

Patient Experience in England



Foreword



How much of the philosophy of ‘listening to patients’ is a reality in the NHS? The question perhaps should be “how much do we listen, in the NHS, to those we serve?” - and on that parameter, based on my experience of working within many national organisations, the answer is probably best phrased as ‘Not Much’.

The data bears that out too - and this approach doesn’t necessarily come from a bad place. It comes from a belief that the expectation of the public is too much - not to mention that we can’t deliver what patients want. But I don’t believe that to be true.

In the vast majority of cases (or at least in my experience) people are understanding of the pressures the NHS is under, appreciative of staff burn out - not to mention the obvious financial pressures. Yet somehow a degree of open honesty about what’s possible and what’s not seems to be always lacking for many of us in the health sector.

This report should perhaps help open eyes about how the approach in general - of not involving the patients - has worked. Bar a few honourable exceptions? The NHS has struggled to deliver on most of its promises. Whatever the title of the plan, the outcome has been similar - mostly dismal. We are now talking about a 10-year plan under a new Government. Yet perhaps there is a need to review the Five Year Forward View from 2015 or the NHS Long Term Plan from 2019 - to see what has been delivered, if at all, before embarking on yet another plan.

The basic facts remain that a leadership which hasn’t been able to deliver the former plans is unlikely to be able to do any further - especially if they are committed to doing the same thing. One does always fall back on reasons such as not enough finances - yet arguing the case for finance to the powers that be is, in my opinion, is part of the job too.

There needs to be openness and honesty with those we serve - including how we develop plans, how we implement them and, topically, the issue involving the NHS Long Term Workforce Plan - of who will be part of the workforce to look after healthcare needs - not driven by ideology or hubris, but by discussion with those whose lives matter.

One hopes this report provokes new thinking which will enable this - rather than smoke and mirrors - which leads us to what Albert Einstein once said: “Insanity is doing the same thing over and over again and expecting different results”.

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Contents

Foreword	2
1. Introduction	4
2. What we learned in the last year: Surveys	5
2.1 Experience of health and care services	6
2023 Adult Inpatient Survey	6
2022 Cancer Patient Experience Survey.....	7
2023 Community Mental Health Survey.....	8
2023 GP Patient Survey.....	9
Maternity survey 2023.....	10
Under 16 Cancer Patient Experience Survey 2022.....	11
2.2 Public attitudes.....	12
British Social Attitudes Survey	12
Public perceptions of health and social care polling (Wave 5: November 2023).....	13
3. What we learned from research	14
3.1 Health inequity.....	14
3.2 Patient safety	17
3.3 Voice	19
3.4 End of life	21
3.5 Digital.....	23
3.6 Drug companies.....	26
About the Patient Experience Library	30
Appendices	31
A.1 Sources of evidence	31
A.2 Quantity of evidence	33

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

1. Introduction



So here we are, with a new government and, we hope, a new commitment to health and social care.

The debate will undoubtedly focus on finances, workforce and models of care - and of course these matter. But what matters most is the experience of patients and service users, alongside the perceptions of the general public, as taxpayers and voters.

This report offers an overview of the last twelve months of studies and surveys on patient experience. A particularly telling finding comes from the latest British Social Attitudes Survey. The 2022 survey had revealed that overall satisfaction with the NHS was at its lowest level since the survey began in 1983. But the 2023 survey shows that satisfaction has dropped still further and is now down to a mere 24%.

At the same time, “patient experience” is about much more than “satisfaction”.

So as well as covering the big set-piece patient surveys, we look at what wider research is telling us about matters such as equity - the question of whether health, and healthcare, are accessible to all. We also have some excellent studies on “voice” and safety - key concerns in an NHS that is aiming to be “patient-centred”. A set of reports on end of life care takes us into the area of human rights and social justice, and a section on people’s experiences in digital healthcare indicates that patients - like NHS staff - are less concerned with the breathless excitement around AI than with the need for some day-to-day IT basics. Finally, we look at studies of drug company influence on clinicians and on patient organisations, some of which raise important questions about transparency.

An NHS aiming to be both “patient-centred” and “evidence-based” needs a sound evidence base to help it understand people’s experiences in healthcare. This report offers a glimpse into the breadth and quality of the research that is being carried out on a daily basis. To find more, please feel free to visit the [Patient Experience Library](#).

Miles

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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](#).

Some points to note about the list of surveys below:

- There is no reference to the Urgent and Emergency Care survey. The last of these was published in August 2023 and was included in our 2023 Patient Experience in England report. The next one will not be published until October 2024 which is too late for our 2024 Patient Experience in England report.
- There is no reference to the Children and Young People survey. The last of these was published in 2021. We are told that that survey is being redeveloped and that the next one is scheduled for publication in March 2025.

2.1 Experience of health and care services

2023 Adult Inpatient Survey

Published August 2024



This year’s survey report starts by commenting that “people’s experiences of inpatient care have changed little when compared with those from 2022 but continue to be worse than experiences reported in 2020 for most areas of care”.

The effects of longer waiting lists can perhaps be seen from the finding of a significant decline in experiences of accessing inpatient care. 42% of planned care patients said they would have liked to have been admitted to hospital sooner than they were, compared to 32% in 2020. Similarly, 33% of people felt they waited too long to get a bed on a ward, compared to 20% in 2020.

Forty-three per cent of planned care patients felt their health worsened while waiting for admission compared to 41% in 2022, while 49% reported no change (50% in 2022).

Problems with discharge from hospital is a perennial theme in national patient surveys. This one shows that patient experience of leaving hospital has deteriorated since 2022. The 2023 results show:

- People or their family/carers feel less involved in decisions about them leaving hospital
- There are fewer discussions being had about further health or social care services needed, or additional equipment or home adaptations needed after leaving hospital
- Less information about what they should and shouldn’t do after leaving hospital.

There were some positive findings: 82% of respondents felt that they were “always” treated with respect and dignity, and 80% were always treated with kindness and compassion. Three-quarters (75%) of respondents ‘always’ felt included in conversations about their care by both doctors and nurses.

