Almost all men over 60 and all women over 75 in England qualify for statin prescriptions under guidelines adopted by the National Institute for Health and Care Excellence (NICE) in 2014, a new analysis shows.

Some 11.8 million people in England—37% of adults aged 30 to 84—exceed the threshold set by NICE for prescribing statins, the authors found. They said that most of these patients (9.8 million) are healthy, with no history of cardiovascular events, and are eligible for treatment simply because they exceed the risk threshold set by NICE: a 10% risk of experiencing such an event in the next 10 years.

Even some people with no risk factors at all are part of this group by virtue of their age. Nearly all men exceed the 10% threshold by age 60, and all women do so by age 75, even if they are non-smokers of normal weight with low cholesterol and no family history of heart disease, because the tool used for calculating risk (QRISK2) puts a high premium on age.

On average, 200 patients per GP are potentially eligible for statins but not currently getting them, said the study authors, led by Peter Ueda of the Karolinska Institute in Stockholm, Sweden, who worked as a postdoctoral researcher at Harvard University while conducting the analysis. Together with coauthors at Harvard and from Australia, he wrote in the *British Journal of General Practice* that, even if the statins are deemed cost effective, other costs need to be included.

“Implementation of the guidelines should be considered in the context of opportunity costs for primary care and its available resources, in particular given the high and increasing workload facing GPs in England,” the team concluded.

Helen Stokes-Lampard, chair of the Royal College of General Practitioners, said, “We agree that the workload implications for GPs and our teams with so many people being potentially eligible for statin therapy is enormous, so this must be matched with appropriate resources.

“We need to get the risk scores right. If we find that all men over 60 and all women over 75 are going to be eligible for statins with new risk scoring, regardless of any other risk factor, then it should ring alarm bells—because it is not clear that every 60 year old man or 75 year old woman is going to benefit from statin therapy.”

(Continued on page 214)
Charlie Gard
Baby dies after prolonged life support is denied
Charlie Gard, a terminally ill baby with infantile onset encephalomyopathic mitochondrial DNA depletion syndrome, died on 28 July after being taken off a ventilator, in line with a ruling that life support should not be prolonged. After abandoning a four month legal battle with Great Ormond Street Hospital for their son to have experimental treatment, Charlie’s parents applied to the High Court on 24 July asking to spend “a week or so” in a hospice with their son before he was taken off the ventilator. But they could not find an intensive care team required to care for Charlie in the hospice setting, and he died shortly after being transferred.

Kidney disease
Statins are recommended in NICE quality standard
People with chronic kidney disease (CKD) should be offered statins, specifically 20 mg of atorvastatin, to manage their increased risk of cardiovascular disease. The National Institute for Health and Care Excellence (NICE) said in an updated quality standard that adults who have or are at risk of CKD should have their estimated glomerular filtration rate and albumin:creatinine ratio tested frequently and that they should be supported to keep their blood pressure within the recommended range.

Autism
NICE seeks to create national autism register
GPs are being encouraged by NICE to keep a register of their patients who have an autistic spectrum disorder. A 2016 report by the Westminster Commission on Autism, an all party group of parliamentarians and charities, said that such a register would end the statistical “invisibility” of autism in the healthcare system.

Brexit
BMA urges “flexible” immigration for NHS staff
The BMA called for health organisations to be involved in determining the needs of the UK labour market after Brexit. Amber Rudd (right), home secretary, announced last week that the Migration Advisory Committee would publish a report in September 2018, six months before the UK exits the EU. Andrew Dearden, BMA treasurer, said: “The government must work with health organisations to ensure that the immigration system remains flexible enough to recruit doctors and other NHS staff from overseas, especially where the resident workforce is unable to produce enough suitable applicants to fill vacant roles.”

Breast feeding
All countries struggle to boost long term rates
An evaluation by WHO and Unicef of 194 countries found that only 40% of children are breast fed exclusively at age 6 months, against a target of 50%. The UK rate is 1%. An annual investment of $4.70 (£3.60) per newborn to increase rates could save the lives of 520 000 children aged under 5 and potentially generate $300bn in economic gains over 10 years because of reduced illness and increased productivity.

Drugs
Price rises match other health costs
Total spending on medicines “has been roughly in line with increases in total health expenditure” over the past two decades in France, Germany, Japan, the UK, and the US, said a report from the QuintilesIMS Institute, which follows the drug industry. New branded drugs generally comprise less than 10% of spending, while at least 60% consists of generic or non-prescription drugs.

Suicide
Netflix series prompts rise in web searches
Internet searches including the term “suicide” were 1.5-44% higher than expected in the 19 days after the start of 13 Reasons Why, a Netflix series about a 17 year old girl who dies by suicide—900 000 to 1.5 million more searches than normally seen, said a research letter published in JAMA Internal Medicine. Doctors said that broadcasters should advise viewers where to get help if they have feelings of suicide.
MEDICINE

UK Biobank
Genetic data are released for detailed study

Genetic data on half a million people were made available for research by the UK Biobank study on 20 July. All 500 000 UK Biobank participants provided blood samples for long term storage and analysis when they volunteered for the project in 2006-10. In 2013-14 more than 800 000 carefully selected regions of the genome underwent genotyping, enabling researchers to build a picture of each participant’s DNA to allow researchers to look at links between different genotypes and health and disease.

Moving on
NHS director resigns after arrest for voyeurism

Jonathan Fielden, NHS England’s deputy medical director and director of specialised commissioning services, resigned from his post “to pursue other opportunities, effective 10 September 2017,” said a statement by NHS England on 26 July. In February he was arrested by police on suspicion of voyeurism. Fielden, 53, was banned from contact with patients under conditions imposed on an interim basis in January by the Medical Practitioners Tribunal Service, pending a full hearing. He took up the £224 999 job at NHS England in November and took leave from the post in January.

