

## Do Patients Matter?



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I am writing this blog on a train to Manchester, conscious that I have already missed the Editor's deadline by a few days. I am not sure why, but my chosen title has been more challenging than I expected.

At first I wondered about using my Dad's experience of being a stroke patient as my starting point for a diatribe on 'Do Patients Matter?' It would certainly make good reading.

Like the time he woke up in his hospital room feeling really cold. It was always chilly in there. At night it was especially so. This particular night, immobilised by his condition and therefore unable to get out of bed, he asked for an extra blanket. Later, much later, a member of the night staff returned and dismissively threw a blanket, folded, at the foot of his bed where he could not reach it. They then left the room.

And that's not the half of it.

But to prove what? That in this day and age it would seem patients matter some of the time but no patient can expect to matter all of the time? Fact is it all just seems a bit too easy to write and more than a little lazy on my part. We all know the challenges our health and social care system face - it certainly does not need another shot across the bows cathartic though this might be for me.

More critical and urgent are the solutions. Just as important is how we choose to arrive at these.

So, if it's one message that I would like you to take away from this blog it is that patients *and carers* don't just 'matter' in the sense of passive recipients of treatment. It is that they are essential partners in building a modern health system. Strengthening and improving healthcare services and the way we deliver care to people must be paved with their experiences and insights. Those leading and managing health organisations must be willing to build the path this way and brave enough to go one step further so that patients and carers are included in deciding what course to follow.

In my view this path should begin with health research and the evidence it produces. The link between research and quality in health service delivery is well-established. In [England 100% of National Health Service \(NHS\) Trusts and 42% of general practice \(GP\) surgeries are research active](#). Millions of patients, carers and healthy volunteers have taken part in research over the last decade. The majority of the British public see [research as an important part of what the NHS does](#). They know that high-quality research is a marker of a modern health system, which aspires to continuous improvement and aims to be the best.

My reason for optimism is that health research in the UK is increasingly informed by patient and carer insights: its outputs, whether new treatments or better service design, more relevant to their needs and their priorities. Researchers and institutions funded by the National Institute for Health Research (NIHR) are expected to demonstrate how they have actively involved patients and carers in their work from refining research questions to designing and delivering research up to and including disseminating its results.

One such example is the NIHR's Primary Care Patient Safety Translational Research Centre in Salford and Manchester. One of three such

Centres in the UK recently [awarded a further £17 million in funding](#) over the next five years (3). It is the facility where I am headed today. From day on, patients and carers from across the local area have been partners in developing and implementing its research strategy through a Research Users Group (RUG) but also in every one of its projects which span from informatics to multi-morbidity.

Last week the Centre announced the conclusion of its [James Lind Alliance Patient Safety in Primary Care Priority Setting Partnership](#). This brought patients and carers together with health professionals to define the top ten unanswered questions around patient safety in primary care. The top question being: How can patient safety be assured for the most vulnerable in society (e.g people who are frail, have mental health problems or cognitive impairments)? The other nine priorities and the background to this work that started in January 2016 can be found [here](#).

Which sort of brings me back to the beginning of this blog and my Dad at his most vulnerable. I am pleased to say he is at home now and doing better each day. He is busy most days in study and I know he has spent a lot of time writing up his experiences as a patient. So that others will benefit from them - other patients, carers, health professionals and researchers.

'Do Patients Matter?' I know what he would say....

Yes, right from the start.

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