Breakthrough T1D UK white paper on early detection screening for type 1 diabetes

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Breakthrough T1D is calling for an early detection programme for type 1 diabetes to be established in the UK. Support must also be provided for those who are identified as "at-risk" or in the early stages of type 1 diabetes.

This white paper has been developed by Breakthrough T1D with funding from Sanofi UK who has had no editorial input or control over the contents.

Executive summary

This paper outlines Breakthrough T1D UK's position on the early detection of type 1 diabetes (T1D) and the urgent need for a national screening programme in the UK. Currently, there is no comprehensive NHS screening for identifying individuals at risk of T1D, despite compelling evidence that early detection of the condition significantly reduces life-threatening complications, particularly diabetic ketoacidosis (DKA). International programmes, such as those in Italy, Australia, and the US, demonstrate that comprehensive national screening, paired with public awareness campaigns and psychosocial support, can successfully reduce DKA rates and improve long-term health outcomes. Early detection offers multiple benefits: reduced emergency diagnoses, improved glycaemic control, lower long-term healthcare costs, and vital preparation time for families. With a pipeline of disease modifying drugs now emerging, future generations of people who have been identified as having markers for developing type 1 diabetes will for the first time be able to delay the onset of the condition.

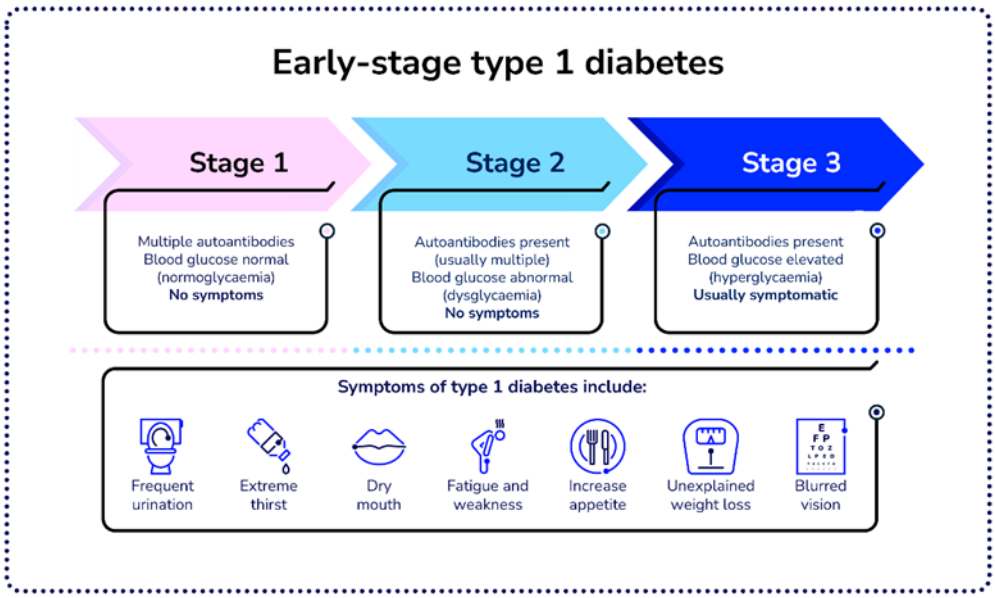
Introduction

Early detection is a way of finding out if people are at risk of a particular health issue, so that treatment can be planned and information and support can be offered. Currently, there is no NHS screening programme to identify who is in the early stages of type 1 diabetes.

This paper sets out Breakthrough T1D UK's position on early detection for type 1 diabetes. There are benefits in offering screening, such as the reduction in rates of diabetic ketoacidosis (DKA). DKA occurs when the body stops producing insulin and results in the build-up of a harmful substance called ketones.

As early detection of T1D becomes more widespread it is important that correct terminology is used consistently. In this paper, we use the term T1D to refer to the entire disease spectrum. T1D can be divided into three distinct stages. Stage 1 is where there are two or more autoantibodies present with normal blood glucose levels, also known as normoglycaemia. Stage 2 is where multiple autoantibodies are present with abnormal blood glucose levels, also known as dysglycaemia. These two stages can be referred to as early-stage diabetes or presymptomatic T1D. Finally, in stage 3, individuals with T1D will become symptomatic, as insulin production has been severely inhibited by the autoimmune process.[1]

How are antibodies linked to a person's risk of type 1 diabetes?



