

# this week

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## GP shortage threatens long term plan

Chronic staff shortages in key areas such as general practice are jeopardising the NHS's long term plan to strengthen primary and community care in England, experts warn.

New research by the Health Foundation has found "ongoing deterioration" in workforce numbers in primary and community care, nursing, and mental health services, with staff numbers failing to keep pace with demand.

Shifting care out of hospitals and closer to people's homes was identified as a priority in the long term plan, published in January. But Anita Charlesworth, a director at the Health Foundation, said, "If [the NHS] can't recruit and retain more professionals in primary, mental health, and community care, this will continue to be an unrealised aspiration. There is no sign that the long term downward trend for key staff groups, most notably GPs, will be reversed."

The number of GPs in England fell by 1.6% (450 full time equivalent staff) in the year to September 2018, the report said, despite ministers' pledge to recruit 5000 extra by 2020. The report also highlighted the continuing decline in numbers of community nurses and health visitors, falling by 1.2% (540 FTE staff) in the year to July 2018. It noted slow progress in

mental health recruitment. Psychiatrists saw the smallest percentage increase (0.6% or 50 FTE) among doctors, and numbers of mental health nurses rose by less than 0.5% (170 FTE) in the same period.

The importance of international recruitment was being hampered by broader migration policies and Brexit uncertainties, the report said. Although the number of doctors from other EU countries had risen by 5.5% since 2016, recruitment of EU qualified nurses and midwives had fallen respectively by 8.5% and 3.1%.

Charlesworth said, "So much now hinges on the workforce implementation plan. But to bring an end to chronic workforce shortages for good, action must address the underlying major fault lines in the current approach, particularly the lack of alignment between staffing and funding."

A Department of Health spokeswoman said some of the report's figures were out of date. Latest statistics, from October 2018, showed 2564 more health visitors, 473 more mental health nurses, and 233 more psychiatrists than a year ago, she said, adding, "Last year a record number of doctors were recruited into GP training."

Gareth Iacobucci, *The BMJ*

Cite this as: *BMJ* 2019;364:l686

**The Health Foundation report said there was a 1.2% fall in the number of community nurses and health visitors in the year to July 2018**

### LATEST ONLINE

- GP partner is struck off for dishonesty in research
- More doctors need to train as expert witnesses, says MDU
- Finalists are announced for 11th BMJ Awards



# SEVEN DAYS IN

## Measles cases in Europe trebled in a year, despite rise in vaccinations



REX

More than 80 000 people in 47 European countries contracted measles in 2018, and 72 died, WHO has said. In countries with the relevant data, 61% were admitted to hospital.

The number of people infected was the highest this decade—three times the 2017 total (23 927 cases) and 15 times the record low recorded in 2016 (5273 cases), despite more children in the WHO European region being vaccinated than ever before.

Vaccination programmes are uneven between and within countries, leaving clusters of people unprotected, particularly in middle income countries, WHO said. Ukraine had an incidence rate of 1209 per 1 million population and 53 218 cases; Serbia had a rate of 579 and 5076 cases; and Georgia had a rate of 563 and 2203 cases. WHO urged affected countries to target interventions to where immunisation gaps persist.

In 2017 Europe achieved its highest estimated coverage for the second dose of measles vaccination, with a rate of 90%. And more children received the full two dose series on time in 2017 since WHO started collecting data in 2000. However, progress at national level can mask subnational gaps, which are often not recognised until an outbreak.

Zsuzsanna Jakab, WHO regional director for Europe, said, “We must do more and do it better to protect each and every person from diseases that can be easily avoided.”

Jacqui Thornton, London [Cite this as: BMJ 2019;364:l634](#)

### Childhood trauma

#### Government rejects call for national strategy

MPs expressed disappointment at the government's failure to act on their recommendation for a national strategy to reduce the ill health and social problems in later life that can result from adversity and trauma in childhood. Norman Lamb, chair of the Science and Technology Committee, said, “It is extremely frustrating to see the government largely dismiss our recommendations, opting instead to list existing programmes and shifting responsibility onto local authorities. We already know that this isn't working as well as it could or should be.”

### Addiction

#### MPs warn over alcohol and drug services budget cuts

Almost six in 10 local authorities in England (58%) reduced their budgets for treating alcohol and drug dependence last year despite rising alcohol related hospital admissions, MPs warned. A freedom of information request by Liam Byrne, who chairs the All-Party Parliamentary Group on Children of Alcoholics, found that 16

councils had cut their budgets by at least £500 000 in 2017-18 and four had reported cuts of over £1.5m. Some 38 authorities reported that alcohol related hospital admissions were rising in their area amid funding cuts.

#### Royal society backs online gambling rules for children

The Royal Society for Public Health welcomed new rules from the Gambling Commission for online operators, aiming to protect children from gambling harms. Current rules give online operators 72 hours to carry out age verification checks. The new rules, which will apply from 7 May, will require operators to verify, as a minimum, customers' names, addresses, and dates of birth before allowing them to gamble. In 2019 the society will establish a Gambling Health Alliance to help reduce the damage to health and wellbeing from gambling.

### Public health

#### England's CMO steps down

England's first female chief medical officer, Sally Davies (right), is moving

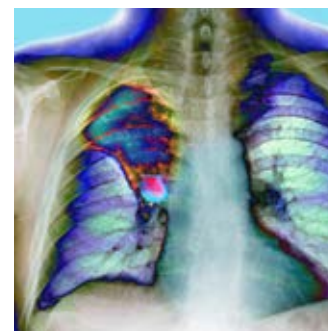
on to become the first female master of Trinity College, University of Cambridge, at the end of September. During her eight and a half years as CMO she has advocated globally on antimicrobial resistance and led the UK government's response to health emergencies including Ebola, pandemic flu, and the Novichok nerve agent attacks. She said that it had been an honour to be the first female CMO, adding, “I can assure everyone that I will continue contributing to the global fight against antimicrobial resistance from my new role.”

### Screening

#### Women with family history of breast cancer to benefit

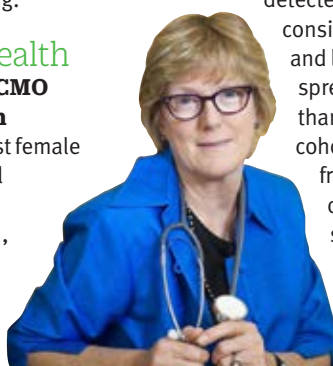
In women aged 35-39 at moderate or high risk of breast cancer that is due to family history, a prospective UK trial found mammography detected cancers that were considerably smaller and less likely to have spread to lymph nodes than in an unscreened cohort. The researchers from the University of Manchester suggested that regular screening among

women identified as having a raised risk of breast cancer could be extended from ages 40-49 to also include women aged 35-39. The study was reported in *EClinicalMedicine*.



#### NHS to roll out lung cancer scanning trucks

The NHS in England is investing £70m in a targeted screening campaign that will operate from trucks in supermarket car parks. The scheme will offer chest scans on the spot as part of a drive to improve survival rates. The money will initially fund 10 mobile clinics in areas with the highest death rates from lung cancer. NHS England estimated that the scheme could reach around 600 000 people over four years, detecting around 3400 cancers and saving hundreds of lives around the country.



# MEDICINE

## Lyme disease

### Bull's eye rash should lead to diagnosis, says NICE

People showing erythema migrans, the characteristic skin rash associated with Lyme disease, can get a diagnosis solely with clinical assessment and without the need for blood tests, said NICE draft guidance. It said early lab tests may not detect the condition and could slow diagnosis, as antibodies can appear six to eight weeks after a person has been bitten by a tick. The draft guidance is out for consultation until 12 March.

