this week

SODIUM VALPROATE p 128 • **DECRIMINALISING DRUGS** p 130 • **ALCOHOL PRICING** p 130

PA

Connie Yates, the mother of Charlie Gard, has been involved in discussions to formulate a law that would prevent the sort of dispute she had to engage in before the death of her son

"Alfie's law": quest to end conflict

Doctors, lawyers, ethicists, politicians, and parents are working on proposals to improve the way disputes between parents and doctors over children's treatment are handled, after a series of bitter court battles.

The move was announced the day before Alfie Evans, the severely brain damaged boy at the centre of a dispute between his parents and doctors, died in the early hours of Saturday 28 April at Liverpool's Alder Hey Children's Hospital, four days after he was removed from the ventilator that was keeping him alive. Alfie, who would have been two on 9 May, had an undiagnosed neurodegenerative condition that had almost completely destroyed his brain.

Connie Yates, the mother of Charlie Gard, who died last July after an equally high profile court fight between his parents and Great Ormond Street Hospital in London, said, "Since Charlie's passing, we have been working with paediatric consultants, medical ethicists, lawyers, politicians, and other parents who have suffered through similar situations as us, to try to propose a law that will prevent painful and prolonged conflicts with medical professionals.

"This involves addressing problems around the 'best interests' test as well as creating a platform for transparency and openness so that cases like these can be dealt with before they ever reach the courts."

Alfie Evans's parents, like Yates, used social media to boost support for their case around the world. Doctors at Alder Hey who had cared for him since the age of 7 months wanted to remove him from the ventilator and draw up a palliative care plan. But his parents, Tom Evans and Kate James, argued they should be allowed to take him to Rome where doctors had suggested he might be kept on the ventilator and be given a tracheostomy and feeding through a PEG tube.

Alder Hey won a High Court ruling in February to discontinue ventilation. His parents then made a succession of appeals and applications to the UK Supreme Court and finally to the European Court of Human Rights, which rejected their bid to take Alfie to Rome. He died three days later.

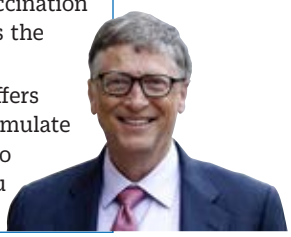
Steven Woolfe, MEP, has called for a new "Alfie's law" to give parents greater rights in disputed cases. But Yates said, "We would ask for those pushing for law change to take account of the careful work already done and join us as we continue to push for a solution that is best for all involved."

Clare Dyer, *The BMJ* Cite this as: *BMJ* 2018;361:k1895

EDITORIAL, p 137; MARGARET McCARTNEY, p 147

LATEST ONLINE

- Whistleblowing junior doctors need protection they can trust, says Robert Francis
- European Commission moves to boost vaccination cover across the continent
- Bill Gates offers $12m to stimulate research into universal flu vaccine



SEVEN DAYS IN

Valproate ban for women of childbearing age

The Medicines and Healthcare Products Regulatory Agency (MHRA) has banned the antiepileptic drug sodium valproate for women of childbearing age who are not enrolled on a pregnancy prevention programme designed to highlight the risks of the drug.

Women or girls who are already taking valproate should consult their GP to have their treatment reviewed, the MHRA said, but added that no one should stop taking the drug without medical advice. It highlighted evidence that if valproate is taken in pregnancy as many as four in 10 babies are at risk of developmental disorders, and around one in 10 are at risk of birth defects.

The MHRA said that its changes would be further supported in the coming months by smaller pack sizes to encourage monthly prescribing, a warning image on valproate's labelling, and new GP computer alerts designed to ensure prompt changes in prescribing behaviour. NICE also immediately amended its guidelines to reflect the new regulatory position.

Helen Stokes-Lampard, chair of the Royal College of General Practitioners, said, "GPs are acutely aware of the risks associated with sodium valproate, and we welcome this change in legislation as a logical way forward to help ensure our patients' safety."

Gareth Iacobucci, *The BMJ* Cite this as: *BMJ* 2018;361:k1823

Patient safety

Blame culture stops doctors from speaking out, says Hunt

The NHS's blame culture makes it "almost impossible" for doctors to raise concerns, England's health secretary said. At a Westminster Health Forum event on patient safety on 26 April, Jeremy Hunt said that it was extremely difficult for doctors to be completely transparent with patients and families when things go wrong. He said that, like aviation, the NHS needed to move from a blame culture to one that learns from mistakes.

Transparency

BMA reports NHS England over information failure

The BMA reported NHS England to the Information Commissioner's Office over its failure to respond to a freedom of information request about Primary Care Support England services, which is commissioned out to Capita. The BMA said it requested information on GP pensions on 2 March 2018, and organisations are required under the Freedom of Information Act to respond to requests within 20 working days. The BMA's GP committee said it had received "no adequate response" as of 25 April and alerted the commissioner.

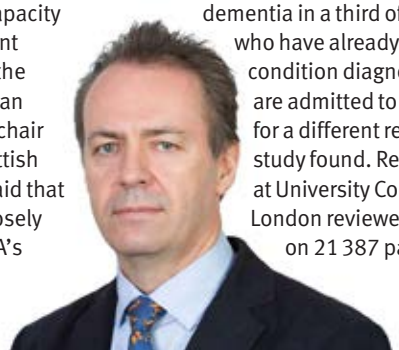
Workforce

Immigration rules hinders doctor recrtuitment

Immigration rules hamper the NHS's ability to recruit doctors, its leaders warned. The Home Office currently caps the number of skilled non-EU workers granted UK visas. But NHS trust leaders said that more doctors were being refused permission, exacerbating the current workforce crisis. NHS Employers said that at least 400 "essential medical colleagues" had been unable to enter the country to take up posts, calling on the government to tackle the issue urgently.

Scotland has new primary care workforce plan

The Scottish government published the latest phase of its workforce strategy for primary care. Areas of focus include developing and expanding multidisciplinary teams, implementing the new GP contract, and building primary care workforce capacity through significant investment over the next 3-5 years. Alan McDevitt (right), chair of the BMA's Scottish GP committee, said that the objectives closely reflected the BMA's vision for primary care but that more detail was needed on how the additional workforce will be delivered.



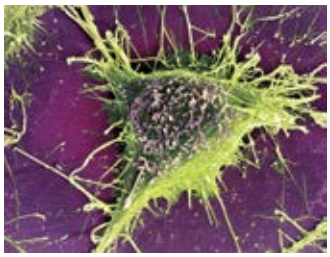
Research news

Early endovenous ablation speeds up leg ulcer healing

Early use of endovenous ablation to close varicose veins in patients with leg ulcers achieved significantly faster healing and more time free from ulcers than treatment with compression therapy alone followed by deferred endovascular ablation if required, in a randomised trial reported in the *New England Journal of Medicine*. "With this trial, we have shown that by intervening early you improve the healing of the leg ulcer, and help a patient recover quicker," said Alun Davies, lead author, from Imperial College London.

Dementia is often missed in subsequent admissions

Hospitals fail to recognise dementia in a third of patients who have already had the condition diagnosed if they are admitted to hospital for a different reason, a UK study found. Researchers at University College London reviewed data on 21 387 patients aged over 65 assessed at the South London and Maudsley NHS Foundation Trust's memory clinics from 2008 to 2016. Results published in *Alzheimer's and Dementia* showed that hospitals were more likely to miss dementia in patients who were younger, single, had more physical illness, had better cognitive function, or were from an ethnic minority group.



