

Patient Experience in England



Foreword

MONIKA NIZIOL



In 2017, I was asked by Jeremy Hunt, the then Secretary of State for Health, to chair an investigation into 23 cases of alleged avoidable harm and death at the Shrewsbury & Telford Hospital NHS Trust. Since then, the number of families who have directly contacted my team, together with cases provided by the Trust for review, has reached 1,862.

The investigation owes its origins to Kate Stanton Davies and her parents Rhiannon Davies and Richard Stanton and to Pippa Griffiths and her parents Kayleigh and Colin Griffiths. Kate's death in 2009 and Pippa's death in 2016 were avoidable. Their parents' unrelenting commitment to ensuring their daughters' lives were not lost in vain continues to be remarkable.

In a void described by the families as 'incomprehensible pain', they undertook their own investigations to highlight the deaths of their newborn daughters, and to insist upon meaningful change in maternity services that would save other lives. We have since heard from many families who tried to raise serious concerns about maternity care and safety at the Trust, and who have told us they were not listened to.

This is why the work of patient experience staff and volunteer patient representatives matters so much. Patient feedback is not merely "stories" or "anecdotes". We need to take it seriously as a key component of evidence-based practice.

This annual overview from the Patient Experience Library shows just how much we can learn. It gives a patient's-eye view of service quality, and of the wider challenges that we all face - growing waiting lists, the shift to digital healthcare, health inequalities and more.

I am delighted to see the Patient Experience Library making the case for better support for patient experience staff, via analytical tools, rigorous professional development, and help to make sense of the ever-growing volumes of patient experience evidence.

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. I firmly believe that NHS staff who are cared for, listened to, respected and valued will always go "the extra mile". I have found that over and over again in so many roles over many decades. We must work to ensure that patients and staff are always directly involved in the design and implementation of processes to improve services and procedures for all.

Donna Ockenden

*Chair of the Independent Maternity Review at
Shrewsbury and Telford Hospital NHS Trust*

Contents

Foreword.....	2
1. Introduction.....	4
2. What we learned in the last year: Surveys.....	5
Community mental health survey.....	6
GP patient survey.....	7
Inpatient experience during the COVID-19 pandemic.....	8
3. What we learned in the last year: Research.....	9
How are we waiting.....	9
Digital, data, apps and AI.....	11
Continuing concerns in maternity.....	13
Compliments and complaints.....	19
Primary inequality.....	22
Inadmissible evidence.....	24
4. About the Patient Experience Library.....	26
Appendices.....	27
A.1 Sources of evidence.....	27
A.2 Quantity of evidence.....	28

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And last but not least, everyone who reads and comments on our newsletter and quarterly magazine, and who engages with us via Twitter. Keep the feedback coming!

Cover image: Nik Wallenda walks a tight rope to Wonder Mountain, Canada/kevint3141

1. Introduction



Just before Christmas last year, we published [Inadmissible Evidence](#) – our account of a double standard in evidence-based practice which causes persistent harm to patients. We have been overwhelmed by the response: over 8,000 copies have been downloaded – far in excess of any other report in the entire Patient Experience Library.

It is clear that people understand the need to start taking patient feedback more seriously. An NHS that wants to be both person-centred and evidence-based has to stop dismissing patient feedback as “anecdotal evidence”, and start putting it on the same footing as medical evidence. So over the last year we have been:

Building new analytical tools. Our [waiting list tracker](#) helps GPs and their patients to find waiting times for the treatments they need at Trusts near them. It can also help Integrated Care Systems to understand performance across their patch. And we have joined up with Care Opinion to create [integrated search](#) across both our platforms.

Developing accredited learning with [Leeds Beckett University](#). Patient experience staff are almost unique in the NHS workforce in having no professional qualification or systematic professional development. We think they deserve better.

Mapping the patient experience evidence base with the [University of Plymouth](#). None of the national NHS bodies have a strategic overview, so there is both duplication and gaps. We aim to work out how patient experience evidence-gathering might be better steered.

Provided input to reports by [National Voices](#), the [House of Commons Health and Social Care Committee](#) and [Policy Exchange](#), among others. Policymakers, like practitioners, need to be evidence-based, and we are happy to help.

We are fuelled by financial support from the [Joseph Rowntree Reform Trust](#). And we are driven by [Baroness Cumberlege's demand](#) that: “**Patient experience must no longer be considered anecdotal and weighted least in the hierarchy of evidence-based medicine**”.