An antibody is a protein that a person's immune system produces when it detects a threat. But in type 1 diabetes (T1D), an individual's immune system makes these antibodies in response to their own insulin-producing beta cells. These are called autoantibodies, and scientists can test for these to see if the person has these antibodies, and therefore whether they are likely to go on and have T1D. If an individual tests negative for autoantibodies, they are at low risk of developing T1D - although this does not completely guarantee they will not develop autoantibodies or T1D later in life. The diagram above illustrates that these autoantibodies can be detected prior to an individual becoming symptomatic.

If somebody tests positive for only one autoantibody, they are at a higher risk for developing T1D in their lifetime than someone who tests negative. They may

[1] Vercauteren, Jurgen, et al. "Harmonising terminology for type 1 diabetes: the EDENT1FI lexicon initiative." *The Lancet Diabetes & Endocrinology* (2025).

be able to participate in a clinical trial to slow the development of T1D. Almost everyone who tests positive for two or more autoantibodies has already begun the destructive process that will ultimately mean the individual will need insulin therapy. However, the test cannot indicate how soon this will be.

Benefits of early detection

Currently, most people with type 1 diabetes (T1D) are diagnosed during stage 3 when they become symptomatic, many of these whilst presenting with DKA symptoms. It is difficult to give a precise number because the NHS does not routinely gather data on this topic for adults, but a 2020 study found that in the UK, around 25% of those newly diagnosed with T1D present with DKA. This number rises with young children (30% in children under 5) and ethnic minorities.[2] Death from DKA is rare in the UK, but not unheard of. The Fr1da study, a Breakthrough T1D study carried out in Germany, where diagnosis whilst presenting with DKA was 30%, screened more than 90,000 children and successfully reduced this figure to 3.2 per cent. This is because children who were identified as having multiple antibodies could be monitored more closely and diagnosed more promptly.[3]

Being diagnosed whilst presenting with DKA can be a highly traumatic event, especially for children and young people, as it results in hospitalisation and emergency treatment. A study conducted in the United States of America found that being diagnosed whilst presenting with DKA was associated with significantly greater use of health services and more substantial health care costs in the long-term.[4] Early identification of T1D could therefore reduce the instances of DKA occurring by identifying those with the condition during stage 2, before they ever become symptomatic. Given the value of early detection screening, Breakthrough T1D supports not only screening of those with a known family risk of T1D, but also across the wider population. This is crucial, because 85% of newly diagnosed patients have no family history of T1D.[5]

Reducing rates of DKA at diagnosis is associated with a number of long-term benefits for the individual with T1D. Several studies have found that an absence of DKA at diagnosis resulted in lower HbA1c (a measure of blood glucose over a period of several weeks) over time, fewer episodes of low blood glucose levels

[2] Cherubini, V., Grimsmann, J.M., Åkesson, K. et al. Temporal trends in diabetic ketoacidosis at diagnosis of paediatric type 1 diabetes between 2006 and 2016: results from 13 countries in three continents. Diabetologia 2020. https://doi.org/10.1007/s00125-020-05152-1

[3] Ziegler A, Kick K, Bonifacio E, et al., Yield of a Public Health Screening of Children for Islet Autoantibodies in Bavaria, Germany. *JAMA* 2020. http://doi.org/10.1001/jama.2019.21565

[4] Sharon H. Saydah, Sundar S. Shrestha, Ping Zhang, et al., Medical Costs Among Youth Younger Than 20 Years of Age With and Without Diabetic Ketoacidosis at the Time of Diabetes Diagnosis. *Diabetes Care* 2019. https://doi.org/10.2337/dc19-1041

