International Diabetes Federation

75 YEARS 1950 - 2025

ISPAD International Society for Pediatric and Adolescent Diabetes

Detect Early, Act Early: Improving Diagnosis of Type 1 Diabetes

A policy brief by the International Diabetes Federation (IDF) and the International Society for Pediatric and Adolescent Diabetes (ISPAD)

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Images courtesy of the International Diabetes Federation (IDF)

Executive Summary

About this policy brief

The International Diabetes Federation (IDF) and the International Society for Pediatric and Adolescent Diabetes (ISPAD) developed this policy brief to target advocates, healthcare professionals and policymakers and provide recommendations to advance type 1 diabetes screening and early diagnosis.

This policy brief:

- Highlights the impact of type 1 diabetes worldwide.
- Underscores the severity and potentially life-threatening consequences of a late type 1 diabetes diagnosis.
- Showcases the latest techniques to screen and potentially delay the progression of type 1 diabetes.
- Provides policy recommendations to improve screening and early diagnosis of type 1 diabetes.
- Shares lived experiences of living with type 1 diabetes from different regions.

Type 1 diabetes

What is type 1 diabetes?

Type 1 diabetes is a lifelong condition caused by an autoimmune response against the insulin-producing beta cells in the pancreas. As a result, people with type 1 diabetes produce little or no insulin, the hormone that moves glucose from the bloodstream into cells for energy. Without insulin therapy, blood glucose levels rise dangerously (hyperglycaemia).

Eventually, hyperglycaemia damages blood vessels, nerves and organs, increasing the risk of life-threatening complications (heart disease, stroke, kidney damage, vision loss and peripheral neuropathy leading to lower-limb amputation) and premature death.

Untreated severe hyperglycaemia can lead to diabetic ketoacidosis (DKA). The cells cannot use the glucose in the blood, so the body uses fat for energy. This metabolic process leads to the production of ketones, acidic byproducts of burning fat that accumulate in the blood and urine. Ketones elevate the acidity of the blood and are a life-threatening medical emergency.

Currently, there is no cure for or prevention of type 1 diabetes. However, recent advances make early diagnosis and reduction in DKA rates possible and the potential delay of type 1 diabetes more feasible.[1]

The stages of type 1 diabetes

Type 1 diabetes develops in stages over months or even years before diagnosis. Understanding these stages can help healthcare providers identify people at risk and intervene early. The four clinical stages of type 1 diabetes are: [2]

STAGE 1

Autoimmunity without symptoms

Two or more islet autoantibodies are present in the blood. In the meantime, blood glucose levels remain normal, and people have no clinical symptoms. Identifying people in this stage opens possibilities for early interventions to delay or potentially prevent the progression to symptomatic type 1 diabetes.

STAGE 2

Autoimmunity with abnormal blood glucose

Autoantibodies remain present, with increasing beta-cell damage. Blood glucose levels rise above normal levels during fasting or after meals. People still have no observable symptoms at this stage. The risk of progression to type 1 diabetes increases.

STAGE 3

Clinical diagnosis of type 1 diabetes

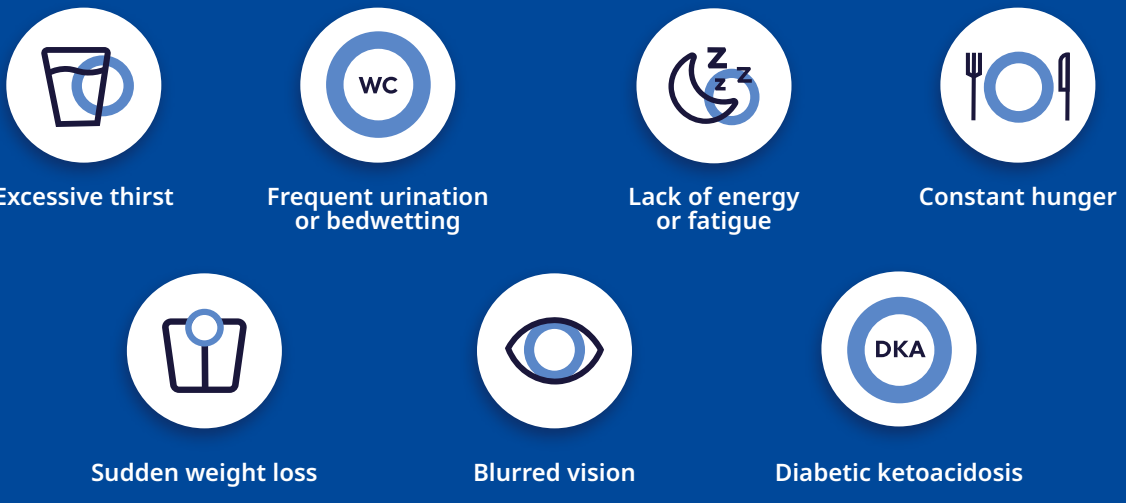
Blood glucose regulation is impaired, causing hyperglycaemia and increasing the risk of DKA. The classic symptoms appear. Typically, type 1 diabetes is diagnosed at this stage, and insulin therapy is introduced.

STAGE 4

Long-standing type 1 diabetes

At this stage, individuals have lived with type 1 diabetes for many years. The possibility of developing diabetes-related complications increases, depending on access to treatment and glycaemic management.

The typical symptoms of type 1 diabetes



Excessive thirst

Frequent urination or bedwetting

Lack of energy or fatigue

Constant hunger

Sudden weight loss

Blurred vision

Diabetic ketoacidosis

Reasons for type 1 diabetes misdiagnosis

Traditional terminology

Historically, type 1 diabetes was called 'juvenile diabetes', a term that reinforced the misperception that the condition only affects children. Although no longer used in medical contexts, this misconception remains common. Increasing public understanding that type 1 diabetes can develop at any age can promote quicker recognition of symptoms and more accurate diagnoses.

