comment

> Decisions in general practice are often as frequent as our heartbeats. We are calculated risk takers. It's impossible always to make the right call

NO HOLDS BARRED Margaret McCartney PPA COLUMNIST OF THE YEAR

Breaking down the silo walls

The "silo mentality" in medicine, in which information is kept secret from others in the broader team, is rightly castigated—for example, NHS organisations not sharing data, or separate professional workforces duplicating work without sharing results. Silos need breaking open, but the NHS creates and enforces these working patterns daily.

Take, for example, the worthy campaign to reduce antibiotic prescribing. Quite right: this should lead to fewer drug resistances. But there's also a campaign to recognise and treat potential sepsis earlier—with antibiotics. The two campaigns inevitably conflict.

Or consider the push for patients to be screened. Requiring specific numbers of people to take tests goes against the General Medical Council's requirement that people should make informed choices about tests or treatment.

I attend meetings to discuss alternatives to hospital referrals—yet we GPs are warned that we must refer patients with cancer urgently.

Here are the real silos: structural pushes and pulls by one group working towards its aims will, in effect, conflict with another group. "But no!" they cry: "We don't mean each other any harm. We mean to reduce the number of inappropriate antibiotics. We don't mean to force screening on anyone. And how dare you suggest that, by encouraging GPs to use resources carefully, we're delaying cancer diagnoses."

Often the people in one silo don't know about their opposite numbers, let alone what they're saying or what influence they exert. But GPs do: we have to manage these conflicts every day with our patients. Anyone can become septic from an infection that seems to be low risk and viral but later becomes bacterial and lethal. (And evidence shows that reductions in antibiotic prescriptions are associated with small increases in pneumonia and peritonsillar abscess.) We compare our referral rates with those of other practices, but it's impossible to know whether high rates are good or bad—do they represent patient choice or doctors' unnecessary doubt?

Decisions in general practice are often as frequent as our heartbeats. We are calculated risk takers. It's impossible always to make the right call. GPs are used to being judged by specialists and found variously wanting. That's because we exist among the silos, from which people rarely look out.

It doesn't have to be this way. The time has come for GPs to be authors of their own clinical guidelines, looking to the silos for dialogue and information. We need to accept that good doctors practising good medicine can't be right the whole time. These conflicts are inherent to medicine and can't be broken down; but, with a little more generalism, some of the silo walls could be.

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YANKEE DOODLING Douglas Kamerow

What do we need to know about the presidential candidates' health?

Standardised information may not really help

In the circus that is the 2016 US presidential election campaign, one of the newest sideshows has been the issue of the health of the candidates.

Hillary Clinton, now 68, began her campaign in 2015 by releasing a conventional report from her doctor describing recent examinations and her overall physical fitness to serve as president. This was updated in the past few weeks to include a discussion of Clinton's widely publicised case of pneumonia and a recent sinus and ear infection.[1] These became especially relevant because of Donald Trump's continuing insistence that Clinton does not have the "stamina" to be president.

Trump, 70, at first refused to release his own medical records, instead publicising a rather strange letter from his doctor stating that Trump would be "the healthiest individual ever elected to the presidency."[2] Then he selected the television doctor Mehmet Oz, hardly a bastion of medical accuracy,[3] to perform a televised review of systems and an off the cuff evaluation of a set of laboratory test values that Trump supplied.[4] Weird.

We can laugh at these shenanigans, but that obscures a serious question: how much should the public know about the health of candidates for president? Would it matter if we had standardised health information about all the candidates?

History supplies some cautionary tales of public lack of knowledge about presidential health. Woodrow Wilson was in poor health even before he had an incapacitating stroke in 1919, after which he went into seclusion for the rest of his last term. His deteriorating health was hidden from the public. John F Kennedy is now known to have had undisclosed adrenal insufficiency and was taking literally dozens of drugs, some appropriate medications, others stimulants and vitamins, during his presidency. Other recent presidents have had major medical events—myocardial infarctions, colon cancer surgery—while serving in office. Could any of these problems have been prevented by better disclosure while they were candidates?