Miles

Miles Sibley, Editor

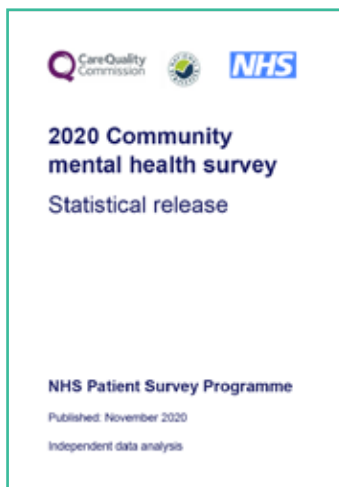
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2. What we learned in the last year: Surveys

There have been a limited number of national patient surveys over the last year. Details are as follows:

- The Maternity Patient Survey and the Cancer Patient Experience Survey were cancelled because of the Covid crisis.
- The British Social Attitudes survey, which usually seeks public opinion on the NHS and healthcare generally, asked only one question about overall satisfaction with the NHS.
- The Adult Inpatient Survey was rescheduled to enable changes to the survey method, aimed at encouraging a greater online response.
- The Children and Young People's Survey and the Urgent and Emergency Care Survey both ran – results will be forthcoming during autumn 2021.
- The next National Neurology Patient Experience Survey will run during autumn 2021.
- Two further cancer surveys – the Cancer Quality of Life Survey and the Under 16 Cancer Patient Experience Survey are both scheduled for publication in autumn 2021.
- The Personal Social Services Survey of Adult Carers in England (SACE) is published every other year, and was not published last year.

Community mental health survey



The opener to this report states that “people are consistently reporting poor experiences of NHS community mental health services, with few positive results”.

One area for positive findings was “Organising Care”, where most people (97%) who had been told who was in charge of organising their care said they knew how to contact this person if they had a concern. Another was “Respect and Dignity”, where most people (73%) reported that they were “always” treated with dignity and respect.

Areas for improvement included:

Support and wellbeing, where 36% had not had support with their physical health needs, 43% did not receive help or advice with financial matters, and 43% did not get help or advice in respect of finding paid or voluntary work. Over a third of people (37%) did not receive support in joining a group or taking part in an activity, but would have liked this.

Crisis care, where 28% said they would not know who to contact, out of office hours in the NHS, if they had a crisis.

Accessing care, where 44% of respondents who have received NHS therapies in the last 12 months felt they waited too long to receive them. Almost a quarter felt they had not seen services often enough, although 59% said they were ‘definitely’ given enough time to discuss their needs and treatment.

There was a disparity in the experiences of people with different diagnoses. People with more challenging and severe non-psychotic disorders, as well as those with complicated cognitive impairment and dementia disorders consistently reported worse than average experiences.

Analysis also found differences in the experiences of people in different age groups, with those in the 18 to 35 age group reporting worse than average experiences across 11 of 14 themes, and those aged 66 and older reporting better than average experiences across the same 11 themes. In addition, those who had been in contact with NHS mental health services for less than a year and people who identified as heterosexual reported better than average experiences across many areas of care.

GP patient survey



Patients continue to have high levels of trust in GP services, with 95% of respondents saying that they had confidence and trust in the last healthcare professional they saw.

Experience of appointments is mostly good, with 70% saying that the overall experience of making an appointment was good, and just over two thirds (67%) saying that they were satisfied with the appointment times that were available to them.

Interestingly, the experience of getting through to GP practices by phone, which has been in steady decline since 2102, rose slightly last year, from 65% of respondents (2020) to 68% (2021) saying that it was easy. Expectations of being seen the same day are reducing, from 42% of respondents in 2018 to 38% in 2021.

42% of respondents had avoided making a GP appointment in the last year. The biggest single reason (20%) was worry about increasing the burden on the NHS. The second (17%) was worry about catching Covid-19.

Online use of GP services is becoming more common, with 44% of respondents having used at least one online service in the last 12 months. Use of GP websites has been increasing from just over a third of respondents in 2018 to just over one half (53%) in 2021.

Inpatient experience during the COVID-19 pandemic



This survey asked about people's experiences of hospital stay during the peak of the pandemic. These were generally positive, with most patients (83%) feeling safe from the risk of catching COVID-19 in hospital. However, people with a COVID-19 diagnosis reported consistently poorer experiences than people who did not have the virus. The greatest differences were during discharge and knowing what would happen next with their care after leaving hospital.

Older patients (aged 75+) were generally more positive than younger people (aged below 55), but were more likely to say they were unable to keep in touch with family and friends during their stay.

Overall, feedback on person-centred care was positive. Most people said they were involved 'a great deal' or 'a fair amount' in decisions made about their care and treatment, as well as in decisions made about their discharge (77% and 73% respectively). Patients were similarly positive about the emotional support that they received from staff during their stay, and most people (83%) said they 'always' had confidence and trust in the staff treating them. However, COVID-19 patients were consistently less positive than people without a COVID-19 diagnosis on all measures of person-centred care.

Overall, patients were positive about communicating with staff during their stay - however, 24% said they were 'sometimes' or 'never' able to understand the information that staff gave them, and 27% said that this information was 'often' contradictory. Certain groups of patients found communicating with staff who were wearing PPE especially difficult. People aged 85 and over were less likely to always understand what they were being told, as were people with dementia or Alzheimer's, patients who were deaf or hard of hearing, autistic people and those with a learning disability.

