DIABETES
Research
MATTERS

In this report, we share the research priorities that **matter most** to people living with diabetes and family members.

More than 650 Australians affected by diabetes share their priorities.

Read on to find out more.

Why did we do this?

More than **1.5 million** Australians are living with diabetes[1]

Of these **9%** have type 1 diabetes; **87%** have type 2 diabetes; **3%** have gestational diabetes; **< 1%** have less common types.

Diabetes has a significant impact on the health and well-being of those with diabetes. It also affects their families.

Research to find a cure for all types of diabetes is ongoing. Research is also needed to identify how to best support the health and well-being of all Australians affected by diabetes.

Researchers and funding bodies typically decide on the topics to be researched. Yet, it is people living with diabetes who are most affected by research outcomes. Their views matter.

So, we asked Australians affected by diabetes what research they believe is important to improve their health and quality of life.

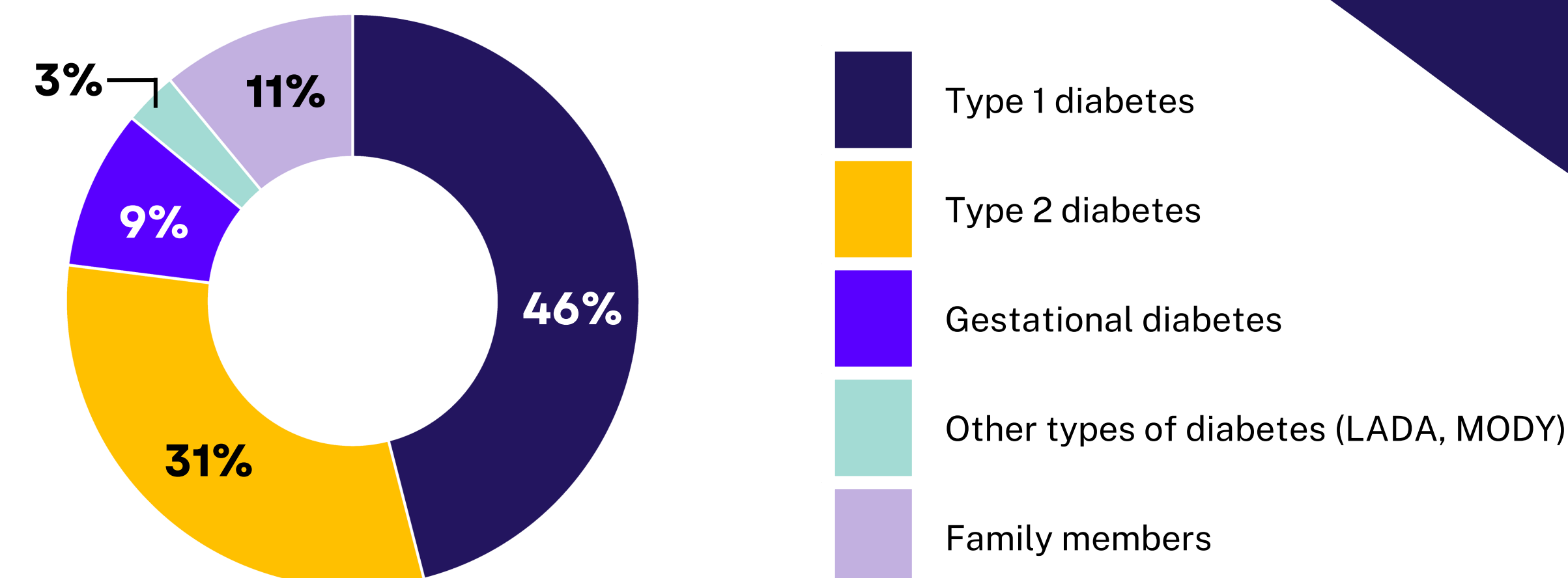1. National Diabetes Services Scheme Data Snapshot March 2023
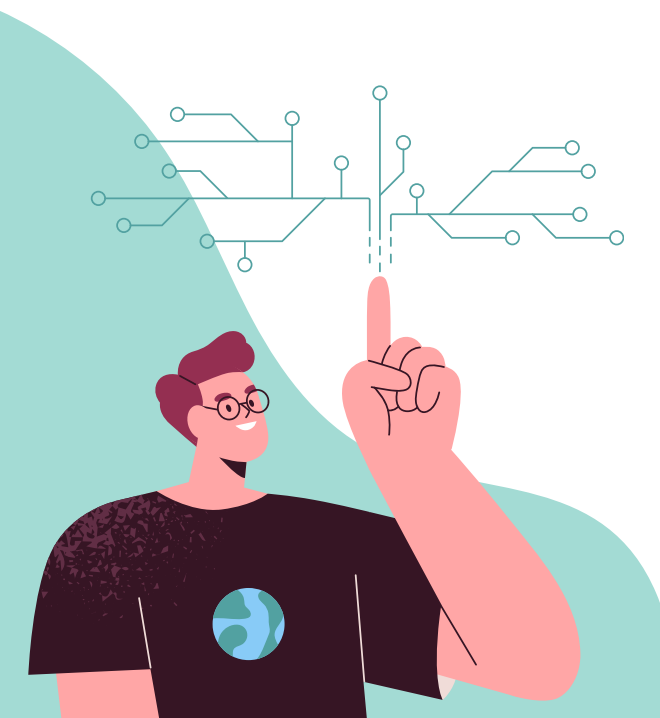
What did we do?