What purpose, other than vague reassurance, would a "clean bill of health" in a candidate provide us?

I am not sure they could have. Certainly today's constant glare of press attention would make hiding a sitting president's diagnosis, treatment, or disability virtually impossible. Also, the 25th amendment to the Constitution, ratified in 1967, provides a clear path for removing a president who is incapacitated, even if he or she does not agree.

But what purpose, other than vague reassurance, would a "clean bill of health" in a candidate provide us? What level of blood pressure or

ACUTE PERSPECTIVE David Oliver

Treating NHS staff fairly when things go wrong

In some recent high profile NHS scandals patients and their families have been failed horribly—think Mid Staffs,[1] Morecambe Bay,[2] and Southern Health.[3] Hurt can be compounded by complacent, obfuscatory responses to complaints.[4]

It can be hard to defend the reputation of NHS staff amid justifiable anger. You can't redress wrongs for one group by wronging another, but rebalancing the perspective can bring accusations of insensitivity.

The NHS constitution sets out rights for employees and patients.[5] Simplistic narratives focusing on individual accountability aren't always fair to staff, and it shouldn't be taboo to say so.

Simplistic narratives focusing on individual accountability aren't always fair to staff, and it shouldn't be taboo to say so

Practitioners' and managers' lack of accountability often features in heated discussions about health services. Definitions of "accountability" encompass being responsible for your actions, giving satisfactory reasons for them, and disclosing information readily.[6,7]

I'd say that senior NHS executives are hugely accountable for their organisation's performance. Their work is high profile, in a business where people using the services are often emotionally distressed, and it is subject to constant media and regulatory scrutiny and political interference. Underfunding, rising demand, and workforce gaps add to the pressure. Tenure in such roles is often short. Vacant posts are hard to fill.[8]

Frontline clinicians are also accountable for their practice, requiring serial qualifications, mandatory training, revalidation, and continuing professional development. Registration means that regulators can investigate, prevent, or restrict practice. A new statutory duty of candour exists.[9] Negligence law applies—sometimes criminal.[10,11] And staff who commit criminal offences are as accountable as any citizen, with extra consequences for their registration.

Nonetheless, complaint handling in the NHS can leave much to be desired.[4] Prompt, transparent,

RICK WILKING/AFP/GETTY IMAGES

cholesterol or blood urea nitrogen would be acceptable—or disqualifying—for a candidate? Some have suggested that a blue ribbon commission be named to define what health information the candidates should disclose and then perhaps also serve as interpreters of these data to the public.[5]

This sounds like a good idea at first, but I'm not sure it would accomplish anything. We're not very good at predicting the future health of individuals. Most of our data are adequate for populations, but is there really an important difference between a 3% and a 5% risk of a heart attack in a person over the next five years? Can't we just leave it to the candidates to supply whatever health details they consider appropriate to the public and judge them on that?

I think Trump's unconventional, reality television method of revealing his health status was very much of a piece with the rest of his inappropriate candidacy: poorly prepared, offensively focused on him, insulting to the intelligence of viewers, and ultimately inadequate and unsatisfying.

What more do I need to know about his fitness for office?

Douglas Kamerow, senior scholar, Robert Graham Center for policy studies in primary care, professor of family medicine at Georgetown University, and associate editor, *The BMJ*

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rigorous investigation should be fair to all parties. Some allegations are demonstrably false or unfair, or they rest on misunderstandings rather than substandard care. A response to a complaint that doesn't unconditionally accept and apologise for every allegation, or which sometimes argues back, isn't necessarily a cover-up or a sham.

Adverse incidents and failures in care can create "second victims" of staff experiencing guilt, loss of confidence, or threats to their career.[12] They may not be able to respond to media or online slander without breaching patient confidentiality or employer protocol.

Although some errors are clearly down to individual incompetence or poor behaviour, wider system factors may be to blame, such as staffing gaps, poor supervision, or unmanageable workload. Saying so is not an excuse. But fair treatment fosters good workforce morale and wellbeing and an open, "no blame" culture for reporting incidents, which helps to improve patient safety.[13]

Despite a febrile atmosphere around failings in healthcare, a fair discussion shouldn't mean ignoring the problems identified. An excessive focus on individual blame won't deliver the constructive solutions we need to improve care.