## Violent crime

### Stabbed teen hospital admissions surge

Hospital admissions for stabbings involving victims aged 10-19 increased by 60% in England in the past five years, figures from NHS Digital showed. In 2017-18, 1026 teenagers were admitted to hospital with a knife wound, up from 654 in 2012-13. Doctors warned that knife sales were helping to fuel the rise in stabbings and called on high street retailers to do more to restrict their availability. Admissions for all knife injuries increased by almost a third in England in the same period, up from 3888 to 5052.

### Drug use review won't look at decriminalisation

Carol Black, who has led several medical organisations and chaired government reviews on work and health, will lead a "wide ranging" review of how illicit drug use fuels serious violence. But the review, which will publish its initial findings this summer, will not look at drug decriminalisation. The review, commissioned by the Home Office, will look at who drug users are, what they are taking, who is supplying the drugs, related harms, and the best ways to prevent misuse.



Symptoms of Lyme disease include a bull's eye rash at the site of a tick bite

## Cervical cancer

### Deaths increase as HPV vaccine is underused

Cervical cancers will become an increasing health burden unless more people are immunised against human papillomavirus, warned the World Health Organization's International Agency for Research on Cancer. About 570 000 new cases were diagnosed around the world in 2018, and more than 310 000 women died from the disease. The death toll could rise to 460 000 by 2040 if preventive efforts are not stepped up, the agency predicted. Its director, Elisabete Weiderpass, said, "Unfounded rumours about HPV vaccines continue to delay or impede the scaling up of vaccination."

## Brain injury

### Most women prisoners show trauma signs

Almost two thirds of inmates at a women's prison may have had a traumatic brain injury, a study found. The Disabilities Trust and Royal Holloway, University of London screened 173 women at Drake Hall prison in Staffordshire, and 64% reported a history indicative of a brain injury—96% of which indicated a traumatic brain injury. The authors called for brain injury screening to be a routine part of induction assessments on entry to prison.

Cite this as: *BMJ* 2019;364:l667

## MEASLES

The Philippines recorded **4302** cases of measles and 70 deaths up to 9 February. This compares with **5120** cases and 18 deaths during the whole of 2018.

[Department of Health, Philippines]

## SIXTY SECONDS ON... NANNYING



### AH, KINDLY WOMEN WITH CAVERNOUS BAGS?

Not likely. Sally Davies, England's chief medical officer, nearly choked when she thought presenter Nick Robinson was being sexist on the BBC's *Today* programme last week. They were discussing the latest advice on children's use of screens (see p 258) when he asked about getting the balance right "between nannying and stating things that are obvious." She replied, "I wonder whether you would say that to a male chief medical officer?"

### HE MIGHT NOT HAVE TO WORRY FOR MUCH LONGER . . .

You're right. Davies announced last week that she would be stepping down from her post (see left) to take up a new role as master of Trinity College, Cambridge. But, anyway, that's not the point.

### OKAY, BUT ISN'T NANNYING NOW GENDER NEUTRAL?

Well, Britney Spears and Gwyneth Paltrow, among many others, have employed male nannies or "mannies."

### BUT THIS IS ABOUT PUBLIC HEALTH, NOT ACTUALLY NANNYING

Yes, we're talking about the "nanny state," much bemoaned by former prime minister (and woman) Margaret Thatcher. But it's worth noting that public health policies that have been perceived by some as nannying have led to some powerful behavioural changes.

Think of all the people who have stopped smoking because of high taxes on cigarettes and the ban on smoking in public places.

### AND A SPOONFUL OF SUGAR?

Not on your nanny. The sugar tax is trying to put a stop to that as well as helping to solve the obesity crisis and save children's teeth.

### IS THIS JUST A BRITISH PROBLEM?

No, in fact there is a "nanny state index" ranking "the worst places in the European Union to eat, drink, smoke, and vape," based on the level of regulation. The UK ranks second out of 28 countries on the 2017 index, while Finland comes top.

Susan Mayor, London

Cite this as: *BMJ* 2019;364:l658







**FRAUD** of this type costs the NHS an estimated **£256m** a year, and it has set a target to halve the losses by 2020

# Fines for claiming free prescriptions rose by a third last year

**EXCLUSIVE** The number of penalty prescription charges issued in England rose by a third last year and has increased by 60% in the past three years, *The BMJ* has learnt.

Figures released under freedom of information legislation show that 1 379 957 notices were issued in 2018. The previous year 1 052 430 were issued and in 2016 there were 864 366.

The figures were disclosed by the NHS Business Services Authority, which issues the penalty charges to patients believed to have incorrectly claimed free prescriptions or free or reduced cost dental treatment.

The disclosure comes amid a prescription fraud crackdown. The NHS estimates this type of fraud costs £256m a year and has set a target to halve the losses by 2020. It launched a campaign last September, alerting patients to check before they claimed and warning that they faced a fine of up to £100 if they were not eligible.

The NHS will also pilot a digital system in England this year to allow pharmacists to instantly check patients' entitlement to free prescriptions and has created online tools for patients to check their eligibility.

## Disproportionate effect

But medical and pharmacy leaders warned the crackdown would have a disproportionate effect on people on low incomes. They include those who qualify for free prescriptions but have not renewed exemption cards, and people on benefits who did not realise their exemption status had changed when switching to universal credit.

According to the authority around a third of penalty charges were withdrawn last year once the patient had proved an entitlement to free prescriptions, but it told *The BMJ* it had recovered "in excess of £80m" since September 2014, after factoring in operating costs.

## Skills log will stop failed NHS managers from being "moved on"

Forcing whistleblowers out of their jobs is "morally abhorrent and operationally foolish," England's health secretary said, unveiling plans for a list of core skills for senior NHS managers.

Matt Hancock told a London conference that he would also set up a central database to log the qualifications, experience, and employment history of England's NHS trust directors.

The two moves were recommended in a review, led by Tom Kark (above right), to increase directors' competence and to end the practice of moving failing managers to other trusts. The review suggested that core competencies for directors should include an understanding of the importance of learning from whistleblowing, empowering

staff to raise concerns, and encouraging compliance with the duty of candour.

### Fit and proper persons test

The recommendations form part of a review of the "fit and proper persons test," which was introduced after a series of scandals but that is widely seen as having failed to live up to its promise. Kark, who was counsel to the inquiry into failings at Mid Staffordshire NHS Foundation Trust, said he was told the test was seen as a distraction or a "tick box exercise."

Hancock told the Improving Patient Safety and Care conference that other

recommendations from the review will be considered as part of the workforce implementation plan led by Dido Harding, who chairs NHS Improvement.

These include the establishment of the Health Directors Standards Council, with power to bar directors who have been found guilty of misconduct from moving on as NHS directors.

The review noted cases of managers being "quietly moved on." Sometimes there was a settlement agreement, a payout, a bland reference, and "the wrongdoing hushed up by a



confidentiality clause." It recommended a mandatory reference form for when a director moves from trust to trust, which could not be curtailed by a settlement agreement.

Misconduct that could bar a director would include victimisation of whistleblowers.

"Whistleblowers are doing the NHS a great service," Hancock said. "Yet, all too often, they're ignored, bullied, or, worse, forced out. Making someone choose between the job they love and speaking the truth to keep patients safe is morally abhorrent and operationally foolish. It's an injustice I am determined to end."