1 Come together

We set up a steering group to guide the process.

People with various types of diabetes and family members joined the research team.

Figure 1:

	%
Type 1 diabetes	46%
Type 2 diabetes	31%
Gestational diabetes	9%
Other types of diabetes (LADA, MODY)	3%
Family members	11%

2 Collect research topics: 1st survey

We asked one single question *"Whilst researchers are working hard to find a cure, what other research do you think is needed to support people with diabetes to live a better life?"*

We advertised the survey via the NDSS*, diabetes websites and social media. We invited more than **20,000** NDSS registrants who agreed to be contacted for research.

3 Organise responses: long list

Over **650** people took part. Figure 1 shows the breakdown of participants. Together, they submitted more than **1,500** responses.

We read every response and identified common themes. This led to a long list of **125 questions** within **25 themes**.

4 Prioritise research questions: 2nd survey

We asked people to select up to 10 research questions that were most important to them.

Nearly **300** people selected their 10 priorities.

5 List top research priorities: short list

We made a list of the most frequently selected questions. The priorities differed by type of diabetes and for family members. So, we created separate lists for each group.

6 Rank research priorities: 3rd survey, final lists

We asked people to rank the short-listed questions from 1-10, i.e. from least to most important.

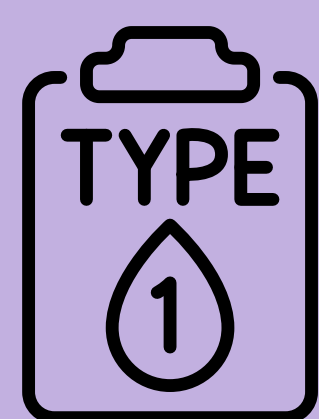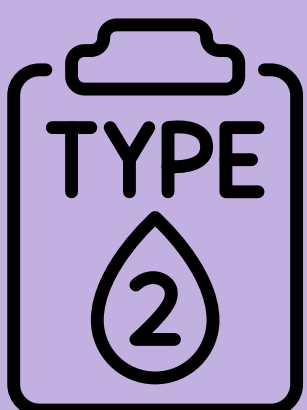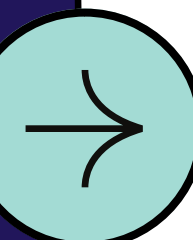Over **300** people ranked their priorities.

What did we find?

People with diabetes and family members have clear views about the research that matters to them.
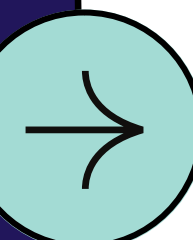
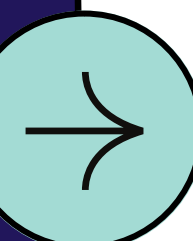You can use the buttons below to skip straight to the groups that interest you.

