Patient Experience

and patient/public involvement in health and care services

Autumn 2023

SPEAK HEAR

Patient Experience Library

Editorial

The importance of staff and patient voice has been starkly revealed in recent weeks – first by the jailing of Lucy Letby, and then by Merope Mills' call for a new Martha's rule after the avoidable death of her daughter. In both cases, concerns were raised – and ignored.

The incidents remind us that listening to feedback is not some sort of optional extra. Sometimes it is a matter of life and death.

It is also a matter of justice. Kath Sansom (page 3) has for many years been speaking up about the harms done to thousands of women by pelvic mesh. (On page 15 you also can read a new Scottish review showing how women were misinformed about the device with devastating results.) Efforts by Kath and many others has now resulted in a government consultation on disclosure of industry payments to the healthcare sector. We join Kath in urging readers to have their say.

Patient voice is also an important component of "epistemic justice": the question of what counts as valid evidence in healthcare. All too often, scientific knowledge is given top billing, while lived experience is dismissed as "anecdotal evidence". On page 4, Nicole Thomas describes the genuine difficulties faced by researchers when trying to hear from patients, and how the Patient Experience Library has helped her to overcome some of the barriers.

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

Miles

Miles Sibley, Editor *info@patientlibrary.net*

www.patientlibrary.net

Services

Feel free to browse the Patient Experience Library – a wealth of evidence 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.

Check out our research-based publications, and sign up to our weekly newsletter for regular updates. We offer bespoke search and literature reviews like this and this – get in touch to find out more.

Our Patient Surveys Tracker and Waiting Lists Tracker help you make sense of the things that matter to patients. Let us know if you want to talk about custom-made analytics, adapted to your specific requirements.

Contact: *info@patientlibrary.net*

If **Quality** IS TO BE AT THE **HEART** OF EVERYTHING WE DO it must be understood from the perspective of **Patients**

The Darzi Review: High Quality Care for All

www.patientlibrary.net

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*

Spotlight on industry payments

Kath Sansom. Founder, Sling The Mesh
@MeshCampaign

Following years of lobbying by Sling The Mesh, the government is running a six-week consultation on the potential for a Sunshine Payment Act in the UK. This would force industry to openly publish all payments and benefits in kind they give to the healthcare sector.

It's important that everyone who cares about patient safety gets involved. Carry on reading to find out more and complete the consultation. Deadline: 11:59pm on 16 October 2023.

Politicians must, by law, declare their conflicts of interest. So it remains a mystery to us as patient safety campaigners that such declarations are not standard for healthcare professionals and organisations.

Industry gives millions of pounds every year to doctors, researchers, teaching hospitals, surgeon societies and healthcare charities. Not because industry is a generous benefactor. But because industry recognises the value of key opinion leaders who can raise awareness of their products – whether that's in a doctor's consulting room, a health charity's social media posts,

parliamentary meetings or within the pages of scientific research.

This is why we are passionate advocates for a Sunshine Payment Act in the UK as they have had in America since 2013. We want to shine a light on industry money changing hands.

As campaigners, we saw that American doctors who were heavily promoting mesh or publishing studies into mesh success, were taking large sums of money from companies making the product.

We were able to obtain this information thanks to America's open access CMS Database which lists industry money given to the healthcare sector, in easy to search categories.

And while there were strong indications that industry money was also affecting doctors' opinion in the UK, we had no way of proving it.

We did, however, see industry payments at play when the BBC covered the story of a Scottish surgeon who secretly took £100,000 from makers of a mesh sling he was trialling. The type of TVTO mesh he was using has caused some of the most harrowing injuries to women leaving many in wheelchairs or needing sticks to walk.

Patients deserve to know about industry payments to healthcare, and we are not the only ones who think that. The United States, Australia, Denmark, France, Portugal and South Korea have all realised that *legislation* is the only way to ensure industry money to doctors is logged. They have set up systems where drug and

device companies are required by law to declare their payments to the healthcare sector. Information is held on a central public register.

Here in the UK, the government is finally getting around to thinking about whether a similar system might be a good idea. There is an open consultation, and it is vital that the government hears from a diverse range of healthcare professionals and patients.

