# Patient Experience

and patient/public involvement in health and care services

Winter 2023

INSIDE

Engaging people Healing Hearts and Minds

Patient Experience Library

### Editorial



People in healthcare talk a lot about "engagement" with patients and public. Sometimes they call it "involvement" or "participation". Other terms are "co-production", "co-creation" and "co-design".

What does it all mean? The answer seems to be that nobody is quite sure.

Back in 2018, NIHR Involve described a lack of

consensus around the concept of co-production. In the same year, an academic paper spoke of "a lack of a common language" for patient and public involvement (PPI) and said that "the term PPI is not universal in its application or definition". More recently, the Social Care Institute for Excellence has said that There is no single formula for co-production.

If anyone does know about co-production, however, it is Gill Phillips, who has huge experience in bringing patients and professionals together in common cause. Her prescription for good engagement? Make it engaging! On page 3, you can pick up some great tips for what that looks like in practice.

Of course engagement is not always about "professionals" seeking to involve "service users". Patients are perfectly capable of acting for themselves - through peer support, education, shared experience and more. On page 4, Liza Morton describes her journey from congenital heart disease in infancy to a career as a psychologist and advocate for psychologically informed medicine. And she explains how engagement with both hearts and minds is essential for healing.

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

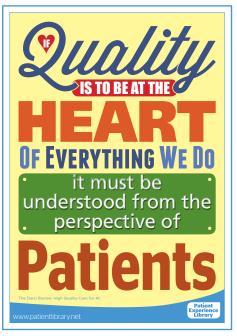
Experience Library - over 70,000 reports on all aspects of patient experience and engagement. We can build tailor-made local libraries for your Trust or Integrated Care Partnership drop us a line to find out how.

### 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



### 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*  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* 

# Engaging people

**Gill Phillips** 

**Creator of Whose Shoes** 



If you want to engage people, you have to be engaging. That might seem obvious, but it's surprising how often it gets forgotten.

I got into co-production around the time that "personalisation" in healthcare started to pick up steam. As a social care manager, I had seen a lot of things "done for" people using services, but not so much "done with" them. And I then saw people and providers struggling with how to work better together. The tendency was for professionals to "involve" people in their own agendas and own ways of doing things: formal meetings, minutes, actions plans, objectives. Again, it wasn't very engaging. Sometimes it wasn't very inclusive either.

So I have developed my own ways of bringing people together around action for improvements in healthcare. I have had a lot of fun over the years, and have seen people all over the country achieve great things together. Here are some of the things that I have learnt along the way.

#### Lesson 1: Look after people

Healthcare is about caring. So public engagement in healthcare should be caring too. The way you welcome people to an engagement process sets the tone for the whole thing. There are lots of ways to be accessible and inclusive, but I always find that bunting and cakes go a long way.

#### Lesson 2: Keep it simple

I prefer not to get bogged down in definitions of "co-production", "cocreation", "participation" and all the rest. All I'm interested in is honest conversations – and those work best when people speak to one another in ways we can all understand.

#### Lesson 3: Informality is key

It's perfectly possible to run engagement events that are very carefully planned and structured but are also very informal. I have used poems, board games, art and singing to help people connect as fellow human beings, rather than as "professionals" and "service users". Once people loosen up, the ideas and creativity can flow more easily.

#### **Lesson 4: Trust people**

If you're looking for improvements in healthcare, you can trust both patients and staff to have a pretty good idea of what needs to be done, and how it might be achieved. Most people genuinely want to listen to one another - so as long as you prepare well and provide a welcoming atmosphere, you can trust that your engagement events will more or less run themselves.

### Lesson 5: You don't need to manage expectations

Again, you can trust people. By and large, they know what is realistic. But dreams - however unrealistic they might seem - are also valuable. We ran an engagement event in Liverpool that was the spark for eventually creating a new neonatal surgical unit. Once people start talking together, you never know where it might lead.

All of this is underpinned by some basic principles:

- The action focus. We can all individually make change and we don't have to wait for permission.
- Lemon lightbulbs. Engagement is stronger when people realise for themselves what needs to change (including their own behaviour) rather than when they are told by others.
- The power of connecting and sharing. It is much less lonely to make change TOGETHER.