Clare Dyer, *The BMJ*

Cite this as: *BMJ* 2019;364:l632

**"All too often, whistleblowers are ignored, bullied, or, worse, forced out of a job they love"** Matt Hancock, health secretary



**“In Wales and Scotland patients get prescriptions for free—we think medicines should be free in England”**

Sandra Gidley, RPS

Richard Vautrey, chair of the BMA's General Practitioners Committee, said, “It's almost always the case that people have unwittingly not renewed their certificate that entitles them to free prescriptions. Real care needs to be taken in the messaging, as it can come across as very threatening. It's not unusual for patients to be extremely distressed by the suggestion they have committed fraud.”

Sandra Gidley, chair of the Royal Pharmaceutical Society's English pharmacy board, said the new system of checks may put pharmacists in the firing line if they had to be “the bearers of bad news.”

“It's not pharmacists' job to police every single prescription,” she said. “The average pharmacy staff is not an expert in the benefit system.”

Gidley added, “Our view is quite simple. In Wales and Scotland patients get prescriptions for free—we think medicines should be free in England.”

#### **“Dysfunctional” system**

Rachel Power, chief executive of the Patients Association, said the current system “appears to be dysfunctional.”

She said, “Far from a tougher system being needed, it's essential

that it stops slapping fines on patients who have done nothing wrong. The impact on people of receiving letters threatening court action, particularly those who are receiving treatment for mental illnesses, should not be underestimated.”

A spokesperson for the authority said, “Increasing the number of checks to verify entitlement to free prescriptions is important to protect NHS funds from loss through both error and deliberate fraud. While GP practice and pharmacy staff are encouraged to support their patients, it remains the patient's responsibility to check their entitlement before claiming free prescriptions.

“We are working to educate patients on the importance of keeping the details on both their GP records and their exemption or prescription prepayment certificate up to date.”

The authority said that it could cancel charges if they were incorrectly issued. It also said it could waive penalties if patients could show that they “did not act wrongfully or with lack of care, or if there is an exceptional reason why they should not pay the penalty charge.”

Gareth Iacobucci, *The BMJ*

Cite this as: *BMJ* 2019;364:l651

## **GMC loses appeal to strike off locum**

The GMC has failed to persuade a High Court judge that an ophthalmologist who had conditions placed on his work by a medical practitioners tribunal should instead be struck off the medical register.

The GMC argued that erasure was the only correct sanction for Przemyslaw Sledzik, whose fitness to practise had been found to be impaired because of misconduct and poor professional performance.

Mrs Justice Lang found flaws in the tribunal's determination and sent the case back for the sanction to be revisited. But Sledzik, who represented himself in court, persuaded the judge that the tribunal

was not at fault in imposing conditions on his registration, including requiring him to work under supervision.

The tribunal's findings related to nine months in 2015 when Sledzik worked as a locum ophthalmic medical practitioner for Boots Opticians and as a locum optometrist for Specsavers.

#### **“Broad failures”**

The tribunal found “broad and repeated failures over a sustained period in fundamental areas of clinical practice such as history taking, examination, record keeping, and providing advice.”

His failures in dealing with a child with a squint could have allowed serious pathology to

be missed, the tribunal found, and he had failed to refer some patients for hospital eye services, in breach of guidance.

Sledzik told the tribunal that from his hospital doctor experience he was aware that referral guidance was imperfect, that it had since changed to reflect his practice, and he therefore did not consider his actions amounted to misconduct.

The judge noted there were no previous disciplinary findings against Sledzik, adding, “I do not consider the allegations of misconduct were so grave that erasure was the only proper course to adopt.”

Clare Dyer, *The BMJ*

Cite this as: *BMJ* 2019;364:l646

## **Assisted dying: terminally ill man urged UK law change**

A terminally ill man with motor neurone disease urged UK MPs to change the law to allow assisted dying in an open letter sent on the day of his assisted death in Switzerland.

Geoffrey Whaley, 80, was given a diagnosis of motor neurone disease in 2016. With no legal option of assisted dying at home, he decided to travel to Dignitas in Switzerland to end his life. But several weeks before his journey, he and his wife, Ann, were investigated by the police after an anonymous call to social services.

#### **Peaceful and dignified death**

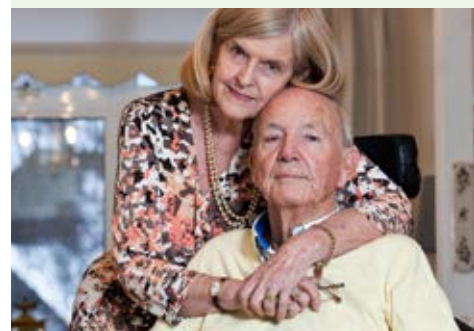
In his letter he said, “The blanket ban on assisted dying has not only forced me to spend thousands of pounds and endure months of logistical hurdles to secure a peaceful and dignified death overseas, but it has meant that my final weeks of life have been blighted by visits from social services and police.

“The thought that I might not make it to Switzerland, or that, if I did, Ann might be facing 14 years in jail for helping me, was almost too much to bear,” he said.

Sarah Wootton, chief executive of Dignity in Dying, a campaigning organisation, said, “Geoffrey and Ann's story is a heartbreaking reminder of the cruelty the current law. Banning the practice in this country does not make it go away; it simply outsources death overseas, at huge financial and emotional cost to the families involved.”

Susan Mayor, London

Cite this as: *BMJ* 2019;364:l631



# Use your common sense: chief medical officers' advice on child screen time

The government asked for formal guidance for professionals and parents on the health effects of social media, but the CMOs say the evidence is not there. **Nigel Hawkes** reports

**I**s time spent on screens and social media a risk to children's health? In the latest report to be published on this topic, Sally Davies and the UK's other chief medical officers conclude there is insufficient evidence to answer this or to support guidelines on optimal screen time lengths.

Instead, they repeat advice from the Royal College of Paediatrics and Child Health (RCPCH), which suggests families ask if screen use is out of control: does it interfere with family life, with sleep?

But England's health secretary wanted more clear cut advice. "Unrestricted use of social media by younger children risks being damaging to their mental health," Matt Hancock told the *Observer* last September. "So I have asked the chief medical officer to bring forward formal guidance." He also wanted advice on a minimum age to access certain sites. He got neither.

Davies's dilemma is made clear by a recent report commissioned from a team at the Institute of Education at University College London, which forms the basis for the CMOs' commentary. The team found 82 reviews of evidence linking screen based activities to

mental health and psychosocial outcomes. They covered areas such as problematic or addictive internet use, cyberbullying, gaming, and sexting.

## No reviews on gaming or sexting

Of the 78 primarily quantitative studies from which they distilled their conclusions, 33 were classified as low quality and 27 of medium quality. There wasn't a single review of the effects of gaming, sexting, or smartphone use that they could classify as high quality. Prospective studies were rare, there was a lack of longitudinal studies, and very few reviews used meta-analysis. "Key methodological weaknesses were identified across many of the reviews," the authors concluded.

This forced the CMOs to offer advice without the quality of evidence demanded in medicine. Andrew Przybylski, director of research at Oxford Internet Institute, gives them credit for honesty. "The report acknowledges that much of what we think we know about

the effects of technology on young people is hype and not solid, reliable science," he said. "In the absence of evidence, the CMO is quite clear that the report is making suggestions out of an abundance of caution."

Pete Etchells, reader in psychology and science communication at Bath Spa University, took a similar view. "We must be resistant to overgeneralising from anecdotal experience," he said.

"The best research evidence we currently have suggests that although there may be associations between screen use and poorer mental wellbeing, these are incredibly small."

## Beneficial effects

Etchells added, "Despite persistent news headlines claiming that screen time is fundamentally a harmful activity for children—and adults—to engage in, the report rightly acknowledges that there can also be beneficial effects, and that the research evidence is not of sufficient quality to determine the direction of any causal links."



