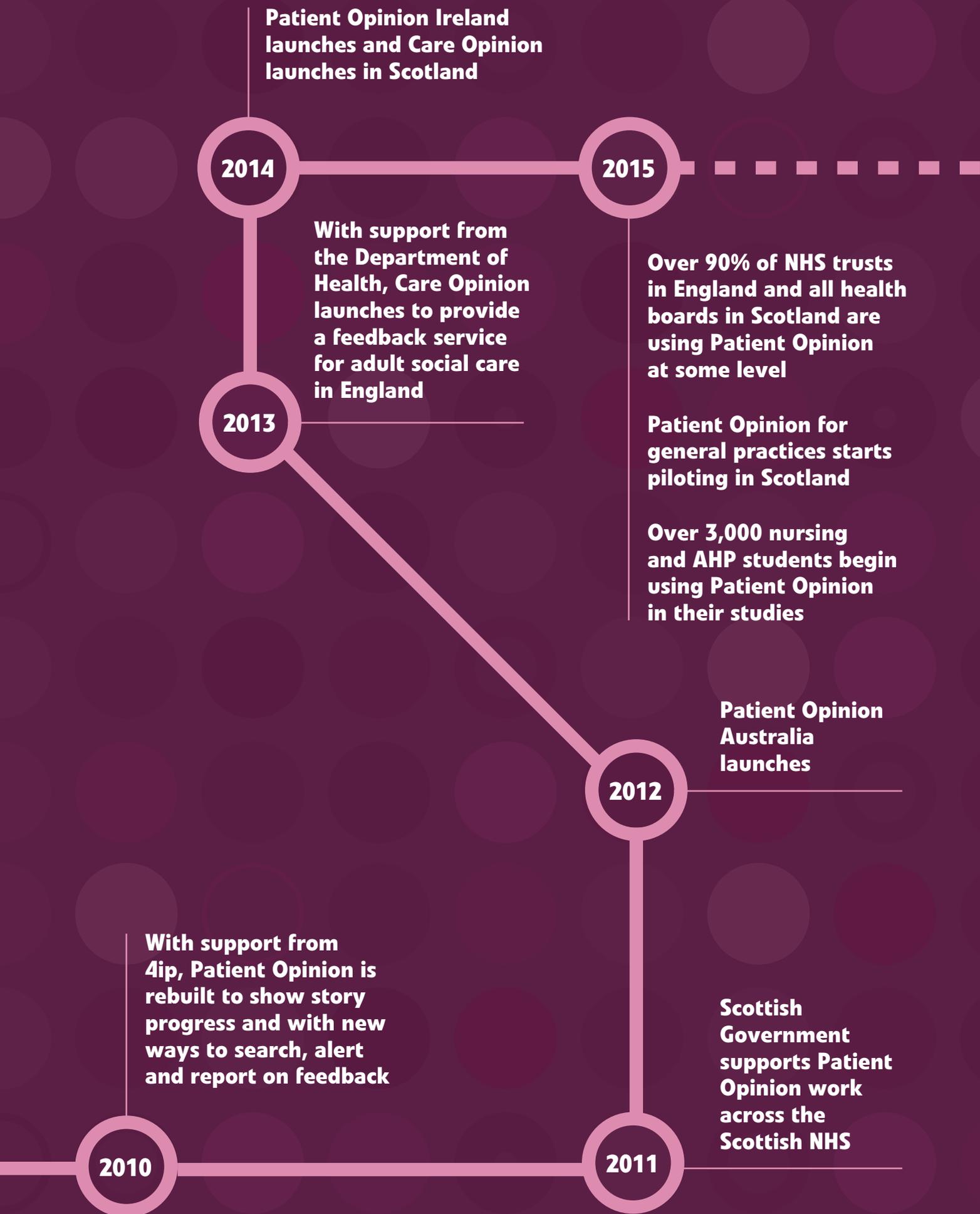
I think all of this leads to constraints about how we hear what people say – and yet, what people really want first is to know they have been heard.

I love Patient Opinion because I think it moves us some way towards having a 'fat' channel: a space where, if services are properly tuned in to listen and not bureaucratise the process, there is the potential to connect in a different way.

We need to help the people that matter to listen – empower front-line staff to hear and respond. And it's good to hear great feedback. It motivates teams and helps them stay on track. 'Fat' channels like this have the potential to improve what we do and, at the end of the day, that is what matters most.