My intent with all of this is serious. I truly believe that the best way to improve healthcare is via open dialogue between patients, carers and professionals. But I also truly believe that if you want to engage people, you have to be engaging. So make it fun – and bring cake! 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* 

# Healing Hearts and Minds

#### Dr Liza Morton, Counselling Psychologist, Glasgow Caledonian University



A growing number of people are living with a heart condition from birth. Congenital heart disease (CHD) is the most common birth defect, accounting for a third of all congenital conditions.

CHD can impact every area of life, beginning in childhood, and often creating physical limitations and the need for medical interventions throughout life. It can impact relationships, education, finances, selfesteem and social inclusion. People with CHD have much higher levels of anxiety, depression and post-traumatic stress, yet psychological needs remain poorly met.

This is a gap I have felt since childhood. Born with complete heart block and a hole in my heart, I was fitted with my first cardiac pacemaker at 11 days old in 1978, a world first at the time. By the age of seven, I had been fitted with five pacemakers. Early devices were set at a fixed rate, limiting me physically while I was unable to take part in PE lessons, active play or keep up with my peers.

I had open heart surgery to repair a hole in my heart when I was 13 years old.

Fitted with my 11th pacemaker a few years ago, I spent a month in hospital leading up to this surgery waiting on a surgical slot with a specialist team. Growing up, my family and I were not offered psychological support. My career as a Psychologist and researcher is motivated by a desire to make sense of my unusual life experiences and to promote better understanding about the psychological impact of living with a serious medical condition from childhood.

To this end, Tracy Livecchi and I have written our book, 'Healing Hearts and Minds'. Tracy was also born with a complicated CHD requiring several surgeries and hospitalizations throughout her life. We met online, across the Atlantic, through our advocacy efforts.

Both pioneering CHD survivors, therapists and health activists, Tracy is a Clinical Social Worker working in Connecticut and is the Mental Health Consultant to the ACHA's Peer Mentorship Program. I am a Counselling Psychologist practising in Scotland, a part time Lecturer in Psychology and I sit on the management board of UK's Somerville Heart Foundation successfully campaigning for Scottish CHD healthcare standards and improved psychological support.

Despite the ocean between us, and having never met in person, we have spent the last few years writing the book that we have been looking for yet could not find. In the book, we explore the medical history and unique collective story of this medically new population and the potential psychological and emotional impact of living with a lifelong heart condition. We aim to promote hope, connection and to normalise an understandable response to the often cumulative, hidden barriers and challenges we can face from infancy. We draw from evidence-based psychological theories and tools to manage stress, validate and process difficult feelings, tackle discrimination and develop strong social support. By building on self-management strategies and resilience we hope to help readers cope with physical symptoms, medical emergencies, hospitalisation and the global COVID-19 pandemic.

Real-life testimonials are included throughout to foster a sense of community and shared experience. We also consider the 'gifts of CHD' such as post-traumatic growth, finding meaning and positive adaptation. A section for family, friends and healthcare professionals includes what I have termed Psychologically Informed Medicine; an approach that aims to mitigate medical trauma, and improve wellbeing by promoting a holistic, trauma-informed, compassion focused approach to healthcare.

We hope our book brings hope, connection and healing to the global CHD community and beyond. Anyone living with chronic health conditions or motivated to improve psychologically informed healthcare may also find it of interest.

Healing Hearts & Minds: A holistic Approach to coping well with congenital heart disease is internationally available to preorder and will be published on 13 January 2023.

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* 

Austral & State (BS | Austral Life) (BS | August Store (BS ) BE REAL-AUSTREE GRADIERAL ARTICLE WELEY

Contributors are representative, as long as they agree: How confirmation logic overrides effort to achieve synthesis in applied health research

Sarah E. Knowlee PhD 6 | Pat Walkington: | Jackie Plynn: | Sarah Darley PhD 6 | Ruth Readen PhD 6 | Roman Kalky PhD 6