Sling the Mesh will of course be responding. We have three concerns with the Sunshine consultation wording which feels deliberately vague:

1. Can commercially sensitive information be omitted? If so what classes as commercially sensitive?

2. We hope the Association of British Pharmaceutical Industry will not run the database. We need a database that's independent of industry. Plus, the ABPI doesn't cover medical devices like mesh.

3. We want information on payments from industry to be held on *one central, government registry* to act like a one-stop-shop for industry payment information.

We're not campaigning for industry payments to stop. However, we do think that such money should be publicly declared. Declarations of interest are standard practice in politics and commerce and they should be in healthcare as well. If you agree with us, please make your voice heard.

The consultation is open until 16 October 2023.

A treasure trove of narratives

Dr. Nicole Thomas, University of Plymouth

As a researcher, I mostly draw on peer-reviewed articles and academic literature. However, needing to understand marginalised voices which were not well represented in the literature, I decided to lean on the expertise of the Patient Experience Library. This digital haven has breathed life into my research journey, allowing me to uncover a treasure trove of narratives centred around the healthcare system.

Involving patients and public in research can be easier said than done. Funding constraints, for instance, can limit engagement, sometimes leading to tokenism — a sentiment echoed by patients and the public themselves. Furthermore, the ethical review process can occasionally blur the boundaries between research and consultation. It's crucial to

acknowledge that sometimes individuals just might not want to talk to us, and approaching vulnerable individuals also presents ethical implications.

This is where the Patient Experience Library has played a crucial role, acting as an ethical compass that enables me to gain authentic insights without infringing on the delicate balance of research ethics.

The beauty of this repository is that it provides access to narratives which inform our reflections if full-scale involvement efforts might not be feasible. By drawing on existing evidence, we can safeguard against replicating activities, and avoid burnout or overutilisation of valuable partnerships with patients and community groups.

Underrepresented voices are shouting loud and clear from the gallery of real stories — stories that encapsulate the struggles and triumphs of those navigating the complex pathways of the healthcare system. If it sounds like I'm fangirling, I totally am.

In the realm of digital health, collaboration isn't just a choice — it's a necessity. As researchers within the Centre for Health Technology, our journey intertwines with the innovative minds striving to transform healthcare. For me, the Patient Experience Library served as a hub where the voices of

end-users merged with innovators bridging the gap between theory and real-world application. It offered insights in how to guide co-production of solutions tailored to the genuine needs of patients, as well as the usefulness of co-production methods themselves.

Navigating through this vast repository enabled me to access over 700 documents all related to underrepresented groups. Of these documents, around 170 all hold invaluable insights into reasons why underrepresented groups may or may not access healthcare or engage with research. It also provided a way to map all those involved with underrepresented groups across the UK.

This may be sound a bit...full on, considering the relationship is new, but The Patient Experience Library has transformed my approach to research. It's been a reminder that research isn't confined to the pages of journals.

It's about delving into the raw, unfiltered experiences that define the human journey. It's about acknowledging the passion of organisations like Healthwatch and the strength of grassroots initiatives that often go unnoticed. But in the true nature of research, I like to be the bringer of brand-new news.

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*
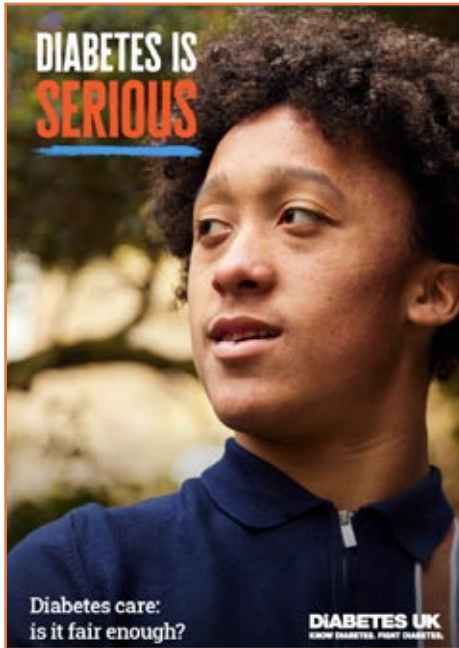
Fair care for diabetes

There are, says this report, "stark inequalities in diabetes care and management, which ultimately lead to worse health outcomes for those in the most deprived areas".

People from South Asian, Black African, and Black Caribbean backgrounds, for example, are two to four times more likely to develop type 2 diabetes, frequently at a younger age and lower BMI than White Europeans.

