

Patient Experience

and patient/public involvement in health and care services

Spring 2021



**Patient
Experience
Library**

INSIDE

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A healthcare system that wants to be both person-centred and evidence-based has to have a really good evidence base for patient experience.

The NHS does have an evidence base for patient experience - but it is patchy. Data pours out of the Friends and Family Test, national patient surveys, local patient surveys, Healthwatch reports, academic studies and more. Most of it is very good - but no-

one has a strategic overview of the evidence gathering, so there are big areas of duplication, as well as big gaps. While medical research is guided by processes for research prioritisation, patient experience research is a bit of a free-for-all.

So we are delighted to announce a new partnership with the University of Plymouth. We'll be working with them to make an assessment of the patient experience evidence base. We want to try to make sense of the quantity, age, and sources of different types of evidence. To identify areas of saturation, and areas where the evidence is thin. On the back of that, we aim to suggest ways in which the research effort could be better steered, with time and money better used. Look out for more news on this in future editions of this magazine.

Why does any of this matter? The answers are amply provided by our contributors to this edition.

On page 3, Vincent Rajkumar shows how a patient with myeloma gave researchers a vitally important reality check. While clinicians got excited about possible new drug combinations, the patient - Mike Katz - questioned the use of one particular drug in the first place. His insights from lived experience altered the course of the research, and many lives were saved.

Julia Hamer-Hunt and Claire Murray on page 4 show how they are moving patient and public involvement in research from a "neglected afterthought" to a process based on shared values and needs. Their aim is to make involvement more meaningful, and get better results - both for the people and for the research.

As usual, we have been picking through the latest and best in patient experience research, and summarising it for your interest and enjoyment 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

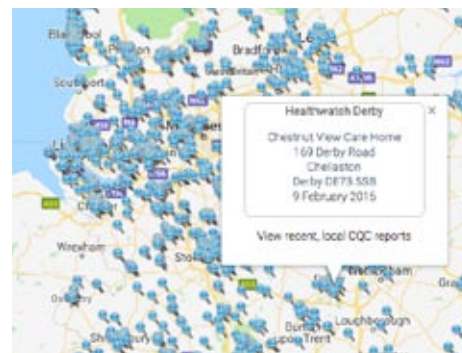
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Free resources

Our one-click [surveys and feedback tool](#) gives every NHS Trust in England instant access to all its patient experience data, all on one page. A cross-referencing function gives a quick and easy overview of common themes emerging from different datasets.

Browse the map, select your Trust, then click and collect!



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

Saving lives by listening

S. Vincent Rajkumar, M.D., Mayo Clinic



I would like to share the story of how a patient with cancer came up with the idea for a randomized trial, and how listening to him saved a lot of lives.

In 2002, I had just completed a randomized trial with the notorious drug thalidomide for a type of cancer known as multiple myeloma. Thalidomide would later be approved by the US Food and Drug Administration on the basis of this trial. As a young investigator I was thrilled with the success and eager for the next exciting trial testing fancy new regimens.

But a patient with myeloma, Mike Katz, had other ideas.

Mike was on national patient advocacy committees. He had lived with myeloma for years and knew all of the recent advances. More importantly he attended numerous patient support group meetings and had his finger on the pulse of what myeloma patients were going through. Mike listened as we debated ideas for the next myeloma trial.

While clinicians talked about creating “exciting” combinations, Mike said, “Listen, what patients really want is freedom from the side effects of Dexamethasone”. He said, “All these new drugs don’t help if patients cannot take them. You guys are giving too much Dexamethasone. And people are suffering”.

Dexamethasone was used in myeloma at high doses to kill the cancer cells. We saw it as an important component of therapy. Mike disagreed. “You are giving Dexamethasone at a high dose on the basis that this is how it has always been done. Please run a trial and see if in the era of new drugs you still need such high doses of dexamethasone”.

We were all sceptical, but Mike was not going to give up. He insisted we do a randomized trial of high dose dexamethasone versus low dose dexamethasone.

To us the idea seemed destined to fail. It seemed so boring. We had waited 40 years for new drugs and Mike wants us to test Dex dosing!

However, we respected Mike. We knew he was aware of what patients were going through. We saw 100-200 myeloma patients a year. He interacted with thousands. He was also leading meetings of support group leaders who were leading meetings with lots of other myeloma patients.

