

# comment

‘The NHS has also provided the British public with an absence of something: not having to worry’

**NO HOLDS BARRED** Margaret McCartney

## Trust is earned and easy to lose

**T**he NHS is a brand beyond advertising. The British public is proud of it and trusts it more than any other institution, and 90% support its founding values. Some of this is a genuine, deep emotional bond; some is a loving tolerance despite its struggles and failings.

The NHS has also provided the British public with an absence of something. Not having to worry about accessing healthcare when we need it. Not fretting over policy documents and expiry dates or about adding new conditions to our coverage.

When we sleep at night, the fear of getting the healthcare we need doesn't prey on us. And we expect that our trust is repaid—that our data are stored confidentially, that we will be treated with courtesy, and that mistakes or errors will be owned up to. Even if much of the way healthcare is organised and delivered is devolved across the four nations of the UK, the NHS provides a security that my generation has always known.

These are some of the reasons why the case of Albert Thompson induces disquiet. He arrived from Jamaica as a teenager with his mother who worked as a nurse. Thompson, who has never applied for a British passport, worked as a mechanic and brought up his children here.

Then, at age 63, he was told by the Royal Marsden Hospital that he needed to either pay more than £50 000 up front or give proof of his residency before he could be treated for prostate cancer. The documentation he has doesn't



satisfy the Home Office, and his lawyers are aware of several similar cases.

What does this mean now for the children of immigrants? Can they feel ease that they're protected under the umbrella of the NHS—or frightened that they're excluded from it?

Trust is hard to earn and easy to lose, and we diminish the need for it at our peril. We see fundamental differences of opinion on the

role of NHS Digital in terms of data sharing with the Home Office. NHS Digital feels justified in supplying information to the Home Office despite not being legally compelled to do so—distinct from its responsibilities for assisting the police with serious crime. Many organisations have spoken out about their concerns on how this will adversely affect vulnerable groups.

We can feel no ease with giving our health data to a system that doesn't understand that we need to trust that it will be kept confidential. This trust in the NHS is a moral one, where we're willing to tolerate imperfections and to work harder than we're contracted to, because we know that the underlying case for it is one to admire and aspire to.

As the UK appears to harden its stance on immigration, the case for applying the founding standards of humanity and compassion to today's NHS gets stronger.

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## The “greener grass” of a consultant post looks like a tired lawn

Increasing workloads challenge the “offer” implicitly advertised to doctors in training

**T**he state of UK medical careers is a cause of great concern. The car crash that surrounded the introduction of a new junior doctors contract in 2016 has left all parties weary, damaged, and tribal.

Medicine has always been a fulfilling career, with rewards offered by few others. It is an attractive option for many young people, with the number of applications to study medicine higher than for almost any other career.

After qualifying, the challenges are considerable. An educational landscape that has become burdensome, coupled with immense work pressures, has resulted in more doctors choosing not to progress beyond their foundation years

or leaving the profession before completion of higher specialist or vocational training. Although the increased opportunity to train or work in less than full time posts is to be welcomed, we must acknowledge that this has reduced the number of hours of clinical time available to the NHS.

However, the greatest challenge we face is the “offer” we advertise to doctors in training. In the last century, the implied contract was one of intense study and service as a junior, offset to a large degree by the professional independence and little regular out of hours activity when a consultant. This form of delayed gratification served both parties satisfactorily for 50 years or so.

However, the increase in patient numbers, complexity, acuity, and the

**The gradient of reward to effort ratio has become very slight**

need to ensure a truly 24/7 service has increased the intensity of training posts and similarly increased the burden for consultants of both in and out of hours work. When seen from the trainee perspective, the “greener grass” of a consultant post is looking like a tired lawn. The gradient of reward to effort ratio has become very slight.

### The proposals

I propose two non-pecuniary amendments to the next consultant contract to tackle this.

First, the issue of work-life balance must be approached. If someone works a higher proportion of evenings, nights, and weekends, then the recompense needs to be just as valuable. To work a Sunday and be rostered off the following Wednesday



## Will the public use emergency department alternatives?

I've argued before that we shouldn't blame the public for using emergency departments, as has a joint observational study from the Royal College of Emergency Medicine and the Patients Association. The position was that urgent need is defined by service users in real time. The public are intelligent consumers who go where the lights are on, and many are in any case directed to acute hospitals by NHS emergency numbers.

But I'm always prepared to reflect and reconsider. A study in January of emergency department attenders at North Middlesex University Hospital has made me wonder. Researchers examined 37 000 pieces of data and interviewed 630 patients, seeking to



**The finite resource of NHS acute care is for the entire population, however difficult that might be for politicians**

determine what brings patients to emergency departments even for conditions that aren't life threatening. I know that it's only one unit, in a deprived part of London, with a young, multicultural population, but here are the headlines.

More than a third of interviewees reported being aware of alternative services, such as pharmacists, NHS 111, GP extended access hubs, and urgent care centres. Around half (rising to three quarters at weekends) had come to the emergency department because it offered a convenient way to see a healthcare professional 24/7, even if that meant waiting. A similar proportion said that they would happily use

a 24/7 walk-in centre near their home, instead of the emergency department, if it provided instant access to diagnostics.