Deprivation is also key factor in diabetes inequality, with 24% of people diagnosed with type 2 diabetes living in the most deprived areas, compared to 15% in the least deprived.

A further factor is geographical variations. In some parts of England, health services have restored their diabetes care to above pre-pandemic levels. But the majority have not, with the lowest performing areas seeing only 1 in 10 people with diabetes get all of their checks.

The consequences can be serious – including amputation, stroke, heart attack and heart failure. There are emotional costs too – not just from lack of access to health services, but also from issues such as the increased cost of living and difficulties maintaining healthy diets.

The report makes a series of recommendations – both for government and for Integrated Care Boards. It concludes that "With the right care and support, people living with diabetes can lead healthy, productive lives". And, it says, "NHS England and ICBs could shift the focus of healthcare to empowering people with long-term conditions to stay well, rather than treating the devastating and complex consequences down the line".

The Hidden Work of Self-directed Support: A Seldom Heard Reality from the Perspective of Two Disabled Women

Katy Evans and Sally Whitney-Mitchell

This article is a reflective piece from two disabled women in the UK who use self-directed support. It will encompass the practical difficulties of gaining and maintaining budgets; employing support and managing this, in addition to the resultant emotional labour/work and its impact. We feel the labour undertaken is unrecognised and undervalued in wider social work practice and by society at large. This labour is not seen as equal to other work and the impact is seldom considered when looking at our lives as a whole.

Our understanding of emotional labour moves on from Hochschild's (2013) definition where one has to 'hide or change their feelings in order to manage the emotions of others', but with regard to paid work only, to acknowledge that labour and emotional labour of some sort is undertaken by everyone in different forms. We embrace the use of this terminology for the work involved in all relational activity, with special regard to those receiving care, as discussed extensively by Liddiard et al. (2022).

Both our lived experience as disabled women and our previous research (Liddiard et al., 2022) show that the needs of individual employers are often overlooked. We recognise that for us and many disabled people personal budgets are a tool for liberation, control and promote better well-being. Yet, this comes at a cost to the individual in terms of practical and emotional labour. We want to highlight this hidden work to better inform the support given to disabled people managing personal budgets as we feel that we currently do not have access to the same

The hidden realities of personal budgets

"For us and many disabled people", say the authors of this paper, "personal budgets are a tool for liberation". But, they say, "this comes at a cost to the individual in terms of practical and emotional labour".

Liberation comes in the form of "self-determination over our lives". Personal budgets can give disabled people freedom from institutionalised care, as well as freedom to buy services and support to suit their own priorities. But within these freedoms are "hidden realities".

The authors reflect on how words like 'fight' and 'battle' are associated with the process of gaining a budget and maintaining the support they need. They have had to educate themselves about rights, laws and policies, in order to advocate for themselves. Even so, their advocacy is from a position of "being seen as inferior because we do not hold a professional status". It is also on top of the task of managing the disabling conditions that they are trying to get support for in the first place.

After winning a personal budget, the work continues. Recruiting a personal assistant involves advertising and interviewing, along with the difficulty of selling a job that is underpaid, and undervalued by society.

Then there is the task of managing the support: producing staff rotas, recording leave, maintaining timesheets, seeking training, managing employees, and submitting spending proof to the council.

"The relentlessness of this work", they say, "can and does cause burnout". Indeed, some disabled people have abandoned self-directed support in spite of the increased quality of life a personal budget provided.

The authors call for the voices and experiences of disabled people to be heard in order to inform the approaches of commissioners, social workers, policy makers and other individual employers. "Person-centred support is rightly celebrated for the choice and control it affords disabled people but managing this should not come at a cost to our health and well-being and more support needs to be in place."