Misdiagnosis with other conditions

Several symptoms of type 1 diabetes are shared with other health conditions, such as urinary tract infections, viral illnesses, dehydration or even stress. Symptoms of DKA (vomiting, Kussmaul respiration) are also often mistaken for gastroenteritis or pneumonia. These commonalities may result in healthcare professionals attributing symptoms to other conditions instead of type 1 diabetes, which can prevent early detection and timely treatment.[3]

Misdiagnosis with other types of diabetes

Some studies indicate that 40% of adults with autoimmune, adult-onset type 1 diabetes are initially misdiagnosed as having type 2 diabetes. This misdiagnosis often occurs because the destruction of pancreatic beta-cells progresses more slowly in adults than in children, producing a more gradual onset of symptoms that closely resemble type 2 diabetes.

Diagnostic bias also plays a role: since type 2 diabetes is far more prevalent, clinicians may default to that diagnosis when adults present with hyperglycaemia, unless clear signs of type 1 diabetes are present. Misdiagnosis is further complicated when individuals have higher body weight and/or metabolic syndrome.[4]

Accurate diagnosis often depends on specific blood tests to confirm whether there is a routine autoimmune response. However, these tests are sometimes unavailable, too expensive or are not ordered – especially for adults whose symptoms are compatible with type 2 diabetes.[5]

John Story

United Kingdom

In May 2025, my wife, Emma, took our daughter, Lyla, to the doctor because she seemed unwell. The GP diagnosed tonsillitis. We followed the advice given, as any parent would. Less than a day later, Lyla died. She had developed diabetic ketoacidosis (DKA), and none of us knew she had type 1 diabetes. The shock was indescribable. We had never been told that children could be screened for type 1 diabetes, or that simple warning signs even existed.

At the inquest, the coroner ruled Lyla's death was due to natural causes but also issued a Letter of Concern to the Royal Colleges, warning that doctors need greater awareness and education about diabetes. His words confirmed what we already felt: our daughter's death was preventable.

That is why we started campaigning for Lyla's Law. We want every child who shows any of type 1 diabetes to be given a simple blood or urine test. These checks take seconds and could save lives. But we also believe in going further: introducing screening for type 1 diabetes so that families can know early, before a child becomes seriously ill.

In the UK, more than 42,000 children and young people live with type 1 diabetes. Each year, hundreds are hospitalised with DKA because of delays in diagnosis.

Talking about Lyla publicly is painful, but remaining silent would be worse. Our petition for Lyla's Law has already gained tens of thousands of signatures, and communities across Hull and beyond have rallied behind us. Lyla's Law is about awareness, screening and early action, so no other family loses a child to something preventable.

Read the full story

Risk factors for type 1 diabetes

Although the exact cause of type 1 diabetes remains unknown, the underlying pathways and contributing risk factors are well documented.

Genetic predisposition

Type 1 diabetes has a strong genetic component involving more than 50 genes. The most significant genes involved in its onset are the Human Leukocyte Antigen (HLA) genes on chromosome 6.[6]

Genetic risk levels vary between different world regions. Generally, the further from the Equator, the higher the prevalence of type 1 diabetes. This pattern is well-documented in Northern Europe, North America, Australia, and New Zealand.[7] Globally, Finland has the highest type 1 diabetes incidence, with approximately 1 person in 100 developing the condition by age 15.[8]

While some genetic markers clearly increase the risk of type 1 diabetes, not all people with these markers develop the condition. This suggests that environmental factors play a role in whether a person develops type 1 diabetes.

A family history of type 1 diabetes

The overall risk of developing type 1 diabetes in people with no known family history of the condition is between 0.3 and 0.5%. This risk varies by region: in Europe and the US, it is around 1 in 250 people (0.4%), whereas the global average is around 1 in 333 people (0.3%).[9]

The likelihood of developing type 1 diabetes increases with a family history of the condition. Combined with genetic factors, the risk varies depending on the familial relationship.[10] People with a first-degree relative (a parent, sibling or child) with type 1 diabetes are at much greater overall risk than the general population:

- 30-50% for someone with an identical twin living with type 1 diabetes.[11]
- 3-8% for someone with a sibling living with type 1 diabetes.
- 6% for someone with a father living with type 1 diabetes.
- 3% for someone with a mother living with type 1 diabetes.[12]

For a person with a second-degree relative (such as a grandparent, aunt, uncle, or cousin) who has type 1 diabetes, the risk is between 1% and 2%. This risk is higher than that of the general population. It is worth noting that 90% of people diagnosed with type 1 diabetes have no known relatives with the condition.[13]

Kerry Murphy

Blue Circle Voice from the US

Type 1 diabetes runs in my husband's side of the family. He was diagnosed in 2010 at 37, his niece was diagnosed in 2013 at two, and her mother, my husband's sister, was diagnosed at twelve in 1996. I have been a full-time caretaker for my daughter since she was diagnosed seven years ago. When my husband first went to the hospital with extremely high blood glucose, he was misdiagnosed with type 2 diabetes and sent home without treatment. A year later, an endocrinologist correctly diagnosed him with type 1 diabetes. Misdiagnosis in adults is common due to the misconception that type 1 only affects children.

Despite my daughter having three relatives with type 1 diabetes and showing symptoms, our primary care provider never tested her glucose or suggested screening. We ultimately diagnosed her using my husband's glucometer after we noticed common symptoms. At her first endocrinologist appointment, I learned about early screening for type 1 diabetes and TrialNet, which offers free test kits for families at risk. After my sons tested negative, I requested retesting in 2020 through our primary care doctor. One son, now 19, tested positive for one autoantibody in 2020 and now has three. The other, now 22, tested positive in 2023 for one autoantibody.

