Involving a greater diversity of people in healthcare processes

By Josephine Ocloo | 22 February 2018

Why is patient safety and quality improvement excluding so many groups with the poorest health outcomes, asks Josephine Ocloo

Current evidence across clinical commissioning groups and NHS England shows that the dominant demographic in terms of patient and public involvement in the work of the NHS tends to be white, middle class, educated and older people. Why do patient safety and quality
improvement processes frequently exclude so many groups who also often have the poorest health outcomes?

On 25 January 2018, an event called *From tokenism to empowerment: improving quality and safety for patients and public through diversity in participation*, attracted a range of national and international speakers and patients and the public to explore this question.

Organised by NHS England, and supported by King’s College London, The Health Foundation and the The National Institute for Health Research Collaboration for Applied Health Research and Care South London, it was the first event of its kind in the field of patient safety and quality.

Caroline Dinenage, the new minister of state at the Department of Health and Social Care, opened the event and echoed conclusions from my published paper about the importance of finding ways to genuinely involve and support a greater diversity of individuals in healthcare processes, allowing them to work in partnership to genuinely influence decision making.

### Inequalities in health treatment

In my keynote address, I outlined longstanding evidence about a range of groups that routinely face discrimination in their care, making them more at risk of harm. These groups are also least likely to be involved in improvement processes. For example, we know that those with learning disabilities face institutional discrimination that results in premature deaths and poorer quality healthcare for these individuals.

Equally, in 2015-16, 15.3 per cent of people from black or black British minority groups in contact with mental health/learning disability services spent at least one night in hospital. This was higher than any other ethnic minority group and more than double the rate for white adults (5.6 per cent).

In 2014-15, 40.1 per cent of people who stayed in a mental health hospital were detained under the Mental Health Act. Of these, 56.9 per cent were black or black British, 50.4 per cent Asian or Asian British and 37.5 per cent from white ethnic groups.

In 2014, white British people were most likely to report receiving psychological therapy (13.3 per cent), while black adults had the lowest treatment rate (6.2 per cent) and were least likely to finish it when referred.

While race based social and economic disadvantage has been identified as being at the root
of ethnic differences, racial injustices in forensic psychiatry come in for particular criticism for the way that black people have faced "complex, coercive and adverse pathways, into, through and out of mental healthcare... with poorer access to effective interventions and poorer outcomes”.

Unequal access to cancer services

Another highlighted area of inequality related to data showing cancer and diagnosis analysed by ethnicity in the period 2006-13. This showed that when it comes to the two week wait pathway – in which a GP suspects cancer and makes an “urgent referral” so that the patient is seen by a specialist within two weeks – white people were more likely to see their GP one or two times and then be referred.

In contrast, mixed, Asian, black, Chinese and other groups were found to have more consultations with their GP prior to referral to cancer services. The difference in experience was greatest in black and Asian groups. Ultimately, the white population was most likely to be referred to cancer services through the two week wait pathway than other minority ethnic populations.

These examples were particularly strong in highlighting inadequate or adverse care that could lead to adverse outcomes. Broader areas of health inequalities were also highlighted as needing further investigation to understand the higher risks that particular groups face and how these could be addressed.

For example, rates of maternal mortality vary by age, socioeconomic status and the ethnic background of women, all of which are known to be independently associated with an increased risk of maternal death. The risk of maternal death is significantly higher among women from black minority ethnic backgrounds compared with white women.

Higher rates of myocardial infarctions, diabetes and stroke are also particularly prevalent among UK South Asian, black African and African Caribbean groups compared to the white UK population.
These issues highlight the safety implications of not addressing inequalities and discrimination in healthcare processes. Yet, discussion about the higher risk of being harmed faced by some groups has been absent to date in the field of patient safety. This omission has considerable implications for the individuals affected, and impacts on the wider system in terms of the costs of not addressing these problems.

Everyone should have the same right to be safe and to be involved in their care. In developing systems of quality, safety of care and patient experience in the future, there is a need for a much wider distributed leadership to establish practical approaches based on addressing diverse needs, which encourages and supports truly inclusive participation for all, including healthcare staff, in finding solutions to these problems.