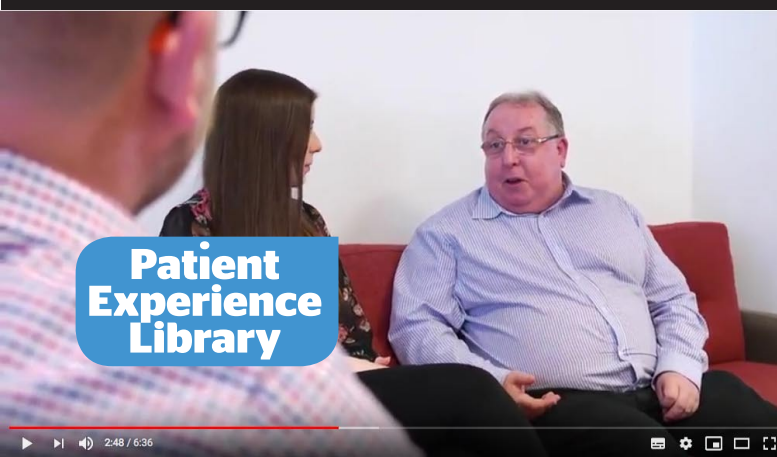


# Patient Experience

and patient/public involvement in health and care services

Autumn 2019





## Editorial



**“You can argue with figures and statistics, but you can’t argue with personal experience”.**

These are wise words from a person who knows that in an NHS driven by targets and performance measures, it is still the human experience that matters most. They come from Stephen Elsmere, who has used the NHS both as a mental health patient and as a general patient. He is also a carer.

And on top of all that, he is an Experience of Care Partner with the NHS Leadership Academy. This is someone who knows what he’s talking about.

Stephen is one of a number of patients who are helping the NHS Leadership Academy to think about “patient leadership”. You can read their stories on page 5 and can click through to a series of short videos where they outline their experiences and motivations.

In terms like “patient experience” and “patient leadership”, the word “patient” is used as a bit of a catch-all. It can often encompass relatives and carers, who can also draw on their own experiences to develop their own forms of leadership.

Jennifer Johannesen was the main carer for her son Owen throughout his childhood, up to his early death. Her book *No Ordinary Boy* is a record of her “encounters with healthcare”, and how those are uniquely experienced by a family like hers. I picked it up intending to give it a quick skim and ended up reading the whole thing in one go. I spoke to Jennifer (page 3) and found, once again, that although measures matter, the true nature of “patient experience” can only really be found through personal testimony.

Our third contributor (page 4) is Liz Pryor, whose mother Anne Robson died in distressing circumstances in hospital. Liz converted her grief to action, setting up the Butterfly Volunteers, who offer companionship to hospital patients in the last days and hours of their life, particularly for patients who have no other visitors. It is an astonishing story of the power of personal experience to effect change.

We’re always keen to hear from our readers, so if you know of a stand-out report that we should be featuring, or if you want to submit a comment piece, get in touch!

*Miles*

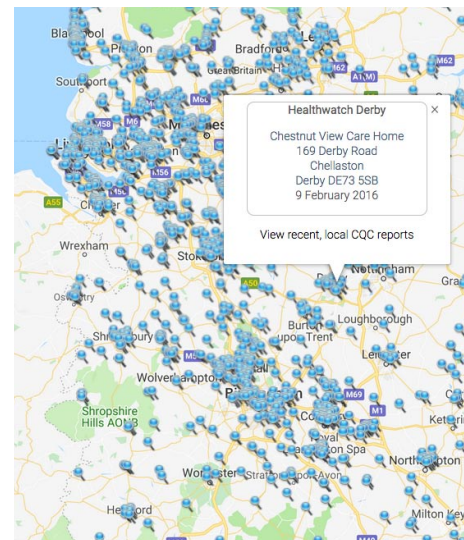
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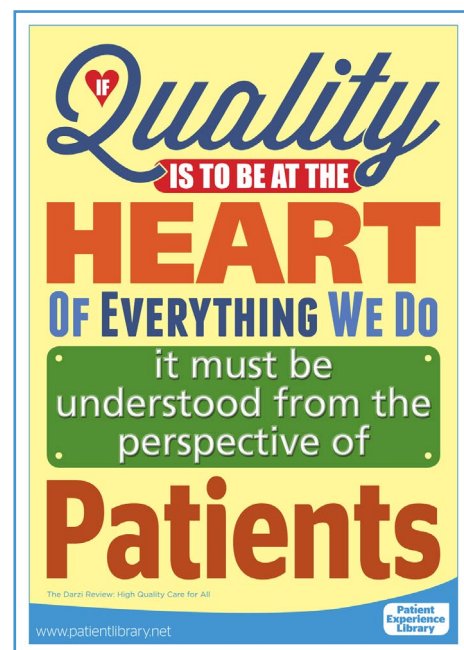
[www.patientlibrary.net](http://www.patientlibrary.net)

## Free resources

Our [Knowledge Maps](#) offer a quick and easy view of what patients are saying about healthcare services across England. Feel free to click and browse at will!