NHS reform

Ministers are "too slow" on NHS sustainability

Peers criticised the government for delays in acting on recommendations of a report on the long term sustainability of the NHS and social care published in April 2017. In a debate on 26 April many peers spoke about the lack of progress since the select committee's report, which called for an independent Office for Health and Care Sustainability and for more NHS and social care funding over longer periods.

MEDICINE

Climate change

UK will explore net zero carbon emissions by 2050

The UK government asked the Committee on Climate Change, an independent body, to advise on working towards a net zero carbon emissions economy by 2050. Claire Perry, minister for energy and clean growth, made the announcement at a parliamentary debate on 24 April. "We are the first developed country to ask for advice on what a zero emissions economy would look like in 2050," she said. Action will follow a report by the Intergovernmental Panel on Climate Change, expected later this year.

Direct greenhouse gas emissions arising from livestock were 6% of the UK's total emissions in 2016, according to the Committee on Climate Change

Litigation

ACOs in the NHS would be unlawful, campaigners say

The NHS would be exceeding its legal powers by introducing accountable care organisations, campaigners told a High Court judge. ACOs aim to help deliver integration in health and social care, but campaigners see them as vehicles for NHS privatisation and service cuts. In the first of two legal challenges against the plans a grassroots campaign group, 999 Call for the NHS, argued that a fixed annual payment to cover the needs of the entire population—the proposed method of financing ACOs—would be unlawful under the Health and Social Care Act 2012.

Trainees need extra legal protection

The Hospital Consultants Association called for new legal protections for trainee doctors accused of medical gross negligence manslaughter, including a state of "legal quarantine" to shield them from initial prosecution until wider details of cases are established. The union also called for protected legal status for trainees' reflections to supervisors to render them inadmissible as evidence, in its submission to the Williams review into medical gross negligence manslaughter, which the government ordered in the wake of the Hadiza Bawa-Garba case.

Child health

UK needs an extra 750 paediatric consultants

Paediatric services could become unsafe and put doctors at risk of burnout without extra resources, the Royal College of

Paediatrics and Child Health warned. In an audit report on UK children's health services the college called for an increase of 752 full time equivalent paediatric consultants. In an accompanying survey of 56 paediatric clinical directors only 16 (29%) said that a consultant was present at weekends during peak activity periods.

Cite this as: *BMJ* 2018;361:k1911

CARDIAC ARRESTS

A **46%** reduction in cardiac arrests was seen at the Royal Liverpool and Broadgreen University Hospitals NHS Trust after a bedside e-observation system was introduced. This equates to 50 fewer patients a year

[NHS England]

SIXTY SECONDS ON . . . THE SECRET TOBACCO PAPERS

BIG TOBACCO UP TO ITS OLD TRICKS?

You guessed it. Tobacco giant Philip Morris has been a bit economical with the evidence on addiction for two decades, according to previously secret internal documents analysed in *PLoS Medicine* this week.

TELL ME MORE

The tobacco industry had denied the addictiveness of smoking for many years. But Philip Morris changed its mind in 2000—after landmark litigation for the medical costs that smoking incurred—and acknowledged that nicotine was addictive.

SOUNDS VERY VIRTUOUS

More like a cover up. An analysis funded by the US National Cancer Institute compared the company's public position with that within company walls. It found that throughout the 2000s Philip Morris reinforced the idea that nicotine's pharmacology was the main driver of addiction. But internally, company scientists were saying that addiction was the result of "interconnected biological, social, psychological, and environmental determinants," with nicotine just one factor.

SMOKE AND MIRRORS?

I should say so. "By publicly focusing on nicotine's innately addictive pharmacology, tobacco companies shift policy away from proven social and environmental interventions and toward the adoption of the industry's new nicotine products," said the researchers.

IS THIS ALL ABOUT PROFITS?

How cynical. But correct. Even the researchers concluded that Philip Morris's "shift from denying to embracing nicotine's addictiveness is an opportunistic attempt to maintain future profit and capitalise on tobacco harm reduction."

BUT E-CIGARETTES ARE A GOOD THING, AREN'T THEY?

Many people now believe they are a healthier alternative to smoking. But while the tobacco industry developed e-cigarettes to create new profit streams, it also continued to advertise and lobby against public health policies, said the researchers, which are more effective at preventing and treating addiction than any other solution.

Susan Mayor, London

Cite this as: *BMJ* 2018;361:k1906

FIVE MINUTES WITH . . .

Hayley Webb

The pro-choice advocate says that doctors need to engage in the debate around decriminalisation of abortion

"Doctors for Choice is a UK based group of doctors and medical students who feel passionately about reproductive rights. We advocate for high quality, evidence based abortion care and campaign for the decriminalisation of abortion in the UK. We also aim to raise awareness of how current abortion law stops patients from getting the best possible care.

"A lot of people don't know that it's still illegal to have an abortion in the UK. This is because the 1861 Offences Against the Person Act, which makes it illegal to procure an abortion or provide an abortion, still stands. The 1967 Abortion Act brought in certain exemptions and it was a great step forward for women. However, it is now 50 years later and there have been many advances in abortion care—the main one being medical abortion.

"We know that it is safe for women to use medical abortion pills at home, for example, but we are not allowed to do that in practice because of the law. The law also states that two doctors' signatures are needed to approve an abortion, which can delay and restrict access to services, especially in rural areas. It is also not in keeping with the ethical principle of autonomy. We believe that the role of doctors in abortion care should be a supportive one, to provide evidence based information and identify any safeguarding issues, as opposed to acting as a gatekeeper. Ultimately, we believe that women should be able to decide for themselves.

WE BELIEVE THAT DOCTORS SHOULD NOT ACT AS GATEKEEPERS TO ABORTION CARE

"One in three women in the UK will have an abortion, and as doctors we will come across women who have had an abortion or who want a referral for an abortion across a wide range of specialties, from sexual health and general practice to emergency medicine. I think we have a responsibility to advocate for our patients.

"We would love to have more doctors involved. We are especially trying to get more medical students involved, and hopefully this will inspire the next generation to care about reproductive rights."

Hayley Webb is secretary of Doctors for Choice UK and a GP trainee in northwest London

Abi Rimmer, *The BMJ*

Cite this as: *BMJ* 2018;361:k1902

Illicit drug use should not be a crime, says RCP

The Royal College of Physicians of London has joined calls to end criminal sanctions against people who take drugs such as heroin, cocaine, and cannabis for non-medical reasons.

The college now endorses the stance of the Faculty of Public Health (FPH) and the Royal Society for Public Health (RSPH). In a 2016 report the RSPH concluded that a "war on drugs" fails to deter misuse but deters people with drug use disorders from seeking treatment and inhibits harm reduction efforts.

Jane Dacre, RCP president, said, "The criminal justice system is not the place to address the complex needs of people addicted to drugs. We are committed to ensuring all people who need to do so are able to access timely and appropriate prevention and care services."

David Cohen, an RCP official, added, "We don't encourage drug use, and we certainly wouldn't want to legalise [the supply of] currently illegal drugs."

Meaningful policy change

Shirley Cramer, chief executive of the RSPH, said, "It is critical that the health community speaks with a united voice to drive meaningful policy change, and so we hope that other medical colleges will soon follow the lead of the RCP."