[5] The EURODIAB ACE Study Group and The EURODIAB ACE Substudy 2 Study Group. Familial Risk of Type I diabetes in European Children. *Diabetologia* 1998. https://doi.org/10.1007/s001250051044

and fewer episodes of DKA post-diagnosis.[6] [7] Therefore, being made aware of the warning signs of T1D prior to the clinical onset leads to far better long-term health outcomes for those with T1D and a reduced cost to the health service. For many families, a T1D diagnosis is an intensely distressing experience, made far worse when it is delivered under the urgent, life-threatening conditions of DKA. Early identification of children and young people at risk of T1D gives families the critical time they need to prepare emotionally, learn how to manage the condition, and avoid the trauma of an emergency diagnosis. Identifying children and young people likely to develop T1D prior to them being diagnosed with clinical symptoms can help reduce feelings of stress, depression and provides time to acquire the knowledge needed to successfully manage T1D. There are other wider socio-economic factors to consider too. Currently, 15% of mothers stop work and a further 11% reduce their hours following a diabetes diagnosis in their child.[8] This effect is likely to be reduced if diagnosis in DKA is also reduced. Identifying those with T1D during stage 2 of the condition via a screening programme is not just a clinical option, it is a public health imperative. It can transform lives, and in some cases, it can save them.

Case study 1

Jim was diagnosed with type 1 diabetes a week before his 21st birthday, during his second year of university although his symptoms started in the months prior, in the summer between first and second year of university. He first noticed extreme thirst and more frequent urination. These symptoms continued and as time went on, worsened. During this time, he lacked energy to attend university lectures or do the activities he used to enjoy and would frequently spend much of his day in bed. Alongside this came very rapid weight loss, losing approximately two and a half stone in less than three weeks. He remembers every few days having to tighten his belt one notch, until he ran out of notches. He lost his appetite almost entirely and anything he did eat he threw up soon after. For Jim, this was a period of extreme anxiety, with no answers as to why he felt so unwell. It was also very isolating, as he didn't want people to see how unwell he was. After he insisted on a blood test, Jim was told to go to A&E where he spent the next two nights as healthcare professionals stabilised his blood glucose levels.

The anxiety, the isolation and the prolonged period of sickness could have been entirely avoided if screening were available to him. If he had been screened earlier in his life and knew he had T1D, he could've been mindful of symptoms

[6] Lundgren, M., Jonsdottir, B., Elding Larsson, H. et al. Effect of screening for type 1 diabetes on early metabolic control: the DiPiS study. *Diabetologia* 2019. https://doi.org/10.1007/s00125-018-4706-z
[7] Duca LM, Reboussin BA, Pihoker C, et al. Diabetic ketoacidosis at diagnosis of type 1 diabetes and glycemic control over time: the search for diabetes in youth study. *PEDIATRICDIABETES* 2019. https://doi.org/10.1111/pedi.12809
[8] Dehn-Hindenberg, Andrea, et al. Long-term occupational consequences for families of children with type 1 diabetes: the mothers take the burden. *Diabetes Care* 2021. https://doi.org/10.2337/dc21-0740

and gone to the doctor immediately when displaying the first signs, completely eradicating the need for a traumatic and costly A&E visit followed by being admitted for two nights. Participation in projects such as the ELSA study[9], the INGR1D2 trial[10] and the T1DRA study[11] demonstrate that screening is needed, wanted and workable.

Case study 2

Peter a 13-year-old from Cardiff, tragically died from undiagnosed type 1 diabetes after suffering a sudden and severe deterioration due to diabetic ketoacidosis (DKA). Despite having seen a GP days earlier, who prescribed antibiotics for a chest infection, the diabetes was missed. Peter's condition worsened dramatically, leading to his hospitalisation. Although doctors and nurses fought to save him and started him on life-saving insulin, the damage to his organs and brain was too severe, and his family had to make the devastating decision to switch off life support. His parents emphasise how quickly his symptoms progressed as just a few weeks before he died, he had gone on a school trip to Germany. Although rare, this story is not unique. Screening during childhood would have drastically reduced the chance of Peter going into DKA and in all likelihood, would have saved his life.

