

# Australian Type 1 Diabetes National Screening Pilot

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TYPE 1 DIABETES

National  
Screening  
Pilot



THE UNIVERSITY OF  
SYDNEY



# Vision

A routine, publicly-funded National Screening Program  
for all children in Australia

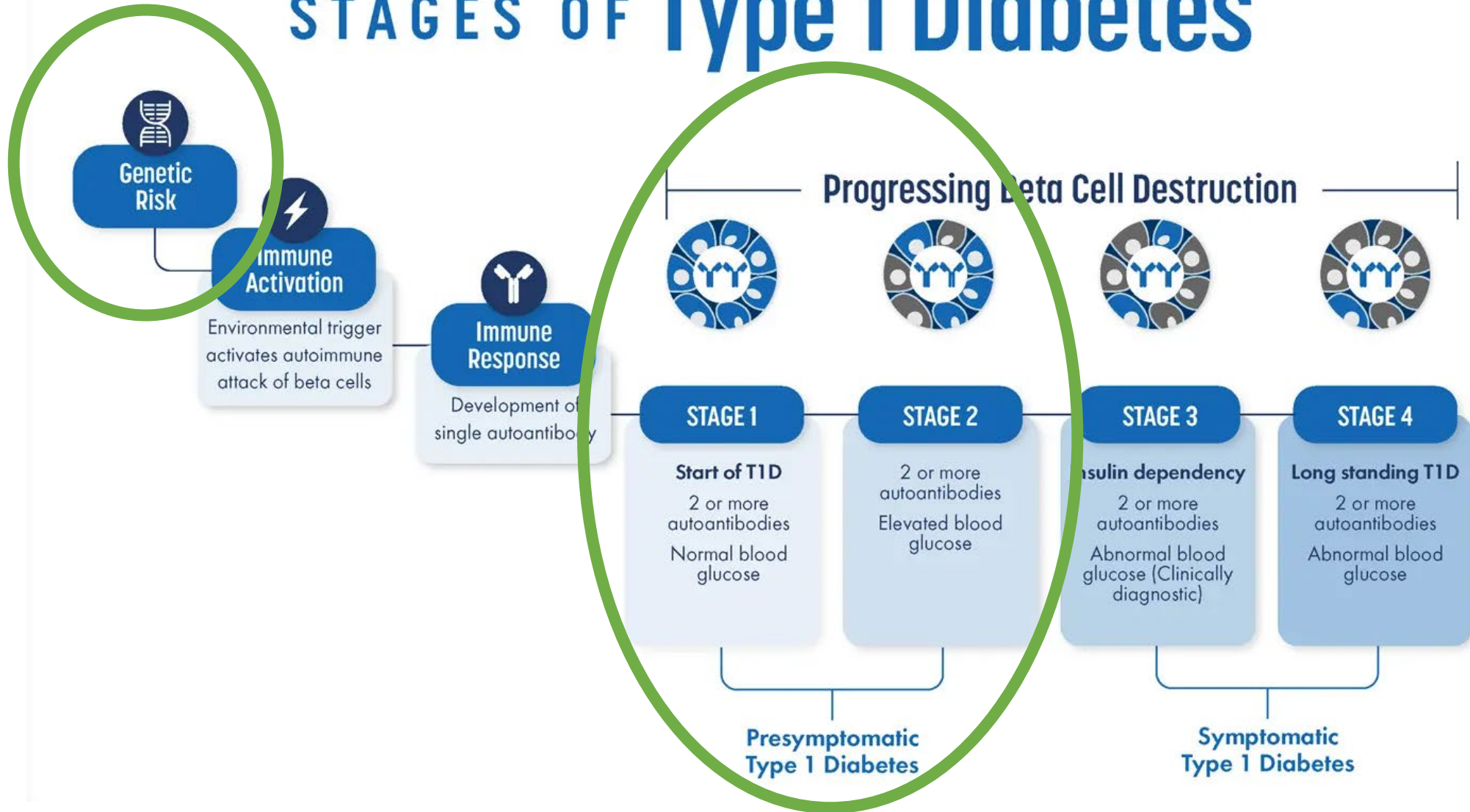
Realistic, scalable, sustainable, equitable and cost-effective

