

Community lexicon
for autoimmune
type 1 diabetes
Reference Guide

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Welcome to the Reference Guide for the Community Lexicon for Autoimmune Type 1 Diabetes

[Click here to jump straight to the Recommended Terms](#) ➔

1. Some general information about this Reference Guide.....	3
1.1 A note on the information contained in this Reference Guide 🗑️.....	3
1.2 Who is this Reference Guide for?.....	4
1.3 What is this Reference Guide for?.....	4
1.4 How can I access the Community Lexicon training course?.....	4
1.5 What is autoimmune type 1 diabetes?.....	4
1.6 I need to translate the Community Lexicon into another language. How do I do that?.....	4
1.7 I would like to give some feedback on the Community Lexicon course or reference guide. How do I do that?.....	4
1.8 Why does the Community Lexicon exist? 💬.....	5
1.9 A note on nuance and lived experience 🙌.....	6
1.10 Adding context: A real world example 🌍.....	7
2. General Tone of Voice and Language Use.....	8
3. The Community Lexicon Recommendations: General Terms.....	9
3.1 General Terms: Descriptors for the condition itself.....	9
3.2 General Terms: How to describe people living with the condition.....	11
3.3 General Terms: How to describe people in different stages of the condition and redefining the term 'diagnosis'.....	13
4. The Community Lexicon Recommendations: Development.....	16
4.1 Development: Talking about the pathogenesis of autoimmune type 1 diabetes.....	16
4.2 Development: Descriptors for the progression and different stages of development of autoimmune type 1 diabetes.....	18
5. The Community Lexicon Recommendations: Screening.....	21
5.1 Screening: How to describe people recommended for screening.....	21
5.2 Screening: Descriptors for the screening process and screening results.....	23
5.3 Screening: Descriptors for the safety benefits of screening.....	26

6. The Community Lexicon Recommendations: General Impact.....	28
7. Country Specific Resources and Further Information.....	30
8. Index of Specific Terms.....	323

1. Some general information about this Reference Guide

1.1 A note on the information contained in this Reference Guide 🗒️

This Reference Guide has been created with real-world use in mind. Situations you may come across in your life or work, where you want to choose the most appropriate language when talking about autoimmune type 1 diabetes.

This Reference Guide covers key points from the Community Lexicon training, in the same order that they appear in the course. The focus however, is on the recommended vocabulary.

The Recommended Terms are listed in full so that you can apply them in presentations, conversations and communications as needed.

There is a detailed Index of Specific Terms with corresponding page numbers at the end of this Reference Guide.

[If you wish to start or revisit the Community Lexicon training, you can find the course here.](#)

1.2 Who is this Reference Guide for?

This document is for anyone who has taken the Community Lexicon for Autoimmune Type 1 Diabetes training course.

1.3 What is this Reference Guide for?

This is your personal Reference Guide for the Community Lexicon recommendations.

It is for you to refer to as and when necessary to help you select the most appropriate language when discussing autoimmune type 1 diabetes in any place, on any platform, to anyone - from healthcare professionals to people living with autoimmune type 1 diabetes. It's your companion guide to help you find the right vocabulary.

1.4 How can I access the Community Lexicon training course?

[If you'd like to return to any of the Community Lexicon modules, or go through the course again, you can find it here.](#)

1.5 What is autoimmune type 1 diabetes?

[Module 2 of the Community Lexicon training explains what autoimmune type 1 diabetes is, what causes it, and how it is treated.](#) We recommend you look at that module if you'd like more background information on the condition.

1.6 I need to translate the Community Lexicon into another language. How do I do that?

We have a translation guide available, please email info@type1lexicon.com for more information.

1.7 I would like to give some feedback on the Community Lexicon course or Reference Guide. How do I do that?

We welcome feedback - language use is constantly evolving and it is our hope that this training stays relevant and up-to-date. Please send your feedback to info@type1lexicon.com.

1.8 Why does the Community Lexicon exist?

As we learned in the course, the aim of the Community Lexicon is to create a collective understanding of the power that lies in our choice of words when addressing topics and challenges related to autoimmune type 1 diabetes, and the resulting impact this has on those living with the condition.

The Community Lexicon sets a global standard of vocabulary that is sensitive, inclusive and reflective of the needs of people living with autoimmune type 1 diabetes when interacting with others.

It can be easy to think of those coming through busy clinics for appointments as an endless list of patients. But the humans at the centre of the delicate conversations around screening and early detection are experiencing a serious diagnosis that will be life-changing in many ways.

What's more, they may have limited understanding of diabetes, have concerns or fears for their future health and emotional wellbeing, or may not be used to speaking in healthcare settings.

It is crucial to ensure that these conversations are as productive and supportive as possible, and the Community Lexicon provides a clear framework from which to do that.

Choosing the right words and communication style can make a powerful and positive difference to the emotional well-being, motivation and health outcomes of people affected by health conditions¹.

It is our hope that the Community Lexicon will make life better for people living with autoimmune type 1 diabetes. Using this document to guide your communications will ensure there's no additional shame, stigma and judgement on what is already a very challenging and complex condition.

Thank you for being a positive part of the conversation!

1. <https://pubmed.ncbi.nlm.nih.gov/33422586/>

1.9 A note on nuance and lived experience

We mentioned this in the course, but it's worth repeating: **often the correct choice of language is situation dependent.**

It's important to focus on progress, not perfection, so don't be afraid to try. If language is compassionate, clear and free of shame or judgment, then we are moving in the right direction.

