

# NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

## QUALITY AND OUTCOMES FRAMEWORK (QOF) INDICATOR DEVELOPMENT PROGRAMME

### Briefing paper

**QOF indicator area:** Learning disability

**Potential output:** Recommendations for indicator development

**Date of Primary Care QOF Indicator Advisory Committee meeting:** 16 June  
2009

**Note:** The content of this document is derived from the previous QOF process and the work of the NICE external contractor. It has been put into a NICE template to allow for consistency in reviewing proposed QOF indicators.

### Introduction

This briefing paper presents an assessment of the suitability of an indicator developed through the previous QOF processes for inclusion in the NICE menu of QOF indicators. It is based on the QOF evidence summarised in the QOF expert panel report (Chauhan et al. 2007).

The briefing paper is split into two sections.

- An overview of the topic, including epidemiology and current management.
- A review of the proposed indicator and a summary of the evidence that informs the indicator.

### Related existing QOF indicator

Learning disability relates to an existing QOF clinical domain as defined in the 2009/10 GMS Contract guidance. The existing QOF indicator is:

LD 1. The practice can produce a register of patients aged 18 and over with learning disabilities.

# Overview of learning disability

## *Epidemiological summary*

### **Definition**

The term learning disability (LD) is used to describe a significant, lifelong experience that has three components:

- significantly reduced ability to understand new or complex information, to learn new skills (significantly impaired intelligence), **and**
- reduced ability to cope independently (impaired social/adaptive functioning), **and**
- onset before the age of 18 years, with a lasting effect on development (Scottish Government Publications 2000).

This definition is based on the World Health Organization (WHO) approach that uses intelligence quotient (IQ), social functioning and age of onset. The IQ element is the conventional cut-off score of 70. Below this score there are four classifications of LD: mild (50–69), moderate (36–49), severe (21–34) and profound (20 or lower). In a primary care setting IQ score is not always readily available, making these distinctions more difficult to apply in practice. For this reason it is suggested that LD indicator(s) should apply to all people with a diagnosis of LD and not one particular subgroup.

### **Incidence, prevalence and evidence of variation by age and ethnicity**

It is estimated that in the UK approximately 20 in 1000 people have mild to moderate LD and 3–4 in 1000 people have severe or profound LD (Department of Health 2001). It can be estimated that there are about 210,000 people with severe LD in England (around 25% of whom are under 16 years of age), and about 1.2 million people with mild to moderate LD.

These figures are thought to be overestimates in primary care. The LD report expert panel estimates that most general practices are likely to have about 8 in 1000 people with any form of LD identified on their practice list. The prevalence in adults (judged

by the number of people on QOF registers in England in 2007/08) is 0.3% according to data from the NHS Information Centre (HSCIC 2008).

Evidence suggests that the number of people with severe LD may increase by around 1% per annum for the next 15 years as a result of:

- increased life expectancy, especially among people with Down's syndrome
- growing numbers of children and young people with complex and multiple disabilities who survive into adulthood
- a sharp rise in the reported numbers of school-aged children with autistic spectrum disorders, some of whom will have learning disabilities
- greater prevalence among some populations of South Asian origin.

### **Morbidity and mortality**

People with an LD have a different pattern of morbidity and mortality than the general population. Life expectancy – a key public health measure used to determine the relative health of a population – is lower for people with an LD than for the rest of the UK population. People with an LD are 58 times more likely to die before the age of 50 than the general population and 4 times more likely to have a preventable cause of death (McGuigan et al. 1995). Life expectancy is shortest for people who have the most support needs (Bittles et al. 2002).

The leading causes of death also differ from those in the rest of the population.

People with an LD:

- are 3 times more likely to die from respiratory disease (Hollins 1998)
- have a higher risk of congenital heart disease (Cooke 1997)
- have higher rates of gastrointestinal cancer and stomach disorders (Cooke 1997).