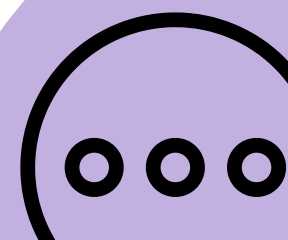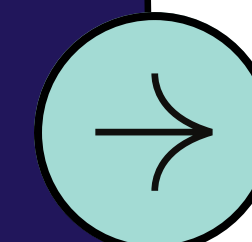Research priorities for people with **Type 1 diabetes** →

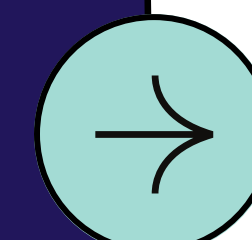Research priorities for people with **Type 2 diabetes** →

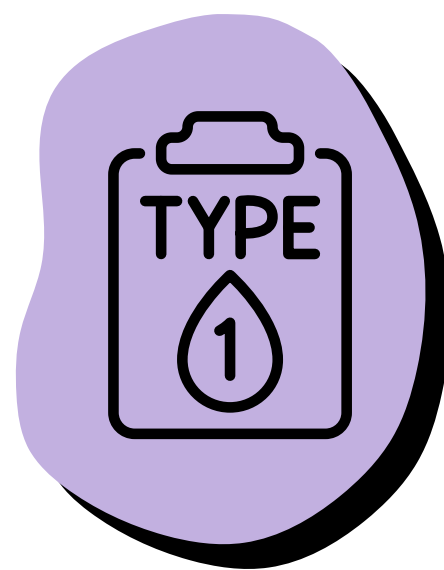Research priorities for people with **Gestational diabetes** →

Research priorities for **Family members** →

Research priorities for people with **Other types of diabetes** →

Type 1 diabetes

The responses of 661 participants in the 1st survey were narrowed down with the help of 158 participants with type 1 diabetes in the 3rd survey.

1 How can diabetes technologies be improved to make diabetes management easier, more effective, more accessible, better integrated with other devices, and/or more environmentally friendly?

2 How can type 1 diabetes be prevented or onset delayed?

3 What are the causes or triggers of diabetes (e.g., genetic, medical, and environmental)?

4 What is the link between diabetes and other health conditions (e.g., other autoimmune disorders, PCOS)?

5 What is the latest evidence on the search for a cure for diabetes?

6 What is the financial cost of living with diabetes, and what are the physical and psychosocial impacts of this?

7 What is the link between diabetes and mental health?
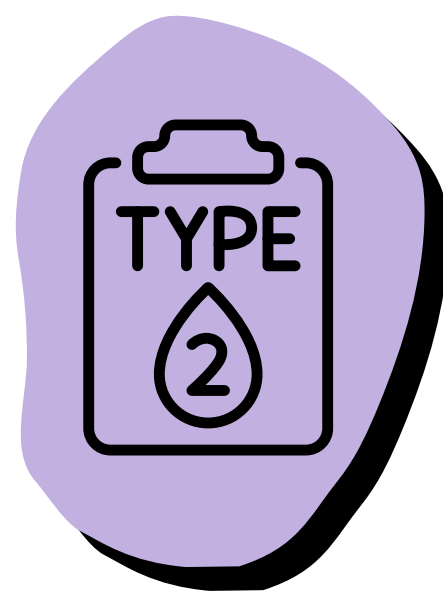
8 How can current regulatory processes in Australia be improved to speed up and increase access to diabetes treatments and technologies?

9 What are the costs and benefits of improved access to diabetes technologies in Australia?

10 What can be done to better inform the public about diabetes types, causes, treatments, and first aid response to hypoglycaemia?

Type 2 diabetes

The responses of 661 participants in the 1st survey were narrowed down with the help of 104 participants with type 2 diabetes in the 3rd survey.

1 How can insulin resistance be reversed and the body's normal response to glucose be restored?

2 What is the most effective diet and exercise plan for people with diabetes?

3 How can diabetes complications be delayed or prevented?

4 What is the long-term effect of diabetes medications on the body?

5 What are the causes or triggers of diabetes (e.g. genetic, medical, and environmental)?

6 How can more people be supported to achieve type 2 diabetes remission?

7 Is there a diet or exercise plan that can reverse diabetes?

8 What are the most effective ways to manage weight for different people (considering age, fitness goals, mobility, lifestyle, etc.)?
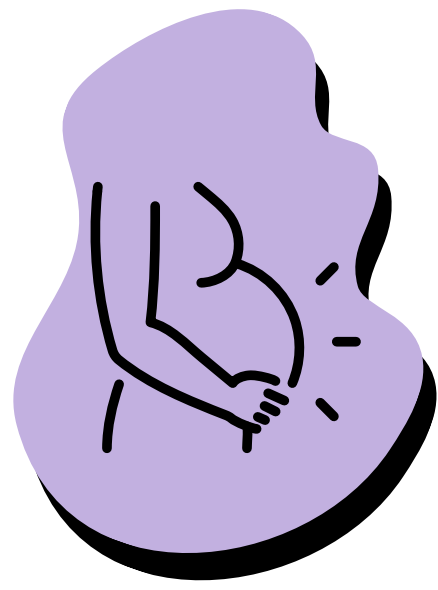
9 What complementary or alternative treatments for diabetes management have scientific evidence?

