

## VIEWS &amp; REVIEWS

## STARTING OUT

## Whose data are they anyway?

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I accept my body is mine to do with as I please—heaven knows, no one else would want it. And no, this is not a moment of existential angst. But the question that strikes me is how much should the information about me be mine?

I've taken some time off the clinical treadmill, which is driving me relentlessly forward to a consultant job, where the managers won't think I need any more of that pesky training that interferes so with service delivery. I'm doing a research degree for the next couple of years, which in part involves looking at data about thousands of people at a national level.

Many would say that sounds boring, and to the extent that it involves poring over a computer screen for hours a day, I suppose most would agree. But that is the real joy of medicine: the diversity in what we can do with our careers.

The struggle however is not where you might think. It's not in the thinking, the analysis, the writing, or even the rather irritatingly pervasive statistics. It's in the journey to get the data.

Now I fully accept that the details about that embarrassing mole shouldn't really be made publicly available. Unfortunately the

pendulum has swung too far the other way. Are we really that concerned about a colonoscopy of someone in the L37 postcode area showing an 8 mm adenoma being made public?

We shouldn't be. In fact, we should be making a concerted push for open access. Because the consequence of the bureaucracy that now engulfs anything to do with even completely anonymised patient data is a real turn-off. And that means research doesn't get done, which in turn means patients don't derive a benefit.

The best example of this is probably Apple. There were other portable music players around when the iPod was launched, and smartphones were sold for years before the iPhone. Yet what they did was make activities that were previously difficult easy. The interesting thing is that the results have been intentionally unpredictable: I can now control my central heating from my phone anywhere in the world.

What this relies on of course is the ability to let go of control to some extent. At the moment, as it has always been throughout history from the Bible to Google, those with jurisdiction over information have both the power and prestige associated with it. When combined with the accusatory headlines in the papers every time a laptop containing identifiable data is lost, the inclination to keep control is just too seductive.

As we are slowly dragged into an era where we for the first time have decent electronic data, it is imperative that this inclination is resisted: for while the results of open access publishing may be unpredictable, they will inevitably be beneficial.

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