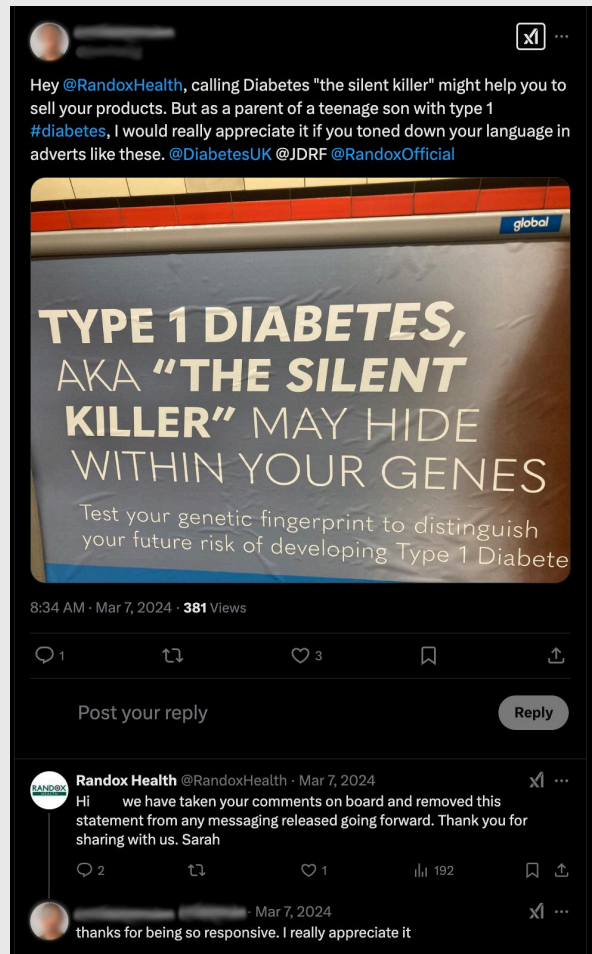
You can highlight in any given situation that you are still learning, which may in turn even encourage further the types of conversations we hope to facilitate with this work.

Furthermore, **autoimmune type 1 diabetes is unique to each individual who lives with it, and each person's feelings towards the language around it will differ.**

People living with autoimmune type 1 diabetes are of course free to choose the language that resonates with them - **the recommendations in this e-learning are reflective of a collective majority**, based on extensive research and validation.

So if you're unsure, stick with the recommendation. Afterall, that's why the Community Lexicon was created 😊

1.10 Adding context: A real world example 🚨



The media can be a source for positive awareness, but unfortunately it can often perpetuate stigma and confusion around autoimmune type 1 diabetes.

This is a real world example from a London Underground tube advert in the UK.

It was later removed after the company received complaints that it was using fear and stoking anxiety to push its product².

2. <https://www.bmj.com/content/384/bmj.g744>

2. General Tone of Voice and Language Use

Health-related language that resonates with most people is person-centered, neutral, non-stigmatizing and non-labelling.

Medical terminology can intimidate and contribute to power imbalances between care providers and people with diabetes³.

<i>Be More</i>	<i>Be Less</i>
Empathetic: Show that you understand the person, their condition and unique circumstances. Appreciate the challenges.	Stigmatising: Avoid language that portrays the condition as a negative aspect of the person's identity.
Person-centered and empowering: Equip people with the tools they need to make informed decisions, ask questions and help them find more support when needed.	Authoritarian and demanding: Avoid threats of long-term consequences. Avoid using words like 'should', 'must', 'allowed', 'cheat'.
Respectful: Offer information in a way people can understand. Acknowledge individual preferences and decisions. Recognise cultural practices and values. Understand people are trying to do the best they can with the resources available to them.	Judgemental: Avoid language that implies moral judgement of behaviour or perspective. Avoid language that implies a person is wholly responsible for having their condition or experiencing complications.
Accurate and neutral: Use plain language that describes the behaviour without judging, in an active voice, using words that are used in everyday language, with three or fewer syllables.	Jargon-centric: Use words like 'about' rather than 'approximately', 'take part' not 'participate'.
Collaborative and engaging: Invite and motivate people to actively participate in the management of their condition, and try to establish a clear call to action as a takeaway.	Labelling: Avoid using labels that define people based on their condition e.g. instead of 'diabetic' use 'person with diabetes'; instead of 'suffering from' use 'living with'.
Individualised: Tailor communication to health needs, language needs, dietary needs, religious practices, cultural beliefs. Use a screen reader, translation tools and localisation tools if needed.	Generalised: Avoid taking a one size fits all approach to healthcare interactions and appointments. Individual lifestyles and therefore needs are different.
Inclusive: To communicate effectively with under-resourced and historically marginalised communities.	Stereotyping: Avoid using language that assumes that all individuals with a condition fit a particular stereotype.

3. <https://pubmed.ncbi.nlm.nih.gov/32616274/>

3. The Community Lexicon Recommendations: General Terms

Like all conversations in life, individual discretion will often need to be applied in real-world settings. But what follows is the baseline from which to work from in all contexts, all situations, and all settings to make important progress.