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BLOG OF THE WEEK Mary Higgins

Breaking bad news in maternity care

There's one thing I really hate about my job, and that's a particular phone call. A midwife will ring and ask if I can come down straight away. A woman has presented because her baby hasn't moved in a couple of hours, and the midwife can't hear a heartbeat. As I enter the room a woman there, hopefully with someone, looks up as I walk in. Her face tells a story—fear, hope—and what I say next will be remembered for the rest of her life.

I have attended many seminars and workshops on how to break bad news. I have read numerous articles and research papers. I have taught medical students and trainees how to care for women with pregnancy loss. And there are two truths that I have learnt over the years.

The first is that I am always a novice at this and will remain humble for the rest of my professional life—always willing to learn how to do this better. The second truth underlines the first: there is no right answer that is suitable for every family. Care needs to be tailored to meet the individual needs of each woman, each man, each grandmother, grandfather, sister, brother, friend, child.

When I can't fix something, the next thing I have to do is care. To hold a hand and listen

The UK Miscarriage Association recently released a series of short educational reviews of communication at different stages of early pregnancy care: in an ambulance, the emergency department, and the ultrasound department. They are strong, powerful, upsetting, and thought provoking videos, with important teaching points. The first is to listen to the woman—and her partner—about what they need.

The second is a harder lesson to learn. As a doctor I want to be able to stop miscarriages, make ectopic pregnancies move into the uterus, turn molar pregnancies into healthy babies, prevent congenital heart disease from ever starting, stop the neural tube defect, take away an extra chromosome, prevent preterm delivery, identify every baby that isn't tolerating labour, stop all neonatal infections. Many of us are actively working on education and research in these areas, but the research isn't yet at the stage that we can put it into practice. Some of these problems will inevitably lead to loss.

And when I can't fix something, the next thing I have to do is care. To hold a hand and listen. To make a cup of tea. To give people some privacy. To write information to be brought home. To write a letter for work, if appropriate. To keep people company. To say I am sorry this has happened to you and that I recognise your loss.

I have watched midwives, junior and senior, do this beautifully—medical colleagues who have shown their humanity in their care of bereaved women. I have listened to friends and family talk about their experiences of care. I wish to learn from what we do well so as to practise excellence. And I am not perfect at this, but I am trying.

Mary Higgins is an obstetrician at the National Maternity Hospital, University College Dublin

ANALYSIS

Realising the health benefits of sharing data

Accessible data are not enough. We need to invest in systems that make the information useful, say **Elizabeth Pisani and colleagues**

As little as a decade ago, many researchers working in global health recoiled at the idea that they should openly share individual patient data with one another. Now, data sharing is being herded into the mainstream by pioneering researchers, with added pressure from funders, medicine regulatory authorities, public health agencies, and medical journals.[1-6] But even those researchers most willing to share data are given little guidance on how that should happen, and the practice is still unusual, especially in low and middle income countries.

Concerns continue to be raised that researchers in poorer countries will lose control of their data and get little in return. Some fear that data sharing might harm patients and communities by breaching confidentiality.[7]

Our group includes researchers working for academic and humanitarian organisations, as well as public, charitable, and industry funders of data sharing efforts. To what extent have the fears about data sharing been realised in our work and what is needed to get the most value out of shared data?

Why share?

Data sharing is often asserted to be good for health.[14] We found many examples where analyses of pooled data provided new information relevant to appropriate dosing, improved treatment of subgroups, and the development of new treatments.[15-18]

One example is a meta-analysis of individual patient data from a large and diverse population of patients shared through the WorldWide Antimalarial Resistance Network.[19] The meta-analysis revealed that treatment failure associated with a lower dose of piperaquine was particularly dangerous in young children, and contributed to a revision of the World Health Organization's malaria guidelines.[20]

We also identified areas where the failure to share data has disrupted efforts to respond rapidly to outbreaks or foreclosed more detailed evaluation of interventions that may be harmful.[21,22] In these cases, not sharing data has been bad for science and almost certainly bad for health—for example in the 2014 Ebola outbreak in west Africa.[23] In discussing data sharing policies, we propose classifying shared data as accessible, usable, or useful, as shown in the box.