79% felt staff involved them in decisions about their care and treatment, and more than three-quarters (78%) were given the right amount of information about their care and treatment. 9 in 10 (90%) felt they were able to talk to hospital staff about their worries and fears.

Confidence and trust in both doctors and nurses remains high, with 80% and 78% saying they “always” had confidence and trust in doctors and nurses respectively.

On the downside, only a third of respondents (33%) said they were not prevented from sleeping at night while in hospital. And the proportion of those who said that they always got enough help with eating saw a fall from 65% in 2022, to 64% in 2023.

2023 Cancer Patient Experience Survey

Published July 2024



There are good signs of improvement in this year's cancer patient experience survey, particularly in the area of involvement.

81% of respondents were told they could have a family member, carer or friend with them when told their diagnosis, against 76% last year. 70% said family, or

someone close, was definitely able to talk to a member of the team looking after the patient in hospital (65.6% in 2022). And 83.5% said that family and/or carers were definitely involved as much as the patient wanted them to be in decisions about treatment options (80% in 2022).

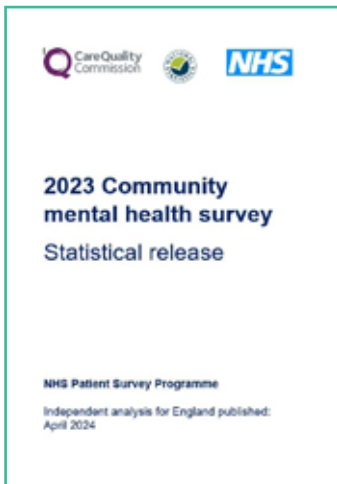
In other areas, headline findings are broadly the same as in last year's survey. Highlights included the following:

- 91.2% said they had a main contact person within the team looking after them who would support them through treatment (91.5% in 2022).
- 87.0% said the administration of their care was very good or good (86.7% in 2022).
- 78.5% said they felt the length of waiting time at the clinic or day unit used for cancer treatment was about right (78.0% in 2022).
- A further 78.5% said that the results of diagnostic tests were explained to them in a way they could completely understand (78.3% in 2022).

Against this is the fact that fewer than two thirds (63.7%) said they were given enough information about the possibility of the cancer coming back or spreading, such as what to look out for and what to do if they had concerns. Only 60.1% said the possible long-term side effects, including the impact on their day-to-day activities, were definitely explained in a way they could understand. And less than half (46.4%) of respondents who said their GP practice was involved in their care while they were having treatment said they got the right amount of support from staff at their practice.

2023 Community Mental Health Survey

Published April 2024



The survey report states that people’s experiences of NHS community mental health services are poor. Fewer than half of all respondents (39%) were ‘definitely’ given the help they needed the last time they saw someone. Half of all respondents (50%) were not always given enough time to discuss their needs and treatment.

Experiences of waiting for care are especially poor, with almost half (44%) reporting that their mental health got worse while they waited. 42% of respondents were not offered support between their assessment with the NHS mental health team and their first appointment for treatment, while 4 in 10 (40%) thought they waited too long.

For the first time, the survey was able to identify respondents using Child and Adolescent Mental Health Services (CAMHS). Results for people using CAMHS indicate especially poor levels of treatment and care across most areas, including ‘waiting for care’, experiences of the ‘mental health team’ and ‘involvement in care’. For instance, only 1 in 4 people (25%) said they were ‘definitely’ given the help they needed when they saw someone from mental health services, and 6 in 10 (60%) said their mental health deteriorated while waiting for care.

The report goes on to say that “There are few areas where most people reported good experiences”. But among the positives was that fact that 74% of respondents definitely had enough privacy during talking therapy, and 77% had been asked how they were getting on with their medications.

The list of “key areas for improvement” is extensive, taking in quality of care, crisis care, support while waiting, planning and involvement in care, and support with other areas of life.

Finally, the report notes “disparities in the experiences of different demographic groups of people receiving care and treatment from NHS community mental health services”. “Most notably”, it says “respondents with a disability reported worse than average experiences for 14 of the 20 questions analysed”.

2023 GP Patient Survey

Published July 2024



Last year's survey showed the proportion of patients reporting a good overall experience of their GP practice falling to its lowest level for six years, at 71.3%. This year, the figure rose slightly, to 73.9%. That might look like a modest improvement but it is worth noting that the report states that changes in survey design mean that trends cannot be reliably presented this year.

Female patients reported the most positive overall experience, and older people reported a more positive overall experience than younger patients. As far as ethnic groups are concerned, patients from African and Caribbean groups reported a more positive overall experience. Patients from Gypsy or Irish Traveller and Bangladeshi backgrounds reported the least positive overall experience.

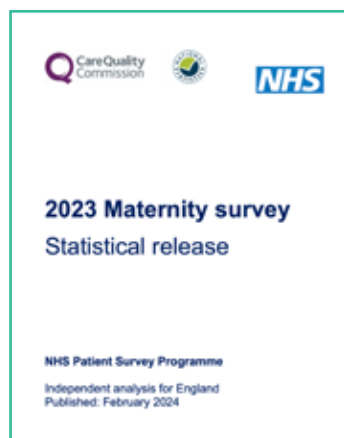
Last year, just under half (49.8%) of patients had said that it was easy to get through to their GP practice on the phone - lower than all previous years since the question was introduced in 2012. This year, the figure remains the same, at 49.7% although we must again bear in mind the caveat about trend reporting.

Half of survey respondents (51.7%) had tried to contact their GP practice via its website, and of those, less than half (47.9%) had found it easy. Around a third (35.6%) had tried to contact their GP practice using the NHS app and of these, just over two in five (44.8%) said it was easy. The most common reason for online contact was booking appointments (41%), with repeat prescriptions a close second (39.9%). Only 16.9% used online contact for access to medical records.