3.1 General Terms: Descriptors for the condition itself

<i>Terms to Use</i>	<i>Terms to Avoid</i>	<i>Why?</i>
[Autoimmune] type 1 diabetes <i>Some discretion can be applied as to whether the word 'autoimmune' is needed on every instance, but it should be incorporated where appropriate in the context of screening and early detection.</i>	Diabetes as a standalone general term, when you are referencing autoimmune type 1 diabetes specifically.	Specifying the type of diabetes is crucial, as the different types of diabetes are not the same. It helps to avoid making broad statements that could be misleading or inaccurate. 'Autoimmune' is an important descriptor to highlight the autoimmune nature of type 1 diabetes in these early conversations. People living with the condition may not use the word 'autoimmune', and this is of course their choice, and we are not trying to change that.
On social media, the hashtag #T1D is appropriate for use as it is commonly used.	aT1D as an abbreviation for autoimmune type 1 diabetes.	'aT1D' is used infrequently, and inconsistently, and should therefore be avoided in external communications as it may cause confusion for the community.

<p>Describing autoimmune type 1 diabetes as a condition.</p> <p><i>In some contexts describing autoimmune type 1 diabetes as a disease is more appropriate, but it is not the community's preferred term, so please use sensitively.</i></p>		<p>The term 'condition' is the primary recommendation. It is more commonly used in community-facing materials and considered less stigmatising than 'disease', which can have negative connotations.</p> <p>In scientific communications the word 'disease' may be more accurate or appropriate. 'Condition' can also be difficult to translate, in which case 'disease' may be more suitable.</p>
<p>Describing the nature of autoimmune type 1 diabetes as complex.</p>	<p>Describing the nature of autoimmune type 1 diabetes as metabolic.</p>	<p>'Complex' is considered an important descriptor when explaining the nature of autoimmune type 1 diabetes, and is commonly used both in literature and online.</p> <p>The term 'metabolic' is more associated with type 2 diabetes, and is not considered easily understood in the explanation of autoimmune type 1 diabetes.</p>
<p>Describing the nature of autoimmune type 1 diabetes as lifelong.</p>	<p>The term chronic should only be used in specific contexts, for example when necessary for health insurance purposes.</p>	<p>'Lifelong' is considered an important descriptor when explaining the nature of autoimmune type 1 diabetes, and is commonly used both in literature and online.</p>

		'Chronic' has been widely adopted by people living with autoimmune type 1 diabetes for themselves, but it is considered less accessible than 'lifelong' for the community. 'Chronic' is also less frequently used in community-facing materials.
Progressive ONLY when referring to the 'progressive nature' of autoimmune type 1 diabetes development .	Progressive when describing the condition overall.	'Progressive' when describing the condition overall can convey that the condition is always declining or getting worse. It should only be used to describe the progressive decline in beta cells or beta cell function, aka the development of autoimmune type 1 diabetes.

3.2 General Terms: How to describe people living with the condition

<i>Terms to Use</i>	<i>Terms to Avoid</i>	<i>Why?</i>
<ul style="list-style-type: none"> • Person with autoimmune type 1 diabetes • Person living with autoimmune type 1 diabetes • Person having autoimmune type 1 diabetes 	<ul style="list-style-type: none"> • Diabetic • Sufferer • Patient • Brittle 	'Person with/living with/having' autoimmune type 1 diabetes are more neutral, and more contemporary terms that align with the shift to person-first language that we've seen across health conditions.

		<p>'Person with [autoimmune] type 1 diabetes' is commonly used by people living with the condition.</p> <p>Terms like 'diabetic' and 'sufferer' are widely considered unacceptable and emotionally-charged terms that are potentially offensive or triggering. Please avoid these terms in any communications.</p> <p>People with autoimmune type 1 diabetes may describe themselves as 'diabetic', but for some people, the term 'diabetic' suggests that they are defined by their condition.</p> <p>The term 'patient' has connotations of a person in receipt of passive care, whereas people living with autoimmune type 1 diabetes play a very active role in the daily management of their condition. It is not recommended to describe someone as a patient, but rather a person living with autoimmune type 1 diabetes.</p> <p>Although the term 'brittle' is sometimes still used, it is medically inaccurate and therefore should always be avoided.</p>
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3.3 General Terms: How to describe people in different stages of the condition and redefining the term ‘diagnosis’

There are further recommended terms around the different stages in later sections.

Terms to Use	Terms to Avoid	Why?
<p>STAGES 1 AND 2</p> <ul style="list-style-type: none"> • Person with early-stage autoimmune type 1 diabetes (Stage 1 or Stage 2) <p><i>The use of ‘Stage 1’ or ‘Stage 2’ is additional detail. Use of the stages alone should be avoided, but the inclusion of the specific stage in parenthesis is encouraged if you wish to reinforce staging or distinguish between Stage 1 and Stage 2.</i></p> <ul style="list-style-type: none"> • Presymptomatic should also only be used as additional explanation, after the qualifier early-stage. 	<p>STAGES 1 AND 2</p> <ul style="list-style-type: none"> • Use of Stage 1 or Stage 2 alone • Presymptomatic on its own, without the qualifier early-stage • Asymptomatic or pre-diabetic • Pre-insulin or insulin independent 	<p>‘Early-stage’ is the recommended primary choice to describe people in Stages 1 and 2, as it is simpler and more accessible.</p> <p>‘Presymptomatic’ should only be used as additional explanation, if accurate. This is also mentioned in the consensus guidance on monitoring led by Breakthrough T1D.</p> <p>The term ‘asymptomatic’ is used less frequently across community communications than ‘presymptomatic’ and is likely to be less accessible.</p> <p>The term ‘pre-diabetic’ is to be avoided to describe people at Stages 1 and 2, as a person has autoimmune type 1 diabetes as soon as autoantibodies are detected.</p> <p>‘Pre-diabetic’ is also an established term for type 2 diabetes and we need to avoid any confusion in the belief that lifestyle modifications can prevent or slow progression of the condition.</p>

