GMC adopts more lenient approach

The UK General Medical Council plans to cut the number of full investigations it carries out, as part of a comprehensive package to reduce stress on doctors who have complaints made against them.

More cases will be screened out after early inquiries, rather than proceeding to a full investigation, and more concerns will be dealt with locally by a doctor’s employer.

The changes follow recommendations by Louis Appleby, professor of psychiatry at the University of Manchester, who was appointed by the UK medical regulator last December to review its fitness to practise processes. The review was sparked by concerns that 28 doctors had committed suicide between 2005 and 2013 while undergoing GMC investigation.

Where a doctor’s mental health was a concern, early treatment rather than a full investigation would be the norm, said Louis Appleby. “There should be fewer investigations—the current rate of 2750 per year translates into a 40% chance that doctors will come before the regulator at some time in their careers,” noted Appleby. “Yet only 13% of investigations lead to any sanction—such a low figure does not justify the impact on individuals.”

He added, “Two principles have guided my work. First, doctors who are ill need to be treated, not punished—investigation is frequently punitive in effect, even if that is not the intention. Secondly, suicide is not confined to those who are known to be mentally ill—it can be those who are thought to be coping that are most at risk.

“The extent of scrutiny—contacting past employers, checking case files—should be proportionate to what has gone wrong. Meetings with the doctor should help clarify what will happen next and give the GMC a human face. Agreement should be the preferred outcome.”

Employers would also have a crucial part to play, he said, “ending the use of GMC referral to resolve conflicts with medical staff” and tackling the high rate of referral of doctors from ethnic minority groups.

Clare Dyer, The BMJ

Cite this as: BMJ 2016;353:i2071

NEWS ONLINE

• UK could turn to India for new GP recruitment drive
• Former Scottish chief medical officer resigns from BMA over junior doctors’ action
• US health officials press Congress for $1.9bn to combat Zika
SEVEN DAYS IN

Cosmetic surgeons get raft of new rules
The Royal College of Surgeons and the General Medical Council (GMC) have published new guidance on cosmetic procedures but called on the government to include legislation in the next Queen’s speech to fully protect patients.

The college’s new Professional Standards for Cosmetic Surgery states that surgeons who perform cosmetic surgery should be certified in the area of surgery in which they practise. The GMC guidance covers surgical procedures, such as breast augmentation, and non-surgical procedures, such as botulinum toxin (Botox).

Surgeons and the GMC have been lobbying the government to tighten current rules that have allowed doctors, including non-surgeons, to perform cosmetic surgery without taking additional training or gaining additional qualifications.

Stephen Cannon, chair of the Cosmetic Surgery Interspecialty Committee and vice president of the Royal College of Surgeons, said, “Cosmetic surgery is a booming industry, but the law currently allows any doctor—surgeon or otherwise—to perform cosmetic surgery in the private sector. This can make it difficult for patients to identify an experienced, highly trained surgeon from someone who should not be practising.”

The GMC guidance says that any advertising of cosmetic procedures must be clear and factual and must not use promotional tactics such as two for one offers.

General practice

GP should take regular breaks like lorry drivers
The Royal College of General Practitioners launched a campaign emphasising the importance of regular breaks for GPs and other practice staff. The college said that rules for preventing fatigue in pilots and train drivers should also apply to GPs in their surgeries. It sent posters to every surgery in the country, saying “Your safety should always come first” and “A rested GP is a safer GP.” (See http://bit.ly/1Yrpm65.)

Only a third of patients need to see a GP
GP surgeries every year, but they and other experts, interviewed by the public services think tank Reform, said that around half of these appointments could be taken by nurses and other clinicians.

NHS news

Rise in uterine cancer
The prevalence of uterine cancer in the UK increased by 54% in the past 20 years, from around 19 women in every 100 000 in 1993-95 to 29 in every 100 000 in 2011-13, figures from Cancer Research UK showed. About a third of the 9000 cases every year (compared with 4800 in the 1990s) are linked to being overweight, and evidence has shown that extra fat can increase hormone levels and growth factors that encourage cells to divide. Survival has also increased, as eight in 10 women with the condition live for at least 10 years, compared with six in 10 in the 1970s (full story doi:10.1136/bmj.i2093).

Mental health services reject a quarter of referrals
Mental health services in England turn away 23% of children and teenagers referred to them by GPs, teachers, and others, a report by the CentreForum think tank found. The reasons given for declining the referrals included young people with anorexia having a body mass index that was not under a certain threshold, people not being unwell for long enough, and conditions not being serious enough.

Single purchasing system for devices
A new single system for purchasing expensive medical devices and implants is being introduced in England and aims to save over £60m in its first two years. NHS England currently spends £500m a year on devices such as implantable cardioverter defibrillators and bespoke prosthetics, but the amount trusts pay for the same products varies widely. The new system follows a review by a Labour peer, Patrick Carter (below), which found that the NHS in England could achieve £5bn a year in savings by 2020-21 through improved procurement, among other things.

Research news

UK Biobank launches body scanning project
A £40m project funded by the Medical Research Council, the Wellcome Trust, and the British Heart Foundation will image the brain, heart, bones, carotid arteries, and abdominal fat of 100 000 current participants in the UK Biobank project. These scans will be analysed alongside the vast amount of data already collected from the Biobank participants to improve the understanding and treatment of major diseases.

