

# Patient Experience

and patient/public involvement in health and care services

Summer 2020



**Patient  
Experience  
Library**

## **INSIDE**

**Speedy boarding**

**Baring all**

**Trapped online**

## Editorial



Have you ever felt lost in the measurement maze? Surrounded by data from feedback forms, patient surveys, complaints and more? It can be hard sometimes to keep track of all the data, and to make sense of it. That's why we have built a one-click [surveys and feedback tool](#) - to give every NHS Trust in England instant access to all its patient experience data, all on one page. Have a go and see what you think - and if you can see ways

we could improve it, please let us know: [info@patientlibrary.net](mailto:info@patientlibrary.net)

Of course understanding patient experience isn't just about data. It's also about the issues and insights that come from lived experience, and which can't always be picked up via questionnaires. We have some great examples in this edition, starting with Angela Cornwall (page 3) who explains why we need special arrangements for appointments for patients with autism and learning disabilities. This is not a plea for preferential treatment. It's about levelling patients like hers up - not levelling the rest of us down.

On page 4, Liza Morton talks about routine hospital practices that can seem normal to staff, while feeling dehumanising for patients. Why do some services make patients wear gowns, when there is no medical need? If it's supposed to be for easier access for medical examinations, why are some patients "double gowned"?

Andrea Downing on page 5 looks at the vulnerability experienced by groups of patients who gather online for peer support. In medicine, confidentiality is sacrosanct. But it seems that some online platforms have no moral qualms about taking patients' data - with or without their knowledge - and selling it on.

We're on a mission to make patient experience an integral part of evidence-based practice. So we continue to seek out and catalogue hundreds of documents every month - and on pages 6 to 16 we bring you our top picks of the latest and best, with handy summaries of the key points.

We're always keen to hear from our readers, so if you know of a stand-out report that we should be featuring, or if you want to submit a comment piece, get in touch!

*Miles*

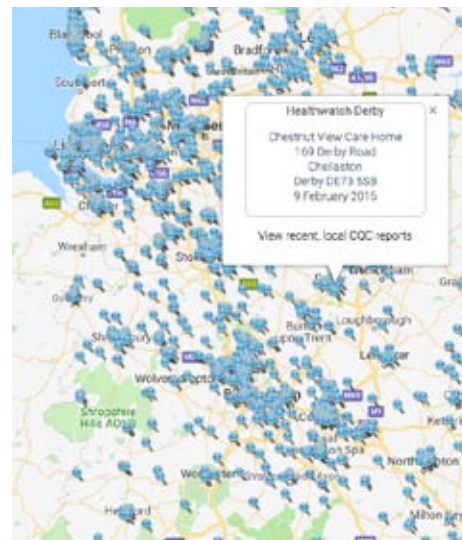
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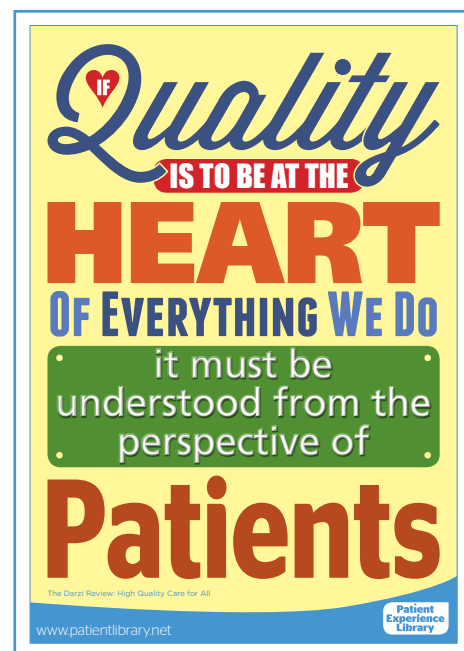
[www.patientlibrary.net](http://www.patientlibrary.net)

## Free resources

Our [Knowledge Maps](#) offer a quick and easy view of what patients are saying about healthcare services across England. Feel free to click and browse at will!



Spread the word about patient-centred care with our [posters](#) for offices, wards, meeting rooms and waiting areas. The quotes are from sources such as the Berwick Review and the Francis Inquiry - so as well as being visually striking they're also on solid policy ground!