<p>STAGE 3</p> <ul style="list-style-type: none"> • Person with autoimmune type 1 diabetes (Stage 3) <p><i>Use of 'Stage 3' alone should be avoided, but the inclusion of the specific stage in parenthesis is encouraged if you wish to reinforce staging.</i></p>	<p>STAGE 3</p> <ul style="list-style-type: none"> • Requiring insulin or insulin dependent in relation to early detection conversations • Use of Stage 3 alone • Symptomatic on its own, without context • Late-stage autoimmune type 1 diabetes 	<p>Not everyone in Stage 3 requires insulin immediately, so 'insulin dependent' may not always be an accurate descriptor. It can be useful when describing people in relation to whether or not they require insulin replacement therapy.</p> <p>While 'symptomatic' autoimmune type 1 diabetes might seem intuitive for Stage 3, it's not always accurate. The EDENT1FI consortium states that Stage 3 is defined by confirmed hyperglycaemia, with or without symptoms.</p> <p>If you are referring to Stage 3, you should refer to autoimmune type 1 diabetes. The term 'late-stage' should be avoided as it has inconsistent meanings across different sources and therefore may cause confusion.</p>
<p>Describing someone as being diagnosed or receiving a diagnosis of autoimmune type 1 diabetes - at Stage 1, 2 or 3.</p>	<ul style="list-style-type: none"> • Talking about pre-diagnosis or early diagnosis when referring to Stages 1 and 2. • The use of <ul style="list-style-type: none"> ○ diagnosis ○ clinical diagnosis ○ clinical autoimmune type 1 diabetes 	<p>For people identified as being in Stages 1 or 2, the lifetime likelihood of progressing to Stage 3 is almost 100%.</p> <p>Therefore, redefining the point of 'diagnosis' to an earlier stage of autoimmune type 1 diabetes can help foster a mindset shift in how people perceive the condition.</p>

	<p>when specifically referring to Stage 3.</p>	<p>Therefore the term 'diagnosis' should be used from the first point of detection.</p> <p>While 'newly diagnosed' was a common term for Stage 3 across scientific literature, it does not instill urgency for earlier active management thanks to screening and early detection advances.</p> <p>As such there should be a shift away from referring to Stage 3 as the point of diagnosis, as people can now be diagnosed prior to the onset of symptoms.</p> <p>Although the term 'clinical' is commonly referenced in relation to Stage 3 in scientific literature, its use is considered non-specific and not helpful for the autoimmune type 1 diabetes community and should not be used.</p>
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4. The Community Lexicon Recommendations: Development

Pathogenesis is the process by which a medical condition develops, and the study of how that occurs. In this case we're looking at the body's attack on the insulin-producing beta cells in the pancreas, which leads to the development of autoimmune type 1 diabetes.

4.1 Development: Talking about the pathogenesis of autoimmune type 1 diabetes

<i>Terms to Use</i>	<i>Terms to Avoid</i>	<i>Why?</i>
<ul style="list-style-type: none"> • Genetic component • Genetic differences • Increased likelihood <p>in relation to how the genetic component affects relatives.</p>	<p>(Situation Dependent)</p> <ul style="list-style-type: none"> • Genetic risk • Increased risk • Increased chance • Genetic predisposition • Genetic susceptibility <p><i>If the terms 'risk', 'predisposition' or 'susceptibility' need to be used, ensure that the language used around these terms does not create any guilt or fear.</i></p>	<p>'Genetic component' acknowledges that genetics are not the only factor involved in the pathogenesis of autoimmune type 1 diabetes.</p> <p>'Differences' is also suitable, for example: 'Certain genetic differences increase the likelihood of having autoimmune type 1 diabetes.'</p> <p>'Increased likelihood' is a softer and more accurate alternative to 'increased risk', which has the potential to instil guilt in parents who may have the understanding that they have 'passed down' the condition to their children. 'Increased chance' should be avoided for its association with luck.</p> <p>As noted in the previous column, there may be certain instances where the terms 'risk', 'predisposition' or 'susceptibility'</p>

		may need to be used. If that is the case please take steps to ensure this does not create guilt or fear.
<p>Autoimmune response and impact on insulin production:</p> <ul style="list-style-type: none"> • Immune system • [Mistakenly] attacks • Mistakenly attacks insulin-producing beta cells <p>This can be used in relation to the role of T-cells in autoimmunity, e.g. 'the immune system mistakenly attacks...'</p>	<ul style="list-style-type: none"> • T-cells • T-cell mediated 	<p>Use of the term 'immune system' is preferable to 't-cells'. 'T-cells' are commonly referred to in scientific literature, but they are not used in the general public spheres, for example on blogs or forums.</p> <p>The notion of the immune system 'attacking' insulin-producing beta cells is a simple way of explaining the autoimmune response, and it is free of blame. The addition of 'mistaken' is a way to soften the view of the body being 'broken', therefore reducing stigma.</p>
<ul style="list-style-type: none"> • Type 1 diabetes autoantibody or autoantibodies <p>The term 'autoantibodies' is medical terminology. There will be lots of people who are not familiar with the term, so it's important to provide an explanation. 'Autoantibodies' are the immune cells that mistakenly attack the body, rather than protecting it.</p>		<p>The presence of 'autoantibodies' is the marker of autoimmune type 1 diabetes.</p> <p>'Insulin-producing beta cells' relates to the impact of the autoimmune response on beta cells.</p>

