

# Patient Experience

and patient/public involvement in health and care services

Autumn 2021



**Patient  
Experience  
Library**

**INSIDE**

**A Perfect Ending  
Too young to die**

## Editorial



Patient experience is not just a matter of customer satisfaction. Sometimes it is about the ways in which people are treated at the most vulnerable points in their lives. And in those moments, the experience of the patient's relatives can matter just as much.

In this edition, we hear from two contributors whose experiences illustrate both ends of the spectrum of care.

Jane Woods was held by a care team through her mother's last hours. The communication, co-ordination and tenderness were so good that Jane is able to remember the whole experience as "a magical time". For her, "It was text book perfect - except you can't teach what these nurses gave us from a text book".

Kate Eisenstein's experience of her brother's untimely death was, sadly, much worse.

As a mental health patient, "He spent much of his adult life in a revolving door of care that oscillated between insufficient community-based support and enforced inpatient care that was often little more than a modern alternative to Victorian-style warehousing".

Kate's brother was, she says, "far too young to die". And "when it comes to supporting people severely affected by mental health conditions, we must do much, much better".

Jane and Kate's stories demonstrate what some might call "unwarranted variations" in quality of care. But human experience is always at the heart of those variations. And it must always be at the heart of any healthcare system that wants to be person-centred.

*Miles*

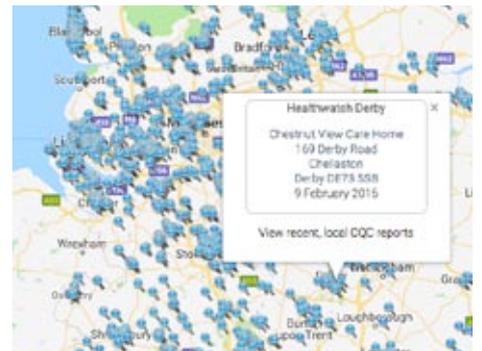
Miles Sibley, Editor [info@patientlibrary.net](mailto:info@patientlibrary.net)

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

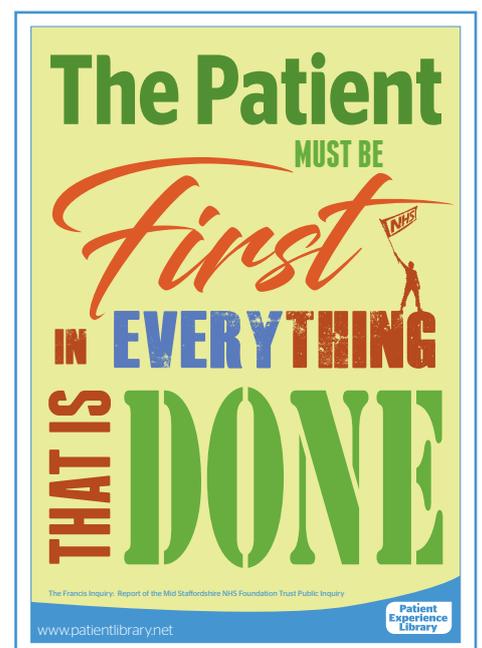
## Free resources

Our one-click [surveys and feedback tool](#) gives every NHS Trust in England instant access to all its patient experience data, all on one page. A cross-referencing function gives a quick and easy overview of common themes emerging from different datasets.

Browse the map, select your Trust, then click and collect!



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)

# A perfect ending

Jane C. Woods



On Sunday, January 29th, 2017, my Mum, Marie Woods, died. She died at home, surrounded by her family, masses of fragrant Spring flowers, and so much love it was almost palpable. We were able to experience such a magical time as a family because our wonderful NHS gave such good end of life care that all we had to worry ourselves about was saying goodbye. We were so lucky.

Mum had been diagnosed with a serious heart condition in 2012 and told she had probably just a few months left. Her motto was never give in. She didn't and had 4 more years of a good life with ever increasing care from the NHS.

Then it became apparent that the end was approaching. At that moment competent, professional 61 and a bit years old me became a scared little girl who was losing her Mum.

I began to let the family know, and the next day one of Mum's regular nurses, Liz, came. Gently she coaxed Mum into bed and set in train something rather wonderful. Within hours we had all the medicines she would require

over the week end and other caring paraphernalia.

Liz told us exactly what she would do and when she would do it, while carefully checking that it was what we wanted. She did her usual for Mum and then said she would be back later with Kim, another of my Mum's regulars, to set up the pain relief. She gently, but firmly, told me night care would be a good thing and she could arrange this through our local 'hospice at home' service. An hour or so later the hospice phoned and told me the name of our carer, Tammy, and when she would arrive. I felt a huge weight lift from my shoulders.

Kim and Liz arrived later that afternoon and set up the pain relief, laughing and smiling with Mum, brushing her hair, and, (this nearly broke my heart), moisturising her face and dabbing her wrists with her perfume. They gave so much more than just pain relief and standard nursing care.