Said and show Strikt of	design of the second se
	e fan fanden fannsen Afrikalen (annen acht annen an die fanke an ensekulter is en fan al er bler Men i hele an
	of bassings. Then allowed light had allowed implications regardly
	stilly in realise a solitable light that sould achievy bland efficient type
	patient unter in implicity durings, Contributes are Readium instead in the
	Conclusion incomplemented to start a continuation has that write a monophone
	the pointing for the sprittenin legit to be address.
	These lights are incompatible in practice, with the confitmation legit constraints
	andhais lags, which emphasized excellutions of developing and active datage
Number Research and Call Dealer	researchers holding a confirmation light. By contrast, contributor accessits mached
HARD Sales and the Lasteria Instantial Hard Street and Can State	described unsigned able as representation of "the papers' word". We dealther the
Family blander	the advent contributor input could be cauld to appoint research activity, it was
	constrainers requiring charges to measurer plans, theaters, we also also the
Santas, Ta Oshariyad Mashamarhitti	Contribut all produce magels, 20 shallings an indeped in segment to
Interchanter, UK and in fault of Fault.	In Particular data managing an unam in mander black and
Anne Main Pull, Tanily of Balance and	Reads that both from interviews with consentury and reported attentions b
	contribution colliderationly by the applied beam of contributions and management
Parchase (R	data and documentary analysis of researcher records or Panel Impacts. Audiotic sec
Cate to Hiney Canad Fault Series	including interviews with the (EAP constitution and second-terr, Panel available
tue, m. Last Carly PD, Unit of Tealth Views.	Industrative PH panel. Secondary analysis was of multiple qualitative data course
	for developmental experience of a topic and a case of on-expert Patient and Pdd
and Departments, makening of fast,	Histbalk We analysed a case of a Lond Experimen Advisory Paral LEAP, chase
Santi, Santa PD, Sata & Botan	case of limit experience, to examine how representation was discussed in such.
	criticium. We conducted a secondary analysis of a case of respect to whereaved and
End of the second division of the second divi	contributions also have againteent experience in research can be a primary larget o
UR.	underlying assumption that expertise undertaines contributions made, more exper-
Apart C. Mauria, Polit James & Robins and Departments (Hearing of the Task	contribute or too troorholgadite to represent You are oge patters". Ones its
Companyon of Compa	trangition, where is paids consideration are seen as all or too reading of
Photos Photos B	brockellen. The parates of regressivalisation public involvement in research lower
Marchane Manhares: 18	Alatad

# lf you agree, you're in

A common debate in patient and public involvement (PPI) concerns the "representativeness" of public contributors. They can get caught in a "paradox of representation" in which they are seen as either too naïve to meaningfully contribute, or too knowledgeable to represent "the average patient".

This can be seen as a form of "boundary defence" in which professionals (in research or quality improvement) resist the encroachment of "lay people" into their territory.

The authors of this study point to an area of neglect in this debate, which is "the absence of the voice of contributors themselves". They say that "Critiques of representation in PPI have largely been written by researchers – and tend to favour their perspectives as opposed to those of public contributors".

The study looked at how representation is discussed and conceptualised. It found an underlying "confirmation logic". The starting point is that "when contributor input provides confirmation of researcher work, it is drawn upon as representative of 'the' patient experience and not contested in terms of representation".

When, on the other hand, contributor input seeks to change or debate researcher work, "representation is drawn upon to dismiss input". Through this logic, say the authors, "only confirmation of the researcher's perspective is possible".

The point here is that judgements about the supposed representativeness of patients are not just a matter of how naïve or knowledgeable they are. It also depends on whether they are confirming or contesting professionals' views. The paper states that "Problematically, contributors are representative as long as they agree".

The study concludes that "relative expertise is not the deciding factor in whether representation is critiqued or not. Instead, the driver behind this appears to be the confirmation logic, whereby representation is assumed or revoked by researchers based on whether their own decisions are supported or critiqued".

Exposing tensions like this is, according to the authors, "essential to move beyond misleading debates about representation". And, they say, "Involving contributors themselves in these debates is both a necessity for making progress and, we suggest, an ethical responsibility".



# What the government should know

This report from the Health Foundation was published very soon after Liz Truss was confirmed as the UK's new Prime Minister. With hindsight, we can see that there were all sorts of things that the new government should have known. But this report concentrates on healthcare – and its messages remain relevant. The briefing is based on rigorous public polling, and the central statement is that "understanding what the public thinks should inform policy".

