Editorial

Patient experience is often thought of as a kind of “customer satisfaction” exercise. An obvious example is the NHS Friends and Family Test, which is described as a way to help service providers and commissioners understand whether patients are happy with the service provided.

But patient experience is also about human rights. And in this edition of our quarterly magazine, we hear from Julia Jones (page 3) about something very fundamental: the right of patients to maintain their closest personal relationships and be supported by someone who loves them. In the crisis period of the pandemic, that basic human need was too often forgotten, with terrible consequences. Julia describes how she is now winning support from MPs for a change to the law.

A third aspect of patient experience is the experience of self managing a long term health condition. Ceinwen Giles on page 4 shows how that is not just about understanding medications and self-care. It is also about weaving your way through the tangles of health service administration. Her tale might have you laughing or crying, or both.

We – the Patient Experience Library - continue to do what we can to help people make sense of the mixed-up world of patient experience and engagement. Our newly launched quote selector gives you hundreds of snappy one-liners for research and reports, or as ammunition for debates! And our evidence mapping project is about to go up a gear thanks to funding support from the Health Foundation (more about this on page 6).

As always, we have been picking through some of the latest and best patient experience research, and summarising it through the rest of this magazine. 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

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Comment

Do you have opinions, insights or good practice examples that you’d like to share with our readers? Drop us an e-mail to receive our guide for contributors: info@patientlibrary.net

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Feel free to browse the Patient Experience Library - over 70,000 reports on all aspects of patient experience and engagement. We can build tailor-made local libraries for your Trust or Integrated Care Partnership - drop us a line to find out how.

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Beginning of the end?

Julia Jones, Co-Founder, John’s Campaign

A week before the notice expired, she died and Ann was finally able to ‘visit’. “Sitting with my mother’s body was the longest time I had been allowed to spend with her since she had entered the care home sixteen months before.”

When John’s wife refused to eat or drink and was thought to be dying, he was allowed into her care home. As soon as her condition improved, he was once again excluded.

This happens in hospitals too. One elderly man with dementia had recovered from covid, but then suffered an adverse reaction to a second jab. He was from Venezuela, and did not understand English – or English food. He spent four weeks deteriorating in a hospital ward until it was decided that treatment should be withdrawn.

As his family were rigorously excluded from all aspects of his care, it seems a mystery to me how any explanations were given or consents obtained. It also seems a mystery, frankly, how people working on the ward could have observed this mute, uncomprehending man day after day, without thinking to buck the ‘rules’ and involve his family.

In fact, this correct and compassionate action would have obeyed that hospital’s ‘rules’. The trust was pledged to John’s Campaign. Family carers of people with dementia were welcome on their wards ‘at any time’. Imagine how his son and daughter in law felt when he was deemed to be at end of life so was moved to a different ward where the pledge was honoured.

They discovered they could have been caring and advocating for him throughout. Predictably, he rallied: clinicians were amazed, treatment was resumed.

There wasn’t a happy ending however. Eight days later, he did die, leaving his grieving family with the forever-unanswerable question, would he have deteriorated so badly had their care been welcomed from the first?

John’s Campaign is not enough. Hospitals have to remember their pledges; families have to know they can insist. In the mindset that “Everything stops for Covid”, too many institutions have also forgotten national protective legislation such as the Equality Act and the Mental Capacity Acts. Family members entrusted with Power of Attorney or Guardianship responsibilities have been ignored. Human-kindness has too often been absent.

The MPs in the meeting were shocked. Sixty of them from all parties signed a letter to the Secretary of State, asking for legislation to ensure that vulnerable people have the right to a care supporter wherever they are – hospital, care home, mental health unit, GP surgery, rehabilitation unit. The right should lodge with them, not the institution. A reply from Sajid Javid is expected: a backbench business debate is currently being arranged.

Could this be the beginning of the end for John’s Campaign? We hope so.
Logistic toxicity

Ceinwen Giles, Director, Shine Cancer Support.

In the times Before Coronavirus, I attended hospital every four weeks for an immunoglobulin infusion and, every third month, a quick blood test. Of course this routine has changed since the pandemic hit. And an easy monthly appointment has turned into something approaching a part-time job.

