

# Patient Experience

and patient/public involvement in health and care services

Summer 2024



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**INSIDE**

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## Editorial



Health literacy matters. With an ageing population, we have more and more people living with long-term conditions. The best solution for most of them - and for the NHS - is if they can be helped to “self-manage” those conditions in their own homes and communities. And for that, they need to understand their illnesses, their medications and other matters such as dietary regimes.

But clinicians too have to be helped with their health literacy. Patients who have been living with a health condition for years can often be as knowledgeable, if not more so, than practitioners. And sometimes carers and family members can also have valuable lessons to share with health professionals.

In this edition of our quarterly magazine, we hear from Tessa Richards who challenges the notion of a “one size fits all” approach to health literacy. As a clinician, medical editor, cancer survivor and patient advocate, she has a great deal to offer. But, she says, “most of the health professionals I interact with assume that I have the literacy of a 9 year old. It’s frustrating and often results in a poor exchange”.

Lesley Goodburn’s husband Seth died suddenly from pancreatic cancer ten years ago. For Lesley, health literacy comes in the form of a series of letters that she wrote to health professionals and organisations. Her aim was to help them understand how it felt to be her or Seth on each of the 33 days from his diagnosis to his death.

Clinicians have expert understanding of the medical progression of disease. But only patients can understand their unique personal journeys through illness. Both ways of knowing have value and only by putting both together can we have truly person-centred care. Perhaps that is what health literacy really means.

*Miles*

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# WHO knows best?

Tessa Richards



I have lived with adrenal cancer for 20 years, pernicious anaemia for 18, and ischaemic heart disease for five. Over this time I've learnt a lot about these conditions. My "health literacy" is good.

So I was interested to see that the World Health Organization is launching a new initiative to encourage all 194 WHO member states to collect data on population health literacy, and to develop material to teach health literacy in schools.

This is good news. It is well recognised that health organisations (as well as individuals) need to be better informed. WHO's rationale is that this improves health outcomes, counters misinformation, "pays off" financially, and helps drive governments to meet their responsibilities to tackle the determinants of health and health equity.

But pitching health information at the "right" level is challenging: the cultural,

linguistic, and educational divides are large. In the UK an estimated seven million adults have a reading age of 9, and many struggle to understand the most basic of statistics. A "one size fits all" approach to providing health information is far from ideal, not least in consultations with individual patients.

My background is as a clinician, medical editor, and patient advocate. Yet none of this is captured in my medical notes, which just record diagnoses. As a result, most of the health professionals I interact with assume that I have the literacy of a 9 year old. It's frustrating and often results in a poor exchange. And I'm not alone: one fellow patient advocate who has had Parkinson's disease for decades has told me that she finds it expedient to "dumb down" in her exchanges with GPs.

But this makes little sense. Health professionals need to adapt to an era of democratisation of health information and more empowered patients. One of their key roles is to promote patient agency, shared decision making, and partnership. Assessing people's experience, capacity, and skills - along with their priorities and preferences - while working out how to support and extend their agency, is surely a key component of professional health literacy.

There are a number of things that WHO could, and arguably should, underline more in its health literacy initiatives.

One is the importance of giving people full free access to personal, as well as generic, health information. This access

is key to helping people understand and self-manage their health - and correct errors and omissions in their records.

Another would be embedding co-production of health information, and the co-evaluation of services, with patients and the public. This could include consideration of how well health organisations collect and respond to patient feedback. Online models such as Care Opinion offer the best way to facilitate this in a timely way.

Third would be the issue of how easily patients can find their way through the labyrinthine mazes that characterise so many health organisations. Some employ "health navigators" - but whether it makes sense to employ navigators to steer patients, rather than co-designing user friendly services with them in the first place, is questionable.

Last but not least is peer support. I know from firsthand experience how the solidarity, insights, wisdom, and resources provided by networked patient communities can support patients and help them become more health literate.