Fusion shows little value in lumbar spinal stenosis
Treating lumbar spinal stenosis by fusing the affected vertebrae adds little value to decompression surgery, showed the results of two randomised...
MEDICINE

The use of the testosterone lowering drug degarelix in a trial including 60 patients with stenosis and spondylolisthesis showed a small benefit from fusion plus decompression on physical health scores but no difference in disability. A similar US trial of 66 patients with stenosis and spondylolisthesis showed a small benefit from fusion plus decompression on physical health scores but no difference in disability.

Earlier test is urged for gestational diabetes

Pregnant women should be screened for diabetes before the current 28 weeks’ gestation, researchers said, after finding that fetuses of women with gestational diabetes were more likely to be large by six months of pregnancy. The authors reported in Diabetes Care that nearly one in 20 (4.2%) of the 4069 nulliparous women in their study had gestational diabetes diagnosed and that their fetuses had twice the risk of excessive fetal growth. Obese women were five times more likely to carry a larger than expected baby (doi:10.11136/bmj.i2043).

Better air quality reduces children’s lung symptoms

Improvements in air quality over the past 20 years in southern California were associated with statistically significant decreases in bronchitic symptoms in children with and without asthma, a longitudinal study published in JAMA found. The prevalence of bronchitic symptoms fell by about 32% in children with asthma and by about 21% in those without asthma (doi:10.11136/bmj.i2083).

Crowdfunding bid for paedophilia treatment

Swedish researchers plan to use the UK based “crowdfunding” site Walacea (https://walacea.com) to raise £38 000 for a trial of a potential treatment for paedophilia. Christoffer Rahm, a psychiatrist at the Karolinska Institute in Stockholm, plans to use the testosterone lowering drug degarelix in a trial including 60 men. The endpoint will be changes in the risk factors believed to contribute to sexual offences: high sexual arousal, disturbed self control, and low empathy (doi:10.1136/bmj.i1997).

Surgery

Protocols will improve surgical outcomes

The move to centralised services in emergency general surgery would not improve outcomes or reduce mortality rates, said a report by the Nuffield Trust. Hospitals that performed 50 or fewer major emergency surgical procedures a year had a mortality rate of just over 12%, similar to those that performed 250 such procedures. The quickest way to improve outcomes was the systematic use of protocols and pathways, particularly in laparotomy and cholecystectomy, said the report (doi:10.11136/bmj.i2054). Cite this as: BMJ 2016;353:i2100

GENDER IDENTITY

Referrals of under-18s to England’s only gender identity clinic have more than doubled in the past year. There were 1398 referrals to the Tavistock Clinic in London last year, compared with 697 in 2014-15.

GMC REGISTRATION

GMC REGISTRATION IS MOVING?

Plans are afoot to move the point at which junior doctors in the United Kingdom register with the General Medical Council: from the end of their first year of foundation training back to the end of medical school.

WHY IS THIS IMPORTANT?

At first glance it could seem a little dry, but the change could mean that UK medical school graduates are not guaranteed a place on the foundation training programme.

ARE THEY GUARANTEED A PLACE NOW?

Currently, Health Education England has a “moral obligation” to provide all UK medical school graduates with full GMC registration. To get full GMC registration junior doctors must complete the first year of foundation training. This has forced Health Education England to fund extra posts.

BUT ISN’T THE FOUNDATION PROGRAMME ALREADY OVERSUBSCRIBED?

It is, and it has been since 2011, but because people drop out or don’t make the grade, all candidates have eventually been allocated a place on the foundation programme. The UK Foundation Programme Office and the Medical Schools Council have warned that if the plan to move GMC registration comes into force, UK graduates will no longer be guaranteed foundation training posts. This is partly because UK graduates would be competing for posts against graduates from other countries.

SO WHY THE CHANGE?

The plan would allow Health Education England to meet its obligations without funding additional foundation training posts. Health Education England said in 2013 that the move should happen “as swiftly as possible.”

WHAT WILL THEN HAPPEN TO GRADUATES WITHOUT A FOUNDATION POST?

In theory they would be able to work as doctors somewhere, as they are registered with the GMC. But, in the words of Derek Gallen, national director of the UK Foundation Programme Office, “I’m not quite sure where that is.”

Abi Rimmer, BMJ Careers

Cite this as: BMJ 2016;353:i2075
Woman with anorexia is discharged after doctors say she is untreatable

A High Court judge has authorised the discharge of a 28 year old woman with anorexia nervosa into the community after 10 years of inpatient treatment failed to stop her starving herself.

The woman, referred to as W, weighed less than 30 kg and had been losing weight at the rate of 0.5 to 1 kg a week. Her history showed that she would eat only when she believed that she might be in imminent danger of death.

The judge, Peter Jackson, acknowledged that “it would at first seem counterintuitive that someone so ill should be discharged from hospital.” He added, “The conventional assumption is that hospital treatment is likely to bring benefits, but the evidence has persuaded me that in this case that is not so.”

Her latest hospital stay, in a psychiatric unit in north Wales, had lasted two and a half years, and “this environment, designed to be therapeutic for W, is not therapeutic at all for W,” said Jackson. “It has become a place for talking about eating, and not for eating. If she is capable of making any progress, it will not be as an inpatient.”

He accepted, however, that W’s life would be at risk and that her family were “acutely apprehensive” about what would happen to her after she was discharged to her flat and her parents’ home.

Sitting in the Court of Protection, the judge ruled that W was not capable of making her own decisions about treatment for her anorexia and that therefore the court had to decide on the basis of her best interests. The decision that Betsi Cadwaladr University Local Health Board should discharge her into the community with a package of support was supported by the official solicitor, representing W.

W had obsessive compulsive disorder diagnosed at age 7 and anorexia nervosa at age 10. She has had six inpatient stays at five different hospital units since age 11, totalling 10 years in all.