With my new “home therapy”, my once-a-month infusion is now five weekly sub-cutaneous injections. I also have to organise medicines and materials via email or phone, and double check them when they arrive (it’s not unusual for the delivery to be short). However, I was unprepared for the Herculean efforts that a blood test would require.

“We’ll have to send you a vial for the blood test”, my nurse emailed. “Take it to your GP and then post it back.” The postage was necessary because I live in south London and there is apparently no way for a blood test to be done south of the river and have it shared with the hospital in the north.

And that was just the start.

Last year, I moved. I should have changed GPs but then the pandemic hit. “We can’t change your address on our system,” my immunology nurse told me when I discovered the hospital had my old address and couldn’t send the vial for the blood test. “It’s linked to your GP surgery, so you need to talk to them.”

I emailed my GP surgery to ask if they could change my address while I waited to switch GPs. No dice. I needed a new GP. Luckily, the GP surgery I’d planned to join now allows for you to join online and that went relatively smoothly.

Having successfully switched GPs and received the vial, I now needed to get my blood into the vial. I booked a phone appointment with my GP.

“Be sure to be by the phone on either side of the time,” the receptionist told me. The GP phoned an hour early and seemed surprised that I was surprised. In any case, the doctor recommended I attend a “shielers’ phlebotomy service” at the local hospital.

“You have the form?” the GP asked.

“The form?” I asked back.

“The vial should have come with a form”, she replied. No form had been provided. This caused some confusion, but by the end of the call she’d put in a request for me to go to the phlebotomy service. They called me the next day to book an appointment.

“You have the form?”, the receptionist asked.

“No”, I replied. “No form”.

“NO FORM?”, she said, sounding confused. “I’m going to have to call you back”.

Half an hour later I received a call telling me that I could come in at 10:30am the next morning. “I’ve made a note about the form”, the receptionist said.

Arriving the next morning at the hospital I was ushered into a room for my test. “You have the form?”, the nurse asked me.

I explained, again, that I’d never been given a form. To this day, I don’t know what form they were looking for.

Having finally filled the vial, I needed to post it. As a shielder, the post office isn’t high on my list of places to visit so I had to get my husband to post it for me.

“You want me to put a vial of your blood in the post?”, he asked incredulously. “Is that allowed?” Assured that it apparently is allowed, he went off, returning an hour later, feeling slightly revolted.

I recently came across the term “logistic toxicity” to describe the administrative burden of healthcare. With my shift to home therapy, what was once a one-off appointment was replaced this month by: two emails about medical supplies, delivery and storage of those supplies, 25 sub-cutaneous infusions, a switch of GPs, a GP appointment, a phlebotomy appointment, and a visit by my husband to the post office. That’s not nothing.

It’s increasingly recognised that patients and patient organisations were shut out of decision-making and planning in the early stages of the pandemic. So if we are going to rebuild a better health system post-covid, we need one that works for everyone. For that to happen, the burden of administration on patients needs to be part of the conversation.

A longer version of this article originally appeared in the BMJ.
Person-centred care: Knowing where to look

This paper begins by casting an eye back over the history of quality measurement in healthcare. It notes that the increased “industrialisation” of health systems brought with it audit and feedback systems whose main purpose was quality control.

But “with the rise in advocacy groups and patient-representative organisations, the... managerialist ideology was challenged”. Quality control gave way to quality improvement, accompanied by notions of “person-centred” care.

In spite of this, argues the author, approaches to quality measurement have not changed much. They “continue to privilege standardised, quantifiable data and... Despite more than 30 years of developments in patient-centred and then person-centred care, the focus on quantitative measurement has continued to dominate, even though it does little to inform stakeholders about the person-centredness of a health system”.

The paper points out the limitations of Patient-Centred Outcome Measures (PCOMs), which, it says, need to “extend far beyond a narrow perspective of pre-determined indicators of clinical effectiveness”.

Widening the perspective means looking at organisational culture - ideally, “a culture that is developed and sustained by person-centred staff and supported by person-centred organisational values and systems”. A failure to do so “only serves to ‘blame’ individual staff for not being person-centred in their care practices without recognising organisational responsibilities”.