When booking appointments at their GP practice, one third (34.9%) had been seen on the same or next day. Two thirds (65.9%) said the length of time they waited for their appointment was about right, as against a third (34.1%) who said it took too long. More than four in five (86.7%) said that the healthcare professional was good at listening to them during their last appointment.

Maternity survey 2023

Published: February 2024



The survey indicated improvement across a number of aspects of care.

In antenatal care, 81% of survey respondents were 'always' given enough time to ask questions or discuss their pregnancy, 83% were 'always' listened to, and 72% were 'always' given the help they needed. All these were up from 2022 survey results. Results were poor for midwives being 'always' aware of medical history (54%) but this was better than in 2022 (49%).

For labour and birth, there were improvements in feeling involved in decisions about induction, receiving appropriate advice and support during early labour, partner involvement, and concerns being taken seriously. Results for 'always' being given advice about the risks of induction was low (69%) but improved from 64%.

In hospital after the birth, only 57% of respondents said that partners were involved as much as they wanted, but this is a significant improvement from 2022 (41%).

Experiences of mental health support also improved: 75% said their midwife 'definitely' asked about their mental health during antenatal care, compared to 71% in 2022, and 88% of respondents 'definitely' received enough support in 2023, compared to 85% in 2022.

Against these improvements were some causes for concern.

A quarter of respondents (25%) were left alone at some point during, or shortly after, the birth at a time when it worried them. And only just over half (55%) were 'always' able to get a member of staff to help when they needed it in hospital after the birth. Fewer than two thirds (60%) had 'always' received the information and explanations they needed in hospital after the birth, and 28% were not always treated with kindness and understanding.

Over one third of survey respondents had considered making a complaint at some point in their maternity care journey. Frequency of contact with the same midwife correlated with better experiences in general and less likelihood of thinking about making a complaint. Unassisted vaginal delivery also correlated with more positive experiences, as against an emergency caesarean birth. Women with a long-term mental health condition were more likely to report poorer experiences and to consider making a complaint.

Under 16 Cancer Patient Experience Survey 2022

Published November 2023



The survey was carried out across three different age groups - 0-7 years, 8-11 years and 12-15 years. It also included parents and carers as well as the children themselves.

Ratings for overall care were good, 75% of children feeling very well looked after by staff (77% in 2021) and 89% of parents/carers rating the overall experience of their child's care as 8 or more out of 10 (89% in 2021).

Over two thirds of respondents (69%) said that information at diagnosis was definitely given in a way they could understand, and nearly three quarters (73%) of parents/carers were definitely told about their child's cancer or tumour diagnosis in a sensitive way. 69% of children reported that they could always understand what staff were saying.

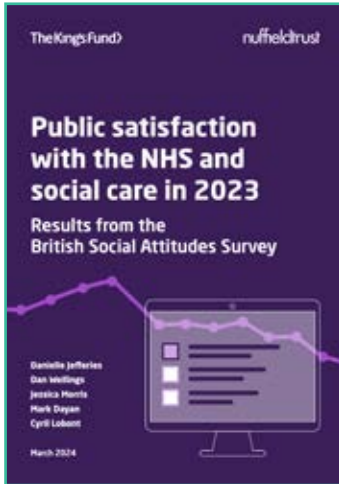
85% of parents/carers were offered clear information about their child's treatment and 79% of parents/carers felt that staff definitely offered them enough time to make decisions about their child's treatment. 61% definitely had access to reliable help and support 7 days a week from the hospital, and 83% felt they always had confidence and trust in staff caring for their child.

There was room for improvement in some non-clinical aspects of care. For example, just 38% of parents/carers felt that the hospital Wi-Fi always met the needs of them and their child. Only 38% were definitely able to prepare food in the hospital if they wanted to. And as few as a quarter (27%) of parents/carers and children reported that it was always quiet enough for them to sleep in the hospital.

2.2 Public attitudes

British Social Attitudes Survey

Published March 2024



The 2022 survey revealed that overall satisfaction with the NHS was at the lowest level since the survey began in 1983. The 2023 survey shows that satisfaction has dropped still further and is now down to 24%. Since 2020, satisfaction has fallen by 29 percentage points.

The main reasons for dissatisfaction were exactly the same as in the previous year: waiting times for GP and hospital appointments (71%), followed by staff shortages (54%) and a view that the government does not spend enough money on the NHS (47%).

Similarly, the reasons for satisfaction were consistent with the previous year: NHS care being free at the point of use (66%), the NHS having a good range of services and treatments available (53%) and the quality of NHS care (52%).

In social care, too, public satisfaction dropped from an all-time low of 14% in 2022 to 13% in 2023. Again, reasons for dissatisfaction followed a familiar pattern: inadequate pay, working conditions and training for social care workers (57%), closely followed by people not getting all the social care they needed (56%) and there not being enough support for unpaid carers (49%).

Satisfaction with NHS dentistry fell to a record low of 24% and dissatisfaction increased to a record high of 48%.

More than eight out of ten respondents (84%) said they thought the NHS had a major or severe funding problem. 48% thought government should 'increase taxes and spend more on the NHS', against 42% who thought it should 'keep taxes and spending the same'. Just 6% chose 'reduce taxes and spend less on the NHS'.

The most important priorities for the NHS were seen as making it easier to get a GP appointment (52%) and increasing the number of staff in the NHS (51%). Improving waiting times for planned operations and in A&E were chosen by 47% and 45% of respondents respectively.

As in the previous two years, a large 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 to use it (91%); that the NHS should primarily be funded through taxes (82%); and that the NHS should be available to everyone (82%).

Public perceptions of health and social care polling

(Wave 5: November 2023)

Published April 2024



This report is part of a two year research programme, based on polls with the UK general public at six-monthly intervals. This report covers the fifth wave of the polling programme, published in April 2024.

Its first finding is that there is still strong support for all of the NHS's founding principles. The majority of the public think the NHS should be free at the point of delivery (88%), provide a comprehensive service available to everyone (84%) and be funded primarily through taxation (82%).