As a parent and caregiver, screening is crucial. Families like mine, who know the signs and symptoms of undiagnosed type 1 diabetes, have avoided diabetic ketoacidosis. But others are not as fortunate. The US public needs to know that screening is accessible, is often covered by insurance, and is sometimes free through research programmes. Identifying autoantibodies before diagnosis slows the progression of the condition, delays onset and moves us closer to a cure. Screening saves lives, gives families time to prepare, and provides critical data that advances research. Everyone should have access to a simple blood test to detect their risk of developing type 1 diabetes, turning a possible crisis at diagnosis into an opportunity to delay and prepare for a life with the condition.

My recommendations for policymakers are clear:

- Invest in educating healthcare providers and the public about type 1 diabetes screening, as well as emerging therapies that can delay onset.
- Make screening a part of universal healthcare, so providers can identify those at risk and can intervene before it is too late.

Read the full story

Autoimmune conditions clustering

Autoimmune conditions often run in families, which suggests a strong genetic component. The autoimmune conditions found in families with type 1 diabetes are most commonly autoimmune thyroid disease, autoimmune adrenal deficiency, celiac disease, rheumatoid arthritis, lupus, multiple sclerosis and vitiligo (loss of skin pigment).[14]

However, genes alone do not explain the onset of autoimmune responses. Environmental factors, such as age, infection and nutrition, can trigger autoimmune responses.

Presence of islet autoantibodies

The presence of islet autoantibodies is a robust marker of the risk of developing type 1 diabetes.[15] Children with two or more types of these autoantibodies have an estimated 85 to 92% chance of developing the condition within 15 years.[16]

Screening for islet autoantibodies, present years before any symptoms appear, allows for early intervention and paves the way for strategies that can help delay the onset of type 1 diabetes. A simple blood test can allow healthcare professionals to identify a person's risk early and reduce the likelihood of serious complications such as diabetic ketoacidosis (DKA).

Age

Type 1 diabetes in children and adolescents tends to have a more aggressive and rapid onset, often requiring immediate insulin therapy. For children, peak onset happens between 4 and 7 (when the immune system undergoes significant changes) and between 10 and 14 (coinciding with the onset of puberty), indicating a link with hormonal changes.[17]

However, IDF estimates that more than half of new type 1 diabetes cases (56.7%) are in people aged 20 years and older.[18] In the UK, a study analysing data from the UK Biobank found that 42% of type 1 diabetes cases were diagnosed in people between the ages of 31 and 60.[19] In the USA, a survey of close to 1,000 respondents suggested that 37% of individuals with type 1 diabetes were diagnosed after the age of 30.[20]

Environmental factors

Environmental factors (such as viral infections, early-life nutrition, gut imbalance and physical activity) interact with genetic predisposition and influence the development of islet autoantibodies and clinical type 1 diabetes. We have significantly advanced our understanding of these triggers thanks to studies such as The Environmental Determinants of Diabetes in the Young (TEDDY), that has followed thousands of genetically at-risk children from birth to age 15 in the United States, Finland, Germany and Sweden since 2004.[21,22]

TEDDY has revealed multiple pathways that may lead to the destruction of insulin-producing cells. Together with other studies, it highlights the role of early-life factors, including maternal health and exposure to infections, in shaping autoimmune risk. These insights are crucial for developing targeted prevention approaches for individuals at risk of type 1 diabetes.[23]

- Infections: Emerging evidence suggests that viral and bacterial infections, particularly enteroviruses and respiratory infections, may trigger autoimmune responses leading to type 1 diabetes. Ongoing research is looking into vaccine-based approaches to prevent enterovirus-related type 1 diabetes.[24]
- Nutrition and bacteria in the gut: Early-life nutrition and gut bacteria play a critical role in immune system development. Diets high in processed foods and low in fibre can disrupt the gut microbiome and cause inflammation, while fibre-rich diets support beneficial bacteria and immune balance.[25] Promising studies suggest that modifying the gut microbiota may lead to new prevention strategies.
- Physical Activity: Regular physical activity plays a key role in managing glycaemia in people with type 1 and type 2 diabetes and is a component of type 2 diabetes prevention programmes. Recent findings also suggest that higher physical activity levels may delay progression to stage 3 clinical type 1 diabetes in children with multiple islet autoantibodies.[22]
- Growth patterns: TEDDY confirmed earlier findings in an Australian at-risk cohort that a higher rate of weight gain in infancy was associated with an increased risk of islet autoimmunity.[26,27] Additionally, slower height growth in infancy followed by a growth spurt in early childhood also seems to be linked to a higher risk of progressing from islet autoimmunity to type 1 diabetes.[28]
- Pre- and postnatal stress: Prenatal environmental factors can determine a child's long-term health and susceptibility to certain conditions. Maternal stress during pregnancy has been associated with a higher risk of autoimmune conditions in genetically predisposed children.[29] While stress in infancy and childhood does not directly cause type 1 diabetes, it may influence the timing of its onset by potentially altering gut microbiome and immune regulation in children genetically predisposed to developing the condition.[30] Prolonged psychological stress and exposure to high-pressure environments can contribute to immune balance disruption, which could accelerate islet autoimmunity and lead to an earlier onset of type 1 diabetes.[31]

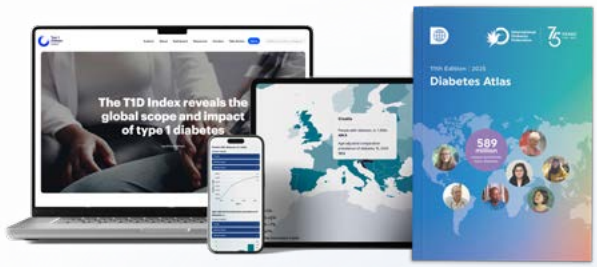
The global impact of type 1 diabetes

Type 1 diabetes figures globally

Our understanding of the global prevalence of type 1 diabetes remains incomplete. Significant gaps persist in mortality, prevalence and incidence data – especially among adults. Distinguishing adult-onset type 1 diabetes from type 2 diabetes remains a key challenge that can be met with improved diagnosis, reporting and care.[32,33]