## 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](mailto:info@patientlibrary.net)



# Speedy boarding

Angela Cornwall  
Long-term carer




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Something that has made a real difference is having a named point of contact at the hospital – someone who is trained in learning disability and autism.

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What happens when a person with “challenging behaviour” encounters a healthcare system with “challenging procedures”?

I care for a young person who has severe autism and learning disabilities. She needs regular check-ups, as all children do, with GPs, dentists, opticians.

For her, hospitals, surgeries and waiting areas are bewildering places. Noises, smells, strange faces and all the rest can create sensory overload and fear. Trying to manage a disturbed adolescent in a public place is really difficult and stressful. And she, too, ends up exhausted and upset.

The care, when we get it, is always excellent. But the process of getting to the care has sometimes been awful. And that has mainly been because of inflexible appointments and waiting procedures.

I have worked hard with my local hospital to give this young person a better experience of care. We wanted her to see hospital as a welcoming and caring place, not somewhere that she should fear and avoid. The trick was to get her in and out of appointments as fast as possible.

It's not about jumping the queue. We can take our turn along with everybody else. But when it is our turn, we need things to happen quickly and smoothly.

Something that has made a real difference is having a named point of contact at the hospital – someone who is trained in learning disability and autism. When an appointment is due, I know I can call her and get everything lined up ready for our visit. She can talk to the receptionists and let them know they need to wave us through. If a wait is inevitable, she can get us a quiet space on our own. If the doctor (with the best intentions) takes too long explaining something, she can help to short-cut the chat, and ask for a follow-up phone call once we are back home.

Before we had this system in place, hospital visits could be a disaster. With the system, four out of our last five visits have gone well. None of it is difficult to achieve. It just requires a little more time and thought – and

a trained and sympathetic point of contact is vital.

In return, the healthcare provider has fewer cancelled appointments. Receptionists and other patients in waiting areas don't have to witness distressing scenes. Best of all, the patient gets the healthcare they need, in a way that makes them feel safe.

I'd like to see something like this happening everywhere – GP practices, dentists, hospitals, the lot. There are wonderful NHS staff ready to give people with autism and learning disabilities the best care possible. Why should inflexible systems be a barrier? Why is it ok for providers to say they don't really know how to deal with patients like mine? Why should someone who is really vulnerable have a worse experience of care than everyone else?

I know a young person who has very challenging behaviour. She can't help that. I also know some healthcare providers who have very challenging appointments procedures. They can help that – and they need to change.

# Baring all

Liza Morton

with Nicola Cogan and Manos Georgiadis

In the UK the open-back, hospital gown is the most common hospital clothing worn by patients during medical interventions, tests and surgery. Clothes express our social status, gender, occupation, personality and individuality. What we wear is part of our social identity and can empower or disempower us. So we need to understand the impact of patient clothing on wellbeing during hospitalisation, when people can feel particularly vulnerable.

Inspired by my own lifelong experience of regular hospitalisation, I set out to explore whether patient clothing impacts on wellbeing. Our team (with colleagues Dr Nicola Cogan and Dr Manos Georgiadis) conducted in-depth interviews with adults living with a lifelong chronic health condition (Congenital Heart Disease). These revealed three themes associated with wearing hospital gowns:

- Symbolic embodiment of the 'sick' role (loss of healthy identity).
- Relinquishing control to medical professionals (passive acceptance and disempowerment).
- Emotional and physical vulnerability (cold, exposed and not fit for purpose).

We followed up with an online survey, open to anyone with experience of wearing the backless gown (928 participants). Findings indicated that adults often reported wearing the hospital gown despite lack of medical necessity while its design was considered to be lacking in dignity. The gown often leaves patients feeling exposed, self-conscious, uncomfortable, cold, disempowered and vulnerable.