**Andrew Przybylski:**  
"What we think we know is hype"



**Shirley Cramer:**  
"Research must be prioritised"

**REVIEWERS** concluded that of **78** primarily quantitative studies, **33** were classified as low quality, and **27** of medium quality

## Australian MPs visit UK GP for low carb advice

A group of Australian MPs travelled to Southport earlier this month to meet GP and low carb proponent David Unwin (left) as part of an inquiry into the role of diet in the prevention and management of type 2 diabetes.

The four MPs and a scientific officer, all

members of Western Australia's Education and Health Standing Committee, spent 24 hours at Unwin's practice, viewing presentations and meeting patients.

The visit was set up after Unwin submitted evidence to the inquiry showing that the low carb approach

saves his practice £40 000 a year on drugs—while helping up to 50% of patients get their diabetes into drug free remission.

The committee chair, Janine Freeman, said, "We felt it was important to investigate drug free options for the treatment of type 2 diabetes. It was clear some of the

leaders of this approach are in Britain and worth visiting. The practice's success shows it is a powerful tool."

Unwin, who was awarded NHS Innovator of the Year 2016 for his research, said, "I was pleased to find the visitors well briefed, pragmatic, and understanding that







**“Parents should make decisions about a child’s screen time based on whether they are getting enough sleep”**  
Russell Viner, RCPCH

The most substantive recommendation the CMOs make is that the technology industry should take its responsibilities seriously. The government plans legislation to tackle online abuse and bullying, but before that, the CMOs say, the industry should establish a voluntary code of conduct.

#### Industry code of conduct

Among steps that might be taken are effective age verification, advertising control, and ensuring behaviours such as bullying and self harm are not normalised. The industry should also share anonymised data with public sector researchers to improve the evidence base. “Technology companies have a duty of care,” Davies said. “They must make more effort to keep their users safe from harm, particularly children and young people.”

The CMOs’ report has nothing extra to offer doctors beyond supporting the recent RCPCH advice. Russell Viner, the college’s president, said, “We suggest parents make decisions about screen time based on their child’s development and health, and whether they are getting enough exercise and sleep. It is when screen use gets in the way or restricts other activities that a child’s wellbeing can be negatively impacted.”

Shirley Cramer, chief executive of the Royal Society for Public Health, said, “It cannot be stressed enough that research must be prioritised to improve our understanding of the relationship between screen use, in particular social media, on our young people’s mental health and wellbeing.”

Nigel Hawkes, London

Cite this as: *BMJ* 2019;364:l643

the real problem is persuading patients that starchy carbs digest down into sugar,” he said. “The visit shows a wonderful energy and a genuine wish to help people. They really liked how what we do is scalable, effective, and inexpensive. Drugs will never be the answer to this epidemic.”

Later, the Australians visited Roy Taylor,

#### “They really liked how what we do is scalable, effective, and inexpensive”

professor of medicine and metabolism at Newcastle University. Taylor said the delegation was “very interested in the understanding of type 2 diabetes as a simple reversible condition

of excess fat inside the liver and pancreas of susceptible people.”

He said that they agreed that, given the rate of increase of type 2 diabetes, “this has major implications for the direction of public health policy and potential recommendations for legislation.”

Jane Feinmann, London

Cite this as: *BMJ* 2019;364:l659

## FIVE MINUTES WITH . . .

### Nikhil Sharma

The consultant neurologist says it’s time to scrap the six month lifespan rule on terminally ill benefit claimants

**“T**he fast track ‘special rules’ process for people with a terminal diagnosis such as motor neurone disease (MND) requires that they are expected to die within six months.

“It’s vital that this six month limit is scrapped, as it has a profound impact on virtually all aspects of care for people with MND. I’ve had examples of patients where the benefits agencies challenged applications made under the special rules for terminal illness because of uncertainty about whether they would live for less than six months.

“I’ve had frank conversations where I explain that it’s often impossible to predict prognosis accurately, particularly in a condition such as MND. And there are some really heartbreaking stories from patients who have been called into meetings in buildings that they can’t access, to assess whether they can go back to work.

“All of this causes a huge amount of stress and anxiety, when they should be spending time with their families, not trying to fight bureaucracy.

“The other implication for patients with MND is that they need to make numerous very complex decisions, such as whether a feeding tube needs to be placed and whether they want support with their breathing. But my experience is that the benefits issue takes the place of much more complicated decisions, which are then delayed.

“What would work better? Scotland has taken a very pragmatic approach and simply requires people to state they have a terminal illness when applying for benefits under the special rules process, as opposed to putting a set limit on their remaining lifespan. I think that this would be a very simple and effective way of solving the problem.

“MND is a universally fatal disorder. Trying to squeeze somebody into a limit of six months is just inappropriate.”

Nikhil Sharma is a consultant neurologist at the National Hospital of Neurology and Neurosurgery, London, and a trustee of the Motor Neurone Disease Association

Susan Mayor, London

Cite this as: *BMJ* 2019;364:l630



**“THEY SHOULD BE SPENDING TIME WITH THEIR FAMILIES, NOT TRYING TO FIGHT BUREAUCRACY”**

## THE BIG PICTURE

# Guggenheim hit by opioid protest

The US photographer and activist Nan Goldin brought New York's Guggenheim Museum to a standstill last weekend by organising a protest against it accepting donations from the family that owns the maker of OxyContin, the prescription painkiller at the root of the US opioid crisis.

Goldin and fellow demonstrators, chanting criticism of the Sacklers, who own Purdue Pharma, handed out fake pill bottles and threw fake prescriptions down the landmark atrium. They also lay on the floor, as if dead.

Goldin, who had an opioid overdose after being prescribed OxyContin, is campaigning for art and academic institutions in the US and the UK to refuse philanthropy from the Sacklers. "I want the Guggenheim and others to disavow themselves from the Sacklers and refuse future funding from them," she told the *Guardian*.

The surviving relatives of the Purdue founders, who now own the company, have been much criticised for its alleged hard sell tactics aimed at doctors while underplaying the dangers of OxyContin.

Figures from the Centers for Disease Control and Prevention show that more than 72 000 people a year in the US die from drug overdoses—and 49 000 are caused by opioids.

Alison Shepherd, *The BMJ*

Cite this as: *BMJ* 2019;364:l691







THE NEW YORK TIMES/REDUX/ETEVINE

# New personalised care plan for the NHS

Change is coming, if funding materialises

**T**he recently published NHS long term plan<sup>1</sup> outlines five large practical changes to the NHS service model, including ambitious plans for personalised care.

The goal is to establish the NHS comprehensive model of personalised care in every local health system. This model consists of six interconnected components: shared decision making; personalised care and support planning; enabling choice; social prescribing and community based support; supported self management; and personal health budgets. Their common aim is to give people more control over their health, care, and support at all stages of life.

None of these approaches are new, each one has an evidence base,<sup>2</sup> and all have been the subject of policy announcements before,<sup>3</sup> generally with little effect.<sup>4</sup> For many people with long term conditions or complex health and social care needs, the gap between aspirations for personalised care and current reality is stark.<sup>5</sup> It is a big ask for any single document to bridge that gap, yet this model gives cause for cautious optimism.

This time there is a delivery plan: NHS England published *Universal Personalised Care: Implementing the Comprehensive Model* on 31 January.<sup>6</sup> It includes a guide for systematic delivery that lists 21 actions to make these approaches standard. Although social prescribing has been making headlines,<sup>7</sup> the combined effect of all six components makes this model more than the sum of its parts.

