

Patient Experience in England

# The Patient

MUST BE

*First*



IN EVERYTHING

THAT IS DONE

The Francis Inquiry: Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry

# Foreword



I was surprised and pleased to be asked to write the foreword to this report. At this time, however, I feel that I cannot write it without recognising two terrible crises.

The first is the awful tragedy of the Countess of Chester Hospital murders. The second is the worsening pressures faced by the health and care system, leading to extended waiting times, demoralised staff and huge workforce challenges. And I fear a reduction in services such as public involvement that are not seen as core business.

In both cases, the open involvement of citizens, patients and carers is essential to ensuring that quality and safety are maintained. Sadly, precisely the opposite is happening. Funding for Healthwatch is now lower than it was when the LINK network was abolished over ten years ago! (p34) And too often involvement activity is reduced to simple quantitative transactions.

Every month the government publishes its Friends and Family Test data with massive returns – almost **1.5m people responded in June!** Most people are positive about NHS services – but, as Ibsen said ‘the majority is always wrong’. Hiding within the FFT data will be people who have had a terrible service from the NHS – yet the monthly return allows the government to say ‘look – the NHS is safe in our hands’!

Instead of limited transactional tools such as the FFT, NHS organisations should build relationships with citizens, and enable ongoing discussions that are appropriately held in public. This might help to avoid what happened at Chester, where concerns were raised but were never properly addressed.

There are plenty of great examples already in existence – here are some that I know about:

- Care Opinion provides a platform for people to relate their experience of using services – and makes it easier for health providers to respond. It is in public, which motivates managers and clinicians to engage. [Read my personal account of using it here.](#)
- Dr Amir Hannan replaced Shipman at his practice. Conscious that he needed to rebuild trust, he pioneered giving all patients access to their records – well before it was seen as recommended practice.
- The Birley Practice in Sheffield has a Facebook page where registered patients can leave comments. Despite initial concerns this has strengthened relationships with patients.
- Freedom of Information Requests need to be used wisely. But they can be very powerful because they – and the responses – can be made in public.

Too often mechanisms for capturing public experience are seen as stand alone services, yet a strategic approach that utilises a range of these can help staff feel more confident about sharing concerns and promoting quality. At this time, meaningful relationships with the public have never been more important.

**Professor Mark Gamsu, Leeds Beckett University**

# Contents

<b>Foreword</b> .....	<b>2</b>
<b>1. Introduction</b> .....	<b>4</b>
<b>2. What we learned in the last year: Surveys</b> .....	<b>5</b>
<b>2.1 Experience of health and care services</b> .....	<b>6</b>
2022 Adult Inpatient Survey .....	6
2022 Cancer Patient Experience Survey.....	7
2022 Community Mental Health Survey.....	8
2023 GP Patient Survey.....	9
2022 Maternity Survey .....	10
Together for the 1 in 6: UK Findings from My Neuro Survey .....	11
2021 Under 16’s Cancer Patient Experience Survey.....	12
2022 Urgent and emergency care survey .....	13
<b>2.2 Public attitudes</b> .....	<b>14</b>
British Social Attitudes Survey .....	14
Public perceptions of the NHS.....	15
Systems research: 4,000 voices.....	16
<b>3. What we learned from research</b> .....	<b>17</b>
Hearing from patients and public.....	17
Waiting list challenges .....	20
Patient safety .....	21
Learning and candour .....	24
Involvement in research .....	27
Digital healthcare.....	29
Engagement and misinformation.....	31
Follow the money .....	34
<b>4. About the Patient Experience Library</b> .....	<b>36</b>
<b>Appendices</b> .....	<b>37</b>
<b>A.1 Sources of evidence</b> .....	<b>37</b>
<b>A.2 Quantity of evidence</b> .....	<b>38</b>
A.2.1 The number of people contributing to national surveys.....	38
A2.2 The number of published reports .....	
on patient experience .....	39

## Acknowledgements

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

### They are...

Our magazine contributors:

Mark Gamsu

Bettina Ryll

Gill Phillips

Liza Morton

Charlotte Augst

Andrea Downing

Maddie

Karl Roberts

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

Caroline Angel, Eastern Academic Health Science Network

Dr. Rebecca Baines, University of Plymouth

Beth Banfield, Health Foundation

Rachel Crook, Midlands Partnership University NHS Foundation Trust

Elena Fabbrani, Royal College of Anaesthetists

Laila Hallam Health Consumer Leader

Heather Hickman, Care Quality Commission

Rachael Hinton, BMJ

Sorcha McPhillips, Huntington’s Disease Association, Northern Ireland

Helen Oliver, Eastern Academic Health Science Network

Clare Price-Dowd, NHS Leadership Academy

Karl Roberts, NHS Leadership Academy

Sue Robins, Bird Comm

Seb Stevens, Apollo Health Innovations

Saul Stevens, Apollo Health Innovations

Nicole Thomas, University of Plymouth

And last but not least, everyone who reads and comments on our newsletter and quarterly magazine, and who engages with us via Twitter. Thank you!

# 1. Introduction



As the autumn begins, it is time once again to bring you our annual overview of research into people's experiences in healthcare. We summarise a swathe of national patient surveys, and then take a themed look at our top picks from wider evidence gathering - both via academic research and from community-based organisations.

In a health and social care system buckling under multiple pressures, it will come as no surprise to find that patients, too, are struggling.

Satisfaction with GP services is down to its lowest level for six years. In Urgent and Emergency care, survey results are worse than in all previous surveys back to 2016. The British Social Attitudes Survey found that overall satisfaction with the NHS is at the lowest level since the survey began in 1983.

On the plus side, there remains widespread public support for the founding principle of the NHS. In the British Social Attitudes Survey, 93% agreed that the NHS should be free of charge when you need it, and 82% said the NHS should primarily be funded through taxes.

Wider research covers topics such as waiting list challenges, patient safety and digital healthcare. But in a sign of the times, we also have a section on engagement and misinformation. Public attitudes these days are shaped as much by "fake news" as by reliable information sources - and as the research indicates, professional attitudes can also succumb.

Our final section covers financial matters, including the fact that the local Healthwatch network now receives less funding than its predecessor (the Local Involvement Network) did over ten years ago. Healthwatch, in the wake of the Mid Staffordshire disaster, was meant to strengthen patient voice. Financially, however, it has been weakened. In a healthcare system beset with difficulties, that does not seem like good policy.

*Miles*

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

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

Here, we take a look through national surveys and polling among patients and public from the last twelve months.

We offer summaries of key findings from each survey - for full details, click on the report pictures. Some of the surveys also produce ratings and benchmark reports for NHS Trusts. To search those by Trust, please use our open access [surveys tracker](#).

## 2.1 Experience of health and care services



### 2022 Adult Inpatient Survey

Published: September 2023

The results indicate that that people's experiences of inpatient care have worsened since 2020.