*"I mean, you don't feel like yourself in the sense that you're not wearing your own clothing. It's just strange, and actually I've been through (medical) procedures in recent years and it's like, you're not sitting with people who've got their clothes on, everyone's sitting in gowns but it's just sort of uncomfortable."* – Helen

*"It's all part of the whole process of not being in control, not being able to wear your own clothes and not being able to do what you want to do and then you have to let the medical team sort of take control of everything"* – Camilla

*"I don't really like displaying my (body) parts to everybody so with the gown you're quite often trying to turn your back on something, trying to cover yourself up or sit down with these gowns, there's basically nothing underneath so if you're sat down it can ride up your leg and people can walk past and see other things."* – Calum

These findings indicate that the open-back gown is not fit for purpose. Indeed, four out of every ten participants in the online survey reported being offered a second gown (double gowning) to wear the other way around to protect their dignity. This solution is not cost effective as it doubles the costs of providing such attire. It also challenges the argument that the backless gown is designed to facilitate access for medical examination. Further, six out of every ten participants reported wearing the hospital gown despite being unsure of medical necessity.

This work is part of a wider effort to promote Psychologically Informed



Medicine that emphasises the importance of challenging cultural norms in healthcare. De-humanising aspects of care, as symbolically represented by the hospital gown, may adversely impact on health and wellbeing. And this is inconsistent with a person-centred approach with dignity and privacy being fundamental cornerstones of patient care.

We are now analysing findings from a further study exploring hospital staff's views of the gown. From this, we hope to gain a better understanding from medical professionals about current use and necessity of the hospital gown.

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You can read more about the study in the British Journal of Health Psychology:  
Morton, L., Cogan, N., Kornfält, S., Porter, Z., & Georgiadis, E. (2020). Baring all: The impact of the hospital gown on patient well-being. British Journal of Health Psychology. DOI: <https://doi.org/10.1111/bjhp.12416>

# Trapped online

Andrea Downing Founder, *The Light Collective*



Seven years ago, I was utterly alone and struggling with the prospect of life-changing decisions after testing positive for a breast cancer gene mutation. I am a Previvor. I searched online for others like me, and was incredibly thankful that I found a caring community of women who could help.

As I found these women through a Closed Facebook Group, I began to understand that we had a shared identity. I began to find a voice, and over time, this incredible support group became an important part of my own healing process.

As a group of cancer previvors and survivors we're not alone. Millions of people go online every day to connect with others who share the same health challenges. Most of this happens on Facebook.

I know what you might be thinking: after all the terrible news about Facebook and privacy, why would ANYONE share sensitive or private health information on Facebook?!

The truth is: we really have no choice. We're trapped.

Many of these health communities formed back before we understood the deeper privacy problems in digital platforms like Facebook. And the network effect is very strong; patients must go where the network of their peers live.

We turn towards peer support groups when we fall through the medical cracks of the healthcare system. When facing the trauma of a new cancer diagnosis and/or genetic test results, the last thing on your mind is whether you should be reading 30 page privacy policies that tech platforms require. We need information, fast. We need it from people who have been down the same path and who can speak from personal experience. And that information exists within these peer support groups on Facebook.

After the news of [Cambridge Analytica](#) broke, I asked myself a simple question: *what are the privacy implications of having our cancer support group on Facebook?*

As a geek with a professional background in tech, I became curious and began to do some research. Along with other experts in the field of cybersecurity I realized that we had found a [dangerous security flaw](#) that scaled to all closed groups on Facebook, and allowed unrestricted downloading of names, employers, locations, email addresses and other info on the group members.

Since discovering these problems and reporting this vulnerability to Facebook's security team, our group has been desperately seeking a feasible path forward to find a safer space. We have

awakened to the deeper issues that created breach after breach of data on Facebook.

Our trust is gone. But we're still trapped.

When health data breaches occur, members of vulnerable groups are at risk of discrimination and harm. For example, [health insurers](#) are buying information about my health—and potentially can use this to raise my rates or deny coverage. And [70% of employers](#) are using social media to screen job candidates.

Without transparency and accountability from tech companies on their data-sharing practices, how will we ever know what decisions are being made about us? If the data generated in the very support groups these patients need is used against them, who is being held accountable?

