comment

"We seem to have reached a new peak of top-down meddling and pressure" **DAVID OLIVER**
"There are unintended consequences of open access to patients' notes" **HELEN SALISBURY**
PLUS The global impact of Roe *v* Wade; failures of the food strategy

THE BOTTOM LINE Partha Kar

Understanding how others relate to you

There are said to be four types of people when it comes to change: enthusiasts, who adopt innovations straight away; cautious ones, who wait for data; followers, who adopt after most others; and Luddites, who will not change the way they do things. In my experience, people in our everyday interactions fall into similar groups.

One group love you to the max—I call them the Blinds. Their love for you is unconditional, their faith unshakeable. They could be your closest friends or your parents or siblings. They can be fabulous constructive critics, but they're your go-to people, your comfort zone.

Then we have a group who gravitate towards you over time because they respect you. They're the Rationals. They've seen what you stand for and they gradually become closer. They're generally solid and reliable, and give a lot of friendly criticism designed to help you. There is mutual respect, and it's not uncommon for someone in this group to become one of the Blinds.

The next group can cause a lot of angst—Shapeshifters. They want to be close because of your position and influence, but friends they are not. They won't hesitate to turn against you, and their volte-face can hurt if you thought of them as Blinds or Rationals. Backstabbing, jealousy, and careerism can make them difficult to decipher, and they can be tricky to spot, but they eventually reveal themselves.

The last group is the Haters. They genuinely don't like you, for whatever reason. It could be your style, looks, or approach to life. It could be a protected characteristic. For most people it's simply not nice to be disliked. When it's based on a particular characteristic you may find it easy to shrug off, but generally it's tough. As we age, we learn ways to deal with all four groups. Here are my tips:

Blinds: just enjoy your time with them. They make you happy. The pressures of life can mean that we rarely make time for them, but it can leave you uplifted.

Rationals: work with them, bounce ideas off them, let the relationship evolve, and see how many become Blinds. Even if they don't, they can become a source of reflection, learning, and growth, from honest feedback. Enjoy their company, as they can be priceless allies.

Shapeshifters: these are the trickiest. Sadly, there's no trick to identify them. You need to walk past the disappointment and remove them from your life, allowing time for peace, self-development, and progress.

Haters: perhaps oddly, I have respect for this group—they put their cards down clearly. No one is, can be, or even should be, universally popular. Whatever their reasons, so be it: don't waste time trying to change them.

Have a think about which group you fit into with respect to others. And make time for the Blinds: they leave you with a feeling of happiness, and that's worth its weight in gold.

Partha Kar, consultant in diabetes and endocrinology, Portsmouth Hospitals NHS Trust drparthakar@gmail.com
Twitter @parthaskar

Cite this as: *BMJ* 2022;377:o1548

No one is, can be, or even should be, universally popular

OPINION Nina Sun

Overturning Roe v Wade: reproducing injustice

The repercussions of the Supreme Court's ruling will be felt globally

On Friday 24 June, the US Supreme Court dealt a devastating blow to reproductive justice. In Dobbs *v* Jackson, the Supreme Court reversed Roe *v* Wade, which guaranteed a constitutional right to abortion.

In doing so, the court turned its back on medical evidence, public health, and human rights. Access to abortion is now under the purview of individual states and governed by a patchwork of abortion laws, with some states banning abortion in all instances.

A core concern from the decision is how criminal penalties might be used to enforce restrictive abortion laws. Thirteen states are poised to severely restrict abortions through "trigger bans." Some of these include penalties for providers that allow up to 10 years' imprisonment. Criminalising providers will have a "chilling effect" on health services, putting physicians and other medical professionals at risk of criminal prosecution, even in instances of obstetric emergencies and post-abortion care. More states are likely to enact similar restrictions—model legislation from the anti-abortion movement explicitly relies on criminal penalties to restrict access to abortion, calling for criminalisation of individuals who provide guidance on self-administered abortions or any other method, as well as for "aiding and abetting" a woman in obtaining the procedure.

The toll of the Dobbs decision will be borne by women on low incomes and from ethnic minorities. Estimates on the impact suggest there could be a 21% rise in mortality overall and a 33% increase among black women. This is against a backdrop where the maternal mortality rate in black women is 2.9 times higher than in white women, with a statistically significant rise among black women from 2019-20.

Exacerbates health outcomes

These data do not include women being forced to seek unsafe abortions, a leading cause of mortality and morbidity worldwide. Within this context, criminalising abortion not only exacerbates health outcomes for women but also feeds into the structural discrimination experienced by ethnic minority communities.

While the impact of overturning Roe will be most acutely felt in the US, its repercussions will be felt globally. Though US foreign policy around abortion has always been complicated, there has always been a clear domestic standard that abortion was a constitutional right. Movements have referenced this standard in efforts to expand reproductive health and rights worldwide. For example, in Kenya, the High Court of Malindi, in affirming that abortion care is a fundamental right under the Kenyan constitution, specifically references and considers key points from Roe. The Dobbs decision cripples efforts to protect reproductive health and justice in the US and strengthens efforts to restrict abortion access globally.

Mitigating the harms needs a broad coalition of advocates and allies

With Roe's reversal, the US will follow the footsteps of countries such as El Salvador, which has a complete prohibition on abortion. Dozens of women in El Salvador have been criminalised for obstetric emergencies, with some sentenced to 30 years' imprisonment. Many are from marginalised communities, with limited formal education. Criminal penalties for abortion providers, as well as for those seeking

---

OPINION Sabine Goodwin

A cursory national food strategy lacks substance and joined-up thinking


HORST FRIEDRICHS/ALAMY

Against the backdrop of a creaking charitable food aid system, the publication of a robust, ambitious, and far reaching food strategy for England was eagerly awaited.

The chancellor's measures on the cost of living crisis were a step in the right direction. There was clear recognition of the need to tackle financial insecurity with cash first interventions, although the scale of the UK's long term poverty crisis was cast aside. The government still insists the best route out of poverty is work, yet many people can't work owing to sickness or disability, and our members are supporting more and more people who have jobs but can't pay their bills.