There are “a variety of qualitative methods” that can help to take account of individual experience alongside the measurement of clinical effectiveness. But are qualitative methods taken seriously enough? The author states that “It is always interesting to me that rigour in the use of quantitative data is assumed, while in qualitative methods it has to be defended”.

The paper concludes that “We need to respect the integrity of both traditions”, given the “urgent need to demonstrate the value of person-centred cultures to health care organisations”. And, says the author, “The more we are able to see, the better we get at knowing where to look”. 
Here be dragons

Medieval maps are a wonderful blend of scientific observation and pure fantasy. Early cartographers did their best to show what the world looked like. But in areas that were too hard to reach, they abandoned facts and relied on imagination instead. Sometimes they gave up altogether and simply left blank spaces – freely acknowledging large gaps in knowledge.

The UK patient experience evidence base is similar. We too have an awareness of people and places that are “hard to reach”. But unlike the map makers of old, we are not good at openly displaying the gaps in our understanding.

The fact is that nobody has ever mapped the patient experience evidence base. No-one really knows where the strengths and weaknesses are, and that leaves us unable to direct the evidence gathering effort to where it is really needed.

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

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

The video allows viewers to see what the maps can do, but does not give them direct access. We aim to improve functionality within the Patient Experience Library so that users can manipulate and interrogate the maps for themselves, democratising the knowledge contained within them.

Our mapping methodology can help researchers to see what is in the existing evidence base before embarking on new studies. It can help funders to see how to get better value for money, by avoiding time-wasting and duplication. And it can help patient advocates to see how and whether different sections of society are represented in patient experience evidence-gathering.

We will be doing more work on this, and will keep readers of this magazine informed of progress.
Humanizing harm: Using a restorative approach to heal and learn from adverse events

In the wake of the Ockenden review of maternity harms at Shrewsbury and Telford, Secretary of State Sajid Javid has vowed to “go after” those responsible.

Accountability certainly matters at times like these – but is a tough or punitive approach the most appropriate?

This paper states that “taking responsibility is not the same as accepting culpability” – indeed, “The endurance of retributive approaches to investigations is a barrier to responsibility taking”.

As the authors see it, “Safety investigations are increasingly characterized by... the criminalization of human error, despite assurances from safety scientists that individuals are rarely solely culpable”. Furthermore, “The adversarial conditions and entrenched positions of lengthy investigations usually prevent opportunities to bring patients, families and health providers together”.

This matters because “When an incident occurs... relationships are affected”. So “If harm is to be adequately addressed... well-being must be restored, and trust and relationships rebuilt”.

The paper advocates a restorative justice approach, based on “active participation, respectful dialogue, truthfulness, accountability, empowerment and equal concern for all the people involved”. The aim is to “restore well-being and relationships alongside understanding what happened”, so the dialogue is guided by “a concern to address harms, meet needs, restore trust and promote repair”.

The authors state that this is “a far more comprehensive and complex response than one which seeks to identify a victim, a perpetrator and a punishment; or indeed, one which simply assumes that system learning is the overwhelming priority”. They argue that “It has the potential to result in a meaningful apology because of the focus on essential apology characteristics; respectful dialogue, acknowledgement of responsibility and actions that address justice needs”.

Mr. Javid’s tough talk might play well with some audiences. But for anyone interested in bringing healing from harm, this paper is worth a read.
Communicating better with patients and staff

“At the end of December 2021, 6.07 million patients were waiting for elective care, the biggest waiting list since records began.” So says the House of Commons Committee of Public Accounts in the opening sentence of its report on waiting list backlogs.

There is a direct link between waiting times and people’s experiences of care, and the report confronts this issue head-on.

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

The committee is clear that the huge backlogs predate the Covid crisis: “The Department of Health and Social Care (the Department) and NHS England and NHS Improvement (NHSE&I) oversaw declines in waiting time performance for cancer care from 2014 and elective care from 2016 as they did not increase capacity sufficiently to meet growing demand for NHS services”. It recognises that “despite the heroic efforts of the NHS workforce”, the pandemic has exacerbated “these previous failures”.

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

The committee finds that “The Department needs to be better at communicating with NHS staff and patients about what the NHS will be able to deliver in the coming years”. And it calls for a “transparent and realistic assessment of… how patients will be kept informed about their own progress through waiting lists”.