Paternalism is yesterday's model. Patient communities are an important source of essential health information, and initiatives such as WHO's should draw on this knowledge and expertise. Health literacy is too important to be left solely to academics and health professionals.

# Seth's Legacy

Lesley Goodburn



As I walked out of the hospital on 14th June 2014, I could not imagine how I could survive the crushing grief that subsumed me. My wonderful husband Seth had just died from pancreatic cancer, 33 short heart-breaking days after being diagnosed.

The first six months after his death were a blur of pain, agony, and trauma. In November 2014 I sat down with Seth's medical records and wrote down what had happened on each of those 33 days.

This was a way for me to process the trauma of his death. I found myself writing letters to healthcare professionals about how it felt to be me or to be Seth on days where there was a focus on person and family centred care, and on days where this basic requirement was sadly missing.

In December 2014 the journey and letters were shared with the hospital

and the clinical commissioning group involved in Seth's care with the assurance that my painful personal experiences would be shared to make improvements. Eight months after sharing no one had come back to me and nothing had changed.

I then worked with the National Council for Palliative Care and a playwright to turn the letters and journey into a play called *Homeward Bound*. The play was launched in March 2016 and a film version called *Seth's Story* along with an educational resource was developed in 2016.

Over the intervening years Seth's Story has been used by health care professionals and educators in health and social care to create the emotional scaffolding for learning.

2024 is the 10th anniversary of Seth's death and although my letters shaped the messages in *Seth's Story* there is so much more in them than could be included in the film or the play.

The letters have remained very personal and have previously only been shared with the people involved in the film. But this year I have been sharing the letters in written form, as digital stories and in audio form. They are currently being included in the health care curriculum at multiple universities across the UK.

Below is a short excerpt from the letter written to the oncologist who Seth went to see about the possibility of palliative chemotherapy.

## Excerpt from the letter to the oncologist

I had become metastatic adenocarcinoma of the tail of the pancreas and the benefits of the chemotherapy which were redacted, combined with the slanted sticker seemed to reinforce and bring into sharp focus the futility of my situation.

Yours Faithfully

Seth Goodburn,  
a person who feels like a disease instead of a person.

As part of marking the 10th anniversary of Seth's death I will be setting up The Seth Goodburn Foundation charity which will help people share their experiences of health and social care via creative methods such as theatre, performance, dance, poetry, and creative writing. The creative outputs of this work will be shared with the universities I am currently working with. They will be used as educational resources and will help to shape the thinking of the healthcare leaders of tomorrow.

If you would like to share the letters in an educational or improvement setting, please do get in touch to [ljgoodburn@aol.com](mailto:ljgoodburn@aol.com) so we can discuss how they may help to improve care, compassion and person and family centred care.

This work is part of Seth's Legacy.

## RECENT REPORTS

Here, we review our top picks of studies and surveys from the last three months. Some are newly published - others are featured because they shed useful light on recent issues and developments. For full attributions, and copies of the original documents, click on the report pictures. Do you know of a stand-out report that we should be featuring? Contact us! [info@patientlibrary.net](mailto:info@patientlibrary.net)



# Parity a long way off

“The issue of unsafe discharge from hospital is nothing new” says the Parliamentary and Health Service Ombudsman in the opener to this report. In 2016, “my predecessor had seen patients not being assessed or consulted properly before discharge, carers not being informed and people being kept in hospital due to poor coordination across services”.

In mental health services, this can present a risk to a great many people. In 2020 to 2021, there were more than 270,000 attendances at A&E departments in England where a person was recorded as having a primary diagnosis of a psychiatric condition.

During 2021 to 2022 more than 50,000 people were detained under the Mental Health Act, and more than 97,000 people in England were admitted into NHS-funded mental health, learning disability or autism inpatient care.

So how much improvement has the ombudsman seen in the years since 2016? According to this report, not enough. Failings in discharge procedures persist, and “The most common failing... is the involvement of patients, their families and carers in decision-making”.