As with the normal Adult Inpatient Survey in previous years, people's experiences of discharge from hospital were less positive. Patients with COVID-19 reported poorer experiences on all measures - for example, being more likely to say their home situation was not taken into account when leaving hospital (19% compared with 15% of patients who did not have the virus). Similarly, 32% with COVID-19 said they were not told who to contact should they become worried about their care or treatment after leaving hospital (compared with 24% for patients who did not have the virus).

3. What we learned in the last year: Research

Every year, thousands of reports on patient experience and involvement are published – by government bodies, health charities, patient voice organisations and academic institutions. This overview outlines a few of the key themes that have emerged over the last twelve months.

If you are looking for more regular summaries of the literature as it gets published, please [sign up](#) for our free weekly newsletter. Or you can search the full Patient Experience Library [here](#). For full attributions, and copies of the documents mentioned on the following pages, click on the report pictures.

How are we waiting

It took Sajid Javid just two weeks from being appointed as Secretary of State for Health and Social Care to announce his [shock at the state of NHS waiting lists](#). Tackling waiting times is, he says, going to be one of his top priorities.

That is welcome news, but if we are thinking about waiting lists from the patient's perspective, we need to ask not just “why are we waiting”, but “how are we waiting”.

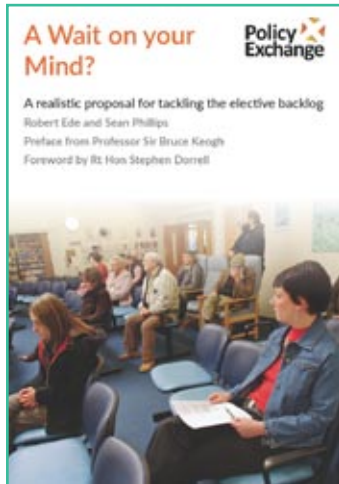


To find out, Mr. Javid could start by reading this report, from National Voices, informed by a literature search in the Patient Experience Library. It shows that patients' journeys through the system are characterised by waiting and delays before the clock officially starts; stop-starts along the way; cancellations; changing goal posts and reversals, which patients simply did not understand.

Waiting affected family, work, and social lives. Some people described “fighting” the system, while others talked of remaining in an information vacuum for long periods of time.

The report points to opportunities to improve the experience of waiting. These can include pain relief and psychological support to deal with pain, as well as access to mental health support. Physiotherapy was suggested by some, while others asked for clear pathways to specialist advice if symptoms escalated. Clear communication between primary and secondary care was important, as patients often speak to their GP for support when waiting for specialist care. Alongside all of this was a need for information about employment and benefits.

These forms of support do not necessarily have to come from the NHS. A recurring theme was the importance of the voluntary and community sector, with support including helplines, information, peer mentoring, groups and policy information.



This report from the Policy Exchange sets out a series of analyses, accompanied by recommendations for policy and practice. Patient experience and engagement emerge as central themes, based on the observation that *“The voice of the consumer – the person waiting for treatment – remains underrepresented in the discussion”*.

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”*.

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”*.



One of those technology-led innovations is our own [waiting list tracker](#), which the Policy Exchange report recommends as a useful tool for GPs, and which was [featured in the Independent](#).

The tracker makes it easy for patients to find waiting times for the treatments they need at nearby Trusts. GPs can use it to support shared decision-making, and can print off a handy aide-memoire for their patients. Managers in Integrated Care

Systems can quickly compare waiting times across providers and services in their area, and can download stats to an Excel spreadsheet for further analysis.

We built the tool after realising that [official statistics on waiting lists](#) are hard to find and even harder to make sense of. That doesn’t help anyone. The waiting list tracker is part of our mission to show that healthcare data can be presented in ways that anyone can understand. That is fundamental to a person-centred NHS.

Digital, data, apps and AI

Matt Hancock, the outgoing Secretary of State, was known for his enthusiasm for “digital”, and Covid-19 has given added impetus to the development of telehealth. So our understanding of patient experience clearly needs to start encompassing patient experience of all things digital.



We cannot talk about “digital” without talking about “data” – and this report sheds useful light on how healthcare data is reported in the media. That is where most people get their information on health, and the national media outlet reporting most frequently on health is the Daily Mail.

The mainstream media tends to report negatively – generally because data becomes more newsworthy when something goes wrong – for example, data breaches. Science and technology media report more positively – often driven by proactive company press releases announcing successes in clinical research and drug development. On social media (Twitter in particular), concern about access to health data drives the majority of conversation, covering access by private companies, data breaches, and a lack of transparency around who data is shared with.