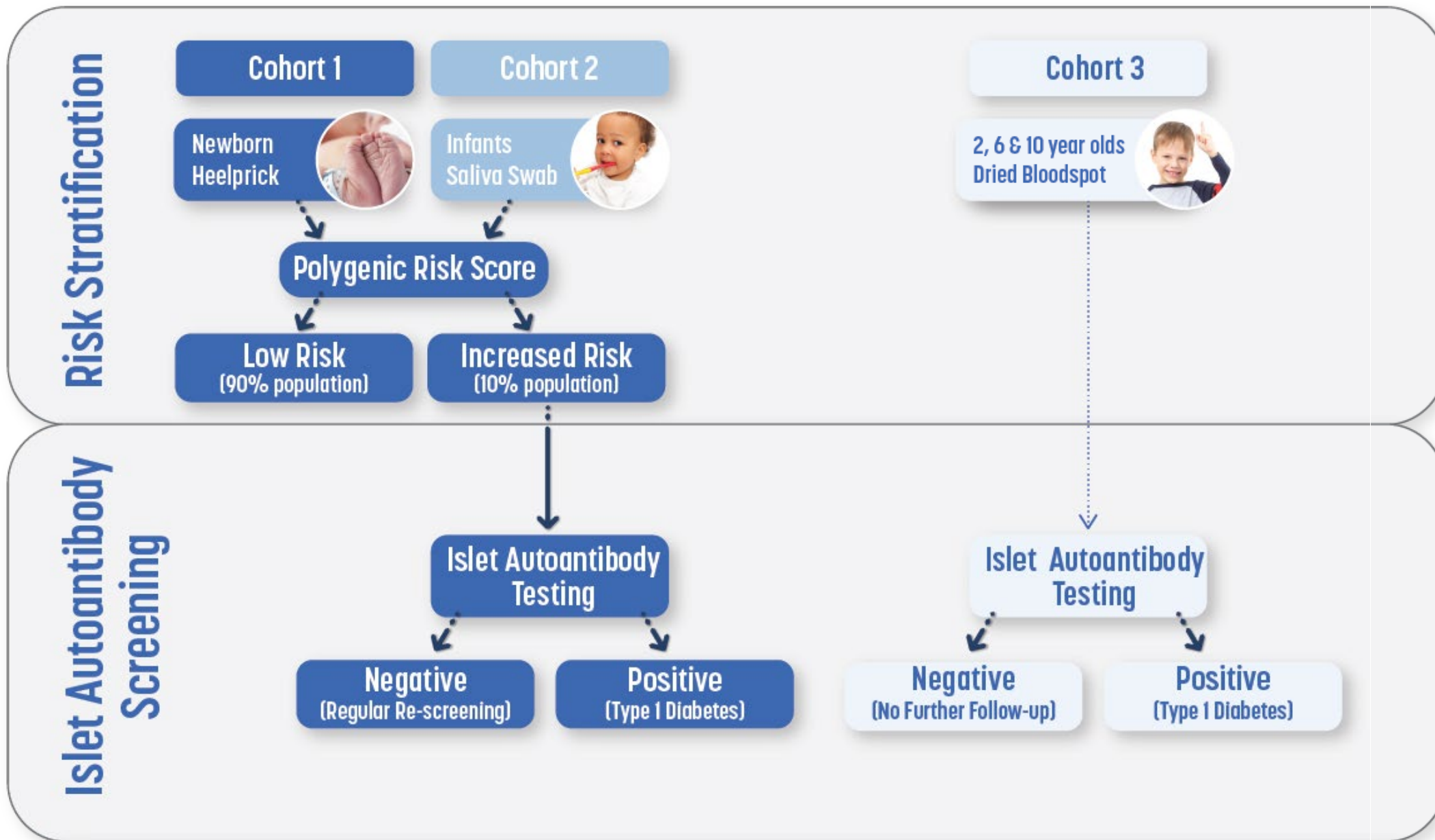
## **Overarching Objective:**

What is the optimal model for routine screening for type 1 diabetes in Australia?



