Undiagnosed type 2 diabetes: an invisible risk factor

There are diseases that puzzle doctors. Patients with these diseases often remain undiagnosed for years and some will die without an accurate diagnosis. The diagnosis of patients with mysterious diseases, many of which are rare diseases, can entail a long, complex, and detailed process that requires specialist knowledge and investigations. Patients and families often have a sense of relief upon receiving a diagnosis. A diagnosis can reduce uncertainty and fear and is essential to ensure appropriate medical treatment (if available), support, and health-care coverage. It also offers opportunities for connecting with a community with shared experiences and for advocacy.

In contrast, the diagnosis of type 2 diabetes is substantially more straightforward. Yet, recent figures from the UK Office for National Statistics (ONS) estimate that 30% (approximately 1 million) of the adults living with type 2 diabetes in England between 2013 and 2019 were undiagnosed. The ONS data indicate that 7–10% of adults in England had type 2 diabetes and around one in nine adults (5·1 million people) had with prediabetes. These figures suggest that a shockingly high number of people are unaware of their condition, have no access to support or treatment, and are therefore at high risk of preventable health complications.

England is not alone in reporting high rates of undiagnosed type 2 diabetes. In the USA, according to the National Diabetes Statistics Report from the Centres for Disease Control and Prevention (CDC), 29·7 million people (including 29·4 million adults) were living with diabetes in 2021. Of those, 8·7 million (28%) of adults were undiagnosed, corresponding to 3·4% of all adults in the USA.

As if those figures were not sufficiently alarming, the ONS also reports that younger adults with type 2 diabetes were more likely to be undiagnosed than older adults (50% of those aged 16–44 years with type 2 diabetes were undiagnosed compared to 27% of those aged 75 years and over). Although young people are often considered to be at low risk of developing type 2 diabetes, this is not necessarily the case. A Review published in The Lancet Diabetes & Endocrinology summarised evidence showing that cases of early-onset type 2 diabetes are rapidly increasing worldwide. To compound this problem,

conventional models of type 2 diabetes care do not seem to work as well in adolescents and young adults as they do in older adults. People who develop type 2 diabetes at a younger age have complications that progress more rapidly, and are often more severe, underscoring the urgency of prompt diagnosis and care adapted to the pathophysiological, behavioural and psychosocial characteristics of a young population.

Furthermore, the ONS report indicates that people from Black and Asian ethnic groups had more than double the prevalence of prediabetes and undiagnosed type 2 diabetes than White, Mixed, and other ethnic groups. Data from the International Diabetes Federation indicates that nearly half of those with diabetes (both type 1 and type 2) living in low-income and middle-income countries (LMICs) remain undiagnosed. Since nearly 80% of individuals with diabetes live in LMICs, these data reflect an enormous burden of disease.

Unacceptably high rates of undiagnosis, or delayed diagnosis, are also seen in other diseases that have become very common at a global level. Of more than 700 000 people aged over 65 years estimated to live with dementia in England, only 459 000 people have a recorded diagnosis, according to 2023 NHS data in primary care settings. Notably, the reported rates of diagnosis point to substantial regional variation: in some towns and districts the rates are below 50%, whereas in others the rates are above 80% or even 90% This variation is not explained by increases in the prevalence of dementia in more deprived areas.

Rare diseases go undiagnosed for extended periods of time; this is often attributed to the complexity of such diseases and little knowledge and awareness of them among health-care professionals. However, the issues precluding diagnosis of non-communicable diseases are of a different nature. There is a range of structural issues that can prevent patients from seeking or obtaining a diagnosis, especially for those from resource-constrained settings. In the case of type 2 diabetes, which is often referred to as a silent disease, many people do not have symptoms. Education, screening for high-risk individuals, and public health messaging are therefore essential. Only by understanding and addressing the barriers to diagnosis can effective treatment be offered.

■ The Lancet Diabetes & Endocrinology





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For the ONS Report see https:// www.ons.gov.uk/people populationandcommunity/ healthandsocialcare/ healthinequalities/bulletins/ riskfactorsforprediabetesand undiagnosedtype2diabetesin england/2013to2019

For the CDC National Diabetes Statistics Report see https:// www.cdc.gov/diabetes/data/ statistics-report/index.html

For more on early-onset type 2 diabetes see Review
Lancet Diabetes Endocrinol 2023;
11-768-82

For data from the International Diabetes Federation see https://idf.org/about-diabetes/diabetes-facts-figures/.

For the NHS data on dementia see https://digital.nhs.uk/dataand-information/publications/ statistical/primary-caredementia-data/september-2023