The authors recognise that health data is highly politicised, often becoming a lens for criticism of broader issues, such as privatisation of the NHS. And there is limited focus on the role an individual can play in managing their own data, potentially reducing opportunities for wider public engagement.

Among the recommendations is a call to “elevate patient voices” by encouraging patient involvement in debates on health data, and offering training to patient influencers to act as spokespeople on the benefits and risks of health data to patients.



This study, from the United States, looked at the development of mental health (MH) apps. While more than 10,000 are available for download, analysis has shown a dropout rate of almost 50%, and a median daily engagement rate of 4%. The findings “highlight a striking mismatch between the degree of enthusiasm... dedicated to MH app development as compared to the extent of our knowledge regarding apps’ effectiveness”.

Factors that could affect take-up and use of apps included whether apps demonstrate an advantage over pre-existing modes of care. Useability and simplicity also matter: “the first question to ask is whether the complexity of an app is needed at all... many app functions can be achieved through simple text messaging”.

Context is critical. User ratings influence the order in which apps are presented in online app stores. But “72% of the 29 most popular depression apps contained no information regarding suicide prevention, and some of these apps contained potentially harmful negative content”. The authors remark that “The current lack of app store regulation is striking”.

The paper concludes that much can be learned from the successful apps we use daily; namely, simpler is better – and plans to integrate full behavioural treatments into smartphone form may be misguided.



Artificial intelligence (often linked to “big data”) can be seen as a force for good in healthcare. Advocates suggest that AI can predict and prevent health deterioration, personalise care and increase patient participation. This Swedish study, however, warns that AI could depersonalise care, as the algorithms regard population averages and not the individual. As such, service users could become objectified through the lens of majority groups and universalism.

Concentrating on community health services, the paper considers “how gender is made in the digital transformation of community care”.

The author argues that “Community care is not characterised by equality: most care personnel and older care recipients are women”. Care work is low-paid and has low status, whereas digital entrepreneurship is associated with masculine values. These power relations “are rarely acknowledged or recognised”.

AI-based systems work from huge amounts of data, so the quality of the datasets is crucial. Biased datasets, built from unrepresentative samples, or based on stereotypes and social constructs, can amplify inequalities and perpetuate discrimination.

Using feminism as a framework for understanding the digital transformation of community care can, says the paper, help us move away from a one size fits all approach. This requires “iterative work, in which assumptions and gender expectations are exposed and the design, implementation and use of technologies in community care are scrutinised, tested, evaluated, revised and tested again”.

Continuing concerns in maternity

Patient safety in maternity services has been a major concern over the last year, given the investigations at Shrewsbury & Telford and East Kent. Both of those follow similar, earlier investigations at [Morecambe Bay](#) (2015) and [Cwm Taf](#) (2019). The common thread throughout has been a failure to take seriously the concerns raised by women, birth partners and bereaved families.



Donna Ockenden's "Emerging Findings" report made the point clearly: *"we convey our sincere gratitude to the many families who tried to raise serious concerns about maternity care and safety at the Trust who have told us they were not listened to"*.

Those “many families” started out as 23 cases when Jeremy Hunt, then Secretary of State, set up the investigation. However, *“Since the review commenced, the number of families who have directly contacted my team, together with cases provided by the Trust for review, has now reached 1,862”*.

Any suspicions about patient motivations are quickly dealt with by Ockenden: “*The families who have contributed to this review want answers to understand the events surrounding their maternity experiences, and their voices to be heard, to prevent recurrence as much as possible. They are concerned by the perception that clinical teams have failed to learn lessons from serious events in the past*”. This ties in with previous inquiries and research, which consistently find that harmed patients and bereaved families are motivated more by a desire for learning than for retribution or compensation.

Ockenden puts forward seven “Immediate and Essential Actions” to improve safety in maternity services. Importantly, she says that *“We also consider it imperative that family voices are strongly and effectively represented... through the Maternity Voices Partnerships”*.



In this context, it is worrying to hear of a decline in response rates for national maternity surveys. According to this report, *“The response rates to the Infant Feeding Surveys, the CQC Maternity Surveys, and the National Maternity Surveys... have fallen with each successive survey”*. For the National Maternity Survey for example, the response rate has gone down from 67% in 1995 to 29% in 2018.

Additionally, “response to the survey by the youngest women, women who registered the birth of the baby in their sole name, and women living in the most deprived areas has become relatively less likely over time”. The authors note that “If this trend continues, women in these groups will become even more underrepresented in such studies”.

The paper concludes that declining response rates “bring into question the viability of continuing to use the survey method to capture the experiences of postpartum women”. It warns, however, that “such data are not routinely available from other sources and currently there is no better alternative method to collect large-scale population-based data”.



Good news in maternity comes from the 2021 progress report from the Each Baby Counts programme. Set up in 2014, it aimed to reduce stillbirths, neonatal deaths and brain injuries incurred during labour.