10 What is the link between the gut microbiome and diabetes?

Gestational diabetes

The responses of 661 participants in the 1st survey were narrowed down with the help of 15 women with current or past experience of gestational diabetes who took part in the 3rd survey. As this is a small group, we have not ranked the questions. There are 11 questions as some were ranked equally.

How can diabetes complications be delayed or prevented?

What are the short-term and long-term impacts of gestational diabetes on the baby/child?

What is the evidence for different diets, and what is the most effective diet for managing diabetes?

How does diabetes management need to be adjusted throughout one's life, and what support is available?

Why do some women with gestational diabetes deliver small babies?

How can diabetes technologies be made more user-friendly (e.g. easier to use, more discrete, painless, less invasive/bulky)?
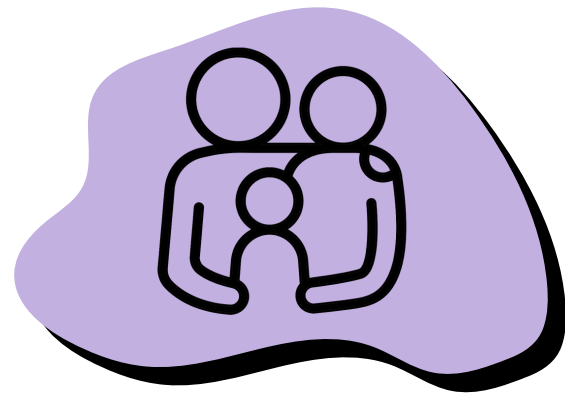
What is the link between diabetes and mental health?

What is the link between the gut microbiome and diabetes?

How does gestational diabetes affect the health and development of an unborn baby?

How can type 2 diabetes be prevented after gestational diabetes?

What are the causes or triggers of diabetes (e.g. genetic, medical, and environmental)?

Family members of people with diabetes

The responses of 661 participants in the 1st survey were narrowed down with the help of 28 family members who took part in the 3rd survey, most of whom are related to a person with type 1 diabetes. As this is a small group, we have not ranked the questions. There are 11 questions as some were ranked equally.

What is the latest evidence on the search for a cure for diabetes?

What, and how do, different factors affect blood glucose levels?

How can type 1 diabetes be prevented or onset delayed?

What can be done to better inform the public about diabetes types, causes, treatments, and first aid response to hypoglycaemia?

How can school teachers and staff be better informed to support children with type 1 diabetes?

How can diabetes technologies be improved to make diabetes management easier, more effective, more accessible, more user-friendly, better integrated with other devices, and/or more environmentally friendly?

How can access to early screening for diabetes risk and subsequent follow-up by health professionals be improved?

What complementary or alternative treatments for diabetes management have scientific evidence?

What is the most effective diet and exercise plan for people with diabetes?

What are the causes or triggers of diabetes (e.g. genetic, medical, and environmental)?

How can insulin administration be made easier (e.g. painless, longer or faster acting insulins, less injections, in tablets)?
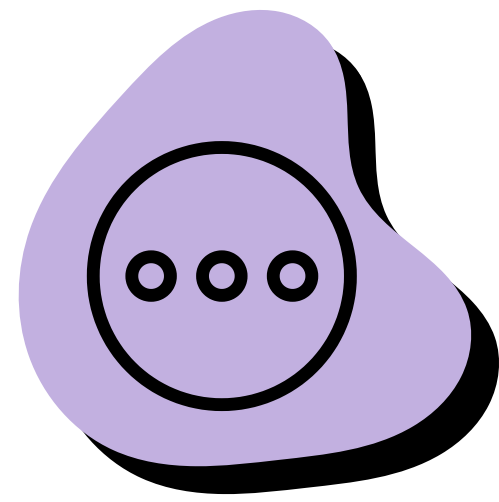
Less common types of diabetes*

The responses of 661 participants in the 1st survey were narrowed down with the help of 9 participants living with other types of diabetes who took part in the 3rd survey. As this is a small group, we have not ranked the questions. There are 12 questions as some were ranked equally.