Tammy sat with us through that long night. She was quiet, unobtrusive and reassuring. She had seen many deaths and knew what to expect. We thought Mum would leave us that night, she was so frail, but we should have known better. She might have had a technically weak heart but she was always so strong.

Throughout Saturday that same level of loving and competent care continued. Kim was our constant. And in the wee small hours of Sunday Mum gently left this world. It was text book perfect - except you can't teach what these nurses gave us from a text book.

These are the things they did so perfectly:

- They knocked when they arrived, or called out who they were and that they were coming in.
- Mum's name was not pronounced Marie in the French way, but 'Mar (rhyming with car) ee' in the Kent way. They got it right every time.
- They made time for the niceties even when they had no time.
- They consulted us in everything but were experienced enough to know sometimes we were beyond decision making.
- They always cleared away after themselves so we didn't see the old bandages etc, and they arranged Mum so that the tubes and bags were hidden.
- They always addressed Mum as if she was conscious and aware.
- When Mum had died, Kim came the next day and asked permission to kiss Mum goodbye. They never took anything for granted.

They were extraordinarily kind. You cannot really teach kindness, you cannot value it. It is priceless.

Jane C Woods began her career as a social worker and worked in hospitals for many years. She now runs her own business focussing on gender equality. A fuller version of this article can be found [here](#).

# Too young to die

*Kate Eisenstein*



In July this year, my brother died suddenly and unexpectedly while he was in inpatient mental health care. He was far too young to die. In the weeks that followed, I was a swirling mix of grief. I was - and still am - sad. But I am also angry. Angry with a mental health system that repeatedly let my brother down.

He spent much of his adult life in a revolving door of care that oscillated between insufficient community-based support and enforced inpatient care that was often little more than a modern alternative to Victorian-style warehousing.

By the time he died, he had lost many of the skills needed to live a fulfilling independent life, having been institutionalised in the very places that are publicly funded to “rehabilitate” people recovering from mental ill health. Some of the inpatient services he stayed in had kitchens, gyms and other facilities that were supposed to support patients’ recovery, but they were locked shut, rendering them pointless.

My brother had lost most of his social network. Endless years of bouncing between mental health units hundreds of miles apart make it very hard to keep friends.

We have desperately few photos of him, particularly from recent years, because why would you take a picture of someone when they’re in hospital? We take photos of moments we want to treasure.

Mental health professionals do very challenging work. My brother was a complex person. It wasn’t always easy to support him or his best interests. People with mental health conditions can sometimes behave in unusual or challenging ways. I believe that mental health nurses and social workers are among the unsung heroes in society.

So I do not doubt the intentions of kind and compassionate mental health staff. It is tough, specialist, undervalued work. Sometimes it does work effectively. There are many people who do find a way to make the mental health system work for them and support their recovery.

But the system as currently constructed is not really set up to support people severely affected by mental health conditions to live a meaningful, rewarding life. It is all too often archaic, dehumanising, restrictive and isolating. It is not set up to make the most of people’s strengths and support them to manage their challenges. It is not set up to enable people to live well with their mental health condition. It is set up to contain people.

We live in a country where people severely affected by mental illness die 20 years younger than people without. That’s not acceptable. And that’s before you think about what quality of life people like my brother have (or, in his case, had) for the time they are (were) alive.

The very nature of inpatient mental health care and the Mental Health Act makes it harder for patients and families to challenge services or complain when something isn’t right. People with mental health conditions are already often disbelieved and seen as challenging. It can be very scary to complain about the place where your loved one is effectively living, for fear that it would adversely affect their care.

Stigma doesn’t help, of course. It’s very hard for someone to speak up about their poor experiences of using mental health services if they fear how people will react when they make their diagnosis public. This is reinforced by lazy, inaccurate and dangerous media depictions, but it’s also reinforced by the inappropriate and stigmatising language many people use daily. So often people will say something was “crazy”, “insane”, or “mental”, or that someone “went schiz” or was “a bit OCD”. I’m tired of asking other people to stop talking in this way.

So I am sad and shocked and tired but I am also angry. I believe passionately in the power of public services to transform lives for the better. But when it comes to supporting people severely affected by mental health conditions, we must do much, much better.

## 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)



# Beyond consumerism

Covid 19 has exposed the fact that a consumerist approach to patient experience is, on its own, insufficient. If we only think about patients as “service users” and only ask them about “satisfaction with services”, we will miss the bigger picture of patient experience.

Vaccine hesitancy is a case in point. The vaccine programme has been a huge success - but why does hesitancy persist? We are never going to find the answers in the Friends and Family Test, or the national patient surveys. But we might find some in studies like this, from Bradford.

“Misinformation” is, of course, a prime suspect. But it would be a mistake to think that public attitudes are only ever driven by conspiracy theories and fake news. The study finds that confusion and anxiety are also important factors.