Parental involvement has been central to the ethos of Each Baby Counts. Nicky Lyon and Michelle Hemmington, founders of the Campaign for Safer Births, and bereaved parents themselves, have been involved from the start. Many others have participated over the years.

There has been a significant reduction in overall stillbirth and neonatal death rates over the life of the programme. Another important outcome has been the number of parents invited to contribute to local reviews of injury or death. Baseline data, published in 2017, showed that parents were invited to be involved in only 34% of reviews. The data in this year’s report shows that 70% were invited to contribute. Alongside the declining death rate, this is a huge step forward.

The report marks the end of Each Baby Counts. From now on, the work of investigation and reporting will be the responsibility of the Healthcare Safety Investigation Branch in England. Nicky Lyon and Michelle Hemmington commend the programme for giving voice to harmed families. But, they say, “*Learning must be turned into local and national action. These babies must not be forgotten again*”.



Patient experience in maternity care is not only the responsibility of providers. Government has a part to play, by setting the policy context for good care.

So it is has been good to see the House of Commons Health and Social Care Committee setting up an independent expert panel to look at government progress against its policy commitments for maternity services in England.

The panel decided to make use of the Patient Experience Library as a key part of its evidence-gathering. This, crucially, enabled them to unearth important aspects of safety 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”.

This has important implications for any government response to the findings of the investigations at Shrewsbury & Telford and East Kent. In a poor quality policy environment, these providers cannot be written off as “rogue Trusts”. Government needs to take its own share of accountability. On the evidence of this report, it has a long way to go.

Compliments and complaints

Patient feedback takes many forms. At one end of the spectrum are formal complaints which offer exclusively negative feedback. Across the middle are channels such as patient surveys, which generate both negative and positive comments. And at the other end of the spectrum are compliment letters, which are wholly positive.

This paper makes the point that while there are standardised procedures for handling complaints and surveys, there appear to be no common methods for receiving and

analysing compliment letters. This, say the authors, is *“symptomatic of a tendency in healthcare... to focus on what goes wrong rather than what goes right”*.



That could be a mistake, as compliment letters could be offering more than just thanks. One example is that by identifying the aspects of care that have gone well, compliment letters could be contributing to safe practice. Traditional health and safety follows a “Safety I” model, focused on breaches of procedure, and learning from mistakes. But “Safety II” recognises safe practice as something that emerges from organisational cultures, teamworking and personal relationships. These day-to-day

working practices can be overlooked by staff, but patients who recognise and offer feedback on excellence can help *“further the goal of understanding high-quality and resilient healthcare”*.

Secondly, compliment letters can offer insights into patients’ own priorities for high-quality healthcare. In effect, patients are encouraging and supporting the healthcare practices they themselves most value.

Analysis of compliment letters found instances where patients went beyond simply “acknowledging” excellent care, to “promoting” excellence by copying their letters to managers and chief executives. This would indicate compliments whose purpose was not simply gratitude, but an attempt to help improve services.

The authors conclude that *“Patient feedback data, despite vast amounts of data collection, have arguably had little impact on improving services”*. But *“Compliments are credible, specific and narrative, and positive, which might make them a relatively effective route to improve quality”*.



Another paper, on gratitude in healthcare, also finds that expressions and effects of gratitude are more complex than they might at first appear.

One example is “social capital”, whereby gratitude encourages social connectedness, and willingness to reciprocate. This, essentially, is how good staff experience leads to good patient experience and vice-versa. But this does not always work for all patients or service users.

The paper warns of “*the problematic nature of gratitude when it exacerbates a lack of autonomy*”. This can happen for physically

disabled people, for whom gratitude is the only currency available: *“For those who are able-bodied, gratitude may well comprise a comfortable and unproblematic response to kindness, but for disabled people it can signify an unbearable state of perpetual obligation”*. Interestingly, *“people who had access to paid personal assistance tended to feel a greater sense of control, comfort, and autonomy than those constrained by feelings of shame and frustration when having to be persistently grateful for the goodwill of others”*.

The paper looks at the wider context for these matters, noting that *“civility in workplace culture has a definitive effect on retention, job satisfaction, and patient safety”*. However, *“We found relatively little attention paid to gratitude as a component of civility in care settings”*. The paper concludes that *“gratitude should be recognized as integral to the social relations that significantly influence what people think, feel, say, and do in relation to health care”*.



Moving to complaints, this report from the Parliamentary and Health Service Ombudsman makes a stark assessment: *“The current complaints system is not meeting the needs of the public”*. The report is unflinching in its critique of how NHS organisations handle concerns raised by patients.

Importantly, it avoids placing blame on complaints managers. It recognises that *“Some receive commendable help from their organisations to do their job, but many others... receive limited access to training and are asked to address serious and complex issues with little assistance”*.

