comment

"The divide between patient and health professional disappeared" **SARAH WOOLF**
"Patients need more than to be passive recipients of a series of activities" **HELEN SALISBURY**
PLUS Access to medical records; patient online feedback

TALKING POINT John Launer

Pressing pause—how my operation was cancelled

Recently, I found myself booked in for an operation that was cancelled at the last minute, quite literally. I was admitted to the day ward, signed my consent form, waited several hours for my turn, and was wheeled into the operating theatre. Only then was the whole thing called off.

You may think the consultant was called away to an emergency because the juniors were on strike, or there was a last minute technical glitch such as an oxygen supply fault. Neither was the case. When you're a doctor as well as a patient, matters are rarely so straightforward. What happened was the consultant changed his mind.

I won't bore you with unnecessary details. Essentially, I'd been booked for a revision of a cardiovascular procedure done at another hospital. I'd discussed this with the original specialist and my new one, and everyone agreed I needed this. The new consultant warned me in his clinic, and again that morning, that the revision might be tricky or prolonged. It was only when I was on the table but not yet sedated—it was due under local, not general anaesthetic—that he scrutinised the imaging from my previous operation one more time and decided the chances of the revision being a success were too low. More specifically, he realised a different form of revision, done by another specialist at another time, might be more likely to have the desired outcome. He asked me to get off the table, showed me the images, explained his reasoning, and sent me back to the day ward.

Since this happened I've told this tale to many friends. Nearly all the non-medical ones have been aghast. They've focused on the waste of NHS resources, the original hospital failing to send the images on time, or my new consultant not scrutinising them sufficiently at an earlier stage. Some friends were also concerned about the likely emotional impact of these events on me as a patient and on my family.

Most of my medical friends have had a quite different response. They've been aware of the ridiculous time pressure most doctors work under. They've been impressed by the capacity of my surgeon to stop, think, and stand down a team of eight people including nurses and radiologists, rather than continuing on automatic.

I have to say I largely agree with the ones who admire the consultant's decision. On my professional days, as opposed to my days as a patient, I spend a lot of time trying to teach what it means to be a reflective practitioner. Without wanting to offer undue flattery, I can't easily think of a better example than this man's willingness to press the pause button when I was already on the operating table.

John Launer, GP educator and writer, London johnlauner@aol.com
Twitter @johnlauner

Cite this as: *BMJ* 2024;386:q1336

I largely agree with those who admire the consultant's decision

OPINION Angela Coulter and colleagues

Patients need access to their medical records—now

Real time access to their notes can help people manage their health

Patients, particularly those with long term conditions, have a pivotal role in managing their own health, but too often they are left without the tools to do the job, the most basic of which is being able to view their medical record.

Ever since electronic medical records became widely available, patients have called for the right to have continuous online access. But professional resistance and policy inertia have proved difficult to overcome. Doctors have argued that patient record access would increase their workload, cause harm to some patients, and increase the risk of litigation.

Policy makers have proceeded cautiously in the face of these objections. The right to request a retrospective download of the record is embedded in law in many countries, but these are often provided at a high out-of-pocket cost. Following recent changes to the general practice contract, patients in England can view at least part of their GP record online or using an app, but most hospital records are still unavailable. Experience in Denmark, Estonia, and Sweden, where full record access has been available for many years, and in the US, where it has been underpinned by legislation and actively promoted, shows the benefits outweigh the risks to a considerable degree.

Patient experiences

We wanted to know more about patients' experiences, so we contacted fellow members of *The BMJ*'s patient advisory panel to find out whether they had this facility and, if so, what use they made of it. The panel is international and most of the 60 people we approached had some access to their primary care records but often only a small sub-section, such as laboratory reports, vaccinations, or medication.

Access to secondary care records was much less common, and several people said access to any type of record was unavailable to them. Even those who were able to view online records from primary and secondary care found it a cumbersome process as only a lucky few could access their complete record via a single portal.

This is an ethical imperative and key to any strategy to support self-care

Several people were concerned about inaccuracies in their records, and we know these are common. One woman was surprised to see she was recorded as having prostate disease. Most people wanted to correct errors because inaccuracies can lead to unsafe care, but they did not have interactive access and finding staff willing to make corrections was hard.

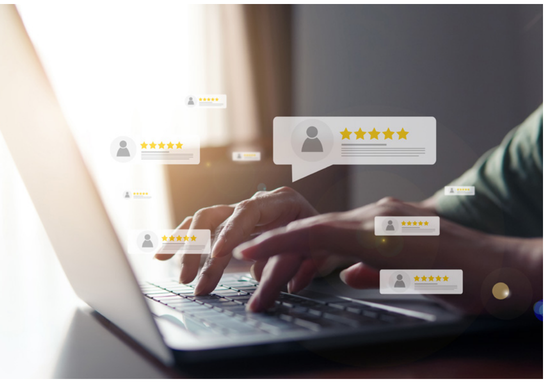
Good access to medical records is highly valued by those who have it. They find the information useful to monitor their condition, view test results, prepare for appointments, check and order medications, and complete insurance forms. Those caring for family find it invaluable for helping them manage their medications. Many of our panel said they liked to be able to show the record to clinicians who lack access to notes recorded by others.

OPINION James Munro

Patient feedback offers important insights into safety

How useful is online patient feedback? Are patients really telling us anything we need to know about the quality and safety of healthcare, beyond the kindness of staff and problems with food and parking?

If you listened to some staff, you'd be forgiven for thinking that online feedback was a waste of time—or worse. "Things are picked up online but it's not usually severe …usually people wanting to have a rant," said one head of patient experience to researchers, while a study exploring attitudes in primary care quotes a practice nurse clearly at the end of her tether: "People know the NHS is on its knees and how it is, so don't sit there slagging and slating, yeah? No, no I can't bear it."



A 2019 survey of medical and nursing staff presents a slightly less negative picture, with around 39% of doctors and 74% of nurses feeling that online patient feedback might be useful in helping the NHS improve services. Even so, it's not exactly a ringing endorsement.

But another study offers a different perspective, suggesting patients are reporting important things that staff don't know about or are failing to tackle. The study analysed more than 146 000 stories retrieved from Care Opinion, a non-profit platform where I have worked since 2006. Stories are submitted by patients and families, with the intent to help improve care. After moderation, the stories are published and are available for anyone to use for research, teaching, or service improvement.