## Delivery plan

Like most NHS plans, this one focuses on structures, such as emerging primary care networks, and targets, including extending this support to over two and a half million people within five years. But it also recognises the critical human relationships needed to make this happen.

Unlike previous top down initiatives, this model has been co-produced—including as equal partners people with lived experience who understand the changes needed and have driven many of the existing personalised care innovations such as personal health budgets. Professional organisations such as the Royal College of General Practitioners and the Royal College of Physicians have also already embraced this agenda.

**The plan recognises the critical human relationships needed to make it happen**

Personalised care is much more than “being nice.” It describes a fundamental shift towards recognising that people who use health services can also help solve problems and take control. Individual professionals, already working in stretched services, cannot realise the full potential of these changes at the proposed scale without widespread cultural transformation. That transformation requires training, new roles, and new infrastructure.<sup>2</sup> The plan says there will be extra funding but does not give details.

The momentum of the long term plan, and the tilt in funding towards primary and community care, will ease the implementation of this personalised care model. The changes being made to the mechanisms in England for contracts and quality standards (such as a revised Quality and Outcomes Framework) will also help progress.

Voluntary sector leaders welcome the move away from a purely medical model but continue to question whether funding will also flow into the voluntary services and support that are so essential to personalised care.<sup>12</sup>

## Striking a balance

Universal Personalised Care acknowledges the spectrum of activities that fall under each component, and the balance to be struck between standardisation, local initiative, and personalisation. This balance is important—we need to set quality expectations and remove unfair variation while allowing local systems to flourish in their own way.

The success of this new model hinges on two key enablers: adequate funding and our collective engagement as people and professionals. The groundswell of support now needs the details of the funding to be clear to deliver the promised transformation in care.

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# Rationalising medications through deprescribing

Careful judgment is required to optimise benefit and minimise harm

**A**n ageing population and growth in multimorbidity and polypharmacy, means increasing attention is being paid to deprescribing.

This term has become widely used in recent years, and there are numerous definitions.<sup>1</sup> Put simply, it is the process of withdrawing drugs to try to improve outcomes.<sup>2</sup> But it is important to recognise this is a complex process; careful judgment is required to balance the potential risks and benefits of withdrawing medicines.

Since *The BMJ* last published an editorial on deprescribing in 2014<sup>2</sup> at least three systematic reviews have been published<sup>3-5</sup> as well as several studies not included in these reviews.<sup>6-8</sup> Here we consider the latest evidence and guidance on withdrawing drug treatments.

Multiple studies of polypharmacy or deprescribing have shown that interventions by pharmacists, doctors, or multidisciplinary teams can reduce the number of medications that patients take<sup>3</sup> and reduce the prevalence of potentially inappropriate prescribing.<sup>5</sup> These reductions tend to be modest, however. For example, in one meta-analysis patients were taking an average of 7.4 drugs at baseline; during follow-up this fell by 0.2 drugs in intervention groups and increased by 0.2 drugs in control groups.

## Clinical outcomes

Research on clinical outcomes is also growing. Overall, deprescribing seems to be safe, but the evidence on benefits remains mixed.<sup>3-5</sup> A meta-analysis of randomised trials showed no overall reduction in mortality



**Key aspects include an emphasis on empowering and supporting patients in their decision making around medicines**

from deprescribing interventions,<sup>4</sup> although a subgroup analysis confined to interventions targeted at patients (rather than education for clinicians) did suggest a mortality benefit. In another meta-analysis, strategies to reduce polypharmacy did not reduce mortality<sup>3</sup> or hospital admissions. At least 15 studies have examined the effects of deprescribing on quality of life, and only one of these reported a benefit (which was modest).<sup>4</sup>

Reliable cost effectiveness data are scarce. Although reducing prescribing, particularly hazardous prescribing, might be expected to save money, these savings must be offset against the cost of the deprescribing intervention. One recent analysis<sup>9</sup> suggests that interventions to reduce polypharmacy are cost saving overall, but more research is needed to identify the most cost effective strategies and their key elements.<sup>10</sup>

The available guidance and published evaluations highlight that, done properly, deprescribing is complex and time consuming. When patients are taking multiple drugs, each must be carefully considered in the context of likely benefits and harms, therapeutic indications, potential drug interactions, the preferences of patients and carers, and adherence. A Scottish study estimated that

this takes up to 30 minutes for a doctor and 75 minutes for a pharmacist.<sup>9</sup> Health services should be under no illusion that benefits can be achieved in the single short consultations typical of general practice appointments in the UK. Investment is required to fund pharmacists, doctors, or multidisciplinary teams to do this work.

Considerable advice is available on deprescribing. Guidance from the Scottish Government Polypharmacy Model of Care Group is particularly helpful, offering a seven step process for reviewing medications.<sup>10</sup> Key aspects include a strong focus on what matters to each patient and an emphasis on empowering and supporting patients in their decision making around medicines. Respect for patient autonomy demands detailed discussion of the expected benefits and risks of all medicines, recognising that these can change over time, particularly with age or increasing frailty.

## Worthwhile investment

More research is needed to help identify the best approaches to deprescribing, and it's important to do this in collaboration with patients. Nevertheless, based on reasonably substantive evidence so far, it is unlikely that we are going to see major breakthroughs in this area. Probably the best we can expect is modest reductions in medication load and hazardous prescribing, and modest improvements in patient outcomes. Given the complexity of the task, overall cost savings are also likely to be modest. Deprescribing remains a worthwhile investment, however, and should be done in partnership with the patients and families who cope every day with burdensome polypharmacy.

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Atrial fibrillation (AF) is detected in around a third of all patients with ischaemic stroke. Data from stroke registries show that in these patients unknown, untreated, or undertreated AF is responsible for most of these often fatal or debilitating strokes. Screening has been the subject of much debate by international collaborations and in the UK parliament because of AF's increasing prevalence (the number of patients in the UK is predicted to rise from 700 000 in 2010 to up to 1.8 million by 2060) and the potential to prevent AF related strokes with anticoagulation.

Although data from randomised controlled trials are lacking, cohort studies indicate that screen detected AF is not a benign condition and, in the presence of additional risk factors, warrants consideration of anticoagulation. In a cohort study of 5555 asymptomatic patients with incidentally detected AF, anticoagulation therapy compared with no antithrombotic therapy was associated with significantly reduced adjusted risk of stroke, from 4% to 1%, and risk of death from 7% to 4%, in just 1.5 years. This suggests that screen detected AF responds to treatment similarly to that detected during routine care.

An effective and economical screening programme could minimise the potential for harm in terms of inappropriate treatment and unnecessary investigations; maximising the diagnostic yield of AF that carries significant risk; and maximising the uptake of appropriate anticoagulation treatment.

#### Accurate detection

Single lead electrocardiographic (ECG) devices are inexpensive, non-invasive, reusable, and convenient, and they have been shown to be cost effective for AF screening. Trained clinicians can confirm AF diagnoses from single lead ECGs with high accuracy and further reduce the risk of treatment of people with false positive results, the main screening risk. As single lead ECGs are not routinely used to detect previous infarctions or hypertrophy, their use would reduce the detection rate of "incidentalomas" compared with 12 lead ECGs.

As a substantial proportion of AF is paroxysmal early in the disease course, intermittent screening with repeat screenings every few years could cut the risk of false negative cases. There is likely to be an optimal screening duration and frequency for detecting paroxysmal AF, which is clinically important in populations at risk—for example, people older than 65.

Advances in wearable technology and algorithms are likely to yield inexpensive and practical options to determine AF burden and help stratify stroke risk. Indeed, "screening" for AF will become part of many people's daily lives because of technology such as the latest Apple watch.