Her psychiatrist told the court, “I honestly can say that in my opinion we have tried everything that we can to enable W to gain and maintain her weight. This has been tried in inpatient settings, outpatient settings, specialist eating disorder units, informally and under detention, using minimal force and restraint to using maximum force and restraint, using nasogastric tube feeding and solid food intake and a combination of both of them.”

A clinical psychologist who had treated her in the past said that W was unlikely

NHS deficits are a resigning issue for Hunt, says head of King’s Fund

Jeremy Hunt should consider resigning because the financial pressures on the NHS in England are putting patient safety at risk, a leading health policy adviser has said.

Chris Ham, former government health adviser and the head of the King’s Fund think tank, said in an article in the Guardian that Hunt should examine his conscience about whether the improvements in patient safety he instigated can be realised in the NHS’s current financial climate. As most trusts are running large deficits, many are looking to cut staff to reduce spending, which risks repeating the failures that led to nearly 500 unnecessary patient deaths in Mid Staffordshire from 2005 to 2008, Ham said. Robert Francis’s report into the scandal in the Midlands was the impetus for Hunt’s patient safety agenda.

Ham wrote in the Guardian, “Hunt now faces unpalatable choices about the direction of health policy, akin to the dilemmas that led Iain Duncan Smith to resign as work and pensions secretary. Just as Duncan Smith felt his mission to reform welfare was undermined by budget cuts, so Hunt’s ambition to improve quality of care is at risk from financial constraints.
to make a significant recovery but added, “The highly structured environment of inpatient care supports the rigid attention to detail and inflexibility which is characteristic of people with eating disorders, allowing these negative behaviours to thrive.”

The judge, who spoke to W before and after making his decision, said that the outcome was to some extent in accordance with her wishes. She told him that she would like to go home, wanted to continue her education, and had a career in mind. The judge said that her situation was “exceptionally worrying” and that the options were extremely limited. As an alternative, the health board had suggested rendering W unconscious for as long as six months and feeding her by tube until she reached a body mass index of 17.5, but this was abandoned by common consent before the hearing.

“It now has to be accepted that it is beyond the power of doctors or family members, and certainly beyond the power of the court, to bring about an improvement in W’s circumstances or an extension of her life,” Jackson concluded. “The possibility that the withdrawal of inpatient mental health services will bring about a change for the better may not be very great, but it is the least worst option.”

Cite this as: BMJ 2016;353:i2038

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“Perhaps the most important consequence of the committee’s work has been an increasing focus, in both intensive care and emergency medicine, on the interests of the dying patient in terms of organ donation. If people wish to donate their organs after death then that alone is a reason to do everything possible, within legal and ethical limits, to try to ensure that donation occurs and that it occurs successfully.”

“The final issues that UKDEC has been discussing include when a family’s wishes contradict the known wishes of the possible donor—and non-therapeutic elective ventilation. Discussion papers will be published on both topics, but of course UKDEC will be unable to make any further contribution.”

Susan Mayor, London
Cite this as: BMJ 2016;353:i2051

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“The final outcomes of the government’s spending pressures mean a reversal of policies to improve patient care that he was instrumental in developing.”

Ham said that there was “now no prospect” of achieving the £22bn in efficiency savings earmarked in the NHS’s Five Year Forward View, outlined in 2014 by NHS England’s chief executive, Simon Stevens.

And, with yearly funding increases of less than 1% throughout this parliament, NHS spending as a proportion of gross domestic product will be almost as low in 2020 as in 2000, when Tony Blair pledged to increase spending.

Ham wrote, “With a growing ageing population, it is not credible to expect the NHS to survive in its present form under these financial constraints.”

More honesty was needed from politicians about how the government planned to get the NHS into the black, he added, even if that involved relaxing waiting time targets, and about how it proposed to meet the “hefty price tag” of seven day services.

So far, however, politicians had shown no interest in exploring how the NHS could be funded, risking “a continuing decline in NHS performance with cuts in staff, compromises to the quality of care, and patients waiting longer,” Ham wrote.

He added, “Observing the NHS today is like watching a car crash about to happen.”

Cite this as: BMJ 2016;353:i2041

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The French model and actress Isabelle Caro featured in an Italian advertising campaign called “No anorexia” to raise awareness about the disease. She died in 2010, aged 28

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Cite this as: BMJ 2016;353:i2038
Protesters have taken to the streets in Krakow (pictured), Warsaw, Łódź, Poznan, Wrocław, and other Polish cities in recent weeks to show their opposition to a draft bill drawn up by a coalition of Catholic associations that would ban all abortions in the country.

Terminations are currently legal in Poland when the pregnancy is the result of a criminal act, such as rape, when it endangers the woman’s life, and when the fetus is seriously malformed.

The Polish Federation for Women and Family Planning said that the draft law proposed “a complete ban on abortion and a new category in the criminal code—prenatal murder—which would introduce a penalty of three to five years in prison for women, doctors, and anyone helping a woman to have an abortion.”

Jaroslaw Adamowski, Warsaw

Pro-choice campaigners rally in Polish cities

Pro-choice campaigners rally in Polish cities
In London supporters of the demonstrations in Poland covered the door of the Polish Embassy with messages of solidarity and wire coat hangers, the traditional tool of back street abortionists.
Excessive noise in intensive care units

Bad for staff and very bad for patients

Noise levels in the intensive care unit are known to be high. World Health Organization (WHO) guidelines suggest hospital noise levels should average 35 dBA during the day and 30 dBA at night.1 Research conducted by our group in five local units recorded levels just under 60 dBA during the day (equivalent to a busy restaurant) with peaks above 100 dBA 22-28 times every hour. Although it was quieter at night, we still identified peak sounds above 85 dBA up to 16 times an hour.2 These data are consistent with those of other studies. Staff activities and alarms are primary sources of disturbance in intensive care units,3 but noises from other patients and infrastructure also contribute.