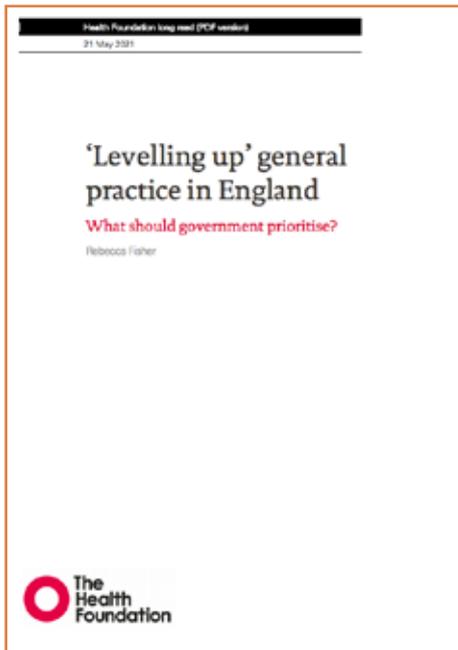
Confusion can come from what has been described as an “infodemic” - so much information from so many sources that people are simply overwhelmed. In Bradford, people were getting information from very credible government sources. But those governments included Poland, Slovakia, Pakistan and India - and different responses by different governments affected how people then viewed the UK government approach.

Anxiety was often driven by social media. But although people were aware of the danger of fake news, their anxieties meant that they sometimes shared stories before really thinking about them. As one contributor said “they just forward it straight away and then it just spreads like wildfire”.

Much of this plays out in the context of a pre-existing “partial understanding of disease transmission and vaccinations”. One widely held view was that “the seasonal flu jab can give a patient the flu”. Some people thought that the COVID-19 vaccine would be “stronger” than other vaccines, making it dangerous for recipients.

Importantly, the study found that “misinformation thrives in times of stress and uncertainty, and COVID-19 has provided a perfect breeding ground”.

There has been much talk recently of a post-Covid “reset” of the NHS. Patient experience work, however, remains rooted in a consumerist model focussed primarily on “satisfaction with services”. This study points to a need to reconsider that focus.



## Inverse care in practice

This report from the Health Foundation considers the state of general practice in the context of the government’s “levelling up” agenda. The starting point is that general practice is the part of the NHS the public interacts with most, with over 300 million appointments annually. It is also well liked by patients, demonstrating “high public satisfaction ratings when compared with emergency or inpatient hospital services”.

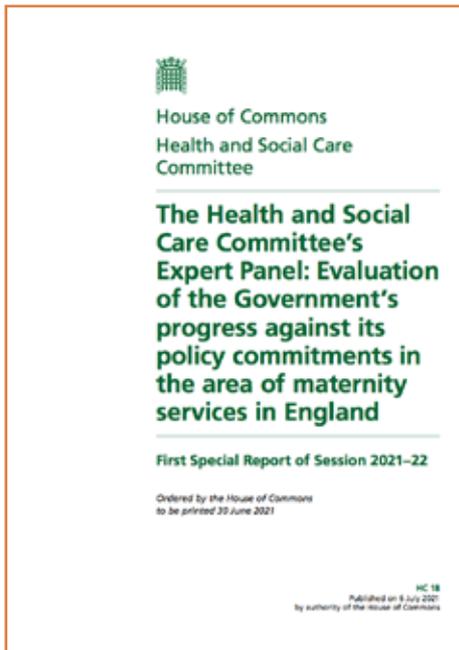
There is a problem, however: the funding formula for general practice “does not sufficiently account for workload associated with the additional needs of people living in deprived areas”. This has led to a 50-year persistence of the “inverse care law”, whereby areas with the greatest health needs have relatively poorer provision.

Practices in deprived areas have, on average, lower Care Quality Commission scores, and lower performance in respect of the Quality Outcomes Framework. Patients have shorter than average GP consultations, despite being likely to have more complex health needs. And although overall patient satisfaction with general practice is high, it is lower in deprived areas.

The report argues that unless policies are specifically targeted at tackling the inverse care law, health inequalities could widen still further. One example is the post-Covid expansion of “digital first” primary care. The risk here is that people in deprived areas are more likely to live with multiple health conditions but are also more likely to be digitally excluded.

A series of “priorities for government” concentrates mainly on funding and workforce. But there is recognition that any such measures need to be set in the context of a wider set of strategies to reduce inequalities. “The inverse care law”, says the author, “is not inevitable or irreversible. It is a consequence of the failure of policies to align resource with need”.

This is a good overview, and is clearly not a one-off from the Health Foundation. Forthcoming work, we are told, will look in more detail at previous attempts to tackle the inverse care law in general practice in England, analysing what was promised, what was tried, and what has (and has not) worked.



## Accountability in maternity care

As we move through 2021, maternity services remain under scrutiny. But we cannot go on condemning individual Trusts as “bad apples”. It is too simplistic (and convenient) to label Morecambe Bay, Cwm Taf, Shrewsbury & Telford and East Kent as “rogue Trusts”. Four in a row over six years looks more like a pattern.