So what does the public think? Key findings include the following:

- People are pessimistic about the state of the NHS. Most (55%) think the general standard of care has got worse in the past 12 months, and less than half (43%) think the NHS is providing a good service nationally.
- Just 13% think the government has the right policies for the NHS. Priorities, for the general public, are reducing waiting times for routine hospital treatment and expanding and supporting the workforce – even if it means extra public spending.
- People want a better health service, not a different health system. 77% believe the NHS is crucial to British society, and 71% think greater government investment in the NHS is necessary.
- A minority believe the government is effectively addressing the leading risk factors for ill health. Fewer than 1 in 5 people believe the government is working effectively to improve physical activity (19%), improve diets (17%), reduce alcohol-related harm (16%) and reduce obesity (14%).

The authors remind us that "Liz Truss promised Conservative party members that she will cut taxes and shrink the state". In what now seems like a masterpiece of understatement, they go on to say that "It is hard to see how the new prime minister can reconcile these commitments with addressing the public's concerns". Finally, they say "Failing to do so risks leaving the government out of step with the public as we head towards the next general election".

#### Reading the signals

Maternity and neonatal services in East Kent – the Report of the Independent Investigation

October 2022



## Responding to challenge with honesty

The report on avoidable harm in maternity services at East Kent has now been published.

There is of course a terrible sense of déjà vu. Not just because it follows hard on the heels of the Shrewsbury and Telford report, nor because it is authored by Bill Kirkup, who led the Morecambe Bay investigation.

The déjà vu also comes from the litany of avoidance and denial that we have heard so many times before – at Mid Staffs and Southern Health and Gosport and Cwm Taf and beyond. Bereaved families have had yet again to fight for justice in the teeth of a healthcare provider determined to resist them.

But there is, this time, a vitally important difference. Kirkup says "It is too late to pretend that this is just another one-off, isolated failure, a freak event that will never happen again". There is, he says, a pattern.

Back in 2020, we made exactly this point in our Inadmissible Evidence report. We said "There are no bad apples".

Our point was that dysfunctional organisational cultures do not arise in isolation. It is not enough to set up inquiry after inquiry, looking at culpable organisations one after another. And it is not enough to say that we will "learn from mistakes" when we see over and over again that the undermining and gaslighting of bereaved relatives is not mistaken, but intentional.

At the heart of the pattern of malfeasance is a problem summed up by Kirkup as follows:

"The default response of almost every organisation subject to public scrutiny or criticism is to think first of managing its reputation... the experience of many NHS organisational failures shows that it is the whole basis of the response in many cases. Further, it has clearly led to denial, deflection, concealment and aggressive responses to challenge... Not only does this prevent learning and improvement, it is no way to treat families, who are heartlessly denied the truth about what has happened when something has obviously gone wrong".

Brilliantly, Kirkup refuses to add to the mountain of recommendations that have come out of previous inquiries and investigations. Why not? Because "The answer cannot be to hope that... multiple recommendations prevent recurrences elsewhere. If that approach were the right one, it would have worked by now. It hasn't."

Instead, he points to four areas for action, one of which is "responding to challenge with honesty". That, surely, is not too much to ask. But, says Kirkup, "if we are to break the cycle of endlessly repeating supposedly one-off catastrophic failures", it is essential.

22 September 2022

Building an organisational culture of continuous improvement

Learning from the evaluation of the NHS partnership with Virginia Mason Institute three Jones



# **Speaking well**

The East Kent report on avoidable deaths in maternity services revealed an organisational culture characterised by "denial, deflection, concealment and aggressive responses to challenge", along with "bullying to such an extent that the maternity services were not safe".

But what does a good healthcare culture look like? This report from the Health Foundation offers some clues. Based on an evaluative study of five English NHS Trusts, the focus is on quality improvement, and how good culture can enable organisation-wide learning.

First of all, stability matters: the report notes differences between one of the Trusts it studied, which had had the same Chief Executive since 2010, against another, which had three Chief Executives in quick succession.

The framing of improvement efforts also has an influence. An initiative seen largely as a technical exercise led by experts is unlikely to enter the "mainstream consciousness" of the organisation. But if it is seen as core to the organisation's identity and strategic vision, it stands a much better chance of having impact at scale.