The report presents a series of case studies set out under headings that reveal the problems experienced by patients. These include incorrect information on self-help support, families not updated on the day of discharge, poor record-keeping, poor communication, poor joint working between professionals, and failure to carry out a Mental Capacity Act assessment.

The report makes a number of detailed recommendations, but an overarching concern is that “when these mistakes happen, the health service must be open and honest in its response, acknowledge the impact it has had, and commit to learning”.

That ought to go without saying, and it is worrying to see the ombudsman feeling that he has to spell it out.

Equally worrying is the fact that we are now seven years on from Prime Minister Theresa May’s call for [true parity for mental and physical health](#). And yet the ombudsman’s conclusion is that “reaching the point where mental health is given equal priority to physical health in terms of access and outcomes of care still remains a long way off”.



# The data gold rush

“Direct-to-consumer virtual care” is the focus of this Canadian study. It looks at “patient-initiated virtual care delivered by for-profit companies via proprietary software platforms”. These services, it says, “allow patients to obtain rapid and convenient access to virtual care without having a prior relationship with the clinician”.

It notes that “Patients appear to value direct-to-consumer virtual care services”, although it then warns that “much of the research has been commissioned by companies in the industry”. Benefits can include better access, convenience, cost savings and positive health outcomes. But some studies have indicated risks including overdiagnosis and overtreatment.

The key question for this paper, though, is the virtual care industry’s data handling practices. That question was explored through interviews with industry insiders and by examining industry websites.

A key finding was that “patient data were highly valued by the virtual care industry and used to generate revenues”. While this could help companies to improve and expand services, it could also mean adjusting patient care pathways to promote pharmaceutical products. One study participant described a “gold rush” to gain access to data.

These data handling practices were seen as both normal and acceptable. One participant explained that “these companies are doing what every other company that collects personal information does - using the data to make money”.

At the same time, study participants were aware of ethical issues.

One example was that “targeted advertising... could interfere in the patient care journey, with implications for patient health”. One participant said “I would like my care journey to be governed by what’s the best care for me, not who paid the most amount of money to get in front of me”.

Another concern was privacy. There were “confusing and vague privacy policies [and] difficulty opting out of data uses”. De-identification was not necessarily a safeguard: the process was described as “subjective” and some providers were said to be “pretty flexible with it”. Furthermore, “if companies combine and share datasets, the extra information also increases the risk of reidentification”.

The authors conclude that “Patients, healthcare providers and policy-makers should be aware that the direct-to-consumer virtual care industry appears to view patient data as a revenue stream, which has implications for patient privacy, autonomy and quality of care”. And, they say, “Policy-makers should consider how other models of virtual care, as well as enhanced privacy legislation and regulation, can address these concerns”.



# Co-opting feminism



“Increased awareness and advocacy in women’s health are vital to overcome sex inequalities in healthcare” says this paper from Australia. But, it says, “Feminist narratives of increasing women’s autonomy and empowerment regarding their healthcare... are now increasingly adopted by commercial entities to market new interventions (technologies, tests, treatments) that lack robust evidence or ignore the evidence that is available”.

One example is the AMH hormone test, used in fertility treatment. Levels of AMH in the blood are associated with the number of eggs in a woman’s ovaries. High levels indicate the presence of more eggs and, in theory, higher fertility potential.

But the authors warn that “the notion that AMH testing can enable women to make informed reproductive decisions rests on the incorrect assumption that the test reliably predicts fertility. The evidence now consistently shows that the AMH test cannot reliably predict likelihood of pregnancy, time to pregnancy, or specific age of menopause for individuals”.

In spite of this, “persuasive feminist rhetoric is being used on upmarket websites to conceal or gloss over the test’s limitations, as well as the commercial incentives behind the test’s promotion”. One website, for example, tells women “You’re not ovary-acting. Understand your hormones and fertility, be the boss of your symptoms and get the expert care you deserve - every step of the way”.

