

this week

HOLOGRAM DOCTORS p 3 • **JUNIOR DOCTOR PAY TALKS** p 4 • **SUMMER COVID WAVE** p 6



Ten doctors take their Commons seats

Ten doctors have been elected as MPs, five Labour and five Conservatives. At least 35 doctors stood for election, fewer than in 2019, when 51 stood and 10 were elected.

For Labour, the emergency medicine doctor Rosena Allin-Khan held on to her seat in Tooting, south London, and four other doctors were newly elected: general, vascular, and transplant surgeon Zubir Ahmed in Glasgow South West; public health doctor Beccy Cooper in Worthing West; GP Simon Opher in Stroud; and ear, nose, and throat surgeon Peter Prinsley in Bury St Edmunds and Stowmarket.

The doctors elected as Conservative MPs all held their seats: Royal Navy doctor Andrew Murrison in South West Wiltshire, mental health doctor Ben Spencer in Runnymede and Weybridge, paediatrician Caroline Johnson in Sleaford and North Hykeham, emergency medicine doctor Kieran Mullan in Bexhill and Battle, and GP Luke Evans in Hinckley and Bosworth.

Two doctors who were Tory MPs in the 2019-24 parliament lost their seats: James Davies, who had been MP for Clwyd East, and Liam Fox in North Somerset.

Prinsley thanked constituents for trusting him. "Hope is a brilliant thing," he said on X, adding, "Let the hard work begin!"

Quoted in *Suffolk News*, Prinsley said he felt "privileged" to have been elected. "I think there has never been anything other than a Conservative member of parliament for Bury St Edmunds and Stowmarket for more than 150 years, so it's genuinely a historic moment and it seems the voters have chosen to join the great change which is coming in this country,"

Cooper also thanked voters for their support. "I will work as hard as I can for you, always trying to be decent and focus on improving health for all," she said.

Speaking ahead of the election, Cooper told *The BMJ* she had previously found politics to be more of a hindrance than a help in her public health roles. "I just found politics really was sort of a major barrier to improving people's health," she said. "In the NHS there are lots of things that hopefully politicians could be more helpful about and definitely get out of the way for. So hopefully I might be useful, if I get elected."

Evans said he was "honoured to be trusted again" in Hinckley and Bosworth. "There is so much more to be done, and I am grateful for the chance to continue building on what we have started," he said. "Thank you. I won't let you down."

Tom Moberly, UK editor, *The BMJ*
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The five Tory and five Labour medics who made it to parliament after the 4 July general election

LATEST ONLINE

- US Supreme Court strikes down Sackler family's immunity, casting Purdue opioid settlement into doubt
- GMC's use of term "medical professional" deepens row with BMA
- Novo Nordisk failed to disclose £7.8m in payments to doctors and others over three years



SEVEN DAYS IN

Phasing out smoking will help Labour narrow life expectancy gap, say doctors



MARK THOMAS

Doctors and public health campaigners have urged the new Labour government to ensure that plans for a smoke-free Britain sit at the “front and centre” of its domestic policy agenda. Labour was the first party to propose a policy to phase out smoking, backed the previous government’s Tobacco and Vapes Bill when it was in opposition, and committed itself to implementing the policy in its pre-election manifesto.

In an open letter to the new prime minister and health secretary, published in *The BMJ*, 1200 signatories urged Keir Starmer to reintroduce the bill as an immediate priority when he sets out his king’s speech. The letter points out that the last Labour government launched a tobacco control plan in 1997 that led to substantial declines in smoking after little or no progress in the previous two decades.

Similar action was now required, the signatories said. “Smoking is still the single biggest cause of preventable death, responsible for half of the difference in life expectancy between rich and poor people in our society,” the letter says. “Labour cannot achieve its manifesto commitment to halve differences in healthy life expectancy unless it prioritises ending smoking.”

Gareth Iacobucci, *The BMJ* Cite this as: *BMJ* 2024;386:q1500

Pay Hospital doctors in Wales accept pay offers

Consultants, junior doctors, and SAS (specialist, associate specialist, and specialty) doctors in Wales have accepted the Welsh government’s pay offers, bringing an end to three separate pay disputes. In a referendum 96% of junior doctors in Wales voted to accept an additional 7.4%, taking the total to a 12.4% uplift for the 2023-24 financial year. The rise will be backdated to April 2023. The ballot also saw 86% of consultants vote to accept a revised consultant pay scale that will improve early years pay and increase career average pay to help retain the senior workforce.

Gun violence Surgeon general declares US public health crisis

The US surgeon general, Vivek Murthy (below), declared firearm violence a public health crisis that should be tackled with the same urgency that had cut deaths from tobacco and road traffic crashes. In 2020 gunshot wounds became the leading cause of death among children and adolescents in the US,



surpassing road deaths. In 2022, 4603 Americans aged 1 to 19 died by gunshot—more than double the number killed by cancer or by poisoning, including overdoses, and four times the number killed by drowning. Gun violence is still below its 1980s peak, but the US recorded 48 204 deaths by gunshot in 2022, including suicides, homicides, and accidents.

Overseas doctors NHS induction is inadequate, says survey

More needs to be done to improve NHS inductions for international medical graduates (IMGs), said the Medical Protection Society. In its survey of 737 IMGs who started in NHS roles in the past five years 58% said that their induction was not adequate or appropriate, and 48% felt anxious about starting clinical duties as a result. Some 38% also said that they had insufficient time to shadow other doctors, 45% said that their induction did not include training on cultural differences and acceptability in the UK, and 61% felt fearful of medicolegal issues arising.

Mpox Deadlier strain is behind DRC outbreak

A deadlier strain of the

mpox virus is being transmitted directly between humans for the first time in the east of the Democratic Republic of the Congo, experts have warned. Trudie Lang, professor of global health research at the University of Oxford, told a World Health Organization media briefing that the clade I mpox virus—a strain of the clade II virus that caused a global outbreak



in 2022—was “definitely the most dangerous strain yet.” Human-to-human transmission is occurring through sexual and non-sexual contact, including among schoolchildren. This is the first time that clade I mpox has shown sustained community transmission.

Illegal imports Jail sentence for importing unlicensed medicines

Antoine Christopher Koliass was sentenced to three and a half years in prison after importing unlicensed medicines from India, the Middle East, and east Asia to the UK. An investigation by the Medicine and Healthcare Products

Regulatory Agency’s Criminal Enforcement Unit found that Koliass was selling quantities of sildenafil citrate (the active ingredient in Viagra) on Amazon and eBay, claiming that the products were a “100% natural remedy” and “risk free.” He ordered unlicensed medicines to be sent to his parents’ address, including the class C drugs tramadol, zopiclone, and pregabalin.

Smoking cessation WHO releases first treatment guideline

The World Health Organization has released a set of tobacco cessation interventions, including behavioural support delivered by healthcare providers, digital cessation interventions, and pharmacological treatments, in a first guideline on tobacco cessation. It advises that combining pharmacotherapy with behavioural interventions significantly increases success rates among people trying to quit. Countries are encouraged to provide these treatments free or at reduced cost to improve accessibility, particularly in low and middle income countries. WHO recommends varenicline, nicotine replacement therapy, bupropion, and cytisine as effective treatments.

MEDICINE

Therapeutics

Screen topiramate patients for pregnancy risk—MHRA

Topiramate, a migraine and antiseizure medicine, will no longer be prescribed to women or girls unless they fulfil the requirements of the Pregnancy Prevention Programme, said the MHRA after it reviewed the latest evidence. While topiramate has been contraindicated in pregnancy for the prevention of migraine since 2010, the drug is now also contraindicated in women of childbearing potential unless they agree to use birth control and take a pregnancy test before starting treatment. It is also contraindicated in pregnancy for epilepsy unless there is no other suitable treatment.

