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Health system performance management: a UK perspective

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'Experience of Care as a Critical Component of Health System Performance Measurement': a commentary

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In the English NHS, an eminent clinician and then Health Minister, Lord Darzi, identified three features of health care quality: patient safety, patient experience, and the effectiveness of care (Department of Health, 2008, p.47). Of these, it is arguably the issue of patient experience that had received less detailed and systematic attention than the other two themes, as Lord Darzi was quick to highlight (pp.47-48):

> *"Reforms have improved quality in terms of patient safety and effectiveness of care. For instance, the introduction of standards through National Service Frameworks has led to major progress on tackling illnesses such as cancer and heart disease. Conversations about quality take place in multi-disciplinary teams rather than in corridors. Independent performance assessment and regulation of providers has been introduced. The positive impact of these reforms has been noted by independent commentators... Nevertheless, it is also true that progress has been patchy, particularly on patient experience."*

To improve quality yet further, Lord Darzi identified seven steps (see Box 1). When listed in this format, such prescriptions look deceptively simple – and yet are extremely difficult to achieve in practice in a challenging policy and financial context, a fragmented system, pressured local services and a series of constantly evolving possibilities, challenges and opportunities. Of these seven steps, the lead essay by Kerry Kuluski and colleagues focuses in particular on the measurement of patient experience, seeking to challenge and broaden traditional approaches. Drawing on a mix of perspectives from research, practice and lived experience, they reflect on a series of 'W' questions: **what** elements of experience should be considered; **whose** experience should be captured and **why**; **where** and **when** experiences should be captured; and (moving away from 'Ws'): **how** to move this agenda forward in practice. In the process, they set out four key propositions:

1) *"Measuring experiences outside the healthcare system can provide insight on what needs to change within the healthcare system.*
2) *Focusing on patient experience is necessary but insufficient; (family) caregiver insights and experiences require attention and can provide insight into the needs of the patient.*
3) *Moving from "one time/single sector" measurement of experience to iterative, ongoing measurement across sectors better reflects the true lived experience of patients (especially those with complex care needs) and their caregivers.*
4) *Embedding measurement within engagement capable environments that adequately resource patients, caregivers, and providers to work together is required to move from collection to meaningful change."*

Writing from the UK, and as former social worker specialising in joint work between health and social care, it is difficult to argue with any of Kuluski et al's propositions. If we are to take patient experience as seriously as patient safety or clinical effectiveness, then we need to focus on understanding and responding to things that matter to patients, and this involves understanding the outcomes that are important to them and the extent to which health services help them lead chosen lifestyles. I was reminded here of debates in UK mental health services about notions of 'recovery.' In one case, a person hearing voices was diagnosed medication. While this intervention was defined as a success clinically (the person's symptoms were relieved), the side effects of the medication made the person impotent and their relationship with their partner broke down. This led to a downward spiral in which the person lost their job and ultimately their home. In this scenario, 'stopping the voices' was a professionally-defined outcome, but nobody looking at this situation from the person's perspective could possibly define it as a good experience or a successful outcome.

Having worked mainly with older people and people with dementia, I also appreciate the importance of including the perspectives of carers. Sometimes this was because the carer remembers something or witnessed something that the older person has forgotten. On other occasions, it was because the older person did not want to be a 'burden' (as they saw it) on public services and was presenting a positive view of their situation, whereas a carer could intervene and provide an alternative perspective (for example, what a 'bad day' was like, as well as just a 'good day'). Of course, this frequently led to situation where the 'user' and the 'carer' had different views on what was best, and it fell to the worker to mediate and try to balance potentially competing perspectives

– something which the approach proposed by Kuluski and colleagues might helpfully illuminate, but which might well lack easy answers. On one occasion, I recall an older man with dementia adamant that a good outcome for him would be remaining living at home with his three daughters caring for him. Equally, I remember his daughters each in tears as they explained that they couldn't manage any longer, that their own health and families were being affected, that they were permanently exhausted and that their father would have to go into a care home. Understanding both experiences here is crucial – but understanding these differing views did not make them easy to reconcile.

Specialising in joint work between health and social care, so many problems arise from the fact that individual professions, services and agencies have their own targets, incentives, regulatory frameworks and inspection regimes. While these are all designed to boost quality, the risk of such silo-based approaches is that one service can provide good care on its own terms, yet the overall experience of the system as a whole can be dreadful. Understanding people's experiences across boundaries and over time is therefore crucial if a more accurate picture is to emerge of what care is really like. In the UK, there are ongoing attempts to promote a new definition of 'integrated care', generated on behalf of the government by and the NHS by National Voices, a grouping of some 130 health and social care charities. Rather than using official jargon ('integrated care' being a good example), this focuses on the extent to which people experience *"person-centred coordinated care"* (patients' preferred terms) defined by them as care which meets the following criteria:

> *"I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me"* (National Voices, 2013, p.3).

Long overdue though such a statement is, operationalising such a definition in practice – and embedding it in a system still designed with single agency incentives and targets in mind – remains challenging.

Finally, Kuluski and colleagues highlight the need to create "engagement capable environments" in order that measures of patient experience might lead to meaningful change. In my experience, this is the hardest challenge of all, and goes to the very heart of measurement debates. In one sense, there is no point measuring patient experience (let alone trying to find ways to measure it in better ways) if we are not really interested in hearing the results – or if the system within which we operate stops us from acting on what we find. In a worst case scenario, approaches which measure experience and then do not act on what they find, might be seen as a form of cynical placation – making people feel as if their opinion and experience is being sought, but with no real likelihood of positive change. I suspect that many user-led and patient organisations would argue that this has long been the case, and one of the reasons why they may be reluctant to get involved in new attempts to measure patient experience, is that they feel they have learned the hard way not to trust policy makers or services to act on what is revealed. This means that anyone seeking genuine reform needs not only to overcome some of the practical and technical challenges identified in the lead article, but also to win back the trust of key stakeholders that things could one day be different.

In one sense, this last reflection made me wonder whether we sometimes approach these issues the wrong way round. If we start with current services and seek to improve them by devising ever-better forms of measurement and, hopefully, acting on the findings, we may only ever get so far. Alternatively, we could conclude that people using services and their families are experts by experience and start with what a good service, a good experience and a good outcome might look like to them. If people using services had greater choice and control over their services (and hence over their lives) then we might not need to measure their experience at all – more the extent to

which these choices met needs and delivered outcomes. These ideas sit at the heart of the UK's 'personalisation agenda', with people receiving adult social care (and now some forms of health care too) able to receive 'direct payments' or 'personal budgets' so that they can design their own care with support from whoever makes sense for them (whether this is a social worker, a service provider, an advocate, a broker or a friend or family member). When this works well, it is meant to ensure that decisions which matter to people are taken as close to the person they affect as possible, ideally by the person themselves. When this isn't possible for some reason, then decisions are taken by someone who knows the person really well and really cares about them. These ways of working are summarised in greater detail by Glasby and Littlechild (2016; see also Needham and Glasby, 2014), but have also encountered a series of cultural and practical challenges as they seek to reform traditional services. Perhaps if we had greater choice and control over our own care – and we had better ways of measuring patient experience – then we really would see radical change?

References

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