

# Patient Experience in England



# Foreword



Back in 2015, I developed early symptoms of a fast-growing cancer. I saw my GP the same day, was assessed by a specialist within two weeks and began treatment immediately. That is why I'm alive to write this foreword.

For most of its 75 years, the UK National Health Service (NHS) was world-famous for six dimensions of healthcare quality<sup>1</sup>: *access* (patients could be seen quickly when needed); *relevance* (services addressed key population priorities); *effectiveness* (treatments were, for the most part, evidence-based); *equity* (services were distributed fairly according to need); *acceptability* (patients were, overall, very satisfied); and *efficiency* (funds were spent prudently).

In late 2020, my mother died of hospital-acquired COVID-19, having fallen and fractured her hip at home. Those of us who thought 2021 would bring an end to the pandemic and a return to 'normality' were disappointed. As many people died of COVID-19 in 2021 as in 2020, and various 'shadow pandemics' also emerged—including a backlog of undiagnosed or untreated non-COVID conditions, persistent COVID-19 ('long covid'), and financial precarity for some vulnerable sectors of society.

This high burden of health and care need occurred in a system whose resilience had been tested to—and perhaps beyond—its limit, with year-on-year reductions in real-time funding, an exhausted and demoralised health and social care workforce, and understaffing due to sickness, retirement and under-recruitment.

Small wonder that many sections of this report reveal a suboptimal patient and client experience in 2021 which has worsened since 2020 (sometimes dramatically). Of particular note are big falls in patient satisfaction with mental health and primary care services, as well as a drop in satisfaction with the NHS as a whole among the general public.

Maxwell emphasised back in 1984 that patient dissatisfaction (for example, at not receiving an antibiotic) may not reflect important aspects of healthcare quality (such as reducing antimicrobial resistance)<sup>1</sup>. But the various surveys included in this report indicate a system in genuine crisis with—in some places—mission-critical reductions in service quality. Notably, the quality dimension which Maxwell put at the very top of his list—access—has been compromised, particularly for some of the most vulnerable groups in society.

I owe my life to the standards of excellence of which the NHS could boast just a few years ago. This report is a wake-up call for policymakers: the causes of most problems described here are structural. They must be addressed as a matter of urgency.

## **Trish Greenhalgh**

Professor of Primary Care Health Sciences, University of Oxford

1. Maxwell RJ, Quality assessment in health. *BMJ*. 1984;288(6428):1470

# Contents

<b>1. Introduction.....</b>	<b>4</b>
<b>2. What we learned in the last year: Surveys.....</b>	<b>5</b>
2020 Adult Inpatient Survey .....	6
British Social Attitudes survey 2021.....	7
Cancer Patient Experience Survey.....	8
2020 Children and Young People’s Survey.....	9
2020 Community Mental Health Survey .....	10
GP Patient Experience Survey .....	11
Inpatient experience during the COVID-19 pandemic .....	12
Maternity survey 2021.....	13
2020 Urgent and Emergency Care Survey.....	14
<b>3. What we learned from research.....</b>	<b>15</b>
Health inequalities .....	16
Maternity .....	18
Mental health .....	21
Waiting.....	24
Patient safety .....	27
Complaints and self advocacy.....	30
Drug companies .....	33
Digital .....	35
<b>4. About the Patient Experience Library .....</b>	<b>39</b>
<b>Appendices .....</b>	<b>40</b>
A.1 Sources of evidence .....	40
A.2 Quantity of evidence .....	41

## Acknowledgements

**We’d like to thank the people who have inspired, supported and encouraged us over the last year. They are...**

Our magazine contributors:

- Jane C. Woods
- Kate Eisenstein
- Tania Daniels
- Cancer Mum
- Kath Sansom
- Sue Robins
- Julia Jones
- Ceinwen Giles

**Our thinkers, signposters, provocateurs and project partners:**

- Charlotte Augst, Rachel Matthews, Keymn Whervin, *National Voices*
- Dr. Rebecca Baines, *University of Plymouth*
- Olivia Butterworth, *NHS England*
- Hannah Davies, *Healthwatch Leeds*
- Juliet Dobson, *BMJ*
- Professor Mark Gamsu, *Leeds Beckett University*
- Lesley Goodburn, *NHS England*
- Meerat Kaur, *NIHR*
- Helen Mulholland, *Sheffield Clinical Commissioning Group*
- James Munro, *Care Opinion*
- Karl Roberts, *NHS Leadership Academy*
- Laura Sheard, *Associate Professor, York Trials Unit*
- Seb Stevens, *Apollo Health Innovations*
- Ben Williams, *Joseph Rowntree Reform Trust*

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!

# 1. Introduction



It is now six years since we began producing this annual overview of patient experience evidence, and we never cease to be impressed by the quality and quantity of published research.

The national patient surveys are produced with a commendable rigour in both the evidence gathering and the analysis. Their findings are always illuminating, and as the years pass, the trends and patterns in patient experience become clearer.

The research studies, by patient voice organisations, health charities, academic institutions and policy think tanks, show a variety of approaches. Formal research is grounded in theory, and quality assured through clarity of method and peer review. Other evidence gathering is less formal, but is based on long-term relationship building in local communities, leading to trusted dialogue and deep insight.

Put together, all of these sources and methods create a rich source of knowledge for an NHS that wants to be both person-centred and evidence based.

But challenges remain.

The last year has seen publication of avoidable harm investigations from the [Ockenden review](#) and, in Northern Ireland, the [Independent Neurology Inquiry](#). Both, yet again, reveal a reluctance to take patient feedback seriously, with terrible consequences.

We can tackle this - indeed many people already are, as evidenced by the wealth of ingenuity and effort that has gone into the work featured in this report.

The part the Patient Experience Library plays is to help people find their way through the mountain of feedback. Here, once again, we present our top picks from the last twelve months of evidence gathering, with summaries of the key points to help you make sense of it and, we hope, to encourage you to dig deeper.

As always, 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

[info@patientlibrary.net](mailto:info@patientlibrary.net)

## 2. What we learned in the last year: Surveys

After a pause on many of the national patient surveys during the pandemic, the last 12 months have generated a bumper crop.

Some of the findings are stark: the British Social Attitudes Survey found the lowest overall level of satisfaction with the NHS since 1997. The fall in satisfaction was seen across all ages, income groups, sexes and supporters of different political parties.

For the GP Patient Experience Survey, overall experience decreased to its lowest level for five years, as did the proportion of patients reporting a good experience of making an appointment. Fewer patients said it was easy to get through to their GP practice than in any year since the question was introduced in 2012.

There was better news in other areas - for example, in cancer care, where patients' overall experience showed an average rating of 8.9, out of a best possible score of 10. The Children and Young People's Survey found that 93% of respondents had been looked after 'very well' or 'quite well', and 89% said that staff looking after them were 'always' friendly.

Surprisingly good news comes from urgent and emergency care, where the proportion of patients who rated their overall experience as '10 out of 10' has increased from 27% in 2016 to 33% in 2020 for Type 1 services (emergencies), and from 33% in 2016 to 44% in 2020 for Type 3 services (minor injuries). Another huge change was in perceptions of cleanliness, with an eleven percentage point increase on 2018 results - one of the largest year-to-year differences ever observed by NHS Patient Survey Programme surveys.

Two areas that seem stubbornly resistant to improvement are mental health services and hospital discharge. The Community Mental Health Survey is blunt, stating that "Positive results, where the majority of people reported good experiences of care, are few". It adds that changes due to the pandemic "have negatively impacted the mental health of many service users, with 48% reporting that their mental health 'got worse'".

For hospital discharge, nearly a quarter of respondents to the Adult Inpatient Survey did not feel involved in decisions around leaving hospital, one fifth did not have their family or home situation taken into account, and around a third were not given any written information to take home with them.