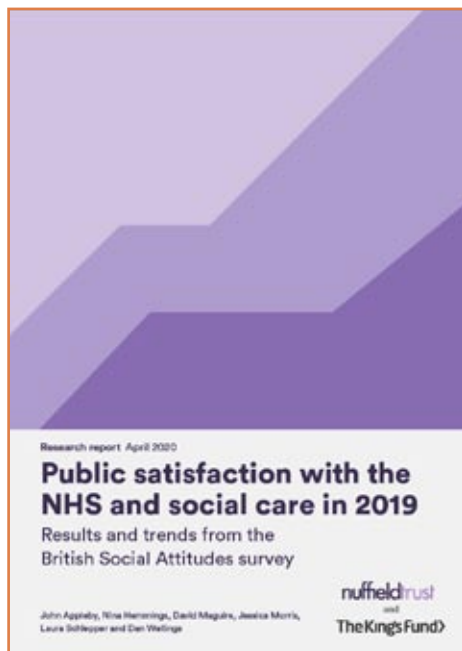
We are truly vulnerable on the platform where we reside. Yet, we can't remain silent. We would rather not be appeased with shiny new features and rhetoric about privacy. Rather, we seek autonomy. We seek a way to take our own power back as a group. We seek to protect our data and shared identity as a group.

Our data is not an abstraction to us. It represents our own suffering and our families' suffering. We have an urgent need to develop a new way forward that protects our identity, and the future of our groups. We will create the future we choose for our community. That future exists with or without Facebook.

If you are in the same boat, please reach out to us [here](#).

## RECENT REPORTS

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



# Growing public satisfaction

Asking about public satisfaction with the NHS may seem unnecessary at a time when people have routinely emerged from their homes to applaud the efforts of healthcare staff. But this survey, carried out before we had even heard of coronavirus, asks questions that are important for society and healthcare in the long term.

As an annual “gold standard” research exercise, the survey provides a rich time trend, adding a depth and context to the findings that, say the authors, no other measure of NHS satisfaction provides.

An encouraging headline is that after falling for the last two years, public satisfaction with the NHS rose significantly in 2019. Overall satisfaction was 60% – a 7 percentage point increase from the previous year. And while 42% of respondents thought that the general standard of care would get worse over the next five years, that was actually an improvement on the 51% who, in the 2018 survey, expected care to get worse.

The top reasons for satisfaction with the NHS were quality of care, followed by the NHS being free at the point of use, and having a good range of services. The main reasons for dissatisfaction were staff shortages, waiting times for GP and hospital appointments, and a view that the government doesn’t spend enough money on the NHS.

On the question of funding, recent government announcements of a new, and more generous five year cash settlement for the NHS could be key in explaining the upturn in satisfaction. It is possible, say the authors, that the public have understood (and believed) that NHS funding is increasing and that this in turn has fed through to an increased optimism about the future of the service.

It is important to note that the survey is about social care as well as the NHS. The satisfaction rating for social care remains “stubbornly low”, at 29% – some way below any of the NHS services. Moreover, users of social care were more dissatisfied than users of any other service, with almost one in two (47%) saying they were dissatisfied. The report states that “governments have promised to ‘fix’ social care, but so far these have remained only promises, and there has been no actual reform of an increasingly challenged sector”.



## Moving engagement online

As soon as lockdown started, videoconferencing rapidly became part of the new normal. So can patient engagement work – via committees, focus groups and so on, simply move into cyberspace and carry on? The answer, according to this report, is “yes but...”

“Yes” because the technology these days is sufficiently mature, and many people – even before the huge increase in use of Zoom and Teams – were already familiar with platforms like Skype and FaceTime.

The “but”, however, arises from the fact that hosting a business meeting online is somewhat different from chatting with friends or family after work.

A key difference is that business use can make far better use of the wide range of features that videoconference platforms offer. “Don’t assume that online meetings are the ‘poor relation’ of face-to-face meetings” says the guidance. “Online platforms allow for lots of different kinds of interaction, including the chance to use break out rooms, run polls, allow people to share their screens with each other, and to use ‘chat’ to comment and share responses.” Hosts who are familiar with these tools have a much better chance of offering enjoyable and effective online engagement.