A second example relates to breast density – a risk factor for breast cancer. The paper states that “Consumer advocacy groups, often sponsored by large companies... argue that all women must be informed of their breast density to enhance their knowledge and health”.

Concerns about population-wide notification, however, include the relatively non-modifiable nature of breast density and the lack of evidence that clinical pathways for women with dense breasts are beneficial. Breast density notification can “increase women’s anxiety, confusion, and intentions to seek supplemental screening”, while supplemental screening itself can “include high rates of false positive results”, perhaps because of “The unreliability of breast density measurement, which varies across time and by assessor”.

Here, the authors point to messaging “evoking fear, guilt, or placing blame on women (eg, ‘If you haven’t had a mammogram, you need more than your breasts examined’).

The authors argue that “Women’s health is vital and cannot be allowed to be hijacked by vested interests”. On the other hand, “persuasive messaging that uses the guise of feminist health advocacy can be difficult to criticise, as legitimate critique may be misconstrued as misogynistic or paternalistic”.

They say that “Health consumers and clinicians need to be wary of the simplistic narratives that any information and knowledge is always power”. And, they say, “Communication between women and their clinicians is a key aspect to addressing this”.

# Ways of knowing



“Permanent medical devices are implanted for a wide range of indications across many medical specialties” says this study. It concentrates on one in particular - the vaginal mesh implant used to treat stress urinary incontinence.

Developed in the 1990’s and initially seen as the gold standard, the device was before long subject to “a cascade of governmental reviews and regulatory warnings” arising from reports of pain, haemorrhage, infection and more.

The study aimed to explore and understand women’s experience of living with complications attributed to vaginal mesh surgery. It found key themes including:

- Loss of dignity. Participants described the humiliation of urine leakage that was the context for surgery, but which could also become a barrier to discussions about post-surgical complications.
- Loss of self. Pain and exhaustion, along with loss of jobs and social lives led some women to feel robbed of present and future selves.
- Dehumanisation. Participants described the need to be treated as a human being, not as body part. Some described being “butchered” by surgeons.
- Trust. Some women felt ‘lied to’, ‘conned’ or ‘tricked’ into surgery. Some were angry that vaginal mesh had been ‘sold to them’ as ‘gold standard’, saying that risks had been underplayed.
- Infallibility. This theme describes encountering an infallible and inflexible medical way of knowing. Participants felt that the medical community ‘denied’ that symptoms were caused by mesh. Some felt treated as if they were ‘neurotic’, or ‘hysterical’.

The issue of “ways of knowing” is crucial. Women described how they sought their own ways of knowing, as well as a sense of solidarity, in online communities. They were sustained by the collective marginality of those existing together in a ‘wilderness’. In community, they found their way out of the wilderness and no longer felt alone or ‘mad’.

The authors find that women, overall, are asking to be treated as “an embodied whole”. Clinicians need to understand that their scientific knowledge (medicine) and craft knowledge (surgical practice) should be tempered with “wisdom” - knowledge that is forged through experience and relationships, and is concerned with moral life and human dignity.

They state that “epistemic injustice - whereby a person’s contribution to the production of knowledge is unrecognised or unjustly excluded... is an ethical issue for careful consideration in healthcare”. And “Differentiating anatomy, or indeed pathology, from the experience of a condition may help us to understand the areas of miscommunication that led to widespread mesh use”.

This, they say, “has important implications for clinical education in the future”.





## Past and future waiting

Waiting times for treatment have a profound influence on patient experience. Four years ago, [National Voices showed](#) how people on NHS waiting lists can feel caught in an information vacuum. Some described “fighting” the system, while others talked of “giving up” and “not thinking about the wait” in order to protect themselves and keep their concerns in check.

This report, from the Institute for Fiscal Studies, looks at waiting list data from the last 17 years and presents new scenarios of what could happen to waiting lists over the years to come.