Spread the word about patient-centred care with our [posters](#) for offices, wards, meeting rooms and waiting areas. The quotes are from sources such as the Berwick Review and the Francis Inquiry – so as well as being visually striking they’re also on solid policy ground!



## Comment

Do you have opinions, insights or good practice examples that you’d like to share with our readers? Drop us an e-mail to receive our guide for contributors: [info@patientlibrary.net](mailto:info@patientlibrary.net)

# No Ordinary Boy

Jennifer Johannesen, parent, author, bioethicist.  
interviewed by Miles Sibley, Patient Experience Library



**No Ordinary Boy** is Jennifer Johannesen's account of the life and death of her son Owen Turney.

Owen was born with severe disabilities and Jennifer found herself providing round the clock care for him during the whole of his childhood. So this is also a story about a mother's and carer's experience.

The events take place in Canada but much will resonate with UK audiences. I asked Jennifer about her motives for writing the book, and what she hoped UK readers might take from it.

She starts by talking about Owen: *"Imagine the most disabled person you've ever encountered. He needed full support for all aspects of daily living".*

*"Owen was deaf and had no language, so it was hard to determine his preferences. But he was always alert*

*to what was going on around him. Slapstick jokes would elicit a belly laugh. And if he saw somebody upset, he might start to cry too. You couldn't talk with Owen about the future or the past. But you could see that he was fully present in every moment."*

***The account shows the futility of trying to reduce "patient experience" to a set of metrics.***

We move on to talk about the book: what is the story actually about? Jennifer is clear that it is not a memoir. It is, she says, a record of encounters with healthcare, and how those are uniquely experienced by a family like hers. She wanted to reveal the kinds of absurdities that are often present, but not always fully visible, or acknowledged. It is what she calls *"the whole special needs business that regular families don't encounter"*.

Those absurdities do not always emanate from health professionals. Jennifer is remarkably frank about her own decision-making on Owen's behalf: *"I presented Owen to the world in a certain way, and it became clear to me after he died that this was purely my fiction. He might have described things very differently"*.

*"Owen was non-verbal, so it couldn't have been any other way - but I had my own hopes and dreams and was battling my own grief, and that was part of what I presented. I was also encountering professionals who had agendas of*

*their own that I was often unaware of. Sometimes I sensed a difference of view or approach - but it was never very clear. And yet all of healthcare presents as neutral, science-based truth."*

*"There are a lot of assumptions about how great our healthcare system is, and the wonderful professionals doing the best they can. But these are platitudes. When it came to individual encounters, it felt so much more complex than that."*

So - by publishing an account of her experiences, what does Jennifer hope to achieve? Again, her response is frank. *"I used to do talks for students and professionals, and people would ask me 'what should we learn from this'? I used to feel pressured to come up with an answer - but not any more. I am not going to workshop my own story."*

Jennifer's answer is a good one because the story speaks for itself. Different readers - professionals, patients, carers - will all have different reactions and draw different conclusions.

One thing that I took from it is that the account shows the futility of trying to reduce "patient experience" to a set of metrics. Measures matter. But personal testimony - dismissed by some as "anecdotal evidence" - is a necessary counterpoint to the so-called "hard evidence" of statistics. Especially when the testimony is as powerful and articulate as this. If you read nothing else in the next week or two, [read this](#).

[@jenjohannesen](http://johannesen.ca)

# Butterfly Volunteers

*Liz Pryor, Anne Robson Trust*



My mother, Anne Robson, was a gentle, elegant lady who sadly died in January 2010, after a very difficult week in hospital.

She had been admitted after a fall and was a bit confused, but she happily sat up in bed, chatting and enjoying coffee and biscuits. She had some x-rays and was then taken up to the ward, where I was told, very briskly, that it was a “closed ward” for infection control, and I would not be allowed in.

I explained how upset this would make mum (and me) and the nurse conceded that I could go in quickly to say what I now know was my last goodbye to my mother. One week later, she died.

Anne Robson was admitted as an elderly lady with a bruised hip. She was discharged a moribund, terminal patient. In the care of health professionals my mother deteriorated unnoticed. On the day she died, when she could not recognise her own daughter, or lift her head from

the pillow, she was deemed fit for discharge by nursing staff.