So we proceeded to make a case for testing the optimal dose of dexamethasone. It wasn’t easy. But we got it approved.

Long story short, the trial accrued faster than any other myeloma trial we had done in national co-operative groups ever! Deaths with high dose dexamethasone were significantly higher than with low dose dexamethasone.

We had hypothesized that by using low dose dexamethasone we would have less toxicity and similar efficacy. Little did we know that just a change in Dex dose would save lots of lives - at one year, 96% were alive with low dose Dex versus 87% with high dose standard of care Dex.

There were other benefits as expected. All serious side effects including blood clots were lower with low dose Dex. The Lenalidomide plus low dose dexamethasone (Rd) regimen was born. The little “d” signifies low dose Dex. Rd is now the backbone of most myeloma regimens. The lower dose of Dex has allowed us to build many new drug combinations.

We are indebted to Mike. We grieve his loss. His legacy and work endures.

Our randomized trial of high dose versus low dose dexamethasone was published in *The Lancet* and is one of the most cited myeloma papers ever with over 1,000 citations.

Yes. Mike Katz was an author on this paper.

This article was first posted as a Twitter thread on the 10th February 2021 via [@VincentRK](https://twitter.com/VincentRK)

Whose values matter?

Julia Hamer-Hunt and Claire Murray, NIHR Oxford Health Biomedical Research Centre (BRC)



Evaluating the impact of patient and public involvement (PPI) is a contentious issue. There are no nationally agreed measures and it is - in practice - often a neglected afterthought.

It is something we have grappled with at the Oxford Health BRC. What should we be measuring to help us understand and demonstrate the difference PPI makes to research? How can we encourage busy PPI contributors and researchers to reflect back? How can we use 'impact' to improve our PPI practice?

From the outset collaboration has been our central principle, so we brought together PPI contributors and researchers to try to answer these questions.

Our [Patients and Research Group](#) began by reviewing the UK Standards for Public Involvement alongside our [PPIE Strategy](#). We worked together to

agree our priorities, and capture short and longer term differences, along with intended and unintended impacts. We recognised we needed a flexible approach to give space for researchers and PPI contributors to identify what is most important to them.

To capture the widest range of voices, we developed a survey that was shared with PPI contributors and researchers to identify what PPI experiences and outcomes were of most interest to them.

Positive experiences, both for the PPI contributors and the researchers were associated with collaborative working, a constructive approach and clear communication.

PPI contributors placed emphasis on their involvement being supportive to researchers, helping ensure research is patient centred and accessible. They wanted their involvement to help in concrete ways, for example to secure funding. For researchers, PPI had encouraged reflection, provided valuable perspectives and brought issues such as ethics and consent to life.

These joint values are reflected in our [evaluation framework](#) which was launched in January 2021. It aims to capture the impact of PPI for the Oxford Health BRC and the experience of PPI contributors and researchers. We hope that through informing the framework with the values that matter to PPI contributors and researchers, we will make the evaluation process relevant and meaningful.

But we still have questions! How strong a measure of impact will this approach provide? How realistic is it to expect

researchers and PPI to make a note of "who said what" and "when that made a difference"?

We know PPI contributors are often frustrated by the lack of opportunities to get involved at the start of the process - at the point of debating a research concept - and to continue their involvement as a project progresses through the research cycle.

We also know that challenges of overburdened workloads, deadlines and funding limitations impact the capacity for researchers to open up their research more widely to involvement.

And, importantly, we are very aware that we need to reach out more widely - into communities that are under-represented in research - and develop more inclusive ways of working.

So, the next step is to consider how we can use the experience and impact we collect to improve our PPI: - to engage more researchers, to bring in diverse voices, to increase coproduction, and to support PPI contributors to be involved throughout the research cycle.

Until PPI routinely runs through research projects from conception to completion, its impact will always be incomplete. However, by bringing PPI contributors and researchers together, we can address the gaps, make involvement more meaningful, and get better results - both for the people and for the research.

Julia Hamer-Hunt is patient co-chair of the Oxford Health BRC's strategic patient and public involvement (PPI) group and Claire Murray is PPI Manager.

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



Ockenden's silver lining

The Ockenden report on maternity services at Shrewsbury and Telford, published in December 2020, was a difficult end to a difficult year. The pain of the families can barely be imagined, and we can only hope that there is some relief for them in knowing that the truth is finally starting to come out.