There are some positive findings - for example, trust remains high, with 81% and 79% saying they 'always' had confidence and trust in doctors and nurses respectively. Further, 82% of respondents felt they were treated with dignity and respect - similar to 2021.

In other areas, downward trends continue, but have slowed. When people asked doctors and nurses questions, 72% and 73% respectively 'always' got answers they could understand. This is a decline from 2021, but less so than the decline between between 2021 and 2020. In respect of involvement with decisions about their care, the proportion of those feeling very involved has decreased since 2021 (down from 35%) but this is a smaller decrease than between 2021 and 2020 (35% down from 38%).

Waiting times are highlighted as an area for improvement. 22% of elective patients would have liked to have been admitted 'a bit sooner' and 17% 'a lot sooner' (compared with 20% and 16% respectively in 2021), and 41% said their health deteriorated while waiting to be admitted to hospital, though half (50%) said their health remained the same.

Hospital discharge, as always, is a concern. 38% of respondents had been involved 'a great deal' in decisions about their discharge, but a quarter (25%) said they had little to no involvement, and 8% said they were 'not at all' involved. Less than half (48%) of respondents were given enough notice about when they were going to leave hospital (50% in 2021), and only 45% 'definitely' knew what would happen next with their care after leaving hospital (consistent with 2021). Respondents who 'definitely' got enough support from health and social care services after leaving hospital, remains at 46%.

Cleanliness from the point of view of patients has declined, with 70% describing the hospital room or ward they were in as 'very clean', down from 74% in 2021.

The proportion of respondents rating their overall experience of inpatient care highly has decreased, with half (50%) rating their experience as a 9 or 10 (where 10 is a very good experience) compared with 52% in 2021 and 56% in 2020.

## 2022 Cancer Patient Experience Survey

Published July 2023



In a change from previous years, the 2022 Cancer Patient Experience Survey offered no qualitative analysis. We are given to understand that qualitative reports may in future be published biennially rather than annually.

From the quantitative analysis, we can glean the following:

Patients' overall experience of care was good, with an average of 8.88 (where the best possible score was 10), similar to the rating of 8.91 in the 2021 survey.

Contact with the care team was good. 91.5% of respondents said they had a main contact person to support them through treatment, and 78.6% of people who had an overnight stay in hospital said they had confidence and trust in the team looking after them.

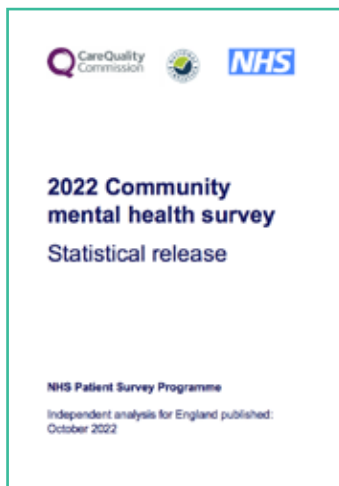
Communications with GP practices were less good. Just under two thirds of respondents (65.4%) who had contacted their GP practice said that the referral for diagnosis was easy to understand. And less than half (44.7%) said they got the right amount of support from staff at their GP practice during treatment.

Most people (86.7%) said the administration of their care was good, and just over three quarters (75.9%) had been given the option of having a family member, carer or friend with them when they were first told they had cancer.

There is, perhaps, room for improvement in the follow-up to treatment. Fewer than two thirds (62.4%) of survey respondents were given enough information about the possibility of the cancer coming back or spreading. Even fewer (59%) "definitely understood" possible long-term side effects.

## 2022 Community Mental Health Survey

Published October 2022



As in previous years, the survey reveals that people's experiences of mental health services provided in the community remain poor. Many of the areas with the poorest historical results were still the worst in 2022.

Access to care has seen a significant decline since 2014, with a decrease of 11 percentage points in the number of people who were 'definitely' given enough time to discuss their needs and treatment. Similarly, there has been a decrease of eight percentage points in the number of people who have 'definitely' seen NHS mental health services enough for their needs.

40% did not have a care review meeting in the last 12 months. Under half (48%) reported that the person they saw was 'completely' aware of their treatment history. Almost a third (31%) had not been told who was in charge of their care.

In terms of crisis care, over a quarter of survey respondents (28%) would not know who to contact out of office hours in the NHS if they had a crisis. Almost a quarter of people did not get the help they needed (22%). One in five (19%) felt they had to wait too long to get through to a crisis worker or team.

In questions on support and wellbeing, 40% said they did not receive support for their physical health needs. Just over half did not receive help or advice in finding support for their finances or benefits (51%) or in finding/keeping work (50%). Only half (50%) of respondents said that the person they saw 'definitely' understood how their mental health affected other areas of their lives.

On involvement, 44% 'definitely' agreed what care they would receive. Around half (51%) were involved as much as they wanted to be in deciding which NHS talking therapies to use.

For medicines, a quarter of people (25%) said that the possible side effects of their medicines had never been discussed with them. Further to this, 25% of people answered 'no' when asked if an NHS mental health worker had checked in with them about how they are getting on with their medicines in the last 12 months.



## 2023 GP Patient Survey

Published July 2023



The proportion of patients reporting a good overall experience of their GP practice decreased to its lowest level for six years, at 71.3%.

Female patients reported the most positive overall experience. Older people reported a more positive overall experience than younger patients. Among ethnic groups, patients from African and Caribbean groups reported a more positive overall

experience, while patients from Bangladeshi and Pakistani backgrounds reported the least positive overall experience.

Just under half (49.8%) of patients said it was easy to get through to their GP practice on the phone. This is lower than all previous years since the question was introduced in 2012.

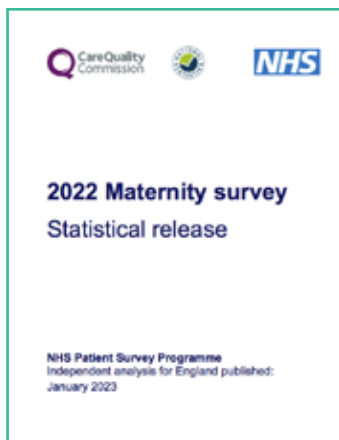
After a series of increases in recent years, online contact with practices dropped slightly from 55.1% in 2022 to 53.5% in 2023. The most common use was for repeat prescriptions (32.9%). The proportion of patients who reported accessing their medical records online increased slightly from 16.5% in 2022 to 17.1% in 2023. The use of GP practice websites for information or to access services was static, at just over 60% in both 2022 and 2023, but over a third of survey respondents (35.2%) did not find their GP practice's website easy to use.