The 2016 report said the UK should consider Portugal's model, which maintains prohibition but in 2001 switched criminal for civil processes for non-violent personal use, while increasing investment in prevention and treatment. It also called for evidence based rather than ideology

Minimum unit pricing clears cheap alcohol from Scottish shelves

Bottles and cans of cheap alcohol can no longer be bought in Scotland, as health professionals celebrate the long awaited arrival of minimum unit pricing.

Replicated across UK?

After a six year legal battle with the drinks industry, Scotland has become one of the first countries in the world to introduce a minimum price for a unit of alcohol in a move campaigners want to see replicated in other parts of the UK.

Although Scotland is being congratulated for its persistence, there is also a warning that a thousand lives could be lost in England over the next five years if similar action is not taken there.

Ian Gilmore, chair of Alcohol Health Alliance UK, said, "Minimum unit pricing will save lives, cut crime, and benefit the public finances. Any delay will only cost lives and lead to unnecessary alcohol related harm. We urge the Westminster government to act now."

From £3.50 to £11

Scotland's minimum price of 50 p a unit is designed to cut the harm caused by the availability of cheap drinks such as 3 L bottles of cider that could be bought for as little as £3.50. The same drink will now cost more than £11.

The average annual quantity of alcohol bought in Scotland is nearly 11 L per person—40% above recommended safe drinking limits. It is hoped to reduce the 22 deaths and 700 hospital admissions that result from alcohol misuse in Scotland every week.

Peter Rice, chair of Scottish Health Action on Alcohol Problems, said, "Health professionals experience at first hand the consequences of having cheap alcohol widely available, with the harms affecting the most vulnerable communities. We all hope we will start seeing fewer patients suffering from alcohol related harms."

The policy will be reviewed in five years.

Bryan Christie, Edinburgh

Cite this as: *BMJ* 2018;361:k1908

HORACIO VILLALOBOS /CORBIS /GETTY IMAGES

A drug user receives a daily dose of methadone from a van in Lisbon. Portugal switched to treating drug addiction as a public health issue in 2001 and now has one of Europe's lowest drug mortality rates

based policy, drug education in schools, the Department of Health to take drug policy from the Home Office, and for drug strategy to align more with alcohol and tobacco.

The RCP joins *The BMJ*, BMA, FPH, and RSPH in calling for drug policy to shift focus from criminal justice to public health. In 2016 *The BMJ* called for a drug policy that prioritises health and human rights, including regulated, legalised supply, to reduce violent criminal trade.

Decriminalisation

Fiona Godlee, *The BMJ*'s editor in chief and a fellow of the RCP, said, "Decriminalisation of use is an important first step, and it is vital to have the medical profession leading on this, but ultimately legalisation may be the right solution."

"The criminal justice system is not the place to address the complex needs of people addicted to drugs"
Jane Dacre, RCP

An unprecedented 2593 people were recorded as having died from drug misuse in England and Wales in 2016. In 2016-17 in England 14 053 people were admitted to hospital with a primary diagnosis of drug poisoning, up 40% in a decade. UK penalties for possession extend to seven years' imprisonment and unlimited fines.

The RCP represents 34 000 doctors worldwide. The RSPH represents around 6000 professionals, and the FPH 3300. The BMA, which represents 160 000 doctors, supports "legislative change so treatment and support are prioritised over criminalisation and punishment of individual drug users."

Drug law reform is also supported by the World Health Organization and UNAIDS. Last year Norway announced its intention to decriminalise drug use.

Richard Hurley, *The BMJ*

Cite this as: *BMJ* 2018;361:k1832

Bowel surgeons are not "gaming" mortality rates

Fears that publishing bowel surgeons' patient death rates would lead to risk averse practices or to exaggerating how ill patients were to justify poor performance can be set aside, a study in *The BMJ* suggests.

It found no evidence of any change in the proportion of patients in England having an elective major resection of the bowel since publication of results began, and death rates have fallen substantially, concluded a team from the Royal College of Surgeons, the London School of Hygiene and Tropical Medicine, and other UK centres.

Transparency

Publishing surgical data has strong professional backing on transparency grounds, but evidence that it improves outcomes was limited.

Derek Alderson, president of the RCS, said, "There has been concern in some quarters that reporting outcomes of individual surgeons could discourage some from offering surgery to high risk patients," he said. "This study is reassuring, as it did not find any evidence of risk averse patient selection. That surgical mortality decreased significantly further underlines the importance of a culture of transparency in improving the overall care of patients."

Heart surgeons were the first to publish outcomes in 2006, and bowel surgeons followed in 2013, providing data to the National Bowel Cancer Audit, which has been running since 2010. This allowed comparison of data from before and after publication began. The characteristics and outcomes of 111 000 patients were included by linking the audit data to the hospital episode statistics database.

If publication had made surgeons nervous the most likely effects would have been fewer surgical resections, a tendency to refer the highest risk patients on to specialised centres, and an increase in surgery offering a lower risk than resection. Alternatively, surgeons might have sought to convey a better picture of their outcomes by classifying more of their patients as urgent or emergency cases, a process known as "gaming."

90 day mortality fall

None of these effects was found in the study. For example, the proportion of major resections classified as urgent or emergency did not change significantly: 15.5% before publication and 15.6% after. There was a change in 90 day mortality, however. In elective patients it fell from 2.8% before publication to 2.1% after, a statistically significant difference.

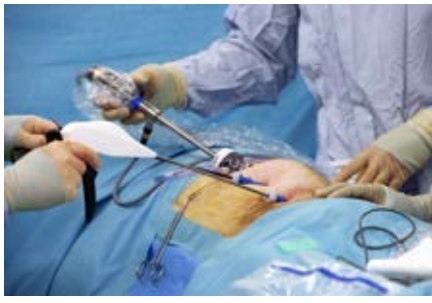
James Hill, president of the Association of Coloproctology of Great Britain and Ireland and the study's lead clinician, said, "The improvements demonstrate that surgeons have an important role in galvanising the entire team involved in managing patients before and after this major surgical procedure."

The study considers another explanation, that patients chose the best surgeons based on published outcomes, is unlikely as the mortality fall was so rapid.

Nigel Hawkes, London

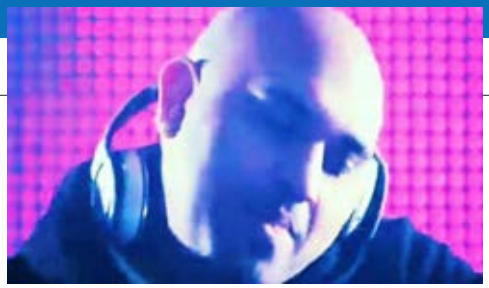
Cite this as: *BMJ* 2018;361:k1931

RESEARCH, p 146



The PROPORTION of urgent or emergency resections didn't change: 15.5% before outcomes publication and 15.6% after

Patient found in contempt of court for trying to claim £837 000 from hospital trust



A DJ and taxi driver has been found guilty of contempt of court for fraudulently claiming more than £837 000 in damages for clinical negligence after he was treated in a hospital emergency department.

Sandip Singh Atwal, 33, is to be sentenced on 1 June, and faces a possible prison term.

Insurers sometimes bring contempt of court proceedings over inflated claims, but the Atwal case is thought to be the first time the move has been used by the NHS.

Calderdale and Huddersfield NHS Foundation Trust brought the case against Atwal, who was treated at Huddersfield Royal Infirmary after being hit with a baseball bat in 2008. He sustained fractures to two fingers, and his lower lip was lacerated. He spent three weeks in hospital.