Shortages are likely to continue, warns EMA

The European Medicines Agency has warned that the shortage of glucagon-like peptide 1 receptor agonists such as semaglutide (marketed as Wegovy and Ozempic) is unlikely to be resolved in 2024. Speaking at a briefing on 26 June, the agency's executive director, Emer Cooke, said, "The shortages continue, and there are no instant solutions. We don't expect them to be resolved this year." The agency has recommended that clinicians avoid off-label prescribing.

NICE backs gene therapy for haemophilia B

The gene therapy Hemgenix (etranacogene dezaparvovec) should be made available on the NHS for adults with moderately severe or severe haemophilia B, NICE has recommended. NICE rejected Hemgenix last year, but it now recommends the drug with managed access over five years while further clinical evidence is gathered. Around 250 adult patients in England with moderately severe or severe

haemophilia B and no history of factor IX (FIX) inhibitors will be eligible for the treatment.

E coli

Outbreak cases fall, but a few more are expected

A further 13 cases of Shiga toxin producing *Escherichia coli* (STEC) O145 were reported in the UK from 27 June to 3 July, bringing the total confirmed cases to 288. Although cases are falling, the UK Health Security Agency said it expects to see a few more cases linked to



this outbreak as samples are tested. One death has been linked to the outbreak,

which the Food Standards Agency has said is likely to have been caused by contaminated lettuce.

Forced sterilisation

Japan must issue compensation, says court

Japan's Supreme Court has ordered the compensation of people forcibly sterilised under a "eugenic protection law" passed in 1948 and repealed in 1996. About 25 000 people were sterilised forcibly or after pressured consent.

Apology

In the 29 June - 6 July print issue of *The BMJ* we referred to Ujjwala Mohite, chair of the committee of SAS doctors in England, as "he" when we should have said "she." We apologise for this error.

Cite this as: *BMJ* 2024;386:q1510

Topiramate should be prescribed only to women who fulfil pregnancy prevention criteria, the UK drug watchdog has ruled

CLIMATE

The world experienced record high temperatures from July 2023 to June 2024, with 12 consecutive months that were

1.5°C above the average in preindustrial times (1850 to 1900)

[*Copernicus Climate Change Service*]

SIXTY SECONDS ON... HOLOGRAM DOCTORS

BRINGING DEAD DOCTORS TO LIFE?

That would be one solution to the recruitment crisis. Unlike holograms of dead actors such as James Dean or musicians such as Snoop Dogg, this is about using artificial intelligence to help doctors carry out remote consultations.

YOU CAN SEE (THROUGH) DOCTOR, NOW Crescent Regional Hospital in Lancaster, Texas, is reported to be the first in the world to use life sized holograms of real doctors.

DO THEY SING TOO?

Unfortunately not. Unlike Abba's digital avatars this is about helping cut travel time for patients and doctors. Chief executive Raji Kumar told a local TV station it means that doctors don't have to travel 30 miles to see patients for pre-op, post-op, or follow-up appointments at another clinic. Instead, they can step into a recording studio at one clinic and record their consultation live in real time or in a prerecorded video. The doctor's voice is projected through a hologram to patients at the other site.

SOUNDS FUTURISTIC

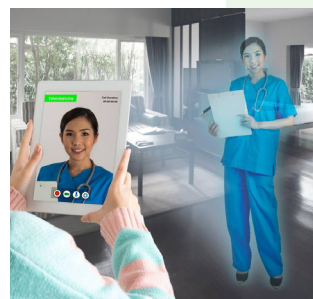
Kumar says she is planning to install the Holobox, developed by Dutch company Holoconnects, in more places throughout the hospital and wants eventually to bring the technology to rural hospitals. "I'm trying to do a mini-box in a mobile van, so I could take it to underserved areas where there's no specialist help."

WILL IT REPLACE A BEDSIDE MANNER?

Cardiologist Saad Hussain said a hologram feels closer to an in-person interaction than a telephone call or Zoom meeting and means the patient is more relaxed. "When I see the patient live in the emergency room, that gives me more sense of what's going on," he added.

IS IT ALL A BIT BLADE RUNNER?

Well, holographic technology could become more widely used in medicine. For example, interactive 3D holograms of patients' organs are being used at a handful of hospitals, including St James's in Leeds. The technology, developed by Norwegian company HoloCare, helps surgeons plan liver surgery and personalise operations to a patient's individual anatomy.



Jacqui Wise, Kent

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New health secretary opens talks on pay with junior doctors



MARK THOMAS

Labour's new health secretary, Wes Streeting, has opened talks with junior doctors in England in a bid to bring to an end their long running pay dispute.

In a statement on 5 July he said, "I have just spoken over the phone with the BMA Junior Doctors Committee, and I can announce that talks to end their industrial action will begin next week. We promised during the campaign that we would begin negotiations as a matter of urgency, and that is what we are doing."

In a statement after the talks



I do expect Labour to value doctors more than the previous government

Philip Banfield

on 9 July the BMA Junior Doctors Committee co-chairs Robert Laurenson and Vivek Trivedi said, "This dispute has lasted far too long and has cost the NHS far more than it would have taken to solve from the beginning.

"As we have said repeatedly, we are open to discussing the timeframe over which pay restoration can occur—but what is important is having a negotiating partner who takes the principle seriously.

"Mr Streeting has said pay restoration will be a journey: we are looking to set off. We thank the

secretary of state for the meeting and have agreed to meet again next week."

Streeting also announced immediate talks with NHS England and the British Dental Association as he gets to work on his policy priorities, including tackling the NHS waiting list, which currently stands at 7.6 million. He said, "From today, the policy of this department is that the NHS is broken. It will take time—we never pretended that the NHS could be fixed overnight. And it will take a team effort. It will be the mission of my department, every member of this government, and the 1.4 million people who work in the NHS to turn our health service around."

NHS England data show that during the latest round of industrial action by

STREETING outlined his priorities, including tackling the NHS waiting list, which currently stands at **7.6** million

Labour pledges to increase funding for GPs

We now wait to see exactly what that funding and support will look like

Kamila Hawthorne

Wes Streeting with Amanda Pritchard, NHS chief executive, at Abbey Medical Centre, St John's Wood, London



YUI MOK/PA

The new Labour government has promised to increase the proportion of NHS funds going to general practice and "bring back the family doctor" so as to "fix the front door of the NHS."

Health secretary Wes Streeting's first major policy announcement came on a visit to a general practice, where he said he wanted to "shift the focus of the NHS out of hospitals and into the community."

"Patients are finding it harder than ever to see a GP.

Patients can't get through the front door of the NHS, so they aren't getting the timely care they need," he said on a visit to Abbey Medical Centre in London on 8 July. "That's no surprise, when GPs and primary care have been receiving a smaller proportion of resources. I'm committed to reversing that."

Streeting also said, "We are committed to bringing back the family doctor, so patients can see the same doctor each appointment."

In 2023-24 primary care accounted for 8.4% of the NHS budget, against 41.4% for acute care. However, Labour has not said how much extra funding GPs will get, and its manifesto did not have details beyond a commitment "to move to a Neighbourhood Health Service" and "over time shift

resources to primary care and community services."

Katie Bramall-Stainer, chair of the BMA's General Practitioners Committee, wrote to Streeting on 8 July calling on him to "start a journey to increase the proportion of funding to general practice by 1% year on year," towards a proportional funding floor of 15 p per NHS pound for primary medical services, including neighbourhood health centres.

Family doctor charter

Bramall-Stainer called on the government to work with the BMA's GP Committee to agree a 2025 family doctor charter, paving the way for a "new substantive contract for England's general practice to be delivered within this parliament."

Kamila Hawthorne, chair of the Royal College of GPs, said it was encouraging to see the new health secretary visiting a general practice as his first visit to the NHS and reiterating his commitment to increase funding.

