Patient Experience

and patient/public involvement in health and care services
Summer 2022

Computer
says no...

INSIDE

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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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Services

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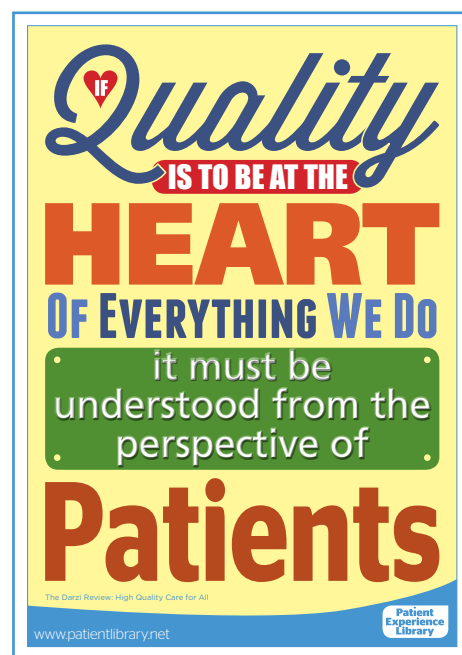
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Do you have opinions, insights or good practice examples that you'd like to share with our readers? Drop us an e-mail to receive our guide for contributors: *info@patientlibrary.net*

Beginning of the end?

Julia Jones, Co-Founder, John's Campaign

Not long ago, I went to a cross-party meeting of MPs to lobby for a new right.

In fact, it's such an old and basic human need that it's astounding that it must be lobbied for. We are asking for the legal right for people in the health and care system to maintain their closest personal relationships and be supported, in time of need, by someone who loves them.

And it's not 'them' – it could just as easily be me, or you.

The meeting heard from people who described the impact of separation policy during the pandemic period. Ann's mother, living in a care home, would call her up to 30 times a day telling her she needed help or was in pain. Ann was not allowed to respond. When she asked for essential caregiver status (as per government guidance) it was denied, and her mother was issued with an eviction notice.

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 "shielders' 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.

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*

Determining the quality of a health system is a complex and challenging endeavour. The variety of perspectives needed to determine quality means that increasingly complex measurement frameworks are often employed. Providing the best possible health care has always been a priority for health system leaders, individual professions and individual professionals. But the importance and significance of measuring quality has increased since the evolution of quality-improvement methodologies for health-care quality standardisation in the 1990s.[1]

Audit and feedback systems evolved into quality-control methods with the increased industrialisation of health systems. As the patient voice became increasingly important, with the rise in advocacy groups and patient-representative organisations, the focus on controlling the quality of services through a managerialist ideology was challenged. Broader, more inclusive, approaches to quality were embraced. Quality-improvement methodologies aim to adopt an inclusive approach to ongoing quality enhancement, ensuring that services are continuously developed and improved.[2] This evolutionary context is important when considering the measurement methods that dominate health systems. To some extent, it could be argued that while health care cultures have shifted their focus from one of control to improvement, approaches to measurement continue to privilege standardised, quantifiable data and information that can be used for quality standardisation. 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 person-centred care movement is not new in health care and there are some who would argue that other approaches, such as relationship-centred care, have superseded person-centredness.[3] The lack of concept clarification and theory-driven methodologies by researchers in the field has done little to help this situation. This failure has also been reflected in approaches to measurement and evaluation. The paper by Cribb[4] in this issue of the *Journal of Health Services Research & Policy* highlights this problem precisely, that is, the interchangeable use of patient- and person-centred care and a lack of definition of either.[4]

In 2017, Dewing and McCormack[5] highlighted the problem of researchers evaluating person-centredness without defining what they mean. After more than 20 years of research in this field, including the publication of concepts, models, theories and frameworks, it is unacceptable not to present a clear definition as a basis of an evaluation methodology.

This lack of precision carries on through the focus on person-centred care as an isolated activity associated with providing care to patients – as if somehow person-centred care practices can be isolated from the context in which they exist. Previously, Laird et al.[6] argued that the majority of patients experience 'person-centred moments' only and few experience 'person-centred care'. Their research highlighted the inconsistencies that exist in and between different practitioners/staff in providing care, influenced by a variety of cultural and contextual factors in different care settings. Key issues highlighted include how work is organised, what practice is prioritised and privileged, leadership practices and multi-disciplinary decision-making.