His lip became infected, and the trust admitted negligence in failing to treat the fractures appropriately and to suture the lip promptly. Atwal was offered £30 000 to settle the case in 2011 but turned it down.

Covert video surveillance showed Sandip Atwal working as a courier and unloading heavy objects

Loss of earnings

He asked for £837 107, including substantial sums for loss of earnings and for future care, claiming that he was unable to work, needed ongoing physical and psychological support, and had become a recluse because of embarrassment over the scar on his lip.

Lawyers for the trust were suspicious and put him under covert video surveillance. This showed him working as a courier, driving a van for prolonged periods, and loading and unloading heavy objects. Next they looked at his postings on social media, which showed that he and another musician had released a single and an accompanying music video, in which he was performing without any apparent embarrassment over his lip.

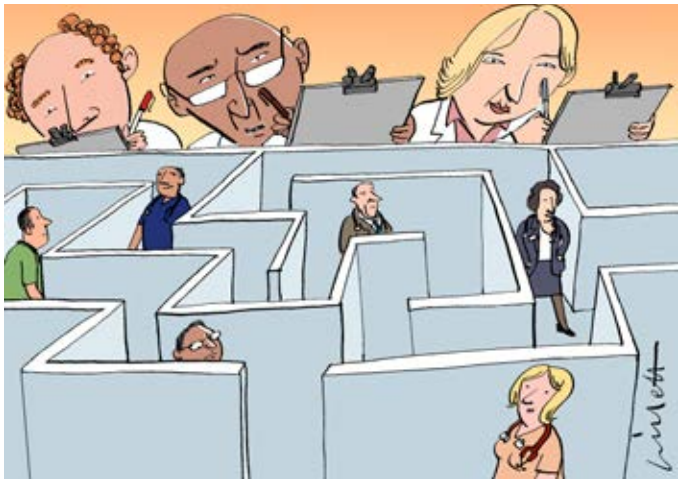
When his dishonesty was exposed, Atwal accepted the original £30 000,

Female and BME doctors' revalidation more often deferred

Deferral of revalidation is likelier among younger doctors, women, and doctors from black and minority ethnic backgrounds, a major impact study has found.

The three year review by the UK Medical Revalidation Evaluation Collaboration (UMbRELLA) found that the GMC's objective to bring most doctors into a governed system of revalidation had largely been achieved since it was introduced in 2012. But it noted that engagement had generally been less straightforward for doctors working for more than one organisation.

Responsible officers (the individuals within designated bodies, such as NHS employers, who have overall responsibility for revalidation) can make one of three recommendations to the GMC after a five year revalidation period: approval, deferral, or non-engagement with the revalidation process. Deferral can be recommended if there is not enough evidence to recommend a doctor's revalidation, if a doctor is under investigation, or if there are exceptional circumstances, such as maternity leave, prolonged sick leave, or sabbatical.



Licence withdrawn

By last November 184 101 doctors had been approved for revalidation, 42 561 deferred for lack of evidence, and 1636 were deferred because of an ongoing process such as a disciplinary procedure. The GMC approved 594 recommendations for non-engagement and withdrew the licence of 3840 doctors on the grounds that they had failed to engage with revalidation.

The report identified particular challenges for locum doctors in collecting supporting information and in obtaining an annual appraisal. Women returning from maternity leave also reported difficulties in meeting requirements, some of whom thought that the process did not make enough allowances for this.

The higher deferral rates among female, younger and BME doctors was not related to where they had obtained their primary medical qualification.

The odds of male doctors being deferred were lower than for female doctors (odds ratio 0.83). And the odds of younger doctors being deferred were as much as double those for older doctors (odds ratio 2.00 for those aged under 30 and 1.93 for those aged 30-39, when compared with those aged 40-49).

Commenting on higher deferral rates among certain groups, Una Lane, the GMC's director of registration and revalidation, said, "This is something we take very seriously, and we have begun work to identify and address any fairness issues."

The ODDS of male doctors being deferred were lower than for female doctors—odds ratio 0.83

five years after it was offered. But the whole sum was swallowed up in the trust's costs. After eight years of litigation he was left with nothing and owing the trust £5000.

During the contempt of court proceedings in the High Court, the trust quoted excerpts from Atwal's medical records over the period when he said he was unemployed and a recluse. These showed a visit to hospital after he was tackled while playing football, a medical examination to work as a taxi driver, and statements he made to doctors he consulted for leg pain that he worked as a taxi driver and courier and was in otherwise good health.

Contempt of court proceedings are quasi-criminal, and the maximum sentence is two years' imprisonment.

Clare Dyer, *The BMJ*

Cite this as: *BMJ* 2018;361:k1913

Lane added that the GMC was working with other organisations to try to reduce "unnecessary burdens" in the revalidation process. "We are addressing issues such as the challenges faced by locum doctors working outside traditional governance structures, the role patients and the public can play, and how being a reflective practitioner can improve the care a doctor gives patients," she said.

Negative effects on practice

A minority of doctors reported changing an aspect of their clinical practice, professional behaviour, or learning activities as a result of their most recent appraisal. But some identified potentially negative effects on their practice or repercussions for professional autonomy.

Doctors and patients reported that the collection of feedback from patients was "inconsistent and at times problematic" and called for tools to be refined. Doctors in specialties such as anaesthetics, psychiatry, and radiology found it particularly hard to gather feedback.

Gareth Iacobucci *The BMJ*

Cite this as: *BMJ* 2018;361:k1925

NEWS ANALYSIS

Lords condemn "wholly inadequate" delivery of life sciences strategy

A hard hitting select committee report finds NHS innovation is being held back by failing government strategy, **Nigel Hawkes** reports

Delivery of the government's much vaunted strategy for life sciences is "incoherent and wholly inadequate," a House of Lords select committee has concluded. In an unusually hard hitting report the science and technology committee said the plans showed complicated arrangements for implementation, a lack of clear authority and accountability, and a failure to engage the NHS effectively.

Although the strategy relies on the NHS, the committee said nobody in the service's higher reaches seemed committed to implementing it and that the NHS's structure stifles innovation. Unless that can be put right the strategy is likely to fail, the committee warned.

NHS management cannot, however, be entirely blamed for failing to embrace the strategy, the committee found, as it is far from clear what the strategy is. Most people take it to consist of the recommendations made in a report by John Bell published last August, plus the life sciences sector deal, an agreement reached the same year between the life science industry and the government on future investment.

Not official targets

With nobody taking clear ownership, however, even that is uncertain. A junior minister in the Department of Business, Energy and Industrial Strategy told the committee that the Bell report "is not a government report" and that, while endorsing some of Bell's ambitions, the government would not make them official targets.

Bell himself told the committee that senior NHS figures he had spoken to wanted to see the uptake and spread of innovation. But he added, "It is not clear who is driving the bus. Whoever is driving the bus, the windscreen wipers do not work, and the exhaust is falling off."

The new report emphasises that somebody should be in charge. It suggests a single life sciences governing body, co-chaired by the health and business secretaries and with a membership of about 12. It would report to a Cabinet committee, while a new statutory body, the Office for Industrial Strategy, would report to parliament each year on the progress made.

Narendra Patel, a cross bencher who chairs the science and technology committee, said, "The strategy stands little chance of success without a detailed plan for implementation and clear lines of authority, responsibility, and accountability."