Just over half of the public (53%) think the general standard of care in the NHS has got worse over the last year. People continue to have pessimistic expectations for the coming 12 months, with 53% thinking that the general standard of care will get worse. Only one in ten (11%) agree that the government for England and the devolved governments for Wales, Scotland and Northern Ireland have the right policies in place for the NHS.

Around half the public (48%) would like to see an increase in taxes to maintain current levels of care and services. In the event that the NHS budget is not increased, the public would like the government to prioritise making it easier for people to access community-based services close to home, including a GP and an NHS dentist (60%), rather than making it easier for people to access care in hospitals including A&E and planned procedures (30%).

The public are divided as to whether they would pay for private health insurance or private healthcare. Whilst just under half (47%) say they are unlikely to pay, nearly one-quarter (24%) say they would be likely to pay, and 14% are already paying (or their company pays).

Around three-quarters of the public (77%) think that social care workers are paid too little, and are generally supportive of measures to increase their pay. When asked about different approaches to funding social care, the public tend to think that the current means-tested system is unfair (74%) as opposed to fair (13%).

More than four in five members of the public think the government has a great deal or a fair amount of responsibility to reduce harms from air pollution, food poverty and fuel poverty (87%, 83%, 82%). In comparison, the public sees the government as having a lesser responsibility for lifestyle harms such as alcohol and gambling related harms, although more than half still think it has a responsibility to tackle these issues (63% and 62% respectively).

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.

3.1 Health inequity

“Inequity” is unfairness. And unfairness can sometimes result in inequality, with poorer patient experiences and poorer health outcomes. Over the last year, various reports have covered inequities in healthcare policies and practice. Here, we summarise a few.

A long-standing inequity within the NHS lies in the treatment of people with mental health conditions.



This report from the House of Commons Public Accounts Committee reminds us that in 2011, it looked as though the government would address this when it set out its goal of achieving “parity of esteem” between mental and physical health services. However, it did so “without setting out what achieving it meant in practical terms”.

The Committee says that “Many stakeholders have welcomed the introduction of new access targets and waiting times standards”. But, it says, “the standards only cover a minority of people who are referred to mental health services and, despite defining further standards more than a year ago, there are still no plans to roll these out”.

In the meantime, data for NHS mental health services (described by the report as “vital for managing performance, developing new services and addressing inequalities”) lags behind that available for physical health services. Furthermore, “many service providers [are] still not submitting data as required”.

The data gap includes patient experience. “Of 29 integrated care boards surveyed by the NAO [National Audit Office], only four said they had all or most of the data they needed to assess patient and user experiences, and none of them felt this in relation to patient outcomes”.

The report states that “There is still no clear definition of the end goal of ‘parity of esteem’ 12 years after the government first set out its ambitions”. It says that NHS England would welcome a definition, but “the [DHSC] current position is not to specify one”.



This article looks at the Women’s Health Strategy for England and starts by listing “important progress” – on matters such as hormone replacement therapy and specialist women’s health hubs.

Progress in these areas is welcome, say the authors. However, the strategy’s priorities reinforce “a traditional view of women’s health as synonymous with women’s sexual, reproductive, and maternal health”. This, they say, is a missed opportunity to take a broader view.

They cite differences in women’s and men’s experiences of heart attacks, including symptoms, age at onset, effective treatments, and overall outcomes. In spite of this, “blood tests to diagnose myocardial infarction are often not reported against sex specific thresholds”.

Similarly, women are at greater risk of diabetes related mortality than men and have a greater risk of complications. And yet women are less likely than men to receive the care recommended by clinical guidelines, and guidelines are not routinely sex specific. A further example is that women comprise 52% of the global HIV population but continue to be under-represented in anti-retroviral drug trials.

“For conditions that affect both women and men”, say the authors, “investments are needed to break the default of research being conducted primarily on men and generalised to everyone else”. They go on to say that equitable healthcare for women “is the right thing to do and is financially intelligent”.



Health inequity is not just a matter for medicine. For children and adolescents, says this report, wellbeing relates much more closely to “the environment and social circumstances in which children grow up”.

The facts are stark:

- Obesity affects 23% of Year 6 children in 2021/22 in England. 80% of obese young people remain obese as adults.
- In 2022, 29% of five year olds in England had tooth decay.
- Vaccination coverage has decreased in 13 out of 14 of the routine childhood vaccination programmes. The UK lost its WHO measles free status in 2018.
- 86% of UK cities exceed recommended limits for airborne particulate matter. The effects of air pollution have a greater impact on children and young people.
- Rates of poor mental health for children and young people are rising. Suicide is the leading cause of death in children and young people.

The report makes a series of recommendations - on food regulation, dentistry, vaccinations, air quality and more. And it makes the point that “prevention is better than cure, but we must also recognise that prevention in childhood is better than prevention in adulthood”.



A persistent inequity (or unfairness) in healthcare is who gets access to care, and who ends up at the back of the queue. So after the first wave of the Covid-19 pandemic, NHS England asked integrated care boards (ICBs) and NHS trusts to address health inequalities as part of tackling growing waiting lists for elective care. This report looks at three Trusts and ICBs to see what progress has been made.

A fundamental first step was for providers to disaggregate their waiting list data, to identify patients by ethnicity and deprivation. Two years on from NHS England’s ask, only one of the three Trusts had achieved this. None of the ICBs were reporting disaggregated waiting times data to their board.

There were also barriers to the idea of a new approach. In one Trust, “work to reprioritise waiting lists had stalled because of resistance from clinicians”. In the other two, “leaders were concerned about how clinicians would react to the work”.

Data issues were another problem. These included poor quality ethnicity coding and limited analytical capability.

In spite of all this, there were some pockets of success. But these were more in terms of simple improvement projects than systemic change. And they were led not so much by executive teams as by individuals with a passion for addressing inequity and inequality. The report makes the point that “the NHS needs to harness that enthusiasm and give these leaders the tools and ideas needed to make change in their clinical areas”.