Unsolicited, unbiased patient reports should be given greater weight

Researchers used a machine learning model to detect stories reporting safety incidents. Qualitative analysis showed many incidents were either unobserved or unresolved by staff, with patients posting online as a last resort.

The researchers found such incidents were "significantly predictive of hospital-level mortality." Alongside this was the finding that staff reports of safety incidents were not predictive of hospital level mortality. The authors suggested this might be because organisational culture determines which safety incidents do or don't get reported by staff. Noting the number of safety concerns patients and relatives felt had been dismissed or ignored by staff, they went on to argue: "Online patient feedback may reveal hospitals that are poor at detecting and responding to safety incidents."

A poor safety culture is increasingly

Access to healthcare has deteriorated in many countries since the pandemic, so it's even more crucial patients are given the tools to self-manage as effectively as possible.

Patients know what they want and are saying it loud and clear—we want full interactive access to our medical records through well designed apps or portals that we can use to inform our decisions and manage our care. We want clinicians, managers, and policy makers to recognise the benefits vastly outweigh the risks. This is an ethical imperative and key to any strategy to support self-care. Facilitating this would mark an important cultural shift and free up professional time to focus support on those who need it most.

Angela Coulter, chair of trustees, Picker Institute Europe, UK

Tessa Richards, patient advocate

Ceinwen Giles, co-chief executive officer, Shine Cancer Support, UK

Sophia Walker, patient editor, *The BMJ*

Cite this as: *BMJ* 2024;386:q1385

---

recognised as a contributor to failings in NHS care. Rob Behrens, the outgoing parliamentary and health service ombudsman in England, wrote that "too often we see the commitment to patient safety in the NHS undermined by a defensive leadership culture," while in her "100 days" report, Henrietta Hughes, the new patient safety commissioner for England, put "culture change" in her top three priorities.

Patients are free of institutional ties and cultures. Their reports are unbiased by any knee jerk defensiveness. Instead of being dismissed as the rantings of the discontented, unsolicited reports should be given greater weight by staff whose own judgment is inevitably compromised by their insider status.

A growing number of healthcare staff are engaging more openly with online feedback and finding, perhaps to their surprise, that there are worthwhile benefits not just for patient safety but also for staff morale, confidence, and pride.

James Munro, chief executive, Care Opinion

Cite this as: *BMJ* 2024;386:q1243

OPINION Sarah Woolf

My note to staff changed everything

Four years after my first breast cancer diagnosis, I received a call from the breast care centre. They had found abnormal cells in my other breast in a recent scan. I couldn't face going through yet more treatment. But then I did something medical staff later told me had never been done before.

For years before my cancer diagnosis, I had worked and published research as a movement psychotherapist in a hospice running an expressive movement therapy group. It was there that I discovered how illness affects our sense of identity and mental health. I remember one woman whose lost mobility meant she couldn't buy food and cook, a fundamental part of who she was. And a man with arthritis who was grieving the loss of his capable, sporty self.

Like them, I too felt a sense of loss and became depressed when fatigue from my cancer treatment prevented me from working, dancing, and doing things that defined my identity as the spirited, social person I had always been.

As my treatment compromised what I could do in my life, it changed how I felt about myself and how I felt seen by others. Being ill made me feel vulnerable and "in pain"—not just physically, but socially and psychologically too.

Yet here I was facing more treatment, this time for my other breast. Although the staff I met seemed kind, I was cut with terrifying "biopsies" and attended appointments where my breast was discussed as an object for dissection. Whenever I was in hospital, I felt that there was a tunnel visioned focus on the physical health of my body, detached from me as a sentient human being. My mental health went downhill, and I became almost mute in appointments.

The day came when I faced the unimaginable reality of having my breast cut off. This felt almost too much to bear and impossible to voice. Then I had an idea. I wrote down my feelings in a note to give to medical staff on the day of my operation. I was waiting nervously in my gown, when my surgeon came in. I handed her my note.

Note to hospital staff from Sarah Woolf

Please read before breast surgery

Please be aware that I struggle with "medical trauma," resulting from years of medical procedures including chemotherapy, radiotherapy, surgery, etc. I don't know how I will cope emotionally with having my breast removed.

I also wanted to ask if you could take a moment to acknowledge that my left breast has nourished my two children with milk, given me pleasure, and has been a tender and much loved part of who I am as a woman. I will really miss her.

Thank you for taking good care of me so that I can continue to live my life in a fulfilling and meaningful way.

With thanks, Sarah

Suddenly the divide between patient and health professional disappeared. I saw her well up with tears, and she told me that no one had ever done this before. Later she told me how moved everyone in the operating theatre had been when my note was read out.

At last I felt really heard and seen, not as a piece of breast tissue, but as a human being. It made such a difference to me that the surgical team treating me listened and understood the impact of what was happening to me as a person, beyond my medical symptoms. It helped restore me when I was feeling so lost.

I wish we cared for people's health in a way that recognised how being ill can alter a person's life and their sense of meaning. Treating a person's body as a separate entity from their sense of identity can exacerbate the psychological trauma of illness.

Simple changes could help to integrate the link between psychological and physical healing in our care of people's health. Imagine if a patient's notes began with a very brief introduction that they'd written about themselves and how their illness affects their life. Starting with who the person is, rather than the details of their disease, could play a pivotal role in making interactions between healthcare staff and patients, and our healthcare, more human.

This would be a simple and effective way to start changing our approach from curing symptoms, towards healing and restoring people—not just physically, but in mind and soul too.

Sarah Woolf, movement psychotherapist, Bristol

Cite this as: *BMJ* 2024;386:q1471

PRIMARY COLOUR Helen Salisbury

Putting the care into healthcare

What do we want from a healthcare service? We certainly want health, and the service tries to maintain this through preventive treatments, vaccinations, and cancer screening.

When our bodies go wrong we can sometimes restore them with curative treatments: antibiotics for infections, surgery for broken bones, chemotherapy for cancer (although, arguably, more effort should be directed upstream, tackling the causes of ill health). In many situations a return to health can't be achieved, but what we can offer is care, to ease symptoms and to limit disability.

The word "care" is sometimes used as though it's an entirely impersonal activity—hence the phrase "episode of care" in medical management, which usually describes doing something to or for a patient. But patients need something more than to be passive recipients of a series of activities designed to keep them safe: they need to feel cared for, and cared about, in the ordinary meaning of that word. In this sense, a service can't care for someone; only people can.