A similar study at Barnsley hospitals showed that, of 951 patients surveyed, only 22% considered their condition an emergency. Their main concern was to gain reassurance that the condition was not serious.

Speed and convenience of access to services matter to patients: the latest social attitudes survey showed that these, alongside waiting times, are key reasons for declining satisfaction with the NHS. And it's hard to escape media coverage about emergency department overcrowding, stacked up ambulances, and worsening waits.



is a poor reward. Similarly, extra payment is a weak currency when compared with companionship, hobbies, and relationships.

Equity, I suggest, is better served by linking regular out of hours working with annual leave entitlements. In this way labouring at weekends and nights is offset by extra leisure at a time chosen by the doctor. This would, in the short term, create more rota gaps, but these could be filled with only a fraction of the money currently spent on locums. Moreover, the enhanced recruitment and retention would reduce the dependency on locums in a very short time. Such an arrangement would be particularly attractive to medical couples with young children, as the need for childcare in holiday times would be reduced.

I accept the suggestion in Bruce Keogh's review of urgent care that the patchwork of alternatives to emergency is often confusing to the public and should be simplified and more clearly communicated. After all, the emergency department is a strong brand, familiar to everyone.

We might argue that, if the emergency department gives the public what they want, we should accept that people want to use it and will do so. But endemic staffing and space problems mean that this isn't a sensible proposition in overcrowded hospitals. Experiments with extended GP opening hours don't seem to have reduced demand convincingly. A recent European analysis shows that we already have longer hours of GP access than most countries, and NHS

Second, we need to recognise that earlier appointments and later retirement ages mean that consultant careers have increased from 20 years to 30 years.

We have already experienced a loss of study leave time and budgets to the point that most practitioners are lucky to be able to attend one short conference a year. This compares unfavourably with posts in other parts of the English speaking world, where study leave allowances are much greater. More significantly, however, we need to enable and promote paid sabbaticals for permanent staff every five years. Opportunities to study and experience other workplaces, systems, and procedures would reinvigorate staff and enable them to return with knowledge and enthusiasm to improve their own institutions, while simultaneously enriching their careers and developing their practice.

Churchill once said that the Americans could be counted on to do the right thing, but only once they had exhausted all other possibilities. It seems to me that we have reached that very position... will the protagonists oblige?

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England vanguard sites focusing on urgent and emergency care have still seen growth in activity—albeit lower than at non-vanguard sites.

Surely, we need to start saying clearly that the finite resource of NHS acute care is for the entire population, however difficult that might be for politicians. Every citizen who uses it for speed and convenience rather than the level of need risks compromising care for other citizens who might need services more. We must be realistic about what acute care is for, what it's not for, and the need for us to find more resources if we really do want 24/7 direct access to specialist care.

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## BMJ OPINION Patricia Cantley

### We must remember how scary hospitals can be for patients

My mum always told me to be wary of doctors, a statement she had good cause to make in light of some of the care my disabled brother received. Recently, I've found myself thinking back to a specific time my brother, Iain, who had Duchenne muscular dystrophy, was admitted to hospital as a teenager. That experience shaped how I viewed hospitals and continues to influence me as a doctor today. I think it's worth us all remembering how strange and scary hospitals are for those who have a child with a disability.



When you are living with a disability, developing your own routine is one of the coping strategies. The problem with hospitals is that they also work to a routine—and it's unlikely yours and theirs are going to match. I remember that Iain needed help to be turned approximately every hour overnight. At home he would call out, one of my parents would shuffle through, adjust him, and return to bed.

In hospital, however, patients were turned according to when the charts said they should be. Each time Iain dropped off to sleep he was woken for a routine "turn," while at other times he lay awake begging for a shift in position only to be told it wasn't time yet. He hated every minute of it.

The power imbalance between patients, their families, and the staff in hospitals can be scary. It can be hard to question what is happening, or to ask for more information.

This story has a happy ending, in the sense that my brother did get home. We knew he wasn't thriving in hospital and within a short time my parents asked that he be discharged home. It took him a while to recover but he did, over time.

I sometimes wonder if the story would play out differently today—there is much talk of being "patient centred," so perhaps the difficulties we experienced back in the 1980s would not be a problem now. When I've spoken with friends who are disabled, however, it seems that the mismatch between patients' and healthcare professionals' routines can still be a problem, even in 2018.

Since the start of my career, I have seen myself as a translator. Whether for patients or their families, I have tried to interpret the mysteries of their illnesses and the treatments we offer. I feel passionately that we need to provide written information. It's hard to take in facts when you are scared and vulnerable, so we need to do everything we can to redress the imbalance, not only in power and knowledge, but also in our respective states of mind. Many of our patients may be scared—or even frightened witless—when, for us, it's just another day at work.

Patricia Cantley works as a consultant physician in the Midlothian Hospital

## ANALYSIS

# Alerting family about heritable risks: the limits of confidentiality

Are there situations when sharing a patient's genetic information with relatives without consent is acceptable?