3.2 Patient safety

It is now over a decade since publication of the final report of the Francis Inquiry into avoidable harm and death at Mid Staffordshire. That report was meant to be a watershed moment for the NHS – but avoidable harm, along with cultures of avoidance and denial, seems to be embedded. And in spite of repeated promises to “learn from mistakes”, this latest crop of reports treads some familiar ground.



David Fuller worked for the NHS for 31 years. “His employment”, says this inquiry report, “started only two years after he committed the brutal murders of two young women in Kent, whose deceased bodies he sexually assaulted”. He went on to commit 140 known offences against deceased women and girls in the mortuaries at Maidstone and Tunbridge Wells NHS Trust.

How can such appalling crimes have gone undetected for so long? The report offers a series of answers, all of which fit a recognisable pattern. They include the following:

- Culture. “The culture... at Tunbridge Wells Hospital, as observed by the Inquiry, was not one of questioning and curiosity. There was a lack of curiosity about David Fuller’s work behaviour in relation to the mortuary”.
- Silos. “Mortuary staff felt ignored by senior managers and separated from the rest of the Trust... mortuary staff were ‘functionally isolated’”.
- Compliance. “Standard Operating Procedures were routinely ignored and security breaches were not thoroughly investigated”.

Putting these together, the inquiry finds that “This is not solely the story of a rogue electrical maintenance supervisor. David Fuller’s victims and their relatives were repeatedly let down by those at all levels whose job it was to protect and care for them”.



In February 2007 a patient (Patient A) died in the operating theatre of the Salford Royal Hospital. This report from March 2024 reveals a litany of poor professional practice, combined with abuse of power, centred on a spinal consultant, Doctor F. Concerns around this doctor’s practice included:

- Negligent and fraudulent clinical practice, leading to serious life-threatening harm to patients.
- Poor clinical practice, including not treating patients in a dignified manner during physical examinations.
- Bullying, intimidation and harassment of colleagues, including unsolicited sexual contact with female staff.

- An extramarital affair between Doctor F and a senior divisional managing director of the Trust, which allowed poor clinical practices and behaviours to continue through undue protection of Doctor F.

So the family of Patient A now have an explanation for their relative's death. But it has taken them some sixteen years to get it.



The findings of the Infected Blood Inquiry run to seven volumes. There is a huge amount of detail. But anyone interested in patient experience need only glance at the first few pages of this volume to see, once again, a recognisable pattern.

The report refers to:

- Repeated and ongoing failures to acknowledge that people should not have been infected.
 - The absence of any meaningful apology and redress.
 - Repeated use of inaccurate, misleading and defensive lines to take which cruelly told people that they had received the best treatment available.
- A lack of openness, transparency and candour, shown by the NHS and government, such that the truth has been hidden for decades.
 - Deliberate destruction of some documents and the loss of others.
 - Refusal to provide compensation (on the ground there had been no fault).

It seems clear that patient safety is not simply a matter of better training, better guidelines, and better regulation. Harmful organisational and professional cultures are always implicated.

On this point, the following report might offer a glimmer of hope.



It contains findings on culture, behaviour and patient safety, including the following:

- A high volume of complaints from patients, and delays in responding.
- Consultant surgeons being dismissive and disrespectful towards other members of staff and displaying hierarchical behaviours towards allied healthcare professionals, particularly junior members of staff.
- Reports of two trainees being physically assaulted by a consultant surgeon in theatre during surgery.
- A culture of fear amongst staff when it came to the executive leadership team, with instances of confrontational meetings where consultant surgeons were told to 'sit down, shut up and listen'.

The report is dated January 2024 and is marked “Private and Confidential”. But in a remarkable display of openness, it was published on the Trust’s website in February 2024, ahead of being discussed at a Board meeting in public.

In a preamble to the report, the Trust’s Chief Executive said, “Problems can’t be solved without first being openly acknowledged”. That statement could be exactly the sort of “learning from mistakes” that some other NHS leaders could benefit from.

3.3 Voice

Freedom to speak up is critical to both quality and safety. Both patients and staff need to be able to raise concerns and know that they are taken seriously. An important step in the right direction was taken in April 2024 with the introduction of [Martha’s Rule](#). But as these reports indicate, there is further room for improvement in strengthening “speaking up”.



This review was commissioned in response to a BBC Panorama programme that showed “appalling levels of abuse, humiliation and bullying of patients at the Edenfield Centre in Prestwich”. The report says that “The horror of what was shown could not fail to touch anyone who watched the programme”.

It states that “Some patients and families described not being believed when they raised concerns or complained about the care received... Others shared how they did not always feel safe to disclose concerns, with many accounts of feeling intimidated, undermined, ignored, or fearful that ‘bad news’ was not welcomed”.

Staff, too, went unheard. Some talked of “feeling exasperated, tired of not being listened to and disconnected from the Trust leadership... staff have felt fearful to speak up for many years”.

Part of the problem was with formal complaints processes: “there was a lack of clarity and accountability throughout all the complaints process... making a complaint was discouraged”.

And in an uncomfortable echo of Mid Staffordshire, the report describes “a Trust that was not sufficiently focused on understanding the experience of patients, families and carers... The lack of both curiosity and focus on improvement led to missed opportunities for organisational learning”.



This report on the latest survey of Freedom to Speak Up Guardians reinforces the importance of voice. “Speaking up is a gift”, it says. But it warns that “The benefits of Freedom to Speak Up can only be realised if leaders and board members are inquisitive about what is presented to them and are keen to embrace the learning”.

Unfortunately, a readiness to listen and learn is not always apparent.

Two thirds (66%) of survey respondents saw “fear of detriment” as having a noticeable or very strong impact as a barrier to workers speaking up. Barriers included professional hierarchies and seniority. Added to this, one third (34%) of respondents thought that “attitudes towards protected characteristics” (such as gender, ethnicity or sexual orientation) could also affect workers’ ability to speak up.