Research news
HIV testing at registration with GP is cost effective

Screening for HIV when adults register at a new GP surgery should be rolled out to all 74 local authorities in England that have high HIV prevalence (>0.2%), researchers argued after finding it to be cost effective. They estimated in Lancet HIV that, over 40 years, primary care based HIV screening in high prevalence areas would cost £26 626 per quality adjusted life year gained—within the range of interventions NICE considers to offer value for money.

UK ranks 11th in supporting elderly people

Norway came first in an index designed to measure an economy’s success in supporting and integrating elderly people, followed by Sweden, the US, the Netherlands, and Japan, with the UK in 11th place. The Global Aging Index is constructed from five “domains”: productivity and engagement, wellbeing, equity, cohesion, and security. John Rowe, a professor at Columbia University’s Mailman School of Public Health in New York, commented, “If we neglect to develop and implement effective policies we will be left with a society rife with intergenerational tensions, characterised by enormous gaps between the have and have-nots, and unable to provide needed goods and services for any of its members.”

DIABETES
Prescriptions in primary care for diabetes in England increased by 40% from 2009-10 to 2015-16, nearly double the rise in diabetes prevalence, which increased by 22.6% (NHS Digital)

A TIPPLE A DAY KEEPS DIABETES AWAY?
That’s what the research says. A Danish study hit the headlines this week, showing that people who drink alcohol three to four days a week had around a 30% lower risk of developing type 2 diabetes than teetotallers. The lowest risks of diabetes were in men who consumed 14 alcoholic drinks and women who knocked back nine drinks a week.

NON-CAUSAL, SURELY?
Well, the authors said that the strengths of their study were its large size (70 000 people) and the fact that they collected information on drinking patterns before diabetes was diagnosed. Also, the findings mirrored some previous studies showing a lower diabetes risk with low to moderate alcohol consumption. But other research has not found this connection.

SHOW ME THE MECHANISM
The Danish study found a lower diabetes risk with wine. In contrast, the risk was increased in women who reported a high intake of spirits. The researchers said that polyphenols found in red wine may have beneficial effects on controlling blood sugar, thus lowering the risk of type 2 diabetes.

BOTTOMS UP... THEN?
Not quite. Nick Finer, endocrinologist and bariatric physician at University College Hospital, London, noted that the study was in a Danish population with a relatively healthy lifestyle and an obesity rate of only 10%, compared with a 25% UK average. And Amitava Banerjee, lecturer in clinical data science at UCL, said that it is important to consider all possible consequences of alcohol intake, not just diabetes. He said that guidelines to restrict weekly drinking to 14 units a week and to spread alcoholic drinks across the week were unchanged by this study.

TAKE ME TO A WALKING BAR
Rather like “walking desks” (incorporating treadmills), the solution might be walking bars, where people can exercise while they drink. Finer argued that diabetes prevention should continue to focus on helping people achieve a healthy weight and take adequate physical activity, adding that alcohol is a potentially important source of calories.

Susan Mayor, London

Cite this as: BMJ 2017;358:j3688

Cite this as: BMJ 2017;358:j3672
Thousands more mental health posts will be created in England

The government has announced a major expansion of the mental health workforce as part of its £1.3bn commitment to transform mental health services and treat an extra million patients by 2020-21.

The plan, developed by Health Education England with NHS Improvement, NHS England, the Royal College of Psychiatrists, and other key mental health experts, outlines how new and existing staff will be incentivised to work in mental health. This will include a retention programme to be run by NHS Employers; a range of initiatives to improve career pathways; encouragement of more flexible and supportive working environments to draw on the skills of recent retirees; and targeted support for the 20 trusts with the highest rates of staff attrition. New professional roles in mental health will create more flexible teams and boost capacity.

HEE will run a major Return to Practice campaign to encourage some of the 4000 psychiatrists and 30 000 trained mental health nurses not substantively employed by the NHS to return, as well as a targeted campaign next year to encourage more trainees to specialise in mental health. A third of training posts in psychiatry are currently unfilled.

The plan aims to create 2000 additional nursing, consultant, and therapist posts in child and adolescent mental health services; 2900 additional therapists and other allied health professionals supporting expanded access to adult talking therapies; and 4800 additional posts for nurses and therapists working in crisis care settings.

Jeremy Hunt, England’s health secretary, said, “We want people with mental health conditions to receive better treatment, and part of that means having the right NHS staff. We know we need to do much more to attract, retain, and support the mental health workforce of the future . . . today is the first step to address this historic imbalance in workforce planning.”

Danny Mortimer, chief executive of NHS Employers, said, “This focus on the workforce that provides this care is hugely welcome—especially given the pressures and challenges staff are facing.”

Ingrid Torjesen, London
Cite this as: BMJ 2017;358:j3676

PSYCHIATRY is currently the specialty with the highest number of unfilled training posts at 35%, followed by histopathology (28%) and general practice (16%)

Children are being failed by substandard mental health services

Many children and teenagers with mental health problems are still being let down by variable service provision, analysts have warned.

The Education Policy Institute said in a new analysis that one in nine inpatient units in England failed to meet the minimum standard for staff to patient ratios, while a quarter (24%) did not employ enough permanent staff.

It said that increasing numbers of young people were being kept in hospitals despite being fit to leave because appropriate specialist or community support wasn’t available.

