

# We need more organ donation from ethnic minorities

There is an incongruity among ethnic minorities between those prepared to donate and those who need to receive organs and stem cells. **Adnan Sharif** suggests we consider ways of prioritising recipients

In December 2006 the British government set up an organ donation taskforce to identify barriers and solutions to boosting organ donation in the United Kingdom. The recommendations, published in January 2008,<sup>1</sup> were intended to rectify one of the worst organ donation rates of any country in Western Europe.

Boosting organ donation from deceased donors by 50% within five years was a laudable aim. Achieving this target in 2013 has therefore been a notable success, although it is too early to ascertain whether the increase in organ quantity has come at the expense of a decrease in organ quality. In addition, over the past four years the number of registrants to the organ donor register (ODR) has increased by 30%, and the numbers of deceased and living donors have risen by 35% and 23%, respectively.<sup>2</sup>

However, since publication of this report there has been a huge failure to boost organ donation from members of black, Asian, and other minority ethnic communities. It is a similar story with the registration of donors for blood stem cell transplantation, with severe shortages of minority ethnic donors skewing the cell type matches available.

Ethnic minorities constitute 10.8% of the UK population but are over-represented on organ waiting lists (24%) and under-represented on the ODR.<sup>2-3</sup> Of actual organ donors, only 4.2% are from minority ethnic backgrounds.<sup>3</sup> Although minority ethnic registrants on the ODR increased by 61.3% between 2008 and 2012, the actual numbers remain small (73 512 on 31 March 2008 and 118 598 four years later), and the increase equates to only 2.8% and 3.5%, respectively, of all registrants with known ethnicity.

Relatives of non-white people are also less likely than white people to give consent for organ donation from loved ones who have died in appropriate circumstances for donation (30.3% v 68.5% for donation after brain death).<sup>2</sup>

For these reasons minority ethnic people have longer median waiting times for organs.<sup>2</sup> This is predominantly a consequence of biological differences between ethnic groups because of disparate frequencies of different blood groups and particular combinations of alleles for human leucocyte antigen found in members of different ethnic communities.

Simply pushing for more registrants on the organ donor register is not the solution because



More ethnic minority donors are an NHS priority

only a third of eventual donors are actually registered at the time of their death (37% in the financial year 2011-12).<sup>3</sup>

A new approach should be to tackle the elephant in the room: the problem of apathy or so called free riders—people who are happy to receive an organ but not to donate.

Lavee and colleagues outlined a novel Israeli approach to this phenomenon in 2010<sup>4</sup>: prioritisation for transplantation is given to previous actual donors or those registered for at least three years to be donors. Israel has subsequently benefited from a boost in organ procurement and a reduction in organ waiting lists<sup>5</sup> (although this cannot be solely attributed to the prioritisation clause

because other relevant laws were concomitantly enacted and a large public awareness campaign initiated).

The prioritisation approach raises ethical difficulties, such as coercion, religious constraints, or strategic behaviour,<sup>6</sup> and translating such a policy to the UK would be fraught with challenges. Consideration of a similar system would require adequate resources and publicity to ensure ample public awareness of embedding incentives in the new allocation system.

However, developing a prioritisation system for organ and stem cell donation has inherent fairness for all—not just for minority ethnic people. Although it would positively affect the general

population it would also likely serve as an impetus for minority ethnic people, who will have an even longer wait under a prioritisation system if they do not commit. Raising awareness of organ and stem cell donation among minority ethnic communities, such as with the Kidney Research UK peer educator model of targeted community based education, would have more impact if prioritisation was introduced because it has personal implications. Minority ethnic people cite many concerns about organ donation relating to distrust, or religious or sociocultural issues,<sup>7-10</sup> but these concerns don't seem to arise when the situation is reversed—to the receiving of an organ or stem cell transplant. That someone can be fundamentally opposed to donation but conversely be receptive to receipt is dissonant—one cannot, and should not, exist without the other. Introducing priority points in allocation scoring systems would reduce this incongruity.

The strategic planning by NHS Blood and Transplant for the next few years has made boosting donation from minority ethnic people a priority. Although NHS Blood and Transplant encouragingly raises hopes of promoting a national debate on reciprocity in its strategic plan up to 2020, there seems little enthusiasm for championing such a dynamic yet controversial allocation system at executive level.

However, the organisation must appreciate that it is unlikely that organ and stem cell donation from minority ethnic communities will substantially improve by 2020. What has not been fruitful so far is unlikely to reap any great benefits in the immediate future. Introducing prioritisation would be one step to overcome apathy in organ and stem cell donation and it must be actively explored.

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References are in the version on [bmj.com](http://bmj.com).