This disregard for the long term poverty crisis, and its impact, permeates the national food strategy. Increasing benefit payments in line with inflation is welcome, but it overlooks the fact that people relying on the benefits system have struggled to afford food for more than a decade. What's more, if social security payments and wages don't match the rising cost of living then people are affected by real terms cuts. The strategy was an opportunity to develop a joined-up approach to improve the lives of whole swathes of our population who can't afford a healthy diet. There is no clear acknowledgment that food insecurity has an impact on physical and mental health.

Disregard for the long term poverty crisis permeates the strategy

The Henry Dimbleby review recognised that, "ideally, of course, the true cost of eating healthily should be calculated into benefits payments." Yet the white paper identifies no meaningful connection between ill health and the paltry sums on which people are expected to survive if they are unable to work or struggling to make ends meet while working. There's mention of Healthy Start vouchers, but no action plan to reduce the hurdles that families face to access these.

LI JIANGUO/XINHUA/ALAMY

care, violate the right to health and, ultimately, for many women and girls, the right to life.

Opening the door to abortion criminalisation raises red flags for decriminalisation efforts on other public health issues. Within the HIV response, for example, public health experts have seen the detrimental impact of punitive and criminal laws on people who use drugs and sex workers. Decades of work with these communities have resulted in global recognition of the need to decriminalise drug use and sex work. Dobbs undermines these efforts to take an evidence and rights based approach to build equitable health systems.

Post Roe, mitigating the harms requires a broad coalition of advocates and allies. Fighting for reproductive freedoms necessitates an interdisciplinary approach—one where healthcare providers and public health researchers work closely with communities and policy makers to craft laws, based on medical evidence, that respect individual autonomy, and that improve health outcomes for all.

Nina Sun, assistant clinical professor and deputy director of Global Health, Drexel University

Cite this as: *BMJ* 2022;377:o1588

The strategy refers to the need for "a sufficient, qualified, and well paid workforce to support every food and drink business" yet doesn't outline how to achieve this. It's vital employers pay a real living wage and guarantee job security. Interest in food poverty is too often limited to marketing and food bank support instead of preventing employees' food insecurity.

Another glaring omission from the strategy is the conflation of food waste and food poverty. The UK has inadvertently normalised surplus food redistribution as a feasible route to stocking food banks. However, "leftover" food for "left behind" people will neither address the underlying cause of a need for food aid nor reduce levels of surplus food.

Sabine Goodwin, coordinator, Independent Food Aid Network

Cite this as: *BMJ* 2022;377:o1549

▶ EDITORIAL, p 10

ACUTE PERSPECTIVE David Oliver

Is England's NHS too "top down"?

This month the government published Gordon Messenger's review of NHS leadership. One key finding is that managers spend too much time responding to pressure from politicians, regulators, and NHS England—creating an "institutional instinct" to please the NHS hierarchy and feed its demands, rather than prioritising the welfare of patients and frontline staff.

The NHS Confederation also said in February that "England has arguably the most centralised healthcare system in the developed world," urging the government to devolve more control to local systems. In 2020-21 the NHS budget in England (excepting targeted covid spending) was £157bn. The Institute for Fiscal Studies has estimated that by 2024-25 around 44% of all UK public spending will be on healthcare.

With Treasury funding at this scale and voters who tend to blame politicians for NHS failings, we shouldn't be surprised by repeated restructuring, calls for reform, or an insistence on better performance per pound spent. England's health secretary, Sajid Javid, reiterated this after Messenger was published, promising a "once in a generation shake-up." At the recent NHS Confederation conference he also said increasing health's share of public money would be unfair on young people, and the NHS instead needed to "improve productivity."

Major elective care backlogs, pressures on acute care, and serious staff shortages have exacerbated the situation. The Health and Care Bill 2022 explicitly gives back power to the health secretary to intervene in NHS operational matters. Simultaneously, however, it ostensibly devolves decision making and accountability to 47 regional integrated care systems—a concern for those who believe this will remove central political accountability.

Over the past few months a slew of directives from NHS England have illustrated the tension. These have included instructions to deliver elective work at 110% of normal levels, to "immediately stop all ambulance handover delays," and to treat at least 15% more covid patients at home. GPs have also had heavy handed directives about weekend opening and face-to-face appointments.

NHS England and NHS Improvement issued 40 pages of operational priorities for 2022-23 and a list of its "10 priorities," many short on feasibility, logistics, risk assessment, funding, or implementation support. This was followed by a lengthy plan from the Department of Health and NHS England to meet numerous waiting time targets for elective catch-up—seemingly without additional staff and resting on an enormous increase in productivity from those still left.

Between the politicians and national NHS bosses, I can't see the managerial and clinical leaders being given the freedom to plan and prioritise local services in the way the Health and Care Bill's architects claim to envisage.

If anything, we seem to have reached a new peak of meddling and pressure, which will place a greater burden on operational and clinical staff trying to make services work for patients.

David Oliver, consultant in geriatrics and acute general medicine, Berkshire
davidoliver372@googlemail.com
Twitter @mancunianmedic

Cite this as: *BMJ* 2022;377:o1550

I can't see the managerial and clinical leaders being given the freedom to plan and prioritise local services

PRIMARY COLOUR Helen Salisbury

The fallout of open access to notes

Patients now have access to their own medical notes, which is surely progress. More patients are now taking advantage of the ability to view all of the coded information in their GP record online—and this November they'll have access to all of the free text written in the consultation from that date onwards.

Leaving aside the question of ownership (is it the patient's record? Is it my record of an encounter with the patient?), if we want people to be active partners in improving their health rather than passive recipients of care, sharing information is a first step.

But there are unintended consequences. One is the demand for explanations. In an ideal world every test is explained to the patient, and consent is taken before blood is drawn. Even when I manage to do this there may be a need for more explanations when the results arrive. Among the dozens of laboratory results I file each day, many are just outside the normal range: a very slightly low sodium level or a subset of white blood cells just above the cut-off for normal. These I mark as satisfactory, but patients who are anxious, or simply pay attention to detail, often ask for further explanation and reassurance. A conversation about probability, normal distributions, and the clinical irrelevance of technical abnormalities can follow. I have no problems sharing my knowledge—but I just don't have time.