A further dampening effect comes from “futility” - the concern that nothing will be done. Here, two-thirds of respondents (67%) saw futility as a ‘noticeable’ or ‘very strong’ barrier to workers in their organisation speaking up.

The report notes that the survey findings are in line with the most recent NHS Staff Survey, which identified “a deterioration in the confidence to speak up by healthcare workers”. It also, ominously, states that “Many organisations still do not have a Freedom to Speak Up Guardian registered with and trained by the National Guardian’s Office”.



Voice also matters in policy work, and this paper notes that “The last decade has seen an explosion of interest in co-production and co-creation”. But, it says, “the extent to which these new forms have resulted in meaningful change...is not fully clear”.

To explore the issue further, the researchers looked at five local Healthwatch organisations - established to “strengthen the collective voice of local people”.

It found that Healthwatch “took care in how they positioned their organizations... conscious of the need to demonstrate activity and impact”. Crucially, “co-creation depended on trusting relationships... which in turn required that they be taken seriously as part of the system rather than be seen as outsiders”.

The authors state that “this disposition also meant that some activities were shunned”. Healthwatch, they say, “maintained a cautious distance from other voices of the public that challenged system organization in a more fundamental way”.

The paper concludes that “Even though they were not explicitly ruled out-of-bounds, Healthwatch officers knew that to be considered legitimate and serious players in the governance of health and social care, they needed to be selective about which issues they brought to the table”. Consequently, “the forms taken by co-creation in practice were largely conservative and constrained”.

3.4 End of life

One of the first things that Wes Streeting announced on becoming Secretary of State was a House of Lords debate on assisted dying. It was, he said, “a debate whose time has come”.

Any prospective legislation will apply to people who are terminally ill. But end of life care is perhaps something that we should all be thinking about.



This paper starts with the observation that advance care planning (ACP) helps people with deteriorating health to think and plan ahead. However “uptake remains low internationally”. To find out why, the researchers explored public perceptions of ACP.

They grouped their findings into four domains:

- Knowledge and engagement. Public knowledge of ACP is low: people have often never heard of ACP, and would not know how to find out about it. And even with good knowledge, engagement may be poor: “Familiarity with ACP concepts did not necessarily translate into active participation in ACP”.
- Fear, mistrust and avoidance. Some patients feared they would be ‘tempting fate’ if they opened up ACP conversations. Many studies described ACP as being too emotional or distressing for patients and families to engage with. Other studies revealed fears that expressed wishes would not be carried out irrespective of having a documented ACP.
- Misconceptions and misinformation. End of life care is seen as care in the last days or hours before death. Accordingly, patients can see attempts to discuss ACP as coming too soon.

The authors note that debates on ACP concentrate on professional and policy perspectives. But, they say, “Although ACP research includes patient and public perceptions, more attention needs to be paid to them in future ACP developments”.



This report from the Parliamentary and Health Service Ombudsman (PHSO) picks up the theme of end of life conversations, which it describes as “sensitive and emotionally challenging”. It goes on to say that any such conversations need to be conducted by appropriately trained professionals, in partnership with patients and families.

The focus of the report is DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) decisions. During the Covid crisis, the PHSO received a higher than normal level of complaints about DNACPR. These revealed that healthcare staff were not always well trained, with consequences including the following:

- Patients and their families and carers were consistently not involved in DNACPR decisions during the pandemic and healthcare professionals failed to communicate with them.
- Records were not checked for existing DNACPR decisions.
- DNACPR records did not follow patients to different health settings.
- Patients were not getting support for a range of communication needs.

In one case, the patient had “learning disability” written as one of the reasons for their DNACPR notice. This, says the report, “raises serious questions about the quality of communication and whether a human rights-led approach is being taken to patients’ care”.

The report makes recommendations on training, communication, regulation and record-keeping. It makes the point that “Having conversations about DNACPR is a legal requirement. Failing to do so constitutes maladministration and a breach of human rights”. And, it says, “A rights-respecting, interactive conversation on how someone wishes to end their life is a basic part of end-of-life care provision”.



Place of death is a government proxy indicator of “quality dying” in most Western countries, according to this paper. It goes on to claim consistent evidence that home is the preferred place of death for most people, regardless of their socio-economic status. In spite of that, “people living in more socio-economically deprived areas... have been shown to be less likely to die at home and more likely to experience (often unscheduled) hospital admissions and intensive treatment in the last few months of their life”.

To find out why, this study examined experiences of home dying for people experiencing poverty and deprivation in the UK.

Its first finding was that there are considerable costs associated with dying at home. People at end of life need warmth – and heating is expensive. They might need non-invasive

ventilation, or a bed hoist. Bedding might need washing more often than usual. All of this adds to electricity bills. On top of this are care costs.

Low income often means poor housing – and study participants described accommodation that was damp, noisy and cramped. This made for oppressive environments that did not offer comfort or safety to dying people.

In spite of these kinds of difficulty, some people stayed at home because it reinforced their sense of self. People feared not being able to personalise a hospice room with pictures, belongings and, in some cases, pets. Identity and autonomy were, to some extent, traded off against physical care needs.

The authors observe that “up until now, insufficient consideration has been given to the social and, crucially, economic capital required to support home dying”. And they say that “the elephant in the room here is the neo-liberal political context and the resource constraints which affect how much, as a society, we are prepared to redistribute to those who are worst off and in greatest need at the end of their lives”.

3.5 Digital

NHS England says that artificial intelligence (AI) has the potential to remove time consuming repetitive tasks from staff and that it also has the potential for further democratisation of healthcare to patients by providing them with information directly.

It may well be that AI “has the potential” to do these things. But in the meantime, **the BBC reports** that staff are struggling with IT systems that are inadequate for basic daily tasks and which are, in some cases, harming patients. The report includes a distressingly familiar fact: while a number of clinicians had contacted BBC News with IT concerns, “None of them wanted to be named because of fears over speaking out”.