We agree that transparency and accountability are vital, which is why we have made our waiting list tracker available free of charge across all English acute Trusts. We will continue doing so, and once again invite NHS England and the Department for Health and Social Care to work with us.
Living in a Covid World

Last February - two years on from the start of the pandemic - the UK government announced its plan for living with Covid. The main thrust of it seems to be that vaccines will be the “first line of defence”. Other than that, we are all “encouraged” to follow public health advice, “as with all infectious diseases such as the flu”.

At the same time, the House of Lords Covid-19 Committee has been taking a somewhat deeper view. Their report recognises that while the crisis stage of the pandemic might be drawing to a close, the longer term impact is “far-reaching, profound and permanent”. The authors state that “we must adapt our lives, and world, to the economic, social and health consequences of the pandemic”.

The learning points start with an admission: that “our current understanding of resilience and preparedness is not fit-for-purpose”. In particular, “a focus on robust supply chains and critical national infrastructure alone will not secure the national resilience that we so desperately need”.

The report calls for “a new resilience agenda”, taking in inequality, digital inclusion and public health. This must be tied to systems of government that look beyond short term electoral cycles to longer term challenges such as ageing population, technological change and climate risk. Importantly, “any new system of government must have the wellbeing of its people at its heart”.

The Committee proposes a move to a “Wellbeing State”, whose purpose would be “to secure the wellbeing of all its citizens, and tackle those inequalities that hold back specific groups and communities”.

We can do this by “reaching into every part of our society, and actively engaging with them about the interventions that will improve their wellbeing”. Equally importantly, “We cannot claim to be resilient, until all groups, communities and neighbourhoods are resilient, and continuing vulnerability amongst specific groups, communities and neighbourhoods will make us all vulnerable to the upheavals of the future”.

Living in a COVID World: A Long-term Approach to Resilience and Wellbeing
Access to and delivery of general practice services: a study of patients at practices using digital and online tools
Geraldine M Clarke, Alison Dias and Arne Wolters

Key points

• General practice in England is facing unprecedented demand. Greater use of digital and online tools for access to and delivery of primary care services has been advocated as a way of easing pressures, and is a long-standing NHS policy objective. Accelerated by the COVID-19 pandemic, most practices have implemented online consultation systems and can offer remote consultation by telephone, SMS/online messaging or video.

• A patient can contact their practice by filling in a form on their smartphone, tablet or computer. This is referred to as making an online consultation and might include booking an appointment, checking symptoms, ordering a repeat prescription or updating personal details. The request is then forwarded to the practice where it is responded to via text or email, confirming the request has been received and giving advice about what to do next. If further action is required, more texts or emails may be exchanged, or the GP practice may suggest a telephone, video or face-to-face consultation.

• Nationally, practices have been advised to implement online consultation systems as part of a hybrid approach where online routes of access are used alongside traditional routes in person or via telephone. Remote consultation via telephone, online/SMS messaging and video is used alongside traditional care delivery by face-to-face consultation.

Facing up to patient choice

Last autumn, Health Secretary Sajid Javid told MPs it was ‘high time’ GPs offered in-person appointments to anyone who wants one – claiming life was ‘almost back to completely normal’.

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

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

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

Unsurprisingly, Covid then accelerated online requests – from 60% in June 2019 up to 72% during 2021.

Further analysis shows different behaviour across different groups. Men, for example, were over 10% less likely to contact the practice online than women. Patients requesting a response via SMS/online messaging were more than 35 times as likely to use the online channel than those asking for a telephone consultation. And during 2021, patients asking about new medical problems were twice as likely to contact the practice online as those asking about an existing medical problem.

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

The authors note that “The October 2021 NHS support plan for improving access for patients and supporting general practice set out a concern that a level of face-to-face care less than 20% may be contrary to good clinical practice”.

However, they say that “136 of 146 practices we studied would have been included in this criticism”. Consequently, they believe that “simple numerical targets on the use of remote vs face-to-face consultations would be inappropriate, and a more holistic view should be taken”.

The Health Foundation
Health inequalities: Clearing the fog

“Despite health inequalities being a priority for many countries, the gap in access and quality of healthcare and health outcomes between the most and least disadvantaged groups is widening”. So says the opener to this study, which examined healthcare policy documents to see how health inequalities are understood and addressed.