The proportion of patients reporting a good overall experience of making an appointment decreased to its lowest level for six years (54.4%). Satisfaction with appointment times also dropped to the lowest for six years (52.8%). Just over half of survey respondents (51.4%) had avoided making a general practice appointment - a slight improvement from the 2022 figure of 55.4%. As with the 2022 findings, the most common reason for patients avoiding making an appointment was because they found it too difficult (27.9%).

Of those who got appointments, 83.6% said that the healthcare professional was good at giving them enough time, and 85% said the healthcare professional was good at listening to them (85.0%). 93.0% had confidence and trust in the healthcare professional they saw at their last appointment, and 91% felt that their needs were met.

## 2022 Maternity Survey

Published January 2023



Survey respondents indicated improvement to service quality in a number of areas. These included the following:

- 44% were definitely given enough information about coronavirus restrictions and any implications for their care. This compares with 37% in 2021.
- 52% were given enough information to help them decide where to have their baby. This is up from 47% in 2021.
- Hospital discharge has improved, with 62% reporting no delays – a steady rise since the 2017 figure of 55%.

Mental health support is also improving: 71% of respondents were “definitely” asked about their mental health during antenatal check-ups, as against 69% in 2021. 85% were given enough mental health support during their pregnancy (83% in 2021). And in terms of postnatal care, 96% were asked about mental health – up from 95% in 2021.

On the downside, just over two thirds of survey respondents (69%) were ‘always’ given the help they needed during antenatal care, down from nearly three quarters (74%) in 2017. During labour and birth, less than two thirds (63%) were ‘always’ able to get a member of staff when they needed attention, and only 57% were ‘always’ able to get help with care in hospital after the birth. Postnatally, 70% were ‘always’ given the help they needed when contacting a midwifery or health visiting team, down from 73% in 2021.

Relational aspects of care also appear to be faltering, with just over two-thirds (69%) of respondents ‘definitely’ having confidence and trust in the staff delivering their antenatal care. Results for staff involved in labour and birth were at 78% – down from 82% in 2017. Postnatally, 71% ‘definitely’ had confidence and trust in the midwifery team, against 73% in 2017.

As far as communications are concerned, 82% said they were given appropriate advice and support at the start of their labour, down from 87% in 2017. 77% said concerns raised during labour and birth were taken seriously, down from 81% in 2017. For information and explanations on care in hospital, there has been a downward trend since 2017, from 66% to 59%.

The involvement of partners can help with communications and relationships, but here, less than half (41%) said their partner or someone else close to them was able to stay with them as much as they wanted during their stay in hospital. Although an increase compared with 34% in 2021, results are still well below pre-pandemic levels (74% in 2019).

## Together for the 1 in 6: UK Findings from My Neuro Survey

Published October 2022



This is the latest in the Neurological Alliance's periodic surveys of the experiences of people with neurological conditions. For the first time ever, the survey was run right across the UK, generating more than 8,500 responses.

A common theme is long waiting times, with more than a third waiting more than a year between first experiencing symptoms and getting a diagnosis. A further 1 in 5 waited more than 12 months between first seeing a GP and seeing a neurologist.

Information provision was patchy, with some patients receiving written information produced by the NHS, and others being signposted to information from charities or patient group websites. One third of children and young people reported receiving no information, and 38% of adults said the same.

More broadly, respondents indicated that they weren't always being offered the services they believed could help them to live independently and minimise symptoms. Many said that they were aware of service limitations in their region, such as a lack of neuropsychiatrists, which meant they were not able to get the support they need.

Nearly 7 out of 10 adults said that their mental wellbeing needs are being met to a small extent or not at all. More than a third of children and young people said their mental health needs weren't being met at all. When people can access mental health support they often say it has a positive impact - 61% of adults who received support said it made them feel better/more positive.

The report concludes that significant gaps remain in access to the right treatment, care and support for far too many people with neurological conditions across the UK. The right information at diagnosis, the right support for mental health and wellbeing, and timely specialist support are too hard to access for many. In some cases, opportunities to slow or stop progression of a condition, to avoid harm to themselves or others and to maintain financial wellbeing are being missed - and with catastrophic consequences.

## 2021 Under 16's Cancer Patient Experience Survey

Published November 2022



This was the second year of this annual survey. It is still at a relatively early point in its evolution, and it is not therefore possible to make reliable comparisons between years. For the 2021 results, thematic analysis revealed the following:

Positive experiences included empathy and kindness from staff, along with examples of good communication. Against this was a sense of feeling unheard by some staff, and a perceived need for staff training to better support children with additional needs.

Delays were a cause of distress and frustration at various points along care pathways. There was a perception of understaffing in hospitals, with specific references to a need to improve access to Cancer Nurse Specialists, named consultants and play specialists. Access to care during weekends and holidays was also mentioned, along with frustration that access to a ward when needed should not be via A&E.

Poor communications included those between and within hospitals and care teams. There were concerns about appointment letters and notices. And there were communication needs unmet in understanding treatment decisions; understanding the reasons for treatment delays; and in discussing treatment holistically as opposed to 'in segments.'

Further unmet needs included inpatient activities and entertainment, as well as sleep and quality and choice of food. There were additional concerns with aftercare, mental health support and financial support.

On "wider hospital issues", there was feedback about unacceptable hygiene and cleanliness on wards, plus comments about a need for updates, e.g. to décor. Mentions were also made of Covid-19 visitor restrictions, although during fieldwork for the survey, such restrictions had begun to ease.

## 2022 Urgent and emergency care survey

Published July 2023



“Compared with earlier surveys (back to 2016)”, says the independent analysis for this survey, “results show that people’s experiences of urgent and emergency care are worse than in previous years”. This is true for both Type 1 (major A&E) and Type 3 (urgent treatment centre) services.

Waiting times have worsened, particularly in Type 1 services, where 32% of respondents waited more than an hour to speak to a doctor or nurse compared with 15% in 2020. Also in Type 1, 17% said they waited more than 4 hours to be examined, compared with 4% in 2020. The proportion of patients who were not able to get help with their condition or symptoms while waiting increased from 45% in 2020 to 56% in 2022.

In Type 1 services, less than half (45%) of patients felt they ‘definitely’ had enough privacy when discussing their condition with the receptionist, compared with 55% in 2020. For Type 3 services, the figure declined from 59% in 2020 to 49% in 2022.

Just over half (51%) of people using Type 1 services said staff ‘definitely’ did everything they could to control their pain (down from 60% in 2020). For Type 3, 58% said this compared with 63% in 2020.

For Type 1 services, 71% ‘definitely’ had confidence and trust in doctors and nurses, compared with 77% in 2020. 72% were treated with dignity and respect all of the time compared with 81% in 2020. Two-thirds (66%) had enough time to discuss their condition with a doctor or nurse, down from 74% in 2020.

Only 40% of Type 1 patients who were prescribed medication, were ‘completely’ told about side effects. 51% were ‘definitely’ given enough information to care for their condition at home compared with 60% in 2020.