But is there any good news from the Ockenden review? Our answer is a clear “yes”.

The review gives us cause for hope because it nails the myth that in our evidence-based healthcare system, only some types of evidence are worth having.

NICE - the National Institute for Healthcare Excellence - offers clinical guidance, drawing on “the highest quality and best available evidence”. But none of that was able to prevent a potential 1,862 cases of harm stretching over a period of years.

The Care Quality Commission regulates healthcare providers, based on rigorous, evidence-driven inspection processes. But none of that was able to detect the scale or severity of harm occurring at the Trust.

It was families - with no formal methodology, no analytical rigour, and no peer review - who were able to reveal the truth about the failures in maternity care. In the end, patient feedback - so-called “anecdotal evidence” - proved more reliable than any other form of evidence.

This was the third time during 2020 that patients showed that their evidence is vital. First it was [Paterson](#). Then it was [Cumberlege](#). And then Shrewsbury and Telford. In every single case, it was patient testimony, more than any other source of evidence, which revealed the shortcomings in care.

So we are hopeful that the tide is turning, and that the medical establishment must now start to take note of Baroness Cumberlege's demand that patient experience “must no longer be weighted least in the hierarchy of evidence-based medicine”.

The Ockenden report reveals some terrible truths - but we don't have to despair. If we can use it to get patient experience seen differently, we can ensure that some good comes from the pain.



Vaccination - why hesitate?

The arrival and rapid deployment of the Covid vaccines is certainly a good news story. That does not mean, however, that the population as a whole is in favour of vaccination.

A [December 2020 study](#) by Oxford University found that 16% of the population are very unsure about receiving a COVID-19 vaccine, and another 12% are likely to delay or avoid getting the vaccine.

So who are the people who might not take up the vaccination offer? We need to understand them and their motivations, and to do so, we may need to avoid simplistic terms such as “anti-vaxxer”.

This report looks at how individuals’ vaccination beliefs and behaviours are formed - and where the opportunities lie to intervene in the interests of public health.

A good starting point is how people assess risk. With busy lives and limited time to seek out information, we all take mental shortcuts. That can lead to over-confidence about our ability to judge risks, and “omission bias” whereby we prefer not to act even when doing so is beneficial to us. In the context of vaccines, this can mean that people give disproportionate weight to the harms of receiving vaccinations and dismiss the dangers of not receiving them.

Some shortcuts, however, are closely tied to previous experience. Research shows that having been previously vaccinated is strongly linked to subsequent uptake of vaccines. So one tactic could be to turn vaccination into routine behaviour that requires less deliberate planning, while simultaneously lowering perceptions of risk through continued experience of vaccination without adverse effects.

Another issue is that people are social animals, so we need to understand social belief formation, including cultural and political drivers. Broadcasters and publishers have a role in this. The authors state that “the media often chooses not simply to report expert knowledge of risk but to simplify and sensationalise it by setting up debates about responsibility and blame”.

The paper finds that “discussion to date has been overly focused on the individual, and often underestimates the role of cultural and political situations and other social drivers”. It says that “to deal with the issue of vaccine hesitancy we need to develop interventions that take social belief formation and maintenance into account”.



Under-representing maternity

Patient safety in maternity services is a major concern at the moment, with the first report on Shrewsbury and Telford recently published, and the East Kent investigation ongoing. Both of those follow similar investigations and reports from Morecambe Bay and Cwm Taf.

The common thread throughout has been a failure to take seriously the concerns raised by women, birth partners and bereaved families. The harm persisted because patient experience was ignored.

In this context, it is worrying to hear of a decline in response rates for national maternity surveys. According to this report, “The response rates to the Infant Feeding Surveys, the CQC Maternity Surveys, and the National Maternity Surveys... have fallen with each successive survey”. For the National Maternity Survey for example, the response rate has gone down from 67% in 1995 to 29% in 2018.

It is not just the overall response rate that matters. The paper states that “the extent to which the response is representative of the target population is key, regardless of the rate of response”.

When the researchers looked at the characteristics of respondents, they found that “women were more likely to respond to each of the surveys if they were older, married at the time of registering the birth of their baby, born in the UK and living in less deprived areas”.