The authors looked at plans published by Sustainability and Transformation Partnerships and Integrated Care Systems. The average length of the plans was 167 pages, and all of them mentioned health inequalities. Five common themes emerged:

- “Vagueness” was exemplified by a lack of detail of the key healthcare and health outcome inequalities within and across different groups. This led to a lack of clear goals to reduce health inequalities.

- “Variation” throughout the documents was demonstrated in three ways: variation in definitions of terms, groups being compared and the use of metrics and indicators.

- “Lack of prior conceptualisation and approach” refers to the way that local healthcare systems appeared not have an established approach or work programme. Documents frequently mentioned gaps in awareness of what inequalities were present.

- “Use of value judgements” was revealed through widespread discussion of lifestyle and behaviour being a major determinant of health, as well as in how certain populations were more frequently included, whilst others were consistently left out.

- “Lack of commitment to action” meant that while there was a high level of commitment to the notion of tackling health inequalities, there was a lack of concrete and accountable targets or actions.

The authors argue that healthcare systems should agree on a coherent national conceptualisation or framework for health inequalities. This needs to go hand in hand with clear guiding principles about how to reduce inequalities. Any such framework should also be part of a partnership between multiple governmental bodies. And, importantly, it should “allow local healthcare systems to prioritise according to their local needs... and contain specified population groups and outcomes measures to focus on”.

**Abstract**

In 2018 local healthcare systems in England were asked to develop formal plans to reduce health inequalities. Here, we present plans to understand how local healthcare systems address health inequalities and why. Our research was part of a larger research project to develop a framework for understanding and tackling health inequalities. 

Health inequalities:

- **Lack of commitment to action** meant that while there was a high level of commitment to the notion of tackling health inequalities, there was a lack of concrete and accountable targets or actions.
- **Lack of prior conceptualisation and approach** refers to the way that local healthcare systems appeared not have an established approach or work programme. Documents frequently mentioned gaps in awareness of what inequalities were present.
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Out of sight – who cares?

The government’s programme for the next parliament promises draft legislation to reform the Mental Health Act. The purpose is to give patients with mental health conditions greater control over their treatment and to make it easier for people with learning disabilities and autism to be discharged from hospital.

This report from the Care Quality Commission is clear that both objectives are much needed.

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

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

This progress report updates the original “Out of Sight” document, published in October 2020. It finds that 13 of the original report’s recommendations have not been achieved. Four have been partly achieved. There are no recommendations that have been fully achieved.

Recommendation 10 is about people’s experience of person-centred care. Here we find that “People and their families still tell us that it is not always easy to raise and escalate concerns to providers or commissioners. Where they do, they can feel labelled as difficult or persistent complainers and are concerned that it will have a negative impact on how providers see and treat them or their loved one”. Moreover, “Advocacy providers have been concerned about the lack of funding for the provision of advocacy for a long time, and progress has been too slow”.

It is now five years since Prime Minister Theresa May described mental illness as a “hidden injustice”, and called for “parity of esteem” between mental and physical health services. We can only hope that the government’s latest promise brings us closer to that goal.
Involvement and innovation in digital healthcare

“The COVID-19 pandemic arguably led to an unprecedented increase in both the innovation and the implementation of digital health technologies”, says this paper. However, “this was often at the expense of meaningful involvement”.

The study, conducted by Plymouth University with support from the Patient Experience Library, looked at patient and public involvement (PPI) in digital health innovation, aiming to identify factors that enable or inhibit meaningful involvement.

Its starting point was that “despite a strong policy rhetoric supported by national agendas… the extent to which patients and the public are involved in digital health innovations… remains largely unknown”. This matters because “evidence-based guidance on how to carry out meaningful PPI in the rapidly evolving field of digital health is lacking”.

The study found that published articles on PPI in digital healthcare reported multiple benefits, including improved useability; insight into patients’ needs and preferences and increased likelihood of app recommendation and use.

In spite of this, there were also many barriers to meaningful involvement. These included time and financial constraints; involvement not being seen as a priority by stakeholders; not involving patients early enough in the process; and a disconnect between developers and end users. For their part, patients were sometimes reluctant to engage because of fears about data privacy and security.