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News: UK aims to increase its organ donor rate by 50% over next eight years (*BMJ* 2013;347:f4500)

Research: Modifiable factors influencing relatives' decision to offer organ donation (*BMJ* 2009;338:b991)

# I blew the whistle on disability assessments

**Greg Wood** went to the media with concerns about the ethics surrounding tests for fitness to work—and eligibility for benefits—that the UK government has outsourced to Atos

**A**ctually, two whistleblowers went public before me, and several other doctors have raised concerns anonymously. I am a former general practitioner in the Royal Navy, where work related assessments are bread and butter stuff. The UK Department for Work and Pensions (DWP) devised the work capability assessment (WCA) to judge whether people who receive out of work sickness benefits could, in fact, cope with most forms of work. A more stringent test came into use in 2011, and the government made no secret of the fact that it hoped this would boost the labour market, improve people's self esteem and personal income, and, of course, reduce government debt.

For many years the information technology and "business process outsourcing" company Atos has had a contract, now worth £100m (£116m; \$155.4m) a year, to carry out several social security benefit assessments, including the WCA, for the Department for Work and Pensions. In my view this risks tension between doctors' professional concerns on the one hand and business imperatives on the other.

The WCA had a troubled childhood. From early on, claimants and disability groups were reporting problems. They felt the assessment was a box ticking process, where medical assessors spent most of their time punching superfluous lifestyle data into the computer. And the likely outcome as they saw it? Computer says no.

In fact, the test, on paper at least, isn't too bad, though it isn't going to win anyone a Nobel prize. But it cannot adequately take into account health conditions that fluctuate unpredictably, and it tries to include too broad a range of jobs. Driving, call handling, shelf stacking, data entry, and cleaning, for example, are all theoretically covered. And although the test is nominally a pre-employment medical test of sorts, it is really still about measuring the person's level of disability.

In early 2013 the WCA was still causing a rumour in public, despite a series of external reviews.

One problem that dawned on me over time was the widespread use of five ill conceived so called rules of thumb that were promulgated during the

training of new assessors. On one, manual dexterity, the guidance was just plain wrong. The training said that this all boiled down to an inability to press a button, whereas the regulations allow points to be awarded when there are difficulties forming a pinch grip, holding a pen, or operating a computer. The other "rules of thumb" showed a combination of discrepancies and questionable interpretations of medical knowledge—for example, moving from one room to another at home was supposed to be equivalent to moving 200 metres. The effect was to reduce a claimant's likelihood of entitlement to financial help.

Another concern was the absence of documentary evidence, which, in my experience, occurred in about a fifth of assessments. This was a simple failure to move important pieces of paper from one building to another but the assessment was expected to go ahead regardless.

And my third concern was that there was an implicit assumption that the most likely outcome of an individual face to face assessment was that the person would be found fit for

work. I have no reason to believe that this was deliberate; it was probably more a question of wishful thinking and a misunderstanding of basic statistical principles. You can't expect the proportions of claimants who are fit to work who are seen by an individual doctor to correspond to national

trends. The general culture was one where, at the point when their file was being opened for the first time by the assessor, it was broadly assumed that an individual claimant was more likely than not to be found fit for work.

My fourth concern was that Atos auditors, for quality assurance purposes, were in the habit of demanding that healthcare professionals change their reports without seeing the patients themselves. This seemed fairly reasonable if the amendment could be justified, but not so reasonable when the doctor who had seen the patient thought otherwise. For instance, auditors supposed that they could tell that a patient with a chronic and only part treated psychotic illness had adequate mental focus, despite not assessing the patient for themselves, and using solely a report.

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The position of the General Medical Council is that doctors should not alter such reports if they think that it would make a report less accurate, or would render it misleading to the body commissioning it—that is, the DWP. I resigned from Atos primarily over this widespread interference with reports, which I felt encroached on my professional autonomy and crossed ethical boundaries.

So I blew the whistle and found myself talking to parliamentarians and journalists, and then making an appearance on BBC news. It was nerve racking trying to choose my words carefully while keeping the message clear and simple. Obviously I worried about the repercussions, but what had tipped it for me was that the DWP had stonewalled on this for more than two years; medical knowledge was being twisted; misery was being heaped on people with real disabilities; and the cost to the taxpayer of these flawed assessments and the subsequent successful tribunal appeals was going up and up.

Three months after I blew the whistle, the DWP announced that all Atos assessors were to be retrained and that external auditors had been called in to improve the quality of the WCA.

To others considering blowing the whistle, I would say this: if it is important enough to you and you do not believe that the problem can be fixed by more conventional means; if you can back up your assertions with evidence; if you are prepared to risk alienating your colleagues; and if you are robust enough to deal with the slings and arrows that might come your way; then blow your whistle loud and blow it proud.

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- News: Half of disability assessment bodies will be from the NHS (*BMJ* 2013;346:f1143)
- Review: The disturbing truth about disability assessments (*BMJ* 2012;345:e5347)
- Observations: Atos and changes to disabled people's benefits (*BMJ* 2012;344:e1114)



The fitness to work test has caused a public rumpus

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FROM THE FRONTLINE **Des Spence**

# The BMA and its staff's private health cover

Gaudy, supposedly personalised, advertising banners flash down the side of my email account. I am surprised that they promote online casinos, budget holiday sites, and, most commonly, private medical insurance. A smiling, white coated young woman suggests that I can "jump NHS queues." These adverts amuse and irritate me by the same token.