Values are important too. One of the Trusts that performed well on quality improvement had co-produced a set of values with its front-line staff. The outcome (which might feel challenging to some NHS Boards) was to "put the patient and quality of care first, above that of finance".

Alongside all of that is the "social connectedness" of staff. The study found "stark differences" between the Trusts it looked at, with Surrey and Sussex, a Trust rated as outstanding by the CQC, having a much higher level of social connectedness among staff than the two Trusts with the lowest CQC ratings. It states that "Whereas the former was characterised by 'close relationships, mutual collaboration and feedback', the latter had a high level of simple, one-directional exchanges, suggesting a lack of collaboration between individuals".

The reports says that "organisations wanting to strengthen their capacity to innovate and improve should put the creation of peer learning and knowledge exchange networks at the heart of their strategy, and treat it as an essential component, rather than simply a desirable one".

It adds that "One of the first steps on Surrey and Sussex's improvement journey was to make sure that staff were, as Michael Wilson, the trust's former chief executive, put it, 'speaking well of ourselves, well of each other, well of our organisation and well of our community'. Once this becomes the norm, it becomes easier for people to have meaningful conversations about improvement".

Government Communication Service



A toolkit for understanding false beliefs and developing effective counter-disinformation strategies

GC3 Behavioural Science Team Cabinet Office September 2022

# The wall of beliefs

This guide is aimed at policymakers and communicators whose efforts may be frustrated by false narratives and misinformation.

In healthcare, that can apply to important issues such as vaccination and maskwearing, as well as to spurious 'cures' for serious illnesses. But the techniques explored in the guide can also apply to more day-to-day matters such as handwashing in healthcare settings.

The starting point is the 'wall of beliefs' - the various influences from which we construct our belief systems, and, to some extent, our personal identities. The point here is that belief is not simply built on facts. It also comes from social conventions, peer pressure, religious faith and more.

Because of this, myth-busting approaches can often fail to change people's minds. The arguments for mask-wearing might be scientifically persuasive – but if none of your family or friends use a mask, you probably won't either.

Rebuttals can also fail to cut through when people hold onto beliefs because they form a foundational part of their identity and worldview. In this case, a counter argument – however strongly evidenced – can threaten people's self-esteem and cause defensiveness rather than a change of mind.

The guide offers a strategy matrix, based on understanding how strongly or weakly beliefs are held, and whether the resulting behaviour is harmful or not. A corresponding set of tactics looks at incentives and barriers for desired behaviour, along with communications that can address harmful beliefs without backing the intended audience into a corner.

"Overturning false beliefs", says the guide, "is not as straightforward as simply supplying true information, or debunking falsehoods". That advice – and the solutions presented in the guide – could be very useful to healthcare practitioners and policymakers. Research report October 2022 Falling short How far have we come in

How far have we come in improving support for unpaid carers in England?

## **Caring for carers**

Unpaid carers provide essential care worth more than £132 billion a year. Their support to vulnerable adults and children has become a fundamental part of the health and care system. Indeed, evidence suggests that the UK relies more heavily on unpaid carers to provide social care than many other countries do.

In spite of this, however, many carers are struggling without adequate recognition or support.

This report measures progress made against policy commitments set out in a series of government strategies, action plans, White Papers and legislative measures from 2008 onwards. It finds that "Despite the laudable policy statements in support of carers... the reality for unpaid carers has been one of diminishing help over time".

There are a number of facets to this, starting with the fact that we do not actually know how many unpaid carers there are. According to the report, "we lack robust up-to-date data".

In the meantime, local authority assessments of carers' support needs seem to be lower in number than might be expected, and among those who have had a carer's assessment, substantially fewer are now receiving direct support. An increasing number are getting only "advice and guidance".

Breaks from caring are essential to protect carers' physical health, and also their mental wellbeing. But, says the report, access to breaks for carers is declining.

People's satisfaction with support is low and has been getting worse.

So why is the policy vision not being achieved? Partly because of a lack of accountability and agreement on who is responsible for policy success and failure. And partly because strategies can be unclear on how success should be measured. But also because of a failure to actively consider carers in wider policy decision-making. And that's before you get to lack of funding...