<ul style="list-style-type: none"> ● Insulin-producing beta cells <p>This can be shortened to 'beta cells' after first use.</p>		
<ul style="list-style-type: none"> ● The use of <ul style="list-style-type: none"> ○ Reduction ○ Decline ○ Decrease <p>in insulin production or insulin-producing beta cells.</p>	<ul style="list-style-type: none"> ● Destruction in relation to insulin production or insulin-producing beta cells 	<p>The term 'destruction' may give the misconception that there is complete abolition of cells with those less familiar with autoimmune type 1 diabetes, which is not necessarily the case.</p> <p>Apart from the use of 'mistakenly attacks the insulin-producing beta cells' mentioned above, in general, combative language like this can be fear-mongering, and should be avoided where possible.</p>

4.2 Development: Descriptors for the progression and different stages of autoimmune type 1 diabetes

<i>Terms to Use</i>	<i>Terms to Avoid</i>	<i>Why?</i>
<ul style="list-style-type: none"> ● The development of autoimmune type 1 diabetes as progressive ● Using staging to convey the progressive nature of autoimmune type 1 diabetes in parenthesis as additional explanation, referred to as: 	<ul style="list-style-type: none"> ● Referring to Stages 1 or 2 or presymptomatic alone, without the qualifier 'early-stage' ● Referring to Stage 3 alone ● Person with symptomatic autoimmune type 1 diabetes as a blanket referral to Stage 3 	<p>There are three stages, and these are the recommended way to discuss the progression of the condition as we now understand it.</p> <p>Stages 1 and 2 are early-stage, while Stage 3 is simply autoimmune type 1</p>

<ul style="list-style-type: none"> ○ Person with early-stage autoimmune type 1 diabetes (Stage 1) ○ Person with early-stage autoimmune type 1 diabetes (Stage 2) ○ Person with autoimmune type 1 diabetes (Stage 3) 		<p>diabetes. Stage 3 is defined by confirmed hyperglycaemia with or without symptoms, although symptoms often occur.</p> <p>These symptoms could include (but are not limited to) increased thirst, losing weight, urinating more frequently, feeling tired, blurred vision, slow healing of cuts, nausea and fruity breath, among others.</p>
<ul style="list-style-type: none"> ● Use of progressive when describing the <i>development</i> of the condition. <p>Clarity around the use of the term 'progressive' is important.</p>	<ul style="list-style-type: none"> ● Use of progressive when describing the condition overall. 	<p>The term 'progressive' is helpful when describing the progressive decline in beta cells, and the progression through stages, from autoantibody development to higher levels of glucose in the blood, and most likely the eventual onset of symptoms.</p>
<ul style="list-style-type: none"> ● Changes in glucose levels in relation to staging 	<ul style="list-style-type: none"> ● Changes in Sugar levels 	<p>The terms 'glucose levels' and 'sugar levels' may have historically been used interchangeably in some languages.</p> <p>However 'glucose levels' is a more specific term than 'sugar levels'. It's recommended to avoid 'sugar levels' due to the association between sugar and type 2 diabetes, which may cause confusion.</p>

		The general public may have a misguided understanding of the term 'sugar' in this context, for example if they only have awareness of sugar in relation to simple sugars that come from food sources.
<ul style="list-style-type: none"> • Reference to specific levels of glucose in the blood 	<ul style="list-style-type: none"> • Discussing glycaemic differences using medical terminology, such as normoglycaemia, dysglycaemia and hyperglycaemia • Reference to 'normal' glucose levels • Reference to 'irregular' glucose levels 	<p>This medical terminology is unlikely to resonate with people with the condition. 'Glucose levels' is a more accessible term, and is widely used.</p> <p>The term 'normal' should be avoided when referring to glucose levels, as the interpretation of not being 'normal' can cause additional distress. We can instead talk about the specific level of glucose in the blood, in relation to confirmed elevated glucose levels for example.</p>

5. The Community Lexicon Recommendations: Screening

The concept of staging is relatively new in relation to autoimmune type 1 diabetes, which means that there's not currently a lot of awareness around the different stages and what they mean.

Unlike other areas of diabetes where language is (rightly or wrongly) established and requires a slow change through education, in this area we have the opportunity to set a precedent for how these topics should be discussed.

Anyone with multiple type 1 autoantibodies, which we can now detect through screening, has autoimmune type 1 diabetes - before any symptoms develop, and likely without their knowledge for a number of months or years. So a person who is in Stage 1, with no symptoms, is still 'living with autoimmune type 1 diabetes'.