When patients phone our surgery or walk into the waiting room, the initial response from reception staff should be one that demonstrates care. It can be hard to convey that sense of care to the patient when the practice can't exactly meet their demands, and I'm often moved when I hear the kindness and gentleness of staff on the phone as they try to reassure and find a solution. That interaction is an important part of the "care pathway"—one that goes way beyond their efficiency in sorting out our appointments.

For me as a GP, the emotional side of care is often intertwined with the practical, demonstrated by making sure that I've done the timely referrals, read the letters, and liaised with the hospital colleagues advocating for my patients. I hope that I'm always conscientious, being the best doctor I can be, but it's much easier to put that effort in when I care about patients—not just in the abstract sense of caring about humankind but in the concrete sense of knowing and caring about these particular people as individuals.

Care is a product of relationships. Not all relationships are easy, in healthcare just as in other spheres of life, but nevertheless, when you know someone you're much more likely to care. That care not only makes your job as a doctor easier and more enjoyable but it transforms the experience of the person you're treating. Care develops over time, and for it to develop we need continuity. Continuity of care—seeing the same doctors, nurses, and reception team—doesn't just make medicine more effective and efficient. It fosters the sense of genuinely being cared for and about: the warmth, trust, and reassurance that we want for our patients, our families, and ourselves.

Helen Salisbury, GP, Oxford
helen.salisbury@phc.ox.ac.uk
Twitter @HelenRSalisbury

Cite this as: *BMJ* 2024;386:q1458

A service can't care for someone; only people can

OPINION Charlotte Augst

STEFAN ROUSSEAU/PA/ALAMY

What the new government means for patients

The recent UK general election, and the preceding campaign, should have been an opportunity to clarify what we want from our healthcare services, and what we are entitled to expect. I don't think I am alone, if I conclude that we have not achieved this clarity.

Now we know we have a Labour government, our new political leaders say it will take 10 years to put the NHS back together again.

Wes Streeting, the new health secretary, has also indicated that an inclusive process will be set up that brings together a range of people. We therefore have a chance to shape more long term thinking. But—what if it transpires that we want a lot of different things that are in tension with each other?

We cannot spend unlimited resources on the health system. As citizens, parents, commuters, and renters we also want other things: bearable tax rates, good schools, punctual trains, affordable housing. Given what we can spend on health is limited, those who understand the impact of interventions all agree that you get the most "bang for your buck" if you go upstream: stop people smoking, help them quit, support them to look well after their health or to manage their illness effectively, intervene early when people indicate they aren't coping well.

This is the urgent conversation we now need to have to build a health system for the future. We need an acknowledgment from politicians that no health system can afford all the things that are medically possible for everyone. The only fair and humane way of sharing resources is to focus on where it makes the biggest difference, not where it includes the shiniest new hospitals, scanners, or drugs. As citizens and patients, we must acknowledge that medicine will not be able to extend our lives endlessly: that our bodies are frail, and that we need to support and challenge ourselves and each other to do more of the things that actually make for a good life—in illness and in health.

Charlotte Augst, patient author

Cite this as: *BMJ* 2024;386:q1503

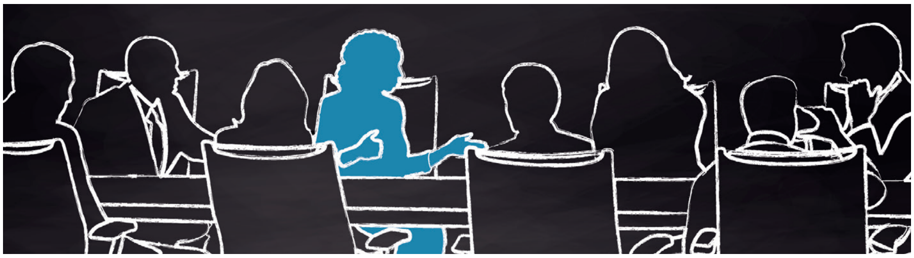
ESSAY

More medical journals must work in partnership with patients and the public

As The BMJ celebrates 10 years since the launch of its patient and public partnership strategy, we ask why more medical journals do not have a similar partnership with patients

When *The BMJ* launched its patient and public partnership strategy in 2014 it was the first commitment of its kind by a medical journal. Being patient centred is one of *The BMJ*'s values. The journal already had a long history of partnering with patients, but it was informal and ad hoc, and the launch of a patient focused strategy was pioneering for a medical publication. A great deal has moved on since then—albeit mostly outside the world of medical journals.

Patients are becoming key decision makers in various aspects of healthcare, including research, where funders actively support patient and public involvement. Notable national examples include the Patient-Centered Outcomes Research Institute in the United States, the Canadian Institutes for Health Research, and the National Institute for Health and Care Research, Wellcome Trust, and James Lind Alliance in the UK. International organisations such as Cochrane, the International Consortium for Health Outcomes Measurement, the Community Health and Information Network Africa, and the World Health Organization also support co-production in research, practice, and medical education. These are just a few examples of organisations making healthcare research more responsive to the needs and priorities of patients, not just scientists and clinicians.



Patient and public partnership is attritional with benefits that can be tricky to quantify

Lucien Engelen, a patient advocate, launched the Patients Included charter for healthcare conferences in 2015 with the support of patients, clinicians, researchers, and advocates. The charter allows conference organisers to assess their performance against five charter clauses to become self-accredited Patients Included events. Self-accreditation enables use of the Patients Included logo and signifies a commitment to involving patients as experts from the planning to the delivery of a conference. Organisations such as Stanford Medicine X, the Cochrane Colloquium, and BMJ Group have embraced this model. Many conferences, including those hosted by BMJ Group, exceed the five clauses of inclusion by finding innovative ways to involve and partner with patients and the public in both online and in-person events. Patients and public representatives lead panels, serve on steering committees, recruit speakers, chair workshops, and coauthor conference reports.

At a policy and government level, the UK's Medicines and Healthcare products Regulatory Agency, the European Medicines Agency, and the US Food and Drug Administration regularly seek input from patients and the public. WHO also involves patients and the public from all over the world in its work, including a resolution on social participation in healthcare. Healthcare delivery organisations such as the Patient Revolution, the International Shared Decision Making Society, and the Care Lab are inspiring redesign of healthcare systems to deliver health and social services that are less industrialised and inhumane, and more careful, compassionate, and kind.

Patient partnership in journals

Despite progress in research and other spheres, medical journals remain an outlier when it comes to working in partnership with patients and the public. Nevertheless, it is encouraging that several journals are dedicated to this topic. *Research Involvement and Engagement* and the *Journal of Patient Reported Outcomes* are both open access and multidisciplinary journals demonstrating, and advocating, a greater role for patients in research while showcasing how to partner with patients in medical journals. These journals make valuable contributions to public and patient involvement, but their focus is narrow. Clinical journals must now pick up the baton.

