

Learning Disability Registers at Primary Care Level in the UK

Geography and scale:	England, national.
Type of disability:	People with learning disabilities of all ages

Involved actors
<ul style="list-style-type: none"> • Department of Health • National Health Service (NHS) England • Public Health England

Best practice description
 In order to reduce health inequalities and improve primary care, learning disability registers were established in 2006 and now cover nearly 285,000 patients. People with learning disabilities are identified and diagnosed by general practitioners (GPs) and then included in a register. This information is coded and added to the patients' electronic health records. In addition, persons with coded clinical diagnoses associated with a learning disability are automatically added to the register e.g., Down's Syndrome. The NHS and Public Health England collect annual data for specific health and healthcare indicators from registers of all participating GP practices; similar data is also aggregated from a group of people without learning disabilities. Data is analysed at a national level and findings from comparative analysis are published in annual summary reports, which are also translated into [easy to read formats](#).

Origin / impetus for best practice

- Mencap advocated for the creation of a registry of people with learning disabilities ("Treat me Right!" report, 2004).¹
- The Independent Inquiry report (2008) revealed that people with learning disabilities experience higher levels of unmet need and receive less effective treatments than the general population.²

Impact / results of implementing best practice

- Registers facilitate identification of patients who are eligible for an annual learning disability health check and seasonal flu vaccination.
- New clinical codes associated to learning disabilities available after [expert review](#).
- Projects derived from data collection e.g., national project to stop over medication ([STOMP](#)).

Critical success factors for best practice

- Financial incentives for GPs who keep learning disability registers.
- Strong advocacy from the learning disability community.

Impact statement

Lessons learned

- Coding of clinical diagnoses should be standardized and consistent across datasets from practices.
- Coverage currently varies across the country and around 75% of people with learning disabilities remain invisible to data collection.³

Sources	¹ Mencap report 2004 Treat me right ² Michael Report 2008 ³ Learning Disabilities Observatory 2016
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Further links & information	<ul style="list-style-type: none"> • NHS - Learning Disabilities and Autism • Learning Disability Data • NHS - Health and Care of People with Learning Disabilities, Experimental Statistics
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