For Type 3 services, 65% of patients were ‘definitely’ given enough information to care for their condition at home, compared with 70% in 2020. When asked if the care and support they expected was available when they needed it after leaving hospital, 65% of respondents using Type 1 services said it was as against 75% in 2020.

## 2.2 Public attitudes



### British Social Attitudes Survey

Published March 2023

This year's survey starts with bad news: overall satisfaction with the NHS is at the lowest level since the survey began in 1983. Over half of respondents (51%) were dissatisfied with the NHS, and the fall in satisfaction was seen across all ages, income groups, sexes and supporters of different political parties.

The main causes of unhappiness were waiting times for GP and hospital appointments (69%), staff shortages (55%) and a view that the government does not spend enough money on the NHS (50%).

On the positive side, three quarters (74%) were pleased that NHS care is free at the point of use, over half (55%) appreciated the quality of NHS care, and half (49%) felt that it has a good range of services and treatments.

In social care, the picture is even worse, with only 14% of respondents feeling satisfied. Dissatisfaction with social care rose significantly in 2022, with 57% of people saying they were dissatisfied (up from 50% in 2021).

The main reasons for dissatisfaction were that people don't get all the social care they need (64%), inadequate pay, working conditions and training for social care workers (57%) and lack of support for unpaid carers (49%).

Asked about NHS finances, 83% said they thought the NHS had a major or severe funding problem. The most important priorities for the NHS were seen as increasing the number of staff (51%) and making it easier to get a GP appointment (50%). Improving waiting times for planned operations and in A&E was also seen as important (47% of respondents).

As far as basic principles were concerned, a large majority of respondents agreed that the NHS should be free of charge when you need it (93%), the NHS should primarily be funded through taxes (82%) and the NHS should be available to everyone (84%).

## Public perceptions of the NHS

Published February 2023



This report presents analysis of findings from Ipsos polling on public views of health and social care in the UK.

It finds that “people are deeply concerned about the state of the NHS”. Only a third think the NHS is providing a good service nationally, down from previous polling in 2022 and 2021. 63% think the general standard of care has deteriorated in the last 12 months, and only 9% expect standards to improve.

Across the nations of the UK, just 10% think their own national government has the right policies for the NHS.

In spite of all this, public support for the founding principles of the NHS remains, according to the Health Foundation, “rock solid”. 90% want access free at the point of delivery, 89% want a comprehensive service and 84% want the NHS funded through taxation. “Each of these principles”, says the report, “commands majority support right across the party-political spectrum”.

Asked about priorities, 39% wanted to see more staff in the NHS, 35% wanted shorter waiting times for routine tests and operations, and 31% wanted shorter waits in A&E.

The authors state that “While both main parties have so far preferred to talk about reforming the health service rather than tax rises or spending increases, 82% of the public think the NHS needs an increase in funding, including 63% of Conservative voters”.

They warn that “With just 8% of people in England convinced the UK government has the right approach to the NHS, our latest survey should ring alarm bells for the Sunak government”.



## Systems research: 4,000 voices

Published October 2022



This one-off telephone survey of people aged 65 and over aimed to provide the CQC with an understanding of older people's experience with health and social care services.

Over three quarters of respondents (78%) rated their experiences as good. Most received the care they needed either completely (52%) or to some extent (29%), while 14% said their needs had not been met at all. Most were satisfied with being able to access services when they needed them (65%) and being able to access services in a way that suited them (66%). However, views were less positive on the process of making appointments (54% satisfied and 34% dissatisfied).

80% had been involved as much as they wanted to be in decisions about their care and treatment, and 82% had felt listened to when discussing their needs. 84% agreed they had been treated as a person rather than a condition.

Just over one in five people (22%) aged 65 and over are on a waiting list for health services. Of these, 37% do not feel well supported. Around one in five say that knowing that they are still on the waiting list and have not been forgotten, or knowing where they are on the waiting list or how much longer they will have to wait, would help them.

One in five people (21%) aged 65 and over receive unpaid help or support from family or close friends/neighbours because of a long-term physical or mental ill health/disability, or problems related to getting older. Ease of getting help is slightly lower among groups who could be more vulnerable due to their circumstances (e.g. being 75 or over, being disabled, being on a waiting list, or getting worse while on a waiting list).



### 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.

#### Hearing from patients and public



‘Most patients and families submit complaints to prevent harm from occurring to others’ says this paper. But does complaints handling actually lead to improvement?

Not necessarily, says this study, which found areas where ‘the design of national rules and policies functioned to undermine a patient-centric and improvement-focused approach’. These included:

- Muddled pathways, with 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, with ‘a persistent belief that complaints are subjective and subordinate to clinical perspectives and hospital data’.
- False information. Complaints administrators considered the KO41a official complaints data collection system to be inappropriate, with one describing it as supplying ‘false information’.
- Adverse incentives, with pressure not to exceed response timelines potentially creating a focus on reducing complaints volumes.

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 ‘well-intentioned staff confined by an overly formalised and bureaucratic system’.



Part of the answer must be increased openness and as this paper says, 'Openness, transparency and candour are recognised as ethical responsibilities of health care organisations'. But, it says, 'delivering on these commitments in health care systems has often proved challenging'.

The authors highlight four necessary conditions for change:

Authentic integration into organisational mission, with openness treated as part of mainstream business, not an optional bolt-on.

Functional and effective administrative systems, including good systems for oversight of disclosure and investigation processes, rapid dissemination of learning, and integration of organisational intelligence about concerns and risks.

Flexibility and sensitivity in implementation. Both staff and patients were unhappy with 'coldly efficient systems' that appeared to serve the system rather than helping those who had been harmed. Doing openness well required judgement, flexibility, and the occasional workaround - and permission from management to work this way.

Continuous inquiry, learning and improvement, based on an organisational ethic of reflection, learning and improvement, with sometimes 'protracted and dogged efforts' to do better.

The paper also notes four persistent challenges that hamper progress towards openness: reliance on staff goodwill to take on extra tasks; lack of care for staff and patients who have the courage to speak up; too much reliance on 'values-driven' approaches, with a reluctance to tackle recalcitrant staff; and a tendency to see patients and families as bit-part players, rather than as having a crucial role.



This study uses the analogy of performance, in which healthcare staff are "actors" who work "backstage" on script development and rehearsals for handling feedback, before going "frontstage" to display their public response.

The researchers looked at the responses of three NHS Trusts to the online feedback platform Care Opinion: a non-responding organisation (site A), a generic responding organisation (site B) and an organisation that provided transparent, conversational responses (site C). Comparisons included the following:

Audience interaction. Site A had 2,120 patient narratives and a response rate of 0%. Site C had 6,500 patient narratives and posted over 7,500 staff responses which had been read more than 1,787,900 times.