Issues to address

Until a cure can be found, what follows from a type 1 diabetes (T1D) diagnosis is a lifelong and non-negotiable dependence on insulin and blood glucose monitoring to survive. Given the weight of such responsibilities, support must be offered for individuals and their families identified as having the autoantibodies which make it likely they have T1D. If people cannot realistically access any such education or services as a result of a positive early screening result, then they may be deterred from accessing a screening test.

The NHS needs to play a significant role in supporting patients in making decisions regarding screening for themselves and their families, addressing concerns and working in collaboration with Breakthrough T1D and other expert information services. This support must include explaining the signs and symptoms of T1D, offering regular blood tests and education around the practical implications of living with T1D such as carb counting. When they become available, support should also include access to immunotherapy drugs which can slow the development of T1D.

There are a number of opportunities for screening for T1D throughout a person's lifetime, but the early years of life are critical given the possibility of becoming symptomatic in childhood. This could for example see genetic screening on a

[9] The ELSA Study, https://www.elsadiabetes.nhs.uk/
[10] The INGR1D2 trial, https://sites.google.com/nihr.ac.uk/ingr1d2/home
[11] the T1DRA study, https://t1dra.bristol.ac.uk/

newborn's fifth day of life, as an inclusion within the existing newborn blood spot test (formerly known as the Guthrie newborn heel prick) screening for multiple conditions; followed by antibody testing at three/four years of age. At hospitals participating in the INGR1D2 trial, screening for T1D is already included in the newborn blood spot test for parents who wish to screen for their child, demonstrating that doing so is completely feasible in a hospital setting.[12] Whilst it would be optimal for screening to occur throughout a number of points in a person's lifetime, as established above, any opportunity for early identification of T1D is preferable to the current likelihood of diagnosis at DKA.

People with T1D will be instrumental in designing an effective screening service, given they have the expert knowledge provided by their lived experience having endured the shock of diagnosis, and the consequences that can come with this. Additionally, those who have participated in T1D risk screening research programmes can provide insight and experience, regardless of whether they were identified as carrying a risk of the condition or not. The expertise of these groups provides the essential background for a partnership with the NHS in the design of any national screening process.

Case study 3

Imogen was first tested in December 2023 and initially found to have one autoantibody linked to type 1 diabetes (T1D). Further tests later revealed she had three autoantibodies, indicating a higher risk of developing T1D. She underwent a Glucose Tolerance Test, which showed her glucose levels were slow to return to normal. This led to a meeting with a clinician, who introduced the family to a new disease-modifying drug, a treatment that can delay the onset of T1D. Though not yet approved in the UK, it was offered to Imogen on compassionate grounds.

Imogen received 14 days of infusions of this treatment during the Easter holidays in 2025. Despite some initial side effects and concerns about her T-cell levels, the treatment went smoothly. The hospital team provided strong support, and Imogen handled the process well. By having access to screening, Imogen and her family were able know that she would develop T1D at some stage in her life. In this case, she was also given access to a drug which will delay the onset of her symptoms, giving her valuable years where she is not burdened by the need to manage blood glucose. As novel treatments, such as one used by Imogen, become available, national early detection screening programmes will be essential in determining who would benefit most from these treatments.

[12] The INGR1D2 study, NIHR, https://sites.google.com/nihr.ac.uk/ingr1d2/home

Screening around the world

Many countries already have well developed pilots or even systematic national screening programmes, helping to identify those at risk of developing type 1 diabetes (T1D) prior to becoming symptomatic. The UK lags behind in these efforts.

