Is healthcare personal or political?

The answer, of course, is that it is both, and our contributors to this edition of our quarterly magazine unpick both strands.

Charlotte Augst (page 3) argues that an NHS creaking from years of underinvestment needs a “laser sharp focus on the experience of people using services”. NHS strategists like to talk about ICBs, place-based strategies and provider collaboratives. But these mean nothing to people stuck in ambulance queues, or on waiting lists, or in GP call handling systems. Patients are also voters, and NHS leaders need to offer pragmatic solutions to stave off political as well as personal discontent.

Andrea Downing (page 4) looks at the advertising and marketing tactics used by digital medicine companies to extract health information from users. Who sees what data, and how are specific patient populations targeted? And to what extent do those companies comply with their own privacy policies? The answers should be of concern to legislators and regulators, as well as to patients.

As always, we also bring you the latest and best patient experience research, packaged in handy summaries for busy people. And we’re always keen to hear from our readers, so if you know of a standout report that we should be featuring, or if you want to submit a comment piece, get in touch!

Miles

Miles Sibley, Editor info@patientlibrary.net
Patients, politics and priorities

Charlotte Augst

News cycles move on, and winters melt into spring. But a chill wind continues to blow through the NHS.

There are still long delays for ambulances and lengthy waits in emergency departments. 7 million people are stuck on waiting lists. Too many people find it hard to get through to their GP on the phone. And too many NHS staff say that they cannot work in ways they feel they should, or give the kind of care they would want for their own loved ones.

I have of course had my own difficult experiences in healthcare, dealing with my husband’s terminal cancer and death. And having led the National Voices coalition of health and care charities over the last few years, I have seen many brave attempts to keep services going in the face of growing challenges.

All of this has led me to believe that any attempt to restore NHS performance needs to start and finish with a laser sharp focus on the experience of people using services.

Only by staying close to the actual touch points people have with a service can we be sure that our efforts are focused where it matters. Only by working backwards from what needs to be different for people and patients can we prevent wasting precious time and money on pointless re-disorganisations and deckchair feng shui.

Some might say that in times of exceptional pressures we simply cannot afford to fret over patient and user experiences. But the opposite is true. When resource is scarce, we should be even more focused on what creates value for the patient.

Healthcare which leaves people confused, angry, discouraged or alienated is not just low value healthcare. Some of the people who decide not to trouble their doctor or not to chase a difficult appointment will die as a consequence. We are seeing alarming levels of excess mortality – and it is not all attributable to disease. Some is attributable to people finding services just too difficult to use.

Particularly troubling is the clear connection of poor experience to health inequalities. Every time a deaf person experiences healthcare that’s confusing because their communications needs haven’t been met, every time a Black person feels disbelieved or alienated because of racism or bias, health inequalities have been increased. And not just for the individual patient. People talk to each other, and far too many conclude that services don’t work for ‘people like me’.

Alongside all of this, there are good political reasons for service leaders to focus on what goes on for people.

The NHS is in direct contact with 1.5 million people every 24 hours. These people vote. Most of their encounters will be good ones. But many also won’t. And it is those ones that compel people to talk to political decision makers. Concerns will certainly continue to be made known to councillors and MPs over the next year.

There are two possible responses from NHS leaders. They can explain how they will address people’s concerns - sorting the 8 o’clock scramble for a GP appointment, or the old person’s emergency experience when their carer was excluded from accompanying them. Or they can keep talking about ICS’s, ICBs, place-based strategies and provider collaboratives. Which somehow magically are going to make all this better.

I know which one will be more convincing to political leaders. And we all have an interest in not letting the most destructive framing of all settle: that the NHS is irreparably broken, that we need a ‘new model’.

To fend off calls for the NHS to be dismantled or based on a different funding model, NHS leaders must show that they ‘get’ the experience of users and have pragmatic responses to make them better.

Improving the experiences of patients and therefore voters could not be a more necessary priority for everyone in charge of NHS services.
When we talk about “digital healthcare”, we often think about the technologies used for health apps, for “wearables” and for remote consultations. But there is another side to digital healthcare that can matter just as much – sometimes more - to patients.

