comment

"Good medicine will always revolve around genuine human connection" **MATT MORGAN**
"Time to embrace the transformative potential of medical leadership" **SCARLETT McNALLY**
PLUS Gillian Leng; Trisha Greenhalgh and Martin McKee on the Leng review

PRIMARY COLOUR Helen Salisbury

PAs in general practice after Leng's review

After some delay, Gillian Leng's report on physician associates (PAs) and anaesthesia associates (AAs) in the NHS was published on 16 July. Her remit was to look at the safety and effectiveness of these roles. One significant stumbling block was the lack of good research evidence, and as most studies were far too small to be generalisable, her conclusions are mostly that we don't know.

A large body of incident reports and concerns that had been collected and submitted by the BMA wasn't included in the evidence that Leng considered, as the incidents couldn't be verified. But one striking research finding she did consider was the mismatch between what PAs felt confident doing (a very wide range of tasks) and what their supervisors thought them capable of (a much narrower range).

A recommendation is that PAs should not see undifferentiated patients except within clearly defined national clinical protocols, as their role should not include making initial diagnoses or treatment decisions. However, the same paragraph suggests they may still see triaged adult patients with minor ailments. The problem here is that many problems are minor only in retrospect: a cough is probably a viral infection, but it could also be tuberculosis, heart failure, or a side effect of blood pressure medicine. Diarrhoea is likely to be mild and self-limiting, but it could be the first presentation of cancer or inflammatory bowel disease.

We need to know who will be doing the triage and initial diagnosis. Assuming this is a doctor, will they be interacting with the patient? If so, this raises the question about what role there is for the assistant. The report points out that there are hospital roles for assistants in helping with the smooth running of wards, by relieving resident doctors of some of their more routine or administrative tasks. There may also be a prevention role in general practice—offering health checks, smoking cessation clinics, or dietary advice.

Leng also notes that research on the cost effectiveness of the PA role is sparse and inconclusive. The starting salary of a PA is on band 7 of the Agenda for Change pay scale (£47 810), which is over £11 000 more than the core salary of an FY1 doctor with more years of training. This reflects sums imported from the US where PAs had more extensive training and experience, but it means we now have a situation where the assistants are paid more than those they're assisting.

Ultimately, the future of PAs in general practice will be decided by market forces. Some surgeries will find a way to continue to deploy the PAs who have proved themselves to be useful members of the team, even if they need to change the assistants' duties to fit the new recommendations. However, now that the money used to employ them (from the Additional Roles Reimbursement Scheme) could be spent on fully qualified GPs instead, it seems unlikely that many new PA posts will be created.

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Cite this as: *BMJ* 2025;390:r1524

We have a situation where assistants are paid more than those they are assisting

CRITICAL THINKING Matt Morgan

Flip phones, flying cars, and 20 years in medicine

Twenty years of working in medicine is just long enough to realise how much things change and how little the core truths ever will.

In 2004, in my first year as a doctor, we lived in a world defined by flip phones, Blockbuster video rentals, and towers of dusty CDs in plastic covers. Medicine involved paper notes, bleeps clipped to belts, and the art of deciphering other doctors' handwriting.

Some things haven't changed. Even this year's Glastonbury headliners were the same artists I saw in my first year—although the past 20 years are now etched clearly into their faces, bodies, and voices. And mine.

Fast forward two decades, and we live in an era of smartphones. Blockbuster has morphed into limitless film and TV streaming, and CDs have been replaced by music streaming platforms. In medicine, electronic health records and telemedicine have replaced messy handwriting, even if endless ward rounds remain.

Yet, despite these technological leaps, the fundamentals are remarkably unchanged. Patients still seek empathy, doctors still grapple with uncertainty, and illness remains stubbornly indifferent to our advances.

Early in my career I thought that medicine was about certainty: diagnoses, treatments, and the rush to solve puzzles. Over time I've realised that it's much more nuanced. Medicine is about navigating doubt gracefully. It's about recognising when technology aids us and when it intrudes, distinguishing genuine patient care from convenience.

Isolated and disconnected

Medicine today is faster, sleeker, more connected—and yet, paradoxically, more isolating. Social media can connect professionals globally, but this often leaves individual doctors feeling disconnected. The abundance of information can obscure wisdom, drowning clinicians in data rather than giving them insight.

I hope that medicine remains deeply human

Just as TV streaming services offer endless choices but can leave us unsure what to watch, medical technology floods us with information but can cloud our clinical judgment.

I've learnt that the true longevity of a medical career depends mostly on having good colleagues: those who challenge your thinking, offer new perspectives, and remind you to stay inquisitive. Staying curious, I've found, is not merely advantageous but is essential for professional survival. Medicine doesn't tolerate complacency: it demands constant questioning, constant learning. And night shifts nowadays demand constant coffee.

Moreover, I never anticipated how deeply medicine was intertwined with life outside the hospital. My external circumstances have shaped clinical practice, just as medicine shapes my personal life. Our emotional, financial, and familial wellbeing profoundly affect our capacity as clinicians. Recognising this interplay has been essential to understanding the sustainability and reality of a life dedicated to medicine.

Looking back, I'd say that the contrast between my first year and today isn't just about technology, culture, or trends. It's about

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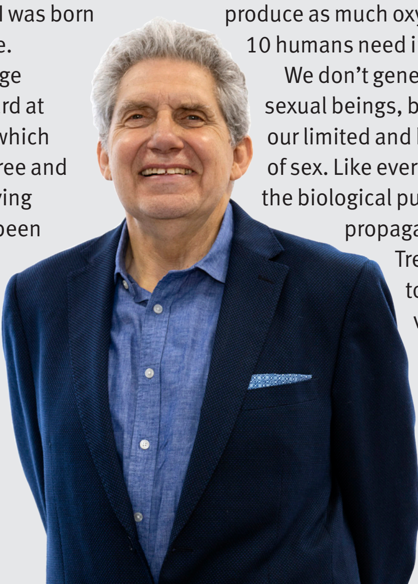
TALKING POINT John Launer

The consolation of trees

I've always loved trees, and as a teenager I taught myself to identify most of the common species. As I've got older my respect for them has grown, and I find it consoling that many of them were around before I was born and will remain long after me.



I recently made a pilgrimage to visit a yew in the churchyard at Llangernyw in north Wales, which is probably the UK's oldest tree and possibly one of the oldest living organisms in the world. It's been dated to be 4000-5000 years old.

We live in a reciprocal relationship with trees. We inhale their waste oxygen while they metabolise the carbon dioxide exhaled by creatures that move, including us, although the relationship is unequal. Some 21% of air is oxygen generated by plant life, but only 0.04% is carbon dioxide. A large mature tree can produce as much oxygen in one season as 10 humans need in a year.

We don't generally think of trees as sexual beings, but this is because of our limited and human centred view of sex. Like every living organism, the biological purpose of a tree is to propagate more of its kind. Trees have been able to evolve gloriously varied ways of doing so, having existed for about 800 times as long as humans.