At a briefing at the Science Media Centre in London, the Labour peer Barbara Young said that the NHS should be a massive resource and a great test bed for the early uptake of innovations.

"But this is not happening," she said. "Even innovations that could save money and increase productivity are not rolled out universally. There needs to be more welly. Innovations should be mandated nationally and implemented with no questions asked."

"IT IS NOT CLEAR WHO IS DRIVING THE BUS"
JOHN BELL, LIFE SCIENCES STRATEGY REPORT AUTHOR

But Young distanced herself from the idea of restructuring the NHS to make it more innovation-friendly. "I'd be worried about that," she said. "It's more about climate and tone."

Patel agreed, saying, "The previous reorganisation didn't work."

Chris Fox, a Liberal Democrat peer, suggested that it would be better to simplify the system, in which accountability was obscured at present by complexity.

The Tory peer Brian Griffiths said he had been a policy adviser to Margaret Thatcher but that even she had skirted around NHS reform.

"We never really discussed it," he said. "A huge reorganisation wouldn't be right, but the NHS is not performing. We need to look at more marginal changes that would make it more responsive, perhaps along the lines of dentistry."

Nigel Hawkes, London

Cite this as: *BMJ* 2018;361:k1856

THE BIG PICTURE

Archive turns back the hands of time

More than 4000 recently uncovered medical archive photographs give an extraordinary insight into pre-NHS healthcare.

Around half the images have been digitised, thanks to funding from the Wellcome Trust, and have been made accessible to the public, to mark 70 years of the NHS.

The black and white images, uncovered by staff at Historic England's archive in Swindon, document healthcare in Britain between 1938 and 1943. They were taken by the Topical Press Agency, but how and when they were acquired by the archive remains a mystery. They record improvised wartime hospital wards, blood donation and transfusion, infection control, treatment of burns and early plastic surgery, alongside nurses in training and relaxing in their time off.

The photos can be viewed and searched at https://historicengland.org.uk

Alison Shepherd, *The BMJ*

Cite this as: *BMJ* 2018;361:k1930

A factory worker places surgeons' rubber gloves on moulds into a curing oven in January 1939

A girl is treated for a squint with a synoptiscope in October 1941 at Birmingham's King Edward VII Memorial Children's Hospital, which had the first orthoptics department outside London

A nurse weighs a baby at St Matthew's Hospital Nursery School, Great Missenden, Buckinghamshire, in April 1941

Surveys suggest increasing public support for a tax rise to meet the demands of hospitals and the wider NHS PA

EDITORIAL

Cross party approach to NHS and social care

Party leaders should come together to find a way forward

When MPs from different parties come together to argue for more funding for the NHS and social care, it is time to sit up and take notice. Last week's statement by Nick Boles (Conservative), Liz Kendall (Labour), and Norman Lamb (Liberal Democrat) could not have been clearer. Spending on the NHS and social care needs to increase by substantially more than inflation over the next 20 years and should be paid for by a dedicated tax.[1]

This initiative follows hard on the heels of a letter to the prime minister Theresa May in March from 98 MPs, including 21 select committee chairs and senior backbenchers drawn from across the political spectrum. The letter made the case for establishing a parliamentary commission on health and social care to examine, among other things, future demand for care and funding options. Signatories argued that a cross party approach to these issues was urgently needed and that the commission should report before Easter 2019.[2]

Politicians are coming together to speak out because of growing pressures on the NHS and evidence of widespread public concern. Survey evidence shows that the public is increasingly anxious about the state of the NHS and that there is support for tax rises to increase funding. Tax rises are now backed by a majority of supporters of all the main parties, including 56% of Conservative supporters, up from 33% in 2014.[3]

MPs have also been emboldened by the existence of a minority Conservative government reliant on the support of the Democratic Unionist Party in parliament. A government weakened by the loss of its majority in 2017 creates opportunities for MPs and peers to exert influence. May's surprise commitment to deliver a long term funding settlement for the NHS is evidence that the concerns of MPs and the public have been heard.

Politicians are coming together to speak out because of evidence of widespread public concern

Attention will now focus on what May says around the 70th anniversary of the NHS, when an announcement is expected on the scale of the promised funding increases. She may also use the anniversary to set out the government's goals and priorities for how extra funding will be used. A more detailed plan is expected to follow later in the year, following engagement with key stakeholders and outlining what the NHS will deliver with the resources the government is able to commit.

Top priorities

Ensuring that the NHS gets back on track in delivering national waiting time standards and balancing its finances are certain to be among the government's top priorities. Equally important is to continue the work that has started to achieve parity of esteem for mental health services, increase the share of spending on general practice, and make improvements in cancer care and urgent and emergency care. The new NHS plan will have to make credible commitments on how to secure the workforce needed to deliver improvements in care.

Another key priority should be to earmark funding for investment in new care models better suited to the changing needs of the population. The pressures facing the NHS will not be relieved by doing more of the same, and some of the care models that have evolved from the NHS *Five Year Forward View* are helping to moderate rising demand for care in hospitals and are delivering more care in people's homes and closer to home.[4] Accelerating the adoption of new ways of working, with an emphasis on the prevention of illness and the integration of care, should be the centrepiece of the new plan.

A constant refrain in the arguments put forward by MPs across the political spectrum is the need for social care to receive additional funding as well as the NHS. May's decision to add social care to Jeremy Hunt's job title and to put him in charge of work on the promised green paper on the future of social care shows that this issue has risen up the agenda. The big prize on offer is a new settlement for the NHS and social care, building on the report of the Barker Commission in 2014,[5] and recognising, as Boles has observed, that the country has arrived at a second Beveridge moment.[6]

If the political will exists to work towards a new settlement, the hard question will be how to pay for it. Ideas advanced by the main parties, like former health secretary Andy Burnham's "death tax" in 2010[7] and the Conservatives' "dementia tax" in 2017,[8] have failed to attract support, suggesting that a cross party approach is needed this time round. The difficulty will be to persuade party leaders to follow the example of their backbenchers and find common cause. The habits of adversarial politics die hard even when so much is at stake.

Chris Ham, chief executive, King's Fund, London
c.ham@kingsfund.org.uk

Cite this as: *BMJ* 2018;361:k1888
Find the full version with references at http://dx.doi.org/10.1136/bmj.k1888

EDITORIAL

Alfie and Charlie: should the law change?

Reforms must be explored to ensure the best outcomes for sick children and their families

In the early hours of Saturday 28 April, 23 month old Alfie Evans died in Liverpool's Alder Hey hospital after a prolonged dispute over his medical care.[1] Alfie had a severe neurodegenerative disorder and had been ventilated in intensive care for much of the preceding 16 months. His parents wanted life support to continue, but Alfie's doctors believed that this would be futile; in late February, the High Court ruled that life sustaining treatment was not in Alfie's interests. Subsequently, a series of (unsuccessful) appeals were heard by the Court of Appeal, Supreme Court, and European Court of Human Rights.[1]

The final stages of the dispute about treatment were accompanied by intense national and international scrutiny. Many drew parallels with the case of Charlie Gard, less than a year earlier.[2] International commentators and politicians were critical of the UK health system and the perceived interference of the judiciary in parental decision making. At the height of the conflict, Alder Hey staff staff reported unprecedented levels of abuse.[3]

What would help?

In the wake of the Evans case, there have been calls for changes to UK law. But what changes could or should be pursued? What would actually help?