**Script.** Standardised scripts were used at site B, to post generic responses. Conversely, site C staff were guided by “stage directions”, encouraging conversational responding, and giving “actors” freedom to improvise.

**Spotlight.** At Site C, all patient experience information was made publicly available. Site A staff were keen to remain in the shadows, turning a blind eye to what was perceived as the “booing online crowds”. Site B were intrigued to peer onstage while taking comfort in handling responses offline and behind the scenes.

**Cast list.** At Site C, over 890 staff were able to monitor and respond to online patient feedback, in comparison to a maximum of two at sites A and B.

The paper addresses the fears felt by some organisations about having interactions in public view where “the whole world and their dog can see”. But it counters with some powerful quotes from Site C staff:

“If you’re not hearing negative feedback, it’s because it’s being said elsewhere.”

“It’s one of the strongest forms of governance... You can think, ‘Well I’ve heard this from the staff and I’m hearing this from the patients. What is this all really telling me?’”

“Two years, and nothing really happened. But when the story was placed on Care Opinion we were able to resolve it in 6 weeks.”

## Waiting list challenges



Long waits for routine treatment continue to be a central feature of patient experience within the NHS. [NHS England data](#) on waiting times is, for most people, incomprehensible which is why we continue to maintain our open access [waiting list tracker](#).

In the meantime, this paper describes how one NHS Trust reduced the waiting list of a paediatric service from 1109 to 212. Waiting times were reduced from a maximum of 36 months to a 70-day average.

The first task was to tackle administrative inefficiencies.

Clinicians lacked time to verify and cleanse waiting list data, so the list was not up to date and it was hard to know who was waiting for an appointment and who had been discharged.

Another problem was the need to gather various reports - school reports, speech and language therapy (SaLT) reports and opt-in/consent forms. Bottlenecks were arising because 'Too many people were involved in chasing too many reports'.

Cleansing the data, improving ways to verify reports, and confirming discharge status resulted in a reduction of the primary target list from 1109 to 556 children.

Alongside administrative improvements, the team took a 'compassionate communication' approach to dealing with patients.

The existing system had failed to do this for patients. As one staff member said, 'A lot of people just don't want to do the data cleansing - a lot of these children then don't get diagnosed and they get forgotten about in the system... What if that was my child?'

There was a similar problem with SaLT reports, which could only be actioned once patients or carers had submitted a formal opt-in. Many had been unaware of this, so the compassionate communication approach introduced follow-up calls to check that people wanted to opt in. Improved flow got the waiting list down to 212, with average waiting times reduced from 421 days to 70.

The approach acknowledged the situation of 'children and their parents stuck in a system of disconnected processes'. Importantly, it also acknowledged 'burden and stress on both administrative and clinical staff'.



This report notes that the NHS has a legal duty to “have regard” to reducing health inequalities, and that it has specifically committed to taking account of inequalities in how it addresses the elective care backlog.

In spite of that, analysis shows that while the number of operations and procedures fell during the Covid crisis, “the falls in activity were not uniform across the different ethnic groups”.

The “Asian group” saw the largest overall fall in the first year of the pandemic. There was a less consistent pattern for the “Black group”, who had larger rate falls than the “White group” for

cardiac and cataract procedures, but otherwise saw similar changes to the White group.

The most deprived groups in the population also experienced larger rate falls overall, and this matters because “There is a strong link between health need and deprivation, which has a disproportionate impact upon people from ethnic minorities”.

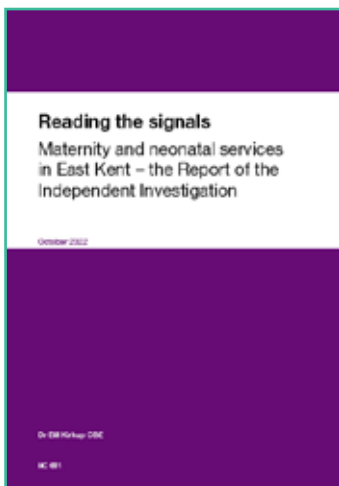
The report calls for more analysis because “Inconsistent, incorrect and incomplete coding of ethnicity in health records means that our understanding of this complex picture is limited”.

“More broadly”, says the report, “the lack of data also limits progress in understanding how to reduce health inequalities across health care - something the NHS has a legal obligation to do”. One important consequence is that “Quite simply, patchy data means that the NHS is flying blind in its attempts to meet this legal, and moral, obligation”.

## Patient safety

Last year's Patient Experience in England report covered three avoidable harm investigations: the Ockenden review of maternity harms at Shrewsbury & Telford, the Independent Neurology Inquiry in Northern Ireland, and the Parliamentary and Health Service Ombudsman's report on the death of Baby J in the care of the NHS in Bristol. All three revealed a failure to take patient feedback seriously.

This year, we have another three telling, once again, the same story.



The report on avoidable harm in maternity services at East Kent repeats the litany of avoidance and denial that we have heard so many times before. Bereaved families have had yet again to fight for justice in the teeth of a healthcare provider determined to resist them.

But there is, this time, a vitally important difference. Lead investigator Bill Kirkup says "It is too late to pretend that this is just another one-off, isolated failure, a freak event that will never happen again". There is, he says, a pattern.

The pattern of malfeasance is summed up by Kirkup as follows:

"The default response of almost every organisation subject to public scrutiny or criticism is to think first of managing its reputation... the experience of many NHS organisational failures shows that it is the whole basis of the response in many cases. Further, it has clearly led to denial, deflection, concealment and aggressive responses to challenge... Not only does this prevent learning and improvement, it is no way to treat families, who are heartlessly denied the truth about what has happened when something has obviously gone wrong".

Brilliantly, Kirkup refuses to add to the mountain of recommendations that have come out of previous inquiries and investigations. Why? Because "The answer cannot be to hope that... multiple recommendations prevent recurrences elsewhere. If that approach were the right one, it would have worked by now. It hasn't."

Instead, he points to four areas for action, one of which is "responding to challenge with honesty". That, surely, is not too much to ask. But, says Kirkup, "if we are to break the cycle of endlessly repeating supposedly one-off catastrophic failures", it is essential.



This report describes safety and quality failings in Child and Adolescent Mental Health Services (CAMHS) at the Tees, Esk and Wear Valleys NHS Foundation Trust. Issues included multiple instances of inappropriate restraint and, worst of all, the deaths of three young women.

The events occurred in a care environment in which family members and carers said they “could not safely raise concerns”, and “felt actively judged and undermined by staff”. There was “a fundamental and consistent failure to inform parents about incidents involving their children under Duty of Candour”.

The key unit – West Lane Hospital – was geographically isolated, and a closed culture developed. There was a constant turnover of staff, and tension between staff teams. Risk registers were poorly maintained. Actions, when required, lacked urgency. Staff training was inadequate. Local observation rules were inconsistent with Trust-wide policy.