Evaluating person-centred care as a specific intervention or group of interventions, without understanding the impact of these cultural and contextual factors, does little to inform the quality of a service. Indeed, measuring person-centred care ignores a central tenet of this approach, that is, the provision of person-centred care is predicated on the existence of a person-centred culture – a culture that is developed and sustained by person-centred staff and supported by person-centred organisational values and systems. Person-centred care can only happen if there are cultures in place in care settings that enable staff to experience person-centredness and work in a person-centred way. With a focus on culture, Dewing et al.[7] adopted the following definition of person-centredness:

[A]n approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development.[7(p.3)]

This definition is relationship-orientated but includes *all* relationships in any health care situation or context. The focus on healthfulness is consistent with contemporary theories of well-being and wellness as health

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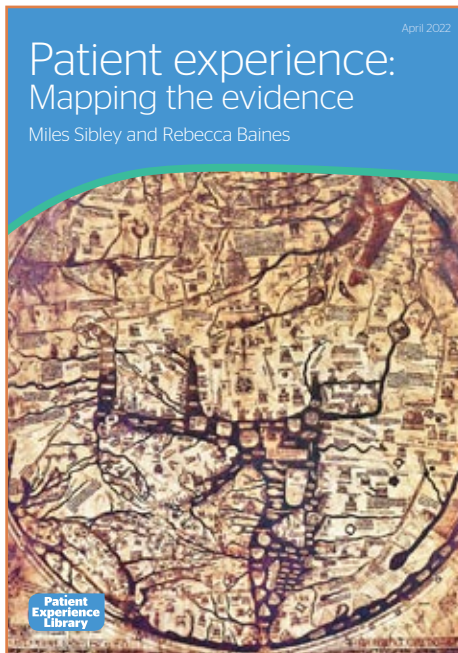
The paper points out the limitations of Patient-Centred Outcome Measures (PCOMs), which, it says, need to "extend far beyond a narrow perspective of pre-determined indicators of clinical effectiveness".

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".

Patient experience:
Mapping the evidence

April 2022

Miles Sibley and Rebecca Baines

Patient Experience Library

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

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Abstract

Background: Healthcare is not without risk. Despite two decades of policy focus and improvement efforts, the global incidence of harm remains stubbornly persistent, with estimates suggesting that 10% of hospital patients are affected by adverse events.

Methods: We explore how current investigative responses can compound the harm for all those affected—patients, families, health professionals and organizations—by neglecting to appreciate and respond to the human impacts. We suggest that the risk of compounded harm may be reduced when investigations respond to the need for healing alongside system learning, with the former having been consistently neglected.

Discussion: We argue that incident responses must be conceived within a relational as well as a regulatory framework, and that this—a restorative approach—has the potential to radically shift the focus, conduct and outcomes of investigative processes.

Conclusion: The identification of the preconditions and mechanisms that enable the success of restorative approaches in global health systems and legal contexts is required if their demonstrated potential is to be realized on a larger scale. The policy must be co-created by all those who will be affected by reforms and be guided by restorative principles.

Patient or Public Contribution: This viewpoint represents an international collaboration between a clinician academic, safety scientist and harmed patient and family members. The paper incorporates key findings and definitions from New Zealand's restorative response to surgical mesh harm, which was co-designed with patient advocates, academics and clinicians.

KEYWORDS
adverse events, incidents, investigations, patient safety, restorative

Rebuilding relationships

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.

House of Commons
Committee of Public Accounts

NHS backlogs and waiting times in England

Forty-Fourth Report of Session 2021–22

Report, together with formal minutes relating to the report

Ordered by the House of Commons to be printed 7 March 2022

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.

HOUSE OF LORDS

COVID-19 Committee

3rd Report of Session 2021–22

Living in a COVID World: A Long-term Approach to Resilience and Wellbeing

Ordered to be printed 30 November 2021 and published 16 March 2022

Published by the Authority of the House of Lords

HL Paper 117
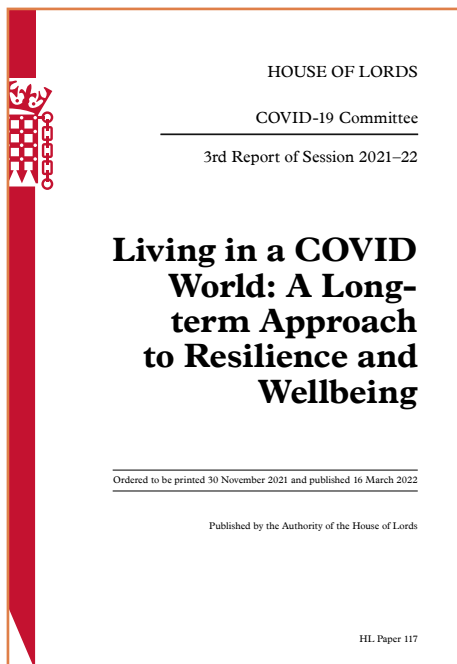
Living in a Covid World

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".