**Anneke Lucassen** and **Roy Gilbar** discuss

**J**ohn has recently received a diagnosis of Huntington's disease. This serious hereditary condition has no cure and early death (aged 40-60) is likely. An affected person has a 50% chance of passing the condition on to their children. Those who inherit the causative mutation (a triplet repeat or "stutter" in the DNA) are likely to develop the disease in mid-life, or earlier if the stutter has enlarged, which can sometimes happen if it is inherited paternally.

John's daughter, Clare, knows her father is ill but not that his condition is heritable. She is pregnant and

**We may need to consider contact tracing of relatives more like we do for STDs**

mentions this to John's clinicians. They wonder whether she has a right to know that he has a heritable condition, but John worries about Clare and that she might terminate her pregnancy. He therefore refuses consent for Clare to be told.

This scenario, recently discussed by English courts in *ABC v St George's Healthcare NHS Trust* and others (box),<sup>1</sup> raises questions that clinicians increasingly face—namely, whether, and how, genetic information discovered in one patient might be communicated to relatives at risk of inheriting it. Tensions around confidentiality and responsibilities to others are well described in practices around, for example, sexually transmitted diseases (STDs), yet for heritable risks the prevailing discourse remains one that gives prominence to patient confidentiality. This is presumably because, until recently, few treatments were available to prevent or ameliorate the course of genetic conditions.

Now that surveillance and interventions are available for people who know they are at risk of certain conditions, we may need to consider contact tracing of relatives more like we do for STDs. Furthermore, genetic technologies have become much cheaper and quicker, and genetic or genomic testing is now entering mainstream medical practice<sup>2</sup> as well as being more available direct to the consumer commercially. Knowing if, or when, it might be appropriate to alert others about risks discovered through

the testing of one person therefore becomes an issue for all doctors.

### Confidentiality and its limits

General Medical Council (GMC) guidance emphasises that confidentiality is usually the rule but that disclosure to others might be an exception.<sup>3</sup> Communication of information given in confidence is generally permitted only if the patient consents or if each of three criteria are met: the patient refuses to inform others, an identifiable person (relative) is at serious risk of harm, and such harm might be prevented by disclosure.<sup>4</sup>

In STDs, disclosure might be justified to prevent transmission of a disease. In genetics, the harm prevention is the access to surveillance or treatments that a relative would otherwise not know to access. In familial polyposis, for example, relatives live on average 20 years longer if they have regular bowel surveillance and preventive surgery. In familial breast or ovarian cancer, women can access early screening, chemoprevention, or risk reducing surgery only if they know they have inherited the BRCA1/2 mutation. Avoidance or termination of pregnancy (to prevent transmission of a condition such as Huntington's disease) might also be considered harm prevention.

Hence, according to the GMC guidance, John's doctors should have considered whether his refusal to allow Clare to be told about her heritable risks could be over-ridden. If their conclusion was that informing Clare



### THE ABC CASE

ABC is the first case in English law to deal with non-disclosure of a patient's genetic information to a relative.<sup>22-24</sup> In ABC, a daughter claimed that her father's clinicians were negligent for not telling her that he had Huntington's disease. The claim was initially struck out by the High Court as it was held that there could be no duty of care to relatives in such circumstances.<sup>25 26</sup>

The Court of Appeal reversed this decision in May 2017, holding that, depending on the circumstances, it may be fair, just, and reasonable to impose a legal duty on a clinician to inform a patient's relatives about their increased genetic risk.

The case can now go to trial, where the court would examine whether the treating clinicians met the reasonable professional standard when respecting a patient's refusal to disclose his genetic status to his daughter.

The Appeal Court emphasised that relatives' interests in autonomy and disclosure are no less important than a patient's rights to autonomy and confidentiality and that a clinician's duty towards relatives "would serve to ensure that a proper balancing exercise is performed by the clinician." The court held that the law in this area should reflect the professional obligations clinicians already hold towards relatives.<sup>1</sup>



## KEY MESSAGES

- Increasing adoption of genetic technology throughout medicine means that questions about communication of heritable risks to family members will arise more often
- Clinicians often believe that preservation of confidentiality prevents them from disclosing genetic information to relatives at risk without the patient's explicit consent
- A recent UK court case highlights that clinicians need to weigh the potential harms of disclosure against the potential benefits
- We argue that in many cases appropriate relatives can be alerted without a breach of confidence of clinical information

would help her avoid serious harm, their disclosure would have been justified despite John's refusal. This balancing exercise is not easy, but it is important to remember that John had no absolute right to veto disclosure.

### Which information is confidential?

The BMA states that identifiable patient information, "whether written, computerised, visually or audio recorded, or simply held in the memory of health professionals is subject to the duty of confidentiality."<sup>5</sup> This includes clinical information about diagnosis or treatment, photos or other images of the patient, and the details of the doctor and the clinics the patient attends.