As junior doctors, we learn everything we write in a patient's notes may potentially be read by them and we should be polite and objective, backing up opinions with evidence. I may note mismatches between symptoms and signs when a patient who says that she's fine has nevertheless lost weight, or when the child with dreadful tummy ache clambers energetically onto my couch. Only a handful of patients have ever asked to read their notes, but when patients have routine access to everything we write, I fear I may have to spend more time explaining my record of the consultation.

Of course, it will be possible to hide some entries electronically, which is vital if they contain third party information, but a decision on this will need to be made for each consultation, clinic letter, or result. The rollout of full access has been delayed over safeguarding concerns: how do we protect the confidentiality of patients who may be in coercive controlling relationships? Do parents of a 14 year old have access to her record, and, if so, what implication does that have for access to contraception? More fundamentally, if there's a high likelihood that all notes will be viewed online, will GPs stop noting their "soft concerns" that are so vital in both child and adult safeguarding?

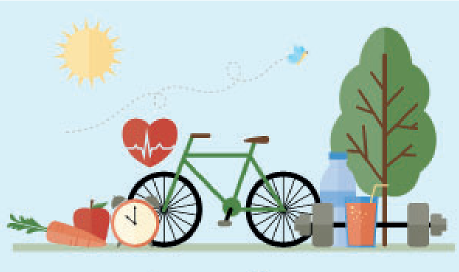
The Royal College of General Practitioners has yet to update its toolkit to cover these areas, but even with its advice I fear mistakes will be made in the pressured world of primary care.

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

Cite this as: *BMJ* 2022;377:o1570

I have no problems sharing my knowledge—but I just don't have time

LATEST PODCAST



Sharp Scratch: Do doctors do what they preach?

At medical school, students learn about the importance of healthy behaviours and how to promote them to patients during consultations. But do doctors always practise what they preach? The Sharp Scratch team discusses this question. Anisha Banerjee, a foundation year 1 doctor, describes how the discrepancy between a clinician's lifestyle and advice can create a tension:

"When you're transitioning into becoming a doctor, you think, 'Well, I'm supposed to be someone who has everything together, and I'm supposed to be the poster girl or boy for health.' It's really difficult when you're not feeling like that. You don't have time to work out. You don't have time to drink water or do any of the things that perhaps used to help you feel sane."

Erica Frank, a professor in the Faculty of Medicine at the University of British Columbia, offers some perspective on how your health habits can affect the way you counsel your patients:

"Our data have shown that what you do yourself influences what you typically talk to your patients about. So recognise that if it's hard for you, you're going to be less likely to talk to your patients about it. The most essential thing to do with this knowledge is to make sure that our patients still get our best advice, even if we're finding it personally difficult.

"We often get told that we have to portray ourselves as infallible, but it's clearly not the case. We have data that show that when we talk about ways that we've been able to overcome barriers and admit that we find it hard, that doesn't hurt our prospects of getting patients to do likewise. It actually helps our patients find us more believable and more credible and more motivating."

Listen and subscribe to *The BMJ* podcast on Apple Podcasts, Spotify, and other major podcast apps

Edited by Kelly Brendel, deputy digital content editor, *The BMJ*

ANALYSIS

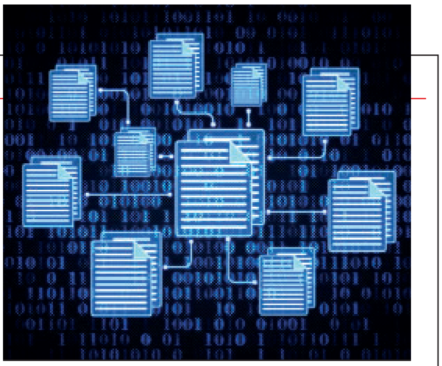
Healthcare systems must get fair value for shared data

Stephen Bradley and colleagues call for action to ensure equitable returns for patients and taxpayers from commercial research bodies

The threats to patient privacy from sharing data have been well publicised. By comparison, the risks of healthcare systems missing out on the gains generated from healthcare data have been largely overlooked. As well as potential benefits from improved treatment or diagnosis, research using patient data can bring financial rewards—for example, by selling artificial intelligence (AI) products the data are used to develop. The indicative market value of the data held by England's NHS has been estimated at £5bn if it were to be sold for commercial purposes.[1]

For cash strapped healthcare systems, stewardship of vast reserves of data presents opportunities for innovative collaborations with industry. However, they are not well placed to ensure fair returns. Although ethics committees examine the privacy implications of research using patient data, they do not generally consider protecting the value of data; nor are such committees well equipped to do so. Mechanisms need to be instituted to share revenues and access to new technologies that arise from private sector collaborations.

Vast reserves of data offer opportunities for innovative collaborations for cash strapped health systems



KEY MESSAGES

- Data from healthcare systems hold value for improving healthcare delivery and in the development of commercially successful products through private sector collaborations
- As well as safeguarding privacy, data sharing agreements must ensure fair benefit for health systems and the public
- Lack of commercial expertise and transparency risks health systems being disadvantaged in agreements
- Health systems and governments must establish terms for sharing data informed by extensive public, professional, and expert consultation

Government policy on collaborations

The UK government's strategy for the life sciences sector highlights the potential for the NHS to embark on partnerships with the business sector.[2,3] Launched five years ago as a cornerstone of the government's long term economic programme, implementation of the strategy has fallen short of its ambitions, with data sharing processes remaining inconsistent and unclear.[4]

In England, a recent review into use of healthcare data for research commissioned by the secretary of state for health and social care (the Goldacre review) called for these processes to be streamlined and clarified.[5] The report also advocates the creation of platforms through which healthcare data may be accessed and analysed. Such "trusted research environments" would ensure greater control over data by rationalising and regulating the types of information being accessed and preventing wholesale transfers of data. The report acknowledges that although trusted research environments can resolve privacy concerns, "there is a need for a frank public discussion about commercial use of NHS data."