For example, there are single and dual sex trees and some that change sex. Some trees fertilise themselves, while others mate by using wind, insects, or birds to scatter their gametes and embryos in the form of pollen, seeds, or nuts.

We should teach medical students more about what we share with other species

Trees are often similar to us in being surrounded by their own forebears and descendants, but they sometimes live alone with no progeny. On average, they're far more successful reproductively than we are. The UK has an estimated three billion trees but a paltry 70 million or so people. It wouldn't be inaccurate to think of our country as principally a habitation for trees with us as intruders, but we've altered the landscape so much that we largely fail to appreciate this.

A recent book has further enhanced my

realising that good medicine will always revolve around genuine human connection, humility in uncertainty, and the wise, careful integration of innovation.

Hopes for the future

Looking forward, my thoughts turn not to predictions but to hopes. I hope that doctors will be taught mostly by other doctors—not just by scientists, educationists, or TikTok.

I hope that patients will be cared for mostly by qualified, skilled, and rounded professionals—not by task trained shortcuts, self-taught gurus, or income generating outlets. And I hope our society will remember that giving poor healthcare to people in poverty, delivered by undervalued staff, is one of the most expensive mistakes a wealthy nation can make.

In another 20 years, when I inevitably find myself on the patient side of the interaction, I hope that medicine remains deeply human, prioritising dignity over efficiency, conversation over clicks, and thoughtful pause over hasty intervention. I also hope that, despite relentless technological progress, doctors will still cherish curiosity, empathy, and humility above all.

And flying cars would be nice—just as the Jetsons promised.

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Cite this as: *BMJ* 2025;390:r1454

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regard for trees. *How to Read a Tree,* by the explorer Tristan Gooley, is true to its title. Gooley explains how each tree is a living sculpture revealing its own life story to an attentive observer, rather like the body and face of any person. Every tree's trunk, bark, branches, roots, twigs, buds, leaves, and flowers display how its genes have interacted with everything around it: sun, water, soil, wind, its neighbours, and other flora—as well as animals, including humans.

I've sometimes argued we should teach medical students far more about ecology, evolution, and what we share with other living species beyond our own. For anyone who wants to go on a journey to tackle this deficit in their training, I can't recommend better companions than trees—or a more informative guidebook than Gooley's.

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Cite this as: *BMJ* 2025;390:r1508

DISSECTING HEALTH Scarlett McNally

How to develop clinical leaders

There's clear evidence that many doctors aren't valued in the NHS, and their potential as leaders is inadvertently curtailed. The resident doctors' strike, the postgraduate medical training review, and the Leng review of physician and anaesthesia associates are all about to become a focus for the NHS.

But we should also consider some other recent publications and the lessons they provide on developing doctors into future clinical leaders.

The Royal College of Psychiatrists has a new "retention charter." This describes psychiatrists as "clinical leaders and experts in the biopsychosocial model," who should be included in multiprofessional structures, organisational decision making, and clinical service design. It provides a framework for retaining and nurturing doctors at the "mature level" to lead teams and services. Such practicalities could be adopted by other royal colleges and organisations to encourage leadership.

The basics of science, education, and clinical experience give a solid foundation for every doctor to build on. The surgeon Rhea Liang has created a new Australian curriculum for respect in medical education, describing the "reflective competence" doctors and leaders should aspire to: a concept requiring humility, self-awareness of knowledge gaps, and the skills to fill those gaps. Developing this high level ability and leadership capabilities needs time, respect, and opportunity.

A change in organisational culture can allow people who may not be considered traditional leaders to thrive. I led the Medical Women's Federation's *Manifesto for Women Doctors*. Women make up 50% of doctors with a licence to practise, but they're often overlooked for leadership roles and development opportunities. This means at least half the workforce is undervalued.

A culture change can allow people who may not be considered traditional leaders to thrive

Changes to help women doctors excel require action at the individual and organisational levels. More flexibility is needed to help women, including secondments and support to return to work after a break. All leadership roles should be offered as role shares with sufficient admin support, time, and financial help.

The potential to achieve change and support for leadership is already in the system. This isn't just about delivering better, safer care or retaining doctors. Doctors have strong instincts to understand a delicate balance: recognising patterns of symptoms and defining protocols while also knowing when to deviate from them. The NHS needs doctors to manage risk at the individual and system levels. This involves planning complex care options with patients, leading teams, and designing services.

The public trusts doctors, and we must make the most of that. Our ageing and increasingly multimorbid population will continue to put strain on the NHS and public finances. The current health model means 45% of hospital costs can be attributed to just 3% of high risk patients. Better prevention can avoid some of these costs, since 40% of ill health is preventable.

This medical approach to leadership, while balancing risks, can expand from patient centred clinical consultations to streamlining care services overall.

The health and economy of the UK would benefit if we embraced the transformative potential of medical leadership. With high quality education, respect, and teamwork, today's doctors could excel as future clinical leaders.

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Cite this as: *BMJ* 2025;390:r1511

Leng review: taking the heat out of the PA debate

Gillian Leng discusses her report on physician and anaesthesia associate roles in the NHS, while Trisha Greenhalgh and Martin McKee analyse her recommendations

OPINION Gillian Leng

My recommendations provide a constructive way forward

It was a privilege to be asked to review the safety and effectiveness of anaesthesia associates (AAs) and physician associates (PAs). It probably represents the biggest review of any NHS staff group that has ever been conducted.

It was evident early on that the longstanding, impassioned views on both sides of the debate would make navigating the task challenging. At the heart of the matter was that AA and PA roles are closer to that of doctors than any other professional, generating frustration, particularly among resident doctors. They raised concerns about PAs operating at unsafe levels, unsupported by adequate training, that limited training opportunities for doctors, and also that—at the extreme—doctors were being quietly replaced by cheaper members of staff.

The review has undertaken intensive investigation to consider safety and effectiveness and the surrounding problems. There was a comprehensive review of international literature, plus national data on patient safety, local audits, and unpublished research submitted to the review. The review process engaged directly with over 1000 people including patients, healthcare professionals, and those involved in workforce planning, training, and education. I particularly valued conversations with relatives of those who died, who had concerns about the roles of PAs.

I had no preconceived ideas about the outcome of the review. I was clear that a range of options were possible for the future.

To recommend abolishing the roles—an unprecedented step for a whole profession—I wanted to see several factors: convincing evidence that the roles were unsafe, an overwhelming lack of confidence from the medical profession, a lack of trust from patients and the

OPINION Trisha Greenhalgh and Martin McKee

Goodbye, associates. Hello again, assistants

On 20 November 2024 the health secretary, Wes Streeting, commissioned Gillian Leng to undertake an independent review of physician associates and anaesthesia associates. The rationale, in his words, was that "there are legitimate concerns over transparency for patients, scope of practice and the substituting of doctors. These concerns have been ignored for too long, leading to a toxic debate where physicians feel ignored and PAs feel demoralised."