Staff and patients may be in a chronic state of alertness when alarms are constantly sounding. Alarms share characteristics with the human scream and tend to activate areas of the brain that recognise danger. Raised sound levels have been associated with increased stress for staff,4,5 and non-clinical studies show that noise adversely affects physiology, motivation,6,7 and general health.8

Sensory overload
The brain has a limited resource for processing information, and sensory overload caused by high noise levels and complex patient needs can lead to fixation bias and loss of situational awareness among staff.4,8 The cognitive cost associated with the subconscious processing of distractor noises limits the brain’s ability to process auditory and visual information.9 Desensitisation to background noise may reduce staff alertness. Up to 75% of alarms are false alerts, require no immediate action, or are simply ignored.13 It is also difficult to distinguish serious problems from minor ones as all machine alerts sound urgent to the untrained ear. Alarm fatigue has been cited as a leading hazard faced by hospitals in the United States,14 and the Royal College of Anaesthetists’ safe anaesthesia liaison group has prioritised this as an area for improvement in the United Kingdom.15

Volunteers exposed to a simulated intensive care environment showed disturbed sleep and biochemical markers of stress.13 A review of intensive care and postoperative sleep studies found that patient sleep in intensive care is highly variable,16 and in two observational studies in Australia and the United Kingdom patients had three to five hours sleep in any 24 hours, with a median duration of unbroken sleep of just three minutes or less.17 18

Not so sweet dreams
Disrupted sleep could be a trigger for intensive care unit delirium. Links between psychological disturbances and poor sleep are recognised, and paranoia symptoms can be reduced in psychiatric patients simply by improving sleep.19 Descriptions of patient experiences in intensive care make harrowing reading.20 21 Between 30% and 75% of patients experience at least one delirious episode while in intensive care. These patients tend to have longer hospital stays and long term health problems after they have been discharged home.22 A recent meta-analysis confirms the link between patient exposure to high noise levels and delirium.23 Ear plugs may be a simple solution. However, ear protection is not suitable for all patients and does not tackle problems of staff communication, staff wellbeing, or potential for clinical error. Side rooms offer some protection from disturbances caused by other patients, but patients remain at risk of noise from their own physiological monitoring.

Lowering environmental noise levels, even modestly, may help patients sleep, improve staff concentration, and result in fewer episodes of delirium. Building design and materials can reduce noise, and various quiet periods have been trialled with mixed results.24 25 Staff education can be effective, as can individualising alarm thresholds and volumes, and use of visual alerting. Anecdotally, changing culture has been one of the hardest barriers to overcome. More and better trials of interventions designed in partnership with patients and families are urgently required, along with newer approaches such as “experience based codesign” (www.kingsfund.org.uk/projects/ebcd). It seems unlikely that WHO limits can ever be achieved in full, and they should perhaps be revised. Changing monitoring standards to take account of psychological effects of noise would be a welcome shift in attitudes to the problem. But moving away from a single 24 hour average sound target to include measures of frequency may be a better way of describing acceptable sound levels for hospital environments. Defining an achievable and evidence based target specific to intensive care units would also be helpful.

Cite this as: BMJ 2016;353:i1956
Find this at: http://dx.doi.org/10.1136/bmj.i1956

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Healthcare services in police custody in England and Wales

Recent government U turn leaves police healthcare adrift from the NHS

In December 2015, the UK government announced that planned changes to the commissioning of healthcare for people held in police custody in England and Wales would not proceed. These changes had been well considered (having been in planning since a key report by Lord Bradley in 20091), set out formally, and described as one route to securing excellence.2 The government announcement, however, means that the commissioning of these specialist health services will remain with police and crime commissioners instead of being transferred to the NHS. This sets police healthcare apart from all other healthcare services, including those that are provided in other parts of the criminal justice pathway.

False economy
The decision represents a missed opportunity. It will prevent much needed service development and could set back current healthcare delivery. It represents a policy reversal that flies in the face of several years’ preparation. It seems to have been financially driven,3 but had the proposed transfer to NHS commissioning driven service improvements as expected, the change could have improved health outcomes substantially, and ultimately saved money.

Forty one police and crime commissioners in England and Wales were elected in 2012 and now have a key role in setting local objectives and budgets. Their overall budget is in excess of £8bn, funding a workforce of over 200 000 people. This workforce is in place to deal with up to 6.6 million crime incidents4 and over one million arrests a year, although arrests have been consistently falling since 2007.5 Many of these large numbers of people may not have sought healthcare in the community despite having a complex range of conditions that require investigation and treatment6 and may be acutely life threatening.7 The importance of providing healthcare screening after arrival in police custody is well established, although the screening methods currently used nationally require improvement8—something that could have been achieved through the transfer of commissioning responsibilities.

The prevalence of health disorders among people taken into police custody resembles the prevalence within the prison population—perhaps unsurprisingly given that many of them will ultimately enter prison, whether transiently to await trial or for a custodial sentence.9 They are, however, often much more acutely ill than all but the newest prisoners.