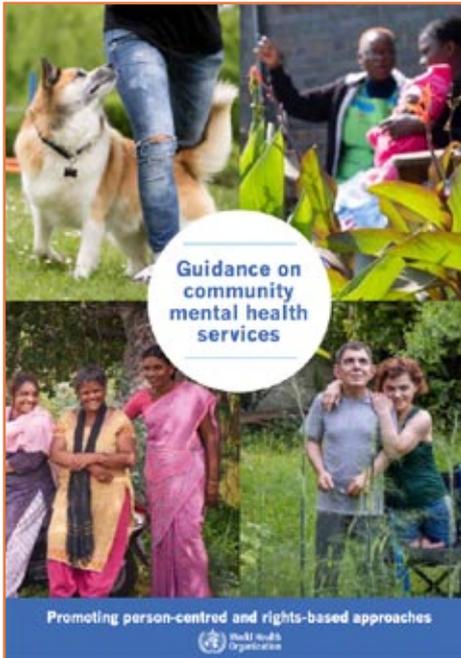
So it is good to see the House of Commons Health and Social Care Committee looking beyond the providers, and asking some searching questions of government.

The Committee's independent expert panel has looked at government progress against its policy commitments for maternity services in England. Using the Patient Experience Library as a key part of its evidence-gathering enabled it to unearth important aspects that do not necessarily show up in official statistics. On the basis of the evidence that we provided, the panel found that:

- Positive impact in maternity safety was not achieved equally across different groups of women, such as women with disabilities or women from minority ethnic or socio-economically deprived backgrounds.
- There is a relationship between charging for NHS maternity care and inequitable outcomes for women from destitute or immigrant backgrounds. It is some of the women that are most in need of maternity care that are charged for it.
- Women with learning disabilities may avoid maternity care due to a lack of confidence, negative staff attitudes, lack of clear explanations of what is going on, or fear of the involvement of social services.
- Asylum seeking women can be more likely to have to move to different areas multiple times during pregnancy, making receipt of continuity of carer more difficult. Similar issues are faced by women from Travelling communities.

Using a CQC-style rating system, the expert panel found that government progress against its own maternity policy commitments “Requires Improvement”. On personalised care specifically, it was “Inadequate”.

It is clear that government cannot go on pointing the finger at Trusts for failings in maternity care. It needs to take its own share of accountability, and it needs to put its own house in order. And on the evidence of this report, it has a long way to go.



## Rights-based mental health

“Mental health has received increased attention over the last decade” says this report from the World Health Organisation. However, mental health services often “face substantial resource restrictions, operate within outdated legal and regulatory frameworks and an entrenched overreliance on the biomedical model”.

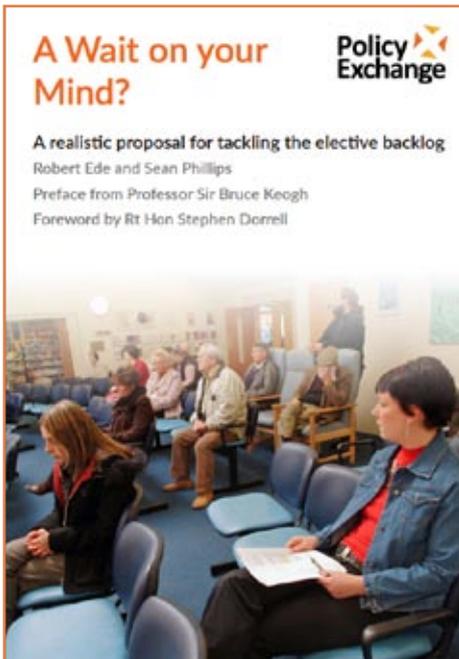
The report highlights the need to promote human rights in mental health care settings. This includes eliminating the use of coercive practices such as forced admission and treatment, as well as restraint and seclusion, and tackling the power imbalances between health staff and service users.

It says that solutions are required not only in low-income countries, but also in middle and high-income countries. (One of those is the UK, where five long years ago, the then Prime Minister Theresa May [described mental illness as a “hidden injustice”](#), and called for “parity of esteem” between physical and mental health services.)

Examples of good practice are given from countries including the UK. What is most important, says the report, is that good practice is not just about person-centred and recovery-focused care, but is also about human rights. This means addressing “critical social determinants... such as violence, discrimination, poverty, exclusion, isolation, job insecurity, and lack of access to housing, social safety nets, and health services”. These factors are “often overlooked or excluded from mental health discourse and practice”.

The report offers guidance and recommendations on mental health policy and strategy, law reform, service delivery, financing, workforce development, psychosocial and psychological interventions, psychotropic drugs, information systems, civil society and community involvement, and research.