Leng was asked to consider two main questions. Were these staff roles (as currently deployed in England) safe? Were they clinically effective? Today, less than eight months later, the 134 page Leng review has been published. It draws on academic research from within and beyond the UK, as well as a survey of more than 8000 healthcare staff and consultation with additional individuals and groups, including patients and the public.

The review makes 18 recommendations, 12 of which relate directly or indirectly to patient safety. PAs, the review proposes, should be renamed "physician assistants." They should be required to wear nationally standardised clothing, lanyards, and badges to distinguish them from doctors. They should not be allowed to see undifferentiated patients, nor should they be permitted to work in primary care until they have at least two years' experience in secondary care. A named doctor should be required to oversee their work within a clearly defined team structure.

AAs should be renamed "physician assistants in anaesthesia" and work within the boundaries set in the interim scope of practice published by the Royal College of Anaesthetists (RCA). There should be an ongoing national audit of safety outcomes. All safety incident reporting should include information on the staff group to allow granularity in audit and monitoring.

These stringent safety proposals imply that the Leng review's answer to the question "are these associate roles (as currently deployed) safe?" is a resounding "no." Its recommendations, if fully implemented, will significantly curtail the scope of practice and autonomy of PAs and AAs and hence are unlikely to be universally popular. But they fall short of another option that was considered but rejected by Leng: to abolish these roles altogether.

"We're not sure"

The review's answer to the second question "are the roles effective?" seems to be "we're not sure." While the research literature on this topic is extensive, it is also of variable (mostly poor) quality and lacking in nuance. Most studies, for example, failed to

VUK VALCIC/ZUMA

public, and redundancy of the roles from a workforce perspective. Having reviewed all the evidence, I did not consider that the threshold was met for removing AA and PA roles. Serious problems were raised, however, that need to be tackled.

The need to be convinced

For the roles to continue unchanged, the opposite of these factors needed to be true. I needed convincing evidence of safety and effectiveness, overwhelming confidence in the roles, support from the public, and an essential workforce need. Again, these criteria were not met. Importantly, AAs and PAs were not satisfied with the roles as they stand. They are a committed group of staff who were often frustrated by the lack of options for career progression.

As expected at the outset, the evidence base for safety and effectiveness was limited, of poor quality, and therefore inconclusive. But clarity is needed now, so it is not the time to sit back and await further evidence. Clarity about the roles, how to work in multidisciplinary teams, career progression, and how to ensure the roles are distinct and easily recognisable is needed.

The first, immediate step is renaming the two associate professions to physician assistants (PAs) and physician assistants in anaesthesia (AAs), positioning them as supportive, complementary roles working alongside doctors.

The review provides further recommendations that should be implemented. These include identifying PA and AA roles using a combination of nomenclature, name badges, lanyards, and uniforms, ideally at a national level. Additionally, standard job descriptions, training and development opportunities, and ongoing safety reviews are recommended, among other changes.

Taking forward these recommendations will require effective change management, learning lessons from the initial rollout of AAs and PAs. This includes the need for strong leadership, especially medical leadership, to co-create and describe a model of future teamwork. An agreed vision is essential to provide clarity on how to introduce the roles at a local level. Doctors will work differently alongside AAs and PAs, perhaps delegating some tasks while spending more time on complex, higher risk patients.

Lessons must be learnt to implement these new recommendations. The tensions around the professions won't evaporate overnight. Strong leadership is required to work with partners and professions to design a way of working that is effective and efficient for everyone. This must include listening to the requirements of doctors in training to energise and reinvigorate their enthusiasm for the NHS.

We should recognise that this process has been a challenging one for affected staff, with a tense period of uncertainty about their careers and livelihoods. My concluding message is that after an extensive period of debate and examination of the evidence we now need to reset the conversation and move forward constructively to provide a better, safe, and effective service for patients.

Gillian Leng, chair, Leng review

Cite this as: *BMJ* 2025;390:r1478

Clarity is needed now. It is not the time to await further evidence

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account for case mix or supervision arrangements.

Small wonder the review concluded that "it was not possible to determine whether the outcome of a patient seeing a [PA] in a primary care setting was as effective as if they had seen somebody, or indeed nobody, else" (page 39) and "there was … limited quantitative evidence about [PA] performance in secondary care and none within mental health trusts" (page 45).

Other recommendations are oriented to improving the credentials and career trajectory of PAs and optimising their contribution to multidisciplinary teams. There will be postgraduate training and the opportunity to become an advanced PA on a higher pay grade.

These proposals are welcome, but we question whether the term "advanced" will sow confusion down the line. The review notes the current short and relatively superficial training, and comments that without core knowledge of the pre-clinical subjects (such as pathology), it is not possible to apply mechanistic reasoning to complex health problems. If the problem is a lack of this foundational knowledge, it is unclear whether further applied training will rectify this.

The review will curtail the scope of practice and autonomy of PAs and AAs

The review's attempt to cover cost effectiveness (even though not part of its remit) is commendable in the circumstances, since the effectiveness of a role means little if that role is not cost effective. But given the lack of firm evidence one way or the other on the effectiveness of associate staff roles, it is unsurprising that no conclusions could be drawn on their cost effectiveness. Future research must tackle the weakness of existing studies that fail to account for the practicalities and cost of the necessary supervision.

Workforce planning

Leng makes two recommendations on workforce planning. One is that safe and effective models of anaesthesia delivery, supported by the consultant community, should be developed with the RCA. The call to be professionally led will land well with anaesthetists.

The other workforce recommendation is that the Department of Health and Social Care should "establish a time limited working group to set out multidisciplinary models of working in different settings" (page 96).

This group will have a dual focus on producing guidance for appropriate delegation of tasks to PAs and AAs and "ensuring a supportive environment for resident doctors" (page 96). The rationale for this proposal is that optimising multidisciplinary team working is not a task that can be delegated to one profession (by which is implied doctors). Whether it can be achieved by a national task-and-finish group in the absence of a wholesale systems analysis of the multiplicity of staff roles in the NHS and the growing use of artificial intelligence remains to be seen. It took such a systems analysis to reveal the many problems with recent proposals to expand medical education, some of which, such as medical apprenticeships, have now been abandoned.

The furore around the safety, effectiveness, and cost effectiveness of PAs was a mess, largely of the government's own making, linked to complex questions around workforce planning and the value of task shifting. The Leng review appears to have been conducted thoroughly and even handedly, and we welcome its recommendations on patient safety in particular. They should be implemented with the highest priority.

Trisha Greenhalgh, professor, University of Oxford

Martin McKee, professor, London School of Hygiene and Tropical Medicine.

Cite this as: *BMJ* 2025;390:r1477

LETTERS Selected from rapid responses on bmj.com

Wes Streeting and chancellor Rachel Reeves with staff at St George's in London last October

UK AND OVERSEAS DOCTORS

Be wary of preferential treatment for UK graduates

In April, Wes Streeting said he would end the "crazy" situation of UK doctors losing out on jobs to doctors from overseas (Medical news in brief, 19-26 April).