Conversely, “response to the survey by the youngest women, women who registered the birth of the baby in their sole name, and women living in the most deprived areas has become relatively less likely over time”. The authors note that “If this trend continues, women in these groups will become even more underrepresented in such studies”.

The paper concludes that declining response rates “bring into question the viability of continuing to use the survey method to capture the experiences of postpartum women”. It warns, however, that “such data are not routinely available from other sources and currently there is no better alternative method to collect large-scale population-based data”.

A final observation is that “it is important to find strategies to halt the decline in survey response rates, particularly amongst under-represented groups, and to validate the data collected”.



Making integration work

While healthcare systems wrestle with the twin challenges of Covid and delays in elective care, a third challenge is looming: integration.

This report sets out a vision for “common purpose” in patient and public engagement at the system level. It starts with an observation about Covid-19. “The pandemic”, it says, “created a common purpose that in many areas broke down barriers and enabled services to be transformed”.

The authors see this as an important foundation for integration. In just a few months, they say, “every area of the country will be part of an integrated care system, with a ‘system by default’ approach”. A “critical enabler” will be effective engagement and communications.

This is good to hear. It is well known that patients and public can find the healthcare system confusing, with its mix of providers, services, commissioning bodies and so on. It should not be assumed that patients and public will, unaided, be able to keep up with the forthcoming changes. Nor should it be assumed that healthcare professionals can successfully integrate services without understanding them from the patient’s point of view.

The report recognises these challenges, and there is much in it that is welcome. It talks of embedding a strategic approach to engagement and communications. It mentions continuous relationship building. It recommends shared vision and narrative. And for all of these, it offers real life case studies.

As always, however, the devil is in the detail. The report sets out five success factors for high-performing communication and engagement. It lists ten communication and engagement functions. Those can be applied across three levels within integrated care systems. They can be delivered via four broad operating models. Finally, to summarise the findings, there is a ten part model for shared purpose public engagement and communications. It all gets a bit confusing.

The report is frank about the challenges. One example is its acknowledgement that healthcare leaders can often have “broad agreement on the strategic value of engagement and communications”. But there is a tendency to act strategically in moments of crisis, then quickly revert to a purely operational approach once the crisis has been resolved.

All in all, a good report - but our sense is that hard pressed staff, coping with the mountainous challenges of Covid, delays in elective care and the urgency of integration, will need practical help to get the alignments and synergies that the report recommends.



A vital partnership

“The pandemic has brought new attention to how people live their lives” says this report from the London School of Economics. “Questions are being asked particularly about housing, about inequality, residential care of the elderly, the health and care workforce and, of course, death”.

The authors point to an important and authoritative source of guidance on these matters: charities. They recognise that the lockdown had a “dramatic impact” on charities’ fundraising activities. In spite of this, they say, many showed great agility in adapting to changing circumstances and needs.

Far from simply plugging gaps in the welfare state, charities have often led the way in “improving standards of care, in professional collaborations, in reaching out into the community, and in making rapid adaptations”.

The report considers the contribution of charities under five key headings: Wellbeing, Workforce, Inequality, Ageing, and Dying. It looks at the many ways in which charities have responded to the new challenges thrown up by the pandemic, taking in both policy and practice. Above all, it looks at “human impact” - an issue which is of course central to people’s experience of care.

The report makes the important point that charities “not only rearranged their own services in response to the pandemic but often also helped guide NHS services through the coronavirus challenge”. Charity staff and volunteers are not necessarily qualified healthcare professionals - but their different skill sets and experience, plus local knowledge and networks, can be a powerful complement to NHS skills and knowledge.

The report states that “The year 2020 simply accelerated the advance of the major challenges that the health and social care system needs to address. In particular it is a ‘wake up call’ around dying. Death rates seen at the height of the pandemic in spring 2020 will become the norm within the next 20 years”.

Faced with growing needs in healthcare, it would, say the authors, “be both disingenuous and dangerous to assume that charities will forever be able to fill gaps in health and social care under ‘business as usual’”. They call for “a culture that respects charities as important partners in care planning and delivery, and an honest discussion of a shared role in filling the gaps now laid bare”.



Engaging men earlier

In the world of patient and public involvement, it is well known that “engagement” is not evenly distributed. Terms such as “hard to reach”, “seldom heard” and “underserved” are hotly debated – but all indicate a recognition that healthcare is better at hearing from some groups than others.

