Autism: register

NICE indicator

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www.nice.org.uk/indicators/ind175

Indicator

The contractor establishes and maintains a register of all autistic people.

Indicator type

General practice indicator suitable for use in the Quality and Outcomes Framework.

> This document does not represent formal NICE guidance. For a full list of NICE indicators, see our menu of indicators.
>
> To find out how to use indicators and how we develop them, see our NICE indicator process guide.

Rationale

The aim of this indicator is to encourage practices to record the diagnosis of autism using appropriate clinical codes. An accurate register is a prerequisite to ensuring proactive

engagement with people with a defined condition. Establishing a register of autistic people could provide a number of opportunities to improve care and outcomes including measuring access to wider care services, identifying where there is evidence of unequal access or enabling services to make reasonable adjustments for autistic people. It would also provide an identifiable population to assess and measure longer term health outcomes and care process indicators.

Source guidance

- Autism spectrum disorder in adults: diagnosis and management. NICE guideline CG142 (2012, updated 2021)

- Autism spectrum disorder in under 19s: recognition, referral and diagnosis. NICE guideline CG128 (2011, updated 2017)

Specification

A register of autistic people.

Exclusions: None

Diagnoses should be made according to the criteria in ICD 10 or DSM V, usually by an appropriate autism assessment team.

O'Nions et al. (2023) estimate that people with a diagnosis of autism represent 0.82% of the population in England; on this basis, the Office of National Statistics (2024)'s population estimates for the UK, England, Wales, Scotland, and Northern Ireland: England, mid-2022 data suggests that 468,272 people in England may be autistic. The data shows that 0.8% of people in England may be diagnosed with autism: 82 patients for an average practice with 10,000 patients. It is likely that 82 may be an underestimate as the data does not include people with undiagnosed autism.

Reference

O'Nions et al. (2023) Autism in England: assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data. The Lancet Regional Health – Europe 29: 100626.

Update information

Minor changes since publication

September 2024: Information about the minimum population was replaced by that of the expected population size. We changed 'patients on the autistic spectrum' and 'people on the autism spectrum' to 'autistic people', to align with the NICE style guide.

October 2020: We added a specification and information about the minimum population.

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