There are increasing numbers of online patient communities, often based around specific health conditions, and frequently offering education, networking and peer support. People need safe spaces in which to open up about their physical and emotional wellbeing, and to share sensitive personal information about their daily lives.

So we need to talk about surveillance capitalism in healthcare.

Social media platforms like Facebook have become common places for patients to seek support from their peers online. And health and pharmaceutical companies spent almost one billion dollars on Facebook mobile ads in 2019.

So I have been gathering data for two years on the advertising and marketing tactics used by digital medicine companies to extract health information from users. I’m particularly interested in how browsing data can be exchanged between those companies and Facebook for advertising and lead generation, and to target specific patient populations.

My focus has been on cross-site-tracking middleware which can make patient populations vulnerable to online scams, medical misinformation, and privacy breaches.

Put simply, the ways in which internet browsing data reveal facts about health to advertisers can be deceptive when patients seek knowledge on the internet. A “dark pattern” is a user interface design that can nudge or coerce users into making unintended and potentially harmful decisions. “Privacy Zuckering” is a known type of dark pattern that occurs when a user is tricked into publicly sharing more information than they really intended.

With my co-author Eric Perakslis I found digital medicine companies that did not comply with their own policies or claims about privacy, and companies that created digital footprints to enable ongoing tracking and surveillance of patient populations on Facebook. This ties in with similar findings from another recent study demonstrating that in an ecosystem of digital medicine apps available on Google Play, only 47% of user data transmissions complied with each company’s own privacy policies.

This matters because health privacy is a basic requirement in digital medicine for reducing the abuse of power and supporting patient autonomy. My investigations have shown that personal data and personal health data can be easily obtained without the aid of highly sophisticated cyberattack techniques but with rather commonplace third-party advertising tools.

While privacy Zuckering dark patterns are deceptive, it is not clear that companies in our study intended to deceive their users. Nor is it clear the extent to which these companies were aware how tools are feeding data about users’ health information to Facebook as they engage with ads.

But it does appear that some marketing tools reveal a dark pattern used to track vulnerable patients’ journeys across platforms as they browse online, in some ways unclear to the companies and patient populations who are engaging through Facebook. Meta may have made billions in ad revenue without being clear or transparent about how they attain health data to target ads to patients in the past few years.

While the digital medicine ecosystem relies on social media to recruit and build their businesses through advertising-related marketing channels, these practices sometimes contradict their own stated privacy policies and promises to users.

We hope that the details around these vulnerabilities inspire deeper introspection into the tools and tactics that digital medicine companies use to increase their reach toward the patients they seek to serve and protect.

The full study: “Health advertising on Facebook: Privacy and policy considerations” can be seen here.
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

Data-driven inequality

“Data saves lives” says the Department for Health and Social Care, in a document advocating better use of data for purposes including “tackling unequal outcomes and access”.

The Ada Lovelace Institute agrees that data-driven systems can provide better health and wellbeing outcomes but warns in this report that they also risk exacerbating existing inequalities in health. In particular, “Data-driven systems can both alleviate and entrench inequalities - but the latter may be more likely when people's needs are sidelined in service of an overreliance on data”.

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

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

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

Accordingly, there is a need for system designers and users to take a people-centred approach – always considering the context in which data is collected, used and understood, and considering who is involved in decisions.
Access to records? Not yet.

Back in 2019, the NHS Long Term Plan called on health services to deliver more person-centred care. Part of the follow-through was that all GP patients would have “online access to their full record, including the ability to add their own information, as the default position from April 2020”.

This paper looks at what has happened since then.

According to the authors, NHS England planned to provide citizen access to general practice records in December 2021. But the launch was put back to April 2022, and then further deferred to November 2022. Then, just two days before the November deadline, the BMA called for a total rethink of the programme. “It remains unclear”, says the paper, “when default access will be available for everyone”.

In the absence of default access, patients still have a legal right to apply for access to their own health information. But “those who request it often face barriers or are given only limited data”. Similarly, information on things like consultations and test results is technically accessible through the NHS app. But “most patients have not been ‘enabled’ to see it, and many are unaware that this is possible”.

The paper makes the point that “Incomplete and uneven access to personal health information makes little sense to patients and their carers. Lack of timely access adds to their healthcare burdens”.