The T1D Index, a joint initiative of Breakthrough T1D, Life for a Child, IDF and ISPAD, has enabled more current and accurate estimates to be calculated for all ages.[34,35,36] The IDF Diabetes Atlas 11th edition includes the latest T1D Index estimates for 2024.[37]

A notable feature of the T1D Index is its estimate of the number of people who would be alive today – currently 4.1 million – if they had not developed the condition.[38] Education and awareness initiatives targeting both health professionals and communities have been shown to reduce rates of diabetic ketoacidosis (DKA) in some high-income countries[39] and increase type 1 diabetes diagnosis rates in low-income countries.[40,41]



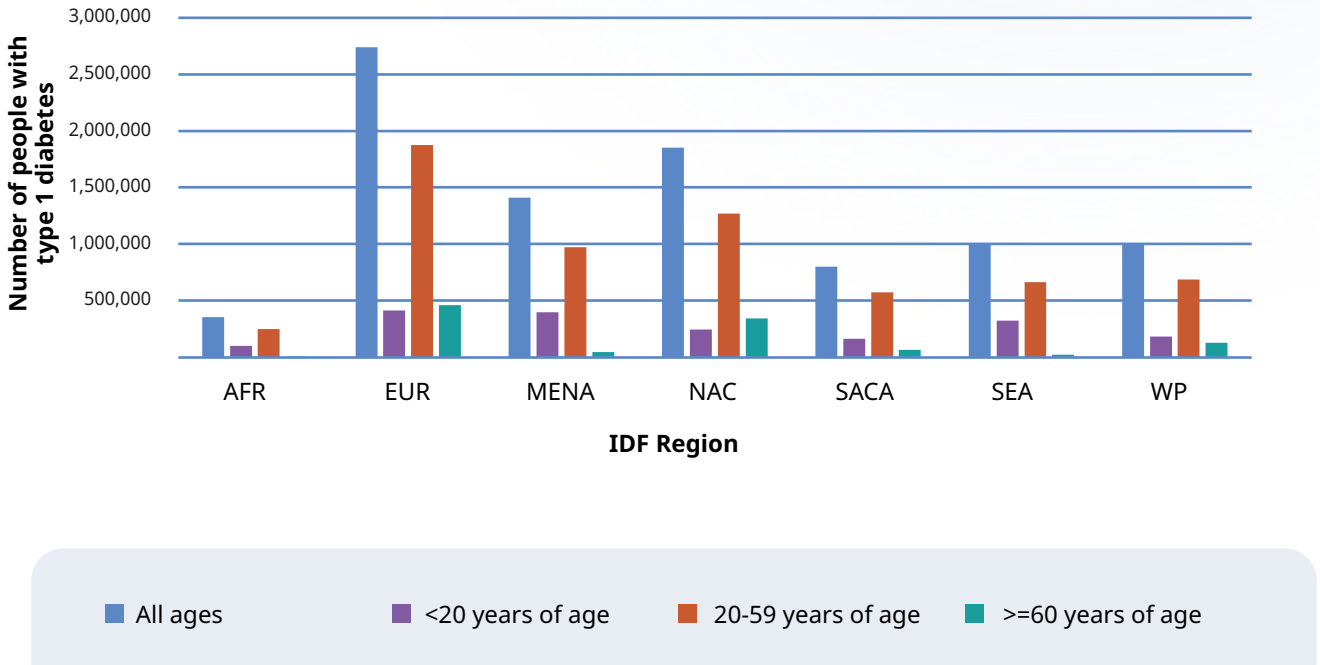
diabetesatlas.org

t1dindex.org

Key type 1 diabetes statistics (2024) at a glance[8]

- In 2024, 9.15 million people are living with type 1 diabetes globally.
- 2.04 million live in low- and middle-income countries.
- 1.81 million are under 20.
- 6.29 million are aged between 20-59.
- 1.06 million are over 60.
- More than half (284,000) of the 502,600 new cases of type 1 diabetes diagnosed in 2024 occurred in people aged 20 or older.
- The average age of people living with type 1 diabetes is 35.
- An estimated 168,000 deaths were attributed to type 1 diabetes: 31,000 in Africa; 34,000 in Europe; 27,000 in the Middle East and North of Africa; 18,000 in North America and the Caribbean; 14,000 in South and Central America; 30,000 in South-East Asia; and 14,000 in the Western Pacific.
- Approximately 35,000 of these deaths happened in non-diagnosed people under 25, who died within 12 months of the onset of symptoms.

Number of individuals with diabetes in each IDF region, by age (2024)[8]



The importance of awareness

Awareness campaigns are instrumental in promoting early detection of all types of diabetes and reducing the risk of life-threatening complications.[42] Some of the campaigns that have tried increasing public and professional understanding of the condition's early signs are:

4Ts Campaign by Diabetes UK

This campaign focuses on four key symptoms of type 1 diabetes in children: Toilet (frequent urination), Thirsty (increased thirst), Tired (extreme fatigue), and Thinner (unexplained weight loss), so parents, carers and educators recognise the condition early and seek diagnosis, reducing the risk of DKA at onset.

Read more

"Detect So You Can Decide" by Breakthrough T1D

This campaign promotes early detection through screening for islet autoantibodies to identify type 1 diabetes before symptoms develop.

Read more

Warning Signs Awareness Campaign by Beyond Type 1

This campaign educates the public on common diabetes symptoms to encourage prompt medical advice when symptoms first appear.

Read more

World Diabetes Day by IDF

Held every year on 14 November, World Diabetes Day is a global awareness campaign aimed at drawing attention to different aspects of all types of diabetes, including type 1.

Read more

The importance of education

People living with any type of diabetes must make frequent daily decisions to manage their condition – balancing food, physical activity and insulin doses to regulate their blood glucose levels. Most of this management occurs outside the healthcare setting, with people with diabetes relying on their judgment and support from family and friends. Supporting people with type 1 diabetes and their carers to understand and manage their condition effectively must be recognised as a core component of diabetes care.