#### Acceptability

Crucially, the Strokestop study (7173 participants) showed that screening for AF twice daily, over 14 days, is well accepted (only 1% of participants recorded fewer than 15 single lead ECGs over two weeks); it detected new AF in 3% of the screened population, and more than 90% of those accepted anticoagulation treatment. In the UK, national database data showed that oral anticoagulants in people with AF with a CHA<sub>2</sub>DS<sub>2</sub>-VASc score  $\geq 2$  increased from 48% in 2006 to 78.6% in 2016. (Suboptimal treatment was one of the key points raised by the UK National Screening Committee when it recommended against screening in 2014.) The increase in anticoagulation treatment from 2009 is estimated to have prevented more than 75 AF related strokes resulting in hospital admission each week in England.

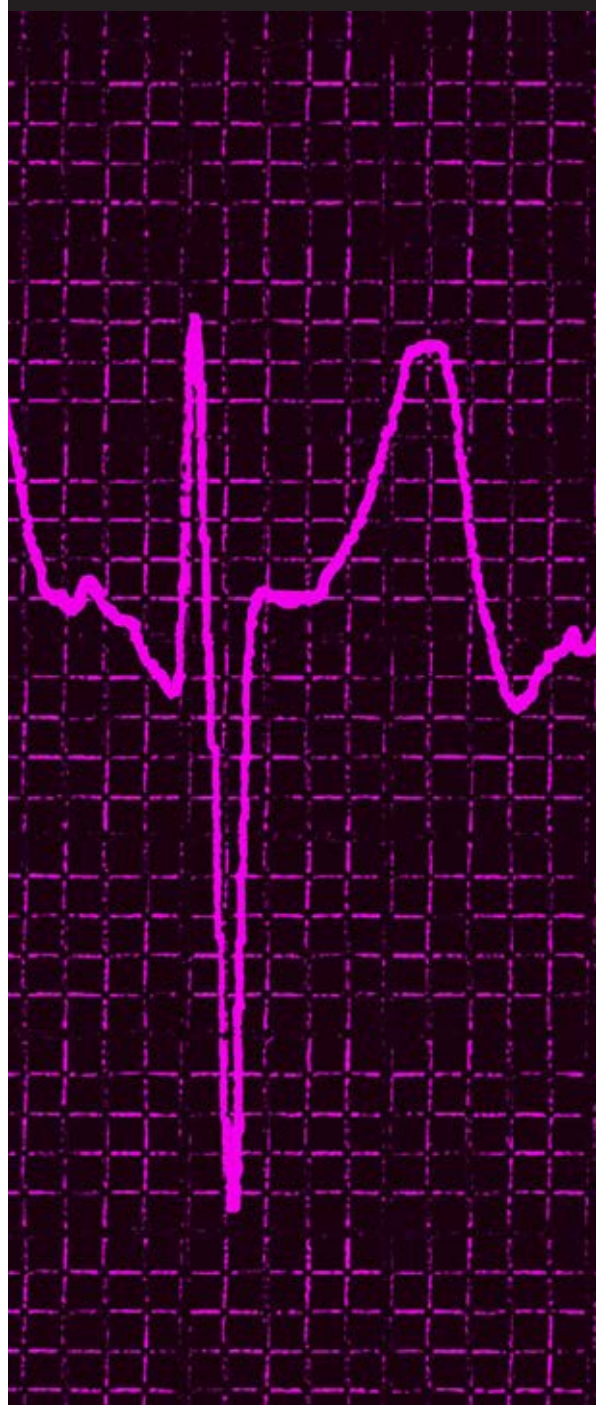
Comprehensive patient centred informed consent can ensure patients are made aware of benefits and harms of screening, including false reassurance. There is also the potential to manage reversible bleeding risk factors at scheduled reviews.

The prevalence of AF is rising steeply and is associated with increased risk of heart failure, myocardial infarction, and death. Evidence is also growing that AF is associated with cognitive decline and dementia, and if the mechanism is vascular anticoagulation could mitigate the risk.

Current evidence provides a strong case for introducing AF screening now. The outcomes of large randomised trials, such as that proposed by Mant and colleagues, would strengthen the evidence base.

## HEAD TO HEAD

# Should we screen for atrial fibrillation?





Current evidence is sufficient to justify a national screening programme, argues **Mark Lown**, but **Patrick Moran** says too many questions remain and evidence from randomised trials is needed to avoid overdiagnosis

**no**

We cannot be sure that improvements in stroke outcomes would sufficiently outweigh any harms to justify prioritising screening

Patrick Moran, senior research fellow in health economics, Trinity College Dublin, Ireland  
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The case for making screening a central pillar of efforts to tackle the looming epidemic of atrial fibrillation is promising, but important gaps in the evidence base remain. These include questions about the effect of screening on stroke outcomes; the optimal combination of test, strategy, and target population; and the opportunity cost of population based programmes.

The momentum behind screening should be harnessed to ensure these gaps are filled, and not overlooked in an understandable eagerness to act against a major challenge facing health systems across the world.

AF seems to meet many Wilson and Junger's criteria for screening. It is an important problem that can be diagnosed using a readily available test, and proved treatments exist to cut the risk of AF related stroke. However, although experimental and observational evidence indicates that screening increases AF detection, we have no evidence from randomised controlled trials that it cuts stroke incidence or severity in screened versus unscreened populations.

#### Risk profile assumptions

In an era when the scale of overdiagnosis and overtreatment is becoming clear, any assumption that greater AF detection equates to improved health outcomes requires serious scrutiny. Such an assumption implies that the risk profile of screen detected patients—and by extension their propensity to use, benefit from, and be harmed by, anticoagulant treatment—is the same as those presenting clinically.

Potential harms of screening include the consequences of being labelled with a serious health problem, the risk of bleeding from anticoagulation treatment, and the opportunity cost of the health benefits that would be lost by allocating scarce resources to this intervention. Central to estimating the scale of these harms is knowing the risk of stroke in untreated AF, and as recent research shows, there is considerable uncertainty surrounding this, even in clinically diagnosed patients.

Given how little we currently know about the clinical risk profile of the cohort that

would be identified through screening, we cannot be sure that improvements in stroke outcomes would sufficiently outweigh any harms to justify prioritising screening over other interventions. Although the balance of benefits and harms has been explored using simulation models that combine the best available evidence from multiple sources, the external validity of these types of studies is low. Fortunately, clinical trials that seek to definitively answer these questions are under way, and we must wait for their results rather than push ahead with a costly public health intervention that may prove difficult to withdraw.

#### Screening strategy unclear

From a policy perspective, there is much ambiguity about how screening would be scaled up and implemented, given the high level of heterogeneity in the target population, screening test and strategy used in previous studies. For example, the three trials that showed increased AF detection rates used different populations, tests, and ECG readers. The available evidence does not, therefore, present decision makers with a uniformly defined solution that can be transposed into policy.

Furthermore, the rapid development of ECG diagnostics—including smartphone apps, wearable devices, and automated ECG interpretation—has the potential to diminish the applicability of previous research carried out using older technology.

All studies to date have used one-off testing within a given population, so the effect of successive screening rounds on the detection of incident or paroxysmal disease is also unknown. The only available data on the comparative effectiveness and cost effectiveness of different start ages and screening frequencies come from simulation modelling studies.

Coordinated, concerted efforts are required to combat the steep rise in AF associated with global population ageing. But, in the absence of research that reliably confirms the health benefits of screening and provides sufficient information to guide implementation there remains considerable uncertainty about screening's potential to reduce the burden of AF related morbidity and mortality in society.