Invisible no more

This paper starts with a frank statement: "Covid-19 brought radical shifts in healthcare policies and practice, including the abandonment of families as partners in care".
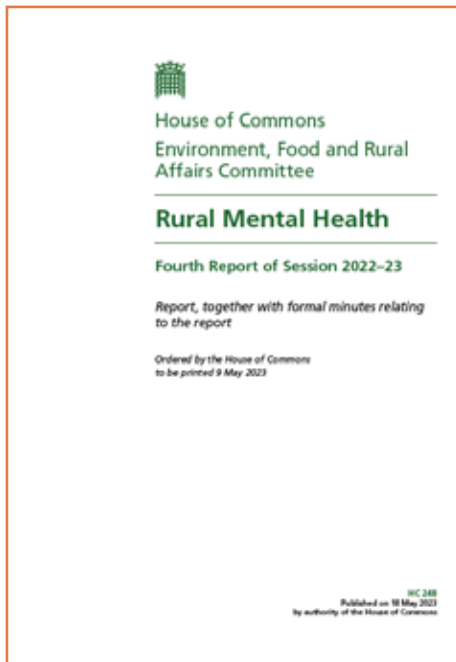
Can such a statement be justified? Yes, say the authors, who all have experience of informal or unpaid caring. Their home countries of England, Canada and Australia all saw the swift imposition of strict visiting bans during the crisis phase of the pandemic. In England, the practice of blanket bans on visiting in hospital and care homes was subsequently condemned by the House of Lords.

The bans were introduced as part of well-intended infection control measures. But they had unintended consequences, including poorer patient experience and a greater burden on overstretched staff. The burden was not just physical: "Service providers experienced the moral anguish of turning families away and maintaining forced separation between people who were in clear distress".

The authors argue that the exclusion of family carers flies in the face of evidence that they bolster patient health and healthcare systems. In all three countries, the financial value of informal care runs into billions of dollars or pounds every year. Additionally, patients with supportive families are more likely to adhere to treatment plans, have better communication with their clinicians, and have better clinical outcomes and quality of life.

While visiting bans have eased, wider exclusion continues. "Debates within health systems about 'living with Covid-19' focus on matters such as workforce, delivery models, and funding, but not on the role of families". To counter this, "government policies should formally recognise families as care givers, including paying for their labour, offering universal respite funding and services, and providing care giver benefits".

The authors conclude that "Valuing family care giving will finally make unpaid care giving visible, enable families to improve patient care and outcomes, support health systems, and better prepare systems for future healthcare crises".

House of Commons
Environment, Food and Rural
Affairs Committee

Rural Mental Health

Fourth Report of Session 2022–23

Report, together with formal minutes relating
to the report

Ordered by the House of Commons
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HC 248
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by authority of the House of Commons

Glaring gaps in mental health

In 2011, the coalition government published "No Health Without Mental Health". Described as a cross-government strategy, it had a central ambition: "establish parity of esteem between services for people with mental and physical health problems".

Twelve years later, this report from the House of Commons Environment, Food and Rural Affairs Committee is clear that, in rural areas at least, "parity of esteem" is still a very long way off.

The starting point is that the picture of rural mental health across England is "complicated and incomplete due to gaps in health data, the suppression of demand by over-centralised services, and the under-reporting of rural deprivation which is inextricably linked to poor mental well-being".

The Committee points out that "access to nature and the countryside is consistently identified as beneficial for people's mental health". But "the isolation inherent in rural living represents a significant challenge to the mental health of adults, children, and young people living in rural areas".

A key aspect of isolation is that "NHS mental health services are often not fairly accessible for rural communities, with services largely centred in towns and cities creating barriers to access, compounded by the limitations and weaknesses of rural public transport and digital connectivity".

Inadequate services and opportunities for young people is another feature: "Far too much avoidable demand ends up at the door of Child and Adolescent Mental Health Services (CAMHS) in rural areas because of a fundamental lack of social infrastructure and youth services".

The report notes that "The Government's flagship levelling up agenda includes over-arching reference to the 'rural proofing' of policy". It says that "The fundamental need to provide equitable access to effective services for mental health and well-being must be part of this picture".

The Committee does not suggest that there is a mental health crisis in rural England. But, it says, "there are more than enough glaring gaps, and obvious red flags, to warrant urgent and meaningful action... rather than having to wait for an inevitable crisis to create a political imperative and free the necessary resource".

Women's burden of care

"The COVID-19 pandemic created a crisis of care" says this paper, "with millions of people now more reliant on unpaid caregiving". It goes on to say that "The burden of unpaid care needs continues to disproportionately fall on women, with devastating effects on health, well-being, and labor force participation".