The investigators state that “patients and their families (and some staff) were ignored and that their concerns and complaints are now found to be, on the whole, justified”.



Sir Brian Langstaff, Chair of the Infected Blood Inquiry, describes this interim report as “an unusual step”. It is unusual because even before the Inquiry has completed its work, it is recommending a compensation scheme for people harmed by infected blood.

The scandal has been described as “the worst treatment disaster in the history of the NHS”. People with haemophilia were particularly affected but so were many others, including 380 children with bleeding disorders who were infected with HIV. More than half have now died.

Other people were infected with Hepatitis C or Hepatitis B. The latter aggravates both Hep C and HIV, making the effects of those diseases worse. As well as losing their health, many lost their jobs. Family members have turned into carers.

Successive Secretaries of State – Andy Burnham, Jeremy Hunt, Matt Hancock – acknowledge the harm caused not just by the treatment, but by a persistent failure of response at the government level.

Sir Brian has this to say: “I cannot in conscience contribute to that further harm...This is why I am taking the unusual step of issuing one set of recommendations in advance of all others”. His recommendation? “It is time to put this right... a compensation scheme should be set up now and it should begin work this year”.



# Learning and candour

The East Kent report on avoidable deaths in maternity services revealed an organisational culture characterised by “denial, deflection, concealment and aggressive responses to challenge”, along with “bullying to such an extent that the maternity services were not safe”. But what does a good healthcare culture look like? The following reports offer some clues.



This paper points to a common thread in avoidable harm: “Failure to listen to the voices of patients and carers is a recurrent theme... and one that the system seems incapable of heeding”. It makes three key recommendations:

**Listening.** “Psychological safety – a sense among staff and patients that it is safe to speak up without fear of retaliation or being undermined – is critical.”

**Learning.** “Collating, and acting on intelligence, quantitative and qualitative.”

**Leadership.** “Making patients ‘the first and foremost consideration’ [with] an uncompromising focus on addressing cultural and behavioural problems.”



This paper, based on an evaluative study of five English NHS Trusts, brings in further considerations, including the following:

**Stability matters.** The report notes differences between one Trust, which had had the same Chief Executive since 2010, against another which had three Chief Executives in quick succession.

The framing of improvement efforts has an influence. Initiatives seen as technical exercises led by experts are unlikely to enter the “mainstream consciousness” of the organisation. But if they are seen as core to the organisation’s identity and strategic vision, they stand a much better chance.

Values are important. One of the Trusts that performed well on quality improvement had co-produced a set of values with its front-line staff. The outcome was to “put the patient and quality of care first, above that of finance”.

“Social connectedness” of staff counts. A Trust rated as outstanding by the CQC had a much higher level of social connectedness among staff than the two Trusts with the lowest CQC ratings.



The study adds that “One of the first steps on Surrey and Sussex’s improvement journey was to make sure that staff were, as Michael Wilson, the trust’s former chief executive, put it, ‘speaking well of ourselves, well of each other, well of our organisation and well of our community’. Once this becomes the norm, it becomes easier for people to have meaningful conversations about improvement”.



This paper starts from the fact that patients can be reluctant to raise safety concerns if it means challenging staff. Key to this is vulnerability: patients are dependent on, and place their trust in, healthcare staff. Fear of damaging their relationship with staff has been identified as a significant barrier to patients’ involvement.

One implication, say the authors, is the importance of relational work for patients as a way of keeping themselves safe. To demonstrate that they are ‘good patients’, they avoid being too demanding, comply with instructions, and display gratitude to staff for the care that they receive.

For patients, then, safety is about vulnerability to harm from both their health status, and from their dependence on the healthcare organisation and the professionals within it. They conduct risk work by seeking reassurance and undertaking relational work - but this can conflict with their additional need for vigilance, and double-checking aspects of their care.

“The difficulty for patients”, says the paper, “is that both options may increase their vulnerability, one from harm if trust is misplaced and another from potential damage to relationships from challenging healthcare professional expertise”.

The authors suggest that we need to rethink the idea of the ‘good patient’ - recognising and valuing vigilance alongside compliance. “Both patients and healthcare professionals”, they say, “need to recognise how their interactions co-produce safety at the point of care. Seeing safety as co-produced by patients and professionals... might allow risk work to take place without disrupting relationships”.



Mistakes in healthcare are inevitable. This study recognises that for patients, caregivers and family, the consequences of medical error can be profound, encompassing physical, emotional and psychological harm. And it notes that healthcare workers too, can feel guilt, shame and distress.

The study found that in the aftermath of harm, patients and healthcare workers have considerable common ground. “Both want to tell their stories - and to listen and be heard... both desire to learn from the experience and make sure it does not happen again”.

But there are also clear barriers: healthcare workers may be afraid of legal action, or of a psychologically unsafe culture within their organisation. Patients, for their part, can feel a sense of betrayal and mistrust, or can fear that re-opening discussion of the error might retraumatise them.

The key to unlocking a healing dialogue, say the authors, is to bring the common ground and common barriers into the open. This can help all parties to understand “how, why and under what circumstances these purposeful conversations could be most valuable and effective”. The goal, ultimately, is to “breach barriers and foster the desired outcomes of apology, understanding and learning from the experience, ultimately improving the quality and safety of healthcare”.

# Involvement in research

Patient and public involvement (PPI) in research is, these days, a given. But as these papers point out, there are still barriers to equitable participation.



This study tackles the “representativeness” of public contributors. They can get caught in a “paradox of representation” in which they are seen as either too naïve to meaningfully contribute, or too knowledgeable to represent “the average patient”.

The authors looked at how representation is conceptualised, and found an underlying “confirmation logic”. This means that “when contributor input provides confirmation of researcher work, it is drawn upon as representative of ‘the’ patient experience and not contested in terms of representation”.

When, on the other hand, contributor input seeks to change or debate researcher work, “representation is drawn upon to dismiss input”. Through this logic, say the authors, “only confirmation of the researcher’s perspective is possible”.

The point here is that judgements about the supposed representativeness of patients are not just a matter of how naïve or knowledgeable they are. It also depends on whether they are confirming or contesting professionals’ views. The paper states that “Problematically, contributors are representative as long as they agree”.

Exposing tensions like this is, according to the authors, “essential to move beyond misleading debates about representation”. And, they say, “Involving contributors themselves in these debates is both a necessity for making progress and, we suggest, an ethical responsibility”.



A similar power imbalance appears to exist in randomised trials.

Generally, around 70% of trial data relates to outcomes. However, say the authors of this paper, ‘Not all outcomes are created equal’. Trial teams (researchers), patients and healthcare professionals can all have different ideas about what matters most. But it tends to be trial teams who decide what is to be designated as the ‘primary’ outcome.