Between October 2015 and February 2017, children spent nearly 9000 “wasted days” in NHS hospitals when they could not be discharged, according to the analysis. The number of delayed days was 42% higher between December 2016 and February 2017 than in the same period in 2015-16, the institute said.

It said that some aspects of care were improving—including the quality of inpatient services and a reduction in the use of police cells for young people in mental health crisis—but there was still a “long way to go” before all services reached a high standard.

David Laws, the institute’s executive
The first lesson from this case is that it is bad medical practice to give patients, and in this case parents, false hope. That’s not an indictment of the practitioners involved, it’s an indictment of all the external bodies, medical and non-medical, who got involved without knowledge of the details of the case. I regularly teach junior doctors that while we all want to give people hope, giving false hope is not helpful.

“The second lesson is that trust between doctors and patients is crucial to delivering good patient care. When trust breaks down it is questionable whether care can ever be optimal.

“The third message is that the wider public, including patients, need to understand what the process of using experimental treatments is. Just because someone somewhere says, ‘I’ve got this new medicine, let’s try it,’ it’s not the way we do things in this country. We’ve got very clear processes.

“The other lesson is that external interventions are unhelpful.

“The medical and science professions also need to be better at explaining their practice. I would not want the public to think that we make these things up as we go along—we don’t. We do have multiple frameworks for practice. We are very privileged in this country to have these frameworks, and at the heart of them we, in paediatrics, have our ultimate duty of care to the patient: the child.

“In this case it was much more complex because the parents felt that they were acting in the best interest of the child and the paediatricians felt that they were not. There was a breakdown in trust and a breakdown in communication. I don’t know about the extent to which that sprung from the parent’s inherent wish to not give up hope or the extent to which it was fuelled by these unhelpful external influences saying there was hope when there wasn’t.”

Abi Rimmer, BMJ Careers

Cite this as: BMJ 2017;358:j3700

FIVE MINUTES WITH . . .

Neena Modi

The president of the Royal College of Paediatrics and Child Health reflects on the case of Charlie Gard

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Abi Rimmer, BMJ Careers

Cite this as: BMJ 2017;358:j3700

KEY FINDINGS

- There were 1440 child and adolescent mental health service inpatient beds in the NHS in England as of December 2015, a 71% increase since 1999
- Around 47% of beds are run by independent providers
- The north east is best provided, with 3.03 beds per 100,000 people, compared with the average of 2.5 beds per 100,000 in England and 1.1 per 100,000 in the south west
- In 2016-17 there were three occasions when no beds for under 18s were available
- In 2016 children under 16 spent 1657 days on adult wards
Antidepressants and murder: case not closed

A primetime documentary that points the finger at antidepressant use as key evidence in a mass murder case misses the mark, argues forensic psychiatrist Gwen Adshead.

Samuel Johnson observed in 1734 that it was “incident among physicians to mistake subsequence for consequence.” His observation might apply more to journalists; and especially the BBC Panorama programme “A Prescription for Murder,” broadcast on 26 July. The programme’s premise was that a rare side effect of antidepressants may be to induce violent thoughts; and it offered as evidence the case of James Holmes, who in July 2012 went into a cinema in Aurora, Colorado, and shot into the audience, killing 12 people and injuring 56 others. Holmes did not deny his role in the massacre, although at trial he offered a defence of not guilty by reason of insanity, which was not accepted by the jury.

A current trend among journalists is to review criminal cases and suggest that they have found a “truth” that a jury, judge, and experts who actually saw the evidence have somehow missed. Panorama stated that the role of antidepressants in causing the massacre had not been considered in the Holmes case; and so a single journalist was filmed going through the legal case papers and making a timeline setting out the programme’s hypothesis. The journalist displayed a mix of wide eyed concern and shock that no one had considered the possible role of antidepressants in this sad case. Her timeline focused only on the date of the prescription of drugs and Holmes’s self report of violent intentions after that date.

Expert conclusions

Among the psychiatrists interviewed was William Reid, who questioned Holmes for the trial. Reid, a highly respected forensic psychiatrist in the US, patiently and thoroughly explained why he had concluded that antidepressants had played no part in Holmes’s undoubtedly abnormal mental state at the time of the homicides. The chief prosecutor also explained that the potential role of antidepressants had indeed been considered at trial by everyone, including the defence, and been rejected as materially irrelevant.

The programme said that increasing dosages of the drug led to increased homicidal thoughts but also that when Holmes stopped taking the drug this abrupt cessation was responsible for his homicidal thoughts. How then is it possible to safely conclude a relation between the drug and his homicidal thoughts, rather than that there was no relation?

The medication was also said to have rendered Holmes unaware of the consequences of his actions. But Holmes said he indicated he understood what was to come.

At no point did the programme say that it might be helpful to consider the published scientific evidence about antidepressants; the meta-analyses and systematic reviews about antidepressants and their side effects; and the role of randomised controlled trials in excluding confirmation bias and other confounding factors.

No simple answers

What is the purpose of programmes like this? It seems shameful to make a drama out of terrible events like the Aurora massacre. I have worked with perpetrators of terrible crimes, and they are terrible because of the enormity of the damage done and the lack of any good quality explanation. My clinical experience has taught me that homicide is a complex human action and that we should be cautious about simplistic assumptions about causes. Panorama proves the validity of H L Mencken’s 100 year old comment that there is always a well known solution to every human problem: neat, plausible, and wrong.

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Rising indemnity fees could lead to worst ever winter crisis, says new GP leader

The new chair of the BMA’s General Practitioners Committee has a long “to do” list, reports Abi Rimmer

The rising cost of GPs’ indemnity cover could lead to the worst ever winter crisis, as fewer doctors are able to afford to work, the new chair of the BMA’s General Practitioners Committee has warned.