Disagreements about potentially inappropriate medical treatment are not unique to the UK.[4] Many jurisdictions have struggled to find satisfactory legal responses to the problem of so called medical futility.[5] Although the recent cases have been criticised, the UK approach compares favourably with others in its transparency, rigour, and consistency.[6]

One option would be to respect parental autonomy—allowing parents the final decision about medical treatment. Such a solution would avoid legal disputes. However, it would also come at considerable cost. It would require health professionals

to continue to provide treatment even when it would cause substantial harm to the child. It would also, by consuming limited medical resources, compromise the ability of the health system to treat other children and distribute resources fairly.[7]

A different solution would be to resolve disputes without recourse to court. A treatment tribunal model, as applied in Texas, applies an explicit process for assessment and arbitration in cases of potentially inappropriate treatment.[8] This model has the advantage of potentially allowing timely decision making and avoiding costly and protracted legal appeals.[8] (A modification could help separate out important questions of limited resources from those relating to the interests of the patient[9]). However, this due process model has its critics, who argue that it compromises patients' and families' legal rights.[10] It would require substantive legal reform.

One question, debated in the Evans and Gard cases, is whether courts should reach decisions based on their view of what would be best for the child (the best interests standard) or on whether parents' preferred treatment would risk substantial harm to the child. Currently, courts apply the best interests test to medical treatment decisions. There are strong ethical arguments that decisions to over-rule parents should be based on the second, more stringent question.[11] This may or may not have led to a different decision in either case; it would make legal decisions about treatment consistent with the standard applied to other types of decision.

The UK process was criticised during the Alfie Evans case, but its approach compares favourably with others

Act earlier

A simpler legislative response to these cases would be to promote ways to resolve conflict at an earlier stage. One option would be improved access to clinical ethics consultation. Such consultation can provide a consistent process for dealing with conflicts. It can help identify the nature and source of disagreement. When there is reasonable disagreement about what would be in a child's best interests, parents' wishes should be respected.[12] There is some evidence that provision of ethics consultation in intensive care can help resolve conflicts and reduce provision of non-beneficial treatment.[13] In the UK, however, clinical ethics committees are available in only a minority of acute NHS trusts.

Another option would be to offer mediation with a neutral external facilitator to help parties reach a negotiated resolution. After a pilot training programme, paediatric staff reported greater ability to recognise nascent conflicts and to manage and de-escalate conflict.[14]

Paediatric medical care is, at its best, a partnership between professionals and families, working together to promote the wellbeing of children. These prolonged and painful disputes are devastating for families and traumatic for the medical and nursing staff. There are no winners, only losers.

There is a pressing need for professionals to come together with families to explore and implement new constructive solutions to avoid, mitigate, and resolve disagreements about treatment. That would be in the best interests of all children.

Dominic Wilkinson
professor
dominic.wilkinson@philosophy.ox.ac.uk

Julian Savulescu
professor, Uehiro Centre for Practical Ethics, University of Oxford

Cite this as: *BMJ* 2018;361:k1891

Find the full version with references at http://dx.doi.org/10.1136/bmj.k1891

Home devices deliver dementia care data

A Surrey study is a test bed for how internet enabled objects could support patients with long term conditions and better target care, reports **Fran Robinson**

In a room in Chertsey, a clinical monitoring team remotely track the physical and mental wellbeing of 408 people, 24 hours a day.

As this team—four healthcare assistants, two senior nurses, and a project administrator—monitor their computer screens, a large digital dashboard flashes with alerts to highlight potential problems with patients, who have mild to moderate dementia. The warnings are coloured according to the level of urgency, red being the most urgent. An audible siren ensures the team is alerted to the highest priorities.

This is the hub of a project called Technology Integrated Health Management (TIHM) for dementia, a randomised controlled study evaluating the effectiveness of using internet connected technology and data analysis to remotely monitor and support patients' health in real time, round the clock.

It is one of seven NHS Innovation "test bed" initiatives, launched in January 2016 and funded by NHS England and the Department of Health and Social Care–TIHM received a £4.4m grant. All are testing how healthcare could be modernised to deliver practical benefits for patients with long term health problems.

The aim is to be able to identify trigger factors and intervene before the problem turns into a crisis

At a time when buzzwords such as AI (artificial intelligence), data, personalised medicine, and the internet of things (the networking of physical objects) are increasingly used to signal the future of healthcare, TIHM for dementia is an example of how these technologies are beginning to be put into practice and gives a flavour of the potential benefits and problems.

Pooling expertise

Connected to the clinical monitoring unit's monitors and dashboards are up to 22 devices—a range of sensors, monitors, and trackers—in each of 101 homes in Surrey and north east Hampshire, with 103 homes in the area acting as the control group.

Data from the devices identify important or unusual changes in the patient's health or behaviour, such as a blood pressure reading out of the normal range, whether they are drinking enough fluid, have wandered off, or have early signs of a urinary tract infection (such as using the bathroom more than usual, a temperature, or wetting the bed).

The team then decides whether to offer extra support. This could range from a conversation with the carer to check everything is OK, through arranging a visit from an Alzheimer's Society volunteer (called a dementia navigator), to referring the patient to a GP or the emergency services.

Led by Surrey and Borders Partnership NHS Foundation Trust, the study is pooling expertise from a collaboration of partners from the health, academic, voluntary, and commercial technology sectors. As well as the Alzheimer's Society, these include University of Surrey 5G Innovation Centre, Royal Holloway University of London–and eight technology companies who have jointly contributed more than £500 000 to the project.

Ramin Nilforooshan, consultant psychiatrist and associate medical director for research and development at the trust, has been working

How patients are monitored in the TIHM programme

- Sensors
  Motion sensors Positioned, for example, on the front door, bathroom doors, landing, and hallways to monitor movement around the home
  Pressure sensors Placed under sheets on beds and under chair cushions to detect restlessness and movement
  Multisensors To monitor temperature, humidity, and light
  Electricity sensors To identify if kitchen appliances are being used as usual
- Enuresis mat: placed under bed sheets to measure sweat and bed wetting
- Indoor falls monitor: a wearable wrist device that identifies if someone has fallen
- Blood pressure cuff
- Oximeter
- Thermometer
- Scales measuring weight and hydration
- Tracking device: a wearable device that tracks movement outside the home and can
  trigger an alert if a person wanders outside of an agreed area
- Interactive monitors, one of which uses an avatar, to record mood and sleep patterns through short daily questionnaires

with the University of Surrey to produce algorithms personalised to each patient. These can determine whether a slight rise in blood pressure is normal for that person, for example.

As data are collected the system is being fine tuned to automate algorithms by analysing the outcome of clinical responses. The algorithms will then be able to prompt the monitoring team to take a course of action based on what worked the previous time or to ask specific questions of the carer.

The algorithms are also being tested to see if they can accurately predict problems such as infections, agitation, irritability, and aggression—common risk factors for hospital admissions among elderly psychiatric patients. The aim is to be able to identify trigger factors and intervene before the problem turns into a crisis.

Early results

One serious risk to health was avoided when a patient with raised blood pressure was advised to go to their GP and was immediately sent to the emergency department. In other instances, the data have alerted clinicians that a patient has needed a change in their medication or has unintentionally taken an overdose. Patients who have wandered off have been quickly found.

One couple reported that they had visited the emergency department five times in six months after one of them had dementia diagnosed, but once the technology was installed at home these visits stopped because they felt reassured by the monitoring process.