The report addresses these via a series of recommendations. Ultimately, though, the fact remains that in spite of policy pledges, "Carers report finding it harder to access adequate advice and support, and satisfaction with carer support services is declining".



All-Party Parliamentary Group on Menopause nquiry to assess the impacts of menopause and the case for policy reform Concluding report 12<sup>th</sup> October 2022

This is not an official contractor other Revise of Commercy of the Neural of Local, if has not here approached the effective Revise of all committees, in Perfy Personal and an informal project of Memory of ComMunication with a communities of particularities, if the mercil environment in the revised in theory of the grade. This regist

## Breaking the menopause taboo

"Despite the fact that 51% of the population will experience the menopause, the entrenched taboo around women's health issues, at times underpinned by sexism and ageism, has meant that the support for the 13 million women currently going through peri-menopause or menopause is completely inadequate."

So says the All Party Parliamentary Group on Menopause whose aim, in writing this report, was to assess the level of understanding and consider how government can drive policy change.

A key finding was that women themselves are often not equipped with the information they need to understand what is happening to them. Similarly, a "lack of awareness and understanding within the medical profession, has meant that many suffer without their symptoms being recognised". The report notes that "It is astounding that 41% of the UK's medical schools do not have mandatory menopause education on their curriculum".

The consequences are not just medical - they are social and economic as well. The report states that "Evidence shows that those experiencing menopause at work... are less likely to go for a promotion, and are more likely to leave their roles before retirement". It says that "With women often at the peak of their careers during the menopause transition, this exacerbates gender inequality in senior roles and adds to the gender pay-gap". In spite of this, "the majority of employers do not consider menopause a proper health condition and do not have policies in place to support staff going through it".

As in other areas of health care, there are inequalities. The cost of Hormone Replacement Therapy, for example, "remains a barrier for some women". Another is that "women face a postcode lottery on whether they can access the right treatment from their GP". A third is that "there is an assumption that menopause is the same for all those who go through it, and culture and ethnic differences are not accounted for". But "some South Asian communities don't even have a word for menopause... given the taboo in talking about health conditions generally – particularly women's health".

The report makes a series of recommendations, while acknowledging that "There is much that needs to be changed around the menopause, and unfortunately there is not a simple legislative lever that can be pulled to do so". But, it says, with "more widespread conversations and policies in the workplace; better education of healthcare providers and improved healthcare pathways; we can start to make the menopause taboo a thing of the past".

Patient experience in urgent and emergency care Rapid literature review



## How and why people use A&E

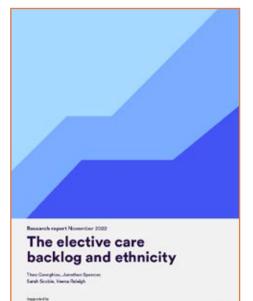
Accident and emergency (A&E) departments have been in the news all year, with photographs of long ambulance queues, and debate over whether or not to scrap the four-hour target for admission, transfer or discharge.

As part of efforts to understand the causes, and possible remedies for the crisis, NHS England commissioned a number of organisations including the Patient Experience Library to look at patient experience in urgent and emergency care (UEC).

We reviewed four years' worth of studies from sources including government bodies, policy think tanks and academic institutions, alongside the biggest single source - the local Healthwatch network. Some key findings were as follows:

- Awareness of the range of UEC options is generally good but patients and public are sometimes confused about the difference between A&E and walkin centres, minor injuries units and urgent treatment centres. Confusion is compounded by the patchy availability of some of these, in terms of both locations and opening times.
- A key driver of attendance at A&E is the difficulty of getting appointments or advice from GPs and NHS 111. Another is that people are not getting the support they need in the community - for example to manage long term conditions. Some of those going to A&E are clear that they would have preferred a GP appointment.
- Some evidence suggests that referrals to UEC might not always be appropriate. Between 2019 and 2021, GP referrals in general increased significantly (179%), but avoidable attendances from GP referrals more than doubled (255%). Care homes might be taking an overly cautious approach - 41% of care home referrals may be avoidable. NHS 111 might also be overcautious.
- Patients enduring long waits in A&E seem less concerned about adherence to the four hour target (if they are even aware of it) than about unpleasant experiences in waiting areas - some with possible clinical or patient safety risks. Some discomfort could be mitigated by better communication - for example regular updates on anticipated waiting times.

