

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE indicator validity assessment

Indicator IND227

The percentage of adults receiving drug treatment for epilepsy who had a structured review in the preceding 12 months

Importance

Considerations	Assessment
<p>The NHS RightCare Epilepsy Toolkit (2020) suggests that there is a lack of optimal management of epilepsy leading to unnecessary emergency care. It indicates that regular reviews are important to allow monitoring and adjustment strategies and improve safety and medicines adherence. Reviews are also important to support personalised care and self-management to encourage shared decision making.</p> <p>The report highlights that it is vital to identify patients that have a higher risk of premature mortality, which may also be related to other comorbidities, in order to provide the support they need. All people living with epilepsy should have risk communication, management and review as epilepsy risk factors can change to become fatal in as short a time as three months.</p> <p>The NHS Outcomes Framework includes indicators on the proportion of people with long-term conditions who feel supported to manage their condition and unplanned hospitalisation for chronic ambulatory care sensitive conditions.</p> <p>The Medicines and Healthcare Products Regulatory Agency's Public Assessment Report of antiepileptic drugs: review of safety of use during pregnancy indicates that antiseizure medications taken during pregnancy are associated with an increased risk of major congenital malformations (MCMs). Valproate must not be used in pregnancy, and it must not be used in girls and women of childbearing potential (including young girls who are likely to need treatment into their childbearing years) unless other options are unsuitable and a pregnancy prevention programme in place, in line with the MHRA safety advice on valproate.</p>	<p>The indicator reflects a specific priority area identified by NHS England.</p> <p>The indicator will lead to a meaningful improvement in patient outcomes.</p>
<p>A study of the standard of clinical care for people with epilepsy in general practice found that annual review fell significantly from 95% in 2010 to 14% in 2016, following removal of annual review from the QOF in 2014.</p>	<p>The indicator relates to an area where there is known variation in practice.</p>

Evidence base

Considerations	Assessment
<p>Epilepsies in children, young people and adults. NICE guideline NG217 (2022)</p> <p>4.5.1 Arrange regular (at least annual) monitoring reviews for adults with epilepsy and any of the following:</p> <ul style="list-style-type: none"> • a learning disability • drug-resistant epilepsy • a high risk of sudden unexpected death in epilepsy (SUDEP; see the section on reducing the risk of epilepsy-related death) • a serious comorbidity, such as complex psychosocial, cognitive or mental health problems • who are taking antiseizure medications associated with long-term side effects or drug interactions • who are able to get pregnant and are taking valproate or any other high-risk teratogenic antiseizure medication (see also the MHRA safety advice on antiepileptic drugs in pregnancy). 	<p>The indicator denominator includes people for whom annual review may not be necessary based on the recommendations in the updated NICE epilepsy guideline. However, feedback from consultation and piloting generally suggested that focusing on all people receiving anti-seizure medication is an acceptable pragmatic approach to identify a population.</p>

Specification

Considerations	Assessment
<p>Numerator: The number in the denominator who had a structured review in the preceding 12 months.</p> <p>Denominator: The number of adults receiving drug therapy for epilepsy.</p> <p>Exclusions: None.</p>	<p>The indicator has defined components necessary to construct the indicator.</p>
<p>The indicator would be appropriate to assess performance at individual general practice level. To be classified as suitable for use in QOF, there should be an average minimum population of more than 20 patients per practice eligible for inclusion in the denominator prior to application of personalised care adjustments. QOF data for 2020-21 shows that 0.8% of adults in England are receiving drug treatment for epilepsy. This equates to around 63 patients for an average practice with 10,000 patients (using ONS population statistics).</p>	<p>The indicator does outline minimum numbers of patients needed to be confident in the assessment of variation.</p>

Feasibility

Considerations	Assessment
Data can be collected from GP systems using SNOMED coding.	The indicator is repeatable.
The denominator matches QOF EP001, derived from the following clusters: EPIL_COD EPILDRUG_COD There is an existing SNOMED code for epilepsy annual review. A similar logic is used in QOF, INLIQ and NCD datasets.	The indicator will measure what it is designed to measure. The indicator will use existing data fields.

Acceptability

Considerations	Assessment
Piloting highlighted some concerns regarding potential duplication with reviews conducted in secondary care. This can be mitigated by allowing those already reviewed in secondary care to be included in the numerator and for primary care not to have to re-review them. It was noted that notifications from secondary care about reviews could be delayed or difficult to code. Improved integration of templates and clinical systems between primary and secondary care could resolve this.	The indicator assesses performance that is attributable to or within the control of the audience.
Results could be used to understand national performance and compare practices. The indicator would be suitable for inclusion in an incentivised performance framework such as the Quality and Outcomes Framework.	The results of the indicator can be used to improve practice

Risk

Considerations	Assessment
Piloting indicated a risk that the indicator could become a 'tick-box exercise' without more guidance on what the review should include. Detailed guidance including standardised templates detailing the content of the review can mitigate this risk. The committee noted that SIGN guideline 143 indicates the annual review should encompass seizure control, seizure frequency and date of	The indicator has an acceptable risk of unintended consequences.

last seizure, antiepileptic drug dose, adherence and adverse effects, mood and anxiety, diet and lifestyle advice to reduce osteoporosis risk and alcohol consumption. Epilepsy action have developed a care planning and review template .	
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