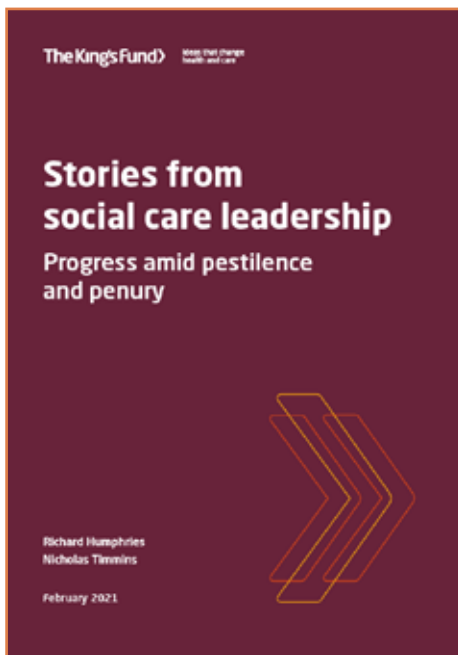
Men are not generally seen as “underserved”. In fact, gender inequalities, gender pay gaps, glass ceilings and so on might suggest quite the opposite. But there are at least some men who, according to this report, are “going through tough times before reaching crisis point”.

The report is based on discussions with men who “had not yet reached a mental health or suicidal crisis point, but who had been exposed to risk factors”. Evidence indicates that men like these do not receive support early enough. But it also shows that some men do not see wellbeing initiatives as relevant “until they had hit rock bottom and were looking to rebuild their lives”.

The study looked at initiatives that might support men’s wellbeing before they reach crisis point. Findings included the following:

- Study participants gravitated towards existing community groups and hobby-based activities rather than formal mental health or crisis services.
- The men were not particularly drawn to activities that were exclusively for men or based around what might be considered stereotypically ‘male’.
- Avoiding ‘awkwardness’ when first joining an initiative was important, and it was felt that a focus on activities could help.
- A playful and fun atmosphere is the best way to foster meaningful relationships among participants. If an activity takes itself too seriously, it risks putting participants off.

There are plenty of other useful tips in the report, as well as examples of projects that embody these kinds of principles and approaches. The authors also consider how to adapt such approaches during lockdowns and physical distancing. It concludes with a “principles checklist” and an “action plan template”, both of which could be useful tools for engagement practitioners.



Pestilence and penury

Campaigners and commentators on adult social care must feel stuck in a perpetual Groundhog Day, with government promises of reform followed by indecision and inertia, followed by more promises...

In the meantime, service users and carers carry on with a system which has for years been under acute financial pressure. Now, of course, the penury is compounded by pestilence - the added complications and strain of coping with coronavirus.

Amid that gloomy scenario, this report looked for signs of leadership and progress. And while it found “widespread complaint about a lack of leadership from the Department of Health and Social Care”, it did manage to find local instances of initiative, and the will to provide good care.

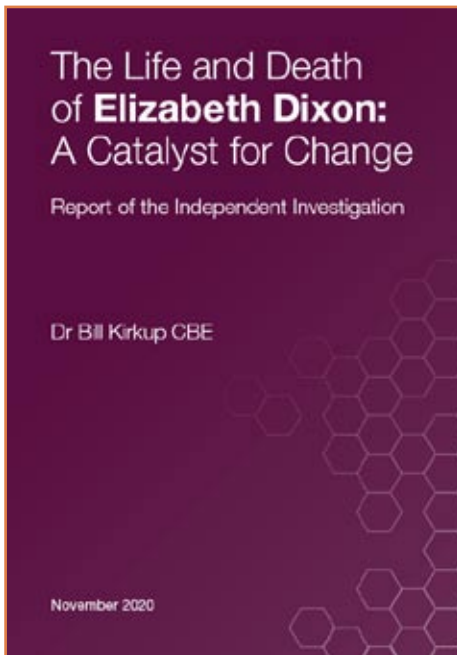
Some of the most inspirational leadership, say the authors, comes from care staff themselves, and from adults of working age who have been empowered by personal budgets and direct payments.

The report gives examples of innovations and partnerships. It finds that engagement and listening are crucial. One local authority is praised by a service user who says “We know where we stand. Not just the social services director but the chief executive comes to visit us - comes to our homes”. In another area, a provider describes the basis for a good relationship with the county council: “The county consults. It listens. It adapts where it can”.