The analysis is from the US, but contains much that will be familiar to UK readers. The authors make the point that "deep-rooted norms result in family caregiving still being widely perceived as so-called women's work... Accordingly, US women provide 2.2 times more unpaid family caregiving on a time-per-day basis relative to men".
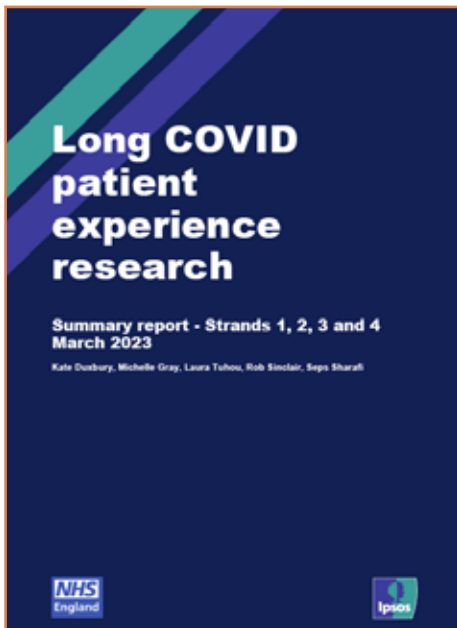
Unpaid care is also becoming more complicated: "More than half of all caregivers perform medical tasks typically done by health care workers [and] are also expected to help navigate complicated health care and social service systems, understand and track complex health information, and serve as surrogate care coordinators, advocates, and decision-makers".

At least some of this is driven by healthcare reforms, which are decentralising care away from inpatient settings toward the home and community. This is "based on the implicit assumption that family caregivers – the majority of whom are women – will provide this increasingly complex care at home without additional support".

The paper states that caregiving can be personally rewarding. But it also notes harmful consequences: depression, anxiety, and social isolation; impaired physical health; decreased preventive and self-care behaviours; greater acute care use; and even increased mortality. At least some of this arises from the fact that "60% of caregivers are juggling unpaid caregiving with paid job responsibilities".

The authors see a pressing need for reforms to policies that largely exclude family caregivers from receiving direct services or financial and other support, limiting them instead to the person directly receiving care. "This", they say, "is detrimental to both patient and caregiver health".

The paper concludes that "The COVID-19 pandemic has spotlighted the critical role of unpaid family caregiving [and] how women disproportionately assume these responsibilities". "Challenging this gendered dimension of family life", it says, "is essential to better supporting caregivers".

**Long COVID
patient
experience
research**

Summary report - Strands 1, 2, 3 and 4
March 2023

Kate Duxbury, Michelle Gray, Laura Tuhou, Rob Sinclair, Seps Sharafi

NHS
England

Ipsos

Life with Long Covid

The crisis phase of the Covid-19 pandemic might be over. But the long tail persists – not least for the up to 2 million people experiencing Long Covid.

This study, commissioned by NHS England's Insight and Feedback Team, looked at enablers and barriers to care for Long Covid, and examined public attitudes towards the condition.

Lack of awareness is a particular problem. While people are generally aware that Long Covid exists, they are much less clear about what it actually is. Turning to advocacy and support groups may give mixed results: "advocates reported very low or non-existent awareness of Long COVID services, making it difficult for them to signpost people to services".

The pathway to Long Covid services relies on GPs. But, says the report, "patient access to appointments are well-known challenges...this produces a perceived bottleneck however and places GPs in a 'gatekeeping' role, which impacts on how equitable and accessible Long COVID services are perceived to be".

One consequence is that people "tended to find the referral process complex and time consuming, particularly in cases where they felt they had to chase or drive progress".

Another consequence is that patents are self-managing their symptoms outside the support structures of the NHS. The report notes that "People had experimented with lifestyle changes... either because they had given up hope of finding a cure, or while they waited for treatments". And while peer support groups and online forums provide an important source of fellowship and learning, the report warns that "misinformation is rife".

People who can get to a Long Covid clinic are positive about the experience. "They described feeling a mixture of gratitude and relief... particularly that their condition had a name and that others were also experiencing similar ongoing symptoms".

The report makes various recommendations – on advice and information, on outreach to vulnerable groups, and on good practice in clinics. It also recommends partnership between the NHS and non-NHS groups, including community organisations and peer support networks.

Broken trust

Parliamentary
and Health Service
Ombudsman

Broken trust: making patient safety more than just a promise

HC 1444

"There is no shortage of programmes, policies, new initiatives and roles to try to reduce instances of avoidable harm", says this report from the Parliamentary and Health Service Ombudsman. But, it says, "there is a disconnect between the increasing levels of activity... and the level of progress we see on the frontline".