UK trained doctors work side by side with international medical graduates (IMGs) throughout the health service, and the NHS wouldn't survive without international doctors' crucial influx. Resident doctors don't want to be dragged into a debate about immigration, which is ever present in the political landscape of this country and others. One could argue that the fairer and more rational course of action would be to dramatically increase the overall number of specialty training posts, in line with the increase in undergraduate training posts. This would encourage UK graduates to remain in the NHS, while still giving IMGs the chance to come to the UK and contribute to our health system and wider society.

I worry that the reintroduction of preferential treatment for UK graduates will lead to an increasing feeling of ill will towards IMGs. Many IMGs have already moved to the UK and are working in non-training grades. They face being trapped in these jobs, a poor way of repaying them for their invaluable contribution to the health service.

Streeting is clearly trying to enact change for the health service, but we as doctors should not be blind to the motivation behind these actions, which are unlikely to be purely for the good of the NHS and doctors, but also for the good of the parliamentary Labour party. We must ensure fair and compassionate treatment of IMGs who have already served in the health service and perhaps moved to the UK in search of higher specialty training. Resident doctors should be mindful of this while we lament the ridiculous battle that is the search for a job we want, in a place we want to live.

Adam R Flannigan, junior clinical fellow in oncology, London

Cite this as: *BMJ* 2025;390:r1421

GP UNEMPLOYMENT CRISIS

Do the right things in the right order

The BMA's local medical committee conference in May passed a motion that international medical graduates should not be disadvantaged when applying for training posts (News, 17-24 May). The BMA has warned that up to 100 new GPs face unemployment. And local graduates are struggling to get training posts in most specialties. These three problems can't be reconciled without a clear systemic approach.

A more sustainable solution can only be achieved by doing the right things in the right order. First, estimate the required number of GPs and consultants in all specialties in line with projected service needs. Second, adjust the number of medical students and training posts to match. Finally, determine how many international medical graduates are required at different grades at different times while keeping an eye on long term needs.

A balanced recruitment and retention strategy would be a start towards more effective and fairer NHS staffing for the long term.

Yin Shiong Choong, foundation year 2 doctor, Redditch

Cite this as: *BMJ* 2025;390:r1438

BLOOD TRANSFUSION SAFETY

Correct patient identification is essential

Vickers and colleagues' recommendation to implement electronic blood management systems for transfusion safety is timely (Opinion, online 9 May). Most reports made to the UK haemovigilance scheme each year are "near miss wrong blood in tube" incidents—where the blood in the tube is not that of the patient named on the tube. This regularly results from the same two errors: failure to identify the patient correctly at the time of sampling or failure to label at the patient's side (80.4% in 2023), or both. Between 2016 and 2023 there were 31 ABO incompatible transfusions, but 2390 near misses.

Most of the ABO incompatible red cell transfusions in 2010-22 could have been detected by the final bedside check if completed correctly (55 of 71, 77.5%). There were four deaths and 18 cases of serious complications caused by ABO incompatibility in this period. Seamless electronic systems (when set up and used correctly) should prevent all of these.

Paula H B Bolton-Maggs, retired haematologist, Prescot

Cite this as: *BMJ* 2025;390:r1446

SPECIALTY TRAINING POSTS

Structured integration of IMGs

The discussion around competition for medical specialty training posts is important (Editorial, 31 May – 7 June). The integration of international medical graduates (IMGs) into specialty training should be carefully managed to ensure that UK trained doctors have clear career progression. A tiered application should be considered—the first round could prioritise UK medical graduates, followed by a second round open to IMGs who already have experience in the NHS. Only then should wider international recruitment occur.

Introducing a period of structured foundation training or equivalent for IMGs seeking to enter specialty training could ensure a consistent baseline of experience and understanding of NHS practices before they compete for specialty posts. Standardising the entry point into competitive training would benefit patient safety and clinical consistency across the board.

A UK-wide medical workforce committee is critical. Such a body, equipped with accurate data including migration status, must implement transparent guidelines for training post appointments.

Joshua H Wang, core trainee year 1 psychiatry resident doctor, Leicester

Cite this as: *BMJ* 2025;390:r1433

MALCOLM WILLETT

GABAPENTINOIDS AND SELF-HARM

Gabapentinoid pharmacovigilance in Africa

Yuen and colleagues present UK data on the temporal association between gabapentinoid use and self-harm (Research, 3-10 May). Extrapolating these findings to Africa requires a pragmatic approach owing to diverging prescribing practices, regulatory disparities, and healthcare system limitations.

Across many African nations, gabapentinoids are frequently prescribed off-label for chronic pain, anxiety disorders, and epilepsy, often in the absence of stringent pharmacovigilance or routine mental health assessments. African pharmacovigilance systems lack the resources to systematically monitor gabapentinoid related self-harm. Underdiagnosis of mental health conditions, alongside cultural stigma and limited mental health literacy, further obscures the accurate attribution of self-harm incidents. In resource constrained settings, gabapentinoids might be used inappropriately as substitutes for inaccessible psychiatric care, potentially exacerbating adverse outcomes.

African policy makers must prioritise pharmacovigilance strengthening, prescriber training, and stricter gabapentinoid dispensing controls. Region specific research should evaluate behavioural risks associated with gabapentinoid use, incorporating cultural, systemic, and socioeconomic determinants.

FP Omullo, medical doctor, Murang'a, Kenya

Cite this as: *BMJ* 2025;390:r1355

REDUCING AVOIDABLE DEATHS

We must invest in injury prevention

Public health has considerable potential to reduce the number of early deaths, and data from the Office for National Statistics show the scale of the opportunities for prevention (News, online 29 April).

The Royal Society for the Prevention of Accidents' seminal report *Safer Lives, Stronger Nation* uncovered the full scale of unintentional injuries. Deaths caused by unintended injury have risen sharply over the past decade. In 2022-23, 840 000 people were admitted to hospital and a further seven million people attended emergency departments for unintentional injuries. This costs the NHS at least £6bn annually, with extra costs to individuals, families, fire services, and other organisations.

There is considerable evidence from a range of sources that indicates that many incidents can be prevented. We need a national accident prevention strategy that would reduce the enormous human and economic costs of rising rates of unintentional injuries and substantially reduce demand on the NHS.

Michael Craig Watson, trustee; Karen E Neil, member, Institute of Health Promotion and Education

Cite this as: *BMJ* 2025;390:r1371

IMPACT OF RETRACTED TRIALS

Problematic studies have huge impact

We agree that examining the effect of retracted trials on systematic reviews substantially underestimates how problematic studies can affect healthcare evidence (Research, 3-10 May). Retracting untrustworthy academic publications can take years, and most often never occurs.

We investigated 172 clinical trials from one group and notified serious integrity concerns to all journals and publishers in July 2019. More than five years later, only 22 of the 157 trials covered by Web of Science have been retracted. The 135 unretracted trials have 1989 citations in systematic reviews, clinical guidelines, and consensus statements.