Importantly, “development of a human rights agenda and recovery approach cannot be attained without the active participation of individuals with mental health conditions and psychosocial disabilities. People with lived experience are experts and necessary partners to advocate for the respect of their rights, but also for the development of services and opportunities that are most responsive to their actual needs”.



## A wait on your mind

It is common knowledge that backlogs in elective care are a major problem for the NHS, with over 5 million people now on waiting lists across England.

Equally well-known is that the experience of waiting for care is, for the most part, bad. Many people on waiting lists are enduring chronic pain, coupled with anxiety - often exacerbated by feeling left in an information vacuum. This is well documented in a [recent report](#) from National Voices.

Against this backdrop, this report from the Policy Exchange sets out a series of analyses, accompanied by recommendations for policy and practice. It is good to see patient experience and engagement emerging as a central theme.

A key aspect is “operational transparency” which, according to the report, must improve. The authors state that “...clinical prioritisation and waiting times are hidden from patients. Few are informed about their likely wait time, and how this compares to their rights as set out in the NHS constitution”. They go on to say that “The ‘consumer’ of the service is being left in limbo, with limited support whilst they wait”.

We welcome the report’s recommendation that “All GPs should be actively encouraged to access tools such as the new [Patient Experience Library waiting time tool](#)”. And since our waiting list tracker is free to use, adoption will cost the NHS absolutely nothing.

In the meantime, as the report points out, “The voice of the consumer - the person waiting for treatment - remains underrepresented in the conversation”. That cannot be right in an NHS that wants to be person-centred.

The report concludes that “For both the NHS and the Government, the narrative must not be that the backlog was simply addressed, but that opportunities were taken to do things differently, including embracing proven technology-led innovations and addressing health inequalities along the way”.

Importantly, it adds that “addressing the backlog from the patient’s perspective could positively transform our existing approach to planned care - which remains largely unchanged in decades”.



# Tackling digital inclusion

One very noticeable effect of the pandemic has been the huge growth in online activity. Patient experience and engagement work has been no exception - meetings, conferences, focus groups and training sessions are all held online, in ways that might have seemed inconceivable a year or so ago.

That has given rise to concerns about digital exclusion - so it is good to see NHS Providers producing this informative two-sider which offers practical tips on ensuring digital inclusion.

The guide keeps service users front and centre, recommending the involvement of patients and service users (along with staff) from the outset, to identify barriers to access and prevent people slipping through the net.

Public participation gets a mention too, with reference to “volunteer digital ambassadors” who can help to build confidence among patients and service users who are hesitant about using IT.

“Digital poverty” is recognised and addressed: some trusts have provided users with individual devices and supported improvements in local connectivity infrastructure.

The guide also features some handy design principles for digital inclusion, the first of which is “Put people at the heart of everything you do”.

Importantly, “digital” is not held up as a panacea. The guide recommends “outcomes first, then digital”. It also makes the point that “Digital inclusion isn’t about ‘either or’ - the strategy should be digital for those who can, so you can spend more time with those that can’t”.

This is a concise guide - quick and easy to read, but with plenty of links to more information, should you need it. And although aimed at “Board leaders”, there is much in here that could equally be used by people working on patient experience and engagement.



# The self advocacy safety net

“It is still the case that, despite major redesign of care delivery, little is known about patient safety incidents occurring in acute medical units” say the authors of this study.

To learn more, they dug into ten years’ worth of patient safety incident reports from the National Reporting and Learning System. Their findings included the following:

- **Patient trajectory:** A common theme with patient trajectory was lack of active decision-making and communication between teams. Errors included poor documentation, patient monitoring errors, and lack of continuity of care.
- **Arrival to diagnosis:** Common problems here included diagnostic error, often because the system relies on the most junior (and inexperienced) doctors seeing patients first.
- **Management of care:** Patients were at a higher risk of patient safety incidents when there were multiple handovers between teams, and transfers between wards.

Drawing back from the detail, the researchers looked for “metathemes”, a term describing themes that are overarching and cross-cutting.

They found that the strongest metatheme was the system largely depending on patient advocacy. This was “necessary due to a lack of care co-ordination during the patient journey, resulting in patients having to remind staff about investigations or referrals”. Worryingly, “patients who were unable to self-advocate were often overlooked due to system pressures”.

Further metathemes were “Lack of care co-ordination” and “Decision-making using incomplete information”.

This points, say the authors, to “the necessity of self-advocacy from patients as a safety net”. They say that “The learning from these reports represents an invaluable opportunity to improve the safety of the acute medical unit for future patients”.



## Mental health inequities

“The Covid-19 pandemic has exacerbated the already existing inequity in population mental health in the UK”, says this report from the Centre for Mental Health. However, “longstanding limitations in mental health research mean that we do not have the necessary evidence to inform responses”.

The report points to major gaps in mental health research, including that mental health research investment is not prioritised compared to physical health. The funding that is available is skewed towards scientific and clinical research, with less for research on prevention or social interventions.