Summaries of survey findings are below - for further detail, click on the report pictures. And to find specific details for your local NHS Trust(s), feel free to use our open access [surveys tracker](#).

## 2020 Adult Inpatient Survey



Responses on communications and trust were generally good – for example, most patients (75% for doctors, and 77% for nurses) understood the answers to their questions all of the time. Most people felt included in conversations about their care (74% for doctors, 77% for nurses). An even higher proportion had confidence and trust in the doctors (84%) and nurses (83%) treating them. When asked if they had been treated with respect and dignity, 85% of patients said ‘Yes, always’.

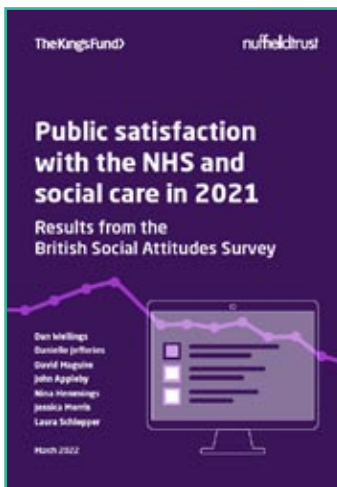
Cleanliness scored extremely highly, with 98% of patients experiencing good levels of cleanliness in their hospital room or ward. 92% were also able to receive help from staff to keep themselves clean all of the time or sometimes, fulfilling their basic hygienic needs.

Help with fundamental needs was generally good – however, just over 1 in 7 patients said that they did not get enough help from staff to eat their meals (15%) and just over 1 in 10 were not able to take their medicines (12%). Additionally, 5% of people were not given enough to drink while in hospital.

Hospital discharge scored less well: 23% of people did not feel involved in decisions around leaving hospital and 21% did not have their family or home situation taken into account. 30% of people were not given any written information about what they should or should not do after leaving hospital, and 21% said that after leaving hospital, they did not get enough support from health and social care services to help them recover or manage their condition.

For people needing medicine after their inpatient care, only 28% were told about the side effects, and just 55% were given an explanation of how to take it. Finally, 24% of people were not told who they could contact if they were worried about their condition or treatment after leaving hospital.

## British Social Attitudes survey 2021



Overall satisfaction with the NHS fell to 36 per cent – an unprecedented 17 percentage point decrease on 2020. This is the lowest level of satisfaction recorded since 1997. The fall in satisfaction was seen across all ages, income groups, sexes and supporters of different political parties.

The main reason people gave for dissatisfaction was waiting times for GP and hospital appointments (65%) followed by staff shortages (46%) and a view that the government does not spend enough money on the NHS (40%).

Of those who were satisfied with the NHS overall, the top reason was because the NHS is free at the point of use (78%), followed by the quality of NHS care (65%) and that it has a good range of services (58%).

The fall in satisfaction was observed across a range of services, as follows:

- GP services fell to 38% – 25 percentage points lower than the previous lowest level (63%) recorded in 2018.
- Inpatient services fell from 64% in 2019 to 41% in 2021, a fall of 23 percentage points.
- Outpatient services fell from 71% in 2019 to 49% in 2021.
- NHS dentistry services fell to 33% compared to 60% 2019.

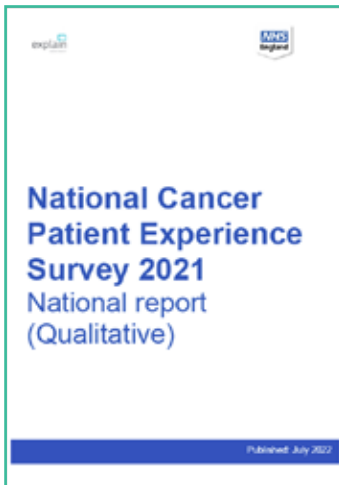
For all the above, satisfaction is at the lowest level since the BSA survey began in 1983.

For accident and emergency services, satisfaction fell sharply by 15 percentage points, from 54% to 39%. This is the lowest level recorded since a question on A&E was introduced in 1999.

In social care, 15% of respondents said they were satisfied, against 50% who were dissatisfied. The main reasons for dissatisfaction were that the pay, working conditions and training for social care staff are bad (59%), that people don't get all the social care they need (59%), and that social care is not affordable to those who need it (44%).

The overwhelming majority of respondents agreed that the founding principles of the NHS should 'definitely' or 'probably' apply: that the NHS should be free of charge when you need it (94%), the NHS should primarily be funded through taxes (86%) and the NHS should be available to everyone (84%).

## Cancer Patient Experience Survey



Key points emerging from the thematic analysis were as follows:

Patients' overall experience of care was good, with an average rating of 8.9, where the best possible score was 10. An overwhelmingly strong theme was gratitude, with staff being praised for their kindness and compassion. 89.2% of respondents were always treated with respect and dignity while they were in hospital. 76.2% said they could always get help from hospital staff when they needed it but in spite of this, a common concern was that staff were 'too busy' and/or wards were 'understaffed'. Hospital wards were also seen as lacking privacy and for some, Covid visiting restrictions meant a lack of emotional support.

Views of general practice were less positive. Concerns tended to focus on diagnosis, with respondents feeling that their GP had not listened to their concerns or had misdiagnosed them. There was a sense that symptoms and concerns had not been taken seriously and that referrals to relevant specialists were unduly delayed. Follow-up by GPs following cancer diagnosis was also commented on, with respondents describing feelings of being 'abandoned' with this expectation unmet.

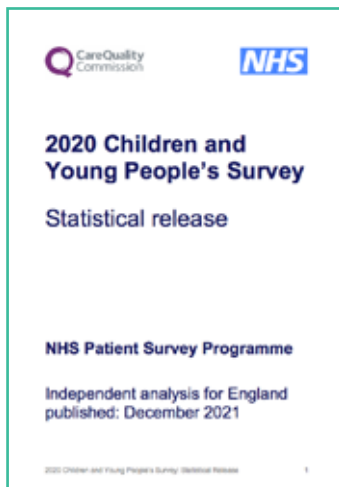
On communication, 82.2% of respondents said their treatment options were completely explained to them in a way they could understand. However, many felt that the rationale for treatment decisions was not always properly explained, nor was information about potential side-effects, and how to monitor themselves for signs of recurrence. 91.9% said they had a main contact person within the team looking after them and 85% said it was 'very' or 'quite easy' to contact this person. After discharge however, some felt that they were not followed up effectively, with appointments either lacking entirely or being infrequent.

Communication and information sharing between different hospitals and departments was problematic. When a respondent was under the care of multiple different departments, it was felt that poor information sharing resulted in a delay to treatment and caused unnecessary anxiety.

81.9% said that the length of the time they had to wait for their test results was about right, as was the length of waiting time at the clinic or day unit for cancer treatment. However, there was less satisfaction with the length of time taken to start treatment, and some understood this wait to be associated with poorer prognosis.



## 2020 Children and Young People's Survey



Feedback was generally positive: 93% of respondents had been looked after 'very well' or 'quite well', and 89% said that staff looking after them were 'always' friendly. Communication was good: most children 95% were able to ask staff questions and get answers (93%) and felt that staff 'always' listened (85%). In spite of this, 29% said they only 'sometimes' understood what staff said when they spoke to them.

86% were always given enough privacy when receiving care and treatment, and 92% felt able to speak to a doctor or nurse without their parents being there. 94% felt emotionally supported during their time in hospital.

There were poorer experiences around having enough to do and play, with less than half (44%) saying that there were enough things for them to do in hospital. Other aspects of fundamental care were also poor: under half (47%) of children said that it was 'always' quiet enough to sleep, and only 52% said that they liked the hospital food.

Parents and carers were also mostly positive and largely agreed with their children's feedback on communication. Importantly, given visiting restrictions during the COVID-19 pandemic, most parents (95%) said they were 'always' able to be with their child as much as they needed to.