In prisons, the combination of high morbidity10 and commitment to equivalence of healthcare11 has led to relevant healthcare services being commissioned from the NHS since 2006. Although this handover of commissioning responsibility took a decade after the publication of the landmark report Patient or Prisoner12 in 1996, recognition that these changes identified substantial unmet needs13 should weigh against abandoning, or even delaying, similar reforms for those in police custody. Furthermore, failure to see through the commissioning changes goes against current international trends in progressive thinking about healthcare systems, which highlight the need for service integration across complex clinical pathways.14

Lord Bradley’s proposal for the development of liaison and diversion services—integrated across the whole criminal justice pathway and with other relevant services in order to provide information where required and transfer people away from custodial care at earlier points in the criminal justice pathway—is still government policy. There is increasing recognition that these services can be effective,15 and mounting evidence that healthcare interventions that broadly sit within the liaison and diversion portfolio, such as court based mental health interventions and intensive drug treatments can ultimately save money.16

Fragmentation of services
The government’s U turn on commissioning health services in police custody seems set to leave these services disconnected from the NHS as a whole, and from one another, through disjointed commissioning. This is a far cry from the seamless integration that had been sought, and that is still government policy.14 The decision seems more focused on a short term financial fix than longer term strategic health and economic gain.

We believe that consistent NHS based health commissioning arrangements across the entire criminal justice pathway would result in considerable improvement in the safety of the community and those arrested as well as cost benefits for the government. We therefore hope that this position can be restored at the earliest possible opportunity.

Cite this as: BMJ 2016;353:i1994
Find this at: http://dx.doi.org/10.1136/bmj.i1994

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Pamela J Taylor, professor of forensic psychiatry, Division of Psychological Medicine and Clinical Neurosciences, Cardiff University School of Medicine, Cardiff, UK
Simon Howard, acting consultant in health protection at Public Health England, wrote: “If all food is labelled with an ‘activity equivalent,’ then the sum total activity recommended by all items consumed by an individual in a typical day will appear absurd. Assuming that walking burns around 5 calories per minute... ‘the calories in a can of fizzy drink take a person of average age and weight about 26 minutes to walk off,’ the total activity recommended by the packaging of a typical 2000 kcal daily diet would be more than 400 minutes of walking per day... consumers may disregard the labelling as unrealistic.”

Frank Eves, reader in lifestyle physical activity at the University of Birmingham, wrote: “It is not clear that physical activity labelling would be encouraging. For example, one digestive biscuit made by the original manufacturer contains 71 kcals. To match the energetic contents of this biscuit with the simple, achievable lifestyle physical activity of climbing stairs would require ascent of 25 floors.”

Labelling food with the exercise needed to expend its calories

Giving consumers an immediate link between foods’ energy content and physical activity may reduce obesity, argues Shirley Cramer, chief executive of the Royal Society of Public Health (see page 106).

Cramer’s personal view, published online last week, sparked a lively Twitter debate via @bmj_latest.

Readers also commented via thebmj.com

THE BMJ.COM POLLS

Would adding “exercise needed to burn off calories” to food labels reduce obesity?

Yes: 462 (57%)
No: 352 (43%)
Total votes cast 814
GENETIC RESEARCH

The sequencing revolution

Part research project, part commercial stimulus, the enormous 100 000 Genomes Project could usher genomic medicine into mainstream use, Mark Peplow reports

Nobody could deny that Mark Caulfield, chief scientist of Genomics England, has a bold vision. “This will bring genomic medicine across the healthcare system,” he enthuses. “It is, in essence, an NHS transformation programme.”

He’s talking about England’s 100 000 Genomes Project, which is now ramping up into high gear. Overseen by Genomics England, it is one of the biggest whole genome sequencing projects in the world. And it is working to a breathtaking timetable: most of these genomes will be sequenced by the end of next year.

The genetic material will come from patients with rare diseases or common cancers and their families (box, right). By identifying any genetic anomalies, and linking them to participants’ medical histories for the rest of their lives, the project aims to build up a unique database for treatment and research. “It will allow us to find things in the data that we might not notice in ordinary clinical care,” says Caulfield. That should offer better diagnoses and more targeted therapies. It also gives scientists a treasure trove of information that could help to develop more effective drugs.

That remit is impressive enough. But the project’s broader goals are to kickstart a national genomics industry and make the UK the first country to routinely use DNA sequencing in mainstream healthcare. “If we get this right, our ambition is to see new treatments, new diagnostics, coming to patients in the UK first,” says Caulfield.

Clinical potential
The project is already having clinical impact among people with rare diseases, with the first child participants receiving a genetic diagnosis in January. There are about 7000 known rare diseases, and roughly 1 in 17 people (about three million in the UK) are affected at some point in their lives. 1

“Collectively, the burden is high,” says Caulfield. “They are a huge cause of disability, and the toll on individuals is huge.”

More than 80% of rare diseases are suspected to have a genetic component. But their rarity makes diagnosis a huge challenge, which can be time consuming and frustrating for patients and clinicians. “Many of these disorders are totally unique,” says Beverly Searle, chief executive of Unique, the rare chromosome disorder support group (www.rarechromo.co.uk). “That’s why it’s so important to have these projects where you gather large datasets.” With tens of thousands of genomes from patients with rare diseases, it becomes much more likely to find a statistically robust association between genetic variants and a particular disease.

Once that link is established, the experiences of those who share the same genetic anomalies can be compared to predict how a particular patient’s condition might develop in the future and which treatments are likely to be more effective. Not only could this improve clinical outcomes, it could also save time and money. “It’s important that expectations are managed—not every family will get a diagnosis,” cautions Searle. “But we’ve got the potential for one test to give you an answer.”