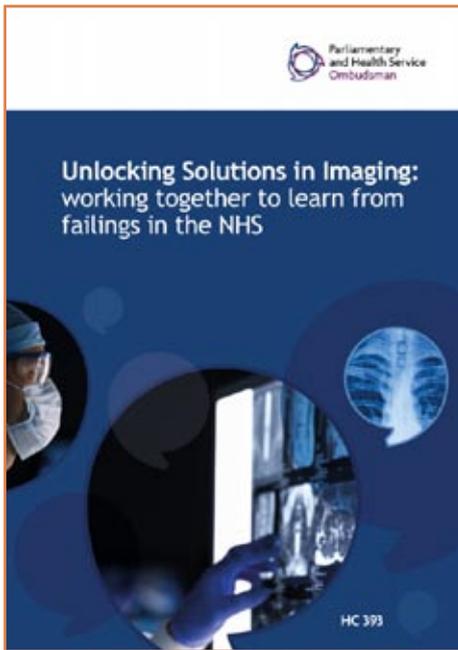
To understand preventative and social aspects of mental health, it might be necessary to draw on lived experience. Indeed, contributors to the report were clear that ‘peer research’ approaches can lead to deeper and more authentic findings.

However, “While research generally now includes ‘patient and public involvement’ as a necessary element, the extent to which its potential has yet been realised is open to question”.

Realising the potential might mean overcoming tokenism in patient involvement in research: “Those with lived experience often have little opportunity to influence what happens... the nature and impact of their involvement becomes challenging to identify and at times, is lost completely”.

It might also mean looking at the structure of research pathways: “Some people from service user led organisations found it much harder to gain funding [for research] due to a questioning of the reliability and credibility of their skills”.

A section on “Doing things differently” highlights some approaches that have been used in practice to overcome inequities and structural failings in mental health research. And the authors conclude that “While there may not be one right answer to addressing inequities in mental health research, there may be many better ways of doing research to get there”.



## Learning from complaints

This report from the Parliamentary and Health Service Ombudsman (PHSO) shows why complaints matter.

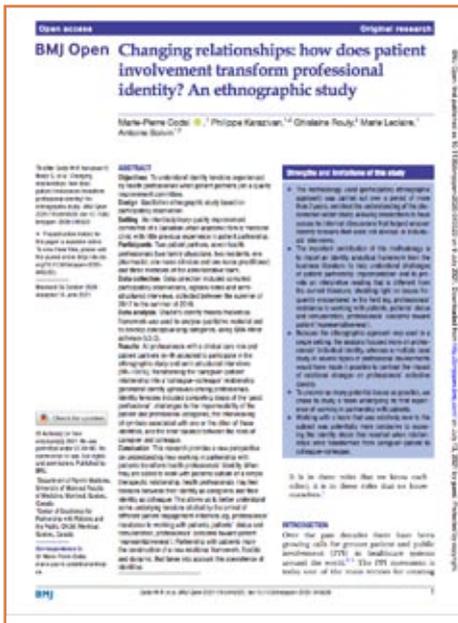
It focuses on imaging services which, says the PHSO, can mark a crucial point in people's NHS care. "The results of an X-ray, CT or MRI scan can provide reassurance and relief, or the start of essential medical care and treatment". However, "when something goes wrong... it can have life-changing consequences for patients and their families".

- By collating and analysing complaints, the PHSO found serious failings in imaging services. In particular:
- Half of the cases show that Royal College of Radiologists' guidelines on reporting clinically significant unexpected findings were not followed.
- Half of the cases show that local NHS trust policies were either not followed or were not clear enough to enable adequate follow-up of important unexpected findings.
- In nearly a third of the cases, there were delays in reviewing or reporting on an image.
- In nearly half of the cases there were missed opportunities to learn from mistakes. In some cases this meant the same mistake happened to the same patient more than once, or there was a missed opportunity to resolve issues earlier for them.

Importantly, the failings came to light because of patient complaints, not because of actions by providers. One Trust "did not take any action to address [their] mistake". Another, after two years of efforts by the complainant "had still not addressed the gap in their duty of candour policy". A third case found "failings in how the complaint was handled", and that "The Trust did not apologise to the family for their loved one's avoidable death".

As so often in patient experience work, the effects were felt not just by patients but by relatives as well: "Families told us they experienced great distress because the outcome for their loved one could have been different if these failings had not happened".

The report makes a series of recommendations, one of which is about taking complaints more seriously: "Clinical directors and senior managers of NHS-funded radiology services should triangulate the learning from... complaints, claims, serious untoward events, patient safety issues, Freedom to Speak Up Guardian data and candour learning".



# Changing relationships

The question posed by this study is “how does patient involvement transform professional identity?”.

This tends not to be a question that is considered very much - indeed some readers might wonder what it even means. The authors explain that healthcare professionals hold a “strong and deeply entrenched relational ideal: that of the ‘good caregiver’ looking after patients”.