Some of its findings restate known facts. NHS waiting lists were already growing pre-pandemic, doubling from 2.3 million in 2010 to 4.6 million in 2019. The Covid crisis accelerated the growth, with 7.8 million on waiting lists by 2023.

Equally, it will come as no surprise to read that “The NHS and government have failed to achieve most of their waiting list and waiting time targets in England since 2010”. The report goes on to say that the “target that 92% of patients should receive treatment within 18 weeks of referral has not been met since September 2015 and looks unlikely to be met any time soon”.

Digging into the detail, the study finds big variances across geography and services. Compared with January 2020, the waiting list in December 2023 was 71% higher in the North East and Yorkshire but 113% higher in the East of England. The waiting list for general internal medicine was 2% below its January 2020 level in December 2023, while the waiting list for gynaecology was 109% above.

The authors make the point that “There is a lot of uncertainty over what could happen to waiting lists in England in the coming years, and so it makes sense to consider a range of scenarios”. Their most likely scenario is that waiting lists start to fall from the middle of 2024 - but even by December 2027, would still stand at 6.5 million - “far above pre-pandemic levels”.

A more optimistic scenario indicates 5.2 million people on waiting lists by December 2027, and a pessimistic scenario suggests little or no reduction from current levels.

[A simple analytic](#) allows users to create their own scenarios, factoring in treatment volumes and new joiners. (This could be useful to analysts but will offer little comfort to anyone currently facing the misery of a life on hold.)

The authors conclude that “NHS waiting lists are, and will continue to be, a major policy issue”. Their analysis indicates that the next government could inherit a falling waiting list - but, they say “getting the waiting list back to pre-pandemic levels could require more than one parliament”.



# Women's wider health needs

This opinion piece 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. 2024 priorities include better care for menstrual and gynaecological conditions; improving support for victims of sexual abuse and violence; and more research to tackle maternity inequalities.

Progress in these areas is welcome, say the authors. However, the 2024 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 of women's health.

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".

The article concludes with a view that the Women's Health Strategy's priorities "are critical for achieving positive change". However, "to truly take advantage of this opportunity, 2025's priorities will need to tackle women's wider health needs".



## Experience of the NHS App

This report comes from the Patient Coalition for AI, Data and Digital Tech in Health - a group of organisations aiming to champion the patient perspective in digital health. They surveyed 637 people to ask about 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”.



# Dying in the margins



Place of death is a government proxy indicator of ‘quality dying’ in most Western countries, including in the UK, 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 barriers to, and experiences of, home dying for people experiencing poverty and deprivation in the UK.

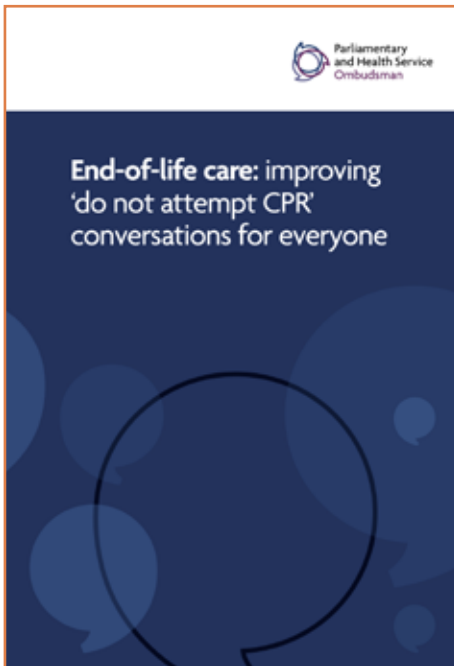
Its first finding was that there are considerable costs associated with dying at home. People at end of life need warmth - and heating is expensive. They might need non-invasive ventilation, or a bed hoist. Bedding might need washing more often than usual. All of this adds to electricity bills. On top of this are care costs and for some people, taxis if other means of transport are unavailable.

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”.