Controversial collaborations

Several high profile transactions involving patient data have shown the need for accountability and transparency in terms of both the data shared and the value of what is received in return for patients and health systems. A collaboration between DeepMind (a subsidiary of Alphabet, owners of Google) and the Royal Free NHS Foundation Trust used patient data to create an app to identify acute kidney injury.[6]

The project entailed sharing a wide range of healthcare data on 1.6 million patients and was subsequently deemed to have proceeded without an appropriate legal basis.[7,8] A memorandum of understanding between both organisations set out the aspiration to establish a "broad ranging" partnership through which the trust would receive, besides bespoke software, "reputational gain" and a "place at the vanguard of developments in ... one of the most promising technologies in healthcare."[8] As DeepMind is an AI company and the app simply implemented an existing NHS algorithm, concern has been expressed that the company's motivation may have been to acquire data for machine learning research.[8,9]

Another DeepMind-NHS collaboration has used AI to predict progression to wet age-related macular degeneration through interpretation of optical coherence tomography scans—an application with substantial promise in establishing more consistent and efficient triage of patients in busy eye clinics.[10-12] DeepMind has made its AI model available to its NHS collaborator, Moorfield's Eye Hospital, but has not disclosed whether this access is time limited or under what terms it will offer this software to other NHS organisations or healthcare systems.[11]

Controversial collaborations are not confined to individual trusts. NHS England agreed a contract with Amazon that offered the tech giant access to "all healthcare information" aside from patient records, apparently with nothing in return for the health service.[13] Meanwhile, in the United States a partnership with the hospital chain Ascension that gave

Models of value sharing between health systems and private sector. Adapted from Ghafur et al[27]

Agreement	Description	Potential concerns	Example
No value sharing	Health system shares data for free	Health system receives no share of value of data	Amazon-NHS[13]
Free or discounted products	The product developed is provided to the health system organisation or to the whole of the health system for free or at a discount (for a defined or unlimited period)	No value captured from non-UK income. If the product is discounted or free only for one organisation, other organisations within the health service will have to pay	DeepMind-Moorfields[28]
Royalty or revenue share	Health system receives a royalty or a portion of the revenue from products developed using its data	Health system does not share ownership of the products being developed	Sensyne Health-Oxford University Hospitals NHS Trust (also includes equity share)[29]
Profit share	Health system receives a royalty or a portion of the profits from products developed using its data	Health system does not share ownership of products being developed. Value captured will depend on the profitability of the company, rather than product revenues	
Intellectual property ownership share	The health system receives partial ownership of the intellectual property generated	High cost and complicated arrangement	
Equity share	Health system receives a share of the equity of the company developing solutions from the data	Unappealing to established companies	Sensyne Health-Oxford University Hospitals[29]
Fee for access	Health system receives a one-off payment in exchange for access to the data	Depending on the pricing, health systems could get limited value. May penalise smaller companies that have less funding	Hospital Episode Statistics data from NHS Digital[30]

Google access to the detailed health data of millions of patients without their knowledge in return for data storage and software tools[14] has been investigated by the Department of Health and Human Services' Office for Civil Rights.[15]

It is striking that in these cases the data sharing arrangements came to light only after investigations by journalists. The resulting discussion has tended to be framed in terms of consequences for patient confidentiality, chiming with a critique of a business model that relies on extracting, combining, and commodifying personal data, something that has been described as surveillance capitalism.[16 17] The protections on healthcare data are more stringent than those for data which consumers have notionally consented to share. Nevertheless, even if these protections are followed, the lack of recourse to scrutinise the terms of data transactions, or even to discover that such agreements exist, is troubling.[6-19] The repeated attempts to institute routine sharing of English primary care data at scale show that it is not enough simply to demonstrate that such plans are not illegal.[20 21] Public and professional acceptance requires that any use of data for means other than that originally intended must be in service of the public good without disproportionately benefiting other interests.[22]

Obstacles to protecting the value of healthcare data

Several factors may prevent the value of health data being realised in collaborations with commercial partners. Unlike commercial companies, many healthcare providers lack specialist expertise in commercial law and intellectual property, making them vulnerable to asymmetric agreements that benefit private sector collaborators.[23]

Since agreements made with technology companies are often not made public, it is not possible to monitor whether they deliver proportionate value to taxpayers and health systems. The opacity of such arrangements has been likened to a "one way mirror" through which technology companies are able to analyse and profit from patient data but the public cannot see how the data are being used and what, if anything, the healthcare system can expect to receive in return.[8 24] Policy research has highlighted the need for greater accountability, and a recent public consultation emphasised that transparency is paramount throughout the data lifecycle.[25 26]

The opacity of such deals has been likened to a "one way mirror"—companies can profit from patient data but the public cannot see how the data are being used

Polling and qualitative research indicates broad support for sharing patient data with commercial partners provided that it delivers demonstrable public benefit and does not disproportionately reward private interests.[24] But defining what constitutes sufficient public benefit is challenging, and it will vary from case to case. However, we contend that satisfying this test requires more than the development of proprietary technology that could be used to improve patient care. When technology has been developed using patient data or co-produced using health system resources, the resulting value should be returned through proportionate mechanisms such as cost-free access to the technology or a revenue share for the health service (table).

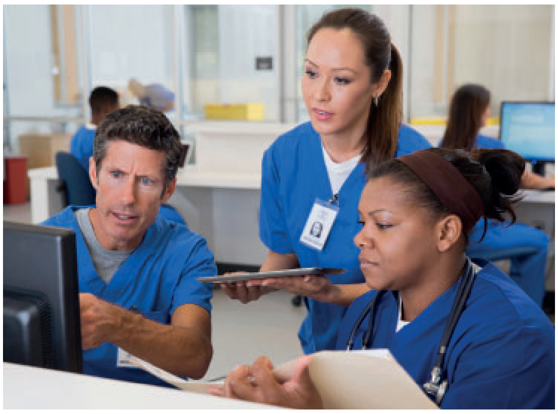
How should the value of data be protected?