A key role for the good caregiver is to “protect the patients’ trust in their professionals”. Consequently, professionals can be “afraid to become too familiar or to reveal flaws or imperfection”. They want to “maintain a professional ‘healthy distance’”.

Patient involvement introduces a new, and different, model for professional identities. To move from ‘good caregivers’ to ‘good partners’, professionals’ relationships with patients “should not be hierarchical, but rather built on reciprocity and transparency”. This could be demonstrated through “informal terms of address (eg, using first names), sharing of personal stories and demonstrations of camaraderie between patients and professionals”.

This process of transforming the ‘caregiver--patient’ relationship into a ‘colleague--colleague’ relationship can generate ‘identity upheavals’ among professionals”. For example, some professionals in this study feared that a patient partner presence in the ‘backstage’ of professional practice could uncover ‘imperfections’ or ‘shortcomings’ that would undermine professionals’ identity story of excellence.

Remuneration for patient partners also crystallised identity questions. Most professionals felt that as they and patient partners shared the same identity within a quality improvement committee, they should all be paid. “However, when questioned on the salary [patient partners] should obtain, professionals showed discomfort”.

A further problem for professionals was that if patient partners are seen as full members of the team, that could “distance them from the ‘ordinary’ patient”. This issue was “repeatedly expressed by professionals as a concern regarding the insufficient ‘representativeness’” of the patient partner.

The study finds that for professionals, it can be hard to maintain the inner balance between the roles of carer and colleague. “Professionals struggle with this dual identity and transfer this ambiguity to their perception of the patient’s identity as a ‘real patient’ or not”.



# Patient Experience in England

“Patient feedback is not merely stories or anecdotes” says Donna Ockenden in the foreword to this year’s Patient Experience in England report. Her view is that “We need to take it seriously as a key component of evidence-based practice”.

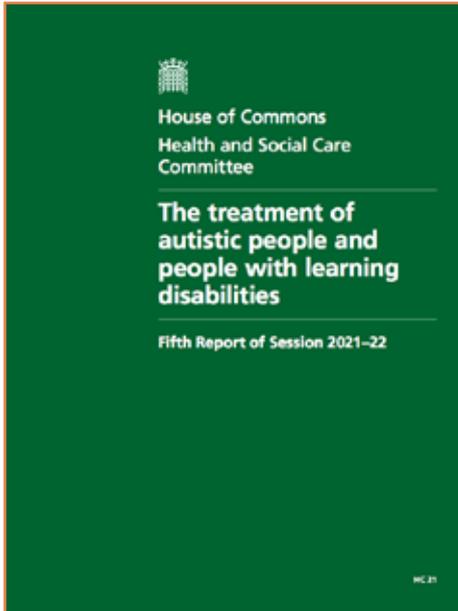
In a year in which Covid has dominated the headlines, the daily realities of patient experience continue. And researchers have continued to document those realities, through surveys, focus groups, online engagement and academic study.

Our annual overview of the evidence shows just how much we can learn. It gives a patient’s-eye view of service quality, and of some of the big issues in healthcare, including:

- The elective care backlog, where the question for patients is not just “why are we waiting”, but “how are we waiting”.
- Digital healthcare, taking in people’s anxieties about data sharing, and looking at the quality and reliability of healthcare apps.
- Compliments and complaints, including how thank you letters can offer insights into patients’ own priorities for high-quality healthcare.

Donna Ockenden is clear about the need to help providers to use patient feedback as a basis for learning. She makes the point that “To deliver patient-centred care, an environment must be nurtured in which the organisation’s most important asset - its workforce - is valued and treated with the same level of dignity and respect as they are expected to show to patients”.

We agree - and we think that in a person-centred NHS, patient experience teams (both staff and volunteers) are one of the most important parts of the workforce. Taking an evidence-based approach can make us stronger together - and we hope that this report will help.



## Ten years on from Winterbourne

“Autistic people and people with learning disabilities have the right to live independent, free and fulfilled lives in the community and it is an unacceptable violation of their human rights to deny them the chance to do so.” So says this report from the House of Commons Health and Social Care Committee.

However, it also notes that “The poor treatment of autistic people and people with learning disabilities has been a long-standing problem for the NHS and care system”.

The report refers to the 2011 Winterbourne View disaster, and says “the fact that these issues have not been resolved even a decade later is a scandal in its own right”. Despite efforts to enable autistic people and people with learning disabilities to live independently in the community, “there remain over 2,055 people in secure institutions today where they are unable to live fulfilled lives and are too often subject to treatment that is an affront to a civilised society”.

They “can find themselves experiencing intolerable treatment [including] abusive restrictive practices; being detained for long periods of time... and being kept long distances away from their family and friends”.