In this respect, the Covid emergency has actually helped, by breaking down barriers. One domiciliary care provider described “peeling back of the layers around decision-making. People needed to just take action -- really, really quickly. Just find a solution to the problem. There was that need for speed, and it worked really, really well”.

The report carries plenty of good insight - but it is also realistic about the barriers to faster progress and better care. One is a lack of good data. One director of services said, “Certainly compared to the NHS but even compared to the police, we just don’t really know what’s going on”. Another pointed to the lack of national leadership, observing that local leadership exists “in the vacuum of a nationally defined vision and plan”.

So while the care system struggles on, local dialogue and relationships are vital. As the report says, “The best local authorities appear to value feedback, the worst hide from it”.



The Life and Death of Elizabeth Dixon

Bill Kirkup's report on the Life and Death of Elizabeth Dixon is by turns harrowing, desperately sad, and depressingly familiar.

The story, once again, is of a patient (this time, a baby) who died, and of bereaved relatives who had to spend years (this time, twenty years) fighting for the truth about what happened.

The report describes "failures of care by every organisation that looked after her, none of which was admitted at the time, nor properly investigated". That statement has echoes of the Morecambe Bay report, which found "a series of missed opportunities to intervene that involved almost every level of the NHS".

The report reveals "a cover up... propped up by denial and deception, which has proved extremely hard to dislodge over the years". That sounds like Gosport, where "Over the many years during which the families have sought answers to their legitimate questions and concerns, they have been repeatedly frustrated by senior figures".

The report says that "The fabrication became so embedded that it has taken a sustained effort... to demolish it". That mirrors the Northern Ireland Hyponatraemia inquiry, where investigators noted "how difficult it was to persuade some witnesses to be open and frank... concessions and admissions were extracted only with disproportionate time and effort".

There is a culture in healthcare that has to change - and it is not about individual staff, or individual organisations. It goes to the top.

It is about system leaders like NICE and Health Education England, whose National Core Content of evidence contains no dedicated component for patient experience.

It is about the Department of Health which, down the years, has failed to preserve organisational memory via an archive of patient experience evidence.

It is about NHS England, which knows that NHS staff struggle to make sense of patient experience data, but has not developed good analytical tools.

Kirkup's report says "It is vital that what happened acts as a catalyst for the significant changes that are necessary to ensure that this does not happen again".

Those "significant changes" should not be focussed solely on clinicians, with the usual litany of updating practice protocols and refreshing training. There also needs to be a focus on system leaders - NHS England, NICE, and Health Education England. They set the tone, they set the culture, and they need to set a lead in giving patient experience its rightful place in the evidence hierarchy.

Primary inequality



A key starting point for this study is the 2012 Health and Social Care Act, which set out a duty for healthcare commissioners and providers to reduce inequalities in both access to and outcomes of care. A particular focus was inequalities experienced by people living in the most deprived areas.

The authors acknowledge that there are well documented variations in patient experiences of primary care in relation to socio-demographic characteristics. However, they say, “there is limited evidence on longitudinal trends”. So they set out to explore whether inequalities in patient experience of primary care had widened, narrowed, or remained the same between 2011 and 2017.

They found few substantial changes for the better. In particular:

- At both practice and national level, variations in patient experience persist, notably in relation to age, deprivation, ethnicity, sexual orientation and geographical region.
- At the national level, inequalities in access to care start to appear from 2015, with access declining fastest amongst practices serving the most deprived areas.
- Reported continuity of care is declining fastest amongst the oldest age groups when compared to other patients registered at the same practice. This matters because poorer continuity of care has been associated with higher rates of both generalised and preventable hospitalisations in older adults and higher rates of mortality.

The authors conclude that “Despite a sustained policy focus on reducing unwarranted variations in care, there have been no substantial improvements in inequalities in primary care patient experience between 2011 and 2017”. And “Whilst access is getting worse everywhere, it is declining faster at those practices that serve deprived populations”.

The paper warns that “With UK primary care under increasing pressure, widening socio-economic inequalities...are of particular concern”. And it suggests that “public reporting alone is not an effective tool to drive reductions in inequalities in the UK”.



Private data, public reporting

While Covid news continues to dominate the headlines, the government is busy preparing its [Data Strategy for Health and Social Care](#). This, it says, “will set the direction for the use of data in a post-pandemic healthcare system”.