The Data Protection Act 1998 defines personal data as that which "relate to a living individual who can be identified by those data," or by those data together with other information held by the data controller (eg, a clinician). The act considers health records as "sensitive personal data" that can be disclosed only if certain conditions are met (such as patient consent).<sup>6</sup> The forthcoming European General Data Protection Regulation defines personal data as "any information relating to an identified or identifiable person," and perceives genetic information as sensitive personal data.<sup>7</sup>

However, since 99.9% of the genetic code is the same in all humans this cannot be considered sensitive, just as it cannot be considered sensitive to say that a person has lungs or kidneys.

**"Your family history suggests there might be an inherited predisposition" would not breach confidentiality**

It is the (0.1%) differences in genetic codes that lead to potential sensitivity. Biological relatives share an even greater proportion of their genetic code, so a particular BRCA1 mutation, for example, may not identify an individual but rather a group of related individuals who have a family history of breast and ovarian cancer. Alerting relatives that their family history may mean they have an increased chance of developing a condition therefore does not breach confidentiality because no identifiable information is communicated in such a statement, even if genetic findings in one person first led to that conclusion.

We have previously argued that relatives' interests in the patient's genetic test results should be taken into account and that disclosure practices should be amended accordingly.<sup>8,9</sup> This view has been endorsed in clinical practice guidance<sup>10</sup> but has not yet gained wide enough acceptance by clinicians to be applied in John and Clare's case.<sup>11</sup> Most western countries seem to take a similar position to the UK, presumably because clinical practice usually prioritises the consent and confidentiality of the patient under investigation. As genetic and genomic medicine is becoming more integral to general medical practice we need to have a debate about when relatives' interests play a part in decisions.<sup>12</sup>

### Family history

In our scenario, John is known to have a family history of dementia,

and some of his relatives had the movement disorder characteristic of Huntington's disease before they died. Clare remembers John's mother having dementia at an early age. John's clinicians used this information to consider a diagnosis of Huntington's in John. Clare observes John's symptoms and asks his clinicians whether they have implications for her. John's clinicians are now in a difficult position. They need to place a high value on keeping his clinical information confidential, but can they tell Clare her family history may have important consequences for her without breaching John's confidentiality?

We suggest that in these situations clinicians could say to relatives like Clare, "Your family history suggests there might be an inherited predisposition in your family," because John has refused disclosure of his information not of information that is not unique to him. Clare could then seek further advice about whether testing might be available, without any breach of John's confidence. Clare's test results might eventually lead her to infer things about John, but we would argue that this is not the same as a breach of his confidence because the information discovered is not about a particular individual. If Clare concludes that her father has the same genetic finding, it does not reveal confidential information about John that she is not already party to.<sup>13</sup> Since family members share the same gene pool,

certain inferences about their genetic status will be inevitable regardless of clinicians' disclosure.

In some cases it will not be possible to use a family history to suggest to a relative they are at risk: clinical findings and their heritable explanation may be evident in only one person, for example. Even here we argue, alerting relatives to their risk is not the same as breaching confidentiality, because it is not unique information that is being disclosed.

We do not underestimate the difficulties of implementing such an approach systematically. The threshold of risk, severity of the condition, as well as the interventions that would be available after disclosure, would need to be defined. Furthermore, there are practical difficulties in communicating with people who might not be easy to find, or who might not want to receive such information. For now, we simply posit that relatives can sometimes be told about their genetic risks without breaching the confidences of the patient in whom the heritable tendency was first identified. This does not equate to a duty to contact all, but to a responsibility to contact some people, some of the time.

A next step therefore might be to agree that clinicians could consider disclosure in cases such as that of John and Clare. Documenting these considerations and how decisions about disclosure are made will be an important part of this process. We then need a much wider debate about when, and at what level of risk or available preventive options, such disclosure might be more proactive, and how.

### Empirical evidence

Families often share their genetic information, and it is rare for a patient to explicitly refuse to inform relatives.<sup>14</sup> However, this does not mean that appropriate communication always takes place. Patients may find such communication difficult for many reasons, including lack of contact, not finding an appropriate time, or not understanding its importance.<sup>15</sup> Many genetic services offer "family letters"



for patients to pass on to relatives, but these are also not always effective.<sup>16</sup>

Other research suggests that both patients and clinicians within genetic services already distinguish between personal and familial information on some level and have no objection to disseminating familial genetic information when the benefit from disclosure is high in terms of surveillance or treatment.<sup>17</sup> Patients think that their relatives should have the opportunity to receive relevant familial genetic information and perceive reproductive choices in the same way as they do treatment options.<sup>18</sup>

### Professional guidelines and the law

In the UK, the GMC considers disclosure to others without consent is justified "if failure to do so may expose others to a risk of death or serious harm."<sup>3</sup> For genetic information, the GMC says that if a patient refuses to disclose relevant information to relatives, clinicians need to balance their duty to make the care of their patient their first concern against their duty to help protect another person from serious harm. The GMC suggests that doctors should not reveal the patient's identity when contacting relatives, thus acknowledging that familial and individual information might be separable.<sup>3</sup>

English law, like professional guidelines, imposes a duty of confidentiality on clinicians and grants discretion to warn relatives.<sup>19</sup> Whereas the GMC can initiate disciplinary actions against doctors who transgress guidelines, the courts can direct clinicians to pay compensation to patients for breaching confidentiality.