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Listen to the authors debate the issue in the podcast on [bmj.com](https://www.bmj.com)

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# Where will the NHS focus its proton beam therapy plans?

As the UK's first national centre for this developing radiotherapy opens, **Matthew Limb** reports on the hopes of doctors, policy makers, and patients

**A**dvocates view this winter's opening of the NHS's first high energy proton beam therapy unit, at the Christie NHS Foundation Trust in Manchester, as a service landmark. "It is a confirmation that radiation oncology is absolutely a key part of modern cancer treatment," says Adrian Crellin, NHS England clinical lead for proton beam therapy.

Stuart Green, director of medical physics at University Hospitals Birmingham NHS Foundation Trust, also sees a "milestone for our NHS radiotherapy community" being reached. When the second planned proton beam unit opens at University College Hospital (UCH), London, in 2020, he says, "Whatever we can do with protons we'll be doing as well as anyone can possibly do in the UK."

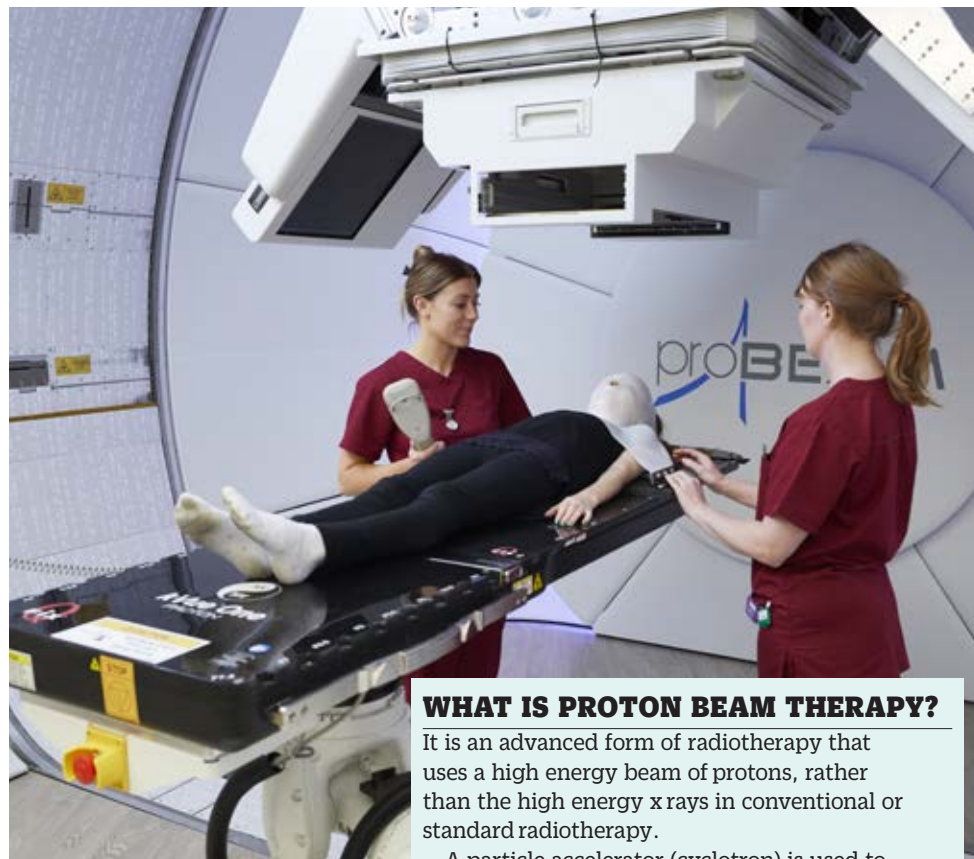
Proton therapy for rare eye tumours has been available on the NHS at the Clatterbridge Cancer Centre on the Wirral since 1989. But for other cancers, patients requiring high energy proton beam therapy have had to go abroad for treatment. Since 2008, some 1400 patients have been referred

to hospitals in the US and Europe under an NHS overseas treatment programme that funds treatment, transport, and accommodation.

When fully up and running, the two £125m centres will each treat up to 750 patients a year. "Many of the patients we'll be treating will be children, young people, and those with what could loosely be termed as rarer tumours," says Ed Smith, who heads the Christie unit. "I suspect in the next three or four years all of those patients who would have gone overseas will be treated in the UK."

This will be "fantastic" for patients and their families, according to a 25 year old PhD student who had NHS funded proton therapy in the US in 2015. "I think it's a necessary step forward," she says.

She developed inoperable Ewing sarcoma at the bottom of her spine and was referred to Jacksonville, Florida, for two months of intensive treatment combining chemotherapy and proton beam therapy. Her scans have been clear since, and she believes her risk of internal damage was lower than if she had had conventional or standard



## WHAT IS PROTON BEAM THERAPY?

It is an advanced form of radiotherapy that uses a high energy beam of protons, rather than the high energy x rays in conventional or standard radiotherapy.

A particle accelerator (cyclotron) is used to speed up the protons, which are aimed at the tumour using a gantry that rotates through 360°. The beam of protons stops once it "hits" the cancer cells, rather than carrying on through the body, so there is little or no dose to surrounding tissues.

radiotherapy. Nonetheless, she would have preferred treatment in the UK had it been available. "It means your life, your medical treatment, and your family's support networks aren't disrupted so much."

## Growing evidence

Research has advanced since the NHS announced investment in the national proton beam centres in 2012. Smith, a consultant clinical oncologist, says protons now have "an increasingly proved role in the indications we will treat" and suggests the evidence is "beginning to firm up" for the reduction of long term toxicities.

Conventional radiotherapy uses x rays from multiple directions; a modern variant is high precision, intensity modulated radiotherapy (IMRT), which aims to maximise the dose to the tumour while minimising the dose to the surrounding tissue. But IMRT's multiple beam approach still leads to healthy tissue receiving



substantial doses, and in selected cases proton radiotherapy can provide important dose advantages compared with best quality IMRT.

In children and young adults the indications for proton therapy include some tumours in the brain, the head and neck area, and near the base of the skull or spine, and in the pelvis as well as some soft tissue tumours. In adults, accepted indications include some difficult to treat tumours close to sensitive organs, such as in the base of the skull or the spinal cord.

Research published in 2016 showed proton beam therapy achieves similar survival to conventional radiotherapy in children with medulloblastoma and may be less toxic. Another 2016 study analysed children with ependymomas treated through the UK proton beam therapy overseas programme. It found this had been “a successful and feasible treatment option,” with early outcomes and toxicity acceptable compared with other published data.

Chris Nutting, consultant clinical oncologist at the Royal Marsden Hospital, says “repatriating” patients from the overseas programme, and also treating those who are too unwell to be referred abroad, is a “success story.” “I don’t think there are any real dissenters to that,” he says.

#### Contested area

A more contested area is how far proton therapy should be rolled out to other groups of patients. In principle, any condition that can be treated with

conventional radiotherapy can be treated with proton radiation. But key questions are whether that would be the better option for the patient, and whether it justifies the extra cost and substantial challenges in delivering proton therapy.

Smith says proton therapy’s theoretical advantage—the potential to spare toxicity or enable the delivery of curative doses of radiation in certain situations—does not necessarily translate into clinical benefits.

Nutting, a past president of the British Oncological Association, says in breast cancer, for example, protons may give a more accurate treatment dose that will damage less of the lung tissue underneath and might seem to be the best option. “But clinically there are no consequences to the minor lung damage caused by breast radiotherapy so protons wouldn’t be considered clinically advantageous.”