Groups with multiple retractions often have narrow research fields. Including their publications in systematic reviews and guidelines on these topics can have a disproportionately large impact. In one extreme case, after systematically assessing trustworthiness of eligible studies underpinning 12 meta-analyses, all of them were excluded leaving no evidence base to assess.

The current system for publication of scientific literature is fatally flawed.

Hugo Studd, undergraduate student; Alison Avenell, professor, Aberdeen; Mark J Bolland, associate professor; Andrew Grey, associate professor, Auckland

Cite this as: *BMJ* 2025;390:r1412

UK COVID RESPONSE

No one is immune to getting things wrong

Costello's article on the UK's covid-19 response contains little criticism of the elected politicians who were ultimately responsible for decisions, instead focusing on the scientists who are alleged to have made obvious technical errors that, if corrected, would have led to completely different policies (Analysis, 17-24 May).

Many others have made similar initial sweeping criticisms of SAGE and the civil service before recommending a variety of divergent policies, but we should consider three things. Firstly, human error rates are reasonably constant, and no group or individual proved themselves immune to getting things wrong. Secondly, pandemic response is inherently based on values and politics rather than technical scientific assessment alone, which probably explains much of the continued disagreement. And finally, rather than focus solely on the appointment of experts and advisory bodies, we should instead seek to maximise democratic public input—including from most of the population without doctoral degrees—into pandemic policy and response.

Thomas A House, professor of mathematical sciences, Manchester

Cite this as: *BMJ* 2025;390:r1415

DIAGNOSIS EXPLOSION

Expansion of medical diagnoses into personal realms

Both Suzanne O'Sullivan's book and Smith's review of it (Opinion, online 16 April) contain evidence for the uselessness of many recently invented diagnoses and their considerable human and economic cost. How has this has happened?

Before the 1960s, diagnoses dealt almost entirely with bodily diseases or functional impairments that were evident to others. But screening technology now attempts to predict or prevent possible future illnesses. Increasingly, we deal with the possible, not the actual. Medical practice works best when a patient's experience is matched to the objective observations of others. Diagnoses based on personal experiences alone lack this anchorage and become contentious, capricious, and difficult to define.

Moreover, the drug industry has potently exploited the almost limitless opportunities to give diagnoses to the many people chronically troubled by their subjective experiences. Likewise, to ensure their professional credibility, survival, and expansion, specialists must all make more diagnoses and treat more patients.

David Zigmond, retired psychiatrist and GP, London

Cite this as: *BMJ* 2025;389:r1298

THE BMJ COMMISSION ON THE FUTURE OF THE NHS

NHS must tackle racism and sexism for the benefit of patients, staff, and society

The evidence and policy options for eliminating inequity are clear; what is needed now is political and institutional commitment and action, say **J S Bamrah and colleagues**

Despite the NHS being founded on the principle of equitable treatment for all,[1] discrimination remains rife.[2] Inequities related to protected characteristics such as race, sex, gender reassignment, age, disability, sexual orientation, marriage and civil partnership, pregnancy and maternity, and religion and belief contribute directly to increased risk of physical and mental health conditions, limit access to care, shape negative experiences of illness and encounters with services, and lead to worse overall health outcomes, including mortality.[3]

"Proportionate universalism"—adjusting the intensity of universal services to combat discrimination—has not gained widespread acceptance.[4]

Extensive evidence of bias and mistreatment of patients and staff is unequivocal, and recurring discrimination worsens lifelong health.[5-8] Health inequalities lead annually to productivity losses of £31bn-£33bn, lost taxes and increased welfare payments of £20bn-£32bn, and direct healthcare costs of at least £5.5bn.[9] As one senior NHS leader puts it, an investment in equality and inclusion is a "strategic investment that pays dividends in the form of better patient care, a more inclusive work environment that supports retention of valued staff, and the eradication of health disparities."[10]

Adversity and harm are magnified when protected characteristics intersect.[11,12] A black woman living in poverty who is also disabled on average experiences worse health than a white woman with those characteristics, with the effect on health worse than the additive impact of each characteristic considered in turn. Because of the scale of injustice in the NHS caused by race, ethnicity, sex, and gender bias, this work focuses on inequity related to these forms of discrimination and their interaction.

SUMMARY RECOMMENDATIONS

For the UK government

- Implement the independent Messenger report on inclusive leadership in full
- Give the NHS Race and Health Observatory (RHO) statutory responsibility for producing equity based impact assessments of new NHS policies and programmes and make it the main repository for all matters related to race and ethnicity in the NHS, including the Workforce Race Equality Standards
- Mandate national research and health bodies to establish equality standards in all research grants, studies, and approvals of drugs, medical devices, and technologies

For the NHS

- Collect and report transparent, accurate, disaggregated data on race, ethnicity, sex, and gender in all organisations
- Prioritise equitable research, with financial support from government research funders such as the National Institute for Health and Care Research (NIHR) and UK Research and Innovation (UKRI)
- Implement the starkest findings of research on inequitable clinical care and ringfence funding to support improvements
- Set national standards for diversity and inclusion to produce culture change
- Make evidence based training focused on reducing bias and discrimination (including intersectionality training) readily available
- Improve working conditions by facilitating flexible and remote working and reducing reduce bullying, harassment, and discrimination

Racism, sexism, and gender bias have been alarmingly normalised[62,63] and are pervasive and pernicious within the structures as well as in interpersonal interactions throughout the NHS. Most patients and staff are at risk of one or both. Institutional racism—racially discriminatory processes, policies, attitudes, and behaviours arising from systems and norms embedded within an organisation—is clear in the NHS's history and current practice, as is ongoing sexism.

Racism, sexism, and gender bias have been alarmingly normalised

Learning lessons from the past and acknowledging those historical injustices requires a high level inquiry by the government, to ensure that people who were wronged in the past can start the process of reconciliation and healing, and to ensure that wrongdoing is not perpetuated.

Equality in healthcare means offering everyone in society the same choices, opportunities, and treatment. Equity, however, acknowledges that people have different needs, necessitating responses to those circumstances with varying resources. Policies committed to equitable outcomes must adjust for the people who experience discrimination, especially those who experience multiple inequities simultaneously.

The social determinants of health drive inequity beyond the workings of the NHS, and tackling these inequities is the greatest opportunity to further an equitable health agenda.[4] Social and economic inequalities have worsened health inequities in the past 15 years,[65] but these factors do not sufficiently account for inequity related to race and sex.[66,67]

The NHS cannot maintain legitimacy as a publicly funded healthcare system rooted in principles of fairness while perpetuating discrimination. Multilevel interventions are required to tackle racism and sexism, including committed leadership scaffolded by governance mechanisms, targeted clinical research, employment improvements, and staff education. Such changes are eminently achievable: the evidence and policy options already exist but will only be realised with political and institutional commitment. Although health is a devolved matter across the four nations, efforts should incentivise collaborative, UK-wide action. Implementation of the following recommendations would transform organisational performance, care quality, and staff wellbeing and save costs in all NHS organisations.