Equally, the extended healthcare team needs to receive specialised training in the diagnosis and management of type 1 diabetes to identify early symptoms, diagnose type 1 diabetes before the onset of complications, and provide the best possible recommendations to people living with the condition.

Read more about the **Understanding Diabetes** platform for people living with diabetes:

understandingdiabetes.org

Read more about the **IDF School of Diabetes** for healthcare professionals:

idfdiabeteschool.org

Type 1 diabetes in the global political agenda

The Global Diabetes Compact, launched by the World Health Organization (WHO) in 2021, aims to improve the prevention, diagnosis and management of diabetes worldwide. The Compact brings together governments, health organisations, civil society and the private sector to accelerate progress on global health commitments and address the growing impact of diabetes.[43]

The Compact aligns with the Sustainable Development Goals, notably target 3.4, which aims to reduce premature mortality from noncommunicable diseases by 30% by 2030. It encourages countries to:

- Strengthen primary healthcare systems to ensure early detection and continuous care.
- Guarantee access to affordable insulin, particularly for people with type 1 diabetes.
- Integrate diabetes care into universal health coverage (UHC) strategies.
- Promote prevention by implementing policies that address unhealthy diets, physical inactivity and other risk factors.
- Invest in data systems and monitoring to ensure progress is tracked and inequalities are addressed.

The five targets to be achieved by 2030:[44]

- 80% of people with diabetes are diagnosed.
- 80% of people with diagnosed diabetes have good control of glycaemia.
- 80% of people with diagnosed diabetes have good control of blood pressure.
- 60% of people with diabetes aged 40 years or older receive statins.
- 100% of people with type 1 diabetes have access to affordable insulin and blood glucose self-monitoring.

The achievement of these targets would mean a significant improvement in the lives of millions of people living with all types of diabetes – and would ensure that everyone living with type 1 diabetes receives the essential care they need. However, the targets can only be achieved with sustained political will, financing and cross-sector collaboration. Governments and stakeholders must act now to ensure that no one is left behind.

Learn more about the WHO Global Diabetes Compact

Type 1 diabetes prevention, screening and early detection in at-risk populations

Can type 1 diabetes be prevented?

Currently, **type 1 diabetes cannot be prevented**. Despite ongoing research in approaches such as immunotherapy to alter the immune response, no proven method has yet been found to stop its onset.

Researchers are exploring the links between certain viral infections and the development of type 1 diabetes. Understanding these links may pave the way for future prevention strategies, including vaccines, to lower the risk of onset among those at risk.[24]

Another promising area focused on gut health and early-life nutrition. Evidence suggests that imbalances in gut bacteria may disrupt immune function and contribute to the onset of type 1 diabetes. Researchers are investigating whether probiotics, dietary modifications in infancy, or other methods to support a healthy gut microbiome could help reduce risk.[45]

Can type 1 diabetes be detected before the onset of symptoms?

Before the onset of symptoms, healthcare professionals can screen and detect type 1 diabetes through autoantibody screening and regular monitoring.

Screening opportunities worldwide

Screening for type 1 diabetes is not yet widely adopted, but several countries have pilot programmes investigating feasibility and cost-effectiveness. These initiatives focus on early detection of children with early-stage type 1 diabetes, aiming to reduce serious complications at diagnosis and support timely intervention.

Some of these initiatives include:

- The European action for the Diagnosis of Early Non-clinical Type 1 diabetes (EDENT1FI) consortium has conducted public health screening and provided education and support since 2023. Countries include the Czech Republic, Denmark, Germany, Italy, Poland, Portugal, Sweden and the UK.[46]
- In Germany, the Fr1da study screened children aged 2 to 5 and found that screening supports early detection and may improve long-term health outcomes.[47] The average cost per child screened is approximately EUR28, with a cost per diagnosed case of around EUR9,100.[48]
- Australia's National General Population Screening Pilot, launched in 2022, evaluates the best model for the uptake, feasibility and cost of childhood screening for type 1 diabetes. Once completed, the pilot is expected to provide insights into the broader implementation of screening programmes and detailed cost data.[49]
- In the US, the Autoimmunity Screening for Kids (ASK) programme screens children aged 2 to 17. The cost per child screened within the programme is USD47, with a cost per diagnosed case of USD4,700-14,000.[50]

The potential benefits of screening for early diagnosis

Screening for early-stage type 1 diabetes in people at risk offers several potential benefits, including: a reduced risk of DKA at the time of symptoms onset;[51] an improved education and preparation for people who will develop type 1 diabetes, which could allow them to build a support network and begin appropriate management; and potential access to treatments to delay type 1 diabetes progression, as explained in the following section.

The potential benefits on the mental well-being of the people at-risk and their parents (when the person at risk is a child) remain to be shown. While an early diagnosis may provide an opportunity for preparedness and reduce diagnosis-related anxiety, it can also have the contrary effect and increase anxiety, notably among parents, who can experience a change of attitude towards their child, including dietary changes and restrictions.[52] The full impact on families, especially in the general population and different ethnic groups, remains under investigation.

Learn more about the steps to establish islet autoantibodies screening programmes at the T1D Early Detection Toolkit.

Ricardo Eleuterio de Oliveira

Young Leader in Diabetes from Portugal

I first became aware of type 1 diabetes screening and diagnosis through EDENT1FI, the European project I am currently involved with as an advisor. Before that, my knowledge of screening was mostly limited to individual or small-scale initiatives, rather than coordinated efforts at a national or European level.

The project's objective is to introduce screening for children and teenagers across Europe. This would mark an important step towards earlier detection and the prevention of serious complications. I strongly believe that with a proactive screening policy, we can identify the condition before symptoms appear. Late diagnosis often brings physical complications and emotional distress, leaving a lasting impact on a person's life. If we can remove that uncertainty, we can reshape what it means to live well with diabetes.

Looking ahead, I would like to see screening embedded within national health strategies, integrated into schools, sports clubs and other youth-focused settings. By normalising screening, we can strengthen public health, raise health literacy and reduce long-term healthcare costs.