Richard Vautrey, who became chair of the committee last month, said that, after a reduction in the so called discount rate, GPs would see an unparalleled rise in indemnity fees. The “discount rate” is the rate that people receiving lump sums for personal injuries are expected to get if they invest the money. A reduction in this rate, which came into effect on 20 March, means that awards will have to be much higher to compensate.

Vautrey said, “We have secured, in the last contract negotiations, funding to pay for the typical indemnity rises that would have happened year on year. [However], we are now facing a situation that with the discount rate change we’re going to potentially see a rise for indemnity which is unparalleled, compared with previous rises.”

He said that if GPs were deterred from working extra sessions, such as in out-of-hours settings or extended surgeries, because of escalating indemnity fees, “we’re going to have a winter crisis that is a lot, lot worse than we have seen in previous years.” He added, “Doctors will simply not be able to afford to work in an out-of-hours session or to do an extra session within a practice, because the indemnity cost would be prohibitive.”

He added: “We are calling on the Department of Health about how we can get a sustainable solution for general practice as a whole.”

National indemnity scheme

One possible arrangement could be for all GPs to be protected by a national scheme, Vautrey said, with their own personal indemnity on top at a much lower cost.

Vautrey warned that medical defence organisations were currently holding off making big changes to their annual fees, “but they can’t hold off for much longer.”

He said, “If the government doesn’t act quickly, those big bills are going to be appearing in GPs’ letterboxes very soon, and that’s just going to cause absolute consternation among the profession as to how they can possibly carry on working in some settings with these prospective indemnity costs.”

QOF reforms

Despite previously welcoming plans for the Quality and Outcomes Framework (QOF) to be phased out, Vautrey said that the General Practitioners Committee was now working on a reformed version of the framework rather than scrapping it entirely. He said that after reductions in some indicators and the removal of others, many GPs now believed that they had a set of indicators that they could support. There was also recognition, Vautrey said, that QOF was heavily embedded in the way many practices worked.

He said that GPs had raised concerns about how the funding currently allocated to QOF would be used if the framework were to be scrapped, “because the existing work wouldn’t go away.” He added, “So the management of patients with diabetes, heart disease, and lung disease, for example, still needs to take place and still needs to be resourced.

“You still need to employ your practice nurses, your healthcare assistants, your practice manager and other staff, and QOF funding is crucial to the way that the practice works.”

List closures

Last month balloting began of general practices in England on the potential mass closure of patient lists in response to the ongoing crisis facing the profession.

If GPs do vote to take action, the BMA will begin the formal process of balloting them on industrial action, Vautrey said, adding that practices needed to be clear about what level of action they were willing to take.

“What we don’t want to do is repeat what happened with the pensions dispute,” Vautrey said, “where large numbers of people said that they were prepared to take action and didn’t take the action that they said they would—and that made us look weak.

“So we need to know exactly what practices are prepared to do, and then they need to follow through.”

Abi Rimmer, BMJ Careers

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Children infected with cholera are treated in a hospital in Sana’a, Yemen’s capital, amid the “world’s worst cholera outbreak”
“Redouble” aid for Yemen, say humanitarian agency leaders

The heads of three of the world’s biggest humanitarian agencies have urged Yemeni authorities to take action to help millions of people affected by cholera and famine and for the international community “to redouble its support for the people of Yemen.”

“If we fail to do so, the catastrophe we have seen unfolding before our eyes will not only continue to claim lives but will scar future generations and the country for years to come,” wrote Anthony Lake, executive director of Unicef, David Beasley, executive director of the World Food Programme, and Tedros Adhanom Ghebreyesus, director general of the World Health Organization, in a statement after a joint visit to Yemen.

They described the situation as “the world’s worst cholera outbreak in the midst of the world’s largest humanitarian crisis.”

Their plea included a call for the country to immediately pay 30,000 healthcare workers, who have not received their salaries for 10 months, and to allow aid workers access to areas of the country affected by fighting.

In the past three months 400,000 cases of suspected cholera and nearly 1,900 associated deaths have been recorded. At the same time the military campaign, which began in 2015, has destroyed health, water, and sanitation facilities.

The three leaders wrote, “The country is on the brink of famine, with over 60% of the population not knowing where their next meal will come from. Nearly 2 million Yemeni children are acutely malnourished. Malnutrition makes them more susceptible to cholera; diseases create more malnutrition. A vicious combination.

“At one hospital, we visited children who can barely gather the strength to breathe. And, as we drove through the city, we saw how vital infrastructure, such as health and water facilities, [has] been damaged or destroyed.”

The agencies have set up more than 1,000 diarrhoea treatment centres and oral rehydration corners and are sending food supplements, intravenous fluids, and other medical supplies, including ambulances, to the area. They are also helping to rebuild hospitals, district health centres, and the water and sanitation network.
Who was fighting for Charlie Gard?

Populists, religionists, and those opposed to government intervention in healthcare on both sides of the Atlantic sought to influence an emotional public, writes Richard Hurley

“Manslaughter”—the Daily Mail’s lead story was on a different subject but its headline was juxtaposed with an old photograph showing Charlie Gard at 2 weeks of age. “As judge rules Charlie must die in hospice, parents release new picture and say, ‘We’ve been denied our final wish.’”

Later that day the critically ill baby, who had been at Great Ormond Street Hospital in London for the past eight months, died after doctors withdrew mechanical ventilation and tube feeding.

Months of conflict between Charlie’s parents and his doctors, played out in a series of high profile court cases, defined his brief but highly medicalised and uniquely publicised life.