The road to 100 000 genomes
• Roughly 25 000 cancer patients will each contribute two genomes: their own and that of their tumour
• About 17 000 people with rare diseases, plus two blood relatives of each patient, will add another 50 000 genomes
• The project is also sequencing genomes from a smaller number of patients with severe infections

“Not every family will get a diagnosis but we’ve got the potential for one test to give you an answer” — Beverly Searle

Georgia Walburn-Green was one of the first patients to have her genome sequenced

PHILIP HARDMAN PHOTOGRAPHY
The other arm of the project focuses on common cancers, including those in the lung, breast, colon, prostate, and ovary, where a genetic diagnosis could affect treatment options. About half of melanomas are caused by a mutation in the BRAF gene, for example, and these can be treated with a drug that specifically targets the BRAF protein. “A mutation can help to predict a medicine’s effectiveness,” says Caulfield.

Collecting and using the data
Most of the project’s participants arrive via one of the 13 NHS Genomic Medicine Centres that were established last year around England. People give a small blood sample, and (if they have cancer) a small piece of their tumour, which can have a substantially different genome.

The project has already sequenced more than 7000 genomes and is recruiting more than 200 patients with rare diseases per week. But the pace of sequencing will quicken in the coming months, when a dedicated facility at the Wellcome Genome Campus in Hinxton, Cambridgeshire, opens. The American company Illumina is setting up a world class sequencing facility there, stuffed with machines that can read an entire genome in about a day, for less than £1000 (see box above). Caulfield hopes that most of the sequences will be completed by the beginning of 2018.

The information will be stored at a secure government data centre in Corsham, Wiltshire, along with each participant’s health records. Any findings that are relevant to the participant’s condition are sent back to their doctors, to help with diagnosis and treatment. Unexpected findings—for example, a genetic mutation that has no immediate health impact, but may affect their children—are also communicated if the patient has stated a wish to receive this information.

This first phase of the project—gathering samples, generating genomes, curating the data, and providing diagnoses where possible—should cost around £200m, funded by government. The second phase, supported until 2020 with an additional government commitment of £250m involves a deeper analysis of the data to tease out associations between genetic variation and disease.

This analysis will be done through the Genomics England Clinical Interpretation Partnership (GeCiP), which already includes more than 2250 researchers from the NHS and universities. Researchers can access the data for free as long as an independent review committee approves their research proposal. A dozen companies have already joined in, too, including GlaxoSmithKline and AstraZeneca, although they have to pay for the privilege: £250 000 for big drug companies.

Commercial concerns
Caulfield is adamant they are not selling access to the data, merely recouping the project’s costs. But this commercial element has raised concerns. “These are NHS data that can be accessed for a fee, whatever language you use,” says Stephan Beck of University College London’s Cancer Institute.

Indeed, Genomics England itself is a company, owned by the Department of Health. Caulfield says that this structure helps them to operate faster and more flexibly than a conventional academic research consortium. Genomics England will own the intellectual property that the project generates, for example, so it will be easier for companies to negotiate with them, as a single point of contact, than with multiple university research partners. Any profit that Genomics England makes goes back into genomic medicine in the NHS, Caulfield adds.

Acting as a company also helps to demonstrate that the UK is fertile ground for the genomics industry. Illumina, for example, is not simply contracted to carry out the sequencing work—it is a fully fledged research partner, and the project was a key factor in the company’s decision to base its new European headquarters in Cambridge. “It’s about making England the place to bring your genomics project,” says Caulfield. “The ambition is to generate commercial opportunities—

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**Sequencing revolution**

- A human genome contains about 3.2 billion base pairs of DNA. Most variations are harmless, but sometimes a change to a single base can lead to disease
- Previous sequencing efforts have tended to focus only on DNA that codes for proteins. But this ignores more than 95% of non-coding DNA in the genome that may have important functions, such as decreasing the chances of mutations, or switching other genes on or off
- The Human Genome Project took 13 years to deliver the first full human genome sequence in 2003, at a cost of more than £2bn. Today, a whole genome sequence costs less than £1000 and takes about a day, depending on the accuracy needed
- In the 100 000 Genomes Project, each genome from a patient with a rare disease will be read 30 times and those from cancer patients 75 times

"These are NHS data that can be accessed for a fee, whatever language you use" — Stephan Beck, UCL
not just for us, but for universities and the NHS itself.”

“There’s an aversion to mixing health and commercial interests,” says Mark Sheehan, a bioethicist at the University of Oxford’s Ethox Centre, who is involved in an ethical and social science study within GeCIP that will monitor the project and provide ongoing advice. For now, he is maintaining a “cautious scepticism,” but he believes that as long as commercial relationships are handled appropriately and transparently, they don’t necessarily pose ethical problems: “At the end of the day, we need the companies to do the research.”

Patient confidentiality

In the early stages of the project, some had voiced concerns about the risks of patient data being misused or even stolen. Could an insurance company or employer use a patient’s genomic data to deny them coverage or other rights? “We raised issues when the project was first mooted, but so far the way it’s being developed is really good,” says Searle. All of the data are pseudonymised, so individual patients cannot be identified by the researchers analysing the data. “We’re very honest with patients about this—it’s very hard to guarantee anonymity—but we’re doing everything we can,” says Caulfield. As an additional security measure, researchers will be able to access the data only at the Corsham site: “You can’t take the data away,” say Caulfield firmly.