But what do patients think about the use of IT in healthcare? These reports shed some light:

This paper tackles the AI question head-on. It notes that “Use of artificial intelligence in healthcare is on the rise” and says that if used as part of a robust production process, AI can streamline the production of health information.

Benefits can include automatic translation of leaflets and videos to help teams serve seldom-heard communities. Automated chat bots can respond to online information requests, both in and out of office hours. And AI can help with accelerated data analysis.

But the paper warns of risks, which, it says “are of critical importance in the health information space where we strive to produce accurate, unbiased, inclusive materials”.

One risk is that AI models learn from the data they are given. If the training data contains bias, this is likely to be reflected or compounded in the AI model’s outputs. If data sources are of poor quality, AI outputs may also be of poor quality. Some AI models are trained on out-of-date information. The paper cites the example of the first free-to-use version of ChatGPT which was trained on data published before 2021. So “searches relating to COVID-19 returned drastically out-of-date results”.

A specific problem for health is that AI “tends to over-simplify health topics because it lacks the ability to apply context or nuance to its results, or to understand the meaning behind the data”. The “high risk of inaccuracy” is not just about the quality of information. It also raises “complex and unanswered questions” about the liabilities of organisations using AI to produce and distribute information.

In spite of these risks, say the authors, “Taking no action is not an option... We need to manage the risks, not ignore them”. Their recommendation is that organisations should develop AI usage policies - and the paper points to the kinds of headings and issues that a policy should cover. In the meantime, they say, AI “is not suitable for the creation of health information and content in isolation”.



The Health Foundation states that “The NHS is looking to advances in digital health technologies and data to help tackle current pressures and meet rising demand”. “But”, it says, “ensuring new uses of technology and data have the backing of the public is critical if they are to become business as usual”.

The authors surveyed 7,000 members of the public to test their views.

The good news is that people are generally supportive of technology in healthcare. Over half of those surveyed (51%) said that the NHS should make more use of self-monitoring devices, such as blood pressure or heart rate monitors. And nearly half (48%) said the NHS should be making more use of electronic health records.

There was less support, however, for the use of chatbots to check symptoms or get health advice and less support for video conferencing to speak to a health professional. The authors note the difference between technologies aimed at supporting the public, and those that might be perceived to come between the clinician and patient.

As far as healthcare data is concerned, the survey found that nearly two-thirds (61%) knew “very little” or “nothing at all” about how the NHS is using the health care data it collects.

In spite of this, two-thirds said they trust GP practices, local NHS hospitals and clinics and national NHS organisations with their health data “a lot” or “moderately”. But national and local government organisations and health technology companies are less trusted. There is, says the report, a need to “grow trust in organisations with currently low trust levels”.

The authors conclude that “Over the coming years, policymakers and NHS leaders will need to prioritise meaningful public engagement on the future of technology in health care”. And they say that “it is important that this public engagement is inclusive, seeking out the voices of those who can often be excluded in public consultations”.



This paper reminds us that in 2021, NHS England announced that patients would have prospective access to their primary care records online, by default. But by November 2023, one in four general practice surgeries across England still did not offer online record access (ORA).

Why the delay? Part of the answer, according to this paper, is that “Although patients often welcome transparency, studies show many doctors... express scepticism about patient access”.

So this study set out to explore the experiences and opinions of English GPs about the potential impact of ORA on both patients and doctors.

There were plenty of negatives. 91% of those surveyed “somewhat agreed” or “agreed” that with full online access, a majority of patients would “worry more”. 85% believed that most patients would “find their GP health records more confusing than helpful”. And 95% “somewhat agreed” or “agreed” that a majority of patients would “contact me or my practice with questions about their health record”.

Against this were some positives. 70% “somewhat agreed” or “agreed” that most patients would “better remember the plan for their care”, with 61% believing patients would “feel more in control of their healthcare”. Around half (52%) “somewhat agreed” or “agreed” that most patients would “better understand their health and medical conditions” or “be more likely to take their medications as prescribed” (50%).

Interestingly, 60% “somewhat agreed” or “agreed” that a majority of patients would “find significant errors in their GP record”.

The authors say that their findings “suggest patients in England may be vulnerable to negative stereotyping with regard to their capacity to understand and emotionally cope with reading their own health information”. However, they say, “in England, patients’ online access to their GPs’ records is here to stay. In the coming months, it will be crucial for GPs, primary care staff and patients to adapt to this radical change in practice”.



Access to health records and GP attitudes come up again in this report on a survey of awareness and use of the NHS App.

Just over three quarters (78%) of respondents were actually using the App and most of those (81%) found it easy to use. The most common uses were ordering a repeat prescription, reviewing personal health records and checking test results.

The quarter of respondents (23%) who were not using the App cited a number of barriers. 10% did not have a smartphone - others had problems with downloading the App, registering and logging in. Many were not aware that it can be accessed via a tablet or laptop, and some were completely unaware of the App.

The report states that “There is a lot of frustration among people who can’t access the services that are listed on the NHS App”. More than a third (39%) of respondents wanted to see their test results but couldn’t and 36% wanted access to their personal health records. “These responses”, say the authors, “highlight how many people still don’t have access to these services”.

They go on to say that “While GPs restricting access to information via the App may call this ‘stewardship’, many people in the survey... perceive this as GPs acting as gatekeepers, disempowering patients”. There is a sense that “GPs shouldn’t be able to control the flow of information, as this results in a lack of consistency and leads to disadvantage”.

The report covers other issues such as the needs of carers who are helping others to use the App. And it touches on issues of data security, noting that some respondents said their use of the App was limited by their concerns about what will happen to their health data.

A series of recommendations concludes with the statement that “some human issues will never be addressed by improvements to the App, and it is, therefore, always important to retain alternative methods of accessing healthcare”. In particular, “Healthcare providers need to ensure healthcare services will still be available for use via traditional face-to-face or telephone appointments and make it clearer to people that using digital services is a choice”.