5.1 Screening: How to describe people recommended for screening

<i>Terms to Use</i>	<i>Terms to Avoid</i>	<i>Why?</i>
<ul style="list-style-type: none">• Family history of autoimmune type 1 diabetes• People who have a relative with autoimmune type 1 diabetes• Mentioning specific relatives in the context of people who require screening, such as siblings or parents.	<ul style="list-style-type: none">• Close relative• First degree relative• Second degree relative	<p>'Family history' and 'relative' are accessible and recognisable terms, and they're considered broad enough to encompass all family members. This doesn't limit the people recommended for screening, or exclude anyone who would benefit from screening.</p> <p>Specificity of any relatives who require urgent screening is recommended to highlight the urgency, such as siblings or parents.</p>

		In contrast the term 'close relative' is subjective and open to interpretation. Similarly the phrases 'first' or 'second' degree relative can also cause confusion, and are not as widely used. Therefore it's recommended to avoid these terms.
<ul style="list-style-type: none"> • Increased likelihood of autoimmune type 1 diabetes <p>This can be applied specifically in relation to having another risk factor such as coeliac, thyroid disease or another autoimmune condition.</p>	<ul style="list-style-type: none"> • People at risk • People with a high risk • Increased chance of autoimmune type 1 diabetes • Increased risk of autoimmune type 1 diabetes 	<p>The terms 'at risk', 'increased risk' and 'high risk' are used across published scientific literature and community-facing materials, but in discussion this may cause worry, so 'likelihood' is preferred. This could be situation dependent, if for example you need to express urgency or gravity.</p>

5.2 Screening: Descriptors for the screening process and screening results

Terms to Use	Terms to Avoid	Why?
<ul style="list-style-type: none"> • Early detection of autoimmune type 1 diabetes [through screening] 	<ul style="list-style-type: none"> • Autoantibody testing 	<p>The term 'early detection' is simple to understand. It's less medical than 'autoantibody testing', while 'early diagnosis' could be inaccurate.</p>
<ul style="list-style-type: none"> • Blood test only in relation to the finger prick process itself • Screening for autoimmune type 1 diabetes autoantibodies • Autoimmune type 1 diabetes autoantibodies have been detected • Autoimmune type 1 diabetes autoantibodies have not been detected 	<ul style="list-style-type: none"> • The term test on its own, or to describe anything other than the finger prick process • Blood check • Positive or negative <i>in relation to screening results, if possible. It may not always be possible to avoid these terms.</i> 	<p>When discussing specifically how screening is done, use the phrase 'blood test' only in relation to the fingerprick process itself.</p> <p>The phrase 'blood test' is common lexicon and very recognisable, more so than terms like 'blood check'. However it can imply passing or failing, so should be used with care, and only in relation to the finger prick process. We are 'screening' for type 1 diabetes autoantibodies, not 'testing'.</p> <p>The phrase 'autoimmune type 1 diabetes autoantibodies have (or have not) been detected' is specific and factual. It is recommended over saying something like 'the results are positive' or 'the results are negative', which are more open to misinterpretation, even though these terms are less medical.</p>

		<p>In certain instances where this is not possible, for example if you're explaining screening results from a third party that uses these terms, ensure that sufficient context is provided to avoid any misunderstanding.</p>
<ul style="list-style-type: none"> • Monitoring for changes in glucose levels • Glucose monitoring • 'Tracking' or 'keeping track of' autoimmune type 1 diabetes progression 	<ul style="list-style-type: none"> • Monitoring for changes in sugar levels • Sugar monitoring • Using the term 'monitoring' alone 	<p>'Glucose' is a more specific term in this context, and many people living with autoimmune type 1 diabetes are used to hearing the term 'glucose', for example in relation to HbA1c tests, 'continuous glucose monitoring' and in some countries, 'glucometer'.</p> <p>It's recommended to avoid 'sugar levels' due to the association between sugar and type 2 diabetes, which may cause confusion</p> <p>The general public may have a misguided understanding of the term 'sugar' in this context, for example if they only have awareness of sugar in relation to simple sugars that come from food sources.</p> <p>The terms 'tracking' or 'keeping track of' the progression of autoimmune type 1 diabetes through the stages reinforces that people involved are being actively</p>

		<p>supported through the care pathway. You can include 'through glucose monitoring' to provide clarity and context here.</p> <p>'Monitoring' is considered a useful term in communications, but only with sufficient context. For clarity please specify 'glucose monitoring', rather than just using the word 'monitoring'.</p>
<ul style="list-style-type: none"> The term repeat screening in relation to people who are being screened again to detect the presence of new type 1 diabetes autoantibodies. 	<ul style="list-style-type: none"> Re-screening Follow-up screening 	<p>'Screening' is a well recognised term, and the qualifier 'repeat' is an accurate and simple term that simply states that screening is being performed again.</p> <p>The term 're-screening' can give the impression that previous screening was unreliable, and 'follow-up screening' may cause confusion about what the follow-up entails.</p> <p>When discussing 'repeat screening', it's best to include more detail and specify the group that are being referred to.</p> <p>For example, a group whose first screening detected one autoantibody and so they're being screened again to check for the development of a second autoantibody.</p>

5.3 Screening: Talking about the safety benefits of screening

Talking about the progression of autoimmune type 1 diabetes can be very daunting for those involved.

These conversations of course need to be approached carefully to make sure that feelings of fear around living with the condition are heard and understood. At the same time, it's also important to communicate the importance of monitoring as a person progresses beyond Stages 1 and 2, to reduce the likelihood of a medical emergency such as diabetic ketoacidosis (DKA).