Developing and maintaining curated platforms for "useful" sharing of data tends to be expensive. Data from different sources, often collected in different formats using different protocols and endpoints, must be quality controlled and standardised so that analysis can be performed across studies.[25] The upfront costs of developing community standards and networks of collaboration can be high. However, once these investments have been made, the time and effort required by potential users is relatively low, and the potential for data to be reused in ways that benefit public health is high, making the investments cost effective.

Datasets and even data repositories have multiplied so rapidly and chaotically that one of our group likened them to an asteroid field

Currently, most efforts to standardise clinical data in this way occur within consortiums or networks of people with similar interests who work together to formulate new questions and to answer them in contextually appropriate ways. Data shared in these networks may thus not always meet the journal's transparency criteria.

Replicate analyses have been done with usable datasets, and their open availability promotes transparency in research. Drug companies have recently taken a lead in making data from individual clinical trials available in increasingly usable forms.[26,27] The first evaluation of prominent platforms for sharing clinical trial data found that, although individual patient data from more than 3000 trials had been made available to investigators over the past two years, only

KEY MESSAGES

- Simple accessibility of data is enough to promote research transparency; public health gains require more complex models
- Meaningful and equitable collaboration with local researchers and policy makers in low and middle income countries is needed so the right research questions get asked and research results are used
- Useful data sharing requires long term investment in infrastructure, networks, and scientific careers, including in the data sciences
- It is not enough to share data: we need to share governance structures, scientific questions and ideas, and interpretation

Levels of data sharing

Accessible—online repository

Usable—repository with discoverable, well documented metadata

Useful—data are curated, standardised, and comparable across time and place

15.5% of the trial datasets had ever been requested.[28] Most proposals focused on new analyses rather than validation of study results, and only one of the proposals led to a published pooled analysis.[29] These repositories are only recently established, however, and data requests are on the rise.[30]

Power of technology

Datasets and even data repositories have multiplied so rapidly and chaotically that one of our group likened them to an asteroid field. Better technology and metadata standards—especially common search portals, improved discoverability, and tools for reliable anonymisation and standardisation of heterogeneous data—could begin to reshape the asteroid field into an organised solar system.

Developing that solar system and keeping the planets in orbit will require substantial long term investment. In recent years, the pharmaceutical industry has expanded efforts in data transparency and has begun data standardisation and curation in fields such as oncology. In some cases it is outsourcing this work to academic institutions—for example, the YODA platform held at Yale. There is scope to expand these public-private partnerships using fees from well resourced diseases to subsidise curation of data for conditions with less commercial appeal.

Do no harm

Concerns that patient confidentiality and consent may be breached are often cited by researchers as a reason for not sharing data.[13] Several of us have been sharing data for a decade or more, including around illicit behaviours and stigmatised diseases.[31] We could find few examples of harm—certainly far fewer than examples of benefits—partly because we have strong governance structures. We have also consulted with patients and communities because we believe that efforts to expand data sharing can succeed only with broad social support.[32] While governance structures for secondary analysis should be simplified so that they are proportionate to the often more limited risks of data reuse, they must remain robust.

Equity in research

A common generalisation in discussions of data sharing is that it undermines the career prospects for researchers, especially in low and middle income countries, exposing them to "research parasites" who will use their data to beget papers for high impact journals.[33 34] We could find no evidence for this. When well documented data are shared usefully in professional networks, our experience is that sharing has increased our work's visibility and expanded our collaborations.[13 35]

Changing the incentive system to reward the publication of quality assured datasets with standardised metadata in the same way that we reward the publication of research papers in high impact journals would go a long way to damping down the panic about data parasites.

A data sharing solar system

In our experience sharing data can lead to advances in knowledge that wouldn't have been possible without bringing those data together. But knowledge improves health only if it leads to changes in policy and practice.

