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Harmonising terminology for type 1 diabetes: the EDENT1FI lexicon initiative



As screening and early treatment for type 1 diabetes become more widespread, the European action for the Diagnosis of Early Non-clinical Type 1 diabetes For disease Interception (EDENT1FI) consortium highlights the need for clearer, more consistent terminology. In this context, the group proposes a set of preferred terms to support communication around early-stage type 1 diabetes, including the use of ‘early-stage’ or ‘presymptomatic’ type 1 diabetes for stages 1 and 2, and ‘symptomatic type 1 diabetes’ for stage 3. The term type 1 diabetes is used to describe the full disease spectrum, from early autoimmunity to clinical diagnosis. The consortium aims to emphasise person-first, non-stigmatising language and distinguish between genetic risk screening and autoantibody screening, which indicates the presence of early-stage disease. Reference is made to existing classification systems, such as WHO’s International Classification of Diseases, 10th revision (ICD-10) and Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT), which now include codes for early stages of type 1 diabetes. These recommendations aim to support more accurate and accessible communication as early detection becomes part of routine care.

Currently, the terminology used to describe stages of type 1 diabetes varies widely across clinical, research, and public health settings as do the terms used to describe initiatives targeted at identifying individuals in stages of type 1 diabetes where insulin therapy is not yet required. Terms, such as ‘pre-diabetes,’ ‘at risk,’ or ‘latent autoimmune diabetes’ are inconsistently

applied, leading to confusion among clinicians, researchers, and families. This lack of clarity hinders communication, delays diagnosis, and complicates trial recruitment. Globally, initiatives are emerging on genetic screening for type 1 diabetes risk and detection of individuals in early stages of type 1 diabetes, alongside multiple trials using disease-modifying therapies. The first such therapy, teplizumab, has been approved by regulators in several countries, including the USA, Canada and the UK, and is entering clinical practice. As new ways of diagnosing and treating type 1 diabetes are adopted, aligning terminology is essential to avoid confusion.

Here, the EDENT1FI consortium—collaborating in the context of the Innovative Health Initiative-supported EDENT1FI project—proposes a lexicon with a selection of preferred terms related to early detection of type 1 diabetes by screening for the presence of islet autoantibodies (panel). When communicating about screening for islet autoantibodies, it is important to introduce the natural history and stages of type 1 diabetes. The heterogeneity of the disease course in children and adolescents, where most data have been collected, should be emphasised, as should the paucity of data in adults, despite this population representing over half of all clinical stage 3 type 1 diabetes diagnoses. In referring to individuals at any stage of type 1 diabetes, we support the use of ‘person or individual living with’ as this is considered less stigmatising.¹ We also propose that type 1 diabetes should be presented as a disease in communications to all audiences.

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Panel: Selection of preferred terms related to the early detection of type 1 diabetes

- T1D: type 1 diabetes
- Early-stage or presymptomatic T1D (stage 1 and 2):³ when using early-stage or presymptomatic T1D, it is recommended to include 'stage 1 and 2' in parentheses to reinforce the use of stages (ie, stage 1 T1D with the presence of two or more islet autoantibodies and normoglycaemia, and stage 2 T1D with the presence of two or more islet autoantibodies and dysglycaemia).
- Stage 3 T1D:³ confirmed hyperglycaemia, with or without symptoms; marks clinical diagnosis.⁵
- T1D genetic screening: uses genetic signatures to identify people at risk of developing autoimmune T1D.
- T1D autoantibody screening screening:⁸ measures islet autoantibodies in blood to detect early-stage T1D.
- Staging:⁹ after detecting the presence of multiple autoantibodies and confirmation in a second test, individuals are classified into stage 1, 2, or 3 T1D based on metabolic dysregulation.
- Monitoring:⁹ disease progression is tracked over time with metabolic assessments; the frequency depends on the predicted progression speed towards stage 3 T1D (eg, based on stage, age, type, and level of autoantibodies and other biomarkers).

Confusion often arises when referring to individuals in the early stages of the disease—eg, a person who has normoglycaemia but shows evidence of autoimmune activity given the presence of autoantibodies—as already having 'diabetes'. Diabetes is clearly defined by glycaemic and clinical definitions. To resolve this, we propose to use the term 'T1D', rather than type 1 diabetes, when referring to the full spectrum of the disease, including early, presymptomatic stages.

T1D is a chronic autoimmune disease, defined by a persistent immune attack on pancreatic β cells, which leads to progressive and irreversible β -cell-loss, even in early stages of disease. Emerging evidence suggests that β cells might also play an active role in their own destruction.²

T1D can be divided into different stages based on the presence of multiple islet autoantibodies and the level of glycaemic dysregulation.³ Stage 1 T1D is defined as the presence of two or more islet autoantibodies with normoglycaemia; stage 2 T1D is defined as the presence of two or more autoantibodies combined with dysglycaemia, and stage 3 T1D is defined using the current American Diabetes Association (ADA) criteria for diabetes, currently marking the clinical diagnosis

of T1D.^{4,5} Progression from early stages to clinical stage 3 is a matter of time, varying per individual, but reaching nearly 100% over 20 years.⁶ We recommend using the terms early-stage or presymptomatic T1D for stages 1 and 2 (panel). Including 'stage 1' or 'stage 2' in parentheses reinforces the staging concept. Although 'symptomatic T1D' might seem intuitive to describe stage 3 T1D, it is not entirely accurate as stage 3 T1D is defined by confirmed hyperglycaemia with or without symptoms.^{4,5} Coding for early T1D stages is available in disease classification systems. ICD-10 includes: presymptomatic T1D (E10.A0), stage 1 (E10.A1), and stage 2 (E10.A2) alongside the overall T1D code (E10).⁷ SNOMED CT includes a code for early-stage, presymptomatic T1D (1290118005). More granular staging terms, such as stage 2a or 2b and stage 3a or 3b, are emerging to reflect the progression of disease and the need for insulin introduction, but we advise against their use in communications targeting the general public at this stage.

Screening for T1D involves both genetic screening and screening for the presence of islet autoantibodies. Genetic screening identifies people at relative risk of ever developing autoimmune T1D (reflected by development of presence of islet autoantibodies) based on gene signatures. Screening for antibodies aims to detect the disease at an early stage³ and entails detection of the presence of multiple autoantibodies against β -cell antigens in blood.⁸ After a positive result and confirmatory testing, individuals are staged for metabolic dysregulation using oral glucose tolerance tests, HbA_{1c}, and then monitored over time.⁹

Many uncertainties remain. Autoantibody screening is the primary method for detecting T1D before clinical onset, identifying individuals who will progress towards symptomatic stage 3 T1D, but the pace of progression is variable and poorly understood. Single autoantibody positivity is particularly unpredictable, with outcomes ranging from disease progression to stage 3, to reversion to antibody negativity. Individuals with confirmed single antibody positivity and normal glucose levels, along with those at genetic risk, can be categorised as being 'at increased risk' of developing T1D. In contrast, individuals with multiple persistent autoantibodies should be considered as having early-stage T1D (stage 1 or 2), rather than merely being at risk.

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See Online for appendix