I realise that looking after elderly people is a complex, challenging task. This does not mean I forgive those who failed my mother. I don't. But having worked in hospitals since she died I have learnt what they are up against.

I feel passionately that we should celebrate the amazingness of the NHS – we should “big up” the fantastic nurses, health care assistants, doctors, housekeepers, cleaners, consultants. If we keep on bashing the NHS, the good people will leave – and then where will we be?

Thousands of people die in hospital beds. If we can make a difference to even a few people facing the end of their life – because it is possible to have a “good” death – that would make it all worthwhile. So I set up the Anne Robson Trust and the Butterfly Volunteers scheme to try to make a difference.

The Butterfly Volunteer role is simple: to provide companionship to hospital patients in the last days and hours of their life, particularly for patients who have no other visitors.

Volunteers are trained, and a dedicated co-ordinator works out visiting rotas and provides pastoral and emotional support to the volunteers on their team. That's important because the role is not an easy one. The volunteers might sit with people who seem unconscious, sitting quietly or simply holding their hand. They will comfort

relatives – make cups of tea, and make sure they are aware of other services that might be available for them – ie free parking, or meal vouchers. Even though the role can be challenging at times, volunteers find what they are doing hugely rewarding.

Hospital staff appreciate the additional support as well – we help them to take ownership of the scheme, and to see Butterfly Volunteers as part of their own care team. But it's patients and their relatives who really benefit, as in the words of this person whom we were able to help:

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***“I am an only child, and my Dad was an only child, so there were not many of us around to support him when he was in hospital. To come in every day and read that Butterfly Volunteers had been sitting with him, what their names are, and how long they spent with him, meant the world to me. I can't thank the volunteers enough for the support they gave our family.”***

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[www.annerobsontrust.org.uk](http://www.annerobsontrust.org.uk)



# Developing Patient Leadership

One of a series of articles on patient leadership  
– what it is and why it matters

**Karl Roberts**

*Senior Programme Manager: Experience of Care and Participation, NHS National Leadership Academy*



People often ask me, “What actually is patient leadership?” That’s a difficult question, because there are probably as many answers as there are patient leaders!

We are really pleased that some of our patient leaders have been willing to explain patient leadership in their own words, and on their own terms. Here is what some of them have said:

**Bren** is clear that one aspect of good leadership is humility. As he puts it, “It’s not about me – it’s about what matters to our people and communities”.

Working out what matters is not always easy – sometimes, says Bren, “you have to give uncomfortable messages” to NHS staff. But “what you’re giving to them is an opportunity for them to think ‘Actually, have we got it right? Do we actually need to change some of it?’”.



**Hazel’s** motivation comes from her experience as a carer for her brother who has long term mental ill health. She sees good communication and a holistic approach as vital. “It’s not just the person, it’s the family and the carers and everyone around them. The more different perspectives you’re getting the better”.



I have spent time with Bren, Hazel, Stephen and Emma, and I know that what they and others like them bring to the NHS is invaluable.

In the NHS Leadership Academy, we continue to develop our work around coproduction and co-design with patients, service users and carers. We’re increasing their participation in NHS Leadership Development programmes – aiming ultimately for better care and outcomes across healthcare.

But does patient leadership make a difference? And if so, how would we know? Do we need to be measuring outputs, outcomes, impacts?

**Stephen** is not sure. “You can argue with figures and statistics” he says, “but you can’t argue with personal experience”. For him, “involving patients in the Leadership Academy improves empathy and communication”.



We’re giving opportunities for patients and patient leaders to co-design and co-deliver training workshops as part of the Academy’s course programme. There is a wide range of topics including storytelling, inclusive interviewing, co-production, and participation in health service meetings and events.

If you’re interested in this, or know someone who is, we’d like to hear from you. You don’t have to be a qualified teacher. Like Bren, Hazel, Stephen and Emma, you just have to be willing to help others learn from your experiences.

For more details, or just an informal chat, please feel free to get in touch:

[karl.roberts@leadershipacademy.nhs.uk](mailto:karl.roberts@leadershipacademy.nhs.uk)



**Emma** agrees. “I don’t want anybody to go through what I went through in the 40 years before I was diagnosed with gender dysphoria”, she says. However, her experience is that “patient engagement in the NHS has massively improved. Ten years ago the NHS wasn’t even talking to me.” But “the life I now have is amazing”.

## RECENT REPORTS

Here, we review our top picks of studies and surveys from the last three months. Some are newly published – others are featured because they shed useful light on recent issues and developments. For full attributions, and copies of the original documents, click on the report pictures. Do you know of a stand-out report that we should be featuring? Contact us! [info@patientlibrary.net](mailto:info@patientlibrary.net)



NHS Patient Survey Programme

### 2018 Adult Inpatient Survey

### Statistical release

Published June 2019

Independent data analysis

## Inpatients speak out

The Care Quality Commission's Adult Inpatient Survey has now been running for 15 years, but as the CQC says, "every year brings a new perspective". So what do this year's results show?