Most examples of policy change based on analysis of shared data in low and middle income settings involve compendiums of datasets that are quality controlled, standardised, and otherwise highly curated.[15-20] In general, the analyses are performed in collaborations between global disease experts and local researchers who know their contexts well and who help formulate questions and answer them. These researchers can also act as a bridge to national policy makers, ultimately delivering changes that benefit the populations from which data were collected.

This sort of sharing requires far more effort than simply uploading a dataset to an online repository. Useful scientific collaborations are expensive to develop and require a shift in attitudes, incentives, and investment patterns. A degree of technical and economic efficiency may have to be sacrificed in the interests of fostering collaboration and equity—for example, by investing in building skills in high disease burden countries rather than using skills already available in industrialised countries. The peer reviewed research results paper must lose its supremacy as the major metric of scientific productivity; and funders must commit to long term investments in both technical and human infrastructure.

This cannot happen for all diseases or all types of data at once—it is just too expensive. The alternative is not, however, to downgrade to a usable (but not used) or accessible (and not usable) model of data sharing. Rather, we must think in fresh ways about how existing structures can be made more useful to maximise health gains.

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OBITUARIES

Derek Charles Barker

General practitioner (b 1922; q Middlesex Hospital Medical School, 1947; MRCS, DRCOG), died from a ruptured abdominal aortic aneurysm on 29 July 2016.

Derek Charles Barker ("Charles") trained as a general practitioner under H M Harris in Forty Lane, Wembley Park, Middlesex, in 1950. He bought the house and practice in 1958. In 1968 the practice moved into the new Chalk Hill Health Centre, where Charles practised until he retired in June 1985. He was offered the membership for a £5 fee when the Royal College of General Practitioners was founded, but declined to join yet another college, not realising that he would no longer be eligible to take on trainees. In 1988 Charles moved to Yelverton near Plymouth, where he enjoyed his garden and visits from friends and family. He eventually became housebound but retained a wonderful memory and sharp wit. He leaves his wife, Patricia; two children; seven grandchildren; and four great grandchildren.

Philip Barker, Sheila Barker

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Alfred Leonard Gordon Smith

Consultant psychiatrist and physician superintendent Storthes Hall Hospital, Huddersfield (b 1922; q Glasgow 1946; FRCPsych), d 22 June 2016.

Leonard Smith was a founder fellow of the Royal College of Psychiatrists

After training in Manchester and Norfolk, Alfred Leonard Gordon Smith ("Leonard") worked at St Andrew's Hospital in Northampton before moving to Huddersfield, where he took on the task of improving clinical care for and living conditions of more than 2000 patients. He worked tirelessly and achieved considerable progress, eventually preparing for the hospital's closure. Leonard was elected a founder fellow of the Royal College of Psychiatrists. He was secretary of the Yorkshire Region psychiatrists' group, president of Huddersfield Medical Society, and clan chief of the local St Andrew's Society. Margaret, his first wife, predeceased him. He leaves his wife, Deirdre; a daughter; and two grandchildren.

Michael Hill

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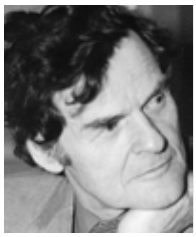
Michael Whiting



General practitioner (b 1917; q Leeds 1941; DA Eng, FRCGP), d 15 July 2016.

John Michael Sturge Whiting ("Michael") took over a large singlehanded country practice in North Cave in 1947, a year before the NHS was created. By the mid-1950s he had formed an alliance with two neighbouring singlehanded practices to share the on-call commitment and some of the administrative work. Michael had an enduring relationship with the Beverley Westwood Hospital, where he did sessions and emergency work as senior hospital medical officer in anaesthetics. He also found time to work as prison medical officer at the local borstal. Stepping back from the practice at the age of 67, he devoted his retirement to bringing up the youngest of his children. He leaves his third wife, Rita; five children; and four stepchildren.

John Keel, Bill Hart

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Claire Thomas

Consultant anaesthetist Calderdale and Huddersfield NHS Foundation Trust (b 1969; q University of Nottingham 1994; MSc, FRCA), d 11 September 2015.