Of course, there are challenges to overcome. The first is resources: screening must be low-cost, practical and not overly reliant on laboratories or complex logistics. The second is emotional: we need to change attitudes towards screening, shifting it from something associated with illness to a routine part of maintaining good health. Meeting young people where they are, in schools, clubs, or community activities, will be key to making screening both effective and accepted.

Learn more about EDENT1FI

Lucia Feito Allonca

Blue Circle Voice from Spain

I first learned about early detection of type 1 diabetes (T1D) in 2023 at the Diabeter Centre in Rotterdam during the ISPAD conference. I discovered that diabetes can be detected before high blood sugar appears, something impossible 30 years ago.

A year later, at the EASD 2024 conference in Madrid, I took my first autoantibody test and was surprised to find that I did not have any antibodies. This result is something I share with many others who have lived with type 1 diabetes for many years. I now participate in the Leading Team of the T1D Early Detection Programme within INNODIA in Spain. The programme identifies people at risk, generates key data for secondary prevention and supports clinical trials for new therapies.

My role is Lived Experience Lead in the PSAD (PsychoSocial Aspects of Diabetes) group. I bring the perspective of people living with diabetes to this work and have co-chaired workshops on the psychosocial aspects of screening. These sessions highlight the importance of emotional support during the early detection stage.

As someone living with type 1 diabetes, I believe early detection is invaluable. It gives families time to understand the condition and prepare emotionally, can help prevent diabetic ketoacidosis, and allows for the early use of medicines that may delay the onset of symptomatic diabetes. Every day gained against the condition is a victory, something deeply understood by those of us who have lived with it all our lives.

For policymakers, I recommend promoting type 1 diabetes screening programmes, including autoantibody testing for at-risk populations and beyond. Screening should also be included in universal health coverage schemes to ensure access for all children and families at risk.

Since my diagnosis in 1992, I have often heard that a cure for diabetes is “five years away.” It has not yet arrived, but each step forward is meaningful. Early detection should become universally accessible within public health systems. Every action we take today in this direction is a step worth taking—for individuals, families, future generations and for societies.

Learn more about INNODIA

Can progression to type 1 diabetes be delayed?

Recent research shows that the progression of type 1 diabetes can be delayed, particularly in people at an advanced stage of the condition.

Some treatments can retrain the immune system to stop attacking insulin-producing cells, showing promise in delaying the onset of type 1 diabetes. One such therapy is teplizumab (Tzield, known as Teizeild in the European Union), a laboratory-developed antibody that helps protect insulin-producing beta cells. In clinical trials, a two-week course of teplizumab delayed the onset by approximately two years in people with stage 2 type 1 diabetes.[53,54,55,56,57] The FDA (the U.S. Food and Drug Administration) approved its preventive use in November 2022. In January 2026, the European Commission approved it to delay the onset of stage 3 type 1 diabetes. It has also been approved in several other countries.[58]

While teplizumab is a breakthrough in delaying the disease's onset, it is not a cure. It slows down the destruction of insulin-producing beta cells, but it does not fully eliminate the immune response.

There are also increasing numbers of immune-modulating agents shown to preserve some insulin production in recent-onset clinical type 1 diabetes.[59,60] The updated list of these agents can be found in the ISPAD Clinical Practice Consensus Guidelines.[61] Oral insulin trials are also underway, exploring whether timely insulin therapy could help the immune system build tolerance and prevent an autoimmune attack. The multiple immune targets of type 1 diabetes allow for the design of combination therapy trials, and in the future, will lead to more personalised approaches.

Barriers to type 1 diabetes screening and intervention

Type 1 diabetes screening presents difficulties due to limited access to autoantibody testing, the high cost of screening tools, and poor integration of electronic health records. Many public and healthcare providers are not aware of recent advances in early detection. Psychological concerns such as stigma, fear or anxiety about a potential diagnosis can deter families from seeking testing (though it is important to note that early diagnosis provides families and individuals time to prepare and seek comprehensive healthcare support ahead of a clinical diagnosis).

In a world where many people living with type 1 and other types of diabetes do not have sustainable access to affordable essential care, the main challenge to screening and intervention remains its high cost, the resources required to follow up at-risk individuals for a long time, the need for psychological support, and therapeutic inertia.

Addressing these barriers requires a coordinated, multisectoral response. Priorities include integrating diagnostics and treatment into universal health coverage services, expanding access to decentralised point-of-care devices, integrating psychological services into screening programmes, and strengthening laboratory networks and quality assurance. Public education and professional training will be key to raising awareness, while sustained funding and improved logistics are essential to scaling up screening services.

Ana Alvarez Pagola

Blue Circle Voice from Argentina and Spain

When I first learnt about type 1 diabetes screening and early diagnosis several years ago, I was living in Latin America. At the time, the concept felt almost out of reach, something closer to science fiction than a real possibility. It was only later, through my involvement with initiatives such as INNODIA, that I began to understand the real potential of screening. Beyond preventing diabetic ketoacidosis (DKA) at onset, screening helps families prepare both emotionally and practically for a diagnosis that might otherwise come as a surprise.

At INNODIA, I work with INPACT (INNODIA People Living with Type 1 Diabetes Community), which brings together people living with diabetes, their families, and researchers. Our shared aim is to ensure that lived experience informs every stage of research and the development of new treatments. INNODIA also runs the DETECT Programme, dedicated to identifying type 1 diabetes before symptom onset and improving access to screening for at-risk families across Europe, informed by insights from the lived-experience community.

As an INPACT coordinator, I help facilitate dialogue between researchers and people with lived experience. I am ensuring that conversations around screening remain transparent, inclusive, and sensitive to the emotional realities involved.

Screening and early diagnosis represent a fundamental shift in how we view type 1 diabetes. For too long, people have been diagnosed too late, often in DKA. Recognising risk earlier gives families the chance to prepare, seek support, and avoid unnecessary trauma. Yet screening must always be accompanied by counselling, follow-up, and clear communication; otherwise, we risk replacing one form of distress with another.