The GMC if approached by Clare might conclude that John's clinicians failed to adequately consider GMC

**Clinicians need to consider not only their patients' wishes and interests but also those of relatives at risk**

guidance on confidentiality. However, if Clare wants compensation, the courts first need to examine whether her father's clinicians owed her a duty of care.<sup>1</sup> If they did, the courts must decide if clinicians breached this duty of care and whether it caused the harm the claimant experienced.

The assessment of whether clinicians owe a duty of care (to inform, in this context) to particular relatives needs to meet three criteria: could they have foreseen that their (in)action might cause harm? Could they have identified a particular relative as being at risk? And is it "fair, just, and reasonable" to impose such a duty?<sup>20 21</sup>

### Implications for clinical practice

In the ABC case (box, p 26) the Court of Appeal's decision that doctors may have a legal duty to inform a patient's relatives of their risk of Huntington's disease has important implications. Although the court held that such a duty of care to relatives might be limited to genetic practices, this limitation will reduce as genetics becomes part of every branch of medicine. Clinicians treating patients whose conditions have a major, and definable, inherited component (for example, a BRCA1 or 2 mutation) need to consider not only their patients' wishes and interests but also those of relatives at risk, who may in turn become patients to be advised about surveillance or risk reducing measures.

The ABC case therefore guides clinicians to use their professional judgment and consider whether harm might be prevented by disclosure of (potentially) familial rather than personal genetic information. What we will now need to be determined in cases where patients explicitly refuse disclosure to relatives, is how to fulfil this duty—namely, if, how, when, and by whom might Clare be informed, and which other relatives such a duty also applies to. In practice, we suggest that clinicians call on multidisciplinary expertise, including regional genetic or genomic services, clinical ethics committees, and professional guidance from the GMC and royal colleges.<sup>3 10</sup>

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## SUING FOR LACK OF BREAKS

**Break pay is taken for locum rota cover anyway**

Junior doctors are right to take a trust to court for denying them breaks every four hours (News, 3 March).

We as junior doctors also often have to do extra locum shift work to help to cover staff shortages. In obstetrics and gynaecology we have been working with 50% rota gaps nationally. On-call shifts in most specialties and in most hospitals are extremely busy on most days.

Mistakes and omissions may lead to serious problems, which is why we don't take a break. When you are on call there is no one to hold your bleep, for you to have a break.

We are supposed to take a 30 minute break every 4-6 hours. On any locum shift the system automatically deducts 30 minutes every six hours, which adds up to several unpaid hours over time.

Victoria Asfour, clinical fellow, London  
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## TUITION FEES

**Medical students report effect of tuition fees**

An English, Welsh, Scottish, and international student await a lecture. They pay respectively £9250, £3000, £0, and £30 000 yearly in tuition fees (Briefing, 3 March). The lecture is cancelled because the clinician is called away. For paying students, missed lectures and cancelled days add up. Many of us desperately count pennies to afford basic necessities such as rent, taking jobs and loans to bridge the gap between living costs and maintenance loans. In London, rent is £9000 and a maintenance loan £5500 yearly.

When applying for medicine we're told that a loan won't be a black mark, but how it's factored into future finances isn't discussed.

## LETTER OF THE WEEK

**Need for EU folic acid fortification**

The debate (Do the benefits of folic acid fortification outweigh the risk of masking vitamin B<sub>12</sub> deficiency?, 3 March) agrees that mandatory fortification would reduce neural tube defects and improve population folate deficiency, Reynolds advocating additional mandatory vitamin B<sub>12</sub> fortification.

Recent national audits in the Irish Republic found no improvement in neural tube defects with periconceptual folic acid supplementation and voluntary folate fortification of food.

The 2017 Safefood report on 502 pregnant women in the Irish Republic found that median total dietary folate intake was only 235.2 ng (interquartile range 143.6), including a median percentage contribution of 10.9% from voluntarily fortified food. Only 2.6% of the women achieved the WHO recommended daily allowance of ≥600 ng. Notably, 19.5% of the women were also deficient in vitamin B<sub>12</sub>.

This supports the case for mandatory food fortification with both vitamins to optimise the prevention of neural tube defects, but consensus on how to implement this is lacking.

Mandatory folic acid fortification has been successfully introduced in more than 80 countries but not in the EU, despite medical advice. If the UK pursues a cheap food policy after Brexit, EU-UK regulatory divergence on food may lead to unforeseen consequences for women at risk of a preventable major congenital anomaly.

Michael Turner, professor of obstetrics and gynaecology, Dublin  
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Given England's junior doctor reforms, Scotland and Wales stand out for jobs and education, and we can apply anywhere. Perhaps we should cherish medical school, because the doom and gloom starts on graduation and after prized GMC registration.

