

T1D Expert by Experience Advisory Panel Terms of Reference

1. Purpose

We believe that involving people with lived experience of type 1 diabetes in the research cycle, leads to more relevant and impactful research, which is more likely to receive funding. The T1D Expert by Experience Advisory Panel has been developed to support the research funded through the **Type 1 Diabetes Grand Challenge**. Members will guide various patient and public involvement and engagement (PPIE) activities through consultation and co-production.

The Panel will support the review of the research funded through the Grand Challenge (initial grant application review is undertaken by the [Grants Advisory Panel](#)), be involved in co-producing the Patient and Public Involvement and Engagement (PPIE) sessions for Grand Challenge related events, and support ad-hoc activities as they arise. Please refer to the full role description for more information.

2. Membership

- Membership is undertaken on a voluntary basis.
- The Panel will be composed of up to 10 members.
- The Panel will be composed to reflect various experiences and opinions of people with lived experience of type 1 diabetes including parents of children with type 1 diabetes.
- Ideally the Panel will include members from each nation, and from underserved communities. Where this is not possible, we will aim to co-opt members when required.

- Members shall serve one term of three years. It is possible to serve for a second term of office (additional 3 years). Members will not serve more than 6 consecutive years on the Panel. After a second term of office, 3 years must elapse before applying again to join the Panel.
- Members are expected to attend meetings, wherever possible. If a member is absent from two consecutive meetings, the Diabetes UK Grand Challenge Team will discuss their membership term of office to ensure that any mitigating circumstances are satisfactory.
- Members are expected to prepare for meetings where necessary, including any pre-reading. We will send materials 2-weeks prior to the meetings.
- Members of the Charity's staff may not be members of the T1D Expert by Experience Advisory Panel.

Diabetes UK is actively and openly committed to promoting equality, diversity and inclusion. We aim to be a diverse and inclusive funder, both in terms of the people who deliver and are involved in our funded research.

3. Meetings

There will be a minimum of four meetings held each year. Members will be reimbursed of out-of-pocket expenses incurred while carrying out activities for Diabetes UK, for example travel costs, lunch and accommodation if required.

- Two in-person meetings
- Two online-meetings

If you are unable to attend a meeting, it is your responsibility to inform the [Grand Challenge Team](#) at Diabetes UK.

4. Secretary, Chair and Vice Chair

- The Senior Research Manager (or equivalent post-holder) shall serve as Secretary to the Panel or may appoint such other staff member to this role as she/he sees fit.
- The Chair is a member of the Panel and appointed by Diabetes UK. Together with the Secretary, they will co-design meeting agendas, and co-deliver meetings where appropriate.

- If the Chair is unable to attend a meeting (or part of a meeting), the Vice Chair will step in to co-chair the meeting with the Secretary.

5. Confidentiality

Panel members will be required to sign a non-disclosure agreement upon joining the group. This is to ensure confidentiality of any discussions taking place.

6. Code of Conduct

Members shall:

- Promote equality by not discriminating unlawfully against any person.
- Treat others with respect.
- Give others an opportunity to voice their opinion.

Members shall not:

- Disclose confidential information, or information given to them in confidence, without the prior consent of the Head of Research Funding or Senior Research Manager, or unless required by law to do so.
- Prevent any person from gaining access to information to which he/she is entitled by law.
- Not do anything which compromises, or which is likely to compromise, the impartiality or integrity of the Panel or any of its members.

7. Recruitment

The appointments process shall be established by the Type 1 Diabetes Grand Challenge Research Team at Diabetes UK. The process shall be publicised by appropriate means.

8. Data Protection

All parties will comply with the Data Protection Act 2018 (and any guidance issued from time to time by the Information Commissioners Office) in relation to their processing of personal data. All parties will process any personal data collected in relation to Panel members only for the purposes of achieving the Panel's aims, and for administering the Panel. Diabetes UK will be the controller

of personal data of Panel members in relation to the administration of the Panel and undertakes to comply with its responsibilities in relation to processing of any such personal data.

9. Variation

Diabetes UK reserves the right to amend these Terms of Reference at any time at its discretion or make any necessary alterations to the way the T1D Expert by Experient Advisory Panel is running temporarily due to extraordinary circumstances. Diabetes UK will publish any permanent changes to the Terms of Reference on its website and will notify the Chair that a change has taken effect.

Version	Changes	Effective date	Author	Approver	Next review date
1.0	n/a	December 2022	Liz Eves (Patient and Public Involvement Lead)	Kamini Shah (Head of Research Funding)	November 2025
2.0	Updated all sections	July 2025	Kamini Shah (Head of Research Funding)	Anna Morris (Assistant Director of Research)	December 2026