Shaping Clinical Trial Participation in Type 1 Diabetes

Lived experience Participation Information Sheet

We are inviting people with, or caring for someone with, type 1 diabetes (T1D) to share thoughts, opinions and/or experiences of clinical trials in the UK.

This leaflet outlines who we are, why we are looking into clinical trials in the UK, and how you can help. It is also available online on our website.

Why are we looking into clinical trial participation in the UK?

Clinical trials are an essential part of developing new therapies and technologies to prevent, manage and cure T1D. But the number of people participating in clinical trials in the UK is going down. We need your help to understand why.

We are looking for people who live with, or care for someone with, T1D, to share their thoughts and/or experiences of clinical trials in a focus group.

From these focus groups we hope to understand:

- What you know, and what you don't know, about clinical trials
- What you want to know about clinical trials before deciding to take part in one
- How you would want to hear about opportunities to take part in clinical trials.
- What would motivate you to take part in a clinical trial
- What would stop you from taking part in a clinical trial

Who can take part?

To be eligible to take part in the focus group, you must:

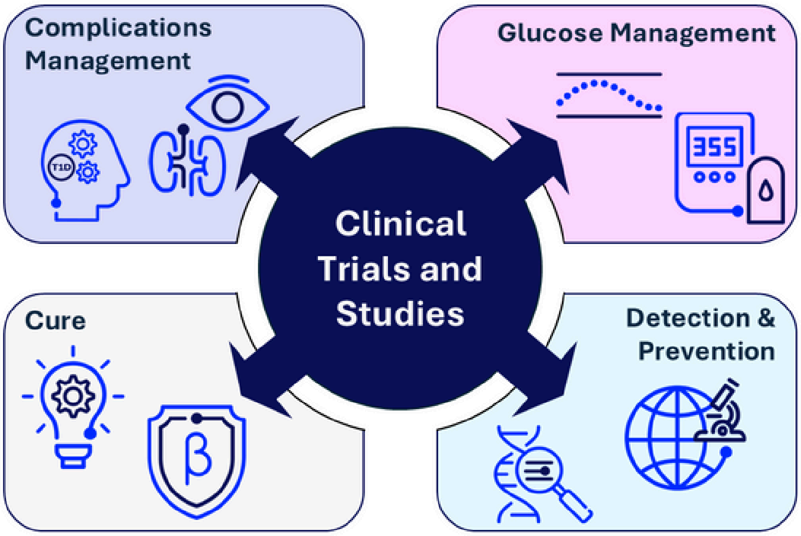
- Live with T1D, *or*
- Care for someone who lives with T1D, *or*
- Be at risk of developing T1D*, *or*
- Care for someone who is at risk of developing T1D*,
- *and* Live in England, Scotland, Wales or Northern Ireland,

**determined by a specialist screening programme or your health provider.*

Why should I be involved?

Without clinical trials we cannot bring new therapies or technologies for T1D to the people who need them. Advances in glucose management such as hybrid closed loop systems, continuous glucose monitors and fast-acting insulins would not have been possible.

Your insight is invaluable in helping us understand and address the barriers to participation. With your support, we can work together to improve clinical trial involvement across the UK.



What will I be asked to do?

To express your interest in participating, please complete this form by 1 October 2025.

The form contains questions about you and your experience of T1D and clinical trials. It should take approximately 5 minutes to complete. If we receive a lot of responses, we may use your answers as part of a selection process. This is to ensure we gather insights from a diverse group with different experiences.

Before attending a focus group, you will need to complete and return a consent form. The focus group will be a 90-minute, online session with seven to nine other participants. These will take place in October/November 2025 (date to be confirmed).

After the focus group has been held, and only if you would like to, you may be:

- Invited back for an individual, one-hour, online discussion. This may occur if we want to hear more about your thoughts and experiences. If this is the case, we will contact you within one week of the date of the focus group.
- Asked to complete a feedback form on the focus group, and the process leading up to it.
- Sent email updates on the progress of this project. A maximum of two emails will be sent per year, until the project finishes.

You can change your mind at any point in this process, and decide not to attend, or participate in, the focus group.

Any questions please feel free to contact researchcommunications@breakthrought1d.org.uk.

Breakthrough T1D™
Formerly JDRF

Who we are

Breakthrough T1D (formerly known as the Juvenile Diabetes Research Foundation, or JDRF) is the leading global T1D research and advocacy charity.

Our mission is to improve lives by accelerating life-changing breakthroughs to treat, prevent and ultimately cure T1D and its complications.

This project has been developed by Breakthrough T1D with funding from Vertex Pharmaceuticals, who has had no input or control over the contents.

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