Failing to protect health data as valuable public assets risks making taxpayers pay both to develop and to use novel technologies. This costly model of discovery is now entrenched elsewhere in medicine. Notably, the pharmaceutical industry deploys assertive pricing strategies for drugs developed from publicly funded research, and scientific publishers obtain research and editorial services from academics before selling this information back to the publicly funded institutions that employ those academics.[31-33] Much focus has been dedicated to highlighting and exploring potential remedies to these problems, including greater regulation and more assertive involvement of the state in innovation.[34 35]

The issue of safeguarding the value of healthcare data therefore resonates with wider concerns about profit from public assets being diverted to private interests. The nascent status of technologies such as AI presents an opportunity to formulate regulations and norms to protect value. But these issues are particularly complex with respect to healthcare data, not least because multiple organisations and individuals may be said to have contributed to data creation and curation.[36] We

Questions to address on collaborations using healthcare data

- What safeguards are necessary to fund costs for health services from collaborations, such as preparing data, to ensure resources are not diverted from delivering patient care?
- For the minority of ventures that return revenues, should these be returned to local health service organisations, to the central health service, or to the nation's treasury?
- What kinds of partnership models are suitable for small and medium sized commercial partners versus those that are appropriate for larger companies?
- Should preferential terms apply for domestic companies, as opposed to overseas firms, as a means to foster wider benefits to society and the economy, such as employment and taxation?
- Should organisations which act as subcontractors to health services, such as general practices in the UK, be permitted to negotiate value sharing collaborations independently?



ARIEL SKELLY/GETTYIMAGES

also currently lack frameworks to determine acceptable remuneration in cash, in kind (eg, access to products), or percentage stake in any resulting profits, that should be returned to health systems.

Formulating how health systems should share rewards resulting from collaborations using patient data is therefore far from straightforward. Innovations that have been created entirely independently and are simply validated in a healthcare setting could be judged to be analogous to devices or drugs, with the manufacturer retaining the prerogative to negotiate on pricing without reference to the contributions made by the health service in validating the technology. But, when health systems contribute substantial resources to evaluating new technologies, such as with the NHS Grail study which aims to detect cancer in asymptomatic patients using a novel blood test,[37] or when AI algorithms are validated or improved based on performance, there may be a rational claim to some form of reimbursement.

While most ventures using healthcare data will never prove profitable, there should not be a presumption that it is acceptable to harvest patient data for any innovation that might be commercially or clinically successful. Nor should healthcare systems be expected to underwrite the costs and risks of collaboration in the name of innovation. But there is a strong case that healthcare services and the public research institutes should share the benefit from any collaborations that do generate revenues because they will also bear the costs of efforts that are unsuccessful.[38]

This might be achieved through arrangements such as healthcare systems, or the state, taking an equity share in collaborative ventures.[27 38] Alternative means of sharing value more directly with patients who contribute data, rather than healthcare systems or the state, have been envisaged, including royalty payments to individual patients and creation of independent community development funds for relevant populations.[16-40]

As the Goldacre review highlighted, adequate consultation on these issues by governments and health systems is overdue.[5] Creation of frameworks to guide expectations of value sharing requires expertise and perspectives of ethicists, intellectual property specialists and healthcare technology specialists, industry representatives, healthcare staff, patients, and the public. Such consultations could include public deliberative procedures such as citizens' assemblies. The box lists some questions that could be considered. Experience, as well as numerous reports and consultations, have emphasised that giving the public a say in how people's data are used is crucial to establishing and maintaining trust, which is essential for fruitful collaboration.[5-41] Failure to invest the time and resources in adequate public and professional consultation to create a robust foundation for private-public collaboration using health data is likely to lead to greater cost and delay to innovation in the long term.

Healthcare systems should not be expected to underwrite the costs and risks of collaboration in the name of innovation

Healthcare systems need to invest in staff with expertise in negotiating intellectual property agreements to support those working for healthcare services who wish to use data in pursuit of innovation. Such agreements should be made publicly available. When centralised expertise is available to support health systems to collaborate with industry, organisations within those systems should be incentivised, or possibly even required, to accept that support, rather than striking deals on their own.[42] Central scrutiny bodies, such as the National Audit Office in the UK or the Government Accountability Office in the US could be responsible for ensuring adequate value is returned to the public realm through commercial partnerships.

Collaborations based around applying technologies such as AI to healthcare data promise to unlock new discoveries with both commercial and clinical value. But the public has a vital stake in determining how the value that results from such products is distributed and whether it is reasonable for such collaborations to proceed at all. Neglecting these legal and ethical frontiers in pursuit of innovation risks ceding valuable assets to private interests and could prove a costly legacy for patients and taxpayers.

Stephen H Bradley, clinical research fellow, University of Leeds
medsbra@leeds.ac.uk

Scott Hemphill, resident medical officer, emergency medicine, Sir Charles Gairdner Hospital, Perth, Australia

Sarah Markham, visiting researcher, visiting researcher, King's College London

Shivan Sivakumar, clinical career development fellow, University of Oxford

Cite this as: *BMJ* 2022;377:e070876

OPINION

I witnessed the horrors of offshore detention and am appalled by the UK's Rwanda plans

Australia's scheme is a chilling lesson on the impact on people's mental health, writes **Beth O'Connor**

I spent almost a year working with the Médecins Sans Frontières (MSF) team on Nauru, a small Pacific island nation where the Australian government was indefinitely detaining asylum seekers and refugees. We provided mental healthcare to the camps and Nauruans.

After witnessing the impact of offshore detention on the asylum seekers and refugees, I have grave concerns about the UK government's planned policy to forcibly remove asylum seekers to Rwanda.

During the 11 months I spent on Nauru, I witnessed high levels of depression, post-traumatic stress disorder (PTSD), anxiety, self-harm, suicidal thoughts, and suicide attempts among the 208 asylum seeker and refugee patients we treated. Among these patients, around 60% (124 patients) experienced suicidal thoughts and 30% (63) attempted suicide during our time on Nauru from November 2017 until October 2018.

Psychological damage

During consultations with the men, women, and children seeking asylum and refuge, I began to gain an insight into the psychological damage inflicted on them by not knowing their future or feeling like they had any freedom or agency. One patient told me they believed that if the Australian government could control their breathing, it would be in charge of that too. We found that having a lack of control over their life was associated with patients experiencing PTSD, depression, anxiety, suicidal thoughts, and suicide attempts. I saw how people's functioning steadily deteriorated, including their ability to care for themselves.