The doctors treating Charlie thought that his condition was in its final stage and that they were not serving his best interests by keeping him alive. The parents’ desperation, and a chimeric hope given by a specialist offering experimental nucleoside treatment in the United States, were rocket fuel for the tabloids. They described the potential intervention as “pioneering” and “life saving”—despite it having never been tried in a patient with Charlie’s form of the condition.

Millions of people followed Charlie’s plight—there was international media coverage, thousands of social media supporters calling themselves “Charlie’s army,” petitions with thousands of signatories, and interjections from Theresa May, the pope, and Donald Trump.

As far right radio hosts and celebrity columnists shared their thoughts, Charlie became the topic of intense scrutiny and comment—on both sides of the Atlantic.

In the US, where Republicans have been trying to keep their promise of scrapping the Affordable Care Act, senator Ted Cruz tweeted three weeks ago, “No hospital, no gov’t has the right to deny parents their chance for a medical miracle. I stand with #CharlieGard,” with no sense of irony.

Parents versus the state

A columnist in the conservative US magazine National Review explained how the “precedent established by Charlie Gard’s case will metastasize, as similar decisions have. It will be made to apply to children with more familiar illnesses and better prognoses; it will be used to dismiss the input of parents whose values and priorities when it comes to medical care and end-of-life issues do not align with those of the state; it may be used simply to clear beds for ‘worthier’ patients in a healthcare system with very limited resources. This, presumably, will be ‘compassionate,’ too.”

“The Charlie Gard case threatens all parents,” said USA Today, arguing that “the state is clearly overstepping its bounds, trespassing into the realm of parental authority and family life.”

Charles Krauthammer, a right wing commentator, may have summed up the thoughts of many mainstream commentators in last week’s Washington Post, explaining that he thinks the parents are wrong but would still let them take Charlie abroad because “parents are simply more likely than anyone else to act in the best interest of the child.”

This is the desperately sad story of a little boy who would have been one year old on 4 August. After an apparently normal birth and first few weeks of life he was admitted to hospital at 8 weeks with encephalomyopathic mitochondrial DNA depletion syndrome, a rare disease caused by mutations in gene RRM2B inherited from both parents. He had severe brain damage and could not move his limbs or breathe unaided.

Also desperately sad is how Charlie’s situation was used in political propaganda—by religious fundamentalists who want lives prolonged at any cost, populists and opponents of Obamacare, and religionists given the opportunity of an angry public.

Criticism of Charlie’s care—sometimes ignorant, sometimes false—spiralled. Some encouraged hope where there was almost certainly none; some cast doubt on doctors’ expertise and integrity.

High emotion turned menacing as some Great Ormond Street staff and patients received abuse and death threats.

“I have never witnessed such concentrated ignorance, arrogance, stupidity, and unthinking cruelty as has been displayed by the American political right over the tragic case of Charlie Gard,” fumed the rightwing pundit Melanie Phillips. “Here’s the
really wicked thing about all this… This campaign led the parents to believe that such pressure could change the court’s mind. And so the parents were reinforced in their refusal to face reality.”

Charlie’s parents, Connie Yates and Chris Gard, forwent their family’s privacy to campaign for support and to raise funds to treat Charlie in the US.

And supporters came—with hashtags like #istandwithcharliegard, #charliesarmy, and #charliesfight—signing up to Facebook (facebook.com/Charlegardsfight; 142 000 followers), Instagram (instagram.com/charliesfight; 109 000 followers), and Twitter (twitter.com/Fight4Charlie; 5320 followers).

The family’s website, www.charliesfight.org, invited support in several ways and featured an online shop selling “lovely items made by Charlie’s supporters,” such as wristbands, tote bags, and key fobs. It says that they have had more than 83 000 donations and raised £1 343 220.

The publicity brought to the family’s aid an assortment of advisers and media publicists, including Catherine Glenn Foster, president of Americans United for Life, launching a campaign to “Save Charlie Gard” at a press conference in Washington, DC, on 6 July, emphasising the importance of engagement on social media.

*Time*, the world’s largest circulation news magazine, reported that this campaign had had “major impact”: court hearings to consider new evidence may not have occurred without pressure from these US social conservatives, Gawain Towler, another of the family’s spokespeople, told *Time*. And Twitter has been awash with comments that Charlie had been “held hostage” by the hospital, blaming his fate on the “death panels” inherent in “socialised medicine” and “single payer systems.”

Even many moderate US commentators were incredulous that parents with funds were not able to act autonomously for their child, perhaps reflecting cultural differences and a US legal system that is much more deferential to parents. Few seemed also to recognise that improved treatment was capable of causing Charlie harm.

Ranjana Das, a media academic at the University of Surrey, wrote that public discourse on the case had employed “some classic markers of populism… These have ranged from genuine anguish and expressions of sorrow, to the use of terminology from the Third Reich to characterise doctors, lawyers, and clinicians.”

“No winners”

In his judgment on 24 July, Justice Nicholas Francis said, “A lot of things have been said… by those who know almost nothing about this case but who feel entitled to express opinions.”

“The world of social media doubtless has many benefits but one of its pitfalls, I suggest, is that when cases such as this go viral, the watching world feels entitled to express opinions, whether or not they are evidence based.”

Charlie’s death came nearly five months after his doctors decided that further treatment would be futile for the baby and applied to the High Court to stop life support. “There are no winners,” the pundits and the social media accounts echo. If so it is not for lack of trying: consider the newspapers sold and the religious and political campaigns that have found new support.
Disputes about children’s best interests

The court of public opinion is surely the worst possible place for ethically complex decisions

Difficult and ethically challenging discussions about life prolonging treatment for a seriously ill child usually take place in quiet side rooms adjacent to medical wards. Sometimes, when parents and doctors have struggled to reach agreement, these discussions involve external mediation or take place in ethics committees. Rarely, unresolved dispute moves that discussion to a courtroom. In the recent Charlie Gard case, however, these discussions have taken place in public, on a wide global stage.