Representative leadership that prioritises equity

The composition of NHS leadership and governance groups should be representative of the diversity of the population, with people facing race, sex, and other disadvantages actively supported to reach senior positions, an aspiration in the NHS equality, diversity, and inclusion improvement plan.[68]

Representation of black, Asian, and other ethnic minority people among the most senior NHS leadership increased by a small margin, from 10.3% to 11.2% between 2022 and 2023.[30] In 2021, the then secretary of state for health and social care, Sajid Javid, commissioned an independent report from Gordon Messenger which resulted in seven recommendations (box, p 92).[69]

There has been a persistent failure to implement these recommendations with any consistency or commitment. For a start, government and NHS leaders must publicly acknowledge the pervasiveness of racism and sexism in the health service. They must then be held accountable for evidence informed action to deliver health equity.

Four NHS national directors of health inequity, appointed to each of the UK nations and reporting to its chief medical officer, would be well placed to oversee progress. In an NHS increasingly run as a business, sustained, determined senior leadership championing anti-racism and anti-sexism is vital not only to maximise quality of care but also financial performance.[70 71]

Role modelling needs to be cascaded from the highest level across all NHS services, with a strategy that recognises the moral and economic value of equity in the NHS.

At a local level of service planning and service delivery, all leaders should be responsible for equity impact assessments, and progress towards equity should be a standing item on every board meeting agenda.

Statutory regulation and accountability

Independent regulation of NHS services in the four nations should be increased to monitor, and hold accountable, organisations for healthcare equity. In England, this would fall to the CQC, which assesses services against five criteria—safe, caring, effective, responsive to need, and well led—related to patient experience and organisational leadership.

The CQC (and equivalent organisations in the devolved nations such as Healthcare Improvement Scotland) should add a sixth criterion of "staff wellbeing," which should explicitly include questions on racism and sexism experienced by employees and patients, with regulator accountability to ensure concerns are responded to quickly and effectively.

Equitable data and governance

Collecting accurate data is critical for progressing research and practice to correct health inequities, and yet it is political whim rather than clinical will that determines what data are included, and what are left out.[73] NHS trusts must collect and report transparent, accurate, disaggregated data on ethnicity, sex, and gender, obtained with consent from patients, clinical records, and NHS employees where appropriate. Demographic questions should be asked according to uniform, validated, and sensitive methods (such as the diversity and inclusion survey (DAISY) guidelines[74]), consistent with categories in the UK census. Standardised questions for NHS records would ensure data compatibility among NHS trusts. It should be possible to link data to other health registers, but data must be anonymised, and legal firewalls should prevent repurposing or sharing data with government departments, such as the Home Office for immigration control.

National equity metrics would improve the NHS if all organisations were required to collect and contribute to a centralised database for identifying improvements and guiding equitable research across the life course. These metrics could then feed into health information systems, such as the Race and Health Observatory (RHO).

The RHO's role should be strengthened to provide the basis on which NHS leaders are held accountable for their performance on equity. It should have statutory responsibility for producing equity impact assessments of new NHS policies and programmes. Government and NHS leaders at all levels should act decisively on RHO recommendations.

NHS England and the NHS Equality and Diversity Council developed the Workforce

Actions to improve diversity and inclusion from Messenger report[69]

Targeted interventions on collaborative leadership and organisational values

- A new, national, entry level induction for all who join health and social care
- A new, national, mid-career programme for managers across health and social care

Positive equality, diversity, and inclusion (EDI) action

- Embed inclusive leadership practice as the responsibility of all leaders
- Commit to promoting equal opportunity and fairness standards
- More stringently enforce existing measures to improve equal opportunities and fairness
- Enhance CQC role in ensuring improvement in EDI outcomes

Consistent management standards delivered through accredited training

- Single set of unified, core leadership and management standards for managers
- Training and development bundles to meet these standards

A simplified, standard appraisal system for the NHS

- A more effective, consistent, and behaviour based appraisal system, of value to both the individual and the system

New career and talent management function for managers

- Creation of a new career and talent management function at regional level that oversees and provides structure to NHS management careers

More effective recruitment and development of non-executive directors and encouraging top talent into challenged parts of the system

- Establishment of an expanded, specialist non-executive talent and appointments team

Government must commit fully to these laudable objectives; any dilution will only demoralise staff further

- Improve the package of support and incentives in place to enable the best leaders and managers to take on some of the most difficult roles

Race Equality Standard (WRES)[30] in 2014 to improve equality in career opportunities and fair treatment for black, Asian, and other minority ethnic staff. NHS leaders at all levels should implement change in light of the data WRES publishes and hold employers accountable for doing so.

Responsibility for WRES lies within NHS England, and the abolition of NHS England presents an opportunity to consolidate its role. Bringing WRES within the structures of the RHO would provide WRES with greater independence.

The RHO's influence should be present throughout the UK beyond just England. Funding and support from within RHO should be directed to specialist academic centres researching race and ethnicity, as well as intersectionality with sex and gender, which can feed their data and expertise into the RHO's reports, creating a new "Network for NHS Equity."

Mandating equitable research

The NHS must prioritise equitable research, financially supported by government research funders (National Institute for Health and Care Research (NIHR) and UK Research and Innovation (UKRI)) collaborating with charitable funders. This would require bold action, such as giving primacy to projects which ensure ethnicity and gender are given due consideration wherever relevant and withholding funding where this is not the case.

Evidence shows that diversity of research teams influences the quality and equity of the science that they produce

NIHR should lead a national research agenda co-designed with patients to share a 10 year plan for equitable research funding and implementation across the UK to inform policy questions and public priorities beyond the political lifecycles of individual health ministers and partisan governments. All research grants and studies should be required to show that diversity and inclusivity issues have been considered, and NICE must assess new drugs, medical devices, and technology against equality impact standards, particularly in relation to ethnicity and sex. The thematic approach devised by the World Health Organization might be a useful method of achieving this.[76]

Accounting for demographic differences in research after equitable recruitment would improve if analyses disaggregated by sex and ethnicity became normalised in medical research and were essential criteria for funding and ethical approval.

Evidence shows that diversity of research teams influences the quality and equity of the science that they produce.[83] Clinical academics from black, Asian, and other minority ethnic backgrounds as well as women researchers are under-represented at principal investigator level within the NHS. People in these groups should be proactively mentored, enabling them to develop personally and professionally. Institutes such as HRA, UKRI, NICE should be statutorily obliged to promote diversity and gender equality and have their funding withheld if they fail in their duty to do so.