When leaving hospital, fewer than eight in 10 (79%) 'definitely' knew who to talk to if they were worried about their child when they got home.

Covid restrictions were the likely cause of considerable changes in parents' experiences of hospital facilities. Less than a third (28%) were able to get a hot drink from a kitchen area or parents' room, down from more than half (54%) in 2016. Just 21% had access to a café or vending machine, down from 38% in 2016. A further 61% were unable to prepare food in hospital, up from 38% in 2016.

Hospital discharge also showed room for improvement: just under one in six (15%) were not told who to speak to if they were worried about anything when they got home. One in 10 said when they left hospital, they did not know what would happen next with their care. Fewer than eight in 10 parents (79%) 'definitely' knew who to talk to if they were worried about their child when they got home.

## 2020 Community Mental Health Survey



The Care Quality Commission's summary of survey findings is clear that "Positive results, where the majority of people reported good experiences of care, are few". It adds that "changes made to care and treatment due to the pandemic have negatively impacted the mental health of many service users, with 48% reporting that their mental health 'got worse' because of these changes".

There is some good news in the area of 'organising care', where 96% of those who had been told who is in charge of organising their care, knew how to contact this person or team. Similarly, 90% of people felt the person who organised their care did so 'very well' or 'quite well'. Feedback on 'medicines' is also positive: 63% 'definitely' had the purpose of their medicines discussed with them

- an increase of six percentage points since 2019.

Access to care is less good: only two in five people (41%) had 'definitely' seen services enough for their needs in the last 12 months, while almost one in five people (17%) said that care and services were not available when they needed them. 15% said they were not given enough time to discuss their needs, and 42% had waited 'too long' to receive talking therapies.

More people need help from crisis care services as a direct result of the pandemic, but 26% would not know who to contact out of office hours. Of those who did try to contact a crisis team, 20% did not get the help they needed.

On communication and involvement, just 41% of all respondents 'definitely' agreed what care they would receive, and only half (52%) were as involved as much as they wanted to be in planning their care. This is the lowest reported result for this question in eight years. Similarly, only half (50%) of those who had received NHS talking therapies were involved as much as they wanted to be in deciding which therapies to use. Over a quarter of people (28%) had not been told who was in charge of organising their care.

Financial stability, employment and good physical health are key components of good mental health, but almost half reported not receiving help or advice with finances or benefits, or finding/keeping work. A further 39% did not receive support for their physical health needs. In addition, only half (51%) said that services 'definitely' involved a family member or someone else close to them as much as they would like.

## GP Patient Experience Survey



The proportion of patients reporting a good overall experience of their GP practice decreased to its lowest level for five years, at 72.4%. This represented a 10.6 percentage point decrease compared with the 2021 survey (83.0%).

Just over half (52.7%) of patients said it was easy to get through to someone at their GP practice on the phone. This is lower than all previous years since the question was introduced in 2012, with the largest decrease within the last year (a decline of 14.9 percentage points from 67.6% in the 2021 survey).

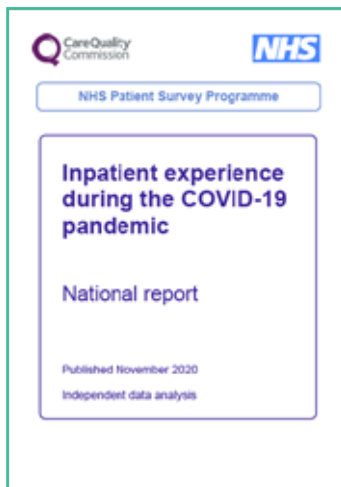
Online contact with practices continues to increase, with 55.1% having used at least one online service - up 10.8 percentage points from the 2021 survey. The most common use was for repeat prescriptions (30.8%), however, the proportion of patients who reported accessing their medical records online more than doubled over the last year (16.5% compared with 7.1% in the 2021 survey). The increase in use of GP practice websites for information or to access services also increased, with 60% of patients now doing so.

The proportion of patients reporting a good overall experience of making an appointment decreased to its lowest level for five years (56.2%) - down 14.5 percentage points from the 2021 survey (70.6%). Satisfaction with appointment times also dropped to the lowest for five years (55.2%) - down 11.8 percentage points to 55.2% as against 67% in 2021.

Over half of survey respondents (55.4%) had avoided making a general practice appointment - up 13.1 percentage points from the 2021 survey (42.3%). The most common reason for patients avoiding making an appointment was because they found it too difficult (26.5%),

Patients with a disability reported a less positive overall experience, while patients living in the most deprived areas reported the least positive overall experience. Of patients who had a mental health need, the proportion who felt that these were recognised and/or understood decreased to the lowest level in five years (80.8%) - 5.2 percentage points lower than the 2021 survey (86.0%)

## Inpatient experience during the COVID-19 pandemic



This survey looked at the experiences of people admitted from March to May 2020, at the height of the first wave of the COVID-19 pandemic. It included patients with COVID-19 (on admission or diagnosed during their stay), as well as patients in hospital for non-COVID related reasons.

Feedback on person-centred care was generally positive, with 70-80% of patients indicating satisfaction with shared decision-making, emotional support, and information on care and treatment. 83% '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 these measures of person-centred care.

In the crucial area of infection prevention and control, 80% reported high levels of cleanliness, and most also remembered seeing infection control measures including staff wearing personal protective equipment, handwashing, provision of waste bins, and cleaning of surfaces. However, fewer remembered seeing social distancing measures.

Communication seems to have been difficult. While 77% were 'always' able to get attention from staff when they needed it, 24% were 'sometimes' or 'never' able to understand the information that staff gave them, and 27% said that this information was 'often' contradictory. A further 27% said that they could 'sometimes' or 'never' understand staff when they were talking when they were wearing PPE. Communication was harder for people aged 85 and over, people with dementia, patients who were deaf or hard of hearing, autistic people and those with a learning disability. There were difficulties among similar groups in staying in touch with family and friends.

Experiences of discharge were less positive than other aspects of the stay in hospital. Patients with a COVID-19 diagnosis were more likely to say their home situation was not taken into account when leaving hospital, and that they were not told who to contact should they become worried about their care or treatment after leaving hospital. 29% said they did not receive the post-discharge care and support they needed.

## Maternity survey 2021



“In previous surveys, the picture of maternity care in England has been one of year-on-year improvement” says this report. However, “This year... results have declined in many areas... likely reflecting the impact that the COVID-19 pandemic had on services and staff”.

One of those impacts was involvement of partners, with a large decrease (from 97% in 2019 to 84% in 2021) in the proportion of women who said that their partner or someone else close to them was involved as much as they wanted. There was an even larger decline in the ability of partners to stay with patients as much as they wanted, from 74% in 2019 to 34% in 2021.

Choice was also affected, with 20% of women saying they were not offered any choices about where to have their baby. 62% were not given a choice about where their postnatal care would take place, much higher than 52% in 2019.

There were substantial declines in experience of information provision, with one quarter of women not being given enough information about coronavirus restrictions and any implications for their maternity care, and 23% not given enough information to help them decide where to have their baby (compared with 12% in 2019).

Staff availability changed, with 65% of women ‘always’ able to get a member of staff to help them during labour and birth, down from 72% in 2019. Antenatally and postnatally, however, staff availability was better, with good rates of face to face appointments (98% antenatally and 95% postnatally). Additionally, 41% of women saw or spoke to the same midwife every time during their antenatal check-ups (up from 37% in 2019) and 30% saw or spoke to the same midwife postnatally, (up from 28% in 2019).

Most women were asked about their mental health during appointments - 69% antenatally and 95% postnatally. 83% were given enough support for their mental health during their pregnancy. However, information could be improved, as less than three-fifths of women (56%) were ‘definitely’ given information about any changes they might experience to their mental health after having their baby, down from 63% in 2019. And only 47% were ‘definitely’ given information about their own physical recovery after the birth.