The Gard case raises ethical questions that are important to debate publicly. Yet much of the discussion about the case has been distinctly unbalanced. Commentators, politicians, and some supporters of the family attacked the hospital, the doctors, and the health system. Overseas medical supporters of the family attacked the hospital, the doctors, and the health system. Overseas medical

“The High Court is not the best place to make medical decisions. But the court of public opinion is surely the worst place for ethically complex decisions.

The intense media attention about Charlie Gard led to abuse and threats to staff and to Charlie’s family. Unrealistic or unfounded claims may also have provided false hope and contributed to the protracted legal battle.

How can we achieve greater balance? One option would be to maintain the anonymity of any child at the heart of such disputes. This is the norm for Family Court cases. While anonymity might be better for the child, it can also limit parents’ options, making it harder to fundraise for treatment and potentially harder to identify supportive expert opinion. It also conflicts with freedom of the press and raises concerns about lack of transparency in decision making.

Another possible solution would be to allow (or require) medical professionals to make public the evidence on which they are basing their decisions. That would enormously increase transparency, and help ensure that any wider discussion is based on relevant and verifiable facts. It would, however, breach the child’s confidentiality.

A way forward

Firstly, most discussions and decisions about treatment will continue to occur in private, though it would be valuable to gather and publish data on the frequency of conflicts and their outcome. One study of end-of-life decisions in newborn intensive care in the Netherlands, reported disagreement between professionals and the family in 12% of cases. Agreement was reached eventually in all, without resorting to the courts. Secondly, where disagreements have reached the court, it is helpful (as already occurs in many cases in the UK) for legal judgments to be published. Publication facilitates understanding about the ethical and legal basis for decisions.

Thirdly, in most cases, health professionals should avoid disclosing patients’ medical details outside the doctor-patient relationship or the courtroom. However, where a court has allowed parents and children to be identified, and particularly if there is already public debate about a child’s medical treatment, it may be in a child’s best interests to make available some of the evidence and arguments underpinning professionals’ decisions.

In the latter parts of the Gard case, Great Ormond Street Hospital elected to publish its position statements to the court. This allowed a more realistic understanding of the medical considerations. It can also facilitate external scrutiny and help identify whether there are alternative viewpoints within the profession.

Finally, in reference to the controversial intervention of a doctor from the US, Justice Francis noted “It seems to me to be a remarkably simple proposition that if a doctor is to give evidence to this court about the prospect of effective treatment . . . that doctor should see the patient before the court can sensibly rely upon his evidence.” His comments serve as a note of caution for the media and the wider community about relying on the opinion of professionals who have not accessed all the clinical details.

The public attention and debate haven’t been all bad. They have brought wider attention to the potential futility of medical treatment, to the suffering of families of children with life limiting illnesses, and to important ethical questions about the rights of sick children and the respective roles of parents and health professionals in protecting them.

They have provided encouragement and support to Charlie Gard’s family. Families who disagree with doctors can feel vulnerable and disempowered, and find it difficult to oppose the medical establishment. Sound ethical analysis depends on knowing more than just the scientific and medical facts. But without the facts, there is a danger of jumping to incorrect conclusions. It is in the interests of all children that cases like Charlie Gard’s are accompanied by fair, accurate, and balanced discussion.

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Dominic Wilkinson, professor of medical ethics, Oxford Uehiro Centre for Practical Ethics, faculty of philosophy, University of Oxford, UK; and consultant neonatologist, John Radcliffe Hospital, Oxford, UK
dominic.wilkinson@philosophy.ox.ac.uk
Sex and disability: women are individuals

Despite an increased focus on the reproductive health of women with physical and learning disabilities, critics say that perceived risks are too often prioritised over the patient’s rights. **Sally Howard** reports

Ann Furedi does not pull her punches. “When people hear ‘reproductive choice’ and ‘disability’ they hear the A word,” she told a recent event to illuminate an area of reproductive rights that has long been dominated by debates over the ethics of aborting fetuses with abnormalities.

Furedi, of the British Pregnancy Advisory Service (BPAS), was echoing a point made by several members of the event’s panel, which was co-convened by the Royal College of Obstetricians and Gynaecologists (RCOG) and comprised sexual and reproductive health specialists, activists for disabled people’s rights, and human rights lawyers. Furedi continued: “They don’t think of a disabled woman who might need fertility treatment or access to contraceptives appropriate to her unique disability.”

**Assumed sexual inactivity**

Research into the reproductive healthcare received by women with learning and physical disabilities in the UK is limited. The most recent study, in 1997, found that professionals often assumed respondents were sexually inactive. Disabled women were rarely asked about contraceptive use or assessed for sexually transmitted diseases. But international studies on disability and HIV transmission have shown that disabled people are as likely to be sexually active as their non-disabled peers.

By contrast, a qualitative study in 2009 highlighted that relative rates of screening—including cervical and breast cancer—were significantly lower for people with learning disabilities than for those without.

The event’s panelists painted a broader picture: women with disabilities are routinely blocked from exercising choices related to sexual activity, contraception, pregnancy, and childbirth, and encounter many barriers to accessing reproductive care.

Claire de Than, law commissioner for the charity Sexual Health and Disability Alliance, told the meeting that the UK’s confused consent legislation promotes overzealous application of safeguarding guidelines.