Eradicating inequitable harms in clinical care

Services and treatment may need to be tailored for people from different ethnic groups and for women. Harmful and inequitable care has been evident in some areas and medical specialties across the UK. Clinical failings in maternity care and worsening maternal mortality inequalities, with black women almost three times more likely to die in childbirth than white women,[87] are of particular concern.[88]

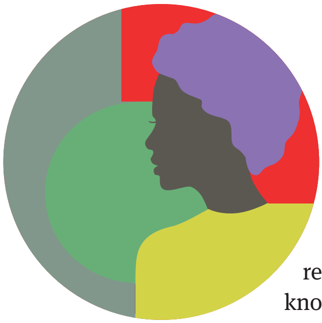
The NHS should prioritise the reduction of preventable maternal and neonatal deaths, and differential adverse outcomes for black, Asian, and other ethnic minority women, as specified in the MBBRACE report.[87] The positive practices of maternity centres performing well need to be shared and scaled, as well as action taken to reduce barriers when accessing maternity services and correct negative experiences (including stereotyping, disrespect, and cultural insensitivity).

There are stark ethnic inequities in common mental disorders with higher prevalence for women than for men in all ethnic groups in England.[89]

Overcoming barriers to make mental health services more accessible by reducing often justifiable patient fears of racist treatment, discrimination, and stigma; distrust of healthcare professionals; and inadequate provision of interpreting services requires an evidence based, coordinated approach, as proposed in the NHS advancing mental health equalities strategy.[91]

Addressing knowledge gaps among clinical staff about the ways in which patient presentations are related to (or unchanged by) race, ethnicity, sex, and gender would improve quality of care, clinical outcomes, and reduce the spread of racist and gender biased stereotypes within health services.[63 92-94] Clinical guidelines should be reviewed through sex, gender, race, and ethnicity lenses.

Recent efforts to improve the quality of healthcare for women in the UK have been encouraging, through the Women's health plan in Scotland (2021)[98] and women's health strategy in England (2022).[48]



All NHS organisations are responsible for fostering an inclusive culture and safe workplace

However, ongoing funding and institutional support from the UK government is overdue.The next iteration of UK based women's health policies must recognise that women's health includes conditions affecting women's lifelong health, not simply their reproductive functions, and should attend to the ways in which conditions and their treatments might differentially affect women and men.

Fostering a culture of learning not blaming

A study published by the King's Fund emphasises that the human costs of discrimination are huge and the effect on patient care is substantial.[100] The authors conclude that the NHS must set national standards around developing cultures of diversity and inclusion in order to bring about change; where staff are overworked, stressed, marginalised by their leaders, and blamed, engagement levels are likely to be low and discrimination and stereotyping high.

Legal reform is needed to protect whistleblowers, to prevent employers using disciplinary measures unfairly to punish people who raise genuine concerns,[103] particularly for employees who continue working with employers where the abuse took place in the first place. A culture that defaults to trusting testimony from people affected by prejudice will increase if greater diversity is visible at the top of the NHS.

Training and education co-designed with staff and patients

Undergraduate and graduate training for NHS professionals should be co-designed with patients and staff to combat negative attitudes and assumptions and to fully reflect the varying health needs of people of different sex, gender, race, and ethnicity, including the needs of migrants.[105] For instance, healthcare professionals need to be confident in diagnosing dermatological conditions and signs in people with different skin tones, as well as the sensitivities around performing physical examinations on women from different ethnic groups.

Continuing education of the NHS workforce at all staff levels, including executive and board members, should be required to embed the knowledge and skills for equitable hiring approaches, working practices, and values. E-learning modules from NHS England's Core20PLUS5[107] training, which aims to narrow health inequalities in hypertension, early cancer diagnosis, chronic respiratory disease, maternity, and severe mental illness, are a good start but are not well publicised. Cultural safety and cultural competency training would encourage professionals to develop awareness about how ethnicity and power shape clinical interactions and to reflect on personal and systemic bias.[108]

Supportive management and flexible working

All NHS organisations are responsible for fostering an inclusive culture and safe workplace. Managers should be responsible for monitoring the diversity of their staff and transparently tracking inequity across roles and career trajectories.

NHS staff from abroad, including healthcare assistants, nurses, midwives, allied professionals, and medics, must be supported and welcomed when starting employment in the NHS through fair assessment processes, induction and mentorship programmes, and opportunities for professional development.[112] Ethical recruitment practices should acknowledge challenges faced by staff coming to work for the NHS from abroad,[113] including employees who bring dependants with potential healthcare needs themselves.

At the same time, the government and the NHS must acknowledge and celebrate the contributions that migrant doctors and nurses (most of whom are black or Asian) make to the NHS, without creating a climate of fear or dislike for them.[41 43]

The NHS faces one of its worst workforce crises in its 77 year history. Without concerted action, the NHS will lose the skills, experience, and knowledge of staff who could have been retained on a part time or ad hoc basis with adjustments to working.[114] Flexible working in the NHS should be supported for anyone, without requiring a reason.[115] Mentorship schemes, standardised across the UK, are needed for returning to work after a period of absence, particularly for parental leave, which is still mainly taken by women. Progression and promotion must be compatible with responsibilities outside the workplace, shouldered most often by women, as well as accommodating employees' life stages and health needs.

Commitment and action must start now

Establishing a core NHS ethic of anti-racism and anti-sexism is long overdue. A deeper understanding of intersectionality is crucial because inequity affects multiple characteristics in many people, and services should be codesigned with those who struggle the most to access care, have the poorest outcomes, and are representative of the target population.

NHS leaders and the public must recognise that prioritising health equity is a proved strategic investment that leads to good patient outcomes, and better retention and recruitment rates of staff. It is also an ethical and legal imperative. NHS leaders must recognise the avoidable and unacceptable effect on mental and physical health caused by discrimination in the health service. They must focus on measuring this impact and taking steps to mitigate it by implementing enduring changes and ensuring accountability in the system. For the migrant healthcare worker, the challenges are considerable; better efforts must be made to ensure longevity of employment and satisfaction in work.

Inaction represents an unacceptable choice that increases harms to patients and costs in terms of increased staff absences, sickness, resignations, and reduced productivity. The evidence and policy options are abundantly clear. The recommendations we make, if implemented, will go a long way to make the NHS a happier and healthier place.

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Cite this as: ***BMJ*** **2025;390:r1334**

OPINION Jane O'Hara and colleagues

Streeting's maternity plan can lead to change, if we recognise the past

At the June 2025 Royal College of Obstetrics and Gynaecology (RCOG) World Congress the health secretary, Wes Streeting, called out, with the frankness that has been his characteristic since taking up his post last year, the unacceptable state of current NHS maternity care. He also outlined key elements of a plan to improve.

Although mentioned again in the 10 year plan for health, the detail, for now, is limited. But two key elements are prominent. First, a rapid investigation into 10 maternity units in England will take a system-wide look at maternity and neonatal care, reporting by the end of the year. As well as delivering "truth and accountability" for families affected by poor care, the investigation seeks to bring together lessons from past inquiries and create a single set of actions for national improvement.

Second, a National Maternity and Neonatal Taskforce of experts, families, and staff will be established to drive improvement.

Well received

The announcement has been broadly well received by groups representing those using and delivering maternity services, and the commitment to working with families is welcome. But will it succeed?