Patient Opinion timeline





2010

With support from 4ip, Patient Opinion is rebuilt to show story progress and with new ways to search, alert and report on feedback

2014

Patient Opinion Ireland launches and Care Opinion launches in Scotland

2013

With support from the Department of Health, Care Opinion launches to provide a feedback service for adult social care in England

2015

Over 90% of NHS trusts in England and all health boards in Scotland are using Patient Opinion at some level

Patient Opinion for general practices starts piloting in Scotland

Over 3,000 nursing and AHP students begin using Patient Opinion in their studies

2012

Patient Opinion Australia launches

2011

Scottish Government supports Patient Opinion work across the Scottish NHS

“THEY WERE SO BUSY AND YET THEY HAD THE TIME TO MAKE ME FEEL LIKE I REALLY MATTERED. THEY WERE LOVELY.”

“My husband and I were going to catch the train to London and we were about half way across the rail crossing when the warning started that a train was coming. I tried to go quicker but I fell, and knocked myself unconscious.

I couldn't stand up. I'd damaged myself badly - my ribs were broken, and my face was all bleeding.

I was taken to hospital in an ambulance and every single member of staff was wonderful with both me and my husband. They were very, very busy but they genuinely made time for me. I couldn't believe they were caring about me - I felt so silly and embarrassed that I'd fallen.

When I felt better I really wanted to let the staff know what a great job they did.

It was a bad fall. It keeps me awake at night sometimes when I think about it but the care I got reassures me.”

SHEILA



Patient Opinion enables us to live our values

DR BEN MEARNS

CHIEF OF MEDICINE, SURREY & SUSSEX HEALTHCARE NHS TRUST

What makes Patient Opinion different from the “normal” ways you deal with feedback?

It is so accessible for patients and carers. The anonymity removes a barrier and enables honest feedback. It allows us to see things as they really are. If anything bad needs to be said it can be said and that is enormously reassuring. It removes the chance of secrets and surprises.

How important is it that Patient Opinion delivers feedback directly to service managers and clinicians?

Hearing of a problem instantly allows you to be able to help. We are in a caring profession and we want to be able to care. Someone may be worried, frightened, concerned, in pain or upset and Patient Opinion gives us the opportunity to know this quickly so we can offer to help. This is powerful in healthcare.

People worry about negative feedback but I see it as a symptom of a person’s distress and an indication that we can help.

How do you feel about receiving stories, rather than scores, through Patient Opinion?

A tick box exercise gives you a report. A story connects us instantly with that individual.

Why does making feedback public matter?

It makes us honest. People can say what they will about us and we can’t censor or edit it and our replies are there for all to see.

I like to use the metaphor of dirty laundry. If a trust is worried about dirty laundry being aired in public, then I suggest it deals with the dirty laundry.

It may seem counter-intuitive but using Patient Opinion is good for our reputation. People see us as a trust that is comfortable with criticism being shared openly. We are ‘happy’ to hear it, we interact with it, and we agree with people. This gives the public great confidence as nothing is hidden.

How does your trust use Patient Opinion?

Our clinical leads have signed up to be responders, and we expect them to reply within a realistic timescale. We use alerts and mobile technology so we can see stories and responses as they are posted.

It is a challenge to keep up with, but we find patients are always pleased to hear from us, even if it has taken a little while to get back to them.



EUNICE GOODWIN

PATIENT FEEDBACK MANAGER FOR NHS
AYRSHIRE AND ARRAN

“An unhappy patient published her story on Patient Opinion. She was offered to meet with staff to address her concerns. As a result of the meeting, the patient was offered a continence assessment. Within six weeks, the patient was continent, delighted and returned to swimming, her life transformed which was clearly communicated in her follow up post on Patient Opinion.

A lovely bonus for NHS Ayrshire and Arran and the patient was that an expensive operation (a stoma) was avoided. The ongoing month on month cost of the new treatment was also considerably less than the upkeep of the stoma. This is a great example of a win:win situation all round.”

Was there an initial fear about using Patient Opinion?

Yes, we felt exposed. No one likes to be criticised or feel judged. But it is like jumping into a cold swimming pool. You adjust and learn how to swim. We have found responding in human terms goes a long way.