“Current criminal law says that anyone with mental incapacity, this includes the 30% of the population who at any point in their lives suffer from depression, is not capable of consenting to sex,” de Than said, adding, “This is patently ridiculous.”

She noted several legal precedents in which disabled people’s private sexual expression had been criminalised, including a case in which a local authority sought powers to monitor a young physically disabled woman to prevent her from being sexually active.

**Bubble wrapping**

A common misconception among healthcare professionals, said de Than, is that they might be legally culpable if they suspect that a patient is having sex without the capacity to understand his or her actions. She described acting on this misconception as “a case of safeguarding overswing.”

The pervasive institutional attitude to disabled people’s sexuality, concluded de Than, is one of “bubble wrapping,” in which “risk is routinely prioritised over rights.”

**Innovative contraceptives**

Jane Dickson, a consultant in sexual and reproductive healthcare for Oxleas NHS Foundation Trust, told the meeting about barriers to accessing effective contraception encountered by disabled women, including the higher risk of side effects such as venous thromboembolism in women who are less mobile or use wheelchairs, and difficulties some women have in remembering to take or swallow pills.

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The BMA’s annual representative meeting in June called for the NHS to stop handing over non-clinical details of patients, including their addresses, to the UK Home Office for immigration enforcement purposes without consent of the patients and the knowledge of their GP. The motion brings into sharp focus the undermining of doctor-patient confidentiality and the insufficient attention paid to evidence in policy making.

The personal details of patients are being disclosed under a “memorandum of understanding” agreed last year between the Home Office, the Department of Health, and NHS Digital. The intended purpose of the memorandum is to facilitate and formalise the exchange of personal data between hospitals and immigration enforcement officials.

The memorandum apparently followed the Goddard review into NHS Digital’s so-called back office function, which was initiated in November 2014 but remains unpublished. The head of NHS Digital at the time, Kingsley Manning, was seemingly concerned about the legal basis for disclosure and has since resigned. He was reported to have been under “immense pressure” from the Home Office.

Correspondence released in April by the House of Commons Health Select Committee reveals that Fiona Caldicott, the national data guardian, considers that the memorandum should have been subject to “more public debate” before it was introduced to allow “more scrutiny of the reasoning and factors which led to the policy position.”

The information released by the committee also shows that Public Health England (PHE) experts believe that sharing of patients’ personal information with law and immigration enforcement authorities “risks undermining public confidence in the public health system and could have unintended and serious consequences affecting the health of individuals and the risk to the public health of the wider community.” They supported their conclusions with peer reviewed and other literature, which “indicates that a fear of being reported to immigration authorities can act as a barrier to access internationally, in Europe and in the UK,” drawing attention to the disproportionate burden of tuberculosis borne by migrants and the importance of early access to healthcare.

Nevertheless, PHE’s chief executive, Duncan Selbie, wrote to the health committee stating that “there is no robust statistical evidence about the impact of knowledge of data sharing on deterring immigrants from accessing healthcare treatment”; while the then junior health minister, Nicola Blackwood, assured the committee that “[w]e have found no evidence that this policy would deter migrants from seeking treatment.”

Yet, fear of deportation is cited as a serious barrier in 65% of research studies on access to healthcare by undocumented migrants.

The risk of deterring people from seeking treatment has now been recognised by the prime minister in the wake of the Grenfell Tower tragedy; she told the Commons that “I would like to reassure people that we will not use this tragic incident as a reason to carry out immigration checks and will make sure that all victims, irrespective of their immigration status, will be able to access the services they need, including healthcare and accommodation.”
Should we allow overseas visitors free access to NHS services?

Some doctors oppose restricting healthcare, while others object to providing it to patients who are not eligible. Tom Moberly reports

Immigration rules should never undermine the right of people to access health services

Why are we doing the Home Office’s dirty work?

Overseas Patients

EDITORIAL

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Reassurances of this kind, however, are no substitute for a legal guarantee of the human right to health, which the UK has signed up to in international law. Migration law and policy must be in line with human rights, and this mandates access to preventive, curative, and palliative services without discrimination and with “strict walls” between health and law enforcement authorities.

To protect doctor-patient confidentiality and the right to health for all, the memorandum of understanding should be terminated immediately, the Goddard review published without further delay, and an inquiry conducted by the national data guardian into the effect on human rights and equalities of disclosure of patient data, including disclosure under the memorandum. In the absence of an adequate legal framework, patients’ data should not be handed over to the Home Office.

Koldo Casla, policy, research, and training manager, Just Fair, London
koldo.casla@just-cfair.co.uk

Peter Roderick, principal research associate
Allyson M Pollock, director, Institute of Health and Society, Newcastle University

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Tom Moberly, UK editor, The BMJ
tmoberley@bmj.com
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Of ministers’ calculations are correct, up to £500m a year will be recovered and reinvested in care after access to NHS services are restricted for overseas visitors. In February, health secretary Jeremy Hunt announced plans to require all hospitals to charge upfront those patients who are not eligible for free non-urgent, planned care. “We have no problem with overseas visitors using our NHS—as long as they make a fair contribution, just as the British taxpayer does,” he said.

But Hunt’s view is not one shared by all doctors. For many, the idea of restricting access to free services, therefore placing financial and administrative barriers between patients and clinicians, remains contentious.

The issue caused a fierce debate on a motion at this year’s BMA’s annual representative meeting. In the end, three of the motion’s four parts were passed. These parts argued that publicity about the cost of treating foreigners was a distraction from NHS under-resourcing; that urgent care should not be delayed by eligibility checks; and that medical staff should not be involved in ascertaining patients’ eligibility for treatment.