After completing her anaesthetic training rotation in the Yorkshire Deanery, Claire Thomas worked as a ship's physician for Carnival cruise liners, sailing the Caribbean Islands. Before securing her consultant post in 2008 she spent time travelling and working around the globe, including in war torn countries such as Sierra Leone. Claire enjoyed a broad anaesthetic practice but had a special interest in obstetric and paediatric anaesthesia. She had a full and varied social life and was well known for her cooking and hosting skills. She had a flair for design and was an exceptional dressmaker and artist, as well as an enthusiastic musician and singer. She had a passion for the outdoors, which she enjoyed with her beloved dog, Daisy. She leaves her mother, sister, brother, niece and nephew, and lots of good friends.

Kirsteen Briscoe, Richard Briscoe

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Eleanor Mary Briggs

Senior clinical medical officer, family planning service, Glasgow (b 1938; q Glasgow 1961), died from metastatic carcinoma on 3 August 2016.

Eleanor Mary Briggs (née Clarke) initially fitted working as a schools' doctor around bringing up her young family, but it was when she joined the Brook Advisory Service in 1969 that she found her niche. She subsequently joined the family planning service, which was assimilated into the Greater Glasgow Health Board. Eleanor would be proudest of her work in the community, primarily in the Drumchapel area north of Glasgow, where she was part of a multidisciplinary team, managing patients in the clinic and in their homes, where the environment could be challenging. Eleanor enjoyed passing on her knowledge and skills. Her influence was such that she inspired one of her daughters in law to follow her into sexual health medicine. She leaves Douglas, her husband of 54 years; five sons; and 11 grandchildren.

Michael Briggs, Paula Briggs

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Peter Hall

Consultant psychiatrist (b 1931; q Birmingham 1955; PhD FRCPsych), d 7 August 2016.

Peter Hall was born Peter Hecht in Czechoslovakia. He and his family escaped to England after their home was ransacked by the Gestapo. After qualifying he completed a PhD on the mental health effects of environmental noise. From 1963 to 1991 he was senior consultant psychiatrist at Worcester Royal Infirmary. He oversaw some of the earliest asylum closures and resettlement and rehabilitation of patients in what was to become a blueprint for the subsequent movement towards "care in the community." Peter was regional tutor in psychiatry in the West Midlands and the University of Birmingham's adviser on psychiatry from 1986 to 1991. After retiring from the NHS, he was medical director of the Woodbourne Priory Hospital, Birmingham, for seven years, where he specialised in treating eating disorders. Predeceased by a son in 2000, Peter leaves his widow, Gwynneth; two sons; and six grandchildren.

Robert Howard

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Peter Draper

Public health campaigner who opposed the "marketisation" of the NHS

Peter Allan Draper, public health physician (b 1933; q Cambridge 1962), d 30 July 2016.

When working as a physician in Manchester hospitals in the 1960s Peter Draper was struck by the variety of factors that brought patients to clinics. And he was horrified by the anger of the senior colleague whose waiting list he had cleared while covering the doctor's holiday. These influences prompted a switch to community medicine and an enduring aversion to private practice and what he saw as the creeping privatisation of the NHS.

In a blog for Doctors for the NHS (previously the NHS Consultants Association) in July 2016, Draper, aged 83, warned of the critical state of health and social care in the UK. "Despite the international evidence, the right in the UK tends to react to increasing healthcare costs by implementing privatisation, cutting services, and closing hospitals, even though we are seriously 'underbedded' in comparison with many countries," he said.

In 2012 he was one of more than 100 signatories of a letter in the *Guardian*, opposing the forthcoming health and social care bill as "marketisation" leading to "fewer, less qualified staff, on lower terms, offering a more restricted and lower quality service."

"Raising hell to reach heaven"

After Manchester, Draper moved to Guy's Hospital medical school in London, where he was lecturer and senior lecturer in community health, before founding the unit for the study of health policy in 1975.

Funded by the King's Fund, the unit aimed to research environmental, economic, and social influences on health and underlying inequalities and provoke public debate on public health. Topics studied included the effects of transport policies, economic growth, unemployment, nutrition, NHS organisation, and media reporting of health.