People with an LD also have more complex health needs than the rest of the population. The types of health needs most commonly experienced differ from those of the rest of the population, and some types of health needs are specific to these individuals. They are also generally poor – living on benefits or a low income, which further exacerbates health issues. It is also acknowledged that people with an LD

who are of South Asian origin are at an even greater disadvantage in terms of morbidity and mortality (Mir et al. 2004).

## ***Impact on health services***

### **Primary care**

People with an LD typically do not seek out healthcare; they also experience barriers in accessing appropriate services and support for their health needs, health promotion needs and lifestyle choices.

Although people with LD in the UK visit their GP with similar frequency to the general population, they are less likely to receive regular health checks (Kerr et al. 1996). It has been reported that GPs feel a lack of confidence in treating people with learning disabilities (Lennox et al. 1997, Stanley 1998, Stein 2000).

### ***Current management in primary care***

Most GPs agree that they should meet the medical needs of people with learning disabilities as part of general medical services, although it has been suggested that fewer agree they should take an active role, such as providing regular health checks (Kerr et al. 1996).

### ***NHS priorities and timeliness for guidance***

LD is a key priority for the Government. The 'Independent Inquiry into access to healthcare for people with learning disabilities' (Michael and Richardson 2008) revealed both evidence of good practice and examples of discrimination, abuse and neglect. The inquiry sought to identify the action needed to ensure adults and children with LD receive appropriate treatment in acute and primary healthcare in England. It cited 'appalling examples of discrimination, abuse and neglect across the range of health services', and identified essential areas for change.

In response, the Government developed the 'Valuing people now' strategy (Department of Health 2009) and set out key aims to improve support, opportunities and services for people with LD.

Other measures taken in response to the inquiry's report included annual GP health checks for people with LD and the 'reasonable adjustments' to general health

services primary care trusts (PCTs) were directed to make in the NHS 'Operating Framework for 2009/10' (Department of Health 2008).

In addition, a directed enhanced service for annual health checks for people with LD who are known to local authorities was introduced for 2008/09.

## **Review of proposed indicator**

### ***Proposed indicator:***

**Percentage of patients on the LD register with Down's Syndrome over the age of 18 who have a record of blood Thyroid-stimulating hormone (TSH) in the past 1 year (excluding those who are on the thyroid disease register).**

### ***Evidence summary for proposed indicator***

#### **Clinical effectiveness**

The most common underlying condition found in people with LD is Down's syndrome, which affects 1 in 1000 of the population. Down's syndrome is associated with many other conditions, including deafness, congenital heart disease and biochemical indicators of hypothyroidism, dementia and coeliac disease. Children and adults with Down's syndrome are at increased risk of thyroid dysfunction, particularly hypothyroidism, compared with the general population, and the incidence of thyroid dysfunction increases with age (Rooney and Walsh 1997). A study that reviewed annual thyroid function tests in 200 adults with Down's syndrome over a 10-year period concluded that routine screening for adults with Down's syndrome who are euthyroid can be reduced to every 5 years (Prasher and Gomez 2007). However, this was a small study with a high attrition rate – 75% over the 10-year follow-up period. Most guidelines recommend yearly screening for thyroid disease (Roizen and Patterson 2003).

#### **Cost effectiveness**

Relevant cost effectiveness data were not identified.

## ***Assessment of indicator against current practice***

### **Reduction of health inequalities**

There was no evidence identified to suggest that the indicator can reduce health inequalities.

### **Will implementation of this indicator lead to cost-effective improvements in the delivery of primary care?**

No evidence was identified to directly show that the recommendations may lead to cost-effective improvements in the delivery of primary healthcare.

### ***Feasibility assessment***

Two key questions were asked to make the initial feasibility assessment.

Question 1: Would the proposed primary care recommendations allow the development of indicators that can be used in primary care information systems?

Question 2: Are the proposed primary care recommendations likely to lead to indicators that can be measured in a clear, reproducible and precise manner?

The proposed indicator received a high consensus score through the previous QOF process and is viewed by NPCRDC as feasible.

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