"We now wait to see exactly what that funding and additional support will look like," she said, adding, "The college has been calling for more funding for the 'front door' of the NHS for years, to ensure patients can access the safe and timely care they deserve."

Hawthorne said that funding community care was much more cost effective than relying on visits to hospital emergency departments.

Jacqui Wise, Kent

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junior doctors, between 27 June and 2 July (their 11th round of strikes), 61 989 appointments, procedures, and operations were postponed, bringing the total of rescheduled appointments during strikes to nearly 1.5 million. Some 23 000 staff were absent from work because of strikes at the peak of the most recent action.

Demand for pay restoration

The Junior Doctors Committee is calling for a 35% pay increase over time to restore pay to the equivalent of 2008 levels but has repeatedly said this could be done over several years. In an interview with the BBC's *Today* programme on 8 July the BMA's chair of council, Philip Banfield, would

not be drawn on exactly what the JDC had already been offered by the previous Conservative government, after it was put to him that the committee had previously rejected a 12% increase. But he said a deal was "there to be done."

Banfield said, "We didn't reject a 12% offer from the Conservatives, and I won't go into the negotiation now. But I do expect Labour to value doctors more than the previous government. It realises that it needs to engage with doctors; it realises that it cannot pay new doctors so poorly and so much less than other staff with less skills and expertise."

Gareth Iacobucci, *The BMJ*
Cite this as: *BMJ* 2024;386:q1514



In Scotland, junior doctors' leaders agreed a deal with the government in last August worth a total of **17.5%** over two years (**12.4%** for 2023-24 and **4.5%** backdated to 2022-23) and a commitment to work towards pay restoration

Sugar tax led to fall in consumption

The amount of sugar consumed per person each day in the UK fell by 11 g in adults and 5 g in children one year after a tax on sugary foods and drinks was introduced, an analysis of health surveys has found.

A drop in the consumption of sugary drinks was alone responsible for half of the reduction, after the 2018 rollout of the soft drinks industry levy, concluded the study published in the *Journal of Epidemiology and Community Health*. Among children the reduction in sugar consumption from soft drinks accounted for an even higher proportion: 3 g of the total daily sugar reduction of 4.8 g, the analysis of 11 years of survey data found.

Recommendations

WHO recommends that an individual's free sugar consumption should account for less than 5% of total energy intake, equivalent to 30 g a day for adults, 24 g for children aged 7-10 years, and 19 g for children aged 4-6 years. After the tax was introduced,

free sugar consumption in the UK fell by 10% in children and 20% in adults, but UK intake remains higher than the 5% set by the WHO.

Energy intake from free sugars as a proportion of total energy consumed did not change significantly after the introduction of the levy, suggesting people did not change their diets substantially by substituting more sugary foods and drinks, the researchers said.

The study's findings are supported by previous research that found a fall in the proportion of soft drinks available that contained more than 5 g of sugar per 100 ml, the threshold at which the tax was applied. The efforts of the soft drink industry to reformulate soft drinks to reduce sugar levels and dodge the tax was likely to have contributed to that reduction and subsequently the drop in the consumption of free sugars, the authors said.

Luke Taylor, Portsmouth
Cite this as: *BMJ* 2024;386:q1518



GP who faked scripts to obtain drugs is suspended for a year

An Essex GP who used drugs at work and obtained them using false prescriptions in patients' names has been suspended from the medical register for 12 months.

Nathan Sandles admitted being under the influence of drugs at work during six weeks in summer 2020 and to being "intoxicated" on the final day of that period. Staff alleged he was "drowsy, sleepy, and disorientated."

He was convicted at North Essex Magistrates' Court of obtaining a scheduled drug through a false prescription in December 2021 and had interim conditions placed on his registration that barred him from prescribing controlled drugs while he awaited his medical tribunal. But just months after being sentenced to 140 hours' community service and 20 days of rehabilitation activity he was found to have self-prescribed again, using a patient's name.

Redacted determination

Much of Sandles's tribunal hearing was held behind closed doors, a standard procedure when doctors plead mitigating circumstances such as medical or mental health problems. The determination was also heavily redacted but showed that Sandles's defence lawyer, the GMC lawyers pressing the charges, and the tribunal panel all agreed his behaviour was driven by a condition named only as "XXX."

Sandles was previously fired from a practice in 2011 for using medication meant for a patient. In 2015 he began working as a GP at Church Langley Medical Practice in Harlow and in 2016 he was offered a partnership.

Public testimony from Sandles showed he found the job stressful. He described the period up to February 2020 as an "overwhelming three month period emotionally for me," and when a young girl went into respiratory arrest at the practice, he said, it was "the final straw."

The practice manager, identified only as Ms E, told the tribunal that on one day that summer Sandles had left the practice several times while being the sole GP partner on duty and was uncontactable by phone.

Numerous staff had raised concerns with her, she said, "everyone except the other GP partners."

She wrote in a statement, "It was clear Dr Sandles didn't have the support he needed from the other partners. It was only ever one partner that was present at any one time. Dr H and Dr I said they'd talk to him. Their general response was that he's ok."

Sandles made full admission to the allegations. Ruth Curtis, chairing the hearing, said the tribunal "accepted that these incidents occurred in the context of XXX" and "concluded this provided a robust mitigation which reduced the moral culpability" of his actions.

Clare Dyer, *The BMJ* Cite this as: *BMJ* 2024;386:q1509



"IT WAS CLEAR DR SANDLES DIDN'T HAVE THE SUPPORT HE NEEDED FROM OTHER PARTNERS"

Are we seeing a summer wave of covid-19?

With cases rising across the UK, **Elisabeth Mahase** asks whether we need better surveillance

May and June saw a rise in the number of people in England testing positive for SARS-CoV-2. The UK Health Security Agency's covid dashboard shows that, of the people who have received a PCR covid test, positivity has risen from a recent low of 4.28% on 26 March to a high of 13.26% on 22 June.

Hospital admission data also indicate that the number of patients in hospital with confirmed covid-19 has been on the rise, although the data have not been updated since the end of May.

Latest data from the Office for National Statistics show there were 153 deaths involving covid-19 in the week ending 21 June. This equates to 1.5% of all deaths registered in England and Wales that week. This is similar to the week before, when 152 deaths reported (1.4%) involved covid-19. In both these weeks



there were far more deaths involving influenza or pneumonia (1803 in total).

Public Health Scotland has reported 1153 new cases in the week ending 30 June, a rise on the 1119 cases reported the week before. The number of hospital inpatients with covid also rose from a seven day average of 487 on 23 June to 564 on 30 June.

Mark Woolhouse, professor of infectious disease epidemiology at Edinburgh University, said, "The surveillance of covid cases in the UK is far less intensive than it once was, so it is difficult to track the rise and fall of waves of infection, or to assess the severity of variants, or to know how effective vaccines are against them.

"Even so, there is a widespread impression of a growing summer wave, much as we saw in 2021 when (coincidentally perhaps) there was also a Euro football tournament, and evidence that this contributed significantly to the spread of infection."

Woolhouse said we should expect to see the pattern of covid waves "driven by a combination of new variants and a partial waning immunity to infection" in the coming years. He added that, in planning for pandemics, this showed the importance of paying "attention to the long term as well as to an immediate crisis."

In her regular covid update, Christina Pagel, professor of operational research in healthcare at UCL and a member of independent SAGE, said wastewater testing for coronavirus in Scotland showed sharp rises in virus levels and no sign yet of peaking. She said this indicated a

"significant wave with a significant minority of the population infected."

Pagel added, "Although it's good hospital admissions are nowhere near what they were at the pandemic's height, waves of infection are never good news. Many people will be off work while sick and some (perhaps 1-2% of infected people) will go on to develop new long covid. It's also evident that covid is in no way a winter respiratory bug. We are still in three to four waves a year, each causing some disruption to people's lives, employment, and the NHS."