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".

Conceptualisation of health inequalities by local healthcare systems: A document analysis

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Abstract
In 2019, local healthcare systems in England were asked to develop formal plans to reduce health inequalities. Here, we explore plans to understand how local healthcare systems conceptualise health inequalities and why. A broad Internet search and targeted search of NHS websites were conducted to identify all publicly accessible healthcare planning documents (National Health Service (NHS) Long-Term Plan (LTP) response documents) produced by local health partnerships in England. A thematic document analysis of the accessible plans was undertaken in NVivo by coding text relating to health inequalities. Of the 44 documents developed, 13 were publicly accessible. These 13 local plans were submitted to NHS England for review between September 2019 and January 2020 and averaged 167 pages (range: 41–273 pages). Only one document contained a chapter dedicated to health inequalities. After analysis, five themes were identified: (1) *variation* and (2) *vagueness* explained how health inequalities were conceptualised and (3) *use of value judgements*, (4) *lack of prior conceptualisation and approach* and (5) *a lack of commitment to action* in the documents to reduce health inequalities explained what led to the overall vagueness and variation. Local healthcare systems were found to conceptualise health inequalities in a vague and varying manner, and their conceptualisations did not reflect established health inequalities frameworks. A clear conceptual national framework for addressing health inequalities is needed to support local healthcare systems, so they can address health inequalities meaningfully and sustainably.

KEYWORDS
health inequalities, health policy, healthcare, quality, access and evaluation, inequalities in health and healthcare, patient care management, public health systems' research

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".

**CareQuality
Commission**

Out of sight – who cares?

**Restraint, segregation and seclusion
review**

**Progress report
March 2022**

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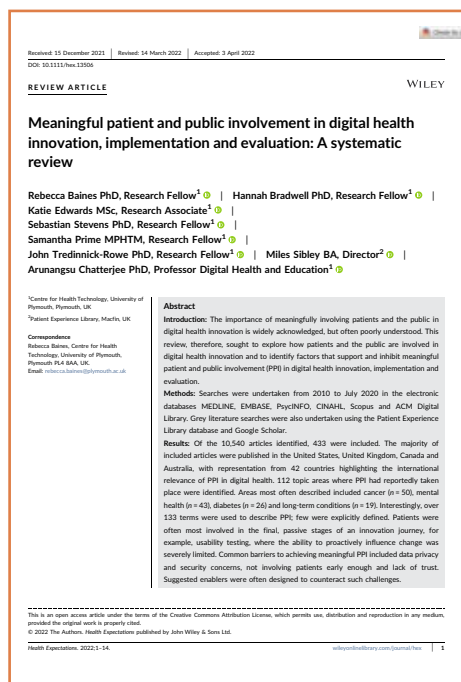
The reasons for this include a "lack of community services" and the fact that "the right housing is not available, nor the right support in place.... People end up moving around the system from one service to another because their needs are not being met".

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.

WILEY

REVIEW ARTICLE

Meaningful patient and public involvement in digital health innovation, implementation and evaluation: A systematic review

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Abstract
Introduction: The importance of meaningfully involving patients and the public in digital health innovation is widely acknowledged, but often poorly understood. This review, therefore, sought to explore how patients and the public are involved in digital health innovation and to identify factors that support and inhibit meaningful patient and public involvement (PPI) in digital health innovation, implementation and evaluation.
Methods: Searches were undertaken from 2010 to July 2020 in the electronic databases MEDLINE, EMBASE, PsycINFO, CINAHL, Scopus and ACM Digital Library. Grey literature searches were also undertaken using the Patient Experience Library database and Google Scholar.
Results: Of the 10,540 articles identified, 433 were included. The majority of included articles were published in the United States, United Kingdom, Canada and Australia, with representation from 42 countries highlighting the international relevance of PPI in digital health. 112 topic areas where PPI had reportedly taken place were identified. Areas most often described included cancer (n = 50), mental health (n = 43), diabetes (n = 26) and long-term conditions (n = 19). Interestingly, over 133 terms were used to describe PPI; few were explicitly defined. Patients were often most involved in the final, passive stages of an innovation journey, for example, usability testing, where the ability to proactively influence change was severely limited. Common barriers to achieving meaningful PPI included data privacy and security concerns, not involving patients early enough and lack of trust. Suggested enablers were often designed to counteract such challenges.