This, however, raises another problem, says Beck, as it severely restricts the number of researchers able to use the data. “The process is too cumbersome, too slow,” he says. Beck leads the UK arm of the Personal Genome Project, an effort that also has its sights set on sequencing 100 000 genomes from volunteers. The big difference is that all of the information gathered will be open access, so researchers around the world can immediately dive into the database. He acknowledges that there are valid concerns about genetic privacy, but that participants should be able to make their own judgment about the risks involved. “We’re very open about the risks, but people can look at that and balance the risks for themselves,” he says. Beck notes that in the United States, where the project began in 2005, no participants have had their data used against them. About 10 000 people have registered to take part in the UK, but only 10 sequences have been completed so far.

Promising future

Caulfield hopes that by 2020, the 100 000 Genomes Project will have instituted a culture change in the NHS, raising the profile of genomic medicine and providing the infrastructure necessary for it to flourish. He believes that in the next five years it will become routine to order a genome sequence for many patients presenting with a rare disease or cancer.

“I hope there will be greater engagement with the possibilities of genomic medicine,” says Christine Patch, a consultant genetic counsellor at Guy’s Hospital in London, who has been recruiting patients with rare diseases to the project. “There will be more tests based on DNA analysis, and clinicians need to understand the power—and the limitations—of the tests,” she says. Genomics England is now working with the NHS to deliver 700 person years of training in genomic medicine in the coming years.

Meanwhile, other UK nations are showing interest in joining the 100 000 Genomes Project, and Caulfield says that the country is well positioned to lead the world in genomic medicine. That’s partly thanks to the NHS, which makes it possible to link the genome to each participant’s medical records over time, something that would be harder to do in the more fragmented US healthcare system. “It gives us a uniquely rich data set,” he says. “Wherever we go, we are the envy of the world—they’re in awe of what we’re doing.”

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“If we get this right, our ambition is to see new treatments, new diagnostics, coming to patients in the UK first” — Mark Caulfield
Snapchat is not for sharing

Photo messaging app Snapchat is one of the most popular ways to share images online. But doctors who use it at work may be breaking patient confidentiality, say Sohini Patel and colleagues

Snapchat is a video and photo messaging application that lets users send images to each other. Its unique selling point is its self-destruct function: users can send images to their whole contact list or to selected individuals and set a viewing duration of up to 10 seconds. After this period the images disappear.

In 2013 Snapchat users sent 700 million photos and videos per day. However, the company’s privacy policies were rated poorly, and a newly developed spy app lets users save snaps without the sender’s approval or knowledge.

Photo sharing by doctors made headlines in July 2015 when Venezuelan student obstetrician Daniel Sanchez posted a smirking selfie on Instagram with a woman, naked from the waist down, giving birth behind him. Another obstetrician’s fingers were still in her vagina as the baby’s head was born.

Sanchez boasted that his team could “bring kids into the world and reconstruct pussies.” A petition signed by more than 4000 people called for the student to face disciplinary action. His is not a lone example: other doctors, medical students, and nurses have posted graphic images of surgery and made inappropriate or degrading comments online.

In early 2015 Michael Salzhauer, a plastic surgeon in Miami, began using Snapchat to create publicly accessible videos of his surgeries in real time. His intentions are understood to be educational and he has a team—including two employees whose sole responsibility is to monitor his account—commenting on the procedures.

Anyone in the world can add this surgeon to their Snapchat contact list and view the images and videos he creates: tummy tucks and breast and gluteal augmentations. Salzhauer has said that older patients who refuse to have their surgeries Snapped are “ashamed” to talk about their bodies. Subsequently, his practice has been limited to those under the age of 50.

There is some evidence that doctors in the UK are also using Snapchat in hospitals. Anecdotal reports describe doctors and medical students sharing x-ray images of patients, posting photos holding neonates during maternity ward placements, and using the app to make mocking comments and jokes in a clinical setting, often breaching confidentiality.

These examples vary in their degree of lack of professionalism. For example, doctors may share x-ray images or other investigation results via Snapchat, and send them to doctors on the other side of the hospital to aid speedy decision making. The choice of the self-destruct function may indicate that doctors realise this conduct is questionable and would prefer to destroy any evidence. Or Snapchat may innocently have been used because it is often the default app for image sharing. Regardless of the intent, using Snapchat may constitute a breach of confidentiality.

Regardless of the method (Snapchat or otherwise), breaching confidentiality can cause harm to the parties involved. If images of confidential patient information shared on Snapchat without consent became public it would undermine faith in the medical profession and contribute to the perception that doctors are untrustworthy and disrespectful to patients.

Although Snapchat presents new challenges to doctors, the General Medical Council’s guidance on doctors’ use of social media states “the established principles apply.” Doctors are entitled to have a life outside work but they should be wary of documenting anything clinical on Snapchat.

Sohini Patel, fourth year medical student, University of Birmingham, UK
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FIVE FACTS ABOUT SPECIALTY FILL RATES

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<th>Health and Education England has published data on the acceptance and fill rates for specialty training, following the first round of recruitment.</th>
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<td><strong>1. OVERALL FILL RATE</strong></td>
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<td>There was a 79% fill rate in 2016 with 5821 doctors being accepted onto a training scheme after the first round of recruitment. This compares with an 82% fill rate in 2015, when 5910 doctors were accepted.</td>
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Junior doctor reunites *Green Wing* cast to support strike action

The cast of *Green Wing* have supported the fourth round of junior doctors’ industrial action from a picket line after they were contacted by a junior doctor.

Five of the cast of the Channel 4 comedy attended the picket line at Northwick Park Hospital, London, on Wednesday 6 April to show their support for the action.