As always, there is good news. Trust in doctors and nurses remains relatively high, most patients (over 90%) report that they had enough privacy, and communication between patients and staff remains a positive experience for most. Patient satisfaction with hospital food has improved over the years, with the proportion of those saying that it was "very good" increasing from 19% in 2009 to 23% in 2018.

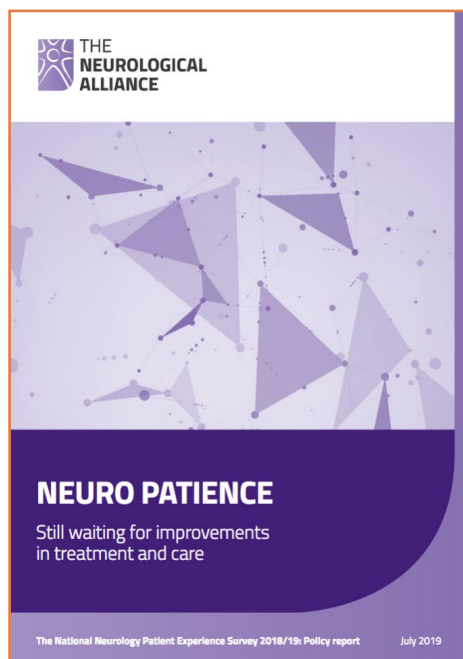
Alongside this, however, are areas that consistently show poor patient experience, including waiting times, the quality of information and involvement around hospital discharge, and experience of integrated care.

Patients' reports of problems with waiting times have been corroborated by the [House of Commons Public Accounts Committee](#), which has deemed it "unacceptable that less than half of NHS trusts meet the waiting times standard for elective treatment, and only 38% meet the standard for cancer patients". The committee is concerned that national bodies "appear to lack curiosity regarding the impact of longer waiting times on patient outcomes and on patient harm".

Hospital discharge is a longstanding source of dissatisfaction for patients, with [Healthwatch](#) reporting back in 2015 (and many times since) on the problems.

The survey also finds that "people's experience of the integration of their care has got worse". 18% of respondents said they did not know what would happen next with their care when they left the hospital, and nearly a quarter of patients (24%) said they did not get enough support from health or social care professionals to manage their conditions after leaving hospital.

The CQC concludes that "While last year we reported on a system still delivering improvements in patients' experiences despite growing pressure, this year, the improvement is not sustained. In 2018, there is a lot of evidence to suggest that pressure on the system is having a real impact on patients' experiences of care".



## Neuro patience

We are all used to the big national patient experience surveys carried out by the Care Quality Commission and NHS England. These cover patient experience of maternity services, community mental health services, GPs and so on. Results are published by provider and the surveys are, essentially, a test of people's access to, and satisfaction with, services.

But there is another dimension to patient experience which is less well explored. That is people's experience of living with long term health conditions. And this really matters, given the increasing emphasis on "self-management" within NHS strategies.

So it is encouraging to see the Neurological Alliance continuing to show a lead in how patients can help to build an evidence base, and a case for change. Their latest patient experience survey highlights key areas for improvement, based on the following:

- Long delays, and a lack of access to specialists. Around a third of survey respondents waited more than 12 months to see a neurologist.
- A lack of personalised care. Only 42% of neurology patients had written information at the time of diagnosis, against 83% of people with cancer. Just 10% had been offered a care plan.
- Poor experience of social care, with many people dependent on unpaid carers.
- Disability discrimination in the workplace, and problems accessing welfare benefits.

This year for the first time the results are broken down to regional level, based on the Sustainability and Transformation Partnership (STP) footprints. The findings reveal wide geographic variation, representing a postcode lottery in access to care. And it may come as no surprise to learn that people in the most deprived areas report the poorest experiences of care.

National patient surveys run by the CQC and NHS England are valuable - helping patients and providers alike to get a sense of people's experiences within individual services. But in an NHS that is building integrated care systems, we need to understand how people experience care across services, and through pathways, and how they cope with extensive periods of self-management of their conditions. This report offers some pointers.



# Involving patients and public in research

Patients and the public get involved in research because they want to help others, and contribute to a better healthcare system. They may also have an interest in a research topic because of relevant personal experience.

These are good reasons to involve patients and public in research and according to this report, researchers often recognise and build on these motivations. However, that is not always the case. Sometimes, for example, patients and public are included in research simply because that is a condition of the research funding.