Samuel Chun, London  
Angelica Sharma, London  
Cite this as: [BMJ 2018;361:k1575](#)

## APPOINTMENT DAY

**The importance of nurse specialists**

de longh's account of a rare appointment with a consultant (What Your Patient Is Thinking, 17 February) underlines for me the importance of nurse specialists: professionals who know a lot about the problem, are accessible and

approachable, and know the patient. They should be able to help with many of the questions that get knocked off the list of things to ask the consultant. They could also be very useful in helping prepare the patient (and the consultant, with the patient's permission) for the appointment, as well as with the debriefing afterwards.

Judith H Harvey, retired GP, London  
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**Personalising care with a Year of Care approach**

de longh describes what happens when someone with long term conditions has an unsatisfactory annual clinic visit. Care and support planning with a Year of Care approach tackles these problems systematically.



It entails a preparation step for the person and professional. This may include an initial information gathering appointment for those with tests and tasks to complete. One or two weeks before the consultation appointment everyone receives an agenda setting prompt with results and supporting information to help to establish what is most important to each party. Professionals then understand what might help the person and are able to incorporate the professional story into the appointment appropriately.

Year of Care can support professionals to implement a care and support planning approach to enable good routine annual visits.

Sue Roberts, chair, Year of Care Partnerships, Ashington  
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## WRIST RADIOGRAPHS

**Misconception about hand positioning**

The article on a child with a painless, deformed wrist contains the commonly held misconception that standard wrist or hand radiographs are anteroposterior (Endgames, 17 February). They are posteroanterior, or dorsopalmar—same thing, different terms.

The true anatomical position has the palms facing anteriorly. The image is taken with the palm down, so the thumb of a right hand radiograph is on the left and vice versa.

A day spent with radiographers ensure that we understand how images are acquired and enables us to appreciate the art of our colleagues. It gives us a new respect for what happens after we simply fill in a form.

Dan Armstrong, consultant hand and wrist surgeon, Derby  
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## OBITUARIES

### Margaret Alison Lush

Psychiatrist, Bristol (b 1922; q 1946), died from bronchopneumonia and frailty of old age on 26 February 2018

Margaret Alison Lush (née Gee) followed her older siblings into medicine and entered King's College London in 1940. As a student she helped deal with casualties straight from the beaches of Dunkirk. Her first house job was in diabetes medicine at King's College Hospital. In 1946 she married my father, Brandon Stuart Lush. They set up home in New Malden and then Wimbledon. She gave up a hospital career to look after their children, but she worked part time in family planning and chairing government medical boards. They later moved to Bristol. Margaret retrained in psychiatry and worked at Barrow Gurney and Southmead hospitals. She was an excellent gardener and used to open her garden to the public until she was in her 80s. She leaves Brandon, two daughters, and a son.

Patrick St Lawrence Lush

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### Frank William Gordon Deighton

General practitioner Glasgow west (b 1927; q Glasgow 1949; AFOM, RCP Lond), died from cerebrovascular disease on 23 February 2018

Frank William Gordon Deighton was a family doctor with additional appointments to Rolls Royce at Hillington, Glasgow, and to Terex, a large American earth moving company with a base in Lanarkshire. He will, however, be best remembered as an amateur golfer. He won many tournaments in the 1950s and 60s. He had an interest in golf course architecture and was invited to design and lay out a nine hole course on the Isle of Skye. His later life was saddened by the deaths of his wife and a daughter. A stroke made him fully dependent, and he spent his last eight years in a care home. His intellect was, however, preserved, and he was able to complete many crossword puzzles, for which he won prizes. Frank leaves a daughter, Nicky.

Stuart McAlpine

Cite this as: [BMJ 2018;360:k1213](#)



### Kingsley Jones

Consultant psychiatrist (b 1925; q Dublin 1953; FRCPsych), experienced declining health after the death of his wife and died on 1 January 2018

Kingsley Jones was the first consultant psychiatrist appointed to St Nicholas Hospital in Great Yarmouth (in May 1958). He introduced changes and, in 1971, the hospital admitted its first female patients. He initially spent half of his clinical time at Norwich's mental hospitals, to which all acute psychiatric patients from the surrounding areas were admitted. In 1982 Kingsley moved to Canada to take up the position of professor of psychogeriatrics at Edmonton Hospital before retiring to Loddon, Norfolk. He wrote many papers on various aspects of psychiatric illness. In retirement Kingsley worked at a military hospital in Greenwich, where he treated personnel experiencing post-traumatic stress disorder after the Gulf war. Predeceased by his wife, Dorothy, in 2017, he leaves two sons; a daughter in law; and two granddaughters.