63% of women said midwives and other health professionals ‘always’ gave them active support and encouragement with feeding their baby, compared with 69% in 2019. Less than half of women (48%) were ‘always’ able to get support or advice about feeding their baby during evenings, nights or weekends if they needed it.

## 2020 Urgent and Emergency Care Survey



Satisfaction with urgent and emergency care has gone up: the proportion of patients who rated their overall experience as '10 out of 10' has increased from 27% in 2016 to 33% in 2020 for Type 1 services (emergencies), and from 33% in 2016 to 44% in 2020 for Type 3 services (minor injuries).

81% said they were treated with dignity and respect 'all of the time' while in A&E, and well over three quarters 'definitely' had confidence and trust in the doctors and nurses. Similar proportions said that health professionals 'definitely' listened to what they had to say, and on privacy, 84% of Type 1 and 91% of Type 3 patients were 'definitely' given enough privacy when being examined or treated. There were also high levels of

satisfaction with information on, and availability of, support after going home.

The biggest positive change was in perceptions of cleanliness, with an eleven percentage point increase on 2018 results. These findings are among the largest year-to-year differences ever observed by NHS Patient Survey Programme surveys and likely reflect enhanced infection control and prevention measures in urgent and emergency care services in response to the COVID-19 pandemic.

Declines in patient experience were evident in the areas of shared decision-making, and discussion about anxieties and fears, where only 51% of Type 1 patients had felt able to 'completely' discuss these. Other areas where satisfaction was lower were pain control, help with managing symptoms and getting the attention of staff.

Room for improvement can also be found in discharge, where 40% of Type 1 patients said they were not given enough information about medication side effects, and just 60% said that staff 'definitely' gave them enough information to help care for their condition at home.

The survey found that age, attendance duration and sex were consistently associated with experience. Patients aged 16 to 35 and people whose attendance lasted longer than four hours reported poorer than average experiences across all experience themes. Females, people who reported a mental health condition, and people who had visited the service recently reported poorer than average experiences on most themes.

### 3. What we learned from 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 Patient Experience Library [here](#). For full attributions, and copies of the documents mentioned on the following pages, click on the report pictures.

# Health inequalities

“The NHS provides a comprehensive service, available to all” says the [NHS Constitution](#).

That statement might work in principle, but it does not always work in reality, as evidenced by entrenched and persistent health inequality. The following reports point to structural and systemic barriers which continue to get in the way of progress.



This study examined plans published by Sustainability and Transformation Partnerships and Integrated Care Systems to see how health inequalities are understood and addressed. Five common themes emerged:

- “Vagueness” was exemplified by a lack of detail and a lack of clear goals to reduce health inequalities.
- “Variation” was demonstrated in three ways: variation in definitions of terms, groups being compared, and the use of metrics and indicators.
- “Lack of prior conceptualisation and approach” meant that healthcare systems appeared not have an established

approach or work programme. Documents frequently mentioned gaps in awareness of what inequalities were present.

- “Use of value judgements” was revealed through widespread discussion of lifestyle and behaviour being a major determinant of health.
- “Lack of commitment to action” meant that while there was a high level of commitment to the notion of tackling health inequalities, there was a lack of concrete and accountable targets or actions.

The authors argue that healthcare systems should agree on a coherent national conceptualisation for health inequalities, along with clear guiding principles about how to reduce inequalities.



Prisons can be seen as places where inequalities are particularly concentrated - and this is even more true in women’s prisons.

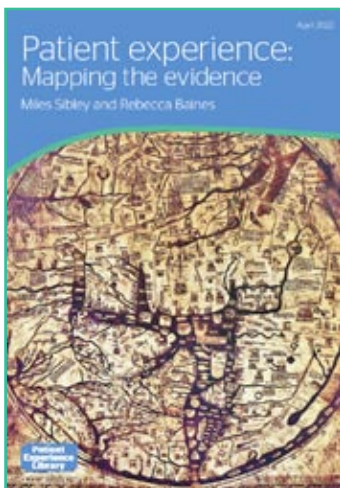
The All Party Parliamentary Group (APPG) on Women in the Penal System makes no bones about this. It says that “Prisons are not healthy environments. They are unable to address the physical and mental health needs of women and in fact exacerbate them”.



Health-related harms in women’s prisons include the following:

- Imprisonment compounds the victimisation of women, the majority of whom have experienced violence or abuse prior to prison.
- The prison system as a whole is designed around the needs of a male majority. Prison rules and prison policy neither support nor prioritise women’s health and well-being.
- Most women in prison do not need to be there. Over half are on remand and a third are serving short sentences.
- The prison environment exacerbates health inequalities for Black and minority ethnic women.
- The lack of continuity for women coming in and going out of prison is detrimental to their care.

The report finishes by considering the government’s Prisons Strategy White Paper. It finds that “the proposals will lead to an expansion of the prison estate, resulting in more women and children experiencing the harms of prison when it is not necessary or appropriate”. Instead, “The focus should be on reducing the unnecessary use of prison for women and on improving and expanding provision for women in the community”.



Our own report (Patient Experience Library with Plymouth University) took the inequality issue upstream - looking at how inequality is built into the evidence gathering that underpins policy and practice.

We all know that some people and places are deemed by researchers to be “hard to reach”. But what does that mean for the evidence base on patient experience? Where are the strengths, and where are the gaps?

The fact is that nobody knows - because no-one has ever mapped the patient experience evidence base. When we try to understand people’s experiences of healthcare, we don’t know who gets heard - and who doesn’t.

Against this background, we set out to explore. Taking two samples - peoples’ experiences of Covid-19 and people’s experiences of digital healthcare, we created visualisations, offering insights into the scale and nature of the evidence gathering.

We found that some parts of the evidence base (for example on access to services) were saturated, with studies adding more to the pile of reports than to the sum of knowledge. Other parts (particularly around areas of health inequality) were persistently thin. You can see what we discovered in a [short video here](#).

The video allows viewers to see what the maps can do, but does not give them direct access. So we are now working to improve functionality within the Patient Experience Library so that users can manipulate and interrogate the maps for themselves.

## Maternity

Maternity services have continued to attract widespread political and media attention over the last twelve months, for all the wrong reasons.

Donna Ockenden’s [final report](#) on large scale avoidable harm at Shrewsbury and Telford (covered in the section on “patient safety”, below) was published in March 2022. In her foreword, Ockenden exposed a fundamental flaw in the Trust’s practice and culture: “for far too long women and families who accessed maternity care at the Trust were denied the opportunity to voice their concerns”.

The government concurred, with [Health Secretary Sajid Javid](#) pointing to “a systemic failure to listen to families affected many of whom had been doggedly persistent in raising issues over several years”.

Shrewsbury and Telford sits alongside [Morecambe Bay](#) and [Cwm Taf](#), where women’s experiences were also ignored, and [East Kent](#) and [Nottingham University Hospitals Trust](#), where similar revelations seem likely. None of these are “bad apples”. They are part of an overarching culture in which patient experience is not given sufficient weight within the “hierarchy of evidence”.



This report from the Care Quality Commission makes the point again: “a failure to engage with, learn from and listen to the needs of local women [continues] to affect the safety of some hospital maternity services”.

Maternity Voices Partnerships are a vital link between maternity services and patients - but the CQC finds that working relationships between MVPs and maternity services vary.

Where relationships are good, MVPs can help with information materials and public outreach, as well as internal provider matters such as safety reviews. Importantly, they have “direct channels of contact” with the Head of Midwifery, and “felt confident that they would be able to raise safety concerns”.

On the downside, some MVPs felt that their role was not well understood by providers. This includes “the MVP not being involved early enough in the process to give meaningful feedback and the trust being defensive to suggestions from the MVP”.