The report aims to build a better understanding of patient and public involvement (PPI) in research, to help ensure meaningful involvement. But that in itself is a major challenge, as *“there is limited agreement about how, when, and why [PPI] should best be done”*.

Definitions are often blurred, and PPI *“lacks standard terminology”*. Furthermore, *“Few studies evaluated the fidelity of their PPI approaches, making it difficult to know whether the approaches discussed were implemented as intended”*. Under these circumstances, *“PPI can sometimes become a tick-box exercise”*.

The report looks at the research tasks and activities that patients and public can undertake, and considers enablers and challenges to involvement. It also explores questions of impact and evaluation, while noting that *“many papers we reviewed lacked detail about PPI activities and were often based on opinion rather than validated measurement”*.

The authors point out that *“Some have assumed the more PPI, the better, suggesting that co-production – the most involved of PPI approaches – is the ‘gold standard’*. Others reject the idea of ‘the more, the better’, raising concerns that it may lead to tokenistic practice or work against meaningful involvement”. They conclude that *“with careful consideration of when to do PPI... all sides can benefit from bringing real-world understandings into research about healthcare”*.





# Navigating the feedback maze

It is no secret that NHS staff can feel swamped by the volume of patient feedback coming from Friends and Family Test, national surveys, local surveys, complaints, social media and more.

There is broad consensus on the value of seeking patients' views. But there is less agreement about how to learn from, and act on, the mass of data gained from widespread evidence-gathering.

According to this paper, *"quantitative surveys [are] the most frequently collected type of patient experience data (often mandated) but the least acceptable to healthcare teams with respect to use within quality improvement"*. On the other hand, there is *"an apparent sense of nervousness amongst hospital teams surrounding the use of qualitative data as it is regarded as time-consuming to collect and difficult to interpret without bias"*.

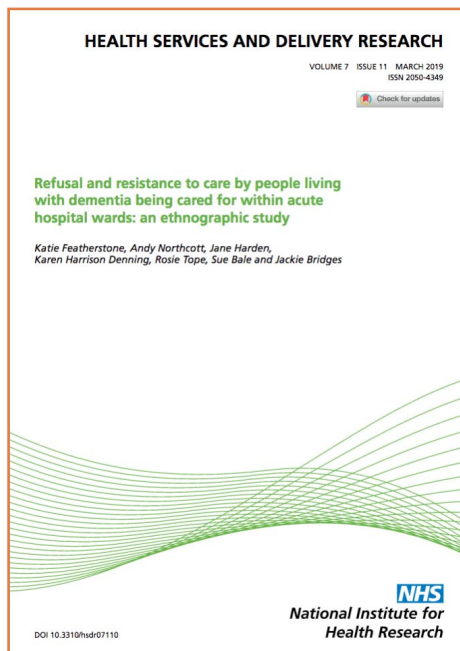
To try to make sense of all this, the researchers looked for a way to define types of patient feedback, and to develop categories that could help clarify potential uses for the different types.

A scoping review returned no fewer than 37 feedback types. These were sorted into 12 characteristics and then into 4 categories, as follows:

- Hospital-initiated quantitative surveys: eg the NHS Adult Inpatient Survey
- Patient-initiated qualitative feedback: eg complaints or twitter comments
- Hospital-initiated qualitative feedback: eg Experience Based Co-Design
- Other: eg Friends & Family Test.

These categories might help us to make sense of the wide range of patient feedback types in use across the NHS. But do they help us to make sense of what patients are actually saying? Unfortunately, the paper finds that few of the routinely collected feedback types elicit "ready-to-use" data. And where useable data is easy to extract, it is *"most suitable for measuring accountability, not for informing ward-based improvement"*.

The authors conclude that *"If feedback is to be used more frequently within quality improvement, more attention must be paid to obtaining and making available the most appropriate types"*.



# Refusal and resistance

Dementia care is often thought of as taking place in the community, or in long-term care. However, as many as one in four acute hospital beds are occupied by a person with dementia.

People with dementia are highly vulnerable within hospital settings, where functional abilities can deteriorate quickly. They are more likely to experience a delayed discharge, more likely to be readmitted and are at much higher risk of dying.

This study examined a common but poorly understood phenomenon within the acute setting: refusal and resistance to care. This can include getting out of bed, trying to leave the ward or hospital, shouting, and refusing food or medicine.

Reactions such as these were typically rational to the patient's perceptions. But ward staff typically interpreted resistance as a feature of the patient's identity, which could become their principal identity in the context of the ward. Refusals were "viewed by staff as problematic, difficult, signifying a lack of capacity, and, because they do not 'fit' the organisation and timetabled routines of the ward, as something that must be overcome or managed".

