

Blacks and Asians are reluctant to donate tissue

Orin Lewis argues for clearer messages

'I don't trust them.' 'What are they going to do with my DNA?' 'I can't be bothered.'
'I don't know anything about that.' 'I couldn't make a difference.' 'I haven't got time.'

How many times have you heard statements like these being used to avoid helping ourselves in moments of crisis involving health issues?

Black communities, particularly in London, know that Imogin Appiah, a 7 year-old Croydon schoolgirl of Ghanaian heritage, had a very untimely death from leukaemia in January 2010. A few responded to bone marrow donor appeals, but many others still fail to realise they can make a difference.

Apathy is costing lives, and will continue to result in loss of life across all ages and backgrounds, such as Dean Sheikh (aged 7, Pakistani heritage) and Kevin Phelps (aged 39, African Caribbean heritage).

Why are we fooling ourselves?

Against the odds

Thirty percent of leukaemia patients receive a transplant from a family member. The remaining 70 per cent have a diminished chance of finding an unrelated donor somewhere in the world. However, these odds are much worse if you're black – there are 24 times more white donors.

Alas, the challenge is the same for organ donation. There are more than 16.9 million people on the NHS Organ Donor Register, but only 1.5 per cent of these are from the Asian community and a woeful 0.4 per cent of those come from black communities.^{1,2} Yet the need is greatest within black and minority ethnic (BME) communities.

Awareness is rising, but few have informed discussion about these issues outside the family or trusted community networks. Misinformation and lack of knowledge persist despite the availability of public health education messages.

Is it just about individuals taking ownership or do everyday experiences elsewhere inform decision making? Is better communication about science in society a key factor?

Reasons for reluctance

Some hold strong yet misplaced fears that the DNA database used to record bone marrow tissue-types is somehow connected to the Police National DNA Database, which retains the details of a disproportionate number of innocent black people. This situation deters people from registering as bone marrow/blood donors.

Some believe that organs will be removed without doctors really attempting to save their lives. Others fear how their body will look afterwards.

Some believe donation is against their religion, although church leaders highlight that these concerns are unfounded.

Some dislike the idea of blood storage and question whether it will be used for unsavoury genetic research.

Some are unwilling to take time out to listen and make an informed choice. Yet all understand the need for racially matched donors to enhance the success of transplantation when this is clearly explained.

Cultural sensitivity

'There are too many myths, fears and taboos and people don't trust the system,' says the African Caribbean Leukaemia Trust's (ACLT) Co-founder, Beverley De-Gale. 'We need clear messages that the bone marrow registries and the National DNA Database are completely separate registers. The wider scientific community has a role to play in promoting better understanding, particularly around DNA usage and religion in order to build trust and increase donation.'

The ACLT has raised the numbers of BME bone marrow donors from 585 to 30,000 through culturally sensitive and personalised communications.

When you ask yourself why is there so much reluctance to come forward, please think how you can help to provide tailored messages. Also... have you set an example and registered as a bone marrow, blood and organ donor?

Do we really understand the impact this is having within BME communities? There is a unique health inequality that is linked to seemingly unrelated experiences. If we all fail to respond to this challenge with positive and meaningful action right now, many more people will die unnecessarily.

1 Synovate Research (July 2009) 1540 interviews carried out in the UK for NHS Blood and Transplant

2 NHS Blood and Transplant Campaign targeted to Black Community, website www.organdonation.nhs.uk/ukt/campaigns/other_campaigns/black/research.jsp



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Communicating uncertainty

Work with the audience, urges **Philip Campbell**

Scientific uncertainty is very hard to communicate in public debates.

Some such debates turn into issues of public trust in science, as happened over the MMR vaccine and is now happening with climate change. Others depend crucially on public trust but arise from an immediate threat, such as the continuing volcanic eruption on the Caribbean island of Montserrat. All of these offer opportunities to study not only the messages from scientists, but also the impacts of those messages.

The importance of perseverance

The continuing eruption of the Soufrière Hills volcano on Montserrat provides a microcosm of issues that arise in the much larger contexts already mentioned. Geoscientists have been studying the eruption since before it began in 1995. They have used a variety of techniques to explore the uncertain regional hazards, leading to sometimes contentious decisions to evacuate regions. There has also been extensive social science undertaken with the island's inhabitants to explore the bases of trust in, and the reception of, the messages from scientists about the volcano's likely behaviour.

We know from past public surveys that the public places high trust in scientists, 'Climategate' notwithstanding. The Montserrat case was no exception, but also shows that how this trust plays out in practice really does matter. There was pressure on the scientists to get involved in the management of the crisis. That involvement can be time-consuming and threaten their independence and objectivity – two key components of the trust enjoyed by scientists above most other groups involved. It is nevertheless an accepted part of the professional code of conduct of volcanologists in such crises, and was valued by others involved.

The social science studies also showed how scientists need to sustain their public communication and engagement. On Montserrat, researchers reportedly believed they had done the job of educating the islanders and then retreated into their primary responsibilities. This had the inevitable effect of diminished

confidence and feedback between scientists and their stakeholders. This seems to me to be relevant to other crises, not least the one currently surrounding scientists in climate change: it is more important than ever that they not tire – let alone despair – of engaging with the media and other means of communicating, even if they perceive waves of scepticism and hostility. But, as was concluded on Montserrat, scientists are likely to need support in such engagement.

Missing the mark

Another message emerges from social science studies of communication in the MMR vaccine and also in the use of carefully calibrated language about probability in IPCC reports. Such research shows how significantly such communications can miss the mark.

For example, psychological studies of cognitive maps of parents of American children who have been MMR-vaccinated show – unsurprisingly – strong considerations of personal values and perceptions of risk. But cognitive analyses of the messages about safety sent out by the Center for Disease Control show how the latter failed to engage with those sensitivities – and also how internet websites of anti-vaccine activists succeed.

Similarly, examinations of how well-educated citizens interpret probabilistic judgements in IPCC reports show how the stated likelihoods are variously under – or over – estimated in the perception of the readers, even amongst those who have understood the numerical table of equivalents of the phrases such as 'likely'.

If there is one practical bottom line that I draw from all of this, it is that any government agency or science institution wishing to convey an important statement about scientific uncertainty, intended as guidance to the public, needs to work with samples of the intended audience in crafting it. Where substantial public interests are at stake, the communication of scientific uncertainty needs to be a much more deliberative process than is generally appreciated.

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This article is based on a talk by the author at the Royal Society.



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