3.6 Drug companies

In the UK, the [Sling the Mesh](#) campaign speaks for thousands of women injured by pelvic mesh implants. They are lobbying for a Sunshine Payment Act to improve transparency by forcing the pharmaceutical and medical device industry to declare all money given to doctors, researchers, lobby groups, health charities, surgeon societies and teaching hospitals.

They are not alone in their concerns, as evidenced by the following papers - one from Europe and two from America.

The paper considers possible reasons for non-disclosure. These, it speculates, could include “journal laxity, researchers’ sense of impunity, conviction that they are not swayed by industry largess, or convincing themselves that funding received was not related to the reported research”.

Whatever the reasons, the researchers conclude that “Self-reporting of financial COI by researchers appears to be unreliable and often contravenes requirements agreed upon by international medical journal editors”.

They go on to state that “Industry funding both declared and, to a greater extent, undeclared, permeates almost all research on pelvic mesh and almost certainly shapes the quality of and conclusions drawn from those studies. This biased evidence in turn skews the risk benefit picture and potentially drives overuse of pelvic mesh in clinical practice”.

About the Patient Experience Library

The Patient Experience Library acts as the national evidence base for patient experience and engagement in healthcare. Our mission is to:

Democratise the knowledge

Evidence on patient experience comes from patients. It is unethical for researchers to extract knowledge from patients and then publish findings via inaccessible professional research databases.

So our [open access repository](#) puts the knowledge back into the hands of patients.

Professionalise the practice

The patient experience workforce includes PALS teams, complaints handlers, patient engagement teams and people in the 150 local Healthwatch across England. They are almost unique among healthcare staff in having no formal qualifications and no systematic support for professional development.

So we are building a learning infrastructure for patient experience work, including [analytics](#) and [publications](#).

Change the culture

There is a tendency within healthcare to dismiss patient feedback as “anecdotal evidence” and to persistently exclude some communities and voices.

So we are helping people to spot the signs of [harmful](#) and [exclusive](#) cultures.

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.

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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	Key features	Sources
1. Surveys	<p>These gather mainly numerical data, often presented in spreadsheet format, and capable of statistical analysis.</p> <p>They involve large sample sizes (typically tens of thousands of respondents), with national overviews, broken down to local detail.</p> <p>CQC surveys also offer benchmarking reports, enabling NHS Trusts to compare their results with those of other similar Trusts.</p> <p>The surveys are rigorous in their methods and analysis. However, timeliness is an issue, with survey results often being published six months or more after commencement of fieldwork.</p>	<p>Care Quality Commission patient surveys for:</p> <ul style="list-style-type: none"> Adult inpatients Children and young people (includes views from parents and carers) Community mental health services Maternity services Urgent and emergency care <p>NHS England patient surveys for:</p> <ul style="list-style-type: none"> GP practices Cancer services Under 16 cancer patient experience
2. Formal research	<p>This takes the form of research papers formally published in academic and professional journals.</p> <p>The papers feature rigorous methodology, are often grounded in theory and are published following peer review.</p> <p>Timeliness is an issue, with lengthy research periods compounded by potential delays and revisions during peer review.</p> <p>Access is also an issue, as many papers are not available through open access publication.</p>	<p>Universities - sometimes in collaboration with health research bodies such as NIHR, HRA, NICE etc.</p>

Type	Key features	Sources
3. Reports	<p>Mainly qualitative evidence based on patient surveys and focus groups.</p> <p>They tend to feature small sample sizes, with a focus on specific named services and/or health conditions.</p> <p>The studies are open to criticism from academic researchers, who might see them as lacking rigour (eg not related to theory, or not peer-reviewed). They can also be seen as containing bias - particularly in the case of studies by health charities which can be linked to campaigning or fundraising goals.</p> <p>Strengths, on the other hand, can come from the fact that some studies are produced by organisations that are embedded in communities of place (eg Healthwatch) or of interest (eg charities linked to specific health conditions). Studies therefore can be based on trusted dialogue, and may reveal insights that are unavailable to more detached academic researchers.</p>	<p>“Patient voice” bodies including Healthwatch, National Voices, Patients’ Association.</p> <p>Health charities and think tanks such as the King’s Fund, Nuffield Trust, Health Foundation.</p>
4. Real time feedback	<p>These forms of patient experience data come directly from patients, service users, families and carers. They are not filtered through predetermined survey questions or mediated through the editing choices of report writers. So the people offering feedback can say exactly what matters to them.</p> <p>A potential disadvantage is that comments can lack detail - eg dates, places or even the service that is being commented on. Sometimes poor spelling and grammar can make the feedback hard to understand.</p>	<p>The NHS Friends and Family Test Care Opinion NHS.UK reviews</p>

Type	Key features	Sources
5. Complaints and compliments	<p>Complaints data is formally logged and reported via collection processes known as KO41a and KO41b. Returns are made annually.</p> <p>Compliments come via thank you cards and letters, emails etc. We are not aware of any formalised or standardised mechanisms for collating and analysing compliments data.</p>	Written communications from patients, families, carers and service users.
6. Other local evidence gathering	<p>Healthcare providers and commissioners gather further patient experience data via standing forums such as Patient Participation Groups or patient engagement committees, and also via occasional local surveys, focus groups and public meetings.</p> <p>We are not aware of any formalised or standardised mechanisms for collating and analysing data from these sources.</p>	Various local sources.

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	699,790
Adult Inpatient Survey	63,573
Cancer Patient Experience	63,438
Maternity Survey	25,515
Community Mental Health	14,770
British Social Attitudes Survey	3,374
Public perceptions of health and social care polling (Wave 5: November 2023)	2,301
Under 16's Cancer Patient Experience Survey	885

In addition:

- Healthwatch England's [2021/22 annual report](#) states that the Healthwatch network supported more than two million people with information, and to have their say on care.
- The NHS England Friends and Family Test hears from very large numbers of people every month. In April 2024 there were [1,866,679 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 2023 and July 2024, we uploaded 2,809 reports to the Patient Experience Library. Some had been published in previous years - the total published between August 2023 and July 2024 was 2,221.