A trust may feel it has a fragile reputation that needs to be protected, but that is the wrong way to view it. Reputation gets better when it lives and breathes its values of transparency and honesty. We have learned to trust our staff. We have learned trust is not brittle, it is a formed opinion of your community.

Single biggest change using Patient Opinion has bought about?

It has liberated our staff to be open and honest and to live their values. The relationship between our staff and patients is our biggest asset.

What are the benefits of using Patient Opinion from a patient perspective?

It helps build confidence in us. It empowers patients. They are reassured they have a level playing field there they can engage with us and help improve things.

TOP TIPS ON USING PO FROM DR. BEN MEARNS

Trust patients and carers

Trust staff to respond (clinical leadership)

Accept imperfection as normal

Solve each problem as it arises

Use positive feedback widely to empower staff and give confidence to patients/carers

Spot patterns and act to change the system

Remember the organisation’s reputation will take care of itself

Executives have to let go and empower their team

Believe in patients and carers as our best cheerleaders and that they expect the best

Allow stories posted on Patient Opinion to help you work together to solve problems

Patient Opinion tells us what services feel like

SAM HOLDEN

QUALITY ASSURANCE & PATIENT EXPERIENCE LEAD,
SOUTH DEVON AND TORBAY CLINICAL COMMISSIONING GROUP

For us, ensuring patients have a good experience of health care services is what we strive to achieve through commissioning local services.

Of course, this isn't without its challenges. As a commissioning organisation, it can be difficult to remain focused on how our work affects those who use our services. We are predominantly office-based, not providing hands-on care to patients and not in a clinical environment. So our challenge is to keep in focus that there are patients, their families, carers and staff at the end of our decisions.

This doesn't mean that we won't have to make unpopular or sensitive decisions. But how we listen to and engage with patients and other stakeholders when making changes can help us with communicating difficult messages. It is also vital that we hear the experiences of the people who use the services we commission, because this feedback informs future service design.

We use Patient Opinion to help us get an overarching picture of what people say about the services we commission. We find people are a lot more honest on Patient Opinion than they might be if they contacted us directly. We also monitor how the organisations we commission respond to their comments and how quickly they do so. Sometimes we respond directly ourselves, or in partnership with a service provider, particularly when comments span a number of services. The comments on Patient Opinion do not stand alone and are part of our wider patient experience

intelligence, through routes such as Patient Advice and Liaison Services, formal complaints and surveys. Patient Opinion provides the undiluted accounts of what services feel like, good or bad.

There is no doubt in my mind that for NHS organisations to be successful, they have to engage with and hear what people who use, interact with or work for them think. Sometimes, even when it's really hard to hear, it is vital that something is done about the feedback we hear – and the best responses on Patient Opinion are those where change has come about as a direct result of a story.

Even at times of huge financial pressure on the system, understanding how the decisions we make impact on the people using our services, and maintaining an overview of the quality of the service, allows us to be sure that quality and patient safety is maintained.



**"I HAVE LEARNT
THE IMPORTANCE
OF LISTENING"**

"We're frequently told that the NHS must be patient-centred. Patient Opinion helps us to understand what that means in practice."

FIONA, STUDENT NURSE, EDINBURGH UNIVERSITY

Every voice matters

Total stories available on PO
(including both PO and NHS Choices stories)

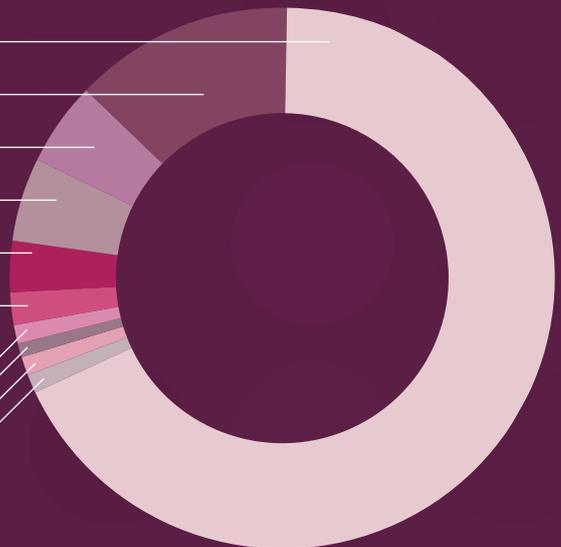
126,404

72
million

Total story views by public

Who do our stories come from?