# STAGES OF Type 1 Diabetes





# Catchment Areas

Each model focused in small target areas in two states  
Goal to offer screening to all eligible children in area



**Cohort 3**  
South-East Perth



**Cohort 1** Women's & Children's Hospital



**Cohort 2**

- Brisbane North
- Western Sydney



**Cohort 1**

- RHW
- RPA
- St George



**Cohort 3**  
North-West  
Melbourne



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# Cohort 1 (Newborns)

Parents of newborns are offered screening through a heel prick dried bloodspot alongside existing Newborn Screening Program.

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I'M READY  
for type 1  
diabetes  
screening

Cards for hospital bassinets

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SIMPLE TEST  
**BIG OUTCOMES**  
TEST FOR TYPE 1 DIABETES

Babies born in this hospital will be offered screening for type 1 diabetes.

Screening is free, simple and safe.

A simple heel prick test when your baby is born helps find and care for these kids as early as possible, before they become very sick.

The Type 1 Diabetes National Screening Pilot is a research study aiming to find the best way to offer screening for type 1 diabetes to children in Australia.

Where can I find more information?



Your midwife can help answer your questions



[www.KidsDiabetesScreen.com.au](http://www.KidsDiabetesScreen.com.au)  
1800 505 909

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SUPPORTED BY:

**JDRF**

This study has been approved by the Sydney Children's Hospitals Network Human Research Ethics Committee (Approval Number: 2022/ETH00537). If you have any concerns or complaints, you can contact the HREC Executive Officer on (02) 9845 1253 or SCNH-Ethics@health.nsw.gov.au. TYPE 1 DIABETES NATIONAL SCREENING PILOT. NEWBORN ADVERTISING POSTER V1.2 29/04/2022

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# Cohorts 2 and 3

- Mailed invitations to eligible children
- Primary care recruitment

**TYPE 1 DIABETES**  
**National Screening Pilot**  
**SIMPLE TEST**  
**BIG OUTCOMES**  
TEST FOR TYPE 1 DIABETES

The Type 1 Diabetes National Screening Pilot is a research study aiming to find the best way to offer screening for type 1 diabetes to children in Australia.

We are offering screening to children aged 2, 6 and 10 years living in your local area for a limited time.

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Screening to children aged 2, 6 and 10 years living in your local area for a limited time.



## Type 1 diabetes screening

### WHAT DOES SCREENING INVOLVE?

Screening is free, simple, quick and safe.

The test involves a saliva swab, rubbed along your child's gums in their mouth. It can be done at home or with your local doctor or participating pharmacy. This test will show if your child has a combination of small variations in their DNA that are linked with type 1 diabetes.

You will receive your child's test result online, along with information explaining what the result means and what to do next. Results can take up to 16 weeks.

### HOW DO I HAVE MY CHILD SCREENED?

Screening for type 1 diabetes is being offered to children aged 6-12 months living in your local area for a limited time.



Sign up online to receive your free at-home screening kit  
[www.KidsDiabetesScreen.com.au](http://www.KidsDiabetesScreen.com.au)



Visit your local doctor or participating pharmacy (see website for locations)



### WHAT HAPPENS IF THE TEST FINDS THAT YOUR CHILD HAS AN INCREASED CHANCE OF TYPE 1 DIABETES?

A positive screening test result means your child has a risk factor for developing type 1 diabetes in childhood. It is not a diagnostic test and it does not mean your child has, or definitely will develop, type 1 diabetes.