They identify a need for “a strong commitment from the various sectors involved - health, housing, social care, social security, and the third sector - to take a whole-system approach to delivering equity at the end-of-life”. 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”.



## End of life conversations

“Conversations about end-of-life care are sensitive and emotionally challenging” says this report from the Parliamentary and Health Service Ombudsman (PHSO). 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 various problems, including the fact that healthcare staff were not always well trained. Consequences included 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.

Almost all of the DNACPR complaints received by the PHSO were from or on behalf of disabled or older patients - the very people most affected by Covid. 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 a series of 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”.

# Drug company payments



This paper starts with the observation that every year medical device and pharmaceutical companies give billions of euros to healthcare professionals and healthcare organisations.

These payments, it says, can create conflicts of interest: “evidence shows that receipt of payments from the pharmaceutical industry is associated with higher prescribing rates, higher prescribing costs, and lower prescribing quality”. It adds that “some medical device industry payments have also been associated with legal breaches”.

Some European countries are introducing disclosure requirements – however, “the preferred approach to payment disclosure in Europe is industry self-regulation”. This, says the paper, creates “transparency limitations”.

The authors looked at the MedTech Europe disclosure database to evaluate disclosure through that route.

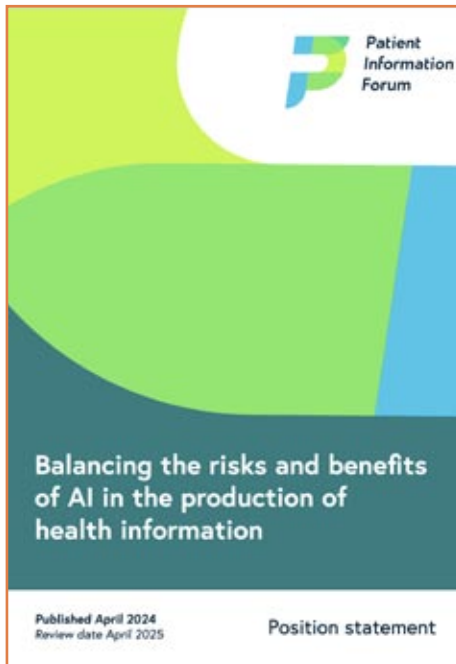
Their first finding was that between 2017 and 2019 medical device companies in Europe declared €425 million in educational grants to healthcare organisations. However, this “likely underestimates the true extent of medical device industry payments” not least because “many companies are not members of MedTech Europe or the national associations within MedTech Europe”.

Another finding concerned accessibility and quality of the database. Here, there were problems with availability of customisable statistics, time limits (data appears to be removed four years after disclosure), and breadth of payment areas (several areas were not included, including consulting, gifts, and charitable donations).

The authors state that the usefulness of the database “is severely limited”. They point to a need for “a publicly mandated payment disclosure database” that “could be EU-wide and cover both the medical device and pharmaceutical industry”.

They also suggest that a mandated database should cover payments not just to healthcare professionals and organisations, but to patient organisations as well.





## Risks and benefits of AI

“Use of artificial intelligence (AI) in healthcare is on the rise” says this briefing from the Patient Information Forum. And it 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”.



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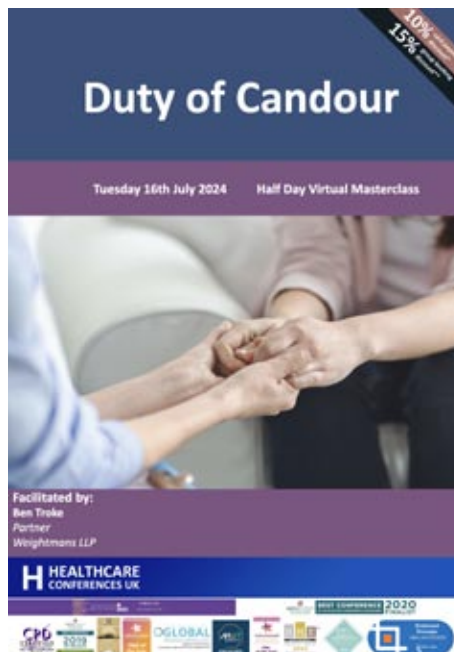
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## NHS Complaints Summit