There are disparities in funding for MVPs, and some MVP Chairs are expected to go above and beyond their paid role. This is seen as “a barrier to women from some communities or groups getting involved, perpetuating issues with a lack of diversity”.

The report calls for “true engagement” with Maternity Voices Partnerships, and says that “local maternity systems need to improve how they engage with, learn from and listen to the needs of women, particularly women from Black and minority ethnic groups”.



The House of Commons Health and Social Care Committee, for its part, has been looking beyond maternity service 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”.



Moving up to an even more strategic level, this study compared Australia’s maternity strategy with similar strategies from England, Wales, Scotland, Ireland, Northern Ireland, Canada, and New Zealand. The analysis included some wider insights into maternity politics, culture and strategy, as follows:

- In the Australian strategy, the term “woman-centred” encompassed the values of safety, respect, choice, and access.
- The essence of these values appeared in every other plan reviewed.
- Continuity of midwifery carer appeared to be an add-on to the Australian strategy, in contrast with the English, Scottish, and Welsh plans, which advocate for continuity of midwifery care for all women.
- There was significant variation in the positioning and professional autonomy of midwifery – however, where the midwifery profession is strong, midwifery models of care and place of birth options were more likely to be discussed and recommended.
- In countries where birth at home and in birth centres is widely accepted, the recommendations in maternity plans were more in line with evidence, human rights, and consumer demands.

There were inconsistencies in all the documents reviewed around where the final decision making lay when it came to choice and autonomy in maternity care. This is in spite of the fact that the right of people to make autonomous decisions about their own bodies is enshrined in the Universal Declaration on Human Rights and applies, without exception, to pregnant and birthing women. This, say the authors, “leaves women in a vulnerable position when it comes to choice and autonomy in nearly every strategy/plan we reviewed”.

The authors conclude that “In countries with an established, valued and autonomous midwifery profession, maternity guidelines appear to better align with evidence”. Their suggestion is that “Priority must be given to the choices women make and the best available evidence, not the power and interests of organisations and individuals”.

## Mental health

Five years have passed since Prime Minister Theresa May described mental illness as a **hidden injustice**, and called for parity of esteem between mental and physical health conditions and services. These reports from the last twelve months indicate that progress continues to be slow.



The opener to this report is stark: “Around a third of people who find themselves in police custody have some form of mental health difficulty, as do 48% of men and 70% of women in prison”. And the follow-up is clear: “people with a mental illness need and deserve treatment”.

The report looks at how - and whether - people in contact with the criminal justice system (CJS) are getting the mental health services they need. The answers include these findings:

- There is no common definition of mental health used across the CJS.
- The mental health flagging system used by probation services is muddled.
- Significant problems in information exchange occur in every agency in the CJS.
- Probation practitioners are often hindered by community mental health service providers who do not allow them access to information held on individuals they are working with.
- Prison officers are not supported well in their continuous professional development in working with prisoners with mental health vulnerabilities.
- Prisons continue to be used as a place of safety, and Mental Health Act transfers out of prison custody are taking far too long.

The authors cite the 2009 Bradley report, which stated that “failure to adequately address the mental health needs of offenders is a fundamental cause of the chronic dysfunction of our criminal justice system”. They go on to say that “not enough progress has been made in the 12 years since the Bradley review”.

The report contains 22 recommendations which address these, and many other, failings. It calls for most of the recommendations to be completed within 12 months.



Lack of progress in parity of esteem has also been picked up by the Care Quality Commission, which published its original “Out of Sight” document in October 2020. This update finds that 13 of the original report’s recommendations have not been achieved. Four have been partly achieved. There are no recommendations that have been fully achieved.

According to the authors, “there are still too many people in mental health inpatient services. They often stay too long, do not experience therapeutic care and are still subject to too many restrictive interventions, which cause trauma. Families have told us clearly that the pain and harm for them and their family member continues”.

The reasons for this include a “lack of community services” and the fact that “the right housing is not available, nor the right support in place.... People end up moving around the system from one service to another because their needs are not being met”.

Recommendation 10 is about people’s experience of person-centred care. Disturbingly, the authors find that “People and their families still tell us that it is not always easy to raise and escalate concerns to providers or commissioners. Where they do, they can feel labelled as difficult or persistent complainers and are concerned that it will have a negative impact on how providers see and treat them or their loved one”.



Another consequence of lack of capacity in the mental health services is inappropriate out of area placements, where a patient is admitted to an inpatient unit far from home because no appropriate bed is available locally.

Out of area placements ‘were always intended to be the absolute last resort’. However, ‘NHS data shows that inappropriate out of area placements are still heavily relied on to manage pressure on the system’.

This report from the Royal College of Psychiatrists (RCP) says that ‘Patients... have been left paying the price. Sometimes hundreds of miles away from home, they are unable to access their usual support networks while at their most vulnerable, often finding their care seriously disrupted with long term implications for their recovery.’

The RCP recognises NHS Long Term Plan commitments to tackle the problem. But, it says, ‘The government’s deadline to eliminate inappropriate out of area placements... by the end of March 2021 has now been missed by a full year’. And in March 2022, ‘over half of all inappropriate out of area placements saw patients travel more than 100km from home because a local bed was unavailable for the eighth month running’.

Ultimately, the RCP's position is clear: 'This situation is unacceptable, and patients experiencing an acute mental health crisis can't afford to wait any longer'.

Improving the experiences of people with mental health conditions is not simply a matter of drug treatments and clinical practice.



This report from the World Health Organisation 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 also 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”.

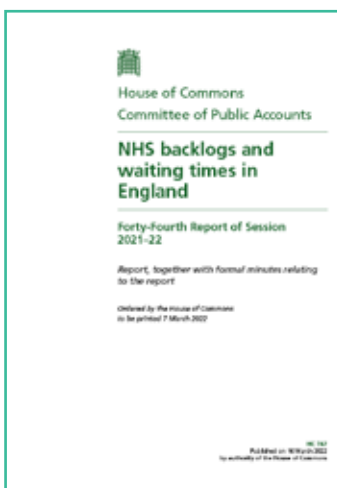
The report offers guidance and recommendations across a range of topics - but importantly, “development of a human rights agenda and recovery approach cannot be attained without the active participation of individuals with mental health conditions and psychosocial disabilities. People with lived experience 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”.

## Waiting

Sajid Javid had been in post as Health Secretary for just a fortnight when he [revealed his shock at the state of NHS waiting lists](#). His response was that it had “absolutely focused my mind, and it’s going to be one of my top priorities to deal with”.

At the time there were 5.3 million people on waiting lists in England. That figure is now creeping up towards 7 million.

Headline figures might be of interest to politicians. But what patients want to know is the waiting times for the treatments they need at Trusts near them. That’s why we chose last year to launch our open access [waiting list tracker](#), as a contribution to greater transparency on waiting times. The following reports also pick up the issue of transparency.



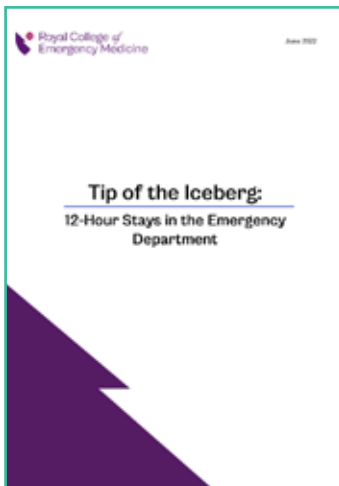
This report highlights the direct link between waiting times and people’s experiences of care, making the point that “People will face serious health consequences as a result of delays in treatment, with some dying earlier than they otherwise would, and many living with pain or discomfort for longer than they otherwise would”. It also states that “Waiting times for elective and cancer treatment are too dependent on where people live and there is no national plan to address this postcode lottery”.