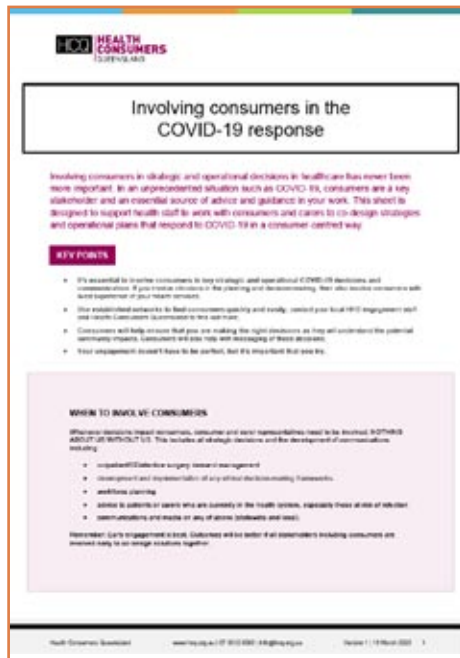
Planning and preparation are important too. The guide suggests opening meetings well in advance of the official start time to allow time for people to log in, and then sort out any problems they may be having with sound and vision.

If you want to share your screen, show powerpoint slides, move people to break out rooms, etc, it might be worth having someone to help. “Trying to facilitate, present and manage the technicalities is really hard – so splitting the roles – with a ‘presenter / facilitator’ and ‘technical support / producer’ working hand in hand really helps.”

The guide offers further tips – for example playing music as people wait for the meeting to get underway, not stressing too much about bad hair days, and having a back-up plan for that crucial moment when the screen freezes or the video clip fails to load.

All in all, a handy guide for changing times and new ways of working.





# Engagement under Covid

Every year, NHS England runs Experience of Care week to highlight the importance of patient experience, and to give people the opportunity to share ideas, case studies and best practice tips.

This year was no exception, even though the week (28th April – 2nd May) had to happen more on line than in real life. But was it meaningful to run Experience of Care week when the coronavirus had put a stop to almost all forms of “business as usual”, and national collation of patient feedback via complaints and the Friends and Family test had been suspended?

This report (from Australia) does not tackle that question directly. But it does explain why public engagement in a time of crisis still matters. It states that “Whenever decisions impact consumers, consumer and carer representatives need to be involved”, and reminds us of the watchword, “Nothing about us without us”.

It sets out some basic, but important, principles. One is that “Consumers will know more than you about their personal situation, and that of their community”. Another is that “If people are affected by a decision they deserve to be included in that decision”. The guidance recommends including as many voices as possible, especially those with high social or health needs, or those who are seldom heard.

The guidance recognises that in a time of crisis, health services need to move fast, so it offers handy tips on how to find “consumers” quickly. Acknowledging the importance of infection control, it tackles some of the practicalities of engaging with people while minimising face-to-face contact.

A section at the end explodes some myths – for example, the idea that public engagement is too time-consuming and difficult at present. That is not to say that the report ignores the challenges. However, it finishes with the observation that “Your consumer partnerships do not need to be perfect; the most important thing is that you try.”





## Lived experience under lockdown

This study aimed to explore the knock-on effects of coronavirus for health and wellbeing in the UK by understanding the experiences of people whose care has been disrupted. It is based on interviews with 12 people in the week beginning 20th April, just after the second 3-week lockdown period was announced in the UK.

It found that in choosing not to seek care, responsibility often trumps fear: “...the primary reason for delaying care was to avoid adding to the burden on the NHS”. But the sense of responsibility was accompanied by anxiety. “Some participants were afraid that by following guidance to self-isolate and avoid risk, they would be discharged from services, or ‘sent to the back of the queue’.”

Fear did also play a part. “One pregnant participant told us that part of her concern about asking for medical help was fear for her baby.” Others “reported that they knew someone who had contracted the virus while in hospital for another condition, a powerful anecdote”.

People whose care was cancelled or postponed could be left feeling in limbo: “the feeling of having built up to a potential resolution and having it snatched away was a source of disappointment, and where no timetable was available for it to be rescheduled, hopelessness”.

An important learning point for health professionals is that in helping people deal with uncertainty, clear personal communication is crucial. “People appreciated being informed at each step of the process, having the time to ask questions and where staff acknowledged the unique situation we are all in.”

The report also considers the practicalities of things like hospital visits, telecare, and the use of apps. For the latter, “telephone calls were strongly preferred, because they allow for questions, which is both practically and emotionally valued”.