Restarting wastewater monitoring would be very helpful Christina Pagel

Pagel said the change in government was an opportunity to reset policies on covid and other airborne diseases, "particularly with the threat of bird flu (H5N1) ever present." She said a commitment to cleaner indoor air would be an important step for public health and that promoting the use of masks in healthcare settings and public transport during waves could be useful. "These measures won't get rid of covid waves, but they should help blunt their impact—and help slow down the spread of winter viruses and any new airborne diseases.

"Additionally, restarting wastewater monitoring (for all sorts of viruses) would be extremely helpful for giving us early warning of issues and tracking levels of different infectious diseases in the UK."

Elisabeth Mahase, *The BMJ*
Cite this as: *BMJ* 2024;386:q1496

Bedfordshire hospitals trust is told to improve maternity services

A shortage of midwives continues to put women and their babies at risk at two hospitals in Bedfordshire, a Care Quality Commission inspection has found.

The CQC said although Bedfordshire Hospitals NHS Trust had taken steps to tackle the problem by recruiting midwives internationally this was being undermined by racism among colleagues and a lack of support.

Ratings for maternity services at Luton and Dunstable and Bedford

hospitals declined from "requires improvement" to "inadequate" after a two day inspection last November. Overall the trust remains "good."

The inspection was prompted by service whistleblowers raising concerns over the trust's safety, culture, and management.

The report said staff did not feel able to report instances of racism on the ward and between staff, including managers.

Stuart Dunn, CQC's deputy director of

Low staffing for midwives was still a big risk to women and babies Stuart Dunn

operations in the east of England, said, "We were concerned to find low staffing for midwives was still a big risk to the safety of women and their babies, despite us telling the trust they needed to tackle this previously."

He added, "Some international midwives told us they often felt excluded and it was normalised for colleagues

from ethnic minorities to experience discrimination from colleagues."

The CQC gave the trust a warning notice in December to make immediate improvements. The trust submitted an action plan, and the warning notice will remain live until the problems are tackled.

The regulator told the trust it must demonstrate it supports its staff by challenging unacceptable behaviours and language.

The report highlighted staffing problems that

meant patients could not always access services. Capacity problems were particularly severe at Luton and Dunstable, which had to redirect women on the first day of the CQC inspection. This led to delays in admitting patients onto wards.

The trust said it had tailored induction programmes for international midwives and was running staff events on preventing discriminatory behaviours.

Jacqui Wise, Kent
Cite this as: *BMJ* 2024;386:q1497

DATA

from the ONS show there

were **153**

deaths involving covid-19 in England and Wales in the week ending 21 June



There is a widespread impression of a growing wave, much as we saw in 2021 when there was also a Euro football tournament

Mark Woolhouse



Bedford Hospital was one of two hospitals at the trust where maternity services were downgraded to inadequate

INTERVIEW

PATIENT POWER: How one editor has influenced research over 25 years

Patient editor Richard Stephens tells **Matthew Limb** what motivates his advocacy



? **Why do you do it?** There are three reasons. First, I've always believed in citizens taking control of their circumstances. Second, I've always been a teacher, I've always enjoyed writing, and I believe writing is a good way to educate people. And third, I believe in health research—largely for self-preservation.

? **Self-preservation?** My main interest remains cancer research—mostly because I'm terrified of getting another cancer. I've also had one heart attack, loads of side effects, loads of late effects, and I'm still here.

? **How did you start out?** I didn't get involved in patient charities until 1998. Before that I was a housing officer working to get people who live in social housing involved in decisions about how to improve their conditions. For nearly 10 years I've been co-editor in chief of *Research Involvement and Engagement*, a health and social care journal committed to delivering the patient or public voice in research.

? **What is the journal about?** Research, to us, is a means to an end. We want better healthcare, kinder cures, to reduce waiting times, and to produce more responsive services. This should be based on evidence, and we can help to provide that evidence. I wanted to tell the stories of how patients had helped research and to share these with other patients to help do it better.

? **What's involved?** We publish around 100 papers a year. We are open access and every paper is reviewed by patients and has a plain English summary. We work either with clinicians or academic researchers—or occasionally with industry. More and more patients are getting good at reviewing, or sense checking, or proofreading, but writing papers from scratch is not something we see as part of our role. Our skill is helping researchers

improve the evidence base for better quality health and social care. We have a publisher contact for any problems around things like ethics. Other than that, all decisions are taken by me and academic co-editor in chief Sophie Staniszewska, who leads the patient and public involvement and engagement and experiences of care research programmes at University of Warwick Medical School.

? **What's your circulation?** I don't know those stats, I don't know what our impact factor is, I don't know what our time to publication is, or how it compares with anyone else. Please feel free to quote me on that. I'm not a proper editor in that sense; I'm more interested in things like how many papers are coming in, what they're about, what the gaps are where I might be able to stir something up, how many papers have patient authors, if the plain language summary actually works, and if colleagues who want to read it can do so.

? **How do you know your impact?** Anecdotally we know people are reading papers we're publishing and it's shaping the way they go about doing things. For example, we've published papers where people experiencing homelessness have helped design a piece of research about it.

? **How have things changed?** The biggest single change is that it used to be rare for papers to be coauthored by patients. Now around 40% of our submissions include a patient author. Where patients are coauthors it's usually because they've been heavily involved in the project. The geographical range is increasing. We have a paper in review about barriers to patient involvement in Bulgaria, Kazakhstan, and Poland. The pandemic changed the papers we get—we had a glut about involving people online. Similarly, we're publishing papers about how to involve people in an emergency.

? **Have you participated in a study?** Yes, I've participated in four clinical trials. I took part in one (about anticoagulants) while I was on a hospital trolley having gone in for a routine angiogram and then collapsed on a treadmill. But I've never been told the results of any. I did find a journal paper for my cancer treatment—and after reading 18 pages, as far as I could understand it, I was still alive—which was good news.

? **Is patient feedback a good thing?** Yes, it's huge. It's something I get passionate about. There's an opportunity to say to patients or their families, "You've helped other people, even if the results were negative. So, take part in research, you can make a contribution to people you're never going to meet—and you've helped medical knowledge." The same is true for the use of our data. We can't stop the scare stories but we should try to have more good news stories about their use by researchers, where we can tell people not a single patient was identified.

? **How do you see things developing?** I'd like to see more research reports on one sheet of paper—a compromise between the 18 page academic article and the 300 word plain English summary. I think we'll see that in the drive to improve reporting of clinical trials to participants. It will start there and spread across other forms of health and social care research.

? **What other roles do you have?** I chair Use My Data (usemydata.org), which is the only patient led movement in Europe that is focused on the use of routinely collected healthcare data for research. I also chair an association of about 100 keen active volunteers who work in cancer research. I spend a lot of time teaching and lecturing. It has brought me a really interesting life, travelling across the world. I've now turned 65 and have mismanaged retirement!