The report is clear that the huge backlogs predate the Covid crisis: “The Department of Health and Social Care (the Department) and NHS England and NHS Improvement (NHSE&I) oversaw declines in waiting time performance for cancer care from 2014 and elective care from 2016 as they did not increase capacity sufficiently to meet growing demand for NHS services”.

There is concern about a lack of transparency in how the crisis is being tackled. The report states that “the Department allowed NHS England to be selective about which standards it focused on, reducing accountability”. It also says that “the Department and NHSE&I appeared unwilling to make measurable commitments about what new funding for elective recovery would achieve”.

There is a recognition that patient experience matters: “The Department needs to be better at communicating with NHS staff and patients about what the NHS will be able to deliver in the coming years”. And there is a call for a “transparent and realistic assessment of... how patients will be kept informed about their own progress through waiting lists”.





This report also tackles transparency, this time in respect of waiting times in emergency services, where ‘Emergency Department crowding is one of the most serious policy challenges facing the NHS’. It states that ‘crowding is not only dangerous, but also inhumane and undignified for patients who have no option but to stay for treatment in precarious conditions’.

The report concentrates on a key measure: the numbers of patients waiting 12 hours or more beyond a decision to admit (DTA). The numbers are ‘staggering’: in the first four months of 2022 alone there were more than 79,000 12-hour DTA waits;

nearly as many as the cumulative total (83,000) of the 11 years since data collection began.

In any case, say the authors, the 12 hour DTA measure ‘does not capture the true extent of the delays experienced by the patient’. A better measure would be 12 hours from time of arrival (TOA), which tracks performance ‘from the moment the patient steps foot into the ED’ and would bring performance measurement in England in line with the rest of the devolved nations.

The Government and NHS England have still not indicated when the data on 12 hours TOA will be publicly available - but publishing these figures matters because ‘Behind every single metric is a patient and the NHS is failing its commitment to provide care to the public without any unnecessary delay; a key pledge outlined in the NHS Constitution’. ‘This data’, says the report, ‘must be published immediately’.



This report considers what might be driving high intensity use of Accident and Emergency. It looks at the one percent of the population who account for more than 16 per cent of A&E attendances, 29 per cent of ambulance journeys, and 26 per cent of hospital admissions.

The study shows a clear link between high intensity use and wider inequalities, being associated with areas of deprivation, and issues such as homelessness, unemployment, mental health conditions, drug and alcohol problems, criminality, and loneliness and social isolation.

It turns out that the key to addressing high intensity use of A&E is not so much about “patient flow” or hospital staffing or ambulance services. Instead it is a matter of “addressing the practical, social and emotional issues that can exacerbate people’s physical and mental health conditions, and ensuring that people have timely and appropriate access to support in the community”.

One suggestion, for example, is to tackle the “high eligibility thresholds” which can prevent people with serious mental illness from accessing support in the community before reaching crisis point.

The report offers a series of recommendations for Integrated Care Systems and national bodies. But it also points to missed opportunities – not least “an ever-shifting, but still widespread, disregard for the importance of addressing people’s wider social determinants of health through de-medicalised care and support”.

## Patient safety

Our first ever Patient Experience in England report covered a twelve month period from 2016 through to 2017. That was just three years after the final report of the [Mid Staffordshire Inquiry](#), and two years after the [Morecambe Bay investigation](#).

Both of those were meant to be watershed moments for patient safety. But since then, we have covered [Hyponatraemia](#), [Gosport](#), [Cwm Taf](#), [Paterson](#) and [Cumberlege](#).

Every single investigation revealed a failure to take patient experience seriously, leading to harms that in some cases affected thousands of people and persisted for years. This year, sadly, is no different.



The Ockenden report on the Shrewsbury and Telford disaster described “an NHS maternity service that failed. It failed to investigate, failed to learn and failed to improve and therefore often failed to safeguard mothers and their babies”.

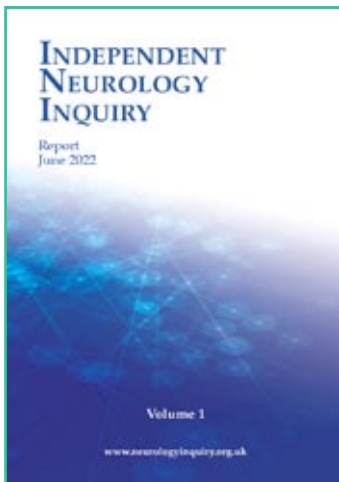
The investigation started as a review of 23 families’ cases, but it grew to include reviews of nearly 1,500 families. Ockenden pays tribute to bereaved parents who showed “an unrelenting commitment to ensuring their daughters’ short lives make a difference to the safety of maternity care”.

That unrelenting commitment was necessary because “for far too long women and families who accessed maternity care at the Trust were denied the opportunity to voice their concerns about the quality of care they had received”. Ockenden states that “So many families have explained to me that for more than two decades they have tried to raise concerns but were brushed aside, ignored and not listened to”.

The families’ efforts were further frustrated by the fact that “the maternity governance team inappropriately downgraded serious incidents to a local investigation methodology in order to avoid external scrutiny, so that the true scale of serious incidents at the Trust went unknown until this review was undertaken”.

The report, and ensuing media coverage, prompted [a response from the Royal College of Midwives](#), promising to “learn from these mistakes”. But denying patients the opportunity to voice their concerns is not a mistake. It is a decision. And downgrading incident reporting is not a mistake either. It is deliberate.

Like so many previous investigation reports, the Ockenden review makes a plea for patients: “Never again should families be left to grieve or suffer in isolation, with the additional pain of feeling their legitimate concerns are being ignored”.



The Independent Neurology Inquiry covered the events which led to the largest ever recall of patients within Northern Ireland’s healthcare system. Over 5,000 people were subject to potential misdiagnosis, mistreatment and avoidable harm at the hands of neurologist Dr. Michael Watt.

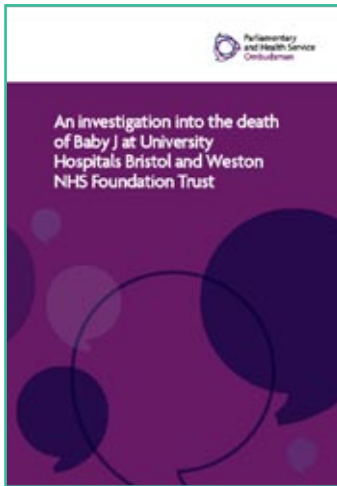
An account of events in Northern Ireland might seem out of place in this report on Patient Experience in England. But we include it because it reveals patterns of behaviour that have come out time and again in English avoidable harm inquiries, and from which the NHS as a whole needs to learn.

The case has uncomfortable echoes of the inquiry into the rogue breast surgeon (now jailed) [Ian Paterson](#). Except that like Paterson, Dr. Watt was not ‘rogue’. He was acting in plain sight, not least because patients were reporting their concerns.

The report makes the point that ‘The failure to learn from complaints was one of the more disturbing aspects of the investigation conducted by this Inquiry. Time after time, information was raised in a patient complaint, which needed to be independently investigated. Consistently the answer given to the complainant was obtuse and unhelpful’.

As well as the tone of responses to complainants, the inquiry found flaws in the processes for handling complaints: ‘there was no consistent method of dealing with clinical complaints... the approach was focused on responding within stipulated time periods and ‘resolving’ complaints’. The result was that ‘the opportunity for learning from complaints often seems to have been missed’.

The Inquiry Panel commends ‘the determination of the patients of Dr Watt to ensure that issues were properly investigated and that lessons will be learned from this Inquiry’. But it also states that ‘Patients are not, and cannot be, responsible for the safety of the health system. That sits with those responsible for governing the system’.



This report takes us from large scale harm to a single death – of a baby (called Baby J in this report) in the care of the NHS in Bristol.