We are standing at a turning point where collaboration between researchers, policymakers and the diabetes community can integrate early detection in routine care. A move that would transform not only healthcare systems but countless lives.

Learn more about INPACT

Best practices for type 1 diabetes early detection

Timely detection of type 1 diabetes is essential to prevent serious complications, reduce long-term health costs and save lives. The best practices below outline the steps governments, communities and international partners can implement together to improve early diagnosis and ensure access to quality and equitable care.

Bring screening to the community

Community-based testing to detect clinical type 1 diabetes early with a simple blood glucose test may offer a practical and affordable way to identify people with clinical type 1 diabetes before DKA develops. Governments should work with local healthcare workers and non-governmental organisations (NGOs) to run awareness campaigns and mobile screening camps in urban and rural areas.

However, it is important to acknowledge that a screening programme for early-stage (pre-symptomatic) type 1 diabetes offering access for all children and providing reliable follow-up care would incur very high costs. The cost-effectiveness and benefits of screening programmes are presently under evaluation in several continents. In low- and middle-income countries, where health resources are often stretched and there are many competing priorities (such as infectious disease control, nutrition, and maternal and child health), implementing such widespread programmes may not be feasible in practice and more targeted approaches may be needed.

Use portable, low-cost technologies

Introducing low-cost, portable diagnostic kits enables point-of-care testing in settings that lack laboratory infrastructure. These devices allow early detection of type 1 diabetes, making it quick and convenient. Governments and partners should support innovation and collaborate with technology developers to scale up non-invasive testing tools for low-resource environments.

Train healthcare professionals to support early diagnosis

Healthcare professionals should receive training to recognise the early signs of type 1 diabetes. This training should include how to educate families and carers of people with type 1 diabetes to monitor blood glucose levels and support safe insulin use. In rural locations, telemedicine can connect these workers to specialists in urban areas for guidance on more complex cases.

Anita Sabidi

Blue Circle Voice from Indonesia

At present, there is no nationwide programme for type 1 diabetes screening in Indonesia. However, last year we conducted a small evaluation test involving forty samples for type 1 autoimmune screening, in coordination with one of the largest labs in the country. The participants included individuals up to forty years old, with a particular focus on relatives—children and siblings—of people living with type 1 diabetes. Although modest in scale, this initiative provided valuable insights into the feasibility and potential impact of broader screening efforts.

Currently, the diagnostic pathway for type 1 diabetes in Indonesia relies heavily on C-peptide testing as the primary marker for confirmation. The process typically begins with a standard blood sugar test. If glucose levels are high, HbA1c levels are tested to assess long-term blood sugar control. When the HbA1c results also indicate high levels, a C-peptide test is performed to confirm whether the patient has type 1 diabetes.

Although this pathway may seem straightforward, in reality, it poses significant challenges. C-peptide testing is only available in major cities, so many smaller hospitals and clinics cannot offer it. Furthermore, the test is not covered by the national health insurance scheme, resulting in increased patient costs. These barriers often lead to delayed diagnosis and, in some cases, misdiagnosis, particularly in adults, who are diagnosed with type 2 diabetes instead.

A misdiagnosis not only delays appropriate treatment but can also result in poorer long-term outcomes. These challenges reveal the need for more accessible and affordable diagnostic tools throughout Indonesia.

Expanding screening and testing capabilities beyond urban centres would enable earlier detection, reduce complications and improve the quality of life for people living with type 1 diabetes. The success of our pilot project demonstrates that with the right resources and support, a national screening initiative is both feasible and essential.

Read the full story

Raise public awareness

Increasing public understanding of the signs and symptoms of type 1 diabetes is key to improving early diagnosis. Education campaigns should be culturally sensitive and use radio, social media, and local events to reach people of all ages. In the school environment, teachers and students should receive accurate information to reduce stigma and encourage early detection of diabetes.

The IDF Kids and Diabetes in Schools (KiDS) programme aims to bring diabetes education to schools to fight diabetes-related stigma, improve the well-being of children living with diabetes and promote healthy lifestyles.

Read more about KiDS

Strengthen policy and build partnerships

Governments must integrate early detection into national noncommunicable disease strategies and universal health coverage schemes. Coordination with civil society, international organisations, and local non-governmental organisations can unlock resources and improve programme sustainability. Policy frameworks must also include the provision of diagnostic supplies, access to insulin, and follow-up care.

Nkiruka Okoro

Blue Circle Voice from United Kingdom

Type 1 diabetes often seems to appear suddenly, yet the body usually gives warning signs long before diagnosis. Without screening, sadly, many families only discover the condition when a loved one ends up in diabetic ketoacidosis. This is why I believe screening and early diagnosis of type 1 diabetes should be a priority in healthcare systems across the world.

Early detection through antibody testing or blood glucose monitoring can prevent hospitalisation and save lives. It also spares families the shock of a sudden diagnosis of DKA. Knowing that type 1 diabetes is both autoimmune and partly genetic, I had my two children tested for the diabetes autoantibody. On my mother's side, diabetes has appeared in every generation until it reached me, the fifth. When the results showed my children have a genetic predisposition, I began monitoring their blood glucose regularly to detect early signs, such as increased thirst or unexplained weight loss.

I first heard about the ELSA (EarLy Surveillance for Autoimmune diabetes) study through a post on a Facebook group. The information on their website was straightforward, so I completed the online consent form and received a simple finger-prick test by post. We returned the sample and received our results within three weeks, followed by helpful check-ins from the research team.

Unfortunately, this autoantibody screening is not yet available in the UK outside of research studies, such as the ELSA study. From my experience, early screening is not optional. It saves lives, reduces trauma and gives families hope. I believe every health system should make type 1 diabetes screening accessible, especially for children in underserved communities.