The BMA recently started offering a private medical plan to its entire staff. Employees pay directly through their salaries but benefit from reductions in national insurance contributions. But the directors and the senior managers of the BMA have had private medicine as part of their remuneration for some time. This is paid for largely through individual BMA membership fees of £343 a year.

Private medical schemes are offered to staff by many other organisations, such as the General Medical Council and even the purportedly NHS supporting newspaper the *Guardian*.<sup>1</sup> The GMC's unconvincing pretext is to attract and retain the best staff.<sup>2</sup> But is it right for the BMA, an



**This BMA policy suggests that the NHS and its doctors are second rate. I object to a single penny of my subscription being spent on private medicine**

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organisation that vigorously campaigns to defend the NHS, expounding its founding principles in BMA publications, to do this? Isn't that clear hypocrisy? I am against private medicine in principle, flatly rejecting the commonly used defence that those opting to go private reduce pressure on the NHS, actually subsidising NHS care.

No: when important institutions side-step standard care it undermines the NHS. Only the influential have the power to ensure that waiting lists are kept down and that the NHS is held to account. Everyone must have a vested interest in the NHS to make it work for everyone. By supporting private medicine, the BMA abdicates any legitimacy and credibility when advocating for the NHS.

Private medicine also offers unnecessary treatment, overinvestigates, and lacks the regulatory oversight of the NHS. Examples are many, from medicals offering unscientific screening,<sup>3</sup> dubious radiography,<sup>3</sup> and the raft of plastic surgery that preys on the financially<sup>4</sup> and

emotionally insecure.<sup>5</sup> Doctors who work in both sectors have a potential conflict of interest (perceived or otherwise) in maintaining waiting lists. Yet many on the political right (and at the *Guardian*, it seems) are blind to these consequences. How can the BMA endorse private practice?

The BMA is no standard employer: it has a duty to uphold the interests and values of its members. I suspect that most of its membership disapprove of queue jumping and believe in the principle of equality of care irrespective of the ability to pay. This BMA policy implies that the NHS and its doctors are second rate. I object to a single penny of my subscription being spent on private medicine. Perhaps I am over-reacting, just typical phony champagne socialist indignation. But what do other doctors think? Do the actions of the BMA elite shame us, its rank and file membership?

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DRUG TALES AND OTHER STORIES **Robin Ferner**

# A bee in the bonnet

The editor's advice to authors can be forthright: "We can assure [him] that we are doing him infinite service by recommending him to restrain his too fluent pen. He is only compromising his position and losing his friends by rushing into fiery print on every possible occasion."<sup>1</sup>

The object of this reproach was not me (or Des Spence), but the redoubtable Birmingham surgeon Joseph Sampson Gamgee.<sup>2</sup> His tirades were sometimes well directed, as when he condemned the army's punishment for desertion: branding the letter D on the soldier's left breast.<sup>3</sup> He was well known for his invective, but also his inventions, including a lightweight splint, the sanitary towel, and a tissue dressing of cotton wool sandwiched between gauze pads. "Gamgee tissue" was widely used for a century but is now being eclipsed by designer dressings using seaweed, silver, and sundry other

slimy substances. The new dressings are expensive, so financial viability is sacrificed on the altar of so called tissue viability. This is true even though systematic reviews have repeatedly found the evidence for better healing of ulcers and wounds with new dressings to be at best unconvincing.<sup>4-13</sup>

Now honey is flavour of the month. In some parts of the world the preferred version is taken not as a teatime treat on toast, but as "mad honey" from bees that have gorged themselves on rhododendrons especially rich in grayanotoxin. Mad honey is an industry in the Turkish province of Trabzon, where men take it (by mouth) to enhance their lust lives. This leads to occasional outbreaks of "mad honey disease," a syndrome of nausea, vomiting, vertigo, hypotension, dysrhythmia, and syncope that may knock the sugar coating off this Turkish delight.<sup>14</sup>



**Despite the efforts of the honey research unit at the University of Waikato in New Zealand, there are few suggestions that honey heals wounds**

The idea that honey, like asses' milk, is good for the skin goes back to antiquity, so there is hardly any need to demonstrate efficacy. This is probably just as well. Despite the efforts of the honey research unit at the University of Waikato in New Zealand ("set up in 1995, with financial support from the New Zealand Honey Industry Trust"),<sup>15</sup> there are few suggestions that honey heals wounds. A Cochrane review found the evidence at best uncertain<sup>9</sup>; honey may even delay the healing of burns. And I foresee a risk of wasp stings. Until someone can show convincingly that wounds heal better with designer dressings or superior snake oil, we might as well stick to non-adherent gauze.

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