The report states that the statistics on patient harm "remain stark". It refers to the estimated 11,000 avoidable deaths every year in the NHS, and the "thousands more" patients seriously harmed. Behind these numbers are "the stories of individuals and their families and friends, whose lives have been shattered as a result of avoidable harm".

The PHSO recognises that healthcare staff, too, are affected by harmful organisational cultures: "nearly 40% reported they did not feel safe to speak up about anything that concerns them in their organisation. More worrying still, less than half of staff felt confident their organisation would address their concern".

The report makes a number of recommendations, one of which is "creating a system that is coherent and easier to navigate". This is based on the observation that "Political leaders have created a confusing landscape of organisations", including the Healthcare Safety Investigation Branch (HSIB), the Patient Safety Commissioner, PHSO, NHS England, NHS Resolution and "at least a dozen different health and care regulators". There are, says the report, "significant overlaps in functions, which create uncertainty about who is responsible for what".

But the biggest threat to patient safety, according to the PHSO, is "a system at breaking point". The Ombudsman recognises that "the NHS itself can only go so far in improving patient safety". It also needs "concerted and sustained action from Government... getting past politics to put patient safety at the very top of the agenda".

"The NHS cannot wait any longer", says the report, "Nor can the people who use it or work in it".

LISTENING TO GUARDIANS

Freedom to Speak Up Guardian Survey 2023

July 2023

National Guardian
Freedom to Speak Up

Unheard voices of staff

It is well known that there are close alignments between staff experience and patient experience in the NHS. So as health services struggle under multiple pressures, the voices of staff, as well as patients, need to be loud and clear.

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

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

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

A further dampening effect comes from "futility" – the concern that nothing will be done. Here, two-thirds of respondents (67%) saw futility as a 'noticeable' or 'very strong' barrier to workers in their organisation speaking up. Disturbingly, this represents an eight percentage point increase over the previous survey (58% in 2021).

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

The National Guardian's assessment is blunt: "This decline in perceptions concerns me, as it should all leaders, whether they are providers, regulators, or government". And, she says, "I fear that in this atmosphere of huge challenge for the sector, we are not always hearing what matters, and what can help us improve – the voices of our people".

House of Commons
Committee of Public Accounts

**Progress in improving
NHS mental health
services**

Sixty-Fifth Report of Session 2022–23

Report, together with formal minutes relating
to the report

Ordered by the House of Commons
to be printed 10 July 2023

HC 1000
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by authority of the House of Commons

Still waiting for parity of esteem

This report from the House of Commons Public Accounts Committee acknowledges that NHS England (NHSE) has made progress in improving and expanding mental health services. But, it says, this was "from a low base".

Only around one in three people with a mental health need have access to mental health services. Around 1.2 million people are on the waiting list for community mental health services. Rising demand continues to outstrip service provision.

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

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

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

The Committee reminds us that "In 2011, the government set out its goal of achieving 'parity of esteem' between mental and physical health services". But it did so "without setting out what achieving it meant in practical terms".

It recalls that in 2019, the Committee highlighted the need for the government to define 'parity of esteem' clearly, including setting out the criteria it will use to measure progress. But, it says, "The government...has still not done so".

Other groups too, according to the report, want to know what parity of esteem actually means. "Many stakeholders told us that a clear definition, objectives and roadmap are important to understand progress towards this end goal". It says that NHSE would also welcome a definition, but "the Department's current position is not to specify one".
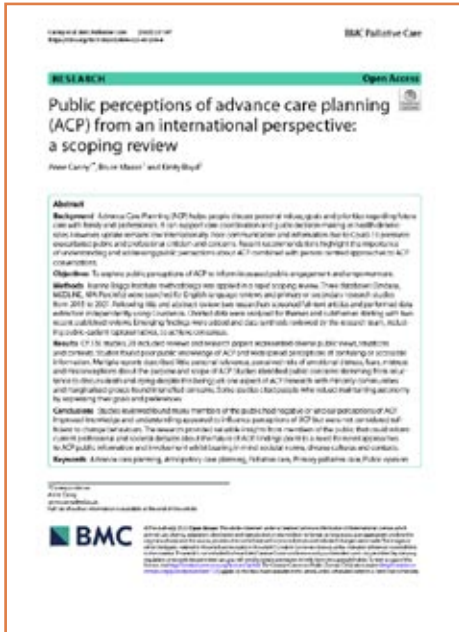
Advance care planning: what patients think.