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".

A comparison of the *Woman-centred care: strategic directions for Australian maternity services (2019)* national strategy with other international maternity plans

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ABSTRACT

Background: In 2019 the Australian government released a guiding document for maternity care: *Woman-centred care strategic directions for Australian maternity services* (WCC Strategy), with mixed responses from providers and consumers. The aims of this paper were to: examine reasons behind reported dissatisfaction, and compare the WCC Strategy against similar international strategies/plans. The four guiding values in the WCC strategy: safety, respect, choice, and access were used to facilitate comparisons and provide recommendations to governments/health services enacting the plan.
Methods: Maternity plans published in English from comparable high-income countries were reviewed.
Findings: Eight maternity strategies/plans from 2011 to 2021 were included. There is an admirable focus in the WCC Strategy on respectful care, postnatal care, and culturally appropriate maternity models. Significant gaps in support for continuity of midwifery care and place of birth options were notable, despite robust evidence supporting both. In addition, clarity around women's right to make decisions about their care was lacking or contradictory in the majority of the strategies/plans. Addressing hierarchical, structure-based obstacles to regulation, policy, planning, service delivery models and funding mechanisms may be necessary to overcome concerns and barriers to implementation. We observed that countries where midwifery is more strongly embedded and autonomous, have guidelines recommending greater contributions from midwives.
Conclusion: Maternity strategy/plans should be based on the best available evidence, with consistent and complementary recommendations. Within this framework, priority should be given to women's preferences and choices, rather than the interests of organisations and individuals.

Statement of Significance

Issue
In 2019 the Australian government released a guiding document for maternity care: *Woman-centred care strategic directions for Australian*

maternity services (WCC Strategy), which resulted in mixed responses from health providers and consumers. How this strategy compares to other contemporary maternity plans is undocumented.

What is already known

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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 plan 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".

Inquiry into women's health and well-being in prisons
Briefing one

Key points

- Prisons are not healthy environments. They are unable to address the physical and mental health needs of women and in fact exacerbate them.
- 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 of the receptions into prison are of women on remand and a third are of women serving short sentences.
- The prison environment is damaging to women's mental health.

- Existing health disparities relating to sex are amplified in prisons.
- The prison environment exacerbates health inequalities for Black and minority ethnic women.
- The impact of the pandemic has exacerbated existing problems within prisons, increasing the damage prison causes to women's health and well-being.
- The lack of continuity for women coming in and going out of prison is detrimental to their care.
- The Prisons Strategy 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.

All Party Parliamentary Group on Women in the Penal System

This is not an official publication of the House of Commons or the House of Lords. It has not been approved by either House or its committees. All-Party Parliamentary Groups are informal groups of Members of both Houses with a common interest in particular issues. The views expressed in this report are those of the group.

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'.

WILEY

ORIGINAL ARTICLE

Exploring invisibility and epistemic injustice in Long Covid—A citizen science qualitative analysis of patient stories from an online Covid community

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Abstract

Background: In 2020, the long-lasting effects of the Covid-19 virus were not included in public messages of risks to public health. Long Covid emerged as a novel and enigmatic illness with a serious and life-changing impact. Long Covid is poorly explained by objective medical tests, leading to widespread disbelief and stigma associated with the condition. The aim of this organic research is to explore the physical and epistemic challenges of living with Long Covid.

Methods: Unlike any previous pandemic in history, online Covid communities and 'citizen science' have played a leading role in advancing our understanding of Long Covid. As patient-led research of this grassroots Covid community, a team approach to thematic analysis was undertaken of 66 patient stories submitted online to covid19-recovery.org at the beginning of the Covid-19 pandemic between April and September 2020.

Results: The overriding theme of the analysis highlights the complexities and challenges of living with Long Covid. Our distinct themes were identified: the life-changing impact of the condition, the importance of validation and how, for many, seeking alternatives was felt to be their only option.

Conclusions: Long Covid does not easily fit into the dominant evidence-based practice and the biomedical model of health, which rely on objective indicators of the disease process. Patient testimonies are vital to understanding and treating Long Covid, yet patients are frequently disbelieved, and their testimonies are not taken seriously leading to stigma and epistemic injustice, which introduces a lack of trust into the therapeutic relationship.

Patient Contribution: The research was undertaken in partnership with our consumer representative(s) and all findings and subsequent recommendations have been coproduced.

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 informan ts 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'.

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H HEALTHCARE CONFERENCES UK

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

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
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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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Patient Experience Library

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