

## **Addressing health inequalities in epilepsy**

The National Institute for Health and Care Excellence (NICE) was originally created to reduce the so-called postcode lottery in healthcare, but there have been regional inequalities in the implementation of NICE guidelines, especially regarding access to specialist care for epilepsy.<sup>1</sup> A national audit, carried out annually by the Healthcare Quality Improvement Partnership, showed that in 2020 fewer than one in five children and young people with epilepsy could access certain specialised diagnostic and treatment procedures locally.<sup>2</sup> Accessing such services farther from their homes might not be feasible for those from deprived backgrounds owing to financial or logistical barriers, thus exacerbating unwarranted inequalities.

A similar audit on epilepsy services for adults could provide much-needed evidence to inform guidelines and commissioning. However, national audits require hefty investment of resources and engagement of multiple stakeholders is needed to assess important drivers of inequalities beyond regional considerations, such as age, disability, ethnicity, and sex and gender. Moreover, national audits are, by themselves, insufficient to provide the evidence needed for NICE guidelines, which rely primarily on evidence from randomised clinical trials. Populations known to experience inequalities are under-represented in such trials, particularly when drivers of inequalities (e.g., older age, disability, sex) are used as exclusion criteria, even in the absence of a sound rationale to do so.<sup>3-</sup>

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The original NICE guidelines on diagnosis and management of epilepsy (NG137) were published in 2004, and the most recent update is expected later this year. However, the lack of high-quality evidence precludes NICE from making specific recommendations for patient subgroups who might experience inequalities in diagnosis and management based on age, sex and gender, socioeconomic status, ethnicity, and disability. Although some evidence from observational or small non-randomised studies is available, lowering the standards on which recommendations are made for those subgroups would put their safety at risk and potentially exacerbate inequalities by incentivising non-evidence-based care in already disadvantaged or underserved subgroups. NICE has formally acknowledged its commitment to address health inequalities in its 5-year strategy, but lack of high-quality data has been a significant hindrance. First, data are not disaggregated by factors associated with inequalities. Second, data are not available either in the public domain or in accessible repositories. Deanonimised and aggregate data should, thus, be shared between agencies within the Department for Health and Social Care for the benefit of population health. If high-quality data are not collected and made available to NICE, its commitment to address inequalities will be in jeopardy.

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