Effective public health was never conventional wisdom but, rather, "raising hell to reach heaven," Draper and colleagues pointed out in a paper in *The BMJ* in 1980.

They argued that the public health tradition was moribund and that all social change would be opposed by conservative forces in society. The paper called for healthier school meals, more wholemeal products, and recognition of the damaging effects of unemployment.

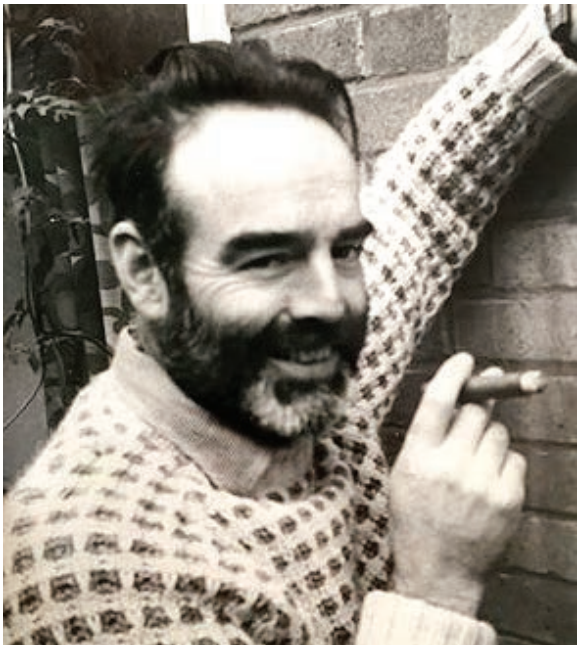
Young researchers employed by the unit included: James Partridge who went on to found the charity Changing Faces; Jenny Griffiths, who became chief executive of NHS health authorities; and Jennie Popay, now professor of sociology and public health at Lancaster University. "Peter got together an eclectic group, and it was an exciting place to be, quite anti-establishment and outside traditional public health. Peter was imaginatively critical," Popay recalls. "He was enabling, but also rigorous."

Shortly before the demise of the unit in 1984, owing to funding difficulties, Jock Anderson, then professor of community medicine at Guy's, paid tribute to "the formidable power blocks taken on by a small research unit."

Shift from "victim blaming"

Gordon Best, who worked with Draper at the unit and then went on to become director of the King's Fund, believes that its research helped shift public health away from the individual and "victim blaming" to a much broader focus.

Draper was born in Blackburn in 1933, the second son of Alan, manager of a textile mill, and his wife, Mary (née King). He studied at Bolton School and Wrekin College, where he was a scholar and head boy. He did national service as a Royal Air Force pilot in Canada.



In a blog for Doctors for the NHS in July 2016, Peter Draper, aged 83, warned of the critical state of health and social care in the UK

He studied medicine at Magdalene College, Cambridge, and in Manchester.

In 1986, with Alex Scott-Samuel, a public health consultant at Liverpool Health Authority, he established the Public Health Alliance, now the UK Public Health Association. He also served as president of the Health Visitors Association and the British Humanist Association. He was also vice president of the Ecology (now Green) party.

In 1991 he edited *Health Through Public Policy*: *Greening of Public Health*, which highlighted the "strikingly unequal" distribution of housing, food, education, and information in Britain, and urged government departments to adopt more ecological and ethical approaches.

Draper was diagnosed with bipolar disorder in 1986 and in recent years wrote about the benefits of self management courses that helped the individual and had the potential to reduce GP visits. If 25 bipolar patients in a general practice with a list of 10 000 became self managing, their visits to the GP per year would drop from 150 to 25, he wrote.

He leaves his third wife, Carol Herrity, a former campaign manager for Mencap, and two children from his second marriage.

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STATIN INDEPENDENT REVIEW

Don't ignore the Cochrane reviews on statins

We read with interest Godlee calling for an independent review on statins (Editor's choice, 17 September). In 2011 our Cochrane review on statins for primary prevention of cardiovascular disease concluded that they should be used with caution for people at low cardiovascular risk. But when we updated the review in 2013, with evidence from new trials and a re-analysis of the individual patient data from the Cholesterol Treatment Trialists, we concluded that statins could benefit people at low risk.