Matthew Limb, London
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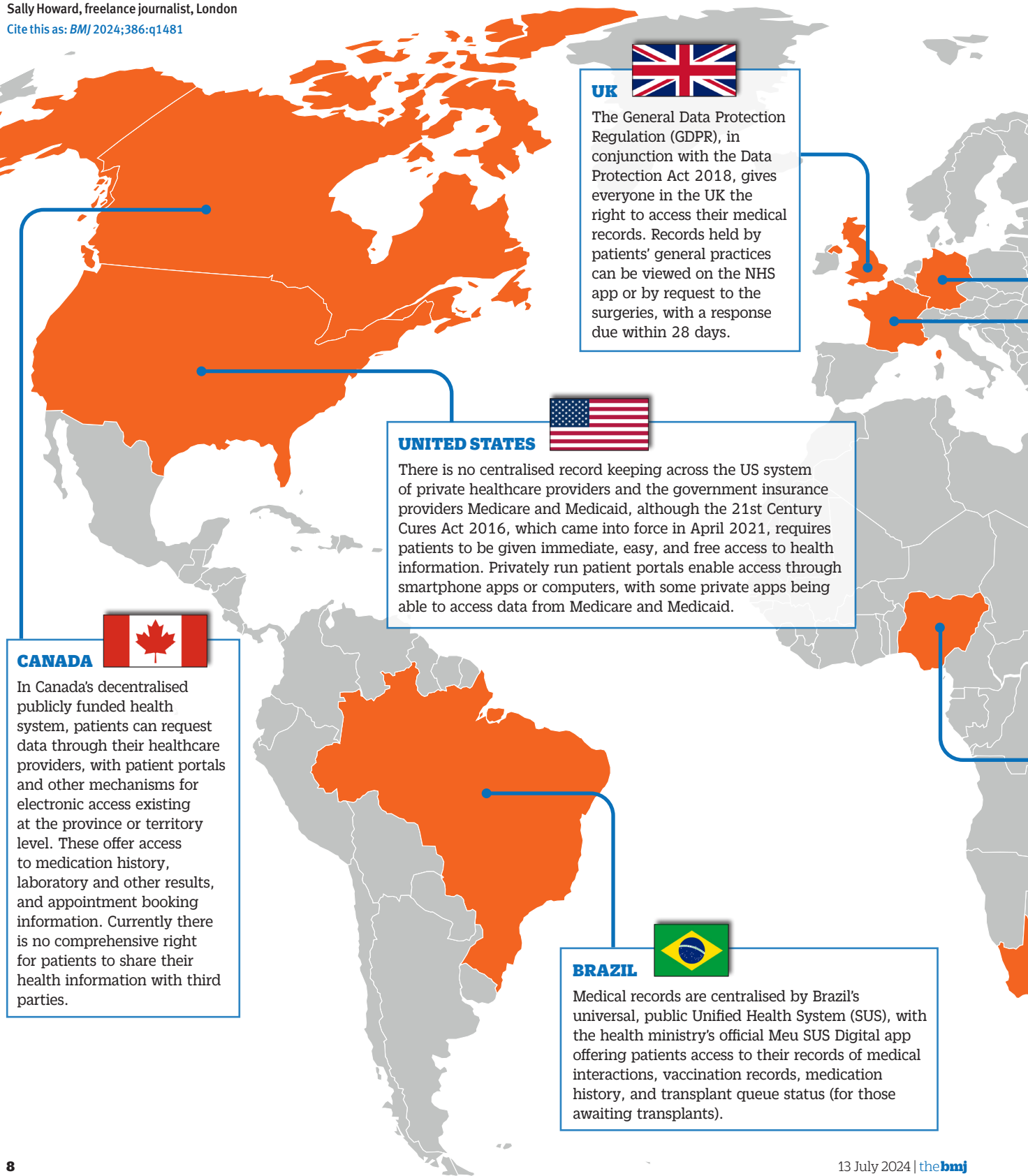
THE BIG PICTURE

Patients' access to medical records worldwide

The ability to see your own health records is generally upheld as a basic right. But complications in infrastructure and law mean access varies from country to country

Sally Howard, freelance journalist, London

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GERMANY

German citizens gained the right to access their digital health records in 2021. The centralised electronic patient health record (elektronische Patientenakte or ePA) is managed by patients, who can access it through the ePA app or website or can view it in doctors' and health insurers' offices. Since 2023 patients have been able to share their data with outside parties for research purposes.



INDIA

Patients' records are paper based and confined to one healthcare provider (but accessible to the patient). The national government's Ayushman Bharat Digital Mission, launched in 2021, aims to create a database of health records that will connect patients to a digital ecosystem including providers and payers and be accessed through an app. It is being rolled out at state level.



FRANCE

A 2002 law gave patients the right to consult their medical records and allowed doctors to share medical notes among themselves to coordinate care. Health records are centrally held and accessed by patients through a digital platform, Mon Espace Santé (My Health Space), which was launched in 2022 and is managed by the health ministry. Patients can also block access to specified documents on the website and app.



NIGERIA

Citizens have a right to access their medical records through the National Health Act 2014. Local healthcare institutions store these records, typically using paper based systems. Attempts are being made to introduce digital records, but these face major barriers, including internet connectivity and lack of functioning hospital websites.



AUSTRALIA

Privacy law gives patients a general right to request access to the health information stored about them. The My Health Records system, launched in 2012, is run by the Australian Digital Health Agency. It gives patients access, through the central myGov website, to information on medical conditions, treatments, prescriptions, allergies, and test and scan results.



SOUTH AFRICA

Each province in South Africa has its own autonomous health department, with records being the property of the healthcare institution, but copies are available on request, by law, to patients (for which a reasonable fee may be charged). Some provinces, such as Western Cape Province, have created electronic health records through which patients can access their clinical records.

Health leaders unite over social participation

Let's amplify people's voices by connecting grassroots to the tree tops

For the first time in the World Health Organization's 76 year history, world leaders have unanimously committed to strengthen, systematise, and sustain social participation in health and wellbeing.¹

This landmark resolution recognises social participation as "empowering people, communities, and civil society through inclusive participation in decision making processes that affect health across the policy cycle and at all levels of the system."² Governments will be held accountable for progress to 2030.

Health is created by people, communities, and civil society.³ Patients develop deep knowledge in caring for themselves and others, navigating complex systems, and finding solutions in everyday life.⁴ Civil society often fills gaps in access for marginalised communities.⁵ While people are increasingly being engaged as partners in health systems,⁶⁻⁸ recognition and influence are highly variable, and too many are still excluded.⁹

Empowered patients

If people are empowered to fully partner in health, the resources, intelligence, and capacities of our health systems will exponentially increase. Global challenges such as access to care, climate change, widening social inequalities, demographic changes, and staff shortages are overwhelming our health systems.¹⁰ They can be overcome only if everyone is mobilised: complementary in their knowledge and interdependent in their actions.

In the past decades, numerous political statements affirmed the value and principles of social participation.¹¹⁻¹³ The WHO



Social participation is a principle to be honoured but also a right to be seized

resolution marks an important step forward, in three ways.

First, it outlines clear government responsibilities to ensure social participation is adequately resourced with stable public funding, and designed in a way that influences health related policies and system change. The resolution holds governments accountable for nurturing a fair playing field, reducing power differences, and making room for everyone.

Second, the resolution makes social participation a core function within health systems, rather than a set of ad hoc initiatives. This global perspective is important to reshape health systems, nurture trustful and long term relationships with communities, and build alliances across health sectors.

Third, it offers powerful mechanisms to influence governments. Because they endorsed the resolution, governments have a political imperative to act and must show progress every two years.¹ The resolution supports national implementation through technical guidance, examples of global practice, and a common evidence base.¹⁴

Ensuring progress

Social participation is a principle to be honoured and enabled by governments but also a right to be seized. As an international

community, we can move forward by recognising people's knowledge, sharing power, and fostering cooperation.

Lived experience and knowledge, especially that of people who struggle the most to access health, is pivotal in helping us design better and more inclusive health systems.¹⁵ We need to acknowledge the extent to which individuals, communities, and civil society are already engaged in health. Grassroot movements, election campaigns, civil society coalitions, and patient organisations offer powerful catalysts for change^{16,17} and can use the WHO resolution to influence governments.

Shared leadership

To ensure the resolution has traction, we need strong, visible, and shared leadership from civil society and governments. We must have equal partnerships: among policy makers and patients, and among health professionals and communities. We need researchers to share the evidence, inform the design of effective approaches to encourage participation, and offer robust indicators to track progress.¹⁸⁻²⁰

Health issues transcend national borders, and all countries must participate to achieve a healthy world. We need to share success stories, challenges, and solutions; learn from people across the globe; gain understanding from our diversities; build coalitions; and nurture the next generation of leaders to have the passion and expertise to ensure that no one is left behind.