The PHSO points to three core system weaknesses:

1. There is no single vision for how staff are expected to handle and resolve complaints. Too many organisations provide their own view on ‘good practice’ and staff are left confused as to which one to follow.
2. Staff do not get consistent access to complaints handling training to support them in what is a complex role. When staff do get training, the quality and consistency of what is covered is variable
3. Public bodies too often see complaints negatively, not as a learning tool that can be used to improve their service. This often leaves complaints staff feeling that they are not valued or supported by senior leaders in their organisation and lacking the resources to carry out their role effectively

The report sets out proposals for a more consistent and responsive complaints handling process that works for everyone. However, it warns that “*change will not happen unless there is effective and inclusive leadership... to make the cultural transformation needed to recognise complaints as a valuable source of learning*”.

Human rights in healthcare

There are many ways to look at patient experience. We can take a consumerist view – thinking about patients as users of services, and asking about their satisfaction with services. We can take a person-centred view – thinking about the personal experiences and needs of people living with illness. Or we can take a right-based approach – thinking about the patient as a citizen with fundamental rights that are protected in law.



This study looks at Do Not Attempt Resuscitation (DNAR) decisions, in the context of Covid-19. The starting point is a concern about the numbers of people accessing health, care and support services during 2020 who had experienced a DNAR order being placed on their file without consultation, or while feeling pressured to agree.

The report makes the point that DNAR decisions are not solely a medical matter. All medical decisions within the NHS are subject to the Human Rights Act and since DNAR decisions are about people's legally protected human rights, all staff have legal duties to uphold those rights in decision-making.

Importantly, human rights do not extend only to the patient. The Act also protects family life, so consultation with family members can also be an important part of decision-making.

Within all of this is the point that human rights should not be restricted in a way that is discriminatory. But the report finds worrying evidence of discrimination – for example, blanket DNARs applied to people with learning disabilities, and frailty scales being used to justify DNAR decisions for people with learning disabilities, but no underlying health issues. It also raises a concern about “assumptions related to capacity” – ie that people have not been involved in decisions about DNARs because they are assumed (but not necessarily known) to lack mental capacity.

Concerns about DNAR decision-making are not new. The report says that whilst Covid-19 has shone a brighter spotlight on these issues, they are part of a wider pattern of the discrimination experienced by disabled and older people within health and care. It finishes with a series of recommendations focussed on integrating human rights across decision making, policies and processes in healthcare.



The Care Quality Commission has also been working on this issue, with its findings published in a report on living and dying well during COVID-19.

It starts with the observation that *“From the beginning of the COVID-19 pandemic, there were concerns that ‘do not attempt cardiopulmonary resuscitation’ (DNACPR) decisions were being made without involving people”*. And its position on this is clear: *“such actions were unacceptable”*.

The review (set up at the request of the Secretary of State) heard about the experiences of over 750 people, with findings that give cause for concern. In the foreword, the Chief Inspector says this:

“What we have found through our review is a worrying picture of poor involvement, poor record keeping, and a lack of oversight and scrutiny of the decisions being made. Without these, we cannot be assured that decisions were, and are, being made on an individual basis, and in line with the person’s wishes and human rights.”

On the plus side, the report does not simply take a big stick to providers. It offers a series of practical recommendations, taking in information and training; consistent approaches to advance care planning; and improved oversight.

“Patient voice” is central: *“providers must ensure that people and/or their representatives are included in compassionate, caring conversations about DNACPR decisions”*. But staff voice is important too: *“providers must ensure that all workers understand how to speak up, feel confident to speak up and are supported and listened to when they speak up”*.

Last but not least, the CQC is willing to take its own share of responsibility. The final recommendation is that *“CQC must continue to seek assurance that people are at the centre of personalised, high-quality and safe experiences of DNACPR decisions, in a way that protects their human rights”*.



This report switches the focus to mental health services which, it says, 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*”.

Primary inequality

In his first speech as Prime Minister, Boris Johnson spoke of a need to “level up across Britain” and “answer the plea of the forgotten people and the left-behind towns”. [A description](#) of “left behind” areas includes a reference to relatively poorer population health – a feature sometimes described as “health inequality”.

This is not new: the 2012 Health and Social Care Act set out a duty for healthcare commissioners and providers to reduce inequalities in both access to and outcomes of care. A particular focus was inequalities experienced by people living in the most deprived areas.



The authors of this paper acknowledge that there are well documented variations in patient experiences of primary care in relation to socio-demographic characteristics. However, they say, “*there is limited evidence on longitudinal trends*”. So they set out to explore whether inequalities in patient experience of primary care had widened, narrowed, or remained the same between 2011 and 2017.