<i>Terms to Use</i>	<i>Terms to Avoid</i>	<i>Why?</i>
<ul style="list-style-type: none"> Allows for tracking autoimmune type 1 diabetes progression through monitoring for changes in glucose levels Reduces the likelihood (of starting the care path with) a medical emergency <p>When discussing keeping people safe through monitoring:</p> <ul style="list-style-type: none"> 'Supporting emotional wellbeing throughout the progression of autoimmune type 1 diabetes'. 'Looking after your health at every stage' 	<ul style="list-style-type: none"> Language deemed to be scary when mentioning a medical emergency such as 'fatal' or 'dangerous', where possible Use of the word 'prevention' when referring to a medical emergency Use of the word 'safe' when discussing keeping people safe through monitoring 'Reduces the chance of (starting the care path with) a medical emergency' 	<p>'Tracking autoimmune type 1 diabetes' is a simple term that reinforces that people are being actively supported along the care pathway.</p> <p>Specific context is encouraged, for example if you're referring to monitoring for changes in glucose levels.</p> <p>The term 'medical emergency' is considered accessible to the community. If you are speaking about specifics like DKA, ensure that an adequate explanation is given.</p> <p>The recommended terms to convey the concept of keeping people safe allow the safety benefits of screening to be conveyed in a positive way without using the word 'safe' - which should be used with caution to avoid over-claiming.</p>

		The term 'prevention' is to be avoided, as there is no guarantee of prevention. Please avoid using the term 'chance'.
<ul style="list-style-type: none"> • Feeling empowered and informed regarding how screening might make people feel • Mention of benefits relating to early identification and easing people into life with autoimmune type 1 diabetes alongside support and education, e.g. having time to prepare, or putting people and their healthcare providers in the driving seat • Screening as a proactive way to detect and manage autoimmune type 1 diabetes, for example to identify when insulin therapy might be needed 		<p>These terms may help to encourage those who would benefit from screening to get screened, and help people prepare for what's to come if autoimmune type 1 diabetes autoantibodies are detected.</p> <p>The idea of being proactive and having time to prepare is in contrast to the shock of diagnosis that many people have faced, with or without a medical emergency.</p> <p>Mention of benefits relating to early identification, and easing people into life with the condition with support and education, may resonate well with the community.</p>

4. <https://diabetesjournals.org/care/article/40/12/1790/36977/The-Use-of-Language-in-Diabetes-Care-and-Education>

6. The Community Lexicon Recommendations: Talking about the general impact of the condition

<i>Terms to Use</i>	<i>Terms to Avoid</i>	<i>Why?</i>
<ul style="list-style-type: none"> Autoimmune type 1 diabetes can affect emotional wellbeing Autoimmune type 1 diabetes can affect mental health - use sensitively, and only when appropriate Autoimmune type 1 diabetes can affect quality of life - use sensitively, and only when appropriate 	<ul style="list-style-type: none"> The burden of autoimmune type 1 diabetes <p><i>Please note these are in the context of screening and early detection conversations, not the condition in general. Descriptors and language use may differ once a person has been living with the condition for some time.</i></p>	<p>'Emotional wellbeing' is a big topic among online communities, and was mentioned more frequently than terms such as 'burden'. Please refer to 'emotional wellbeing' rather than simply 'wellbeing'.</p> <p>While many people living with the condition feel that it can be a burden, in the process of screening and development this language may be frightening or confronting.</p> <p>Use phrasing such as 'autoimmune type 1 diabetes can affect quality of life', or 'can affect mental health' sensitively. These are important conversations to have and should not be dismissed, but the timing of these conversations is important.</p> <p>These recommendations are all in the context of screening conversations. Descriptors and language use may differ once a person has been living with the condition for some time.</p>

<i>Terms to Be Aware Of</i>	<i>Terms to Avoid</i>	<i>Why?</i>
<p>In relation to the impact of diagnosis:</p> <ul style="list-style-type: none"> • ‘Surprise’, ‘shock’, ‘fear’, ‘unexpected’, ‘experience’, ‘trauma / traumatising’, ‘guilt’, ‘exhausting’, ‘tired / worn out’, ‘uncertain’, ‘scared’, ‘anger’ and ‘sadness’ <p>Some time after diagnosis, people may feel:</p> <ul style="list-style-type: none"> • ‘Resilient’, ‘comfortable’ and ‘acceptance’. 	<p>Avoid using dismissive or minimising language.</p>	<p>When discussing the impact of diagnosis, it’s important to recognise the stresses and the emotional impact of the condition, not just the physical health concerns.</p> <p>Avoid using dismissive or minimising language. There are a range of emotions a diagnosis can cause, and of course everybody’s individual feelings are different. There is no timeline as to when these feelings may be experienced, if at all.</p>

7. Country Specific Resources and Further Information

<u>Language Matters Global Website</u>
<u>Language Matters Australia</u>
<u>Language Matters Brazil</u>
<u>Language Matters Canada</u>
<u>Language Matters France</u>
<u>Language Matters Germany</u>
<u>Language Matters Greece</u>
<u>Language Matters India (English)</u>
<u>Language Matters India (Tamil)</u>
<u>Language Matters Ireland</u>
<u>Language Matters Italy</u>
<u>Language Matters Latin America</u>
<u>Language Matters Netherlands</u>
<u>Language Matters New Zealand</u>
<u>Language Matters Pakistan</u>

Language Matters Portugal
Language Matters Sweden
Language Matters South Africa
Language Matters Turkey
Language Matters UK
End Diabetes Stigma Project
A mixed-methods study: Diabetes language matters to adults with diabetes
ACBRD Diabetes And Emotional Health Guide
Language Matters - A Diabetes Canada Consensus Statement
Screening for Type 1 Diabetes in the General Population: A Status Report and Perspective
The Use of Language in Diabetes Care and Education
Talking About Diabetes Sweden
Our language matters: Improving communication with and about people with diabetes. A position statement by Diabetes Australia