The social participation movement is global, but the power to act is rooted locally in the alliances we forge with each other. Share your ideas. Engage in dialogues. Extend a hand.

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Antoine Boivin, Canada Research Chair in Partnership with Patients and Communities, Université de Montréal, Canada antoine.boivin@umontreal.ca

Dani Mothci, chief executive, International Alliance of Patients' Organizations, London

Vincent Dumez, patient co-director, Centre of Excellence on Partnership with Patients and the Public, Montreal

Farin Shore, peer worker in harm reduction, Doctors of the World, Canada
Amanda Bok, chief strategy officer, The Synergist, Brussels

Conservative party's legacy on the NHS

Political failure has left the health system in crisis and caused avoidable harm

The NHS is under new management. The Labour party's election win on 4 July 2024 marks the end of 14 years of Conservative led governments presiding over the English NHS—from David Cameron's coalition with the Liberal Democrats in 2010-15 to Rishi Sunak's stint in Number 10 in 2022-24, with Theresa May, Boris Johnson, and Liz Truss in between. Labour left the Conservatives a vastly improved NHS when it lost office in 2010.¹ How do the Conservatives return it in 2024?

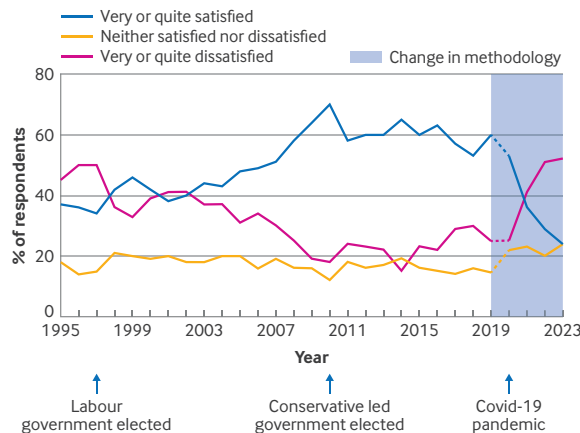
NHS performance deteriorated against headline measures since 2010.² People are waiting longer in emergency departments to get care; longer for planned hospital services—like tests, scans, and surgery—and urgent cancer treatment. Covid-19 made things worse, but NHS performance had been declining for several years before the pandemic hit.³ Totemic NHS targets—such as at least 92% of patients starting consultant led treatment within 18 weeks of a general practitioner referral—have been routinely missed for nearly a decade. The result is avoidable harm to patients.⁵

Quality deteriorated in key areas out of the spotlight too.⁶ For example, the proportion of patients feeling supported to manage chronic conditions has fallen.⁷ Patients are finding it harder to get general practice appointments and continuity of care with named GPs has worsened.^{8,9}

Since 2010, satisfaction has fallen—to an all-time low of 24% in 2023 (figure).¹¹ Satisfaction is low across all population groups and supporters of different political parties.

What went wrong?

Political choices by the Conservatives in government weakened the NHS and made it harder for staff to deliver a high performing service. A decade of underinvestment going into covid-19 constrained what the NHS could do.



Public satisfaction with the NHS, 1995-2023¹¹

Political choices weakened the NHS and made it harder for staff to deliver a high performing service

Health spending grew by around 2% a year in real terms between 2010 and 2019—well below the long term average in England (3.8% a year since the 1980s).¹² Low capital investment left staff working in crumbling buildings, with inadequate equipment and IT.¹³ It also left the NHS falling behind other health systems. If the UK had matched comparable European countries' average capital investment in healthcare as a share of GDP, the UK would have invested £33bn more.¹⁴ Failures in workforce planning meant the NHS went into the pandemic with fewer doctors and nurses per person than most comparable countries.¹⁵

All this and more sent the NHS into crisis long before covid-19, leaving the health system vulnerable to the pandemic and worsening its impact. The NHS is still in crisis. The elective waiting list is now over 7.5 million, and pressures on emergency care are extreme.² NHS staff shortages are widespread.¹⁶ Staff are stressed out, burnt out, and feeling the effects of real terms pay cuts since 2010.¹⁷⁻¹⁹ The long overdue NHS workforce plan published in 2023²⁰ has not been enough to convince striking NHS doctors that the government understands their value.

Policy failures elsewhere made things worse. Public health budgets have been cut.²¹ Investment in wider public services that shape health and inequalities has been weak.^{22,23}

Hugh Alderwick, director of policy, Health Foundation, London
 Hugh.Alderwick@health.org.uk

England's threadbare social care system has been underfunded and unreformed.²⁴ A national strategy to reduce England's vast and growing health inequalities has been shockingly absent.

The Conservatives' approach to health service reform was messy. Despite promising no more top-down reorganisations of the NHS,²⁷ the Conservatives bookended their 14 years in power with two of them, each pulling in different directions. Ironically, the NHS now has a structure that has broad support from its leaders.³¹ But time, energy, and resources have been wasted getting there.

Time for honesty

The NHS is weakened but not broken. The health service sees millions of people each week—delivering our babies, caring for our parents, treating our friends and colleagues. The number of appointments in general practice is now higher than before the pandemic, despite the number of fully qualified permanent GPs falling since 2015.³⁴ Trends in use of private healthcare provide worrying signs that the social contract underpinning the NHS may be fraying as access to care worsens.^{35,36} But public support for the NHS's core principles—available to all, free at the point of use, funded primarily through taxation—remain rock solid.¹¹ The major strengths of the NHS model endure.³⁷

Labour inherits a mess. Other international health systems face similar challenges, such as staff gaps and population ageing. But details on what Labour plan to do about it are—so far—thin. A first step should be honesty with the public about the substantial investment needed to recover NHS services, and the tricky trade-offs this would mean for other areas of public spending and levels of taxation.¹²

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The people who bring lived experience to study teams

Patients often act as co-leads on projects, but the infrastructure to support such collaborations is still in its infancy. **Eva Amsen** reports

In 2015, when the Cambridge Clinical Trials Unit launched its Patient Led Research Hub (PLRH) it noticed that patients were interested in research topics that weren't covered by most published studies.

"Most patient priorities were around quality of life and symptom management, whereas a lot of funded projects were about interventions and drugs," says Laura Cowley, research lead at PLRH.

A similar discrepancy had come to light in the Netherlands in 2006, when the Dutch Burns Foundation invited patients to help set their research agenda. It learnt that this group's main concern was itching, which wasn't a research priority at that time. "It's such a good example to show that people with lived experience ask very different questions," says Sanne Steenhuisen, programme secretary of the participation and citizen

Most patient priorities were around quality of life and symptom management

Laura Cowley

science initiative at the Netherlands Organisation for Health Research and Development (ZonMw).

Many organisations and patient groups around the world, including PLRH and ZonMw, are now creating better ways for patients and researchers to collaborate.

Beyond box ticking

"Patient led" now means that research is driven by patients or by people with lived experience. This might be in consulting roles or as co-researchers. It goes further than merely encouraging researchers to incorporate patient and public involvement (PPI) in their work—something that is already becoming common practice at many medical research funders.