- Italy introduced a law that created a nation-wide programme that tests all children aged between 1-17 to see whether the auto antibodies responsible for causing T1D were present, making Italy global leaders in screening. This test also tests for coeliac disease, which is another autoimmune condition.[13]
- Australia has an ongoing screening programme, predominantly funded by Breakthrough T1D in Australia. Tests can either be taken at home or at a participant's nearest pathology centre. Crucially, the charity supported this programme with an awareness and education campaign so that people and HCPs knew the programme existed.[14]
- The United States has several programmes available to test for the markers of T1D. TrialNet is available to those aged 2-45 who have a relative diagnosed with type 1 whereas the ASK programme provides a simple test to detect type 1 and coeliac and requires no family history of either disease. US programmes also embed psychological support for those testing positive to reduce anxiety.[15][16]

Learning from international efforts, a successful programme must demonstrate three traits:

- Nation-wide and comprehensive in order to minimise health inequalities
- Supported by an awareness campaign to ensure maximum sign up
- Screening should be paired with robust psychological and educational frameworks to ensure families are not overwhelmed.

Opportunities

Disease modifying drugs are already licensed and in use with certain conditions with certain populations. While there is currently no licensed treatment for type 1 diabetes (T1D) which can effectively cure the condition, there is now a licensed treatment that can delay the onset of T1D-related symptoms, and for the first time change the course of this life-long, life-changing condition.[17] There is a whole pipeline of these drugs that in the coming years will be available, but can only be effective when paired with a comprehensive screening programme. This

[13] D1Ce Screen. Istituto Superiore di Sanita.
[14] Screening for the early detection of type 1 diabetes. Type1Screen, https://type1screen.org/
[15] Type 1 Diabetes TrialNet. https://www.trialnet.org/
[16] Autoimmunity Screening for Kids. ASK Health, https://www.askhealth.org/
[17] Thakkar, Simran, et al.. *Teplizumab in type 1 diabetes mellitus: an updated review*, 2023, http://doi.org/10.17925/EE.2023.19.2.7

signals that disease modifying drugs that can make a real difference to people at stage 2 of T1D development will soon be available, so the UK must be ready to ensure that disease modifying drugs are readily accessible to those who can benefit from them.

Earlier awareness of, and education about, T1D, as well as access to networks of people experiencing the same thing, will provide numerous benefits for individuals and their families as they manage this condition should it occur during their lifetime. This will also help them to produce a plan for future monitoring of their condition and prevent hospitalisation from DKA. As previously stated, being diagnosed whilst presenting with DKA is associated with significant long-term challenges such as greater difficulties in managing blood glucose levels, greater risk of recurrent DKA episodes and more episodes of hypoglycaemia and as such, should be avoided at all costs.

Recommendations

1. A screening programme for early detection of type 1 diabetes (T1D) should be made available on the NHS for all children and young adults, with the aim of shifting diagnosis from stage 3 to stage 1 and 2 (presymptomatic stages) of T1D. This must be supported with an awareness campaign so that people know the service is available.

2. Clinical care pathways, education and support must be developed and offered for those who are identified at increased risk via screening, to help them prepare for clinical manifestation of the condition and identify best treatments for them and their families going forward. Clinicians must be supported to identify the most effective package of education and support for those identified as being at risk. This education and support must be provided consistently across different UK geographies.

3. NICE should update its T1D guidelines to include screening for T1D, incorporating pathways, education and support.

4. Patient involvement is key. People with T1D must be involved as partners in the design of an NHS T1D screening programme, to learn from best practice and ensure effectiveness of service. Charities and partners need to work with people with T1D - for example those who experienced DKA at diagnosis - to make the case for screening, addressing hesitancy.

5. Disease modifying drugs, which have been proven to demonstrate effectiveness in delaying the onset of T1D symptoms, must be supported by funders and regulatory organisations, including through MHRA and NICE appraisals.

Conclusion

The UK has the opportunity to identify children and young people with T1D before they ever become symptomatic. This will effectively eradicate being diagnosed during DKA and opens up huge possibilities when a host of disease modifying drugs become more readily available. A combination of screening and these emerging treatments will allow children and young people to live symptom free, without the need for insulin therapy, hypo- or hyper- glycaemia. The dramatic boost to quality of life this can bring for children, young people and their families is possible, but only if we start the process of identifying early stage T1D prior to stage 3 via a comprehensive, national screening programme.

If you would like further information, or to discuss this white paper, please contact Rachael Chrisp, Head of Policy and Public Affairs at Breakthrough T1D: rchrisp@breakthrought1d.org.uk