8. Index of Specific Terms

<i>Term</i>	<i>Page</i>
#T1D	9
Acceptance	29
Affect mental health	28
Affect emotional wellbeing	28
Anger	29
Asymptomatic	13
aT1D	9
At risk, risk	16, 22
Autoantibody, autoantibodies	13, 17, 19, 23, 24, 25, 27
Autoimmune screening	23
Autoimmune [type 1 diabetes]	9
Being diagnosed	14, 15
Beta cells	17, 18, 19
Blood test (for autoantibodies)	23
Blood check	23

Brittle	11, 12
Burden	28
Chance	16, 22, 26, 27
Changes in glucose levels, changes in sugar levels	19, 20, 24, 26
Chronic	10, 11
Clinical autoimmune type 1 diabetes	14, 15
Clinical diagnosis	14
Close relative	21, 22
Comfortable	29
Complex	10
Condition	10
Dangerous	26
Decline [in insulin production or insulin-producing beta cells]	18, 19
Decrease [in insulin production or insulin-producing beta cells]	18, 19
Destruction, destroy (in relation to insulin production or beta cells)	18
Detection [through screening]	15, 23
Development	11, 16, 17, 18, 19
Diabetes	9, 10, 11, 12, 13, 14

Diabetic	11, 12, 13
Diabetic Ketoacidosis (DKA)	26
Diagnosis	13, 14, 15, 27, 29
Disease	10
Dismissive Language	29
DKA	26
Driving seat	27
Dysglycaemia	20
Early detection [through screening]	15, 23
Early diagnosis	13, 14, 15, 23
Early-stage autoimmune type 1 diabetes (Stage 1 or Stage 2)	13, 18, 19
[Person with] Early-stage autoimmune type 1 diabetes (Stage 1 or Stage 2)	13, 18, 19
Empowered	27
Emotions	29
Exhausting, Exhaustion	29
Experience	29
Family history, family, relatives	21
Fatal	26

Fear	29
Feeling empowered	27
Feeling informed	27
First degree relative	21
Follow-up screening	25
Genetic component	16
Genetic differences	16
Genetic predisposition	16
Genetic risk	16, 22
Genetic susceptibility	16
Glucose levels	19, 20, 24, 26
Glucose monitoring	24, 25, 26
Glycaemic differences	20
Guilt	16, 17, 29
Health	26, 27, 28
High risk	22
Hyperglycaemia	20
Identifying, identification	27

Immune system	17
Impact	28, 29
Increased chance	16, 22
Increased likelihood	16, 22
Increased risk	16, 22
Informed	27
Insulin dependent	14
Insulin Independent	13
Insulin-producing beta cells	17, 18, 19
Irregular glucose levels	20
Late-stage autoimmune type 1 diabetes	14
Lifelong	10, 11
Likelihood	14, 16, 22, 26
Keeping people safe	26
Keeping track of	24
Medical emergency	26, 27
Mental Health	28
Metabolic	10

Minimising Language	29
Mistakenly attacks	17, 18
Mistakenly attacks insulin-producing beta cells	17, 18
Monitoring, monitoring for changes in glucose/sugar levels	24, 25, 26
Negative screening results	23
Normoglycaemia	20
Pathogenesis	16
Patient	11, 12
People at risk, people with a high risk, people with an increased risk	16, 22
Person having [autoimmune] type 1 diabetes	11
Person living with [autoimmune] type 1 diabetes	11
Person with [autoimmune] type 1 diabetes	11
[Person with] presymptomatic autoimmune type 1 diabetes (Stage 1 or Stage 2)	13, 18
[Person with] symptomatic autoimmune type 1 diabetes (Stage 3)	14, 18
Positive screening results	23
Pre-diabetic	13
Pre-diagnosis	14
Pre-insulin	13

Prepare, time to prepare	27
Presymptomatic autoimmune type 1 diabetes (Stage 1 or Stage 2)	13, 18
Prevention (of a medical emergency)	26, 27
Proactive	27
Progression	18, 19, 24, 25, 26
Progressive	11, 18, 19
Quality of life	28
Receiving a diagnosis	14
Reduced chance, Reduces the chance (of a medical emergency)	26, 27
Reduced likelihood, Reduces the likelihood (of a medical emergency)	26
Reduction [in insulin production or insulin-producing beta cells]	17, 18
Relatives (Close relative, family history, first degree, second degree)	21, 22
Re-screening	25
Repeat screening	25
Requiring insulin	14
Resilient	29
Risk	16, 22
Sad, sadness	29

Safe	26
Safety benefits (of screening)	26, 27
Scared	29
Screening	21, 22, 23, 24, 25, 26, 27
Screening benefits	26, 27
Screening for early detection	23
Screening process	23, 24, 25
Screening results	23, 24
Second degree relatives	21, 22
Shock	27, 29
Stage 1, Stage 2, Stage 3	13, 14, 18, 19,
Stages of autoimmune type 1 diabetes	13, 14, 18, 19
Sugar monitoring	24, 25
Sufferer	11, 12
Sugar levels	19, 24
Support, supporting emotional wellbeing	26, 27
Surprise	29
Symptomatic autoimmune type 1 diabetes	14, 18, 19

T-cells	17
T-cell mediated	17
Time to prepare	27
Tired	19, 29
Tracking	24, 25, 26
Tracking progression	24, 25, 26
Trauma, traumatising	29
Type 1 diabetes autoantibody or autoantibodies	13, 17, 19, 23, 24, 25, 27
Uncertain	29
Unexpected	29
Wellbeing	26, 28
Worn Out	29