The report, which finishes with a series of recommendations, is a useful addition to the literature on patient experience - and one that might remain relevant for some while yet.



## Patient data sharing - who wins?

The launch of the [coronavirus contact tracing app](#) on the Isle of Wight once again ignited debate over the pro's and cons of sharing personal health data. While advocates of track and trace say that digital solutions are essential, privacy and human rights advocates are not so sure.

Against this background, a briefing paper from the House of Commons Library makes for useful reading. It offers a comprehensive but concise summary of all the main points of the data-sharing debate, including legalities, practicalities and ethics.

It includes some lessons from (recent) history – not all of which inspire confidence in the state's ability to safeguard personal health data. These include the following:

- The suspension of the national Care.data programme, due to concerns over the opt-out system in place and over patient confidentiality. Following the review, the then Life Sciences Minister confirmed that Care.data was to be closed.
- A finding by the Information Commissioner that the Royal Free Trust failed to comply with the Data Protection Act when it provided patient data to Google DeepMind.
- An NHS investigation which found that none of the 80 NHS Trusts affected by the 2017 WannaCry ransomware attack had applied an advised Microsoft patch update.

The report looks forward as well as back – examining cross-border data sharing after Brexit. We learn that in any US-UK trade talks, one negotiating objective of the United States would be to “Establish state-of-the-art rules to ensure that the UK does not impose measures that restrict cross-border data flows”.

In response, the UK Minister for Trade has said that “We would seek to review any rules in place to safeguard data... and ensure that they are not overly protectionist. We set up the pipework, but whether or not the taps are turned on is a matter for the regulators”.

Patients may or may not be reassured by this.



## Taking kindness seriously

This report describes itself as “the first study of patient experience in acute adult mental health settings” and as such, it sets a very high bar for potential followers. At 111 pages, it is not a short read – and with its appendices, it weighs in at an intimidating 337 pages. But there is little in here that could be described as waffle, and a great deal that offers valuable insight.

It outlines the importance of visible changes in response to feedback: “When change was not observed, it disincentivised patients and carers from giving feedback and staff from collecting it, as they felt that there was nothing they could do about actioning it”.

It explores links between staff experience and patient experience: “When staff were over stretched, demoralised... and frustrated at the lack of change that resulted from patient experience feedback, they stopped attempting to collect the feedback”.

It looks at intrinsic versus extrinsic motivations for staff to engage with patient experience work, stating that if quality improvement is “driven by external drivers, such as the CQC, complaints and serious incidents, staff disengage from collecting feedback and develop a siege mentality motivated by fear”.

The often confusing context for patient experience work is also considered: “NHS trusts are required to collect experience data from patients. Currently, there is little understanding of what data are most important, what processes are in place to collect them and whether such data make any difference to the quality of patient experience”.

In fact the report covers so much ground that it is impossible, in this short summary, to do it justice. If you are short of time, it is worth at the very least looking at the discussion, integrated findings and conclusions in Chapter 9. And pages 85 – 88 offer a set of “rules” on how to collect, analyse and use patient experience data to improve the quality of care. It actually says “...to improve the quality of care in adult inpatient mental health settings”, but many of the rules could apply to almost any healthcare setting.





# Beyond lived experience

Patient and public involvement (PPI) in healthcare is a well-established principle. In spite of that, practice remains variable. There are arguments over definitions, tensions over power dynamics, and questions of equality and inclusion.

One of the challenges, according to this paper, is “legitimacy”. For example, “Some professionals do not believe in the value of experiential knowledge, or consider it legitimate only when public contributors are... connected to their particular patient group”. This, say the authors, places public contributors in a “legitimacy double bind”. Contributors who are supposed to speak for a group can be denigrated as “unrepresentative”, while the evidence of those who tell only their own stories can be dismissed as “anecdotal”.

The problem can be exacerbated when PPI is equated solely with lived experience. That is because “To be involved at the higher levels public contributors need to take on more strategic roles in determining healthcare agendas and directions”. However, “In strategic roles, direct lived experience inevitably becomes less and less relevant to the work at hand”.

In this context, the study sought to uncover how public contributors themselves define their legitimacy. It reports that “The most striking results related to the number of valuable roles the public contributors established for themselves, and the way these provided the internal legitimacy left lacking by government and funder mandates”.