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This National Virtual Summit focuses on the New PHSO National NHS Complaint Standards which are now being used and embedded into the NHS. Through national updates, practical case studies and in depth expert sessions the conference aims to improve the effectiveness of complaints handling within your service, and ensure that complaints are welcomed and lead to change and improvements in patient care. The conference will also reflect how involving people and their families in complaints and integrating the process with the new Patient Safety Incident Response Framework (PSIRF) to ensure patient safety actions and learning.

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|--|
| Ben Troke<br>Partner<br>Wrightmans LLP |
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HEALTHCARE CONFERENCES UK

## Duty of Candour

**Tuesday 16th July 2024**  
**Virtual, Online**

Openness, trust and good communication are at the core of the relationship between health and care professionals and their patients / families. But the duty of candour is widely misunderstood, and often misapplied, which can leave practitioners feeling exposed and patients / families feeling frustrated and, perhaps, push them towards other legal processes to get answers.

This course will help attendees to understand the relationship between the statutory and professional duties of candour, in the wider context of the importance of good communication and the reasons why complaints and claims are made.

[Further information and booking](#)



*Virtual Masterclass*

**Insight to Improvement - The Northumbria Way**

Thursday 19th September 2024 Virtual Masterclass

10% discount  
15% discount

Facilitated by:

|   |   |
|---|---|
| Ai Mackintosh<br>Chief Experience Officer | Lainey Fraser<br>Consultant Psychotherapist |
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HEALTHCARE CONFERENCES UK

## Insight to Improvement - The Northumbria Way

**Thursday 19th September 2024**  
**Virtual, Online**

Northumbria Healthcare NHS Foundation Trust has developed a well-recognised and award winning patient experience improvement programme that spans a more than a decade. In 2018, the organisation took important steps to invest in the health and wellbeing of its staff, by developing a similar, integrated staff experience programme. This session will provide attendees with the opportunity to understand the 3 key elements of the Northumbria programmes; measurement and reporting; improvement approaches; and collaborative working practices. Attendees will consider how to enable an organisational culture that reinforces the interconnectedness of staff experience and patient experience and reflect on the principles of collaboration and engagement methodologies to drive improved experience and better care outcome for people and communities.

[Further information and booking](#)

## Want more training?

Our training tracker gives you access to a range of courses on patient experience and engagement - face-to-face, online and bespoke. To find the course you need, use our training tracker [here](#).

# Confused?



Patient experience evidence comes in different formats at different times from multiple sources. It is hard to make sense of it all.

## We can help you with...

**LIBRARY SERVICES:** Free access to the [Patient Experience Library](#), [Healthwatch maps](#) and [Quote Selector](#).

Struggling to keep track of local reports from public meetings, focus groups, surveys, Healthwatch, Maternity Voice Partnerships, Cancer Alliances etc? Ask us about tailor-made local libraries for your Trust or Integrated Care Partnership.

**EVIDENCE SERVICES:** Free access to [research-based publications](#).

Need to contextualise your own local evidence gathering? Ask us about bespoke search and literature reviews like [this](#) and [this](#).

**ANALYTICS:** Free access to our [Patient Surveys Tracker](#), [Waiting Lists Tracker](#) and [Evidence Maps](#). Looking for more like this? Ask us about customised analytical tools to support your insight and engagement work.

Get in touch! [info@patientlibrary.net](mailto:info@patientlibrary.net)



# The Patient Experience Library

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

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

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

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

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

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**Patient  
Experience  
Library**

Cover: Gerard Dou - Portrait of an old woman reading. 1632. Rijksmuseum.