DAN PELED/EPA/SHUTTERSTOCK

> **Among our Nauru patients, around 60% experienced suicidal thoughts and 30% attempted suicide**

The severity and extent of mental illness among the people detained on the island was exemplified when a cluster of children developed a rare, life threatening psychiatric condition known as resignation syndrome. Ten children presented to us with symptoms of depression and social withdrawal, before progressing to refusing food and fluids, becoming bed bound, mute, and unresponsive. When children reach this life threatening state, they require extended time in hospital for supportive physical care, including nasogastric feeding, and psychiatric care. On Nauru this care was not available, and parents had to watch their child deteriorate while the slow process for seeking a transfer to Australia went through the court system. The parents' mental health understandably often deteriorated in response to this distressing situation.

Asylum seekers and refugees have generally experienced many traumas, first in their home country and then during their migration journey. Those on Nauru were no different, with 75% (155 patients) having experienced one or more traumatic events in their country of origin or during their journey. Unfortunately, the decision by Australia's government to send them to offshore detention exposed them to further emotional distress and physical harm, with 23% patients (47 people) experiencing physical violence in Nauru.

People need a safe environment to aid their recovery from past trauma, but this is impossible under such a system. Any detention setting—be it actual detention or "de facto" detention where people are taken against their will and removed from their families and support networks with no certain future—is an environment that not only prevents people's recovery from past traumas but creates further anguish.

We found that 37% of our patients (76 people) were separated from a partner, child, or other close family member. They expressed sadness, hopelessness, despair, and excessive guilt about their situation. I listened as fathers described how guilty they felt for not supporting their wife through the final trimester of her pregnancy and labour, and for not being there to witness their baby's birth, first smile, first word, or first step.

Unspeakably cruel

I saw how this detention system shattered people's resilience, identity, and hope. It is unspeakably cruel to send asylum seekers who have struggled to reach a place of safety, such as Australia or the UK, to a third country. No pharmacological treatment or psychological therapy can help the people kept in these environments to fully recover. Although we sometimes helped people to develop coping mechanisms, ultimately, the environment in which they were trapped continued to cause their mental health to deteriorate.

Asylum seekers and refugees who have experienced trauma should be brought to a safe place, where they can begin the difficult process of recovery, regain hope for their future, and have a meaningful life with their family. I am horrified that this cruel chapter of history is repeating itself, with the UK having learnt nothing from Australia's inhumane forced detention of asylum seekers and refugees in a third country, except how to attempt to replicate it.

Beth O'Connor, psychiatrist, New Zealand

Cite this as: *BMJ* 2022;377:o1502

LETTERS Selected from rapid responses on bmj.com

LETTER OF THE WEEK

Rising cost of living's effect on infant feeding

We at Feed—a charity focused on providing parents with information about infant feeding—are concerned by the cost of living crisis (This Week, 21 May). As a member of the Inequalities in Health Alliance, Feed is calling for a cross-government strategy to reduce health inequalities. The Marmot review found widening health inequalities and an effect on life expectancy, especially for women.

One indicator of the rising cost of living is the number of people turning to food banks. In 2022 the Trussell Trust saw a 14% rise in demand for food parcels from the previous year, with 832 000 parcels handed out for children.

As an independent charity supporting families with all infant feeding methods, Feed is especially concerned by the effect of poverty on the health of infants. We recently conducted an inquiry into the barriers faced by families in accessing formula milk. The inquiry highlighted that families with infants are forced to make choices between feeding, heating, clothing, and travel.

This echoed findings of the 2018 inquiry into formula poverty of the All Party Parliamentary Group on Infant Feeding and Inequalities—that families may resort to unsafe infant feeding practices when access to formula is restricted, negatively impacting on infant health.

Feed made recommendations, including adopting guidelines it developed in conjunction with stakeholders to support food and baby banks in providing formula to formula fed infants in poverty. In addition, it urged the exploration of other routes, such as pharmacy provision and ensuring local authority pathways are fully formed and comprehensive.

We recognise that, although third sector organisations have a crucial role, they are not a long term solution to poverty. There is an urgent need for a top down approach to tackle the root causes of inequalities and the subsequent impact on health.

Rosie McNee, co-founder; Erin Williams, co-founder, Feed

Cite this as: *BMJ* 2022;377:o1459

INITIAL HEALTH ASSESSMENTS FOR NEW MIGRANTS

Valuable beyond humanitarian contexts

Knights and colleagues are correct that "evidence regarding best practice for migrants as a patient group is limited" (Practice Pointer, 21 May). Because of this evidence gap, commissioned services are often driven by individual clinicians' and commissioners' desire to provide for humanitarian purposes, underpinned by the opinions of experts based on experience rather than empirical data.

Anyone working in this burgeoning "subspecialty" of primary care knows that initial health assessments are valuable beyond the humanitarian arguments. They are a cost effective alternative to frequent urgent care attendances for unmanaged chronic diseases and to multiple shorter primary care appointments that are inadequate to deal with the complexity of presentations.

Evidence on both the clinical outcomes and the cost effectiveness of initial health assessments is imperative to support commissioners in decision making, particularly as resettlement and dispersal accommodation become more widespread, away from larger cities with established migrant health teams.

Nathaniel J T Aspray, general practitioner and post-CCT fellow in migrant health, Gateshead; Joanna Dobbin, academic clinical fellow in primary care, London; Abigail Thompson, general practitioner and undergraduate general practice tutor, Newcastle on Tyne

Cite this as: *BMJ* 2022;377:o1475

THE DEATH OF THE DICTAPHONE

We lose medical secretaries at our peril

Morgan mourns the shrinking medical administrative workforce in favour of new technology (Matt Morgan, 21 May). Using speech to text is not new; 20 years ago, my secretary and I used ViaVoice software on a PC network. No one else in the health board would try it. One needed to spend an hour or two "training" the software by reading text samples aloud, then "teaching" it common technical terms and being consistent in one's diction.