Funders that ask for PPI plans include Australia's National Health and Medical Research Council, the Canadian Institutes of Health

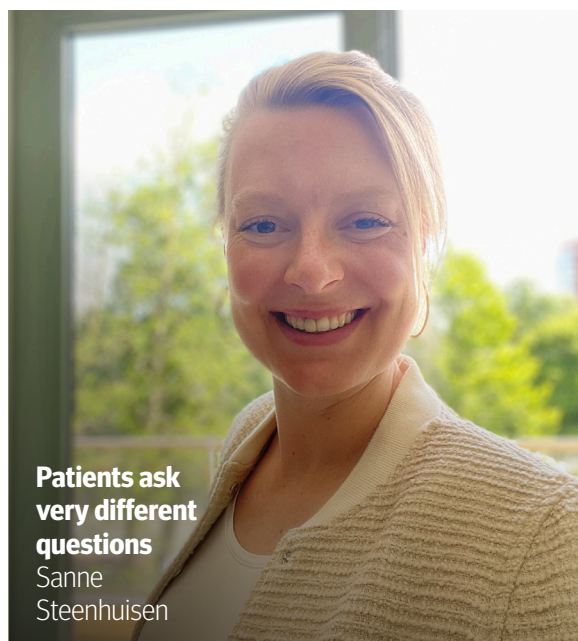
Research (CIHR), the UK's National Institute for Health Research, the National Institutes of Health in the US, ZonMw, and many others, including charitable research funders.

While asking funding applicants about their PPI plans encourages researchers to think about patient involvement in the early stages, there is often very little follow-up and no guarantee that researchers will actually involve patients.

"It's often seen as a box ticking exercise and we want to change that," says Steenhuisen. "Although funders say they want a PPI plan or evidence of PPI, it's still very tokenistic," agrees Cowley.

PLRH is taking a more active approach to getting patients involved. Its current focus is on delivering clinical studies in collaboration with rare disease patient groups.

"Originally, the ethos was to take on any research idea from any patient group," says Cowley. "But that got too big too quickly." Since most of the feasible research ideas came from rare disease groups, it decided to limit the scope. PLRH now takes research suggestions from rare disease patient support groups and facilitates the formation of equal partnerships between patients and research groups if the idea is feasible.



Patients ask very different questions
Sanne Steenhuisen

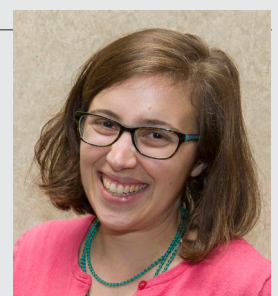
Long covid

Long covid research has been patient led from the beginning.

People who did not fully recover after a covid infection found each other online and created communities to drive awareness. One of these online forums branched out into the Patient-Led Research Collaborative, which facilitates patient led research into long covid by working closely with a group of researchers.

Other members of the long covid community also recently organised the Unite to Fight conference, where researchers and others shared updates on long covid and myalgic encephalomyelitis/chronic fatigue syndrome research.

One of the speakers was Alison Cohen (above), epidemiologist at the University of California, San Francisco. Cohen worked with the Patient-Led Research Collaborative on a report documenting 13 case studies of people who tried nirmatrelvir/ritonavir (Paxlovid) as a long covid treatment, currently available as preprint. "I'm particularly proud of this work as a model of patient driven research—many of the people whose experiences are documented were also involved in the paper as co-authors," says Cohen. "When patients and other people with relevant lived experiences are involved in research, it makes the research stronger."



OpenAPS

In 2013, Dana Lewis (right) was not able to hear the alarms on the continuous glucose monitor that she used to manage her type 1 diabetes.

Together with Scott Leibrand she found a way to pull data from the device and build a better alarm system. Further modifications connected the system to an insulin pump to create a fully functional closed loop automated insulin delivery system.

“We spent a lot of time thinking about safety as it evolved to a closed loop system,” says Lewis. “We wanted people to have the advantage of building from the safety based design that we had.”

That was one of the reasons Lewis made everything openly available through the OpenAPS project, where anyone can download the software they need to run the system on either a small hardware device or through an Android phone. Even now that commercial closed loop systems are available, thousands of people are still using OpenAPS because it's more accessible and affordable.

Lewis connected with researchers and clinicians at conferences where she was invited to speak. This network made it possible to fund and carry out a clinical trial with Lewis as co-investigator. The results of this trial further validated the effectiveness of the new Android based OpenAPS system.



Evidence Alliance in Canada routinely includes patient partners in knowledge synthesis projects, but has recently also selected several new research topics that were submitted by patients or community members who are co-leading their chosen project with a research team.

Becoming equal partners in a research team is currently more common in areas with tangible and applicable outcomes, such as knowledge synthesis at the SPOR Evidence Alliance or clinical effectiveness research, the focus of the Patient Centred Outcomes Research Institute (PCORI) in the US.

PCORI includes patients as advisers in study design and implementation; on some projects it also involves community organisations as co-leaders. “It represents a model that we may be able to repeat over time,” says Harold Feldman, deputy executive director for patient centred research programmes at PCORI.

But while all these organisations and projects are exploring new ways of collaborating and co-creating with patient communities, they're also identifying new challenges.

when approached, or even in co-leading research projects. That level of involvement deserves compensation, but this is not a straightforward process. Paying patients for their involvement may affect any government benefits they are receiving. That's why some organisations give patients the choice between remuneration or gift cards, for example.

“We try to find different options to pay people for their time, and we ask what their preference is,” says Andrea Tricco, principal investigator for the SPOR Evidence Alliance and scientist at St Michael's Hospital, Toronto.

Problems also arise when patients are co-applicants on grant proposals, because existing funding systems aren't set up for applicants without institutional affiliations. “When patient partners apply as co-applicants, they need to submit an academic CV, which is just not appropriate,” says Cowley of UK funding systems. “And there's no box for PPI. If you don't have a medical background, you select 'other.' It's such an unwelcoming first interaction for a patient.”

The situation in Canada is similar. “Right now, patients can't necessarily hold funding unless they're part of a formal affiliation or group,” says Tricco. “But I do know that that's something CIHR is looking into.”

Another roadblock to further implementation of patient led research is that the research community is only gradually becoming aware of how it can collaborate with patients. “It has to become more normalised,” says Steenhuisen. “Why would you do research without involving the people that the research is about?”

“Unfortunately, a lot of research groups are still new to the idea of partnering with a patient or having patients involved at all,” says Dana Lewis. Lewis, who has type 1 diabetes, has worked closely with researchers for the past decade to develop and test a closed loop artificial pancreas system (see box 2). But when she was also diagnosed with exocrine pancreatic insufficiency, a digestive condition, she found it much harder

Patient groups are becoming research partners

Organisations involved in patient led research are exploring different ways of giving patients an active role. Some initiatives are led by patient communities, such as the Patient-Led Research Collaborative for Long Covid (see box 1). Others are spearheaded by research or funding organisations that take research topic suggestions from community and patient groups, involve them as equal research partners, or both.

ZonMw, for example, is currently running a process to connect researchers on youth matters with community members who have suggestions for research topics. “One of our goals is to expand this to other topics,” says Steenhuisen. Other funders are taking similar steps. Diabetes UK, which is already flexible about including patients as co-applicants on some of their funded projects, is broadening its scope to include more people with lived experience.

Meanwhile, the Strategy for Patient-Oriented Research (SPOR)

A system unfriendly to patient led research

Patients can be involved as advisers in setting research directions, in providing feedback



We try to find options to pay people for their time

Andrea Tricco

to collaborate with gastroenterology researchers. “It’s like a different universe,” she says.

This lack of familiarity among the research community is something that the SPOR Evidence Alliance is hoping to tackle. “We’re trying to change the research community to be more accepting of patient engagement,” says Tricco.