- 68% Patient
- 13% Relative
- 5% Service user
- 5% Staff member posting for a patient/service user
- 3% Parent/guardian
- 2% Carer
- 1% Friend
- 1% Staff member
- 1% Staff member posting for a carer/relative
- 1% Other



81%

of stories get
a response

Total responses posted

99,617

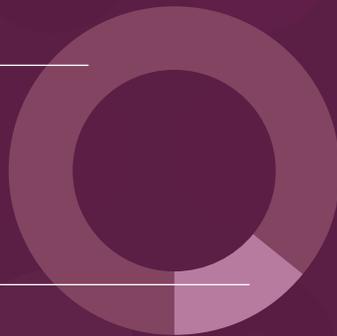
Mean time to respond

5 days

Of patients who rate
the response they get:

86%
Say helpful

14%
Say unhelpful



Most common
tags used
in stories

THANK YOU
STAFF
TREATMENT
MENTAL HEALTH
APPOINTMENT

Changes planned or
made by services in
response to stories

1,274

Number of
staff listening

3,136

Number of
student health
professionals
listening

3,000



People tell their stories in their own way

SIMON BRADSTREET

NETWORK DIRECTOR, SCOTTISH RECOVERY NETWORK

The NHS is a public service and public services are our services. They are used and experienced everyday by millions of people – so it makes sense that they need to be informed by the people who use them.

One challenge has been that traditionally feedback to the NHS has been mainly received via a complaints system which is necessarily focused on when things have gone wrong. As a nation we are rightly proud of our NHS, we are keenly aware it is free, and we don't want to complain unless we really have to.

But feeding back is not complaining. Sometimes we might want to simply say something has worked well and that it might work well for others. Or perhaps something didn't work and may lead to the same experience for others. The psychological entry point for giving feedback is nowhere near as high or stressful as complaining. Complaining is full of tension and stress for all concerned. If an organisation only has a complaints system for feedback, then soon everything starts to feel like a complaint.

Policy has always advocated patient involvement and Patient Opinion allows this to happen in an extremely effective and open way. In the past patient involvement may have meant accepting an invitation to a forum or a meeting, which demanded certain sorts of behaviour and fitting into another culture. This is clearly not for everyone, and for some is an intimidating prospect. Patient Opinion bypasses this and enables people to tell their stories, in their own words, openly, at the time they want to.

Staff within the NHS are under pressure and receiving good feedback is reassuring and good for morale. They are sometimes expected to be infallible by policy makers and public alike, so positive feedback can be both a powerful motivator and an antidote to that expectation.

Feedback sometimes reveals seemingly inconsequential things that can make big differences. A simple hello or touch of a hand can make someone feel valued and taken seriously. Stories which reveal these small acts are powerful in reminding other staff of their importance. In this way Patient Opinion is also a channel to inform policy and practice, with benefits to both users and staff in the NHS.

When people highlight a problem by using Patient Opinion, the decision making and logic behind that situation can be explained in an open forum for all to see. This is helpful for those directly involved and others who are going through similar experiences. You might feel you are not alone or that you are part of a wider community. It may save you years of heartache and frustration as you can see how others have dealt with a problem or sought out advice using Patient Opinion.

Specifically within the field of mental health, Patient Opinion has really helpfully widened the conversation around quality and access. Sometimes in the sector we can have an almost fatalistic view of 'the way things are done in mental health'. Public exposure of feedback on the good and bad in mental health services has helped broaden the debate, leading us all to question whether there might be other ways to ensure people get the right kind of care and support when they need it.



**“I MADE SURE
MY MUM COULD
KEEP IN TOUCH.”**

“I think my story is rather dull – it’s about phones! But I think it made a difference – not just to my mother but to other visitors and other patients in that ward”

HILARY

These 'gifts' of experience will transform health and care services

DR JAMES MUNRO

CHIEF EXECUTIVE, PATIENT OPINION

“We will continue to innovate in support of our mission: to carry the voices of patients and carers into the heart of the health and care system.”

The scientist Roy Amara once wrote: “we tend to overestimate the effect of a technology in the short run and underestimate the effect in the long run”. That sounds familiar.