This designation matters because the primary outcome generally drives the size of the trial, and judgements as to whether the trial intervention is effective. Other outcomes are, by definition, less important.

The authors showed a series of published trials relating to breast cancer and kidney disease to patients with lived experience of those conditions, and to healthcare professionals with relevant expertise. The question was whether their view of what was most important in each trial matched the trial teams' own choice of primary outcome.

The answer was that in just 28% of cases, patients and healthcare professionals agreed with trial teams. 'Given that so much hinges on the primary outcome', says the paper, 'even our small study should give some pause'. It goes on to say that in the collective view of patients and professionals, 'trial teams got the choice of primary outcome wrong more often than they got it right'.

The authors state that 'The kindest thing that can be said about this is that it represents research waste. Less kindly, it means patients and healthcare staff have spent their time, energy, goodwill and perhaps hope on a trial that has failed to provide the key information that people like them need in order to make better treatment decisions'.

'The solution', they conclude, 'is not difficult: ask people with lived experience of an illness or condition, and their healthcare professionals, what they want to know most'.

Their prescription is not limited to trial teams: 'Funders, ethics committees and others involved in study approval have a role to play too. All should be asking to see researchers' rationale for the choice of primary and other outcomes to ensure that the choices made are the right ones'.

## Digital healthcare



**Data saves lives** says NHS England. The Ada Lovelace Institute agrees but also warns that data-driven systems can risk exacerbating existing inequalities in health.

The report looks at the pipelines of data that power health technologies. Its premise is that the ‘smooth’ data pipeline is a “hypothetical ideal that does not reflect the complexity and imperfection of reality”. In real life, it says, data pipelines are knotted, with complexities and flaws including the following:

- Inequalities can be poorly understood, described and measured.
- There can be tension between local and national priorities for design and delivery of data-driven systems.
- Datasets can be of variable quality, or incomplete, or out of date.
- Data curation involves a tension between making data digestible for busy professionals, and making it nuanced and meaningful.
- Data is a proxy for truth and reality – some people’s lived experience might be different from the numbers.
- Data that is devoid of local and historical context can lead to misinterpretation and poorly targeted interventions.

The report makes the important point that “data-driven systems are more than just the technology: they also include the people who develop, design and use these technologies – engineers, product teams, clinicians, hospital administration staff and others”. Those people risk building in inequality while designing data systems, or compounding inequality via their interpretation of the data produced by those systems.

Accordingly, there is a need to take a people-centred approach, including consideration of who is involved in decisions.



The focus of this report is technology-enabled care, or TEC for short. There are various examples of how it works in practice, including the case of “George” (a fictional persona) who has cancer. TEC can help George with pre-admissions screening, virtual appointments and remote monitoring. It can help him to manage multiple medications, and to manage his direct payments. Importantly for person-centred and holistic care, it can also help him to stay connected with family and friends who are central to his wellbeing and recovery.

So the report is clear about the benefits of TEC. But it also notes that debates on digital healthcare are often about “digitising social care, health and housing: re-engineering systems and processes”. We hear less about “technology-enabled lives, where the ambitions and aspirations of the individual come first, made possible by digital”.

The debate is “over-focused on the needs of the NHS”, with less attention paid to the benefits to social care systems and even less on the benefits to people and their communities. “To change this mindset”, say the authors, “we must amplify the voice of people with lived experience so that we deploy technology to support what they want rather than what suits the system”.

Their conclusion is that “It should go without saying that a better understanding of the needs and aspirations of people means that products and services can be developed that are more successful in meeting their needs”.



Digital healthcare is not just about hardware and apps. It is also about how patients organise and mobilise online. This article, by BMJ editor and cancer patient Tessa Richards, is a case in point.

It describes a webinar flagged by Richards’ cancer Facebook group. She admits approaching it with a degree of cynicism, anticipating an “experts talk at patients” experience. Instead, she found a conference organised and moderated by patients, where the debate was assertive, informed and supportive.

In a reversal of the standard “patients included” approach to big healthcare jamborees, this conference featured professionals who were included not by right, but because they had been hand picked and invited by the patients.

This is part of a growing trend. Patients these days are not waiting to be invited to engage. They are doing things for themselves, in online communities. Other examples are the Melanoma Patient Network of Europe, featured in [this edition](#) of our quarterly magazine (page 4), and the Light Collective, shown [here](#) (page 4).

There is a lot of talk in digital healthcare about digital exclusion. Usually the assumption is that the people at risk of exclusion are the patients. Rarely, if ever, do health professionals consider their own risk of exclusion from online debates and initiatives being run by patients.

When patients organise online, they can travel light and move fast, in ways that large healthcare institutions can’t. Health professionals need to keep up – or risk being left out.



# Engagement and misinformation



In June 2021, with both the pandemic and the vaccination roll out in full swing, a study of vaccine hesitancy in Bradford offered some interesting insights.

Misinformation was a key factor – but the study participants were not naïve victims of conspiracy theories. They had good reasons to be confused by information coming from multiple sources, to be anxious about rapid development of a new vaccine, and to be mistrustful of government.

Eighteen months on, this follow-up digs deeper.

11 of the twelve original study participants had had at least two COVID-19 vaccines, and most were intending to get their booster. In spite of this, they still harboured doubts.

A common concern was safety: “most were keen to make clear that they did not believe any ‘conspiracy’ stories about the vaccines, yet common tropes about the vaccines’ safety, such as them changing your DNA or causing infertility, were part of their narratives”.

Mistrust had not been helped by the conduct of people in positions of responsibility, with “reports about those in the Government not abiding by lockdown rules”. One participant also believed that the Government had allowed private companies to “monetise the pandemic”.

Encouragingly, the study found that while trust in the national government was low, the participants’ most trusted health source was the local council. Positive discussion about COVID-19 vaccines with family and friends was also persuasive.

The authors conclude that “Although the misinformation machine is global, continuing to foster and develop strong and trusting relationships locally can help erode some of its impacts... This further underlines the importance of health messaging that leverages personal relationships and positive emotions”.



This guide is aimed at policymakers and communicators whose efforts may be frustrated by false narratives and misinformation.

The starting point is the ‘wall of beliefs’ – the various influences from which we construct our belief systems, and, to some extent, our personal identities. The point here is that belief is not simply built on facts. It also comes from social conventions, peer pressure, religious faith and more.

Because of this, myth-busting approaches can often fail to change people’s minds. The arguments for mask-wearing might be scientifically persuasive – but if none of your family or friends use a mask, you probably won’t either.

Rebuttals can also fail to cut through when people hold onto beliefs because they form a foundational part of their identity and worldview. In this case, a counter argument – however strongly evidenced – can threaten people’s self-esteem and cause defensiveness rather than a change of mind.

The guide offers a strategy matrix, based on understanding how strongly or weakly beliefs are held, and whether the resulting behaviour is harmful or not. A corresponding set of tactics looks at incentives and barriers for desired behaviour, along with communications that can address harmful beliefs without backing the intended audience into a corner.