In addition to the people in the study, 20 "trusted users" (10 people with dementia and their carers) have also had their homes equipped with the technology and are being monitored in the same way as people in the main study to provide ongoing feedback. This group has reported that the devices make them feel more secure, a finding supported by early qualitative data from an evaluation team at Surrey University's School of Health Sciences.

The study has not been without teething issues; initially some of the devices triggered false alerts. The trust was able to work with the technology companies to correct these technical problems. "We were concerned at the beginning that people may find the devices and remote monitoring intrusive, but that has not been the case," says Helen Rostill, director of innovation and development at the trust. "While most of the devices we have been using are passive and do not require active interaction, we may look in the future at using even less interactive devices to make the system even easier to use for someone with more advanced dementia."

Relieving GPs?

Julia Chase, GP and clinical lead for mental health at Surrey Heartlands Sustainability and Transformation Partnership, raises a further concern: "As with any new ways of working, there will always be concerns, such as: could this lead to an increase in the primary care workload?

"However, we need to look at new models of care to improve the patient's experience and the care they receive while also reducing pressures on the system—ie, unplanned admissions and long hospital stays, which can be particularly unsettling for people with dementia and their families."

A spokesperson for the Surrey and Borders Partnership NHS Foundation Trust says that "while TIHM does refer people to their GP if necessary, that referral is likely to reduce the need for emergency GP visits and follow ups.

"We already have evidence of people on the trial sharing data collected by TIHM with their GPs, facilitating more informed clinical decision making at an earlier stage and relieving GPs of some routine monitoring."

The long term aim is to use the learning from the study to turn TIHM into a viable service that can be scaled up to support people with dementia and other long term conditions. The University of Surrey evaluation is due to be published in June, but Nilforooshan says this study is not just about results; the work is looking at a change of culture in the way clinicians practise.

"The machine learning will not replace clinicians' expertise. Instead it will help them to have a better understanding of what is going on with their patients," he says. "For example, people with hypertension have their blood pressure checked regularly, and our data could be sent to GPs to reduce the frequency of those visits.

"Cardiologists could review the ECG, pulse, blood pressure, weight, and hydration data to decide who they need to see immediately and who they don't need to see at all."

Fran Robinson, freelance journalist, Hampshire
fran.robinson8@gmail.com

Cite this as: *BMJ* 2018;361:k1855

Patient and carer experience

"It gives me a sense of security"

Trevor Truman and his wife Moya, who has dementia, have 20 devices installed in their home. The small white plastic movement sensors are discreetly positioned on the front and bathroom doors, in the hallway, and on the landing. There are also sensors in the kitchen—on the fridge door, toaster, and kettle. Plastic pressure pads are hidden under the seat of Moya's favourite chair and under her side of the bed.

More interactive devices, such as a monitor that asks Moya how she feels each day, a blood pressure cuff, thermometer, and oximeter are also small and unobtrusive. A set of weight and dehydration scales looks like regular scales and is positioned in the bathroom.

"The devices are not intrusive; they are there working in the background. It takes a few minutes twice a day to do the basic tests—blood pressure, pulse oximetry, and measuring Moya's weight and hydration," explains carer Trevor.

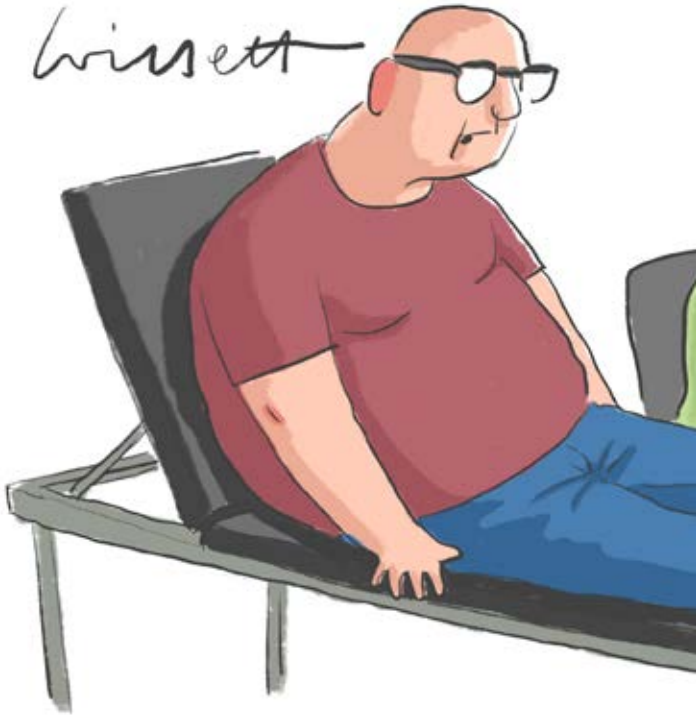
"It gives me a sense of security knowing the technology is there and that someone is looking at the data every day. If they are concerned about anything I know they will call, and I can always ring them with any concerns."

Recently the team noticed that Moya's blood pressure was higher than normal and advised the couple to visit the GP. "We were able to show the GP all the readings over a period of time on our iPad and she was able to instantly assess what was happening. Everybody wants to stay in their own home, and if the devices help us to do that then they will be a very great benefit," says Trevor.

MEDICAL EDUCATION

The patients who help decide who will make an empathetic and effective doctor

Patient involvement in student training is moving to the next level as they become integral to designing and marking assessments, developing curriculums, and informing admission decisions. **Emma Wilkinson** reports



"These marks count," says Nicki Cohen, deputy dean for assessments and admissions at King's College London. She is talking about objective structured clinical examinations (OSCEs). However, the marks in question are not awarded by the senior doctor overseeing the stations, but by patients.

About 10% of OSCE marks at the medical school are awarded by real or simulated patients, with the weight dependent on the skill being tested. It is higher for communication, for example, because the best person to assess that is the person being communicated with, says Cohen.

"The most important thing," she says, "is that the students are aware that assessment isn't just what the senior doctor thinks. They have to really think about maintaining that patient focus."

This is just one example of how UK universities are taking patient involvement in training future doctors to the next level, getting patients involved in designing and marking assessments, developing curriculums, and even admissions.

At the University of Sheffield, a typical OSCE will feature around 70 patients alongside 50 actors. The proportion of patients has increased over the years because it gives the student "a more realistic experience," says programme lead, Martin Hague.

The university began its "patients as educators" programme in 2004, when just seven patients with acute kidney injury took part in simulated ward scenarios. Now 800 patient educators—unpaid volunteers with a range of conditions—also take part in teaching and assessment that contributes 1.5% of students' marks.

"They contribute to the overall mark," says Hague, "and we give the patient educators training on how to do that. We use them to consider consultation skills and language and empathy."

"Students have to really think about maintaining that patient focus" Nicki Cohen, King's College London

"If you give patients a voice you give them power" Jane Moore, University of Oxford

New marking criteria

For Jane Moore, course organiser for the undergraduate teaching course in obstetrics and gynaecology at the University of Oxford, having patients assess OSCEs was not enough.

Around six years ago, Oxford began to recruit women who had experienced miscarriage to speak to the students. This led to a study on patient perception that informed a new marking guide for an OSCE scenario based on delivering bad news. The patient tutors, who are paid and have contracts, worked in collaboration with clinical staff to develop the curriculum and final assessment.

As a result they changed the marking sheet, adding "eye contact, giving accurate information, empathy, and–something which

I would never have thought of–'Please don't ignore my partner,'" explains Moore.