The paper describes nine distinct roles: lived experience, occupational knowledge, occupational skills, patient advocate, keeper of the public purse, intuitive public, fresh-eyed reviewer, critical friend and boundary spanner. Importantly, “All the public contributors played more than one role”.

The legitimacy of these roles is based in a number of factors, of which “lived experience” is just one. Others were “knowledge and skills”, “citizenship” (particularly in service of a greater public good) and the “outsider” status of public contributors.

The paper concludes that “The conflation of PPI with lived experience [presents] a challenge for public contributors and involving organisations alike”. Instead, a broader view of legitimacy could “demonstrate the potential value of public involvement in settings where lived experience appears to lack relevance”. The authors suggest that “all involving organisations could benefit from encouraging public contributors to undertake a wide range of roles”.

You can see a video presentation of the main findings from this study [here](#).

# Experts of experience



Many readers will be familiar with the term “experts by experience”. This is the idea that in a science-driven healthcare culture, we need to make room for the kind of expertise that comes from living with illness, alongside the expertise that comes from studying or treating it. But personal circumstances – often linked with class, gender, ethnicity and so on, can lead to questions of how “representative” experts by experience can be.

This wide-ranging paper considers whose lived experience is represented in healthcare, as well as how and by whom. It recognises that simply sharing an experience does not mean it will be considered evidence, or that the person sharing it will be deemed an expert. It goes on to ask how “experience” is converted into credible “evidence”, and how specific pieces of evidence can then become an accepted part of a healthcare system’s body of knowledge.

The paper identifies three factors that shape the likelihood of an experience being used to generate evidence and create knowledge. Firstly, whether the experience has been sanctioned by being shared through an official feedback channel. Secondly, whether the experience has been solicited by a healthcare professional. Thirdly, whether the experience has been sought with the specific intention of being used for a particular purpose. These, it says, serve as preconditions for an experiential account to be used as evidence in the NHS feedback landscape.

The process of converting experience into evidence and then into knowledge is, to a large extent, steered by NHS staff who gather patient feedback. They have the power to “shape what and whose experiences are incorporated, used and responded to and in what ways... Their work involves filtering, aggregating, collating and isolating patient experience as it comes in through the various sources”.

These staff “develop expertise in... extracting and sharing... experiences within the specific institutional contexts of the NHS and the demands for evidence-based policy and practice”. They are not so much experts by experience, as experts of experience.

The paper concludes that incorporating people’s experience into healthcare remains challenging. “Patient stories” can be powerful because of their subjective and emotive nature. But that also makes it hard for them to be accepted as reliable evidence, and patients often lack the resources needed to produce the kind of evidence deemed necessary by decision makers. The answer could be to recognise that as well as experts-by-experience, we need experts-of-experience.



# Language vs experience

When patients give feedback to healthcare providers, the topic of “communication” often features prominently. That is because when people are feeling vulnerable, the way they are spoken to, and the words that are used, matter a great deal.

There can be few experiences that are more distressing than the death of a baby. So we need to think very carefully about how bereaved parents are spoken to. This paper looks at clinical terms such as “miscarriage”, “stillbirth” and “neo-natal death” and finds that “These categorisations based on gestational age and signs of life may not align with the realities of parental experience”.

The study explored the healthcare experiences of parents whose babies had died just before 24 weeks of gestation. Those interviewed “felt strongly that describing their loss as a “miscarriage” was inappropriate and did not adequately describe their lived experience”.

Many “hadn’t realised properly that I’d have to actually give birth”. One mother said “so in my head I was like... it’s going to be... just blood or whatever. But you know, I had to full on give birth”. Another was reassured when her midwife compared her experience as similar to birth later in pregnancy as “that’s the majority of the hard work, it’s just the same, and you did really well”.

Parents who were treated as if they were having a baby were more prepared for how their baby might look and found it easier to make decisions about seeing and holding their baby. In contrast, the use of the word “miscarriage” created different expectations: “My husband was actually really surprised when they put her in my arms, and he said, ‘She’s a real baby. She’s even got hair’”.