At *The BMJ*, we are committed to involving patients and the public in our content. We employ patient editors. We have a diverse international patient and public advisory panel—unique among journals—that supports our strategy and its implementation. We work with our panel to identify healthcare issues of particular focus for patients and public. These currently prioritise patients' access to health records, involvement of patients in genomic medicine, patient participation in healthcare conferences, and patient safety. We remain committed to diversifying the membership of our advisory panel.

Patient and public partnership is a complex intervention and process that doesn't lend itself to delivering hard endpoints in set time frames; it is attritional with benefits that can be tricky to quantify. Despite these inherent problems, we believe that partnership is right and a reflection of the change that we wish to see in medical journals and in society. By steadily winning hearts and minds we can help close the gap between the hopes and reality of person centred care and democratised healthcare. Most of the over 60 journals in the BMJ Group have adopted or are in the process of adopting a version of *The BMJ*'s patient and public partnership strategy or creating their own.

Funding—the elephant in the room

Although progress has been made, researchers often report funding is not adequate to support high quality public and patient involvement (PPI). Funding, training, and requirements to include PPI have increased since 2014. However, more provision is needed to meet PPI needs and to provide equity between researchers and patient partners.

This need for equity based solutions and funding to compensate everyone fairly is reflected in the PPI declarations included in *The BMJ*'s research, in which the most commonly reported reason for limited PPI is lack of funding, followed closely by lack of training. Continuous engagement is costly, and researchers struggle to sustain initiatives beyond the initial phases. The administrative and logistical burdens of organising PPI activities, including training, compensating patient participants, and providing necessary accommodations, are vastly underfunded.

Addressing these concerns requires ongoing efforts to increase funding, reduce administrative burdens, enhance capacity building initiatives, and ensure that PPI activities are inclusive and sustainable.

Extensive capacity building initiatives are needed worldwide. Smaller institutions and those in low and middle income countries can find this beyond their reach, and they are to be commended for their diligence, sacrifice, and attention to PPI. Additionally, determining the effect of PPI is difficult without adequate support to evaluate and demonstrate its value in individual projects.

Umbrella approaches for training and measuring impact are not sufficient or scalable; just as with other forms of research evaluation, PPI needs to be funded on a study-by-study basis.

Creating effective partnership

Over the past 10 years we have identified four areas, resource constraints permitting, in which patients and the public can be particularly involved in a medical journal (infographic). One of the first steps into patient partnership is publishing patient written or co-written content, providing an opportunity to give space to lived experience. In 2023 nearly 40% of education articles in *The BMJ* had a patient coauthor, and we continue to publish "What your patient is thinking" articles once a month. Over half of BMJ Group journals welcome and encourage patient authored articles, and some have developed patient series.

Another initiative is to introduce statements on public and patient involvement for research papers. All authors submitting to *The BMJ* are required to complete this statement, and around half of BMJ Group journals also demand such a declaration. The aim of these declarations is to help catalyse a culture change in patient and public involvement in research, and the policy is straightforward to implement.

A third approach is to involve someone with lived experience in the governance of the journal. This can be done by appointing a patient or member of the public to the editorial board, as *The BMJ* does, recruiting an informal patient adviser, or appointing a patient editor. The extent of progress in our group portfolio varies, largely determined by a journal's resources and budget. *BMJ Sexual and Reproductive Health*, for example, appointed a patient editor in 2018, and other journals work with patient advisers.

A fourth area is patient and public review, where a patient or member of the public peer reviews an article alongside traditional reviewers. In 2023, 82% of submitted research articles and 85% of education articles under peer review were also sent to a patient or public reviewer. This is one of the most challenging parts of our patient partnership work. It requires resources to recruit, train, and support reviewers, as well as requiring changes to manuscript submission systems and editorial processes. Our view, however, is that the unique and important insights reviewers provide make published articles more relevant to their audience.

The perspectives of patients and the public are embedded in our processes for decision making

The perspectives of patients and the public are embedded, to varying degrees by journal section, in our processes for decision making. Perspectives from lived experience, just like perspectives from clinical experience, do not over-ride our evaluation of the methodological rigour of the research that we are appraising.

Fundamental rules of evidence based medicine, such as ensuring that the methods are appropriate for the research question, cannot be deviated from. It may be, for example, that a patient reviewer's experience of an intervention is positive but when the intervention is valuated in a research setting the same benefit is not seen or harms are identified. Lived experience, in this context, best informs our assessment of the appropriateness of the research question and whether the findings will have real world impact.

We appreciate that incorporating patient and public voices into established journals is hard, and requires time, commitment, and money (box). But we hope that lessons from our patient experience will show that it is possible and encourage others.

Medical journals can galvanise change

Although we acknowledge that our efforts are far from perfect, progress in patient partnership is limited beyond BMJ Group journals. Most lack explicit or public strategies to involve patients in their work. Medical journals serve as a crucible of ideas, able to spark debate and learning on best practice both globally and nationally. Moreover, they provide leadership—and must extend that to what is expected for patient and public partnership in healthcare. Many existing policies are for the benefit of patients and the public—for example, the requirements for clinical trial registration, written patient consent for case reports and images, or using appropriate and patient centred language.

We believe that the requirements for reporting on the involvement of patients and the public in research are similar drivers of cultural change in the healthcare ecosystem. If researchers and institutions seek the visibility and reach that journals can afford their work, it is surely not too much to ask that they show better support of patient and public partnership.

Ten years since the launch of our patient and public partnership strategy, our successes are largely down to individuals championing the cause and guiding, advising, supporting, and cajoling others on this journey. It was hard—it still is—and we have achieved mixed success. But we believe that working in partnership with patients and the public brings unique insights into what we publish as well as adding value. We can also point to objective measures of progress and impact.

We urge others to join us in delivering the patient revolution. It is an embarrassing indictment of medical journal priorities that so many are content to do so little. If medical journals are to fulfil their primary purpose—to improve health and wellbeing outcomes—they cannot continue to fail the test of patient and public partnership.