Enablers for participation included clarity about who has the final design say (patient led vs researcher/designer led); allowing time for setbacks; providing a named point of contact; and reimbursing expenses in a timely manner.

A further consideration is an unequal distribution of power. This, say the authors, rests on “traditional, often hierarchical ways of working, with patient insights and suggestions often seen as inferior during the innovation and implementation process”. A possible solution is “More creative methods that enable patients and innovators to voice their suggestions and ideas in their own words, as opposed to those that have already been defined for them”.

The authors conclude that “Some reported barriers and enablers such as the importance of data privacy and security appear to be unique to PPI in digital health”. They call for “Multi-disciplinary consensus on the principles and practicalities that underpin meaningful PPI in digital health innovation”.

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Woman-centred care?

The starting point for this paper is the mixed reaction to Australia’s 2019 “Woman-centred care” strategy, which set the direction for the country’s maternity services. Following the release, “disappointment and frustration was voiced by consumers and maternity service providers (especially midwives) due to the minimal incorporation of midwifery continuity of care and out of hospital birth place options”.

To try to understand the reaction, this study compared the Australian strategy with maternity strategies from England, Wales, Scotland, Ireland, Northern Ireland, Canada, and New Zealand. The analysis includes some wider insights into maternity politics, culture and strategy, as follows:

In the Australian strategy, the term “woman-centred” encompassed the values of safety, respect, choice, and access. The essence of these values appeared in every other plan reviewed.

Continuity of midwifery carer appeared to be an add-on to the Australian strategy, following substantial consumer protests. It stands at odds in this respect with the English, Scottish, and Welsh plans, which advocate for continuity of midwifery care for all women.

There was significant variation in the positioning and professional autonomy of midwifery in the reviewed plans and guidelines. However, where the midwifery profession is strong, midwifery models of care and place of birth options were more likely to be discussed and recommended.

In countries where birth at home and in birth centres is widely accepted, the recommendations in maternity plans were more in line with evidence, human rights, and consumer demands.

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

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

A comparison of the Woman-centred care strategy (WCC Strategy) with other international maternity plans and strategies. The WCC Strategy was released in 2019 by the Australian government.”

1. When was the Australian government’s Woman-centred care strategy released? 
   
   The Australian government released the Woman-centred care strategy in 2019.

2. What was the reaction to the Australian strategy? 
   
   Consumers and maternity service providers, especially midwives, expressed disappointment and frustration because of the minimal incorporation of midwifery continuity of care and out of hospital birth place options.

3. How does the Australian strategy compare to the strategies of England, Wales, Scotland, Ireland, Northern Ireland, Canada, and New Zealand? 
   
   The study compared the Australian strategy with maternity strategies from these countries and included wider insights into maternity politics, culture, and strategy.

4. What are the values of safety, respect, choice, and access that the Australian strategy encompasses? 
   
   These values are present in every other plan reviewed.

5. How does the continuity of midwifery carer appear in the Australian strategy? 
   
   Continuity of midwifery carer appears as an add-on to the Australian strategy, which stands in contrast to the continuity of care advocated in the English, Scottish, and Welsh plans.

6. What were the findings regarding the positioning and professional autonomy of midwifery in the reviewed plans? 
   
   There was significant variation in the positioning and professional autonomy of midwifery in the reviewed plans and guidelines. Where the midwifery profession is strong, midwifery models of care and place of birth options were more likely to be discussed and recommended.

7. Where birth at home and in birth centres is widely accepted, what can be expected in the recommendations in maternity plans? 
   
   In countries where birth at home and in birth centres is widely accepted, the recommendations in maternity plans are more in line with evidence, human rights, and consumer demands.

8. What inconsistencies were found in the documents reviewed? 
   
   Inconsistencies were found regarding the final decision making around choice and autonomy in maternity care.

9. How do the authors suggest that priorities should be set in maternity guidelines? 
   
   The authors suggest that priority should be given to the choices women make and the best available evidence, not the power and interests of organisations and individuals.
Women’s health in prison

‘Prisons are not healthy environments. They are unable to address the physical and mental health needs of women and in fact exacerbate them.’