This paper starts with the observation that advance care planning (ACP) helps people with serious illnesses or deteriorating health to think ahead and plan for what might happen. However "uptake remains low internationally". To find out why, the researchers explored public perceptions of ACP.

The study team carried out a rapid scoping review, and grouped their findings into four domains, as follows:

- Knowledge and engagement. Public knowledge of ACP is low. The literature indicates that patients and public have often never heard of ACP, and would not know how to find out about it. Even with good knowledge, engagement with ACP may be poor. The paper states that "Familiarity with ACP concepts did not necessarily translate into active participation in ACP".

- Fear, mistrust and avoidance. Some patients feared they would be 'tempting fate' if they became more open to ACP conversations. Many studies described ACP as being too emotional or distressing for patients and families to engage with. Other studies revealed patients' fears that their expressed preferences and wishes would not be carried out irrespective of having a documented ACP.

- Misconceptions and misinformation. Some patients seem to confuse advance care planning with end of life care. And end of life care itself is seen as care in the last days or hours before death. Accordingly, patients can see attempts to discuss ACP as coming too soon.

- Public expectations of healthcare practitioners. Patients can hold an expectation that it is up to healthcare staff to initiate conversations about ACP. This could lead patients not to raise the topic themselves.

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

**Transvaginal Mesh Case
Record Review**

June 2023 · Scottish Government
Riaghaltas na h-Alba

First, speak no harm

In July 2020, Baroness Cumberlege published First Do No Harm, the review of medicines and medical devices, including pelvic mesh. Three years on, the pain continues.

This Scottish review of case records relating to transvaginal mesh details some of the pain. Women affected by it talk of physical pain, sometimes acute, sometimes chronic, in hips, groin, legs and back. They talk of the mental toll of anxiety and insomnia. And they talk of the emotional anguish of feeling a loss of trust in healthcare professionals, and a loss of their own identities – the sense that they have become a different, and diminished, person.

One section of the report discusses communication and clarity of language. It says that "The importance of communication which is accurate, transparent and understood is the foundation of good clinical care", but then goes on to describe ways in which that foundation was undermined by misleading communication.

The two key mesh devices differ in how they are surgically placed, with variation in procedures and risk. But the differences were not always made clear. Sometimes polypropylene mesh was described as "tape", giving women the impression of something that "didn't sound too bad". They were not informed of the size of the device, and not always told that the device would be permanent. None of the women involved in the Case Record Review had been shown an example of the device.

Many women were told that mesh surgery was a "gold standard" treatment. Why? Because, says the report, "the early information that was given to patients [was] largely informed and written by the industry... [and] was described using only positive language. This was because there appears to be no requirement for the information to be explicit regarding disclosure of potential risks".

The review is clear that a "consequence of a failure to clearly communicate is the impact that this will have on the patient-clinician relationship. Trust may be diminished or eroded altogether". It goes on to say that "we cannot underestimate the lasting impact of the erosion of trust or the patient's willingness to engage in the future with healthcare".

GOV.UK

Home > Health and social care > Public health > Mental health
> Rapid review into data on mental health inpatient settings: final report and recommendations

Department of Health & Social Care

Independent report

Rapid review into data on mental health inpatient settings: final report and recommendations

Published 28 June 2023

Applies to England

Contents

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Our vision for a better future
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Whispers on the wind

This rapid review is a response to concerns about information to support patient safety in mental health inpatient care. In particular, it sought to understand how data and evidence was collected, and then used to identify and mitigate risks.

The good news is that "There was a consensus that hearing from patients, carers and staff was essential". However, that consensus was frustrated by practical and organisational barriers.

The review found that routes to give feedback were not clear or were difficult or time-consuming to use. Patients, carers and staff felt that their feedback was not listened to or acted on. They also sometimes felt unable to raise concerns for fear of the repercussions to themselves and others.

There were further problems with data quality. The review found that for data to be effective in providing early alerts on patient safety, it had to be available in as close to real time as possible. However, it "often has a time lag of weeks or months before it reaches frontline teams and local leaders".

One particularly worrying finding was that "At all levels, staff could recall almost no feedback from reports from national or regional data sets... that was useful to help them do their jobs".