How can health professionals be better informed about LADA, MODY and type 3c?

What is the evidence for the eligibility criteria set by the government for subsidising technologies and treatments?

What are the best ways of managing diet when living with diabetes and digestive disorders (e.g. Celiac disease, food intolerances)?

What are the causes or triggers of less common types of diabetes (e.g. genetic, medical, and environmental)?

How does diabetes impact relationships with partners, family, and friends, and how can these impacts be minimised?

What are the best ways to keep health professionals up to date with (the most recent diabetes evidence, treatments, and technologies)?

What is the link between less common types of diabetes and other health conditions (other autoimmune disorders, PCOS)?

What is the evidence for different diets, and what is the most effective diet for managing less common types of diabetes?

How is insulin absorption affected by factors such as food, exercise, illness, mood, and is this different between individuals?

How can insulin resistance be reversed and the body's normal response to glucose be restored?

How can diabetes care be made more holistic (i.e. attention to medical, psychological, and social needs)?

How can early screening, diagnosis, and management of LADA and MODY be improved?

*Latent autoimmune diabetes in adults (LADA); Maturity-onset diabetes of the young (MODY); Type 3c diabetes (secondary diabetes, associated with disease of pancreas)

What's next?

This project has taken the first step in identifying the research questions that are important to people affected by diabetes. But this is only the beginning.

Some of the questions in the lists have already been partially or fully answered.

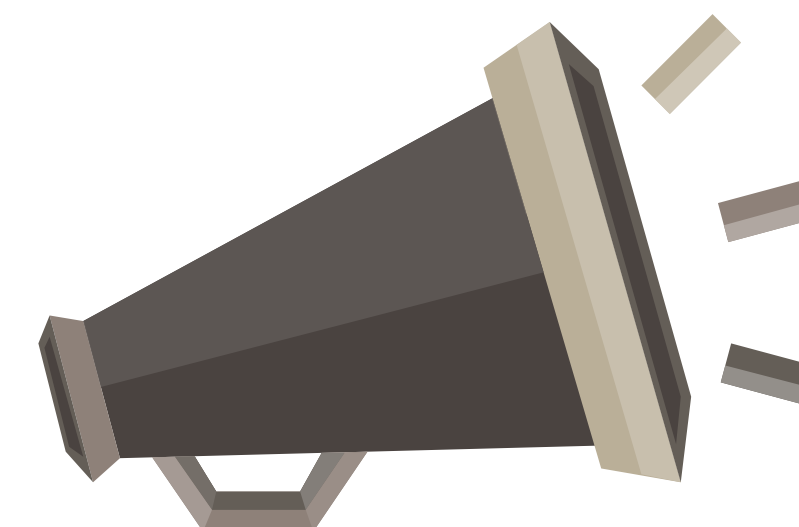Where answers exist, this information needs to be shared with the diabetes community.

Several questions need further research.

Australian funders of diabetes research will be able to use these priorities as they shape their future research strategy.

Australian researchers will be able to use these priorities to support their applications for research funding.

Want to learn more about the findings?

On **DiabetesResearchMatters.com** you can find updates on presentations and actions arising from this research.

Thank you

First of all, a BIG thank you to the **650+ participants** who took part in developing the long lists and the **300+** who helped us shape the short lists.

We also thank the steering group for their valuable input in every part of the project.

Participants in the study were recruited via the National Diabetes Services Scheme (NDSS.) The NDSS is an initiative of the Australian Government administered by Diabetes Australia.
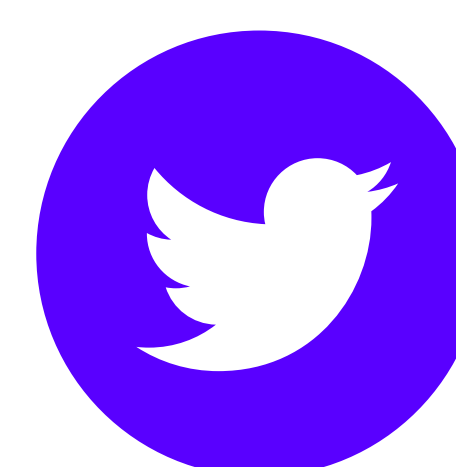
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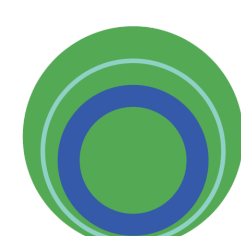
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