Understanding Patient Data has done some good work on patient and public views of health data, and this latest analysis - in the context of the forthcoming government strategy - is well timed.

The focus is not so much the data itself, as how it is reported in the media. But that is crucial, since that is where most people get their information on health. In fact, the national media outlet reporting most frequently on health is the Daily Mail.

In the mainstream media, reporting has a tendency to be negative - generally, say the authors, because data becomes more newsworthy when something goes wrong (eg data breaches). There has also been doubt that the government’s approach to data handling would be effective in managing the pandemic, and scepticism that data would be managed ethically and not compromise human rights.

In more specialist science and technology media, reporting on healthcare data tends to be more positive - often driven by proactive company press releases announcing successes in clinical research and drug development.

On social media (Twitter in particular), concern about access to health data drives the majority of conversation, covering access by private companies, data breaches, and a lack of transparency around who data is shared with.

The study finds that the pandemic has made the benefits of health data clear to a wider audience and driven debate on the technicalities of regulation. On the other hand, reporting on the risks associated with the use of health data receives more cut-through with the general public than any other theme.

The authors recognise that health data is highly politicised, often becoming a lens for criticism of broader issues, such as privatisation of the NHS. And there is limited focus on the role an individual can play in managing their own data, potentially reducing opportunities for wider public engagement.

Among the recommendations is a call to “elevate patient voices” by encouraging patient involvement in debates on health data, and by training patient influencers to act as spokespeople on the benefits and risks of health data to patients.



Out of the cancer maze

“We are at a crossroads for cancer care” says this report. “After a year of devastating disruption to diagnosis and treatment caused by the Covid-19 pandemic, no-one can be under any illusion about the scale of the challenge cancer services face to get back on track.”

In the meantime, patients are caught in the maze - uncertain about their care plan, stuck between services, waiting for appointments and scans, or feeling on a “cliff edge” after their treatment ends. As many as 50,000 people may be missing a cancer diagnosis due to disruptions caused by coronavirus, with many people being too scared to seek help for symptoms from their GP.

The report is entitled “Caught in the Maze” but in fact, it suggests some ways through the maze. The starting point is the innovation and collaboration that the response to Covid-19 provoked.

Responding to the crisis has brought organisations together - improving collaboration while reducing bureaucracy and duplication. It has shown how care can be delivered in the community through diagnostic hubs and mobile units. And technology has enabled services to join up in a way that system leaders have long been attempting.

The report sets out recommendations for how advances can be maintained and built on. Integration of services and personalisation of care are crucial. That means plugging gaps in information and support, particularly during transition points between services. It also means ensuring that Integrated Care Partnerships align with cancer alliances and providers to create a whole-system approach.

Importantly, modern cancer care for the three million people living with cancer is just as much about services outside the hospital as it is about acute treatment. So there should be greater learning from other long-term conditions, along with the removal of professional silos, and expansion of cancer teams to include staff in mental health, end of life and social care.

A final recommendation is that pathways and service redesign should be shaped by the experiences of people living with cancer. “There is”, says the report, “growing evidence about people’s experiences of cancer services across the UK... services should learn from people’s experiences and include people with cancer consistently as partners in the delivery of personalised, integrated care”.

One woman's experience



Patient advocates and patient experience staff can sometimes find themselves caught up in arguments over what constitutes evidence. Patient feedback is sometimes described as “anecdotal”. It can be compared unfavourably, in terms of validity and reliability, with the “hard evidence” of statistics.

But anybody who doubts the value of “patient stories” as a way of understanding patient experience should read this painfully honest account of one woman's experience of incontinence.

This is not about patient experience as “satisfaction with services”. It is about living with a long term condition that “seeps into every area of life”.

It involves talking with doctors, and feeling stupid. Or worrying about making a fuss, or wasting their time. It is about the embarrassment of intimate examinations – even when carried out by health professionals who have “seen it all before”. It is about fear, loneliness, self-reproach and fatigue.

On the plus side are those clinicians who acknowledge that incontinence isn't very easy to talk about. Who say that they want to help, and that a physical examination will help to move things forward. Sometimes it can even be reassuring to hear professionals admit that they don't have immediate answers, and that they need to find out more.