Staff responded with highly repetitive language, instructions to be obeyed, and containment. Raising the side rails of the bed or tucking bed sheets in tightly around the patient were common means of containing a patient. For patients sitting at the bedside, the close placement of the mobile tray table or unreachable walking frames and technologies such as chair alarms were used to keep them in their bedside chair.

These approaches "created damaging cycles of stress for patients, families and ward staff". Furthermore, "approaches to... patient containment at the bedside were a response to resistance but also frequently the trigger for resistance or patient anxiety".

The study concludes that there are "powerful cultures of containment and restraint, with... work in the ward driven by the organisational demands of delivering care within fixed routines and timetables that do not meet the needs of people living with dementia". In response, the authors are developing "simple, no-cost innovations at the interactional and organisational level within wards that can be introduced and used by nurses and HCAs". The feasibility of these is currently being tested within one acute 'laboratory' ward.



## Do what you say and say what you do

*“Many people talk about the importance of public trust” says this report. But, it goes on, “Trust can only be earned, and that starts with understanding what people think, want and expect”.*

The report looks at trust and transparency in the politically fraught area of personal health and care data. It reveals a *“healthy degree of scepticism among publics about whether the proclaimed benefits of better data use are actually realised in practice”*.

It also acknowledges *“significant gaps in our understanding of people’s views, most notably around the perspectives of minority and marginalised groups”*. It notes that *“Some groups may have good reason to feel distrustful of the health and social care system and be inherently concerned that data about them could be used to target or discriminate against them”*.

The report’s focus is development of a Local Health and Care Record system in London. The aim is to make health and care information more consistent, more joined-up and more available to the clinicians, patients and families who need it. This might be complex to implement in practice, but *“there should be no barrier to providing straightforward and comprehensive answers about why, by whom and how patient data is collected, managed, protected and used”*. And this should be informed by meaningful engagement with patients and public – *“those with rights and interests over the data”*.

So how can transparency be achieved in the area of personal data, where there are legitimate concerns over matters such as anonymisation and information governance? The answer, it seems is that transparency can mean different things to different people but boils down to *“do what you say and say what you do”*.

Debates over use of data are rarely easy. But *“It is incumbent upon those managing and using data to describe a clear trajectory from the collection of data to delivery of benefits. Without this, the public will have every reason to question whether the case for using data beyond individual care really stacks up”*.



# Patient centred safety

The newly published NHS Patient Safety Strategy has been *described by the NHS* Confederation as a “paradigm shift” in the way the NHS treats patient safety. A key feature is a move away from a culture of blame to one of learning.

This paper from Ninewells hospital in Dundee shows what a safety learning culture looks like in practice. Better still, it explores – and resolves – a safety issue by using patient experience as a key learning tool.

The hospital’s Radiology Department uses Magnetic Resonance Imaging (MRI) for diagnostic tests. MRI scanners are generally safe – but they can cause overheating and malfunction in implants such as pacemakers and artificial valves.

The safety system requires referrers (GPs, hospital doctors and others such as physiotherapists) to ask patients to list any implants or foreign bodies they have. But, say the authors, *“Despite constant efforts, there have been recurrent incidences of safety breaches with patients attending MRI department with implants, including pacemakers, when none have been declared”*.

Rather than ask referrers what was going wrong, the radiographers went to the patients. A questionnaire found that almost regardless of the type of referrer (GP etc) only 50-55% of patients had been asked about pacemakers, and fewer than 50% had been asked about valves, clips and other metal objects in the body.

In case patients had misunderstood or forgotten their conversations with referrers, a second survey was carried out, using face to face interviews to check and clarify patients’ responses. It found similar results.

Rather than blame the referrers for compromising patient safety, the radiographers developed a “strategy for change”, with risk alerts, and reworking of questions on the referral form. In the twelve months following, there was no incident of any undeclared implant. This, say the authors, *“was in sharp contrast to the continuous stream of significant events earlier that had prompted our intervention in the first instance”*.

The safety exercise was carried out at a Scottish hospital. But *“pathways for MR referral and acceptance are broadly similar throughout the UK [therefore] this survey could be usefully applied to provide further insight to other NHS centres on MRI safety issues”*.