Emma Doble, patient and public strategy editor
edoble@bmj.com

Sophia Walker, patient editor

Amy Price, patient editor

Kamran Abbasi, editor in chief, *The BMJ*, London

Cite this as: *BMJ* 2024;386:q1463

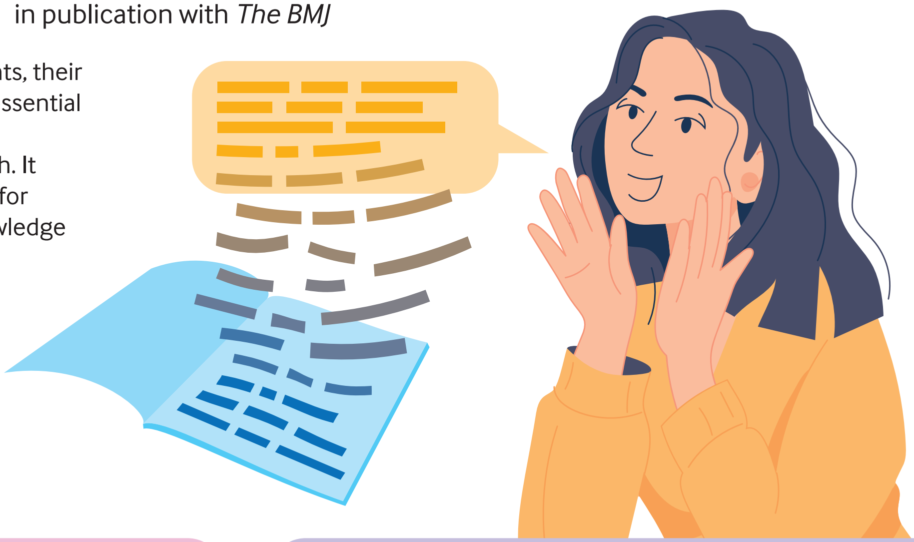
thebmj Visual summary

Involving patients and the public

in publication with *The BMJ*

The BMJ believes that partnering with patients, their carers, support networks, and the public is essential to improving the quality, safety, value, and sustainability of health systems and research. It makes content more practical and relevant for clinicians, and helps to ensure that the knowledge we produce is of value to our readers.

This graphic shows four ways that you can encourage patients and the public to get involved in creating content and working in partnership in all we do at *The BMJ*.



As authors

There are several ways for patients to create articles, describing their unique perspectives and lived experiences

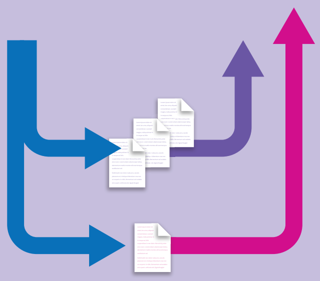
Patient authored content or series

Co-create articles with patients as coauthors

Include patient perspectives alongside other articles

As reviewers

Patient peer review complements academic peer review and invites patients or lay representatives to comment on the value of the research or other scholarly content to patients, its applicability to care in the real world, and whether there are any major omissions



Encouraging co-design in research

Patients can be involved in designing research studies —for example in defining research questions, outcomes, measures, study design, and plans for disseminating results

Patient and public involvement statements

These contributions to co-designing research will be recognised in the statements that all authors submitting research papers to *The BMJ* must include within the methods section of their papers

In governance and strategy

Patients can make valuable contributions to our publishing strategy and help to make fundamental decisions about the journal's values and goals by:

Sitting on our patient advisory panel

Becoming patient advisers or editors

Joining our editorial board

LETTERS Selected from rapid responses on bmj.com

NHS IS FAILING DEAF PEOPLE

Deaf awareness strategies in healthcare

ALL_EARS@UoS is a patient and public involvement and engagement group established to foster a working partnership between researchers and people with hearing loss (What Your Patient Is Thinking, 2 March). We draw on the insights of this group to respond to the recognition that the NHS needs to improve accessibility and services for d/Deaf and hard of hearing people.

People with hearing impairment face major barriers to effective communication in healthcare settings. These are greater in underserved groups and raise the risk of delayed detection of disease and the detrimental effects of long term conditions.

NHS staff should be supported to engage with the Royal College of General Practitioners' Deafness and Hearing Loss Toolkit and to make positive changes to the processes of making and attending appointments.

Most interventions require increased awareness by health professionals rather than new resources. We hope that sharing our lived experiences contributes to better healthcare access.

Kate Hough, research fellow; Dialechti Tsimpida, lecturer in gerontology; Sue Boswell, patient; Chris Satchwell, patient; Sarah Smith, patient; Preeti Dhuria, senior research assistant; Eva Newberry, patient; Bethan Impey, consultant psychiatrist; Marcia Hudson, patient; Tracey Newman, professor of neuroimmunology, Southampton

Cite this as: *BMJ* 2024;386:q1438

The NHS Accessible Information Standard

Since 2016 the NHS Accessible Information Standard (AIS) has been a legal requirement for all health and social care providers to "identify, record, flag, share, and meet" the needs of all patients with communication challenges.

As a deaf-blind person, I engaged closely with NHS England as a patient adviser during its development and have worked to promote its adoption. But take-up has been slow. A revised standard was promised for April 2023. We are still waiting.

In 2022 I was approached by the new Kent and Medway Medical School to contribute to its first module specifically on the AIS. I hope we can expand the "learning package" in its next iteration, adding more examples, resources, and advice to assist the move from principle to practice.

The emphasis on simple steps, learning, and support, and the enthusiastic involvement of the next generation, encourages me that the standard will soon realise its potential.

Howard J Leicester, patient champion, Otford

Cite this as: *BMJ* 2024;386:q1442

HEALTH LITERACY MATTERS

Clarity is power—and ChatGPT can help

I support everything that Richards says about health literacy (Opinion, 25 May – 1 June) and want to add two things.

When I first went to medical conferences, I was stunned that people whinged about patients' health literacy when, to my eyes, most of the problem was how impenetrable the material was. I refuse to discuss health literacy without considering the clarity of the material.

The second item coming over the horizon is generative artificial intelligence (AI) that can take any text and simplify it. I fed ChatGPT my appointment notes and asked it to extract my current problems and intended actions—I was instantly 6 million times more literate and compliant.

When people start playing with these tools to pursue their own questions, they become self-educating. Isn't that empowering? Enabling people to pursue their own interests. If you have not yet become a user of AI tools in your daily work, please do it.

Dave deBronkart, patient empowerment advocate, Nashua

Cite this as: *BMJ* 2024;386:q1413

LANGUAGE MATTERS IN DIABETES

What's in a name?

In 2019 Scibilia and Aldred called for the blame to be taken out of complications of diabetes (What Your Patient is Thinking, 9 February 2019).

