

Type 2 diabetes Priority Setting Partnership (PSP)

FREQUENTLY ASKED QUESTIONS

What is a Priority Setting Partnership (PSP)?

Priority Setting Partnerships focus on a particular condition or healthcare issue. They are made up of organisations and people living with the condition, their carers and the healthcare professionals who treat them.

What does a PSP do?

PSPs work to find and prioritise questions that can be answered through research, decided by people living with a condition and healthcare professionals.

The PSP will first ask people to complete a survey, highlighting the questions they most want to see answered through research. Those questions are then prioritised into a final list of Top 10 priorities, which will be available to researchers and research funders. The process is overseen by an organisation called the James Lind Alliance.

What is the James Lind Alliance?

The James Lind Alliance is a non-profit-making organisation that was set up in 2004. It brings patients, carers and healthcare professionals together to find and prioritise the unanswered questions about different health conditions. It's funded by the National Institute for Health Research (NIHR).

Who is involved in the Type 2 diabetes PSP?

Diabetes UK is funding the PSP. The PSP is guided and overseen by a steering group, which includes people living with Type 2 diabetes, healthcare professionals, Diabetes UK staff and the James Lind Alliance.

Why are PSPs important and why is Diabetes UK investing in one?

As the biggest diabetes research charity, it's important that the research Diabetes UK funds reflects the needs of people with diabetes and those who care for them. The charity needs to influence researchers and other research funders as well. This process allows us to involve people affected by diabetes and healthcare professionals in those decisions.

The survey

How can I complete the form?

The easiest way to complete the form is online by going to www.diabetes.org.uk/T2-top-10.

Do I have to write a question about research and check it hasn't already been answered?

No. The most important thing is to draw on your personal experiences of Type 2 diabetes. It's enough to tell Diabetes UK about something that's important to you, which you don't know the answer to. The responses will be turned into questions and checked to see that they haven't been answered yet.

I have difficulty reading. How can I take part?

If you can't use the online form, Diabetes UK can send you a paper version. You can then send this back to the charity using the freepost envelope. Alternatively, you can call Diabetes UK on [NUMBER TO FOLLOW] and someone will complete the survey with you over the phone.

I can't use the internet. How can I take part?

If you can't use the online form, Diabetes UK can send you a paper version. You can then send this back to the charity using the freepost envelope. Alternatively, you can call Diabetes UK on [NUMBER TO FOLLOW] and someone will complete the survey with you over the phone.

Why is Diabetes UK asking for my age, sex and ethnicity?

Diabetes UK wants to make sure that it reaches as many people as possible, across lots of communities and backgrounds, to ensure that the research priorities that they identify truly represent the opinions of all people affected by Type 2 diabetes. Being able to monitor age, sex and ethnicity (recorded anonymously and separate to any contact details you provide) will help us to do this.

How will Diabetes UK store and use the information that I give them?

The survey is anonymous. The information you give us will be kept on secure servers and it will only be used to help with the second phase of the exercise.

Diabetes UK are only collecting contact details to ask if you would like to take part in the next phase of the process, and to let you know about the results. They won't be using your details for fundraising purposes.

After the initial survey

What will happen to the questions I submit?

Firstly, the questions will be checked to ensure that they haven't already been answered by previous research. Questions that haven't already been answered will be grouped together into themes, to create a long list. This long list of questions will go through a second prioritisation stage, to reach a short list.

Can I be involved in the second prioritisation stage?

Yes, there will be a second survey. If you provide your contact details when you submit your questions, Diabetes UK will get in touch when the second survey is ready. If you don't want to provide your contact details, you can still look out for the survey on Diabetes UK's website.

How will Diabetes UK get to the final Top 10?

The second stage will help to move from a long list of questions to a short list. This short list will then be taken forward to the final stage, which will be a face-to-face workshop involving people affected by Type 2 diabetes and healthcare professionals.

Can I be involved in the final workshop?

A limited number of people can attend the final workshop. Diabetes UK needs to ensure that they have as wide a representation as possible. They can't guarantee that everyone who would like to be involved can do so, but they will consider everyone who provided contact details and indicated that they would like to be involved.

The results and their impact

What will happen to the final Top 10 research priorities?