The part that was not passed elicited the most passionate arguments. It stated: “NHS treatment should not be restricted on the basis of nationality or immigration status.”

Richard Rawlins, a retired orthopaedic surgeon and chairman of the BMA’s retired members’ conference, argued against the motion. Speaking to The BMJ after the meeting, he said that some restrictions on overseas visitors are needed.

“We do have to ration care,” he says. “Essentially, if you are a citizen of a country, and you have contributed to the wealth of the country, you can reasonably expect to draw down on that investment. If you made no contribution at all, then you’re falling back on pure altruism. Is that good enough?”

Rawlins says he has been asked to treat overseas visitors who specifically came to get free NHS treatment. “If people are here and fall ill, then I would be prepared to provide care to restore them to a state whereby they can return to their own country,” he says. “The big problem I see—and I have experienced—is people who come expressly for the purpose of care,” he says.

“I’ve been asked to sign forms saying that people have just developed a particular problem, and I know darn well they’ve had it before they came.”

Piyush Pushkar, a psychiatry trainee who supported the motion, says he understands why people object to removing restrictions. “We must draw a limit somewhere. It seems unfeasible to treat anyone who turns up at a British hospital without checking if they are eligible,” he says.

Consider wider impact

But problems arise, he says, from the way in which eligibility checks are carried out. “When people are put off by fears about passport checks, it can lead to their condition worsening, so when they do seek care, it is less likely to be beneficial, as well as more expensive,” he says. “If the initial problem was an infectious disease, this has consequences for spread of that disease.”

Jackie Applebee, a GP in east London, points out restrictions also have an impact on those whose immigration status makes them eligible for primary, but not secondary care. These include asylum seekers, refugees whose status has not been formalised, those who have overstayed their visas or who do not have documentation.

“These people worry that, if they present to primary care, they will be picked up by the Home Office and deported, so they often don’t seek medical care at all, suffering themselves and potentially spreading infective illness,” she says. “People who do register for primary care, but who aren’t eligible for secondary care, often cannot afford to pay for secondary care so will go without, jeopardising their health and adding to the burden of primary care, as GPs have to handle problems that we are not qualified to deal with.”

Pushkar also argues that introducing barriers for those deemed ineligible may not reduce NHS spending on treating overseas visitors.

“All these systems for checking eligibility require bureaucracies, which can cost more money than simply doing the humane thing in the first place—that is, providing care when it is needed, even if it is not an emergency.”
Learning to deal with the rise in acid attacks

Bystanders and health professionals can make a real difference to outcomes if they act fast

The number of high profile “acid” attacks has been increasing in recent years, especially in London.

The attacks, involving a range of corrosive substances, have brought into sharp focus the need for clinicians, law enforcement officers, and our politicians to find ways to deal with this latest menace on our streets. Treatment in the resuscitation room of the emergency department is only the start of a painful journey for victims, who often experience physical and mental distress for the rest of their lives. The assailants’ intention is not to kill, but to maim and disfigure. As the chemical is often thrown into the face, victims are likely to be left blind and severely disfigured.

Corrosive substances have been used as a form of torture throughout history, and stories of chemicals used as weapons are common in the scientific and fictional literature. Internationally, attacks with corrosive substances are most prevalent in India, Bangladesh, and Cambodia, where acids such as sulphuric and nitric have been readily accessible and inexpensive. These violent attacks are most commonly aimed at women and severely disfigured.

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Recent figures obtained by the BBC from the Metropolitan Police show that men are twice as likely to be victims of attacks. Many of these attacks have been linked to gang related crimes. Currently, the only legislation in the UK on corrosive substances is the explosive precursors and poisons rules aimed at businesses that sell and supply substances in bulk. Carrying corrosive substances is legal, with no restrictions on volume or strength, although a change in legislation is being considered and may need to be fast tracked to ensure that carrying corrosive substances becomes a criminal offence. Corrosive substances are easy to conceal and have even been used in an attack in a courtroom, as well as in nightclubs.

Acids cause coagulation necrosis of the skin by denaturing the dermal proteins. The first management objective is to limit this damage. The medical director of the London Ambulance Service has provided advice on how to approach acid burns and advises thorough irrigation after removing contaminated clothing. Bystanders who come to the aid of the victim of an attack can have an important role in minimising further injury. The victim should be removed from exposure as soon as possible. Irrigation of the affected area with copious amounts of water is vital to remove the chemical and should be performed as soon as possible to minimise the long term effects of scarring and need for surgical reconstruction.

Treatment

Once in the emergency department, patients should have rapid airway assessment and intravenous rehydration, similar to treatment of thermal burns. It is essential to continue washing off all the acid with water to prevent ongoing tissue destruction, starting at the area of contamination or the face and eyes. Irrigation should continue until the pH of the exposed area has returned to neutral. If eyes were exposed or even potentially exposed, then local pH should be checked again after 15 to 30 minutes to ensure there is no re-exposure from acid that pooled in the recesses of the folds of the eyelids. People with ocular injuries should be referred to an ophthalmologist for review, and the burns should be reviewed by a burns specialist or plastic surgeon. Thorough analgesia and tetanus prophylaxis should be given as soon as possible.

The rising incidence of acid attacks is an evolving challenge to law enforcement, and the aftermath is being seen with increasing frequency in emergency departments in some parts of the UK. Education of the public and health professionals is needed on how to deal with these injuries, as immediate treatment can substantially improve the outcome.

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Johann Grundlingh, consultant emergency physician jgrundlingh@nhs.net
Jessie Payne, ST4 trainee in emergency medicine, Barts Health NHS Trust, London
Taj Hassan, president, Royal College of Emergency Medicine, London