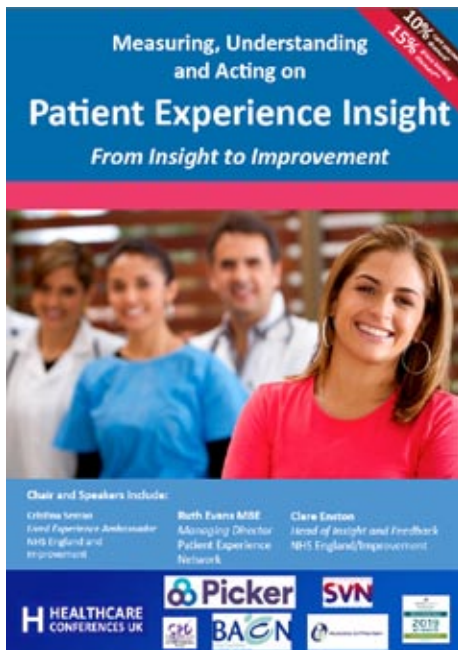
The article comes from the BMJ's excellent “What your patient is thinking” series. It offers the kind of insight that is not reliant on control groups, or peer reviews, or formal methodology. It comes from the heart, and from experience. And it rings true.

Personal testimony offers truths that can rarely – if ever – come from formal research or big set-piece surveys. Not that those don't have their uses. Sometimes we need big data and statistical analyses. But sometimes, one patient's experience can speak volumes.

**H HEALTHCARE
CONFERENCES UK**

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

THURSDAY 8 JULY 2021
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. Through national updates and case study presentations the conference will support you to measure, monitor and improve patient experience in your service, and ensure that insight leads to quality improvement.

Sessions will include:

- learning from patients
- improving patient experience during and beyond Covid-19
- a national update
- practical sessions focusing on delivering a patient experience based culture
- measuring patient experience
- using the NHS Improvement National Patient Experience Improvement Framework
- demonstrating insight and responsiveness in real time, monitoring and improving staff experience
- the role of human factors in improving quality
- using patient experience to drive improvement
- changing the way we think about patient experience
- learning from excellence in patient experience practice.

Visit the [website](https://www.healthcareconferences.co.uk) or email kate@hc-uk.org.uk

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.
- **Healthwatch collection.** Over 12,000 reports accessible via the [Network map](#), and the [Enter and View map](#) or by searching "Healthwatch" in the [Library](#).
- **Publications** featuring research-based summaries to keep you abreast of the latest and best in patient experience evidence.

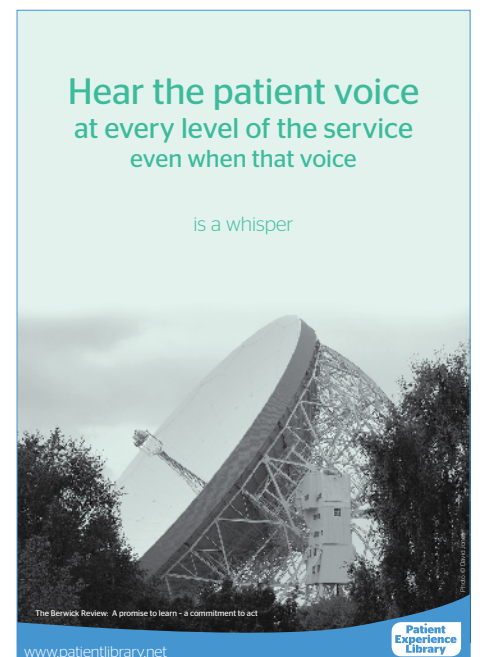
Extras for subscribers:

- **Archive:** Go deeper into the evidence base with access to reports over 3 years old.
- **Quote Selector:** Quick access to bite-sized pieces of evidence.
- **Export:** Batch downloading of documents.
- **Favourites:** Your own personal library.

Want more? Drop us a line to ask how we can help you manage your data on patient experience and involvement: info@patientlibrary.net

Hear the patient voice at every level of the service even when that voice

is a whisper



The Patient Experience Library

We are the national evidence base for patient experience and patient/public involvement. We have collated and catalogued over 60,000 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

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Can't wait a whole week? Follow us: [@patientlibrary](#) 

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Cover image: 1930s pre-RADAR aircraft detection system developed by the Dutch army. The tubes inflate the ear pads for a snug fit. © Nationaal Archief, Netherlands