Instead of comforting the parents and explaining what went wrong, staff at the hospital made things worse:

- “The Trust’s staff were not open and honest with Mr and Mrs N about the events surrounding J’s death as they should have been.”
  - “Immediately after J’s death doctors failed to give Mr and Mrs N important information they needed.”
  - “Doctors [said] they had done tests which were negative, when those tests had not been done.”
- “staff talked about deleting a recording made during one meeting while Mr and Mrs N were out of the room, because it might get the Trust into difficulty.”

The Ombudsman finds that “Mr N and his wife suffered serious injustice in... the way the Trust responded to their questions after J died and in its handling of their complaints”.

## Complaints and self advocacy

Last year’s [Patient Experience in England](#) overview covered the Parliamentary and Health Service Ombudsman’s “Making Complaints Count” report. It set out proposals for more consistent and responsive complaints handling, and called for a “cultural transformation... to recognise complaints as a valuable source of learning”. The following reports, published in the twelve months since, offer some pointers to improvement.



“Most patients and families submit complaints to prevent harm from occurring to others” says this paper. And from the provider perspective, complaints “are increasingly recognised as a critical source of insight for quality improvement”.

But does complaints handling actually lead to improvement? The study found four areas where “the design of national rules and policies functioned to undermine a patient-centric and improvement-focused approach to complaints”. These were as follows:

- *Muddled routes*: a “confusing landscape of routes for raising concerns” and confusion over the role of PALS (Patient Advice and Liaison Service) as against the complaints team.
- *Asymmetry*: investigative procedures “predominantly structured to judge the ‘well-foundedness’ of complaints”, with internal evidence regarded as superior.
- *False information*: the KO41a official complaints data collection system seen as inappropriate, or even as a source of “false information”.
- *Adverse incentives*: performance targets leading to pressure not to exceed response timelines, or creating adverse incentives such as a focus on reducing complaints volumes.

The authors emphasise that procedural problems like these are not necessarily “a consequence of sinister or malign organisational actors seeking to impose silence”. Instead, they can be seen as a case of “well-intentioned staff confined by an overly formalised and bureaucratic system”.

The paper finishes with recommendations for change, including patient involvement in complaints investigations, the establishment of independent investigation bodies, and more meaningful data analysis.



This paper takes a similar view: “Mechanisms for raising complaints and concerns often disappoint those who use them, or fail to produce a resolution that meets their expectations”.

The authors point to one cause of difficulty: the fact that complaints come from highly personalised experiences and motivations, but are met by complaints procedures “oriented towards organisational objectives”. Another way to describe this is as a difference between “communicative rationality” and “functional rationality”.

Communicative rationality is what happens when people engage in deliberation, constructive disagreement, and negotiated consensus. Functional rationality, however, “belongs in the domain of the System”. It enables people to work towards organisational objectives that have already been established, and are not up for negotiation.

Straightforward concerns about uncontroversial matters can be well served by functional pathways. But many patient concerns are more complex - and when complex concerns are channelled into predetermined pathways, they can become “stripped of meaning”. The overriding goal is “packaging them in a form that could be processed”. Ultimately, “the collection of patient experience data... can become estranged from understanding patient experience itself, preoccupied instead with processing data for its own sake”.

The authors do not suggest that existing functionally rational processes should be jettisoned. But they do suggest a greater role for communicative rationality, via processes that can allow for a more sense-making response. This could “ensure that wider considerations were deliberated, rather than being discarded by functionally rational processes that had no means of addressing them”.



Complaints can be seen as a form of “self advocacy” by patients. But they are of course reactive, with concerns being raised after an error has occurred.

This study reviewed ten years’ worth of patient safety incident reports from the National Reporting and Learning System, and looked at self advocacy as a proactive safeguard. Findings included the following:

*Patient trajectory* was characterised by a 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* featured problems such as diagnostic error, often because the system relies on the most junior (and inexperienced) doctors seeing patients first.

*Management of care* created a higher risk of patient safety incidents when there were multiple handovers between teams, and transfers between wards.

The researchers found a system largely dependent 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”. This points, say the authors, to “the necessity of self-advocacy from patients as a safety net”.



Self advocacy might be necessary - but it can be difficult within hospital cultures that deter it.

This study found that when patient need exceeds labour resources (ie at a time of workforce shortages), medical care tends to be prioritised, with a corresponding reduction of ‘fundamental care’ (personal cleansing, dressing, toileting, eating and drinking etc). In spite of this, “patients can be reluctant to ask for care for fear of being labelled difficult”.

Patients interviewed for the study talked about “staying out of trouble” and “not wanting to make a nuisance” or “pester staff”.

They tended to keep an eye on nursing staff to decide whether and how to ask for help with their fundamental care needs.

In some cases, “they would wait to make fundamental care requests... waiting until the next shift if necessary”. But sometimes “they stopped asking for care because they felt it would not be given”.

The study notes that “patients who were most in need of physical support and patients with cognitive impairments experienced serious omissions of care”. And it finishes by stating that unless nursing staff can maintain an “engaged” interaction with patients, the idea of “patient involvement in hospital care decisions will remain at the level of rhetoric”.



## Drug companies

Partnership between patients and drug companies is vital. The [First Do No Harm](#) report on Valproate, Primodos and mesh showed just how badly things can go wrong when the patient voice goes unheard by providers of medicines and medical devices. But there have to be rules governing relationships between patients and providers - particularly when money is changing hands. These reports show why that matters.



This Australian paper references a Finnish study showing that 71% of 55 surveyed groups received pharmaceutical company money and a study of US patient groups showing that 83% received funding from drug, device and biotechnology companies.

The consequences can be troubling - for example, “patient groups in the USA that advocated to maintain ready public access to opioids were more likely to be funded by opioid manufacturers than groups that advocated for restricted access”.

Study participants described “pressure from pharmaceutical company funders to act in ways that prioritise company interests over their group’s interests”. This kind of pressure might not always be visible: “Ways of declaring industry funding were variable, sometimes inadequate. In particular, there was an over-reliance on industry declarations, which may be hard to find, lacking detail or absent altogether”.

Further risks included “sponsor exclusivity, brand marketing, agenda setting, advocacy partnerships and content of patient group communications and events”. On these, the authors “identified variation between patient groups in where they drew the line between acceptable and unacceptable practices”.

All of this, say the authors, “is part of the increasingly recognised link between industry sponsorship of healthcare stakeholders and outcomes that favour the sponsor’s interests”. This, they say, is “a pattern that is being repeated across clinical practice, medical education, guideline development and medical research”. There is “urgency about identifying and managing financial conflicts of interests in the health sector in order to protect the public’s interests, including their health”.



This paper brings the issue closer to home – looking at how the pharmaceutical industry – and the organisations it funds – interact with Parliament to form part of a multi-layered web of influence. It concentrates on All Party Parliamentary Groups (APPGs), stating that “These informal cross-party groups revolve around a particular topic and... facilitate engagement between parliamentarians and external organisations”. There are concerns that “some corporate interests exploit the unique opportunities for access offered by APPGs, turning them into a backchannel for lobbying”.

The study looked at financial reports between 2012-2018 from 146 health-related APPGs, finding that payments from external donors totalled £7.3 million. Of this, it says, the pharmaceutical industry and industry-funded patient organisations provided a total of £2.2 million.

The authors state that their study “shows pharmaceutical industry funding at the upstream stages of the policy process”. Moreover, “pharmaceutical companies are not required to disclose these payments at all and are therefore missing from Disclosure UK, a transparency initiative”.

The authors conclude that APPGs “must go further in ensuring that the public to which they are accountable are fully aware of who funds them, why, and the impact”. Furthermore, “Making this information easily accessible in one place is crucial given the frequent role of industry funded patient organisations in APPG activities, evidenced by their numerous in-kind payments, and the risk that the patient voice might speak with a ‘pharma accent’ when involved in policy discussions”.