Caroline Buddery

Cite this as: [BMJ 2018;360:k1265](#)

### Francis Andrew Boddy

Director of public health research unit, University of Glasgow (b 1935; q Edinburgh 1959; DPH, FRCPE, FFPHM), died from cardiorespiratory arrest on 13 January 2018

Francis Andrew Boddy was the director of the Scottish Office funded social, paediatric and obstetric research unit, latterly the public health research unit, at the University of Glasgow from 1978 to 1998. He also spent time working on primary healthcare for the World Health Organization in Copenhagen. Andrew strongly identified with the founding principles of the NHS and the social values they represent. He advocated a population approach to health creation rather than an approach centred on individual responsibility. Andrew was a keen photographer, fly fisher, and prolific reader, and his love of travel was combined with an enduring fascination with the history and culture of the places he visited. He leaves his wife, Ada; two children; and two grandchildren.

Philip McLoone, Alastair Leyland

Cite this as: [BMJ 2018;360:k1212](#)



### John Graham Buchanan Russell

Consultant radiologist (b 1929; q Manchester 1953; DCH, DRCOG, DMRD, FRCR), died from a ruptured aortic aneurysm on 3 January 2017

John Graham Buchanan Russell ("Graham") was appointed consultant radiologist to Manchester Royal Infirmary and St Mary's Hospital in 1965. A 1989 winner of the Barclay medal of the British Institute of Radiology, he had an inquiring and creative mind and an acute and idiosyncratic sense of humour. In 1964 he was the first to describe ECG gated cardiac imaging, and first compared ultrasound and radioisotope usage with traditional x ray techniques in his 1973 textbook. Graham advocated ultrasound screening for abdominal aortic aneurysm in 1990, 19 years before it was implemented in the UK. He published on paediatric, gastrointestinal and biliary imaging, radiation hazard, and dose reduction. He served on national and international committees and was a staunch supporter of his colleagues. He leaves his wife, Elspeth, and five daughters.

Sylvia Rimmer

Cite this as: [BMJ 2018;360:k1206](#)



### Peter Alexander Murray Weston

General surgeon (b 1924; q 1947; FRCS), died at home after a large stroke on 15 April 2016

Peter Alexander Murray Weston was senior orthopaedic registrar and lecturer in surgery at the University College of West Indies in Jamaica from 1956 to 1962. In 1964 he was appointed consultant surgeon in the accident and emergency department at Cumberland Infirmary in Carlisle. Unfortunately, he developed rheumatoid arthritis, which necessitated a career change to a more administrative and teaching role at Nottingham University Teaching Hospital in 1972. Around 1981 he was able to return to a more active surgical role, and he worked in Zimbabwe, Tanzania, and Zambia for the last five years of his professional career. In retirement, his zest for life continued in a variety of pastimes, with sailing his lifelong favourite. He leaves Ann, his wife of 59 years; four children; and eight grandchildren.

Theo Weston

Cite this as: [BMJ 2018;360:k1243](#)



# James B Richardson

Persuaded NICE to recommend stem cell therapy for cartilage repair

**James Bruce Richardson (b 18 March 1955; q Aberdeen 1977; FRCS, MD), died from a heart attack on 18 February 2018**

In October 2017 the man affectionately known to his team simply as “Prof” delivered a momentous announcement at the 11th annual Oswestry Cartilage Symposium. After more than 20 years of trials and research, the National Institute for Health and Care Excellence (NICE) had finally approved the autologous chondrocyte implantation (ACI) procedure for articular cartilage defect.

ACI involves taking chondrocytes from healthy cartilage, culturing them in the laboratory, and then transplanting them into a damaged area of cartilage. It was developed by Richardson’s team at the Robert Jones and Agnes Hunt Orthopaedic Hospital (RJAH) in Oswestry.

Sally Roberts, a longstanding colleague, says that Richardson’s ability to see a project through was key: “James was an optimist and an enthusiast. He saw the bigger picture. And if he believed in something he would chase it and follow it through.”

## Early years and working abroad

Richardson was born near Inverness in 1955. He went to Tain Royal Academy School in Ross-shire and then to Gresham’s School in Norfolk.

He trained in medicine at the University of Aberdeen, qualifying in 1977. His first post was in orthopaedics as a house officer in Inverness, and he decided to make it his specialty.

He met his wife Shona, a fellow doctor, and they married in 1978. The young couple had a yen to see the world and travelled overland via Iran to Afghanistan, working briefly in Nepal and India. In August 1980 they spent a year working together at a Church of Scotland Mission Hospital in Livingstonia, Malawi.

Richardson might have continued to work abroad. He said: “I undertook a year of full time research in Oxford, specialising in fracture healing, as I felt this would be important in the developing world.” But there were no openings for orthopaedic specialists in mission hospitals, and he was interested in clinical research. He took an appointment at the Glasgow Western Infirmary in 1985 and in 1988 became senior registrar at Oswestry and a senior lecturer at Leicester University. Finally, in January 1994, at just 38, Richardson was appointed professor of orthopaedics at Keele University and RJAH.

## Cell repair and research

Richardson undertook more than 100 hip replacements annually and many other operations. But he used to say, “You can help only so many patients through surgery. You can help far more through research.”

He was keenly interested in cell repair. Writing about the limitations of surgery and artificial joints, he said: “I can only conclude that we need to restore the living surface of the joint and use cells to heal bone.” In 1995, after a visit to Gothenburg in Sweden to see a laboratory cultivating stem cells, he came back full of purpose, establishing the OsCell laboratory at RJAH. It was the first of its kind in the UK.

