

T1D Expert by Experience Advisory Panel Role Description

About the Type 1 Diabetes Grand Challenge

The <u>Type 1 Diabetes Grand Challenge</u> is a bold £50 million partnership between the Steve Morgan Foundation, Diabetes UK, and Breakthrough T1D.

Our shared mission: to accelerate the development of life-changing treatments and ultimately find a cure for type 1 diabetes.

One major focus of the Grand Challenge is beta cell therapies—research aimed at restoring the body's ability to make insulin by providing healthy beta cells. So far, we've committed over £16 million in this area, supporting fellowships to develop the next generation of scientific leaders, backing bold ideas, and driving translational research to bring breakthroughs closer to clinical use. We're also building the infrastructure needed to test emerging therapies across the UK and partnering to make vital stem cells available for research. Progress is well underway, and every step brings us closer to better treatments, and potentially, a cure for type I diabetes.

About the role

The Panel is comprised of people living with or parents/carers of children with type 1 diabetes. They will bring their collective insight and perspective to the research funded through the Grand Challenge which will help improve the lives of people affected by type 1 diabetes.

Involvement of the Panel **will be** specific to the beta cell therapies focus area (managed by Diabetes UK) and will include a range of consulting and coproducing activities. The level of involvement will be agreed in advance of







commencing the activity. This Panel **will not** be focusing on the root causes or novel insulins aspects of the initiative (managed by Breakthrough T1D).

Main tasks and activities:

- Support the Beta Cell Therapy Grand Challenge funded researchers by:
 - Reviewing the progress of the patient and public involvement and engagement (PPIE) activities outlined in the translational programme grants annually, providing constructive feedback and guidance. You will be provided with training to undertake this task.
 - Providing ad-hoc PPIE feedback and guidance for the other Beta Cell
 Therapy Grand Challenge funded grants as required.
- Co-produce the PPIE session at the annual Beta Cell Therapy and Root Causes Symposium with the Grand Challenge team.
- Input and help shape the UK Type 1 Diabetes Cell Therapy Clinical Trial Network. This is being established through the Grand Challenge to ensure that the UK is ready to test new beta cell therapies to enable those living with type 1 have access to cutting edge treatments. This will involve:
 - The Panel being consulted so that the needs and wants of those living with type I diabetes are heard and the Network is built to serve this community.
 - One or two nominated members of the Panel joining our Task and Finish Group to set-up the Network. The Group composed of healthcare professionals, researchers and experts by experience with the Panel member/s selected, responsible for sharing the views of the Panel and to represent people affected by type 1 diabetes more broadly.
 - To note we will provide a summary of the role and time commitment required to allow interested Panel members to determine if this is the right opportunity for them.
 - The representative/s chosen will be closely supported by a nominated representative from the Type 1 Diabetes Grand Challenge team at Diabetes UK.
- You will have the opportunity to support ad-hoc opportunities as they
 arise. These opportunities will be optional and could range from being
 invited to support one of the Grand Challenge funded researchers on an
 aspect of their research, or to input into how we showcase the impact of
 the research progress made to date etc.

Meetings

We will aim to book all meetings in advance and build in flexibility where possible.

We will arrange up to two in-person meetings (including the Beta Cell Therapy Symposium) and a minimum of two shorter online meetings a year. The purpose of these meetings will be for training and to give updates on Grand Challenge research and any other activities. These meetings can also be used to brainstorm new areas of work or plan towards an upcoming activity as needed.

About you

You will have:

- Lived experience of type 1 diabetes or be a parent/carer of a child with type 1 diabetes.
- An interest in diabetes-related research.
- The ability to represent people affected by type 1 diabetes more broadly and tap into your type 1 diabetes networks to gain insights where possible.
- The ability to listen to others, respect differing or conflicting opinions, and encourage others to share their views.
- A willingness to engage positively and challenge where necessary.
- A drive to learn, develop, and seek help when encountering issues you do not understand.
- The capacity to commit your time for meetings and/or activities.
- The willingness to provide feedback and raise any concerns with the Type
 1 Diabetes Grand Challenge Team within Diabetes UK.

Diversity of the Panel

It is important that the Panel represents the diversity of people affected by type I diabetes. Members of the group will be recruited to ensure representation of:

- People of all ages, including young people aged 18-35
- People from Black, Asian and minority ethnic groups
- People from different social economic backgrounds
- People from all four nations in the UK

What Diabetes UK can offer you

Through your Panel membership, we can offer you:

- An induction and additional support, as required.
- An opportunity to develop your knowledge of diabetes, learn new skills and contribute to important strategic work.
- Updates in the form of a e-newsletter on the progress of the projects funded through the Type 1 Diabetes Grand Challenge.
- An opportunity to be involved in other research and non-research activities.
- Reimbursement of out-of-pocket expenses incurred while carrying out activities for Diabetes UK, for example travel costs, lunch and accommodation if required.
- Attendance at the:
 - Annual, face-to-face, Type 1 Diabetes Grand Challenge Beta Cell Therapy and Root Causes Symposium
 - On occasions members will be invited to represent the panel at the annual Diabetes UK Professional Conference

Confidentiality

Members will be required to sign a non-disclosure agreement upon joining the group. This ensures confidentiality and may sometimes exclude them from certain discussions or decisions on specific projects or issues.

Key contacts

Your main contact is the Grand Challenge Team within Diabetes UK. Please email **SMFGrandChallenge@diabetes.org.uk** if you have any questions.

| 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 tasks and | July 2025 | Kamini Shah (Head of Research Funding) | Anna Morris (Assistant Director of Research) | December 2026 |

| meeting | | |
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| details | | |