The "language matters" concept has gained traction in the diabetes community, emphasising that positive language can improve management outcomes and negative language can perpetuate stigma, blame, and shame. The debate includes using "people with diabetes" rather than "diabetic." This shift is intended to be part of a broader movement from a patient centred to a person centred narrative.

Personally, I don't mind being called diabetic or a patient, but I understand others' concerns. For me, the crucial aspect of the language matters movement is fostering a non-judgmental attitude and treating people with kindness and empathy. You can call someone a person with diabetes and still be judgmental or call them diabetic and support them. It's not just about the language—it's about everything else behind it.

Jazz Sethi, founder and director, Diabesties Foundation

Cite this as: *BMJ* 2024;386:q1446

DEMOCRATIC HEALTHCARE DECISION MAKING

Conferences for patients, by patients

Although including patients at conferences is important, we also need more conferences that are led by patients (Editorial, published online 19 May 2021).

Patient led conferences, unlike much of research and healthcare, give patients power and control over all aspects of the event, including resourcing and support. We were involved in a patient led conference, PxP (For Patients, By Patients): Partnering to Make Research Stronger, in September 2023. PxP is about patient engagement in research. Conferences of this type are not often designed solely for and by patients.

Patient led conferences focus on what matters to patients, and many topics resonate globally. But they need patients and support. The Canadian Institutes of Health Research's Institute of Musculoskeletal Health and Arthritis provided resources for PxP, and a patient steering committee fully designed, hosted, and executed it. Lessons learnt from hosting PxP are available for others to consider.

Oluwafemi Ajayi, chief executive officer, Gail Sickle Initiative; Patrick Gee, founder and chief executive hope dealer, iAdvocate; Hetty Mulhall, associate scientific director, Vancouver; Dawn P Richards, patient engagement consultant, Vancouver; Sara Riggare, researcher, Uppsala

Cite this as: *BMJ* 2024;385:q1411

HEALTH INFORMATION GENERATED BY AI

Artificial intelligence for neurodiversity

Algorithmic bias in artificial intelligence (AI) is a problem for patients with mental disorders, particularly neurodevelopmental disorders (Research 23 March). This arises because large language models are trained on “big data” from “average” patients, focusing on single diseases without incorporating the diversity of comorbid patient subgroups.

We urge AI innovators to view cognitive diversity as an opportunity for precision medicine. AI could target comorbid patients; integrate physical and mental health information; streamline use of mental health services; and improve treatment adherence through social support. Otherwise, AI might contribute to technostress or health anxiety.

Neurodivergent AI requires collaboration. Innovators could include patients and care givers in experience prototyping to improve explainability and trust; (social) entrepreneurs could partner with schools, nursing homes, and employers to engage neurodiversity communities; grant makers could fund research on rare neurodevelopmental disorders or neurodegenerative diseases; and policy makers could tackle the digital divide in global health.

Lambert Zixin Li, doctoral candidate, Stanford
Peilin Yang, data analyst, Barcelona

Cite this as: *BMJ* 2024;386:q1384

EATING DISORDERS AND PANDEMIC DISRUPTION

Include patients and carers in research networks

Increased prevalence of eating disorders during the covid-19 pandemic has been linked to stressors brought about by pandemic related public health measures and messaging (Feature, 24-31 July 2021). Service provision was disrupted, with increased demand for specialist care alongside a restricted capacity to provide it.

There are real world implications, as author JD describes: “The lack of information available to me as a patient has meant I can’t be confident about whether the treatment offered is likely to be effective.”

The Eating Disorders Clinical Research Network aims to tackle these limitations by establishing a UK-wide NHS network to enable collaborative research. It has centred the expertise and aspirations of people with lived experience and their carers and supporters since its inception. Author SB reflects: “I hope the inclusion of a range of people affected by eating disorders will transform the outcomes of treatment, enabling patients to recover and lead meaningful lives.”

James Downs, lived experience steering group member (patient); Suzanne Baker, lived experience steering group member (carer/supporter); Anna Carnegie, research associate and coordinator, Eating Disorders Clinical Research Network

Cite this as: *BMJ* 2024;385:q1403

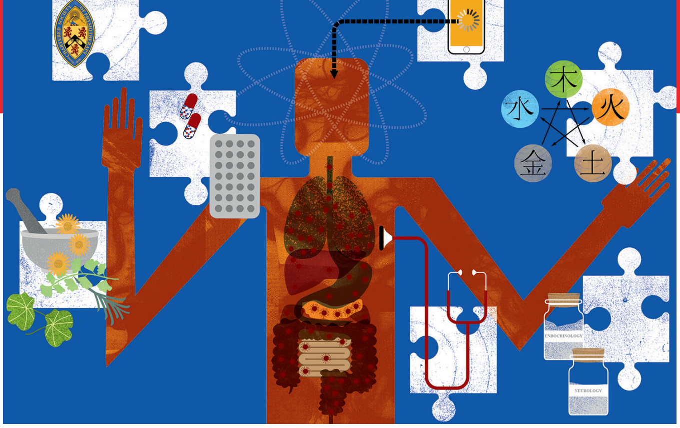
INTEGRATING LONG COVID CARE

Don’t let physicians off the hook

My husband and I both have long covid and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). I can relate to Jreidini’s account of long covid care (What Your Patient is Thinking, 29 January 2022), not least spending hours scouring research papers and contacting support groups.

Almost every clinician I have seen has been less informed than me about long covid and ME/CFS. A patient would be horrified if, seeing a neurologist for a brain tumour, they realised the neurologist knew less about it and was less familiar with the latest research than them. There are many ongoing cases of patients with severe ME/CFS in NHS hospitals receiving treatment not in line with evidence based guidance.

I read the call for patients to become their own physicians, but I am exhausted. Let’s not let our physicians off the hook. I’d rather have a trained, well researched, and well informed doctor.



ROSE LLOYD

Karen L Hargrave, freelance researcher and policy analyst, London

Cite this as: *BMJ* 2024;385:q1398

MANAGING EATING DISORDERS

Understanding a person’s whole identity and lived experience

Downs articulates the importance of adopting a holistic approach, viewing a person’s eating disorder alongside their physiological symptoms and the wider social context (What Your Patient is Thinking, 9 January 2021).

I am in long term recovery and coordinator of the Eating Disorders Clinical Research Network. My professional identity intertwines with my health history, bringing with it myriad challenges and privileges.

