



Nothing about me without me ...?

'Lock the doors' said the practice manager. She was only half-joking. We had tried very hard to advertise our patient participation group for a number of months using all the recommended methods. However I don't think any of us expected 30 people to turn up on a wet Autumn evening. We were in danger of running out of chairs and biscuits.

I've been a big fan of patient participation groups long before they became the right thing to do, but will own that they tend to be too full of people like me (white, middle-aged, middle-class women). So for me, the really exciting part of watching people take their seats was that only 50% were the 'usual suspects', with previous patient participation group form. Our new recruits included teenagers and someone who proudly prefaced every question with 'As someone's who's nearly 82 ...'.

We started with group rules and went through the usual process of asking for views, comments, and issues and then I asked, frankly as a bit of an afterthought, if they'd heard about all the changes that were going on in the NHS at the moment. There were a few murmurs around the room that they'd seen things on the television. Ok, I said, so how many of you understand what's happening to the NHS in these new reforms? About a quarter of the people raised their hands. How many of you would like to know more about the NHS reforms? I asked. We had a full house.

So our November patient participation group was dedicated to explaining what the practice understood about the possible impacts of the reforms. We discussed the changing role of the Secretary of State, the potential for increased commercialisation in hospitals, the advent of clinical commissioning groups, the possibility of commissioning in a more patient-centred way, the concept of any qualified provider. The questions came thick and fast — are we moving towards a US system of health care? Will private providers cherry pick the young and fit? What will happen to people who need a lot of care? The ghost of Aneurin Bevan hovered above the meeting. 'So Mr Lansley's proposals mean the bedpans won't be heard in Whitehall anymore', one older lady said, grasping the implications more quickly than

many health professionals. As the evening wore on, the mood of the group turned from polite interest to concern and even quiet anger. Why hadn't someone explained the changes sooner and in a way they would understand? Who could they write to now? Who should they lobby? We explained that the Bill was now in the House of Lords and was unlikely to change in any truly significant way. 'Best to worry ourselves to death now then, while we still have an NHS', said the group wag.

These were the views of a small group of patients in one city on one winter's evening. But they resonate with the finding of The Patients Association survey in Spring 2011, which had over 1000 responses. They also reported that many patients don't understand the health reforms. The concept of any qualified provider was also unwelcome and there was a sense that changes were happening too fast.¹

The government will reiterate that there's an 18-page leaflet on their website (although its factual accuracy has been challenged) and that 6700 people attended the Future Forum Listening Events last year.² Campaigning groups like 38 Degrees have posted information and (at the time of writing) have nearly half a million signatures on their Save the NHS petition. However I've struggled to find a non-partisan patient information leaflet that clearly explains what's going on and the implications of the reforms for Everyman.

'Nothing about me without me' is the phrase on every politician's lips. But when asking patients for their views on the new NHS, it would help to make sure that they first understand the question.

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REFERENCES

1. The Patients Association. *PAUSE: Patients Association urges serious examination*. May 2010. <http://www.patients-association.com/Portals/0/Public/Files/Research%20Publications/NHS%20Listening%20Exercise%20Report%20-%20FINAL.pdf> [accessed 1 Dec 2011].
2. HM Government. *Working together for a stronger NHS*. 2011. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_125855.pdf [accessed 1 Dec 2011].