Fiona Godlee has called for the chief medical officer (CMO) to open an independent inquiry into statins that should be international, authoritative, independent of conflicts of interest, transparent, and patient centred. Cochrane reviews on statins seem to meet these requirements but are ignored. The CMO supports the Cochrane Collaboration and will not overlook its value in making policy decisions. Is it not time for Godlee to change her mind?

Shah Ebrahim
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George Davey Smith

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Editor in chief's reply

I congratulate Ebrahim and Davey Smith for changing their minds in response to new information (above). I look forward to having the chance to do the same when the anonymised individual patient data (IPD) and clinical study reports (CSRs) are made available. This is what I have asked the chief medical officer to make happen.

You didn't have access to these data, relying instead on the trialists' analysis, which had only half of the IPD from the trials—the half relating to benefits, not harms. In my experience of oseltamivir, when the IPD, CSRs, and other regulatory documents are scrutinised by fresh expert eyes, new and useful information emerges that can better guide patients and doctors in their decisions.

I am sceptical about medicating large numbers of healthy people, especially when alternatives exist. I hope you will put yourselves forward to review the anonymised IPD and other materials when they become available.

Fiona Godlee
(fgodlee@bmj.com)

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LETTER OF THE WEEK

Cost is a barrier to patient involvement

Many thanks for your Editor's Choice (24 September), published on my 85th birthday. Patient participation in medical research has improved since I was invited to be the first patient representative on *The BMJ* editorial board, after complaining about the flawed study of women with breast cancer attending the Bristol Cancer Help Centre.

I have attended many medical conferences and spoken at some. The main deterrent is cost. Even the Cochrane Collaboration, which is keen on consumer participation, has a complicated system of reimbursement. Getting time off work can be another obstacle, and people may have caring responsibilities. I live in Edinburgh, and most conferences take place elsewhere, so expense is an issue.

Some organisations are increasingly focused on the patient's viewpoint—for example, Pink Ribbon, which held a conference in September at the Royal Society of Medicine on a neglected subject, "Breast cancer in the young, the pregnant, and with family history." The first day was mainly for professionals and the second for patients, but patients spoke on both days. One striking finding was that GP referral guidelines (of both England and Scotland) were out of date, as was illustrated poignantly by the testimonies of women diagnosed with breast cancer under the age of 30.

I praise the work of *The BMJ*'s patient panel and encourage you to do even better in future.

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NICE ON NAFLD

Ruling out fibrosis in NAFLD

NICE guidance published in *The BMJ* suggests using a score of ≥10.51 on the enhanced liver fibrosis (ELF) test to diagnose advanced fibrosis in patients with non-alcoholic fatty liver disease (NAFLD) (Guidelines, 10 September). But most research has used a lower cut-off value. Wahl et al showed that an ELF score of 9.39 had a sensitivity of 100% and a specificity of 77% in the diagnosis of incomplete cirrhosis in all cause chronic liver disease. The 10.51 cut-off seems to be derived from a study in children; no data are available on this cut-off for adults.

The ELF test could be used to rule out advanced fibrosis in the NAFLD population. A higher threshold with limited data in the adult population risks devaluing the test and reducing its sensitivity. This may cause patients to slip through the net and develop complications of end stage liver disease that could be preventable.

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Authors' reply

We chose the 10.51 cut-off on the ELF test because of the higher quality of evidence available for this threshold than for two others. We did not find any indication that performance of the test would differ between adults and children and young people, as they have similar proportions of fibrosis.

The studies of lower thresholds examine the ELF test in different populations from those in our guidance (which focuses on adults and children and young people already diagnosed with NAFLD), so they could not have been considered in our review of the evidence.

ELF at a threshold of 10.51 had the highest sensitivity of all the tests analysed in our model. This high sensitivity ensures that those who test negative almost certainly do not have the disease—they are unlikely to be false negatives who will "slip though the net" and develop complications of undiagnosed end stage liver disease.

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