Their main finding was that there were few substantial changes. In particular:

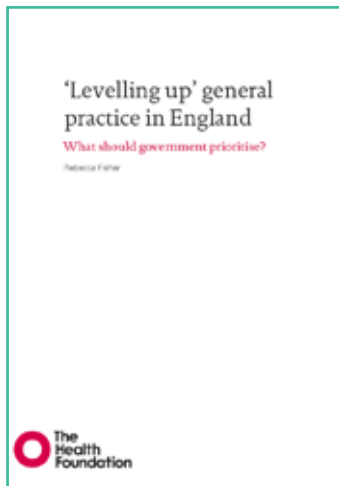
At both practice and national level, variations in patient experience persist, notably in relation to age, deprivation, ethnicity, sexual orientation and geographical region.

At the national level, inequalities in access to care start to appear from 2015, with access declining fastest amongst practices serving the most deprived areas.

Reported continuity of care is declining fastest amongst the oldest age groups when compared to other patients registered at the same practice. This matters because poorer continuity of care has been associated with higher rates of both generalised and preventable hospitalisations in older adults and higher rates of mortality.

The authors conclude that “*Despite a sustained policy focus on reducing unwarranted variations in care, there have been no substantial improvements in inequalities in primary care patient experience between 2011 and 2017*”. And “*Whilst access is getting worse everywhere, it is declining faster at those practices that serve deprived populations*”.

The paper warns that “*With UK primary care under increasing pressure, widening socio-economic inequalities...are of particular concern*”. And they suggest that “*public reporting alone is not an effective tool to drive reductions in inequalities in the UK*”.



The Health Foundation has also been looking at the state of general practice in the context of the government's "levelling up" agenda. Their 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 may 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 section on "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"*.

Inadmissible evidence

Just before Christmas last year, we published [Inadmissible Evidence](#) – our account of a double standard in evidence-based practice which causes persistent harm to patients. Over 8,000 copies have been downloaded from our website, far in excess of any other report in the entire Patient Experience Library.

We see this as a sign that people understand the need to start taking patient feedback more seriously. However, we continue to see signs that – at the system level – the understanding is not necessarily filtering through.



Bill Kirkup's report on the Life and Death of Elizabeth Dixon is by turns harrowing, desperately sad, and depressingly familiar.

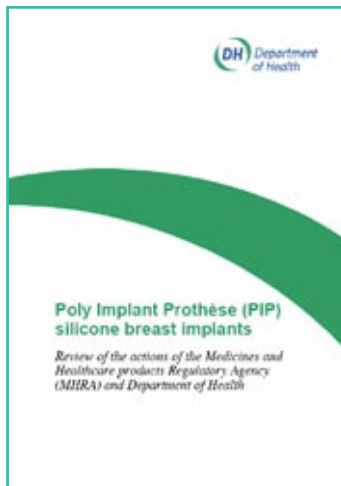
The story, once again, is of a patient (this time, a baby) who died, and of bereaved relatives who had to spend years (this time, twenty years) fighting for the truth about what happened.

The report describes “failures of care by every organisation that looked after her, none of which was admitted at the time, nor properly investigated”. That statement has echoes of the [Morecambe Bay report](#), which found “a series of missed opportunities to intervene that involved almost every level of the NHS”.

The report reveals “a cover up... propped up by denial and deception, which has proved extremely hard to dislodge over the years”. That sounds like [Gosport](#), where “Over the many years during which the families have sought answers to their legitimate questions and concerns, they have been repeatedly frustrated by senior figures”.

The report says that “The fabrication became so embedded that it has taken a sustained effort... to demolish it”. That mirrors the Northern Ireland [Hyponatraemia inquiry](#), where investigators noted “how difficult it was to persuade some witnesses to be open and frank... concessions and admissions were extracted only with disproportionate time and effort”.

A feature of this latest report which has been less evident from other inquiries, is how healthcare organisations were willing to sacrifice front line staff to protect their own reputations. Kirkup notes that “*It is fundamentally unjust that the only person held formally responsible has been the most junior involved, who also happened to be both female and of an ethnic minority*”. This, he says, “*is a sad indictment of an investigatory system that can be deflected so easily, and its convenience for others cannot escape notice*”.



This report dates back to 2012. It refers to “*the fraudulent activities of PIP, the French manufacturer of breast implants, [who] deliberately concealed their use of a non-approved filler material*”. It says that “*We owe it to the thousands of affected women to learn any lessons*”.

The learning got underway, the manufacturer went into liquidation, and the founder of the company was jailed. But that was not the end of the story for the women affected.

Many were left with chronic pain, and continuing anxiety about possible long-term effects on their health. They wanted financial compensation, and they wanted the German TUV Rheinland company, which issued safety certificates for the implants, to accept its own share of responsibility.

It has taken them ten years to fight their way through the courts to get justice.

In May 2021, a French appeal court upheld the women’s compensation claims, and also upheld a previous finding of negligence against TUV Rheinland. [The BBC has said](#) that the ruling could help up to 20,000 other women, half of whom are British, who are taking similar legal action in France.