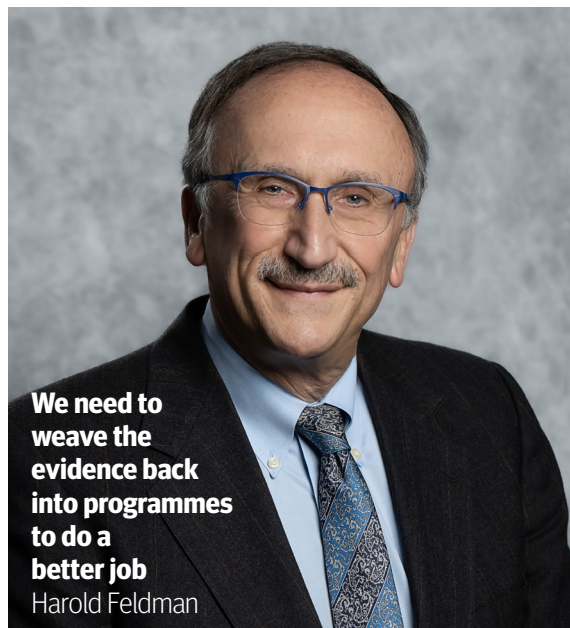
Organisations and funders are learning where the bottlenecks are in managing patient led research. They’re working on building fair compensation systems, supporting researchers, and evaluating best practices.

PCORI is also funding research into the science of engagement, to learn more about the best ways researchers and funders can work together with patients in research planning and execution. “We need to take the evidence and the findings from those programmes,” says Feldman. “Then we can weave that back in so that we can do an even better job of facilitating and promoting patient engaged research.”

It’s a learning process for everyone and the next few years will likely see further progress. Cowley is optimistic, and says, “In general, people are much more aware and are at least having conversations around the challenges of patient led research.”

Eva Amsen, freelance journalist, London
eva.amsen@gmail.com

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We need to weave the evidence back into programmes to do a better job
Harold Feldman

PATIENT SAFETY

“A relentless focus on NHS finance and productivity is failing patient safety”

Concerns about substandard care are the “canary in the coal mine,” but they are too often ignored, Henrietta Hughes, the patient safety commissioner, tells **Erin Dean**

When thinking about the difference patients can make in improving care,

Henrietta Hughes recalls a recent visit to a stroke unit.

“One of the patients said, ‘In the toilets, it would be much better if you had toilet paper on both sides of the cubicle, because if you’ve had a stroke you’ve only got a 50% chance of being able to reach it,’” she says. “Now, the power of that story is that you can have a unit full of experts—clinical nurse specialists, professors, people with PhDs—and they know everything about stroke, but they’ve never been in a cubicle with a patient who’s had a stroke when they’re on the toilet.”

For Hughes, that one moment crystallises the kind of insight that only a patient can bring. However, evidence that NHS patients often aren’t listened to keeps on coming.

Hughes spoke to *The BMJ* in the same week that the public inquiry into the use of infected blood, which claimed more than 3000 lives, was published. This is one of a number of issues where patient led campaigns have demonstrated the devastating human cost of failures in patient safety.

“The patient’s anecdote is the canary in the coal mine,” says Hughes, who also works as a GP locum in London every week. “It’s the thing that tells us there’s something going wrong. But too often we hear about patients

who have raised concerns being gaslighted, dismissed, and fobbed off.”

Listening to patients

In September 2022 Hughes became England’s first patient safety commissioner, an independent role funded by the Department of Health and Social Care. The job was created after a recommendation in the 2020 *First Do No Harm* review, which looked into three devastating medical scandals: hormone pregnancy tests that are thought to be associated with birth defects and miscarriages; sodium valproate, an antiepileptic drug that can cause birth defects when taken in pregnancy; and pelvic mesh implants, which have been linked to crippling complications.

This review, which focused on three failures of care that affected women and other people who menstruate, highlighted the need to better protect and listen to patients. Julia Cumberlege, who produced the *First Do No Harm* report, recommended that an independent patient safety commissioner be appointed as “the golden thread, tying the disjointed system together.”

Too often, patients raising concerns were passed off as “difficult women,” says Hughes. “It shows a very dismissive and very old fashioned, patronising attitude to patients who have identified problems and need to have their voices heard.”

The three strands of work that Hughes is currently focusing on are: developing a safety management system, including an overhaul of the complaints process and clinical negligence; embedding patient safety and the patient voice throughout the healthcare system; and ensuring that patients' voices are heard in their own healthcare.

Martha's rule

As part of that latter strand Hughes leads the oversight group for "Martha's rule," named after 13 year old Martha Mills, who died from sepsis after her parents' concerns about her deterioration in a London hospital were not acted on.

Martha's rule is one of the areas where Hughes believes that she and her team have really made a difference. "I've never seen something happen at that scale and speed before, particularly in such a collaborative way," she says. But she does add that some organisations may have to implement the rule slightly differently, as they don't have access to critical care outreach teams around the clock. These teams, often staffed by senior nurses, are the responders when a family triggers a clinical review.

"We need to take the local context into account," says Hughes—"and take an approach that's very respectful to patients and families but also to the staff who work in a wide range of settings."



The safety commissioner is "the golden thread, tying the disjointed system together"

Valproate and mesh

While Martha's rule is leading directly to change, other victims of patient harm are still waiting for justice.

In February Hughes published a government commissioned report looking into what kind of reparation should be offered to the people harmed by sodium valproate and mesh surgery. Three months later she received a letter from the then health minister Maria Caulfield, which didn't commit to the recommendations and said that legislation would be needed for the recommended financial compensation.

In her letter Caulfield said that the government was "exploring a host of non-financial redress options" and that she was "keen to do what I can regarding the availability of information available to patients, as well as any improvements in access to the support patients are entitled to."

Hughes seems frustrated with this response. "The time for redress is now for those patients who were harmed by valproate and mesh," she says. "I recognise that it's complex, but those patients have been campaigning for decades to get recognition, to get the financial and non-financial aspects of redress that would make a huge difference to their and their children's lives."

Through her work as a GP, Hughes realised that the way in which sodium valproate was prescribed meant that pharmacists often had to split packs and issue tablets in plain white boxes without warnings



HAYDN WHEELER/LAMY

about the effects they could have on unborn children. After she raised the issue the law was changed last year so that safety warnings would be provided with every pack and the tablets would be issued in their original packaging.

But three children a month are still born to mothers who are taking sodium valproate, despite the longstanding knowledge about the harm it can cause, says Hughes. She blames this on the “disjointed nature of primary and secondary care, community care systems not talking to each other, and patients falling between the cracks.”

Cultural change

Hughes, a former medical director at NHS England and national guardian for the NHS, doesn't look into individual cases. But she does believe that knowing where to seek support can be tricky for patients and families in a disjointed system.

“There's over 100 patient safety organisations, and one of the things that we'll be working on this year is doing the *Patient Safety Atlas of Powers*, an easy-to-read guide of the arm's length bodies and regulators and what their roles and remits are,” she says. “Because as far as I'm concerned, they don't join up. They don't reference the next step in the chain.”



Henrietta Hughes (above) says campaigners for mesh compensation (top) deserve payment now

NHS trusts that actively listen to patients are more likely to get it right when it comes to supporting their staff too, says Hughes, and she's keen to bring some of the learning from her national guardian role into creating better routes for patients to be heard.

Organisations that work alongside providers, such as commissioners and regulators, also have a critical role to play in improving culture, she says. Focusing too much on finance at a provider level means that “the culture becomes toxic, and we're just on the road back to the Mid Staffs scandal.”

When considering the challenges of her role, Hughes reflects that she's “swimming against the tide” when it comes to making a lasting cultural change. “People are quite comfortable with the way they do things already,” she says.

Last year she pointed out in a report that neither the Department of Health and Social Care nor NHS England had patient representatives on their boards, nor did they regularly hear a patient story at board meetings. She still believes this to be the case.

“I've been continuously raising this concern that I have, that safety is seen as some kind of sideshow rather than as central and paramount,” she concludes. “The relentless focus on productivity, finance, and performance is really missing a huge opportunity to start with patients and start with safety.”

Erin Dean, freelance health journalist, UK
erin@erindeanwriting.com

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HOW PATIENTS WERE INVOLVED IN THE CREATION OF THIS ARTICLE

Members of *The BMJ's* international patient and public advisory panel collaborated with us on this interview by suggesting questions to be posed to Hughes. They also shared topics of interest which helped to inform question selection.