Janis Burns, an anaesthetic trainee who works at the hospital, where the series was filmed, told BMJ Careers that she emailed the agents of 10 members of the cast, asking if the actors would get involved.

“At the last strike I felt that there was a little bit of apathy and people were quite demoralised and I thought about what we could do to try and improve things,” Burns said.

“Working at Northwick Park I knew that *Green Wing* was filmed there so I decided to contact the actors and see whether they would be interested in reuniting on the picket line with junior doctors, over ten years after *Green Wing* was filmed. And they agreed.”

Burns said that after emailing the agents of the cast members she sent a second email a week later. She was then contacted directly by actors Pippa Haywood and Stephen Mangan.

“Theyir emails basically said to leave it to them and they’d be in touch.”

Burns said that less than 24 hours before the strike started Haywood and Mangan confirmed that five of the cast would be arriving at Northwick Park.

Burns then wrote a press release and contacted all the major newspapers and TV news desks. At 11 am on the first day of industrial action five of the cast—Stephen Mangan, Pippa Haywood, Tamsin Greig, Julian Rhind-Tutt, and Oliver Chris—arrived at the picket line.

Despite having concerns the night before, Burns said that the media coverage of the event was excellent and far in excess of what she had hoped for. “On the day we had camera crews from the Press Association, BBC, Sky, and London Live at Northwick Park all ready and waiting for *Green Wing* to arrive”

Association, BBC, Sky, and London Live at Northwick Park all ready and waiting for *Green Wing* to arrive,” she said. “Photos from Northwick Park were all over social media and it genuinely seems to have lifted morale.”

Burns said that if the government were to press on with imposition, it was important to raise as much support for junior doctors as possible. “The *Green Wing* actors all have high profiles, so I think it helps raise awareness of our cause,” she said. “Also it goes to prove that it’s not just doctors who realise it is bad, our message is getting out there and other people are listening to it.”

Commenting on why she agreed to attend the picket line, Tamsin Greig, who played surgical registrar Caroline Todd in *Green Wing*, said, “I think it’s really important to be part of a group of courageous people who are standing up and saying, ‘Can I just point out that if this goes on something will break. And it will be an institution that is a treasure but it will also be people.’”

She added, “It’s really important to stand alongside something that is unique in the world—this doesn’t happen in any other country in this form. I don’t want to get into my senile years and look back and say, ‘I remember the Dodo that was the NHS.’ I don’t want it to be a picture in a book, I want it to be alive and vibrant.”

Stephen Mangan, who played anaesthetist Guy Secretan in the series, said, “We’ve been watching aghast at what’s been going on: the government’s refusal to listen to the concerns of the medical profession, the government’s demand that the same resources stretch further and further—it’s just not possible. [We’re here] to show our support, hopefully shine a bit of light and bring a bit of publicity, and in a small way boost a bit of morale.”

Pippa Haywood, who played human resources director Joanna Clore, said that the cast really wanted to support the junior doctors that they worked alongside during the filming of *Green Wing*. “All of us felt very strongly that we wanted to support their cause and to ask Jeremy Hunt to start listening again.”

Julian Rhind-Tutt, who played surgeon “Mac” in the series, said that the public might think the junior doctors’ dispute was about pay but that, “the real picture is very different, it’s about the systematic devaluation of the health service, and about the notion we have of what a doctor is in society today being eroded. That’s why I thought I would come. These are thoughts that friends and colleagues of mine in the NHS have talked to me about.”

Abi Rimmer, BMJ Careers
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Neena Modi
Dogged, determined, driven

What was your earliest ambition?
I spent part of my childhood in India in an era when women always took second place, so my earliest ambition was to be better than the boys (and I was).

Who has been your biggest inspiration?
A raft of fictional heroines feature large, but I also admired Margaret Thatcher, though I detested her politics; Hillary Clinton, obviously, for her amazing resilience; similarly, Aung Sang Suu Kyi and Nelson Mandela, for immense personal sacrifice and for showing, like Gandhi, how wars can be fought without violence. And, of course, my dad, who did his best to break away from the conventions expected of an Indian man.

What was the worst mistake in your career?
It may have been prudent, but I regret not taking on a certain head of department.

What was your best career move?
Abandoning my new husband (briefly) and moving to London in 1982 to work with Osmund Reynolds and Jonathan Shaw in the neonatal unit at University College Hospital, where history was being made in care for newborns. To be part of the birth of neonatology, a new medical specialty, was the most exciting and invigorating experience. I would urge all young medics to find an area of practice that really inspires them: they will never regret this.

Bevan or Lansley? Who has been the best and the worst health secretary?
Though not in my lifetime, Bevan was the best: a great politician with a simple, clear vision. Alas, the worst was Lansley, who brought wholly unwarranted destruction to a great NHS, the extent of which has yet to be fully realised.

Who is the person you would most like to thank, and why?
My mum, for always being there.

If you were given £1m what would you spend it on?
I’d develop state of the art technology for my team’s national neonatal research database (www.imperial.ac.uk/ndau) so that parents, clinicians, researchers, and policy makers could access outputs interactively.

What single unheralded change has made the most difference in your field?
The slow realisation by society, the profession, and ethicists that clinical research involving infants and children isn’t unethical, it’s essential.

Do you support doctor assisted suicide?
I support doctor assisted end of life care.

What book should every doctor read?
NHS plc by Allyson Pollock.

What is your guiltiest pleasure?
Owning a small, fast, wholly impractical, convertible red roadster.

What personal ambition do you still have?
To learn Italian.

Summarise your personality in three words
Dogged, determined, driven.

What is your pet hate?
Wasting or throwing away good food.

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