## Digital

Last autumn, [Health Secretary Sajid Javid told MPs](#) it was “high time” GPs offered in-person appointments to anyone who wants one – claiming life was “almost back to completely normal”.

The ensuing war of words drew in the British Medical Association, the Royal College of GPs and various sections of the media. But what do patients think?



This study from the Health Foundation looked at 7.5 million patient-initiated requests for primary care made using the askmyGP online consultation system at 146 general practices in England. Their findings challenge some basic assumptions about patient preferences.

A key finding was that only a minority of patients at the practices in this study requested a face-to-face consultation. Importantly, this was true even before the pandemic.

Unsurprisingly, Covid then accelerated online requests – from 60% in June 2019 up to 72% during 2021. And patients asking about new medical problems were twice as likely to contact the practice online as those asking about an existing medical problem.

The study also found that the proportion of requests indicating a preference for face-to-face dipped from an average of 29.7% before the pandemic to less than 4% at the start of the pandemic. It steadily recovered after that but was only at 10% by the end of the study period in September 2021.

The authors conclude that “simple numerical targets on the use of remote vs face-to-face consultations would be inappropriate, and a more holistic view should be taken”.



This paper turns its attention to the question of patient access to online health records. It starts with a simple statement: “The general practitioner (GP) contract in England states all patients should have online access to their full primary care record”.

Once again, however, some basic assumptions could be getting in the way. Clinicians worry that online records access (ORA) could cause unnecessary anxiety, increase complaints and threaten confidentiality. There are also fears of widening health inequalities and increased clinician workload.

Against that background, this study asked what patients want. It found four main themes:

- **Awareness:** Study participants felt ORA was poorly advertised, and suggested promoting it via media advertisements, posters in surgeries and during GP consultations.
- **Capabilities:** ORA enabled patients to view test results, medication lists, appointment details, and consultation notes. But participants wanted better presentation, including plain English, links to trusted sources of information, and access via one fully integrated system.
- **Consequences:** Some felt that ORA could improve safety by reducing the likelihood that test results would go unnoticed, or enabling them to spot errors in their record. However, others feared safety risks such as unreliable self-diagnosis, self-medication or discouraging clinicians from documenting concerns about mental health or abuse, for fear of upsetting patients.
- **Inevitability:** While there was some resistance to the move towards online services, there was an acknowledgement that much personal data is already held online - for example in the postal system, aviation and online banking.

The authors note further potential for online records access, taking in links with wearable devices, ordering of repeat prescriptions, and the ability to choose between remote and face to face appointments. And they conclude that “If we are to meet patient expectations regarding ORA, we need to go beyond simply enabling patients to view information”.



This paper asks what patients do not want from digital healthcare. It sheds light on the willingness or otherwise of older people using health-related apps to share their self-collected data.

It found increasing use of smartphones and tablets by over 65’s - showing that many older adults have the tools to use health-related apps. But in spite of having the capability, levels of interest in health-related apps are lower among older people. One barrier could be the willingness of older adults to share self-collected health-related data. It found that a considerable number of older adults were willing to share data - but more so with doctors or hospitals than research institutions or health insurance companies.

People who already used health-related apps were more open to sharing their data, as were people with a higher interest in technology, a higher income, and a higher education.

The authors suggest that given the potential for health apps to improve health and behavioural outcomes, there should be efforts to increase health app use among older adults. However, they warn that discussions need to be held around the practicalities of data sharing, as well as around legal, ethical, social, and technical matters. These discussions should include issues such as informed consent, data privacy, data security, and data ownership.



Concerns about data sharing could be justified, according to this report.

It finds growing evidence of “data-related harms, such that certain groups face particular threats from...data sharing within administrative, health, welfare, and/or social care systems, including, but not limited to, intensification of discrimination”.

Concerns were most acute for asylum seekers, those experiencing domestic violence, transgender people, offenders, and ex-offenders. The authors remark that “those who are vulnerable to the greatest potential harms and discrimination

from data-sharing are already those in society who are most marginalized and disadvantaged”.

The authors are careful to balance their assessment: “This is not to say that people with vulnerabilities do not see the potential benefits to be had in terms of improved direct care”. But the question of control remains: “...even those who have the most positive views of data-sharing do not want others to have unfettered access to data in their NHS records”.

The paper suggests that “public engagement work should not be so focused on majoritarian perspectives that it ignores the concerns about potential harms for vulnerable groups. Public engagement can be enriched by careful consideration of the wider context that surrounds the topic of interest and the wider lives of those with whom we seek to engage”.



Issues of power and control are explored further in this paper, which considers how patients have been increasing their adoption of online platforms as a means of giving feedback to providers. With the emergence of the “digital health citizen”, the authors detect a shift in what they call “surveillance”.

At heart is the question of who is examining whom. Traditionally, the “clinical gaze” has been turned by healthcare professionals on patients. Bodies and minds are the subjects of research, physical examination, diagnosis and discussion. But according to the paper, “the gaze is turning, not simply from the patient to the health-care provider, but additionally to the body politic of the NHS”.

This can be uncomfortable for healthcare staff. The paper refers to professionals who “almost universally spoke about the negative feelings online patient feedback elicited in them. This is in spite of evidence showing that most online feedback is positive”. Other staff were dismissive. By “not engaging with online feedback, staff retained control over... their own account of what good care looked like”.

A further response was to “take control” - for example by directing patients to leave feedback on “legitimate platforms” such as NHS Choices; developing a social media strategy; and designating a staff member with responsibility for managing patient feedback. But however staff choose to respond, the fact remains that clinicians’ examination of patients is increasingly being matched by patients’ examination of clinicians - and of healthcare as a whole.

The authors describe the way that online feedback can be used to air issues that healthcare professionals might feel unable to speak openly about. Examples are waiting times to get an appointment, triaging by reception staff, problems with prescriptions - things that are “indicative of a system straining from years of underinvestment, staff recruitment challenges and increasing workload demands”.

The paper finds that “online review and rating sites, then, are undoubtedly a form of surveillance”. So it is important to remain attentive to how they shift knowledge and power relationships and, potentially, turn the observers into the observed.

## 4. About the Patient Experience Library

We are the national evidence base for patient experience and patient/public involvement, holding tens of thousands of 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 tracker](#) and more.

Contact us ([info@patientlibrary.net](mailto: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](#)

### **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.

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

The title and content of this publication © Glenstall IT, September 2022.

The Patient Experience Library is provided by Glenstall IT, 28 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"> <li>• Adult inpatients</li> <li>• Children and young people (includes views from parents and carers)</li> <li>• Community mental health services</li> <li>• Maternity services</li> <li>• Urgent and emergency care</li> </ul> NHS England patient surveys for: <ul style="list-style-type: none"> <li>• GP practices</li> <li>• Cancer services</li> </ul> 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 NHS.UK reviews
5. Other (local)	Feedback gathered via complaints and compliments, Patient Participation Groups, patient engagement committees and forums etc.	NHS providers and commissioners

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 Experience	719,137
Adult Inpatient Survey	73,015
Cancer Patient Experience	59,352
Urgent and Emergency Care Survey	Type 1 services: 41,206 Type 3 services: 7,424
Children and Young People	27,374
Maternity Survey	23,479
Community Mental Health	17,322
Coronavirus Inpatient Survey	10,336
British Social Attitudes Survey	3,112

In addition:

- Healthwatch England's [2020/21 annual report](#) states that the Healthwatch network supported more than two million people to have their say on care and get the right advice.
- The NHS England Friends and Family Test hears from very large numbers of people every month. In June 2022 there were [737,871 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 2021 and July 2022, we uploaded 3,718 reports to the Patient Experience Library. Some had been published in previous years - the total published between August 2021 and July 2022 was 2,184.