Diabetes UK will publicise the final Top 10 research priorities widely to researchers and organisations that fund diabetes research. The priorities could influence those who work in universities and academic institutions, government agencies or in industry. Diabetes UK will use the priorities in the decisions it makes about how research is funded. The [UK Diabetes Clinical Studies Groups](#) will also consider them.

What happens to the questions that are not prioritised or put in the final Top 10?

These questions are not lost. They will be published on the [James Lind Alliance website](#) and can still be looked at by Diabetes UK, researchers and other organisations that fund research.

What difference does this process make?

Many areas of research have seen a benefit. For example, people with asthma were asked about their research priorities. Research has since been funded looking specifically at the effects of breathing exercises.

A separate PSP focused on stillbirth and found priorities of parents that hadn't been considered before. Now, research into bereavement care, maternity care in subsequent pregnancies and helping mothers to respond to the signs and symptoms of stillbirth are priorities.

Type 1 diabetes

Has there been a Priority Setting Partnership for Type 1 diabetes?

Yes. The Top 10 research priorities for Type 1 diabetes were published in 2011. This is available to diabetes researchers and UK research funders. [PROVIDE LINK]

We're looking for the research priorities for Type 2 diabetes because they have never been identified.

What are the Top 10 research priorities for Type 1 diabetes?

1 Is it possible to constantly and accurately monitor blood sugar levels, in people with Type 1 diabetes, with a discrete device (non-invasive or invasive)?

2 Is insulin pump therapy effective? (Immediate vs deferred pump, and comparing outcomes with multiple injections.)

- 3 Is an artificial pancreas for Type 1 diabetes (closed-loop system) effective?
- 4 What are the characteristics of the best Type 1 diabetes patient education programmes (from diagnosis to long-term care) and do they improve outcomes?
- 5 What are the cognitive and psychological effects of living with Type 1 diabetes?
- 6 How can awareness of and prevention of hypoglycaemia in Type 1 diabetes be improved?
- 7 How tightly controlled do fluctuations in blood glucose levels need to be to reduce the risk of developing complications in people with Type 1 diabetes?
- 8 Does treatment of Type 1 diabetics by specialists (e.g. doctors, nurses, dietitians, podiatrists, ophthalmologists and psychologists) trained in person-centred skills provide better blood glucose control, patient satisfaction and self-confidence in management of Type 1 diabetes, compared to treatment by non-specialists with standard skills?
- 9 What makes self-management successful for some people with Type 1 diabetes, and not others?
- 10 Which insulins are safest and have the fewest (long-term) adverse effects?

Have the Type 1 diabetes research priorities been addressed?

Researchers around the world are working to address the research priorities of Type 1 diabetes. Diabetes UK doesn't have all the answers yet, but the charity will be working hard to ensure that researchers and research funders use these priorities.

The priorities of people with Type 1 diabetes are very important to us, and we may review the current list of priorities in the next few years, to make sure that it's still a true reflection.

The charity is currently supporting work to answer a number of the priorities, and have listed some examples below. [\[LINK TO BLOG POST FOCUSING ON THIS TO FOLLOW AS WELL\]](#).

Example: is an artificial pancreas (closed-loop system) effective for Type 1 diabetes?

Diabetes UK is proud to be funding two groundbreaking research projects aiming to develop and test an artificial pancreas device in adults with Type 1 diabetes.

Dr Roman Hovorka, at the University of Cambridge, is working to generate an artificial pancreas. He's evaluating its ability to improve blood glucose control at home and reduce the risk of overnight hypos.

Dr Helen Murphy, also at the University of Cambridge, is adapting the artificial pancreas to control blood glucose levels during pregnancy. This research could drastically reduce cases of stillbirth and mortality rates among pregnant women with Type 1 diabetes.

Example: how can awareness of and prevention of hypoglycaemia in Type 1 diabetes be improved?

During hypoglycaemia, people who are unaware of the symptoms of low blood glucose (hypo unawareness) show changes in brain activity, suggesting that they perceive hypos as less unpleasant than people with Type 1 diabetes who are hypo aware.

Diabetes UK is currently funding Dr Pratik Choudhary's work, at King's College London, investigating effective strategies for treating hypo unawareness in Type 1 diabetes. Dr Choudhary is using advanced imaging techniques to find out if the specific brain activity can be reversed when hypos are avoided, ultimately restoring awareness.

Findings from this study could contribute to the development of psychological and pharmacological treatments for hypo unawareness, to reduce the burden of this condition on people with diabetes.