When we set out on this path, in 2005, we imagined that within a year, perhaps two at most, we would be seeing hundreds of thousands of stories online, with tens of thousands of healthcare professionals engaging: reading, responding and making changes. So we definitely overestimated the effect in the short term. And sadly, it is still the case that the majority of patients and professionals alike remain blissfully unaware of Patient Opinion. The “dose” of our intervention remains too low to be truly therapeutic.

And yet, over the past 10 years much has undoubtedly changed. In 2005 nobody spoke of “patient experience”. Now it is a job title, a network, a topic. National policy reports – Francis, Keogh, Berwick – have urged the NHS to listen to the voices of patients, to make changes, to be transparent in their use of feedback. “Patients, carers and members of the public... should be confident that their feedback is being listened to and see how this is impacting on their own care and the care of others,” urged Keogh. And among Berwick’s recommendations: “All organisations should seek out the patient and carer voice as an essential asset in monitoring the safety and quality of care.”



Most service providers now understand that, increasingly, their feedback will arrive online and in public. And some – though far from all – now see that the insights of patients and carers are indeed essential to safe and effective healthcare. Throughout this report you will find examples of how patients and staff are creating change and learning from the “free gifts” of experience which people are donating through Patient Opinion.

What will the next 10 years bring? Technology will continue to evolve rapidly, running far ahead of the glacial pace of change in the culture of many healthcare organisations. Indeed, it seems increasingly likely that the widening gap between the everyday uses of networked technologies at home by patients and staff, and the absence of the same abilities in formal healthcare settings, will reach crisis point.

But culture does and will change, albeit at a slower pace than technology. The decade ahead will see both patients and staff increasingly networked, informed, and confident online. We will see the growth of connections between these online communities: that is, between those providing health care, and those using it. And these connections “across the divide” will themselves change culture.

And what must Patient Opinion do in the decade ahead? We must stay true to the understanding that, at the heart of all meaningful, memorable care, we will find not x-rays, drugs or surgery but listening, caring, empathic relationships. And sometimes it is relationships rather than the interventions of modern medicine which truly enable healing. But, as one contributor to this report notes, all too often when resources are tight it is the care itself that seems to be squeezed out of services.

So we will continue to innovate in support of our mission: to carry the voices of patients and carers into the heart of the health and care system. We will continue to find ways to connect patients and professionals reflecting on: “What was good? What could have been better?” And perhaps we will find, as we look back 10 years from now, that although we overestimated the effects of public online feedback in the short run, we did also underestimate the effects in the long run.

Knowing my voice is heard helps reduce my suffering

'G'

A MENTAL HEALTH SERVICE USER

I started using Patient Opinion because I felt incredibly alone with my experiences of trying to get support for my physical and mental health problems.

My first post was to praise a service I relied on. But I was wary of talking about my negative experiences. I was fearful that if I complained, I would be seen as whining and my care would suffer.

Over time this has gradually changed. Reading other people's experiences and seeing service providers respond - apparently really wanting to hear feedback so they can make changes - inspired me to speak out.

Patient Opinion has had a tremendous impact on me. Sometimes it has stopped me from harming myself. Instead of internalising my anger when treated badly by a professional, I have been able to voice the shame and grief I have felt. The site has allowed me to dialogue about my complaints in a constructive way, rather than turn my anger against myself.

I am amazed by how a website could give me such a sense of solidarity. I feel at times it has given me a sense of purpose and meaning, because I now know that when I post about my care, many others are experiencing a similar problem. Although I am unable to end my physical and emotional pain, having a voice that is heard does alleviate the suffering. It is very hard to express my enormous gratitude for this.

It has been a privilege to be able to say when people give good care. When you see people working with dedication to provide a service under extremely difficult circumstances, it feels very good to be able to let them know publicly how much they are appreciated.

I would like to encourage all those who use Patient Opinion to find ways to dialogue with the individuals and services they use. It is important that we all work together to create a system that really cares. All too often it is the care that is taken out of our services when money is tight. Yet most patients value the sense of being cared for, above anything else.

If you would like to contact the team that runs Patient Opinion, get in touch via email or Twitter:

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**"I'm pleased my story
has made a difference
and will make changes
so the same doesn't
happen to anyone else in
my situation."**

(from "Banjo",
story no 207044)

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