Improvement Analytics Unit briefing  
July 2019

## Emergency admissions to hospital from care homes: how often and what for?

Arne Wolters, Filipe Santos, Therese Lloyd, Creina Lilburne and Adam Stevenson

### Key points

- In January 2019, the NHS published its 10-year Long Term Plan, including a commitment to improve NHS support in care homes, rolling out the Enhanced Health in Care Homes (EHCH) framework across England. One of the aims of the framework is to reduce emergency admissions from care homes which, although essential for delivering medical care, can expose residents to stress, loss of independence and risk of infection. Care home residents often prefer to be treated in the care home or avoid the need to seek urgent treatment in the first place. Therefore reducing emergency admissions could be good for residents, as well as help reduce pressure on the NHS.
- In this briefing, we firstly present our analysis of a national linked dataset identifying permanent care home residents aged 65 and older and their hospital use in the year 2016/17. In the second part of the briefing we synthesise learning from four evaluations of the impact of initiatives to improve health and care in care homes carried out by the Improvement Analytics Unit (IAU).
- Our analysis, using a new data linkage method that allows us to identify permanent care home residents aged 65 and older in NHS datasets, found that during 2016/17 care home residents went to A&E on average 0.98 times and were on average admitted as an emergency 0.70 times. The overall number of emergency admissions from care homes in 2016/17 was an estimated 152,000, comprising 7.9% of the total number of emergency admission for England for people aged 65 years or older. The overall number of A&E attendances from care homes was 260,000, comprising 6.5% of the total number of attendances for people aged 65 years and older. Reducing emergency hospital use from care homes therefore has the potential to reduce pressure on hospitals.



# Emergency admissions from care homes

It is well-known that one of the pressures on hospitals is delayed discharge – often linked to lack of capacity in care services. However, the care system can also cause pressure at the front end, by referring people into hospital unnecessarily. And A&E departments can take the brunt of this.

This Health Foundation briefing starts by observing that emergency admissions from care homes can expose residents to stress, loss of independence and risk of infection. It says that care home residents often prefer to be treated in the care home – so reducing emergency admissions could be good for residents, as well as help reduce pressure on the NHS.

The numbers are large – in 2016/17, over a quarter of a million care home residents in England attended A&E. But 41% of emergency admissions from care homes were for conditions that were potentially manageable outside a hospital setting, or that could have been caused by poor care or neglect.

The authors were surprised to find that emergency admissions were particularly high from residential care homes as against nursing care homes. Given that residential care homes provide 24-hour personal care, they say, one might expect residential care home residents to be less seriously ill than nursing home residents.

The study looked at four initiatives to improve health and care in care homes that were associated with the NHS's New Care Models programme. It found reductions in at least some measures of emergency hospital use for residents who received enhanced support. This, it says, shows that there is potential to reduce demand for emergency care from care homes, but it also points to implementation challenges.

Co-production between health care professionals and care homes is key to tackling these challenges – but so is access to linked administrative datasets that can provide evidence to support policy making. It is important, say the authors, that these sorts of data are routinely and consistently collected and are easily accessible if we are to understand residents' health care needs and improve care for this vulnerable group.



# Patient Experience in England

Thousands of reports are published every year on patient experience in the NHS, by government bodies, patient voice organisations, health charities and academic institutions.

Academic research has repeatedly shown that NHS staff can find it difficult to keep track and make sense of the literature. And this year, [yet another study](#) confirmed the existence of an evidence-practice gap in patient experience work. It observed the “*overwhelming nature of the industry of patient experience feedback*”, and said that “*Ward staff... reported feeling overwhelmed and fatigued by the volume and variety of data that the Trust collected*”.

Our annual Patient Experience in England report cuts through the bewildering mountain of evidence, summarising a year’s worth of patient experience surveys, and drawing out key themes from wider research.

The “state of patient experience” overview this year shows that:

- Some patients are more equal than others. The NHS offers universal health coverage but some groups do not get the access they need.
- Online patient feedback can build community – if healthcare professionals respond appropriately.
- Patient and public involvement in research is good in parts. There is not yet a consensus about the need for, and benefits of, involvement.
- Public funding for patient voice is declining, and drug companies are moving in to fill the gap.

The report also looks at “learning from deaths”, and finds that culture is impeding progress. And it covers the deepening crisis in social care.

*“Improving patient experience is a key aim for the NHS” says Professor Debra Jackson in her foreword to the report. “In my nursing career, I have seen how the unique patient perspective can reveal things that we can miss in the rush and busyness of providing care. The Patient Experience Library represents a realistic strategy to help health service staff gain insights into patient experiences and concerns.”*



# Why patients miss appointments

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DOI: 10.1111/hes.12959

ORIGINAL RESEARCH PAPER

WILEY

## A mixed-methods exploration of non-attendance at diabetes appointments using peer researchers

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Funding information  
The study was funded by the Scottish Diabetes Group.

### Abstract

**Background:** Non-attendance at diabetes appointments is costly to the health service and linked with poorer patient outcomes.

**Objective:** Peer researchers aimed to conduct interviews and survey people who miss appointments about their beliefs and perceptions regarding their diabetes and diabetes appointments.