This frank assessment comes from the All Party Parliamentary Group (APPG) on Women in the Penal System. Their report pulls no punches in its analysis of health-related harm in women’s prisons.

Contributory factors include the following:

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

These issues, and others, are summarised in this concise and compelling document, which finishes by considering the government’s Prisons Strategy White Paper.

It finds that ‘The white paper rightly recognises that women in the criminal justice system have complex needs’. However, it says, ‘the proposals will lead to an expansion of the prison estate, resulting in more women and children experiencing the harms of prison when it is not necessary or appropriate’. Instead, ‘The focus should be on reducing the unnecessary use of prison for women and on improving and expanding provision for women in the community’.

The APPG concludes that the white paper is ‘a missed opportunity to address the needs of women in the criminal justice system and to reduce the harm caused by imprisonment’.
Invisible illness and citizen science

This study is unique, say the authors, in being the first citizen science qualitative study in the UK. Both the data and the analysis have been driven by an online patient community.

The community in question comes from the 1.5 million UK residents living with self-reported Long Covid. Although recognised as a condition by the National Institute for Health and Care Excellence (NICE), Long Covid symptoms are ‘poorly explained by objective medical tests’.

The study notes that ‘Without objective indicators... Long Covid patients rely on having their illness testimonies believed and taken seriously to access treatment and support’. But in an era of evidence-based practice, this can make them vulnerable to ‘epistemic injustice’, whereby they are seen as ‘unreliable informants of their own illness experiences’.

The study revealed three themes in people’s experiences of Long Covid:

• Life changing: People with previously fit and active lifestyles facing the end of normality, rollercoaster symptoms and uncertainty and fear.

• Validation: Patients with confirmed or suspected Covid-19 feeling that they were not always heard or believed.

• Seeking alternatives: A desire to seek alternatives to formal healthcare, including online support groups, self-help and exercise.

Running through all of this is the gap between lived experience and medical science. In common with other ‘invisible illnesses’ such as fibromyalgia, endometriosis, depression, chronic pain and depression, Long Covid patients found that clinicians ‘did not recognise their condition, did not believe that it existed, did not know how to diagnose it, did not empathise or acknowledge their suffering, [and] did not know how to manage it’.

Addressing this gap must, say the authors, ‘be a priority as guidelines for complex, chronic illnesses like ME and Long Covid require a compassionate and empathic patient-centred approach fundamental to which are advanced communication and interpersonal skills’.
**NHS Complaints Summit**

**FRIDAY 19th AUGUST 2022**
**VIRTUAL, Online**

This National Virtual Summit focuses on the New National NHS Complaint Standards that were published in March 2021 and are due to be introduced across the NHS in 2022.

Through national updates, practical case studies including NHS Complaints Standards early adopters sites, 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 on managing complaints regarding Covid-19 – understanding the standards of care by which the NHS should be judged in a pandemic and in particular responding to complaints regarding delayed treatment due to the pandemic.

Further information and booking or click on the title above or email kate@hc-uk.org.uk

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**Toolkit Using Patient Experience and learning from Incidents to Improve Patient Safety**

**Thursday 15 Sep 2022**
**VIRTUAL, Online**

This one day masterclass will focus on a toolkit to allow organisations to use patient experience and incident to improve patient safety. The Toolkit uses 3 phases: Planning, Implementation and Review. The Francis Report showed that the NHS had stopped listening to the needs of its users. Patient experience is still an underutilised tool in the armoury of a healthcare organisation and commissioners.

We have designed a toolkit, which can use the priorities of the Francis Report to improve patient experience and patient safety. These include Putting Patients First, Openness, Candour, Accountability, Complaints Handling, Culture of Caring and Compassionate Leadership.

Further information booking or click on the title above or email kate@hc-uk.org.uk

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**Patient Involvement & Partnership for Patient Safety**

**FRIDAY 16th SEPTEMBER 2022**
**Hallam Conference Centre, London**

This conference focuses on patient involvement and partnership for patient safety including implementing the New National Framework for involving patients in patient safety, and developing the role of the Patient Safety Partner (PSP) in your organisation or service.

The National Framework for involving patients in patient safety was released by NHS England in June 2021.

Further information booking or click on the title above or email kate@hc-uk.org.uk
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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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