Together, the clinicians and patient tutors decided that an actor would play the part of the patient, with the patient tutor as their partner. The resulting mark is a 50/50 combination of the clinician and patient tutor.

Patient tutors are included in three of the eight OSCE stations—one of which assesses email conversation and is marked solely by the patient—meaning that 30% of the overall grade for the eight week rotation is awarded by patients.

Moore says that putting patients' assessment into the exam makes students take it seriously. "Also, it is about giving patients power," she says. "If you give them a voice you give them power and you can't objectify them. That is something we should be learning right from the start."

Mostly, using the jointly developed marking guide, clinician and patient assessors agree, but occasionally they pick up on different aspects.

Ingrid Granne, lead for recurrent miscarriage and early pregnancy at Oxford University Hospitals NHS Trust, says she would have thought herself a good judge of how a patient was feeling about a consultation. Having the patient tutors involved in the assessment has made her realise she is often quite wrong. "You quickly realise that how you interpret something is based on yourself. It doesn't really matter if I think the student has been sympathetic or communicated well if the patient doesn't think that," Granne says.

Patient tutor Emily Gray, a law researcher, gives this example: "The doctor had ticked all the boxes, but the student had a grin on his face the whole time and looked like he was going to laugh. The clinician present hadn't noticed it until I pointed it out."

The patient tutors have also influenced how care is provided in Oxford through a redesign of the early pregnancy service, which is being relocated to the community so that women having a miscarriage do not have to be seen in the same place as heavily pregnant women.

Responsibility and accountability

Robina Shah runs the University of Manchester's Doubleday Centre for Patient Experience and, with her codirector, Paul O'Neill, has recruited

"Patients are valued and core members of the team and have responsibility and accountability"
Robina Shah, Doubleday Centre for Patient Experience

Involving child patients in postgraduate medical training and assessment

In December 2017 the GMC signed off the Royal College of Paediatrics and Child Health's (RCPCH's) new curriculum—the first created with the help of 170 children and young people plus 30 parents and carers, who shared their views on what would make the "best doctor" for them.

This is the work of the college's children and young people's engagement team, which runs its &Us network for children, young people, parents, and carers, and helps use their views to influence and shape policy and practice—increasingly, in the training and assessing of paediatricians.

As well as supporting curriculum development, the team has been developing child patients' involvement in the Start assessments for trainees who are near to becoming consultants. Scenarios based on the patients' narratives were included in the scenario bank for the first time in the autumn, and the team is working on creating more so that eventually each assessment will include at least one. And that's just phase one, says the college's children and young people's engagement manager, Emma Sparrow.

"Phase two will look at having RCPCH &Us members in the assessment, providing joint feedback with an examiner," she explains. "In Phase three they will run a station—writing the scenario, delivering the assessment, and providing feedback—all supported by an RCPCH assessor."

Now her team is also exploring involving children and young people in the clinical membership exam. "We have started to do some pilot work on how they feel in clinical exams; they could be involved in assessing," says Sparrow.

"We want to bring the examiners and the young people together so the examiners can understand things from the young person's view."

PATIENT VIEW Peter Johnson

"It is important to increase patient involvement in medical training because the relationship between clinicians and patient needs to be a mutually beneficial working partnership.

"I am an active member of the patient and carer group in the faculty of health sciences at the University of Southampton; we are involved in developing curriculums, student selection, and employability, and we are working towards participating in assessments.

"Several of the examples in this article refer to the importance of communication and empathy. I am pleased to see mentions of body language but disappointed that the importance of active listening is not mentioned. When I facilitate a communication session for healthcare students or clinicians, I invariably include the old saying: 'We have two ears and one mouth—use them proportionately.' Clinicians can only help patients get better if they find out what the patient's concerns and hopes are by asking open ended questions and listening with interest to how the patient responds.

"One of the ways I can tell how useful my contribution has been is the feedback I get from academic and clinical colleagues, particularly when a suggestion I made is

"I only offer suggestions if I think they will improve some aspect of a programme or project and are worthy of busy clinicians' time"

implemented. We, as patients, have to be aware how busy clinical and academic colleagues are, often having to work under pressure to tight deadlines. I only offer suggestions if I think they will improve some aspect of a programme or project and are worth colleagues taking time to consider them.

"One of my projects is the implementation of next year's postgraduate courses. It is working well, which leads me to believe that patients should also contribute after qualification, such as coaching clinicians in communication skills as part of continuous professional development.

"Patient involvement in medical training will be particularly beneficial, and help overcome clinician resistance, if we each play to our strengths. Whenever appropriate, it is better to have more than one patient involved. At Southampton, there are two of us on one project and we meet up before a meeting to swap notes.

"The one thing patients have in common is experience of the healthcare system. However, each of us has life and work experience that can add a different perspective for students and clinicians."

23 medical education partners (MEPs) since 2014. The partners are patients, carers, or interested members of the public from all walks of life and participate in the design, delivery, and governance of medical education.

MEPs, who are paid and work between three and 14 hours a month depending on their role, sit on all the relevant committees. They have a say in curriculum design and content and assessment as well as being members of student health and conduct panels.

"Our MEPs are not simulated patients or 'expert patients,'" says Shah, to make the distinction from people who teach about their health conditions. "They are valued and core members of the team and have responsibility and accountability."

They also contribute to the admission of medical students: each year the lead partner for admissions prepares several OSCE scenarios about NHS values and professionalism to test ethics, openness, and honesty.

"The feedback from [clinical] colleagues has been positive: we have been told that the MEP admissions station has great sensitivity in finding those students who demonstrate strong values," says Shah.

Colin Lumsden says the MEP on the curriculum committee, which he chairs, provides a "unique insight on the patient perspective."

"Our MEP often asks us to explain and expand on our rationale for what we do and why," he says. "She has frequently challenged the status quo by ensuring that our practices are transparent and fully justified."

Karim Lajee, an MEP who sits on the programme committee, says it has been a real eye opener. "The importance placed on the patient and public perspective is very refreshing."

The Doubleday Centre has 15 national affiliates who support its work, including NHS England's former medical director Bruce Keogh and Keith Pearson, chair of Health Education England. The programme has already been recognised by several organisations, including the Institute for Healthcare Improvement, for the work it has done on making medical training more patient centred.

"The MEPs are certainly making a positive difference to how we engage and involve the public as partners in medical education," says Shah, who is hoping to find some funding for a PhD student to evaluate the effect.

Clinician resistance

Not everyone recognises the value of involving patients to this extent, says Oxford's Moore, who has heard fellow clinicians claim, for example, that patients cannot contribute to assessment because they have only one perspective. "The solution is the proper criteria to mark against and then quality assurance as for any other examiner," she counters.

Other clinicians have claimed that "patients tend to get things out of perspective," which Moore says is: "a typical 'calm down, dear' type response, in my view—the resort of people with power who know they are in the wrong, perhaps."

Despite such pockets of resistance, Moore believes her approach will slowly take hold in other areas of medical teaching and is planning to harness feedback for trainee doctors from patients attending routine NHS appointments. "Once you start to think about who the healthcare system is for, it is obvious that it is the patients who should be deciding what the standard for doctors should be," she says.

"The patients are not claiming or trying to judge whether doctors have the correct information, but when it comes to communication skills, of course it should be the patients judging that."

Emma Wilkinson, freelance journalist, Sheffield
emmalwilkinson@gmail.com
Cite this as: *BMJ* 2018;361:k1829