The authors conclude that “With access to care in the UK among the worst in Europe, patients have little choice but to be more self-reliant”. They argue that “Ready online access to their full health record would help them and also reduce demand on the health system. The commitment to provide it”, they say, “should be realised”.

Government foot-dragging on harm to women

In July 2020, Baroness Cumberlege published her First Do No Harm report on avoidable harm arising from medicines and medical devices - specifically, Primodos, Sodium Valproate and pelvic mesh. The harms were well known because the many thousands of women affected had been speaking up for years, even decades. But no-one had wanted to hear them.

This report from the House of Commons Health and Social Care Committee comes two and a half years after the Cumberlege Review, and documents an evidence session to consider the government’s response. The Committee’s assessment includes the following:

- Without records of which patient has undergone which procedure, or been prescribed which drug, the health system will continue to... fly blind.

- Although the retrospective audit of mesh implants is an encouraging first step, it will be unlikely to reflect... all of the adverse effects women have experienced due to the nature of data used in the audit.

- We were encouraged to hear that the Government is going ahead with pilots of a register of clinicians’ interests, but we are disappointed by the speed at which the Government is acting on this recommendation.

- Although the Government has also given itself the powers to set up a register of industry payments to clinicians, no decision has been made yet about how to implement it, and officials were not able to share a plan of when the register would be active.

- Although the vision for what the role of Patient Safety Commissioner will achieve is publicised by the Department, no statement of specific assignments or areas of responsibility, have been published yet.

There is more besides, but it is clear that the government response is, at best, sluggish. Worse still, it seems detached from the needs - and knowledge - of the tens of thousands of women who continue to live with mesh-induced injuries, and in the case of valproate, birth defects and developmental issues for their children.

The Committee states that “We... urge the Department to reflect on the experience of some of the stakeholders with lived experience in this instance, and to consider how to improve engagement with them in the future”. 
The lazy language of lifestyles

One of our previous Featured Reports looked at the ways in which health inequalities are understood and addressed in NHS policy documents. It found a widespread use of value judgements applied to local populations – revealed through discussion of lifestyle and behaviour being major determinants of health.

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

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

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

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

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

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

Understanding financial relationships between patient groups and pharmaceutical companies is, according to this Canadian study, necessary for understanding the position that patient groups take when the interests of companies are involved.

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

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

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

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

The study searched the websites of IMC members and patient groups. It found that “only a quarter of IMC members...reported making donations to patient groups on their websites and frequently only the names of the patient groups were given and the value of the donation and its purpose were omitted”. In spite of this, “There were no reports on the IMC website about companies failing to comply with the guideline”.

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

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

Vaccine compliance and defiance

In June 2021, with both the pandemic and the vaccination roll out in full swing, we featured a study of vaccine hesitancy in Bradford.

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

Eighteen months further on, the authors have published a follow-up.

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

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

Confusion continued to arise from discussion and rumour among friends and online groups, and some felt overwhelmed by conflicting accounts.

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

The authors say that their findings “illustrate the continuum of vaccine hesitancy and acceptance and recognize that those who have chosen to have the vaccine may still have doubts and concerns”. This, they say, is important because “it means that we cannot take their current vaccine acceptance for granted”.

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

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

This House of Lords report on adult social care opens with a stark fact: around 10 million of us are affected by the adult social care system in England at any one time. In spite of this, “adult social care continues to be largely out of sight and off the public agenda”, and our understanding of adult social care “is partial and often flawed”.

The report, by the Adult Social Care Committee, says that “Drawing on adult social care should not be seen as a disaster” but it is also clear that the state of adult care is verging on disastrous. It says that:

The last ten years have seen a 29% real-terms reduction in local government spending power, and an estimated 12% drop in spending per person on adult social care.

An estimated 44% of working age adults who were caring 35 hours or more a week live in poverty.

The average person now has a 50% chance of becoming an unpaid carer by the time they reach 50.

The report covers the testimonies of unpaid carers - the people who have to “step up to provide care and support when the system is failing”. It describes the exhaustion of people living with the assumption that social care happens first and foremost in the family circle. An assumption which means the work of unpaid carers is “largely invisible, unrecognised and unsupported”.