Our report fed into wider research, including social media tracking and face to face engagement with patients and public. Further details of the wider project can be found here.



·

nuffieldirus

# **Backlogs and ethnicity**

The starting point for this report is the "huge backlog in routine hospital care (known as the 'elective backlog'), with more than 7 million patients in England waiting to begin hospital treatment".

The authors go on to note that the NHS has a legal duty to "have regard" to reducing health inequalities, and that it has specifically committed to taking account of inequalities in how it addresses the elective backlog.

The report analyses hospital data from March 2019 to February 2022 and finds that while the number of operations and procedures fell during the Covis crisis, "the falls in activity were not uniform across the different ethnic groups".

The "Asian group" saw the largest overall fall in the first year of the pandemic (a fall of 49% for all procedures compared with 44% for the White and Black groups). There was a less consistent pattern for the "Black group", who had larger rate falls than the "White group" for cardiac and cataract procedures, but otherwise saw similar changes to the White group.

The most deprived groups in the population also experienced larger rate falls overall, and this matters because "There is a strong link between health need and deprivation, which has a disproportionate impact upon people from ethnic minorities".

The report offers considerable further detail, but says that more analysis is needed to better understand the variations. In particular, "Inconsistent, incorrect and incomplete coding of ethnicity in health records means that our understanding of this complex picture is limited".

Limitations include restricted ability to look at particular ethnic groups within the broad categories examined in the research. "Understanding how this variation maps across subgroups experiencing deprivation, like Bangladeshi and Pakistani people, would be illuminating".

"More broadly", says the report, "the lack of data also limits progress in understanding how to reduce health inequalities across health care – something the NHS has a legal obligation to do". One important consequence is that "Quite simply, patchy data means that the NHS is flying blind in its attempts to meet this legal, and moral, obligation".

### **EVENTS**

Leadership Academy



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. How are patient experience staff and patient reps meant to keep track of it all – and to start making sense of it?

The good news is that this brand new open access course can help!

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

Patient Involvement & Partnership for Patient Safety



### Patient Involvement & Partnership for Patient Safety

#### FRIDAY 20 JANUARY 2023 VIRTUAL, Online

This conference focuses on patient involvement and partnership for patient safety including implementing the New National Framework for involving patients in patient safety, and developing the role of the Patient Safety Partner (PSP) in your organisation or service. The conference will also cover engagement of patients and families in serious incidents, and patient involvement under the Patient Safety Incident Response Framework published in August 2022.

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

### CONFERENCES UK NHS Complaints Summit Implementing NHS Complaint Standards



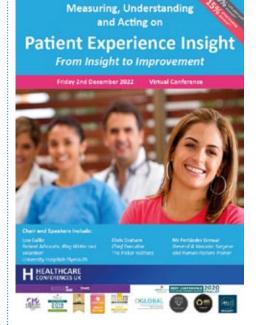
### **NHS Complaints Summit**

#### FRIDAY 3 MARCH 2023 VIRTUAL, Online

This National Virtual Summit focuses on the National NHS Complaint Standards published by the Parliamentary and Health Service Ombudsman.

Through national updates, practical case studies and in depth expert sessions the conference aims to improve the effectiveness of complaints handling within your service, and ensure that complaints are welcomed and lead to change and improvements in patient care. The conference will also reflect on managing complaints regarding Covid-19 - understanding the standards of care by which the NHS should be judged in a pandemic and in particular responding to complaints regarding delayed treatment due to the pandemic.

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



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

#### WEDNESDAY 22<sup>nd</sup> MARCH 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. 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.

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



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.

Funding declaration: In the light of concerns about drug company funding of some patient voice organisations, we declare that the Patient Experience Library receives no funding or help in kind from industries involved in drugs, treatments and medical devices.

Can't wait for your next edition of Patient Experience to appear? **Sign up to our newsletter** for weekly updates on what's new in patient experience and patient/public involvement!

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

### www.patientlibrary.net

The title and content of this publication © Glenstall IT, January 2023. The Patient Experience Library is provided by Glenstall IT, 28 Glenstall Road, Ballymoney BT53 7QN