The review saw good practice as well – for example, where providers had experts by experience on their boards and in their leadership meetings. Some used apps to allow patients, carers and staff the opportunity to give quick, real time feedback, and some had "high quality dashboards that gathered and triangulated data". Alongside all of this were "outstanding examples of action-orientated daily reviews in ward safety huddles".

A key learning point is "the importance of 'soft' intelligence – as one leader put it, 'whispers on the wind' – and the need for leaders to act on information from all sources, rather than relying on one dashboard or data set". And beyond that is the fact that "data on its own is not enough – it has to lead to action".

PATIENT EXPERIENCE FOUNDATION COURSE
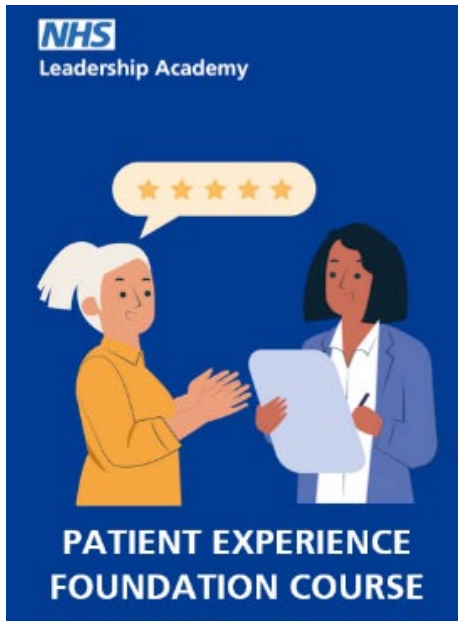
Open access training for patient experience

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

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

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

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

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

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

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

After that, look for "Patient Experience" in "Leadership Modules" and get started!

HEALTHCARE CONFERENCES UK

Measuring, Understanding and Acting on Patient Experience Insight From Insight to Improvement

THURSDAY 12th OCTOBER 2023
VIRTUAL, Online

This conference will focus on measuring, understanding and acting on patient experience insight, and demonstrating responsiveness to that insight to ensure Patient Feedback is translated into quality improvement and assurance.

Sessions will include learning from patients, measuring patient experience, using the NHS Improvement National Patient Experience Improvement Framework, demonstrating insight and responsiveness in real time, monitoring and improving staff experience, and the role of human factors in improving quality.

Further information and booking
or email aman@hc-uk.org.uk

Patient Leadership: Supporting & Developing the role of people with Lived Experience

THURSDAY 9th NOVEMBER 2023
VIRTUAL, Online

This conference focuses on Supporting & Developing the role of **Lived Experience** as well as involving patients in leadership positions. The conference will also cover how patient leadership can influence quality improvement for NHS Trusts and mental health services by looking at examples from across the country.

Further information and booking
or email kate@hc-uk.org.uk

Engaging Patients & Families in Complaints under Patient Safety Incident Response Framework (PSIRF) and the Complaints Standards Framework

THURSDAY 9th NOVEMBER 2023
VIRTUAL, Online

This virtual masterclass will build confidence in compassionately engaging and involving families and loved ones to work within the requirements of PSIRF and the Complaints Standards Framework.

But more than this, the masterclass will support staff to go beyond compliance to understand the issues and emotional component on a deeper level; to have real authentic engagement and involvement with patients and families.

Further information and booking

Confused?

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

We can help you with...

LIBRARY SERVICES: Free access to the Patient Experience Library, Healthwatch maps and Quote Selector.

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

EVIDENCE SERVICES: Free access to research-based publications.
Need to contextualise your own local evidence gathering? Ask us about bespoke search and literature reviews like this and this.

ANALYTICS: Free access to our Patient Surveys Tracker and Waiting Lists Tracker. Looking for more like this? Ask us about customised analytical tools to support your insight and engagement work.

Get in touch! info@patientlibrary.net

The Patient Experience Library

We are the national evidence base for patient experience and patient/public involvement. We have collated and catalogued over 70,000 reports and studies from government bodies, Healthwatch, academic institutions, think tanks and health charities.

Visit our website to get free access to evidence and analytical tools.

You can see more about who we are and what we do **here**.

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

Published items do not necessarily represent the views of the Patient Experience Library.

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Can't wait a whole week? Follow us: *@patientlibrary*

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Patient Experience Library

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