Learn more about the ELSA study

Key interventions for low-income settings

Intervention	Action	Impact
Community health worker training	Equip them with type 1 diabetes knowledge and tools	Improves early detection and care
Subsidised insulin programmes	Negotiate bulk pricing and provide subsidies	Reduces treatment costs
Portable diagnostic tools	Deploy affordable point-of-care glucose testing kits	Facilitates early diagnosis
Education and awareness	Implement school and community campaigns	Reduces stigma and delays in care
Partnerships	Leverage NGOs and global funds for resource mobilisation	Expands programme reach

Policy recommendations

To build on these best practices and create sustainable change, IDF and ISPAD recommend the following policy actions for governments, donors, global health institutions and civil society:

Improve access to care, treatment and technologies

- Guaranteeing access at affordable prices to diabetes-related medicines and devices included in the WHO Model List of Essential Medicines and Non-communicable Diseases kit, including insulin, glucometers and test strips.
- Ensuring access to stress management and mental health support, including counselling and emotional care, to help people newly diagnosed with type 1 diabetes, those identified with early-stage disease and their families cope with the psychological impact of the condition.
- Ensuring insurance or subsidy schemes cover these treatments to reduce out-of-pocket expenses and protect the financial security of the people who rely on them.
- Establishing regional centres of excellence to provide specialised care, coordinate complex case management, and deliver ongoing training for healthcare professionals in diabetes management.
- Including teplizumab in the national essential medicines list of countries that have already achieved universal health coverage for diabetes care and are subsidising continuous glucose monitoring for people living with type 1 diabetes.

Strengthen public and professional awareness

- Developing mass media campaigns to raise awareness of type 1 diabetes symptoms and the importance of early diagnosis.
- Partnering with schools, workplaces and community organisations to improve type 1 diabetes education, reduce stigma and fight discrimination.
- Providing continuous professional development opportunities for healthcare workers on accurate diagnosis, treatment advances and emerging therapies.

Reinforce global collaboration and policy integration

- Embedding type 1 diabetes care into universal health coverage schemes and primary care policies to ensure equitable and sustainable access to all.
- Fostering global partnerships, including with organisations such as IDF, ISPAD, WHO and UNICEF, to improve the exchange of knowledge, resources and best practices.
- Enacting legislation and regulatory frameworks that guarantee access to essential diagnostics, medicines and technologies for people living with type 1 diabetes.

Invest in research and innovation

- Funding longitudinal studies to understand autoimmunity in different ethnicities to improve risk prediction models and deepen understanding of the links between autoimmune conditions.
- Supporting clinical trials focused on immune-modulating therapies, stem cell-based approaches, and other emerging approaches that could delay or prevent onset or restore beta cell function.

Expand early detection and screening

- Developing and implementing regional and national programmes for the early diagnosis of type 1 diabetes through islet autoantibodies screening that includes screening of families with an increased risk of type 1 diabetes.
- Expanding the use of electronic health records and outreach systems to effectively identify, monitor and follow up with individuals with early-stage disease.
- Promoting decentralised screening through trained health workers and community-based settings, to ensure equitable access across urban and rural areas.

Key takeaways

- Type 1 diabetes is a condition caused by an autoimmune response against the insulin-producing cells in the pancreas which requires lifelong insulin therapy and poses significant health risks if undiagnosed or untreated.
- Early symptoms of type 1 diabetes can resemble those of common illnesses, contributing to misdiagnosis and delayed access to appropriate treatment.
- An important percentage of adult-onset type 1 diabetes is initially misdiagnosed as type 2 diabetes, which delays the start of insulin therapy and increases the risk of complications.
- The global impact of type 1 diabetes is increasing, with more than 9 million people living with the condition in 2024. Over half of new diagnoses occur in adults aged 20 years or older.
- Type 1 diabetes risk factors include genetic predisposition, and there are associations with environmental exposures (viral infections, early-life nutrition, gut health, psychological stress, etc). There are no preventive approaches to these exposures yet.
- Screening for islet autoantibodies enables the early identification of type 1 diabetes years before symptoms appear, allowing for close monitoring and timely intervention to prevent severe complications at onset.
- Community-based screening and awareness programmes can support early detection of type 1 diabetes. However, large-scale universal screening remains costly and unfeasible to implement in low- and middle-income countries.
- Recent advances, such as teplizumab, have demonstrated the potential to delay the onset of type 1 diabetes by around two years in the early stage of the condition, representing a major step forward in prevention research.
- Improving access to insulin, glucose monitoring technologies and mental health support remains a global priority, particularly in regions where essential medicines and technologies remain unaffordable or unavailable.
- Stronger health policies and partnerships are essential. Governments must integrate type 1 diabetes diagnosis and care into universal health coverage frameworks, expand public awareness initiatives, and invest in research and innovation.

Useful resources

About IDF

IDF is an umbrella organisation of over 251 national diabetes associations in more than 158 countries and territories working together to improve and empower the lives of the estimated 589 million people living with diabetes and prevent diabetes in those at risk. As the global voice of the diabetes community since 1950, IDF is engaged in actions to tackle diabetes at all levels – from local community programmes to worldwide awareness and advocacy initiatives. IDF activities aim to influence policy, increase public awareness, encourage health improvement, promote the exchange of high-quality information about diabetes, provide education for people with diabetes and their healthcare providers, and ensure the availability of appropriate medications for diabetes management and complications, both in times of peace and conflict.

Learn more about IDF

Access the 11th IDF Diabetes Atlas

Access the IDF School of Diabetes

About ISPAD

ISPAD is the leading global organization dedicated to improving the lives of children, adolescents, and young adults with diabetes. Its strength lies in its members' expertise in childhood and adolescent diabetes. As the only global society focused on all types of diabetes in young people, ISPAD is crucial as this disease increasingly affects children and adolescents worldwide. Our mission is to advance clinical and scientific knowledge, promote education, and advocate for better care and treatment for young people affected by diabetes.

Learn more about ISPAD

ISPAD Clinical Practice Consensus Guidelines

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