

## MEDICINE

# Giving people what they want

Want to know which treatments work best? Try asking patients  
*Sophie Petit-Zeman*

If you wanted to study the effectiveness of epidural pain relief during labour, asking mothers how well it worked might seem logical. Yet the last major review of nine studies in this area found that only two of them asked patients about the experience.

Traditionally, research has relied on applying professional expertise to complex problems, and thus contributing to the holy grail of evidence-based medicine. But now the value of "patient and public involvement" (PPI) is becoming clear. Research into osteoarthritis of the knee, for example, was for decades dominated by trials of non-steroidal anti-inflammatories (aspirin-like drugs). This changed only when patients and those treating them were asked what they wanted, which was studies of surgery, physiotherapy and coping strategies. Such measures can dramatically improve lives, says John Kirwan, professor of rheumatic diseases at Bristol University.

Yet this shift is leaving some in medicine's ivory towers feeling threatened. Patients can only provide anecdote, they argue. And do patients really want to be involved anyway? Just as we hope schools know how to teach, or garages know how to fix a rattling exhaust, isn't it better to let medical researchers get on with their jobs?

Some £3bn of public money goes into medical research each year, with roughly £1bn coming from charities and the rest from the government—and much of this charity support comes from donors driven by personal experience. Could more be done to ensure their money is spent effectively? Emma Halls, chief executive of the Prostate Cancer Research Foundation, thinks so. "British prostate cancer charities spend about £1m on research annually, the US about \$150m, yet where are the breakthroughs? It begs asking whether we're researching the right things."

Seeking answers, Halls is developing a unique approach to marrying patient experience with medical expertise, in partnership with the James Lind Alliance (JLA). Named after the 18th-century Scottish naval surgeon who carried out one of the earliest controlled trials—to find

whether citrus fruit cures scurvy—the JLA unites patients/carers and clinicians to identify unanswered questions about how illnesses should be treated. This project is one of several under way; both of those already completed, in asthma and urinary incontinence, have identified significant research gaps.

The JLA is also investigating whether the drugs industry can better meld profit motives with patient benefit. One route being explored is whether the industry and the National Institute for Health and Clinical Excellence (Nice) can use "patient important outcome measures"—asking them what matters most when they receive treatment—in decisions about drug development and availability. Getting patients to set the bar in this way is a subtle but significant change.

Ann McPherson, a former GP and the medical director of the website Healthtalkonline, argues that "patient experience is so important to research and care, it must be alongside anatomy in the medical textbooks." Many in the health sector now agree. The NHS has its own PPI programme, Involve, and the new government signalled its support for this direction in its first Queen's Speech. Health secretary Andrew Lansley has said that the NHS "must make sure that patient outcomes and clinical evidence are at the heart of any changes to health services."

According to Simon Denegri, chief executive of the Association of Medical Research Charities (AMRC): "The new coalition government mantra around the notion of a 'big society' is an open invitation to those championing patient and public involvement." He warns, however, that we must be pragmatists. An NHS report on public involvement in research, released last November, highlighted a number of benefits (such as increasing recruitment to all types of research), but also revealed huge variation in how patient impact is assessed, and highlighted difficulties in judging it or drawing conclusions. If PPI is to become as integral to medicine as anatomy, how we gather and assess evidence that it "works" must be improved.

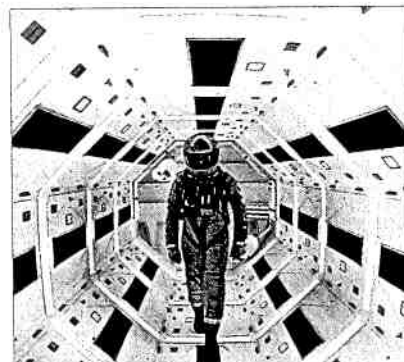
In the end, though, it's a matter of common sense: it is pointless to involve patients in research without checking it improves their lot. But if I needed an epidural, I'd want to know that other women had found it useful—not just that some chap with a test tube had proved that they would.

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## THE MONTH AHEAD

*Anjana Ahuja on new media activists, drugs and gene songs*

• **CP Snow**, who famously highlighted the two cultures of the sciences and humanities, would have relished the cultural blizzard hitting London's Southbank Centre from 25th June to 4th July, in celebration of the **Royal Society's 350th anniversary**. Marvel at *2001: A Space Odyssey* with live orchestral score, and muse on such puzzlers as "Who needs men anyway?" More at [www.seefurtherfestival.org](http://www.seefurtherfestival.org)



See *2001: A Space Odyssey* with a live orchestra at the Southbank

• **Twitter and Facebook** are better for the soul than telly because they make us all activists, argues **Clay Shirky**. Turn off *EastEnders* and hear the new media sage launch his book, *Cognitive Surplus*, at the LSE on 28th June ([www2.lse.ac.uk/publicEvents](http://www2.lse.ac.uk/publicEvents)). You can also read his recent web exclusive for *Prospect*: [www.prospectmagazine.co.uk/2009/12/the-net-advantage](http://www.prospectmagazine.co.uk/2009/12/the-net-advantage)

• **Expect the fuss over mephedrone** (the "legal high" also known as meow meow) to resurface in July, when European drug regulators issue a report on the synthetic stimulant. The government banned it in April, sparking another walkout from its drugs committee—and a suspected link to two teenage deaths has since been disproved.

• On 13th July, the **Royal Society of Medicine** is premiering *Allele*, with singers performing parts based on their own genetic code, accompanied by poetry from Ruth Padel, and a discussion of whether musical and tone-deaf people differ genetically. Tickets cost £12. Tune in at [www.rsm.ac.uk](http://www.rsm.ac.uk)

*Anjana Ahuja writes for the Times*