In the coordinator role, I have autonomy over when, and to whom, I disclose my eating disorder history. Conversely, I must navigate interactions where I encounter people and memories from treatment. My personal connection to the field has furthered my motivation to champion and support improvements.

By providing a welcoming and open space, my colleagues and peers have enabled me to approach my role with authenticity. My team see the whole picture of my eating disorder history and professional expertise—and recognise, appreciate, and champion these different dimensions.

Anna Carnegie, research associate and coordinator, London

Cite this as: *BMJ* 2024;385:q1405

BRAIN FOG IN HYPOTHYROIDISM

Recovery or dementia?

Papautsky describes developing brain fog on starting chemotherapy for breast cancer (What Your Patient is Thinking, 20 May 2020). Brain fog affected my life before and after diagnosis of hypothyroidism.

My doctor thought that I would recover on levothyroxine monotherapy. But the cognitive impairment got worse over the following years. In 2000, 11 years later, I started liothyronine in addition to levothyroxine and gradually experienced a substantial change. Without adequate medication, my cognitive impairment might have developed into severe impairment, seen in dementia.

A recent meta-analytical review found significantly more cases of hypothyroidism among patients with Alzheimer’s disease than among those without. Based on reported relations between hypothyroidism and dementia, it is alarming that lots of people do not get adequate treatment for hypothyroidism.

Researchers and clinical experts recommend longitudinal studies exploring the associations between brain fog in hypothyroidism, developmental trajectories in relation to different medical treatments, and later dementia.

Audhild Løhre, professor emerita, Trondheim

Cite this as: *BMJ* 2024;386:q1426

Maurice Guillochon

General practitioner (b 1934; q Dublin 1964; MRCS LRCP), died from congestive cardiac failure on 25 August 2023

Maurice Guillochon, born in St Helier, Jersey, went to medical school, first St Bartholomew's, London, then the Royal College of Surgeons in Dublin. As a junior doctor and GP he lived and worked in England, Scotland, and Australia. In 1972 he returned to St Helier to join a GP practice, where he was drawn to the care of the elderly and palliative care, as well as developing an interest in acupuncture. He enjoyed many hobbies including gem prospecting, painting, squash, windsurfing, and beekeeping. He began to take a serious interest in his physical health in his 50s—first through regular gym going, and then taking up running, completing several half marathons. Maurice remained in Jersey for the rest of his life, retiring in 2005. He is survived by Marie-Antoinette, his wife of 65 years, their three children, and seven grandchildren.

Rémi Guillochon

Cite this as: *BMJ* 2024;386:q1478

Keith Alexander Sands

Endocrinologist (b 1948; q Manchester 1971), died March 2024 of adenocarcinoma

Born in London, Keith Alexander Sands spent his early childhood in East Africa, returning to England to complete his education before moving to Manchester University, to read medicine and to follow his beloved football team, Manchester United. Graduating in 1971 he worked in Manchester, Derby, and Sheffield before taking up a post in 1976 as consultant endocrinologist at Mansfield General and King's Mill hospitals. In 1984 Keith established the Langwith course for diabetes specialist nurses, which he ran for over 30 years. In 2002 he became medical director at Lincoln County Hospital, returning to clinical work in 2007 and "retiring" in 2010. He returned to work immediately, as medical director at Barnsley Primary Care Trust. From 2015 he worked again at Nottingham hospitals and the city's centre for transgender health. He leaves a wife, three children, and five grandchildren.

Becky Sands

Cite this as: BMJ 2024;386:q1476

Susan Jane Harper Sprigge

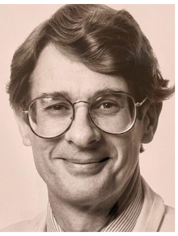
Consultant intensivist and anaesthetist (b 1954; q McGill, Montreal 1979), died from renal disease on 28 March 2024

Jane Harper was the daughter of a Canadian infantry officer and a military nurse, from whom she inherited her integrity, drive, and whimsy—and love of Canada. After graduating, Jane interned in New Zealand and then returned to Montreal, where she met her husband. They moved to Merseyside in 1982. Jane was a consultant in—and, for a term, director of—intensive care at the Royal Liverpool Hospital from 1993 until her retirement in 2013. She helped expand and unite the department, alongside her role as the incisive editor of the *Journal of the Intensive Care Society*. She was dedicated to her job and a role model for many women in medicine. Jane loved music, literature, the outdoors, travelling, and being with her family. She was a loving mother to our two daughters and adored her three grandchildren.

John Sprigge, Martha Sprigge, Libby Sprigge

Cite this as: *BMJ* 2024;386:q1474

David Allden Lloyd



Professor of paediatric surgery (b 1940; q Cambridge/Barts 1964; MChir, FCSSA, FRCS Eng, FACS), died from acute myeloid leukaemia on 2 May 2024

David Allden Lloyd was born in Natal, Union of South Africa. In 1958 he arrived in England to study medicine at King's College, Cambridge, later spent a year training in Cardiff, where his passion for Welsh rugby was born. In 1969 he returned to South Africa as a surgical registrar at Cape Town's Groote Schuur Hospital, scrubbing-in with Christiaan Barnard. In his next post at the Red Cross Memorial Children's Hospital, he met his wife Carol. In 1982 they moved to Pittsburgh for his post as associate professor in paediatric surgery. In 1988 he moved back to England as professor of paediatric surgery at the University of Liverpool and Alder Hey Children's Hospital. From 2000 to 2002 he was president of the British Association of Paediatric Surgeons. David died peacefully at home surrounded by Carol and his four children.

David Lloyd

Cite this as: *BMJ* 2024;386:q1488

George Jamieson Ross McHardy

Consultant clinical physiologist and chest physician (b 1930; q Oxford 1957; BM, BCh, FRCPE, FRCP), died of pneumonia on 29 March 2024

Ross McHardy obtained a scholarship to Oxford University, graduating in 1957. During his 1959-60 RAF national service he investigated high altitude decompression on aircrew, leading to an interest in lung physiology. In 1961, he returned to the Middlesex Hospital as registrar, obtaining his MRCP. His interest moved to exercise physiology and a fellowship led to a year's work at the Johns Hopkins School of Public Health. In 1965 Ross was recruited by City Hospital and Edinburgh University as a consultant and lecturer. He set about creating a lung function service across the city's hospitals. As Lothian Area Medical Committee chair in the 1980s he led a major reorganisation to tackle a £12m deficit. Ross retired in 1995. His wife Val, a GP, died in 2007 and he found companionship with Gillian Sams, a fellow pianist.