Nutting treats head and neck cancer, which he says is very toxic for patients both during radiotherapy and for the rest of their lives. For patients with tumours in the mouth and throat, complications from radiotherapy treatment include damage to the saliva glands that affects eating, pain in the throat, and difficulty with swallowing. “It may be that with a better location of the radiation dose with protons that some of those side effects will be less in the longer term,” he says. “My view as an academic radiotherapist is that we should be doing clinical trials

in this group of patients.”

Nutting has proposed a trial, which is waiting for funding approval, to compare the best current radiotherapy with proton therapy to see what the benefits are for head and neck cancer patients in the long term. “We need about 100 patients over two or three years to come to a conclusion on what the advantages of protons are over the best current radiotherapy,” he says.

#### New indications

The proposed trial is a collaboration with the Christie and University College hospitals. Importantly, both proton therapy centres are sited within a major national cancer service and an associated clinical and medical physics academic framework.

A key role of the centres will be to investigate the benefit of proton therapy in new indications, including through evaluative commissioning studies when trials aren’t possible. Smith says, “One of the main aims of the service, through clinical trials and outcome data collection, is to identify patients who would most benefit.”

For most adult radiotherapy indications, evidence for improved outcomes compared with photons is currently weak or non-existent, says Crellin. It seems likely the benefit will be in “niche subpopulations of existing radiotherapy indications”: those in which the dose distribution of proton beam therapy reduces critical high risks of toxicity or allows use of higher doses compared with photons.



**“We’ll trial in areas of the body where radiotherapy side effects may be ameliorated”**

Chris Nutting,  
Royal Marsden



**“We have an obligation to demonstrate the effectiveness of protons”**

Ed Smith,  
Christie NHS  
Foundation  
Trust

## PATIENT PERSPECTIVE: “DESPITE ONGOING SIDE EFFECTS, WE HAVE NO REGRETS”



Caroline and Stuart Thomas, whose daughter Lucy had proton beam therapy in the US in 2012, have been coming to terms with how, now she is 12, she is experiencing late side effects of treatment.

Lucy was successfully treated for rhabdomyosarcoma, a rare type of muscle cancer in the nasal passage and palate, and is now, says her mother, “well, happy, and enjoying life.”

However, radiation near her pituitary gland has left Lucy needing growth hormone treatment. She has also lost some upper teeth because the roots became shallow, and she has developed a cataract in one eye.

Caroline Thomas says she was made aware of potential side effects of the treatment and has “no regrets.” It was the “best option” given the site of the cancer; there were fears standard x rays could have caused harm to the brain. “It’s been an emotional rollercoaster for us all, but Lucy takes everything in her stride,” she says. “The main thing is that Lucy is still with us. Everything we’ve come up against is controllable and we can do something about it.”

Lucy has regular check-ups at the Christie. Her family fully supports proton beam therapy being available in the UK and want her experience to add to research knowledge so other patients will benefit.

Nutting says, “We’re looking around the body for areas where current radiotherapy is pretty good but there are side effects which we think should be ameliorated and therefore we should choose these particular areas to test protons in trials.”

Crellin adds that proton therapy’s “true role” is likely to be in combination with other radiotherapy forms. He says, “A mythology has grown up suggesting proton therapy is more effective or without toxicity compared with conventional radiotherapy. All radiotherapy is undergoing continuous improvement, with innovations such as arc therapy, stereotactic ablative radiotherapy, and magnetic resonance imaging guided treatment as well as electron therapy, brachytherapy, and molecular radiotherapy.”

In the UK, radiotherapy clinical trials and radiotherapy research are coordinated by the Clinical and Translational Radiotherapy Research Working Group (CTRad), funded by the National Cancer Research Institute. A special strategy group of CTRad was formed in 2017 to develop proton beam clinical trials.

The Christie centre will deliver a mix of single arm and randomised studies, and will start to accept trial patients next year. As well as the head and neck cancer trial, several other research protocols are being developed, including for lung cancer, pelvic tumours, gynaecological tumours, and lymphoma.

Smith says, “We know we have an obligation to the wider clinical community to demonstrate the effectiveness of protons for particular patient groups, and collecting outcomes data is an integral part of that.”

#### **Uncertainties, toxicities, and complexities**

Given that the quality of standard radiotherapy has improved substantially, the test for proton therapy to prove its comparative advantages is arguably now tougher. Specialists accept there are uncertainties and questions surrounding proton therapy that

cannot be ignored, and particular complexities in delivering it.

Uncertainties include concerns about radiological changes in and around the brain. Smith says questions over certain toxicities need “exploring further,” and the Christie will be collecting data on all patients to see if these concerns are valid.

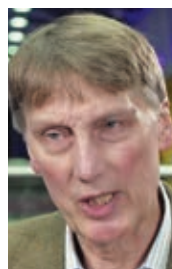
He adds, “There is still toxicity associated with proton therapy, sometimes serious. Every patient seen by us will be counselled about the potential benefits and toxicities of treatment.”

Birmingham’s Green says that brain stem toxicity levels of around 10% could have serious and potentially fatal consequences for patients. He suggests high toxicity might be explained by a variety of factors coming together to affect certain patients. These might include uncertainties in the delivery of the proton beam; differences in patients’ tolerance to radiation; the fact that patients can be on a very rapidly rising portion of a dose-response curve (so a small change in dose can have a large change in effect in certain circumstances); and the possibility that the nature of the damage with proton therapy is different from that produced by x rays (it may be slightly harder for the healthy tissues to repair).

Green says these uncertainties show that proton therapy needs to be “carefully considered and carefully evaluated, and to be rolled out in the kind of centres and in the kind of infrastructure the Christie has.”

Treatment sessions for proton therapy are longer than for x ray treatment but not significantly (20-45 minutes compared with 10-15 minutes). However, the process of planning and preparing patients for proton therapy is complex. About 30-40% of patients will need to have their treatment replanned at some point—for example, because they have lost weight or their body shape has changed—because it is so sensitive to the amount of tissue that’s there.

“With protons . . . movement of a tumour in and out of the area you’re irradiating can be a challenge,” Smith says. “However, we know



**Proton therapy’s “true role” is likely to be in combination with other radiotherapy**  
Adrian Crellin, NHS England



**“The therapy needs to be carefully considered and carefully evaluated”**  
Stuart Green, University Hospitals Birmingham

that, and we can accommodate it in our planning, so it is surmountable.”

Smith says developments in technology since 2012 mean treatment accuracy has continued to improve so there are now better “motion management strategies” and enhanced image guidance.

#### **Value for money?**

Proton therapy centres are huge and costly infrastructure projects. Will the investment prove value for money?

NHS England says that, since 2008 when the overseas programme began, more than 1400 patients have been approved for treatment overseas. Roughly two thirds of these were children. In 2017-18, 216 patients were approved for referral at a cost of about £24m.

It adds that as the number of patients travelling overseas for treatment reduces, the amount available to fund the service in the UK will correspondingly increase. By 2022, when the UK service is at full capacity and treating up to 1500 patients a year, the estimated cost for each patient will be between £41 000 and £43 000, according to the Christie.

Smith says toxicity is “expensive” for the NHS to manage and has a substantial effect on patients’ quality of life. “Those patients who have tumours next to critical structures may benefit from a radical treatment, a curative dose, that is not possible with other methods.

“That can be the difference between survival and perhaps reliance on multiple episodes of palliative chemotherapy or other radiotherapies down the line for retreatment. It may be the difference between a child being dependent on carers as they grow up or not.”

He adds, “We’re very conscious this is a national service. A huge amount of preparation and training has gone into this. But when you start treating patients, that’s when the real education starts.”

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