After retiring, I found that contact with secretaries became the key to getting appointments, investigations, and results. The secretaries are no less busy than consultants, but their work allows more readily for interruption. Secretaries' work goes far beyond finding notes, booking clinics, and typing letters. We can no more run a health service without them than any other trained staff, but they are often not sufficiently visible to be regarded as vital. Lose them at our peril.

Gerald T Freshwater, occupational physician (retired), Lerwick

Cite this as: *BMJ* 2022;377:o1511

POLLUTION OF HEALTH DISCOURSE

Use the "devil's music" for emotional appeal

Maani and colleagues emphasise the need to reframe communication around the social determinants of health (Opinion, 21 May). Reframing still seems to be based on an appeal to the intellect first, but Daniel Kahneman and others make a compelling case for our immediate responses being emotional. These emotional responses determine which intellectual arguments we adopt.

Philip Morris's Marlboro Man relies on a series of images to trigger an emotional response. Despite the apparent success of government warnings and, more recently, graphic images on cigarette packets, these are not designed to have the emotional appeal of the advertising team's creation.

The devil has all the best tunes, and perhaps it is time to consider enlisting the expertise of successful advertising agencies to see if there is a better way to package subtle complex messages for greater initial emotional response. These can then be backed up with compelling intellectual arguments.

Sean Tierney, vascular surgeon, Dublin

Cite this as: *BMJ* 2022;377:o1469

OBITUARIES

Kenneth Chambler

General surgeon, general practitioner (b 1927; q Edinburgh 1951; FRCS Ed, FRCS Lon, MD, MCh Ed), died from myeloid sarcoma on 3 June 2021

Kenneth Chambler ("Ken") ventured to Galveston, Texas, USA, in 1960, undertaking research into the immunological response in burns patients. He subsequently established a general surgical practice. In 1967 he returned to the UK to undertake research at the MacIndoe burns unit in East Grinstead. After several more spells in Texas he retired from surgery in 1977 and took over a small GP practice in Heathfield, East Sussex. He expanded this over the following years, taking on four partners and setting up a purpose built surgery on the high street. He retired in 1992. In later years he settled in Eastbourne with his wife, Marion. Diagnosed with myeloid sarcoma in 2020, he leaves Marion, two sons, seven grandchildren, and two great grandchildren.

Andrew Chambler

Cite this as: *BMJ* 2022;377:o1316

Donald Lane

Consultant respiratory physician Oxford Radcliffe Hospital NHS Trust (b 1935; q Oxford 1960; DM, FRCP), died from dementia, covid-19, and pneumonia on 13 March 2022

In 1971 Donald Lane obtained consultant posts in general medicine at the Radcliffe Infirmary and in respiratory medicine at the Churchill Hospital, Oxford. He developed a particular interest in asthma and cystic fibrosis. He was president of the British Thoracic Society in 1994. He helped set up the National Asthma Campaign in 1990 and was its vice president for many years from 1993. He was instrumental, with Greta Barnes, in setting up the National Asthma Training Centre. Another of his lasting legacies is the Radcliffe Hospital Orchestra, which he started in 1978. Having retired to Deddington in 2000, Donald wrote a book and took composing lessons. Sadly, his last few years were diminished by dementia, but he enjoyed music to the end.

John Stradling

Cite this as: *BMJ* 2022;377:o1320

Aria Maheson

GP (b 1932; q University of Colombo, Sri Lanka, 1961), died from complications arising from bronchial carcinoma on 7 May 2022

Aria Maheson arrived in England in 1966 and worked across a variety of areas in hospital medicine, focusing mainly on infectious diseases. In 1977 he entered general practice and became a partner in a large practice in Coventry. Over the next 30 years he was an active member of the medical community in Coventry. During this period, he developed a special interest in the health of immigrants and refugees, especially those who arrived from Sri Lanka, and he developed close ties with the immigrant community. Aria was well regarded by the general practice community and retired in 2007. He leaves his wife, Loiswary; two sons, Mohan and Haran; and two grandsons.

M S Thambirajah

Cite this as: *BMJ* 2022;377:o1330

Conrad Michael Harris

Professor of general practice University of Leeds (b 1933, q Liverpool 1957), died from bronchopneumonia and bladder cancer on 30 April 2022

Conrad Michael Harris was a GP in Bootle, Merseyside, for 12 years. He went into academia in 1970 and was a senior lecturer in the department of general practice in Manchester for four years. He pioneered the use of professional actors, with video playback, in teaching consulting skills to undergraduates and trainees, and obtained a masters degree in education. In 1974 he moved to London to set up a department of general practice at St Mary's Hospital Medical School. In 1986 he took up the foundation chair of general practice in Leeds. He practised as a GP throughout his career. After retiring in 1998 he gained a London University Diploma in Asian Art. Predeceased by his wife in 1996, he leaves three children and five grandchildren.

Mark Harris

Cite this as: *BMJ* 2022;377:o1319

Alun Owen Davies

Consultant anaesthetist (b 1936; q Cambridge/London, 1961; DA Eng, FFARCS), died from pulmonary fibrosis on 4 February 2022

Alun Owen Davies met his future wife, Angela, when they were medical students together at Westminster Hospital Medical School. They celebrated their 60th (diamond) wedding anniversary in 2021. Alun enjoyed student life in London, especially the Westminster annual pantomimes. In 1969 he was appointed consultant anaesthetist to the North Staffordshire Group of Hospitals. Having taken early retirement in 1992, he obtained a masters in local history from the University of Keele after his health had improved. He published *The North Staffordshire Royal Infirmary* to coincide with that hospital's bicentenary. Alun enjoyed teaching medical students at Keele and giving lectures to local societies. He read widely and was a good raconteur. Alun leaves Angela, two sons, and four granddaughters.

Angela Davies

Cite this as: *BMJ* 2022;377:o1331

Stephen Furniss

Consultant cardiologist Eastbourne (b 1954; q Downing College, Cambridge/Royal London Hospital, 1979; MA Cantab, FRCP), died unexpectedly from ischaemic cardiac arrest on 14 May 2022

After qualifying in London, where he met his future wife, Shelagh, on his first day, Stephen Furniss ("Steve") moved to Newcastle, where he worked as a cardiologist at the Freeman Hospital for 22 years. He loved the time he spent teaching medical students in Newcastle, before moving to Eastbourne District General Hospital to set up an electrophysiology unit in 2008. As a past president of the British Heart Rhythm Society, Steve was passionate about both clinical electrophysiology and service delivery and spent his years in Eastbourne setting up and delivering an excellent atrial fibrillation ablation service. He retired on 1 April 2022 and spent six weeks happily travelling, golfing, and gardening. He leaves Shelagh, two daughters, and one granddaughter on the way.