Memory-making was often extremely important to parents. Official certificates were a potent part of this memory-making process, but parents whose baby was born showing no signs of life before 24 weeks of gestation did not receive an official birth or death certificate. Parents were sometimes offered informal birth and death certificates. However for some they were a stark reminder that there was no legal documentation of their baby’s life. One said, “It’s just like insult to injury... it’s just a printed out bit of paper that the hospital gives you...”.

The study refers to the National Bereavement Care Pathway’s core bereavement care principles which highlight that “some parents may see late miscarriage and premature labour as being very similar even if some staff may view these as very different situations”. And it includes additional recommendations for staff caring for parents experiencing loss between 20 and 24 weeks of pregnancy.

It concludes by emphasising that language in healthcare should “validate the loss of a baby, acknowledge the hopes and dreams associated with that loss, and prepare parents for the experience of labour and birth”.





## Covid worse for women

Medical evidence seems to indicate that men are at higher risk from Covid-19 in terms of serious illness and death. So we might imagine that they would be more concerned than women about the virus, and its effects on society and the economy. But not according to this study.

The survey explored how the public experience of coronavirus varies between men and women. Interestingly, it found that although men are more likely to contract Covid-19, they are less concerned about the disease as a whole than women.

Women are more likely to think the effects of the virus will be greater across various areas including the economy, public services and our system of government. This could be because in some very direct ways, women are more seriously affected than men. For example, one third of women responding to the survey said that their workplace had closed, against one quarter of men. And respondents in general thought that working from home would be more likely to damage a woman's career than a man's.

Women have also been busier than men during the lockdown - partly by engaging in more spare time activities, but also with looking after friends, family and neighbours.

When it comes to mental health, women are finding it harder than men to stay positive - both on a day-to-day basis, and when thinking about the future. They may be less trusting of the government's handling of the crisis, and more likely to be anxious and sleeping less well.

The authors are careful not to speculate on the possible implications of all this, stating that "What this means for the future is uncertain". But they do note that nearly seven in ten women think the government acted too late, and that women are more uncomfortable about some aspects of returning to normal.



## One-click data access

Last year, [a report from the Health Foundation](#) looked at quality measurement – including patient experience – across a range of healthcare services. It described a “measurement maze”, with numerous national bodies presiding over data collection. The data was “hard to locate online, with multiple spreadsheets to choose from and large Excel workbooks to download and navigate”.

We thought that sounded all too familiar. The patient experience corner of the measurement maze is a tangle of datasets emerging from the Friends and Family Test, CQC patient surveys, NHS England patient surveys, complaints data, and more. [One recent study](#) identified no fewer than 37 different types of patient feedback on offer to staff within UK hospitals.

As we thought about the measurement maze in patient experience, we started to wonder about clearing a path through it.

We set ourselves a challenge: what if a Chief Executive of a Trust said, “I want all the patient experience data for this Trust and I want it now”. We wondered whether it would be possible to respond to a request like that with just one mouse click.

Developing the solution took months. We had to trawl endless CQC and NHS England web pages, working through out of date pages, broken links, and poor navigation. Then we had to download vast spreadsheets and plough through complicated layouts. Finally we had to find a way to organise all the data such that every Trust could get all its data with a single click.

We have now achieved exactly that – but we want to go further. Because this is not just about speed and convenience of access. It is also about insight – so we have also developed one-click cross-referencing, to pull out common themes across the survey data.

We think there is more to do. We are keen to hear what you think of our surveys and feedback tool, and whether it could do more. [Please feel free to try the tool](#) (open access) and let us know what you think, via [info@patientlibrary.net](mailto:info@patientlibrary.net). A full version of this account (“Hacking through the Measurement Maze”) is available via [BMJ Opinion](#).

# Confused?



We are clearing a path through the patient experience measurement maze.

Let us help you with...

- [Surveys and Feedback tool](#). One-click access to key patient experience datasets for your Trust, with cross-referencing to aid analysis.
- [Patient Experience in Trusts Map](#). Find your Trust, then click and collect.
- Healthwatch collection. Over 11,000 reports accessible via the [Network map](#), and the [Enter and View map](#) or by searching “Healthwatch” in the Library.

## Extras for subscribers:

- **Archive:** Go deeper into the evidence base with access to reports over 3 years old.
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The French Inquiry: Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry

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