**Design:** A mixed-methods cross-sectional design with interviews conducted by peer researchers with diabetes and a questionnaire was used.

**Setting and participants:** Peer researchers conducted semi-structured telephone interviews in one health board in Scotland with ten people who had missed diabetes appointments. A further 34 people who had missed appointments completed a questionnaire. The study was informed by two psychological theories (the Theory of Planned Behaviour and the Self-Regulation Model), and interviews were analysed using thematic analysis.

**Results:** Interviewees planned to attend appointments but practical barriers, low perceived value of appointments and the feeling that diabetes had little impact upon their lives emerged as key reasons for missing appointments. Questionnaire data supported these findings and showed that respondents perceived diabetes to have only mildly serious consequences and cause limited concern and emotional impact. Participants' understanding of their condition and perceptions of personal control and treatment control were low. Gender, perceived behavioural control and emotional representations were significantly associated with the number of appointments missed in the previous year.

**Conclusions:** These findings highlight the importance of psychological variables in predicting non-attendance at diabetes appointments and provide avenues for how non-attendance might be tackled.

### KEYWORDS

diabetes, health psychology, non-attendance, patient and public involvement

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Non-attendance for appointments increases the cost of delivering care, reduces available appointments and increases waiting times for other patients.

It also has consequences for the person who has missed their appointment. According to the authors of this paper on non-attendance by diabetes patients, *“People with diabetes who do not attend clinic appointments tend to have poorer glycaemic control, more complications, more frequent hospital admissions and increased all-cause mortality”*.

So why do patients miss appointments?

The study involved people with diabetes who had previously failed to attend clinic appointments. It found three main causes of missed appointments:

- **Practical barriers.** These can include work and family commitments, and difficulties in travelling to appointments, particularly via public transport. Participants suggested that a wider range of appointment times and having fewer, longer appointments that addressed various aspects of their care would make it easier for them to attend.
- **Value of appointments.** Participants mentioned aspects of appointments that put them off attending. Some were fearful of hearing bad news. Others felt reprimanded if they had not maintained “self-management” regimes. Others felt that they were not listened to.
- **Perceived impact of diabetes.** The majority of participants felt that their diabetes had very little effect on their day to day lives. Some showed very little understanding of their condition, and one could not say which type of diabetes she had.

The authors suggest that their findings highlight the importance of psychological variables in predicting non-attendance at diabetes appointments. They state that *“whilst interventions to improve attendance should address practical barriers...there may also be a need to take account of the underlying perceptions about diabetes, the emotional impact and perceived lack of value in attending appointments”*.

At a time when NHS strategies are focused more and more on “self-management” of long term conditions, these findings could have implications across a range of conditions and services.

## Autumn events for staff: using online patient feedback to improve care

17 October 2019 – London

### Care Opinion

Hear directly from the Care Opinion team and from organisations using online feedback to serve patients and improve services.

We'll have some expert guest speakers and we'll be discussing topics such as:

- Why is public online feedback so different to traditional approaches?
- Why do people post feedback online? What are their intentions?
- How do organisations use Care Opinion in practice to resolve issues, restore relationships, lift staff morale, support service improvement and stimulate a learning culture in teams?
- What does emerging research say about the importance of online feedback, and how it might be used for service improvement?
- How can you take a strategic approach to online feedback in your organisation?

Our events are friendly and informal, with plenty of time for questions and discussion. We hope you'll go away energised by new possibilities!

We expect these events to fill up quickly, so advance registration is essential.

To register your place, please email [sarah.ashurst@careopinion.org.uk](mailto:sarah.ashurst@careopinion.org.uk)

## Using Insight for Improvement Roadshow

23 October 2019 – Leeds

### The Patient Experience Network (PEN) and NHS England

Working in conjunction with NHS England and NHS Improvement, PEN are delighted to announce a third 'Using Insight for Improvement' Roadshow. These events bring some of the excitement and best practice from this year's National Patient Experience Network Awards into the regions.

Over each day we will be hearing from winners and finalists who have used feedback and insight to drive improvement in healthcare, we will be hearing the latest news from the Insight & Feedback Team, and we will have the opportunity to network and discuss key themes arising from the presentations.

### Details and registration

## Is your event listed here?

Use this space to advertise future patient experience-focussed events.

Patient Experience Quarterly is published the first weeks of

January

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## NHS England is promoting a series of courses for patients, public and professionals on topics relating to patient experience and patient and public involvement.

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- NHS England Patient and Public Voice (PPV) Partners' Induction Webinars
- Developing patient and public participation skills and understanding
- Understanding the value of engagement
- Measuring the impact of engagement
- Planning your engagement activities

[Further details can be found here](#)

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