The judgement came just as the UK government was issuing a [call for evidence](#) for its proposed women’s health strategy.

The call for evidence lists six core themes, the first of which is “Placing women’s voices at the centre of their health and care”.

But evidence shows that women are, by and large, perfectly capable of voicing their needs and concerns. We have seen that with the PIP breast implant scandal, with Shrewsbury & Telford, with the women harmed by breast surgeon [Ian Paterson](#), and with the women harmed by pelvic mesh.

[Baroness Cumberlege](#) described mesh survivors as “*...well informed, knowledgeable, and research based. They never failed to ensure we learnt from them and were up to date with emerging developments. They are outstanding communicators and expert in the subject matter.*”

The government’s desire to place women’s voices at the centre of their health and care is commendable. But the evidence shows that the problem is not with women’s ability to speak. It is with the healthcare system’s ability to hear.

4. About the Patient Experience Library

We are the national evidence base for patient experience and patient/public involvement, with over 60,000 studies and reports from government bodies, patient voice organisations, academic institutions, health charities and more.

Visit our website to get free access to our publications, waiting list tracker, surveys and feedback tool and more.

Contact us (info@patientlibrary.net) to ask about our bespoke services including literature searches and reviews, and help to manage your data on patient experience and involvement.

Follow us on Twitter: [@patientlibrary](https://twitter.com/patientlibrary)

Funding declaration

We are grateful to the [Joseph Rowntree Reform Trust](#), who have given us financial support from their “Speaking Truth to Power” fund.

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.

www.patientlibrary.net

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The Patient Experience Library is provided by Glenstall IT, 8 Glenstall Road, Ballymoney BT53 7QN

Appendices

A.1 Sources of evidence

There are multiple mechanisms for patient feedback and multiple sources of patient experience evidence. Making sense of them all can be difficult. Here, we offer a basic analysis.

Type	Description	Sources
1. Surveys	Mainly numerical data, often presented in spreadsheet format, and capable of statistical analysis. Large sample sizes, with national overviews, broken down to local detail.	Care Quality Commission patient surveys for: <ul style="list-style-type: none"> • Adult inpatients • Children and young people (includes views from parents and carers) • Community mental health services • Maternity services • Urgent and emergency care NHS England patient surveys for: <ul style="list-style-type: none"> • GP practices • Cancer services The NHS Friends and Family Test
2. Studies	Written reports, often with qualitative evidence based on patient stories and observations. Tend to feature small sample sizes, with a focus on specific named services and/or health conditions. Often with recommendations for improvements to policy and practice.	“Patient voice” bodies including Healthwatch, National Voices, Patients’ Association, health charities and think tanks. Care Quality Commission inspection reports – especially the “Caring” domain.
3. Research	Academic papers, usually featuring rigorous methodology, theoretical frameworks and peer review.	Health research bodies including NIHR, NICE, Academic Health Science Networks, Collaborations for Leadership in Applied Health Research and Care. Universities.
4. Online feedback	Direct comments from service users, sometimes backed up with analytics including sentiment analysis.	Care Opinion Hootvox LHM rate and review (used mainly by local Healthwatch) NHS.UK reviews Twitter
5. Other (local)	Feedback gathered via complaints and compliments, Patient Participation Groups, patient engagement committees and forums etc.	NHS Trusts, Clinical Commissioning Groups, GP practices etc.

Note: Patient experience/patient engagement leads may also be looking at data from sources such as Patient Reported Outcome Measures (PROMs) and Patient-led Assessments of the Care Environment (PLACE). We have not included these because, while being patient-led, they focus on clinical outcomes (PROMs) and physical environments (PLACE) as opposed to being specifically about patient experience.

A.2 Quantity of evidence

We are not aware of any way in which the scale of patient experience work is added up across the NHS to give a total sum of activities and participants. However, it is possible to get an indication of the scale of patient experience work in two ways: by looking at the number of people contributing to national surveys, and by looking at the number of published reports on patient experience.

A.2.1 The number of people contributing to national surveys

Survey	No. of respondents
GP Patient Survey 2021	850,206
Community Mental Health Survey 2020	17,601
Inpatient experience during the COVID-19 pandemic	10,336

In addition:

- Healthwatch England's [2019/20 annual report](#) states that the Healthwatch network supported 350,000 people to share their experiences of NHS and social care services.
- The NHS England Friends and Family Test hears from very large numbers of people every month. In June 2021 there were [763,647 responses](#).

A2.2 The number of published reports on patient experience

Again, we are not aware of any way in which this is added up nationally. However, a useful guide is the number of reports that have been added to the Patient Experience Library over the last year. The library is the most comprehensive national database of patient experience reports, so the figures below are a good indication of the scale of reporting.

Between August 2020 and July 2021, we uploaded 3,523 reports to the Patient Experience Library. Some had been published in previous years – the total published between August 2020 and July 2021 was 2,558.