“Overturning false beliefs”, says the guide, “is not as straightforward as simply supplying true information, or debunking falsehoods”. That advice – and the solutions presented in the guide – could be very useful to healthcare practitioners and policymakers.



The effects of misinformation are not only felt by patients and public. Sometimes healthcare professionals can also succumb.

This editorial addresses problems in Australian healthcare policy. It states that “the influence of one’s ‘lifestyle’ in the prevention of chronic disease... continues to permeate national and jurisdictional public health policies, and the professional and public discourse”. This is in spite of the fact that “it is the social, cultural and commercial forces that have the strongest influence on a population’s health”.

The authors contend that the lazy language of lifestyles “perpetuates the myth that improving the public’s health is a personal responsibility”. But, they say, the myth is not just based on lazy thinking. “In some cases... this is explicit – a deliberate ‘pollution of health discourse’, driven by commercial industries with vested interests, or by those with particular ideological standpoints.”



Taking obesity as an example, the paper sees it as “implausible that the dramatic rise in the prevalence of overweight and obesity across most high-income countries... has been due to a sudden, concurrent, generational shift in everyone’s personal responsibility”. And yet, “this narrative continues to pervade, leading to weight stigma among those experiencing overweight and obesity and preserving the belief that improving knowledge and redressing a supposed lack of individual motivation is the obvious solution”.

The effect of an overemphasis on individual lifestyle can be “a diversion of attention away from those upstream primary preventive actions that are likely to be most effective at bringing about equitable, sustained improvements in health”.

“Language matters”, say the authors, and we need to avoid “the ‘zombie hypothesis’ that one’s health is simply down to one’s choices”. They argue that we need to reframe the narrative, “challenging the dominant public discourse on personal responsibility; preferencing evidence that addresses the social, ecological, cultural and commercial determinants of health”.

“Avoiding the lazy language of lifestyles”, they say, “would be a good start”.

# Follow the money



It is now ten years since the Francis Inquiry shocked the nation with revelations of large scale harm at the Mid Staffordshire Trust. The inquiry was highly critical of the Local Involvement Network (LINK) - the government-funded patient voice body which should have spoken up for patients but had manifestly failed to do so.

The government’s response was to abolish the England-wide LINK network and replace it with a more effective version. The government recognised that the weakness of the LINKs was in part due to inadequate funding, at just £27 million per year for the entire national network. So when Healthwatch was established in 2012/13, it was given a considerably increased allocation of £40.5 million.

But the network had hardly got started before the funding began to be cut. It has been whittled down in each and every year of the Healthwatch network’s existence and, according to Healthwatch England’s latest “state of funding” report, now stands at £25.4 million.

Far from strengthening patient voice in England, the government has reduced its financial strength to below that of the LINKs, over a decade ago.

In this context, the promises to learn from the Mid Staffordshire disaster seem empty. There is, however, one key lesson. To really understand the government’s intentions in respect of patient voice, follow the money.



Governments are not the only sources of funding for patient groups, and this study from Canada shows why we also need to understand financial relationships between patient groups and pharmaceutical companies.

In one example from Canada, 87% of patient groups making submissions to an official drug review declared conflicts of interest. The groups also supported funding in over 90% of their submissions to the review.

Correlation is not causation. But the example highlights the need for transparency.

Unfortunately, transparency is somewhat lacking. The paper states that “Innovative Medicines Canada (IMC), the lobby group representing brand-name manufacturers, has included a voluntary guideline for its membership stating that they should disclose... a list of all stakeholders to which they provide direct funding’. But it goes on to say that “there are no penalties for not disclosing and no evaluation has been undertaken to determine if companies are voluntarily complying with this provision”.

Patient groups, for their part, tend to be registered charities, and therefore file annual financial reports. But “those publicly available reports do not contain information about individual donations”.

The findings are, according to the author, “broadly in line with studies in other countries”. For example, “The percent of the membership of the Association of the British Pharmaceutical Industry that reported making donations to patient groups varied from 45% to 66% depending on the year”. Indeed, “Based on the experience in the United Kingdom, voluntary reporting of industry donations on the websites of charity regulators results in significant under-reporting”.

The author argues for mandatory reporting by patient groups, possibly as a requirement for retention of their charitable status. And, he says, “Providing more information about donations will increase the accountability of both companies and patient groups and heighten transparency about their activities”.



Financial support matters as much to individuals as it does to organisations, even in an NHS where care is supposed to be free at the point of use.

This report looks at one important aspect: prescription charges. It starts with some useful facts:

- England is the only UK country where prescription charges still exist, having been abolished in Wales, Northern Ireland and Scotland.
- Charges have risen almost every year since 1979.
- Most of the income to the NHS from prescription charges comes from working-age people with long term conditions.
- Aside from the addition of cancer in 2009, the list of exempt

conditions has not changed since 1968, even though there are new conditions like HIV, and some, like cystic fibrosis, which people can now live with for much longer.

Some people can get help with the costs - but only if they know help is available. In this survey, 83% of respondents had not heard of the NHS Low Income Scheme, and 38% only found out about the Prescription Prepayment Certificate more than a year after their diagnosis with a long-term condition.

30% of respondents reported missing, or taking a lower dose of their medication, and 64% said they would be more likely to take medicine as prescribed if prescriptions were free.

The authors conclude that “charging working-age people with long term conditions for prescriptions is leading to self-rationing of medications”. And since self-management is a key thrust of NHS strategies, it is hard to argue with the report’s finding that “the prescription charge exemption system needs urgent reform”.

## 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.

# 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.	Care Opinion NHS.UK reviews
5. Other (local)	Feedback gathered via complaints and compliments, Patient Participation Groups, patient engagement committees and forums etc.	NHS Trusts, Integrated Care Boards, 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). While being patient-led, these 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	759,149
Adult Inpatient Survey	63,224
Cancer Patient Experience	61,268
Urgent and Emergency Care Survey	Type 1 services: 29,357 Type 3 services: 7,418
Maternity Survey	20,927
Community Mental Health	13,418
Together for the 1 in 6: UK Findings from My Neuro Survey	8,510
Systems research: 4,000 voices	4,013
British Social Attitudes Survey	3,362
Public perceptions of the NHS	2,063
Under 16's Cancer Patient Experience Survey	960

In addition:

- [Healthwatch England's 2021/22 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 2023 there were [1,469,297 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 2022 and July 2023, we uploaded 2,757 reports to the Patient Experience Library. Some had been published in previous years - the total published between August 2022 and July 2023 was 2,121.

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

The title and content of this publication © Glenstall IT, September 2023.

The Patient Experience Library is provided by Glenstall IT, 28 Glenstall Road, Ballymoney BT53 7QN