Rosanne Furniss

Cite this as: *BMJ* 2022;377:o1317

OBITUARIES

James Appleyard

Global leader in child health, medical education, and human rights

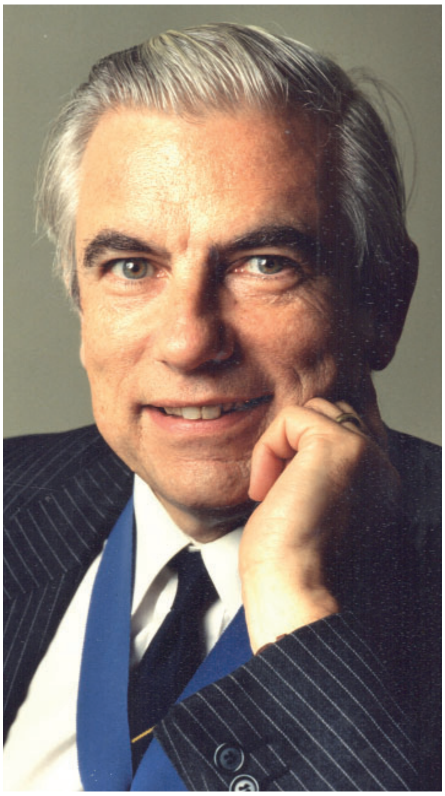
William James Appleyard (b 1935; q Oxford/London, 1960; MA, MD, FRCP, FRCPCH), died from colon cancer on 29 January 2022

A charming, charismatic paediatrician, James ("Jim") Appleyard would "request an opinion" rather than "ordering an x ray," according to his radiologist colleague Stuart Field. This reflected his passionate commitment to teamwork, respect for all perspectives, and hatred of hierarchal organisations.

But Appleyard was also known in the 1960s and 1970s as one of medicine's "angry young men," even though he rarely lost his temper. His wife, Liz, to whom he was married for 58 years, insists that he was more of a "caring young man." In the 1970s he was one of the primary movers in the refusal by junior doctors to pay the General Medical Council's retention fee. A powerful orator, he let loose publicly about senior doctors exploiting juniors. Writing in *The BMJ* in 1976 about the Labour government's proposals for private practice in the NHS, he declared, "To leave the matter in the hands of politicians in parliament would be a total abrogation of professional responsibility."

In a characteristic understatement his curriculum vitae described him as "having developed challenging views about the funding of health services." Writing in the *Lancet* in 2006, he said, "Sitting on the old GMC for 19 years, I witnessed the increasing political influence on medical regulation. In my view, the GMC is no longer the custodian of the medical profession's conscience. Radical revision is required. As has previously been suggested, a physician's conduct should be judged by an independent medical tribunal chaired by a barrister instead of the current politically correct 'star chamber.'"

His wife said that his so-called anger had its roots in a desire for change. She became aware of it in Louisville, Kentucky, where he spent a year training at the Children's Hospital shortly after qualifying. The hospital had a "properly structured training programme" in paediatrics (and other specialties) that put UK training in the shade. Appleyard repeatedly asked, "Why don't we have something like this in the UK?"



James Appleyard was known in the 1960s and 1970s as one of medicine's "angry young men"

Kent and Canterbury Hospital

On returning to the UK and recognising that he would be unable to introduce transformative change within a London teaching hospital, he sought a provincial centre to make his mark.

In 1971 he became the sole consultant paediatrician at the Kent and Canterbury Hospital, whose remit included Ashford, Dover, Folkestone, and Margate. The neonatal intensive care unit was a one cot "cupboard." Using the Kentucky model, he established in 1973 one of the first special care neonatal units outside London. This followed the foundation in 1972 of the Mary Sheridan Centre for children with disabilities, the first such UK centre outside London. Underlining Appleyard's passion for teamwork, the centre—unusually then—brought together different specialisms, such as physiotherapy and occupational therapy, under one roof.

Appleyard was a renowned teacher. His mantras were "listen to the mother" and "listen to the children at their eye level." In April 2021 Appleyard received the prestigious ICPCM Paul Tournier prize for "his stellar work on ethics as a keystone of medical practice and research and the advancement of education at the core of person centred medicine."

Medical politics

Appleyard's dedication was legendary in Canterbury, and he was loved for it, by both colleagues and patients. Heavily involved in medical politics, he would spend at least a day a week at the BMA before returning to Canterbury for late night ward rounds. The idea of a district hospital paediatrician assuming prominence within the British Paediatric Association (BPA) defied tradition: distinguished teaching hospital luminaries had tended to hold sway. But Appleyard was elected to BPA office in recognition of his growing sway within the BMA and his aspiration to enhance the political standing of paediatrics.

Under his influence the two bodies ran campaigns to promote community paediatrics and paediatricians. There are now more than 20 paediatric consultants working in Ashford, Canterbury, Folkestone, and Margate. Much of Appleyard's influence came from the five years he spent as a treasurer of both the BPA and the BMA.

As a prominent member of both bodies, one of his biggest challenges was to reconcile the discord between paediatricians and police surgeons involved in the 1987 Cleveland child sex abuse scandal. A controversial diagnostic test at Middlesbrough Hospital resulted in about 120 children going into care. The Butler-Sloss inquiry in 1988 concluded that most of the diagnoses had been incorrect.

Appleyard and his consultant colleague Mark Rake, a gastroenterologist, were among the drivers of the Kent Institute of Medicine and Health Sciences at the University of Kent, the precursor to the Kent and Medway Medical School, which opened in 2020.

James Appleyard leaves Liz, three children, and six grandchildren.

John Illman, London
john@jicmedia.org

Cite this as: *BMJ* 2022;377:o863