One question is the extent to which this investigation is the right approach to support the needed improvement. While each failure to deliver good care is distinct, and each involves human suffering and grief, many features are strikingly repetitive and well known. They arise from complex tangles of behaviours and systems, poor clinical practice, weak teamwork, lack of good management, and professional conduct involving disrespect both to families and to colleagues.

Problems evade detection and effective action over long periods, and sometimes secrecy and protectionism are entrenched.

Given that similar challenges have been observed by public inquiries and reviews across many sectors of the NHS over several decades, any further investigation is unlikely to add much to the sum of knowledge about the problems of maternity services. It will also delay action, and it may add further to the evident demoralisation of maternity staff.

It may, however, serve two purposes. One of these, if appropriately supported by the taskforce, is to arrive at a single set of actions for maternity services. These are currently challenged by "priority thickets" of goals and recommendations. Last year's Maternity and Newborn Safety Investigation programme annual report alone contained 78 pages of recommendations, adding to the hundreds of recommendations from other bodies and from maternity care inquiries from the first to the most recent. The volume of recommendations, which may themselves compete, conflict, or fail to cohere, is itself a threat to improvement. Consolidating and prioritising recommendations would be a major step forward in providing clarity and direction to services. But the scale of the task should not be underestimated. Arriving at consensus on which actions should be priorities requires a systematic, scientific, multi-stakeholder approach.

To succeed, centring the experiences of families must not be tokenistic

Implementing the actions may be even more challenging. The taskforce should recognise that retrospective analysis of past failures will not on its own provide a map for improvement. Investigations can be prone to the "tombstone effect," where they operate mainly to memorialise rather than to provoke real change. The route out of failure therefore needs to be evidence based, co-produced, and based on an understanding of how maternity care is delivered. It requires an understanding of the work of implementation, proper appreciation of workforce issues, and a genuine commitment to learning and evaluation, given the many previous attempts to improve maternity services.

A second important purpose the investigation may serve is for families, who deserve explanations for their suffering and the dignifying of their experiences. For the investigation to succeed in this purpose, centring the experiences of families must not be tokenistic. Anything that falls short of sincere co-production might even compound the harm.

Harmed families also need accountability for failures. However, investigations are arguably better at "backward looking" accountability (identifying responsibilities for past failures) than "forward looking" accountability (articulating responsibilities for putting things right). Put simply, Streeting's plans will need to be rigorous in identifying problems, but also authoritative in directing future action, if they are to feel more than just performative.

STEVE PARSONS - POOL/GETTY IMAGES

Restorative approach

One way of tackling this web of purposes and stakeholder needs is through restorative approaches of the type used by the health ministry in New Zealand in response to harms associated with the use of surgical mesh. Such approaches ask institutions to explicitly: acknowledge the harm and involve the affected community; respond to the human impacts and needs involved; clarify obligations; and take responsibility for harm and repair. Bringing staff on this journey will be key, given their centrality to better care.

Maternity services have reached a collective nadir. We cannot afford another failed improvement effort. Streeting's plan can support the transformation needed only if it acknowledges the past and takes a responsible, evidence based, and collaborative approach to the future.

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Cite this as: *BMJ* 2025;390:r1459

EDITORIAL

Lived experience: from intention to global action

Time to see lived experience as expertise, and make inclusive engagement business as usual

It is indisputable that people should have a say in the healthcare decisions that affect them. "Lived experience"—knowledge gained by being a patient, caregiver, or relative — is increasingly recognised by clinicians, policy makers, researchers, and the public as essential expertise to ensure that healthcare is relevant, responsive, effective, resilient, equitable, and fully inclusive.[1 2] The BMJ Collection on Lived Experience as Expertise highlights some of the ways that lived experience has helped improve care.

There is much to celebrate, particularly a growing expectation that clinical research should be conducted with patients and not on them. Funders, including the US Patient-Centered Outcomes Research Institute, the UK National Institute for Health and Care Research, Medical Research Future Fund in Australia, and the Canadian Institutes for Health Research, are encouraging or requiring "patient engagement" or "consumer involvement." *The BMJ* requires authors to document in research submissions if and how they involved patients and the public.[3]

In policy development, progress has been more piecemeal. In the US, incorporating lived experience in drug regulation is a legal obligation under the 2012 Food and Drug Administration Safety and Innovation Act, a legacy of HIV/AIDS activism.[4] The UK's Medicines and Healthcare Products Regulatory Agency's strategy involves patients "in every step of the regulatory journey."[5] Brazil's new Law 15.120/2025 mandates the inclusion of people with lived experience in decision making about drugs for the public health system.[6]

High income countries are over-represented among published examples of inclusion of lived experience as expertise. Exemplars from lower income countries need more attention,[7] such as the Movement for Global Mental Health, a network of organisations working with communities to close treatment gaps.[8]

Participatory approaches require power to be rebalanced

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Making patient involvement routine

Radical change is needed for disparate and ad hoc initiatives to become "business as usual" at every level of healthcare, policy, and research decision making, and for patients, caregivers, and relatives to be valued equally to other experts. To this end, the World Health Organization (WHO) created a practical guide to including lived experience in healthcare: the 2023 framework for meaningful engagement of people living with non-communicable diseases (NCDs), mental health and neurological conditions.[9] This is one of four WHO reports co-created with people with lived experience setting the expectation that nothing about people with a health condition should be decided without their involvement.[10-13] Last year's World Health Assembly (WHA) passed a resolution that commits governments to empower and fund people, communities, and civil society to participate in decision making processes at all levels of the health system,[14] and governments must show progress every two years.[15]

To make participatory approaches business as usual brings challenges.[16] The key is dismantling the cultural barriers that deny lived experience the same respect as technical knowledge.[17 18] Participatory approaches require power to be rebalanced. It is essential to re-imagine—or at least be open to—a new definition of what it means to be an expert and what it means to hold authority.

Journals should do more to set expectations and standards to advance the movement, developing formal strategies for working with patients and the public. *The BMJ* launched its patient and public partnership strategy in 2014.[20]

Co-creation has become a buzzword. But paying lip service to the value of lived experience while existing knowledge structures remain is not enough. Involving people with lived experience is just the first step on this culture change. It can be tempting to bring in one or two lived experience experts and think the work is done.[21] But this risks reinforcing existing power structures through tokenism and tailoring healthcare to a few individuals. A truly participatory approach to decision making needs the inclusion of everyone, especially hardly reached populations who have historically been excluded, as the WHA resolution recognises. This is critical to identify biases and gaps in healthcare at the population level that undermine progress towards improving outcomes.

The growing number of examples of patient inclusion, the WHO framework for meaningful engagement, and the resolution on social participation show that national and global stakeholders are serious about making co-creation of healthcare not just a talking point but a reality. The new BMJ Collection showcases the value, competency, and capability of people with lived experiences in improving healthcare and health. Health leaders, at all levels, have the elements to make participatory healthcare business as usual.

Cite this as: *BMJ* 2025;390:r1228

Find the full version with references at http://dx.doi.org/10.1136/bmj.r1228