The Committee calls for adult social care to become a national imperative with an appropriate and long-term funding settlement. It says that people who draw on care should have the same choice and control over their lives as other people. Thirdly, it wants an end to the assumption that families will automatically provide care and support for each other because no other choice is open to them.

The Committee finds that “Without a fundamental rethinking of how we understand, approach and design social care... we will keep failing disabled adults, older people, unpaid carers, and ourselves”.
Mutual healing and patient safety

“It is well known that healthcare workers make decisions that affect patients’ lives while under pressure to do better, faster and with fewer resources”, says this research paper from Canada. It continues: “These circumstances can lead to medical errors, often because of a system failure, and occasionally due to human error”.

The authors recognise that for patients, caregivers and family, the consequences of medical error can be profound, encompassing physical, emotional and psychological harm. And they note that healthcare workers too, can feel guilt, shame and distress.

Organisations such as Patients for Patient Safety Canada believe that healing can be possible if healthcare workers and patients are able to meet, work together and explore harmful events and the feelings associated with them. However, “Research in this area is scant”.

In this context, the researchers asked “How might purposeful conversations between patients and HCWs promote mutual healing and wellness after the disclosure of a medical error?”. They carried out a literature review backed up with semistructured interviews to draw out relevant insights.

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

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

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

“We will put patients at the heart of the NHS.”

Back in 2010, this was the bold promise of the newly elected coalition government, set out in its paper “Equity and Excellence: Liberating the NHS”.

The paper was published as the Francis Inquiry was shocking the nation with revelations of large scale harm at the Mid Staffordshire Trust. That inquiry was highly critical of the Local Involvement Network (LINk) - the government-funded patient voice body which should have spoken up for patients but had manifestly failed to do so.

The government’s response was to abolish the England-wide LINk network and replace it with a more effective version. “Liberating the NHS” said “We will strengthen the collective voice of patients and the public... through a powerful new consumer champion, HealthWatch England”.

The government recognised that the weakness of the LINks was in part due to inadequate funding, at just £27 million per year for the entire national network. So when Healthwatch was established in 2012/13, it was given a considerably increased allocation of £40.5 million.

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

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

In this context, the promises to learn from the Mid Staffordshire disaster seem empty. So too does the promise to put patients at the heart of the NHS.

There is, however, one key lesson. To really understand the government’s intentions in respect of patient voice, follow the money.
Taking patient engagement onstage

Traditionally, patient feedback is channelled through mechanisms such as the Friends and Family Test, or patient surveys, enabling healthcare staff who decide how the feedback is reported.

By contrast, online platforms such as Care Opinion bring patient feedback into the limelight.

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

Three NHS Trusts were studied in the context of Care Opinion: a non-responding organisation (site A), a generic responding organisation (site B) and an organisation that provided transparent, conversational responses (site C). Comparisons included the following:

AUDIENCE INTERACTION. Site A had 2,120 patient narratives via Care Opinion during the study period, and at the start, had a response rate of 0%. Site C had 6,500 patient narratives in the same period, and by the end had posted over 7,500 staff responses which had been read more than 1,787,900 times.

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

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

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

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

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

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

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

Evidence on people’s experience of care comes from many different sources: patient surveys, local Healthwatch reports, academic research, online feedback and more. This open access course helps you to understand how to keep track of it all – and to start making sense of it.

Designed by the Patient Experience library for the NHS Leadership Academy, the course covers:

- Who does what in patient experience evidence gathering.
- Key concepts in patient experience work.
- Why patient experience matters.
- Challenges of hearing from patients.
- How to find different types of patient experience evidence.
- How to start making sense of patient experience evidence.

The course is free, and learners can log in at times that suit them, with the ability to pause part way and carry on at another time if they want.

It is designed to be helpful for people who are new to patient experience work, as well as for people who are familiar with the basics but need to consolidate their knowledge.

As well as people in PALS teams, complaints, local Healthwatch etc, the course could be helpful for patient reps on engagement committees – and for any nursing directorate staff or Trust Board members who need a good grounding in patient experience work.

To find the course, simply go to https://leadershipnhs.uk/, select your region and create an account (free), or log in if you are already a user of the Leadership Academy website.

After that, look for “Patient Experience” in “Leadership Modules” and get started!
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Further information and booking
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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

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