He and his team set up the autologous chondrocyte transplantation/implantation versus existing treatments (ACTIVE) trial with 390 patients in the UK and Norway. This was followed by the ASCOT trial in 2014, which compared the ability of chondrocyte and bone marrow derived stromal cells to repair cartilage.

Richardson used to say: “If you can’t measure things, you can’t talk about them.” To audit patients’ progress, he set up an outcome centre at RJAH, which followed the progress of 5000 patients.



**The remarkable house he built included his own early designs for renewable energy**

Described by a colleague as a “whirlwind of ideas, practicality, and kindness,” he wrote up his ideas and research in contributions to more than 100 articles and 20 books.

## Wider interests

From an early age, Richardson was curious about how things were constructed, perhaps influenced by his father who was an engineer in the army. His drive to innovate manifested in the remarkable house he built for his family, which included his own early designs for renewable energy, such as solar panels, a windmill, and a sustainable smallholding. He never lost his love of adventure—including snow holing in the Cairngorms, and cross country ski marathons.

He travelled widely, and visited India every year.

In November 2017 Richardson was presented with the chief executive’s award for inspirational leadership; he had led the way to an approved cellular treatment for arthritis—the culmination of a long and distinguished career.

On 18 February, Prof died unexpectedly from a heart attack while on holiday in India. He leaves his wife, Shona; two sons; a daughter who is an orthopaedic registrar; and one granddaughter.

Penny Warren, London  
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 WHAT YOU'RE TWEETING ABOUT

## Be Brave

In our recent *What Your Patient Is Thinking* article, *Be Brave*, Sophie Lyons described what it's like to be a frightened child patient, and why being called "brave" didn't help. Here were some of your reactions to the article:

Words matter. Clinicians' well-meaning stock phrases can exacerbate patients' fears and sense of isolation  
[Rachel Clarke @doctor\\_oxford](#)

I've been guilty of doing this. #learningtodobetter  
[Jane Deer @roxyposis](#)

I often tell my patients they are brave and they really are! But I



also tell them, yes this is going to hurt and I'm so sorry about that  
[Kristy McKeon @Stowkristy](#)

[This] can be equally applied to patients throughout the age spectrum. I found myself using stock phrases with older adults, but when I listened to

myself, I realised how shallow and pointless they were  
[Kev Anthony @KevAnthony2](#)

There are parallels to be drawn with the labels "hero" and "warrior" often applied to those living with #lifelongllness  
[Dawn Smith@Dawnmignon](#)  
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ROSE LLOYD

## MOST READ ONLINE

David Oliver: Moral distress in hospital doctors  
[BMJ 2018;360:k1333](#)

Be brave  
[BMJ 2018;360:k1299](#)

Bawa-Garba granted Court of Appeal challenge against erasure ruling  
[BMJ 2018;360:k1455](#)

Sixty seconds on... prostate cancer  
[BMJ 2018;360:k1385](#)

The role of medical manslaughter must be reconsidered, says leading lawyer  
[BMJ 2018;360:k1376](#)

bmj.com highlights is curated by Kelly Brendel, assistant web editor, *The BMJ*

## FROM THE ARCHIVE

# The sinking of the *Titanic*

On this day in 1912, just before midnight, the RMS *Titanic* hits an iceberg and sinks within hours. In the following weeks, *The BMJ* carries notices of doctors lost in the disaster, such as John E Simpson, surgeon on the ship, whose father received this note from its second officer (*Br Med J* 1912;1:1221).

"I am sorry to say that assistant surgeon John E Simpson was on the *Titanic*. I deeply regret your loss, which is also mine. I may say I was practically the last man to speak to Dr Simpson, and on this occasion he was walking along the boat deck in company with Messrs. M'Elroy and Barker, Dr O'Loughlin, and four assistant pursers. They were all perfectly calm in the knowledge that they had done their duty, and were still assisting by showing a calm and cool exterior to

the passengers. Each one individually came up to me and shook hands. We merely exchanged the words, 'Good bye, old man!' This occurred shortly before the end, and I am not aware that he was seen by anyone after."

Later that year, the journal reported (*Br Med J* 1912;2:1017) on a talk from ophthalmologist Karl Grossman discussing recent changes made to the standard of eyesight required of sailors—a subject that must put in everyone's minds "in grim eloquence, the *Titanic* disaster."

"What do we know of the light perception in the dark of those on lookout duty on that fateful night," asked Grossman, noting that "there are fearful gaps in our knowledge which cry out for investigation." He observed that "the man on the lookout must be a man with particularly good



sight," yet his eyesight "is not tested at all, neither under the old nor the new regulations for 1914." He goes on to recommend that "every sailor should have his sight tested compulsorily... This would be of great value to the safety of the ship."

However, Grossman notes that it may have been that no lookout could have prevented the *Titanic*'s collision: "A speed of 21½ knots in a sea of floating ice on a dark night might defy any vision, even if binoculars had been handy."