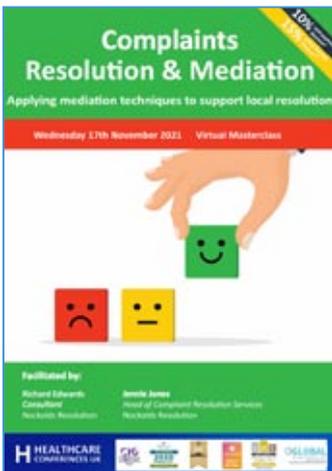
The Committee finds that “autistic people and those with learning disabilities are treated as if their condition is an illness instead of a fundamental part of their identity”. Its report goes on to say that “the tragic result of this fatal misunderstanding is that they often do then develop mental or physical illnesses which are used to justify their continued detention”.

The report makes a series of recommendations, and notes that “Helen Whately MP (Minister of State for Social Care, Department of Health and Social Care)... considers the issues we are raising to be important and has shared her discontent that there remain significant problems with the treatment of autistic people and people with learning disabilities”.

Whately, however, has now moved to the Treasury. It remains to be seen whether Gillian Keegan, her successor, will want to act on the Committee’s advice.

# Complaints Resolution & Mediation

WEDNESDAY 17 NOVEMBER 2021 VIRTUAL: Online



This course is suitable for anybody who deals with complaints as part of their job role, or anybody who may have to handle a complaint. This includes dedicated complaints teams & customer support teams and managers.

A highly interactive and effective workshop to improve confidence and consistency in handling complaints.

A simple model to facilitate effective responses will be shared and delegates will have the opportunity to practise the use of our unique AERO approach.

**Tap here for further information and to book your place.**

or email [kerry@hc-uk.org.uk](mailto:kerry@hc-uk.org.uk)

# Measuring, Understanding and Acting on Patient Experience Insight From Insight to Improvement

THURSDAY 25 NOVEMBER 2021 VIRTUAL: Online



This conference will focus on measuring, understanding and acting on patient experience insight, and demonstrating responsiveness to that insight to ensure Patient Feedback is translated into quality improvement and assurance.

Through national updates and case study presentations the conference will support you to measure, monitor and improve patient experience in your service, and ensure that insight leads to quality improvement.

Sessions will include learning from patients, improving patient experience during and beyond Covid-19, a national update, practical sessions focusing on delivering a patient experience based culture, measuring patient experience, using the NHS Improvement National Patient Experience Improvement Framework, demonstrating insight and responsiveness in real time, monitoring and improving staff experience, the role of human factors in improving quality, using patient experience to drive improvement, changing the way we think about patient experience, and learning from excellence in patient experience practice.

**Tap here for further information and to book your place.**

or email [hannah@hc-uk.org.uk](mailto:hannah@hc-uk.org.uk)

# Confused?



We are clearing a path through the patient experience measurement maze.

Let us help you with...

- **Surveys and Feedback tool.** One-click access to key patient experience datasets for your Trust, with cross-referencing to aid analysis.
- **Waiting times** fundamentally affect people's experience of care. **This tool** gives easy access to waiting times for treatments at Trusts across England.
- **Healthwatch** collection. Over 12,000 reports accessible via the **Network map**, and the **Enter and View map** or by searching "Healthwatch" in the **Library**.
- **Publications** featuring research-based summaries to keep you abreast of the latest and best in patient experience evidence.

## Extras for subscribers:

- **Quote Selector:** Quick access to bite-sized pieces of evidence.
- **Export:** Batch downloading of documents.
- **Favourites:** Your own personal library.

Want more? Drop us a line to ask how we can help you manage your data on patient experience and involvement: [info@patientlibrary.net](mailto:info@patientlibrary.net)

Hear the patient voice at every level of the service even when that voice

is a whisper



# The Patient Experience Library

We are the national evidence base for patient experience and patient/public involvement. We have collated and catalogued over 60,000 reports and studies from government bodies, Healthwatch, academic institutions, think tanks and health charities.

[Visit our website](#) to get free access to evidence and analytical tools.

You can see more about who we are and what we do [here](#).

We welcome copy from contributors for the “Comment” section of this magazine, but cannot guarantee publication and we reserve the right to edit for reasons of space or style. Drop us an e-mail to receive our guide for contributors: [info@patientlibrary.net](mailto:info@patientlibrary.net)

Published items do not necessarily represent the views of the Patient Experience Library.

Funding declaration: In the light of concerns about [drug company funding](#) of some patient voice organisations, we declare that the Patient Experience Library receives no funding or help in kind from industries involved in drugs, treatments and medical devices.

Can't wait for your next edition of Patient Experience to appear?  
**[Sign up to our newsletter](#)** for weekly updates on what's new in patient experience and patient/public involvement!

**Can't wait a whole week?** Follow us: [@patientlibrary](#) 

---

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

The title and content of this publication © Glenstall IT, October 2021. The Patient Experience Library is provided by Glenstall IT, 28 Glenstall Road, Ballymoney BT53 7QN

**Patient  
Experience  
Library**

Cover image: The Creation of Adam (1508-1512)/ Michelangelo di Lodovico Buonarroti Simoni