Anthony Seaton, Robert McHardy

Cite this as: *BMJ* 2024;386:q1493

Ken Stein

Professor of public health (b 1963; q Bristol 1987; MD, DipRACOG, MRCGP, FFPH), died on 3 February 2024 from metastatic kidney cancer

Our friend and colleague Ken Stein was a public health doctor and academic who made major contributions to evidence synthesis and health technology assessment. From the mid-1990s he played a key role in establishing a pioneering evidence synthesis group in Exeter and then PenARC. He was also involved in NICE's technology appraisal work, which led to international collaborations. After training at Bristol, Ken became a GP and for a while worked in Australia and New Zealand. On his return, he trained in public health, moving to Devon in 1999 as a consultant and a year later director of public health for Mid Devon Primary Care Trust, In 2003 he joined Exeter University, named chair in public health in 2007. Ken leaves his wife Kristin, three children, and three grandchildren. Nearly 300 people attended his memorial.

Ruairidh Milne, Stuart Logan

Cite this as: *BMJ* 2024;386:q1492

OBITUARIES

John Stephenson

Paediatric neurologist who found a major area of medical misdiagnosis

John Burdett Primmer Stephenson (b 1935; q Oxford/London 1960; MA, DM, FRCP London, FRCP Glasgow, Hon FRCPCH), died from progressive frailty and cerebral small vessel disease on 16 April 2024

In 1978 the witty and erudite professor John Stephenson gave a name to unexplained syncope among young children: reflex anoxic seizures (RAS). This highlighted a major area of medical misdiagnosis. Up to 30% of children diagnosed with epilepsy when presenting with loss of consciousness, falls, or other paroxysmal episodes were reportedly misdiagnosed and prescribed unnecessary drugs with frequent side effects.

Trudi Lobban's young daughter Francesca could have been one such child. She had been passing out up to eight times a day. Failing to find an explanation, her mother wrote to paediatric neurologists all over the world.

Stephenson replied and asked if Lobban would talk to other affected parents. In 1993 Lobban launched Syncope Trust and Reflex Anoxic Seizures (STARS), a decision that was to help many thousands of children. "John had a vision that no child would be misdiagnosed with epilepsy as long as RAS was recognised and understood," Lobban said.

Stephenson nursed this vision for many years. In 1977 he wrote in *The BMJ*, "Although once upon a time epilepsy encompassed any kind of seizure, syncope cut loose several centuries ago. Please let us keep it that way and not blur the fundamental distinction between epileptic and anoxic fits."

The following year *Archives of Diseases in Childhood* published his paper "Reflex anoxic seizures ('white breath-holding'): nonepileptic vagal attacks," which was based on 58 children diagnosed as having reflex anoxic seizures other than epilepsy. His highly acclaimed and crisply written monograph *Fits and Faints* (1990) contains more than 140 case histories.

Challenges and innovations

In the 1970s Stephenson pioneered the use of video recordings for teaching and to aid differentiation of paroxysmal events and monitor disease. His kit included the Kodak Super 8, which opened up a new era of amateur film making—and clinical observation.

Never afraid to court controversy, he challenged concerns in the 1970s and '80s that whooping cough immunisation could result in a severe encephalopathy characterised by seizures and progressive neurological decline.

He cared immensely about his patients —the children and their parents

His longstanding friend and last senior registrar, Sameer Zuberi, now a consultant paediatric neurologist at the Royal Hospital for Children, Glasgow, said, "John felt strongly that many of the acute seizures associated with immunisation were anoxic, non-epileptic events, and in cases where there was a temporal relationship between immunisation and the first seizures of an epileptic encephalopathy, this was because immunisation was coincident with disease onset." Fifteen years on it emerged that people mistakenly diagnosed with "pertussis vaccine damage" had pathogenic variants in the *SCN1A* gene associated with severe myoclonic epilepsy in infancy.

Stephenson relished the cut and thrust of debate in meetings. Zuberi recalled, "The words, 'Stephenson, Glasgow,' as he asked a penetrating and often witty question, struck fear into many junior and senior neurologists at academic meetings."

He sensed which clinical observations presaged emerging fields in neuroscience and he sought out the leaders with whom he could collaborate. For example, he sent DNA to leading international laboratories and collected cerebrospinal fluid from children with Aicardi-Goutières syndrome and carried it, in his hand luggage, to Pierre Lebon in Paris to measure interferon levels. This led ultimately to a new field of medicine, the interferonopathies, an explanation for several genetically driven autoimmune disorders.

Early life

Stephenson was the son of Keith, a naval commander, and his wife Jane (neé Primmer). Starting schooling in Fife, young John went to St Edward's School, Oxford, as an exhibitioner, and to Balliol College, Oxford, as a state scholar. He concluded his medical training at St Thomas' Hospital Medical School, London, winning the pathology prize.

After early paediatric training in Suffolk he spent three years in paediatrics in Glasgow before turning to neurology. He was exhilarated by a year in neurology and neurosurgery in Toronto's Hospital for Sick Children, a time he described as "one year, one lifetime of continuing education." Toronto helped to make him a pioneer in his rapidly emerging specialty. In 1973, after only 10 years in practice, he became Glasgow's first consultant paediatric neurologist at the Royal Hospital for Sick Children. In the same year he founded the Fraser of Allander Neurosciences Unit, one of the first comprehensive multidisciplinary child neurology and development centres in the UK.

Two years later he joined the inaugural committee of the British Paediatric Neurology Association. Four years after that the Department of Health and Social Security recognised paediatric neurology as a specialty.

Stephenson's many honours included a lifetime achievement award for excellence in paediatric epilepsy from the International League against Epilepsy.

Lobban and Richard Sutton, emeritus professor at Imperial College London and a leading syncope researcher, said, "John was a very special person, often seeing things that others could not imagine. He cared immensely about his patients—children and their parents."

In 2000 the Stephensons retired to Islay and he was awarded an honorary chair in paediatric neurology by the University of Glasgow. He added in retirement to his prodigious output of more than 200 published papers.

A kind, dedicated family man, Stephenson was widely read. He also enjoyed cooking, birdwatching, fishing, the Oxbridge boatrace, and malt whisky. Blindfolded, he could identify several malts at a sitting.

Philippa, his wife, survives him along with their five children, 13 grandchildren, and six great grandchildren.

John Illman john@jicmedia.org

Cite this as: *BMJ* 2024;386:q1485