One in every 10 children has an increased chance of developing type 1 diabetes. However, only a small number (1 in every 40 children) will develop the condition. We do not know which children will or won't develop type 1 diabetes. So all children with an increased chance will be offered free follow-up testing. This follow-up test shows if they start developing the condition, even before they feel any symptoms.

We will be here to help and support you. The earlier type 1 diabetes is detected, the sooner it can be treated.

### WHAT HAPPENS IF THE TEST RESULT IS NORMAL?

Most children (9 out of 10 children) will receive a normal test result. This means your child has a very low chance of developing childhood type 1 diabetes in the future. Less than 0.1% will develop the condition during childhood. Children with a normal screening test result will not require any follow-up testing.

**SIMPLE TEST**

**BIG OUTCOMES**  
TEST FOR TYPE 1 DIABETES



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# Website

[www.KidsDiabetesScreen.com.au](http://www.KidsDiabetesScreen.com.au)

The screenshot shows the homepage of the Kids Diabetes Screen website. At the top right, there are links for "Log in" and "Menu". A "Health Professionals" button is located in the top right area. The main header features the "TYPE 1 DIABETES National Screening Pilot" logo and the text "SIMPLE TEST BIG OUTCOMES TEST FOR TYPE 1 DIABETES". The central message states: "Every day three children are diagnosed with type 1 diabetes in Australia." Below this, it explains that the simple test can help find children as early as possible to avoid the trauma of a missed diagnosis. A button labeled "About type 1 diabetes" is present. To the right, a map of Australia shows several states highlighted in green, with a "Select your State/Territory:" label above it. The text below the map says: "The Type 1 Diabetes National Screening Pilot is open for registrations, select your state to find opportunities in your area." At the bottom, a blue footer contains the text: "The Type 1 Diabetes National Screening Pilot aims to find the best way to offer screening for type 1 diabetes to children in Australia." and "This national 'not for profit' research pilot is led by the University of Sydney, with collaborating universities and hospitals around Australia. It is funded by JDRF, a research foundation for type 1 diabetes." A "Check eligibility" button is also in the footer. Logos for participating organizations (The Royal Children's Hospitals Network, NSW Health South Eastern Sydney Local Health District) and the JDRF logo are at the bottom.

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# Portal/Database

**Type 1 Diabetes National Screening Pilot**  
Is My Child Eligible for Screening?

Thank you for your interest in the Type 1 Diabetes National Screening Pilot.

To see if your child is eligible for type 1 diabetes screening, we'll need a few details. It is important that the information you provide is correct so that we can check if the test is suitable and available for your child.

Already have an account? [Log In Now](#)

**About My Child**

Child's First Name \*  Child's Last Name \*

Date of Birth (dd/mm/yyyy)  Home Postcode \*

Has your child already been diagnosed with type 1 diabetes? \*

**About Me**

My First Name \*  My Last Name \*

Email \*  Mobile (optional)

Screening portal guides families through registration, online consent, ordering screening kit, receiving screening results and completing surveys

Not Secure — 45.113.235.14

Google iCloud FMH Sharepoint Google Scholar CPC Sharepoint MyLab https://www.a...creening.pdf DynaMed BMJ Best Practice Meeting Planner Covidence Power Calculator LibreView Staff Hub - ...Support-APD

Type 1 Diabetes National Screening Program

**Parent1**

**Welcome Parent1**

[Add Another Child](#)

**1 My child's details** [Edit](#) [Withdraw](#)

**2 My details** [Edit My Detail](#)

**3 Invite my child's other parent (optional)**

**4 Find out about type 1 diabetes screening**

**5 Consent for type 1 diabetes screening**  Not yet available

**6 Postal Address for Screening Kit**  Not yet available

**7 Nominate GP (optional)**  Not yet available

**8 Complete Survey**  Not yet available

**9 View Screening Result**  Not yet available

**10 Complete Survey**  Not yet available

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# Cohort 2 Saliva Kits



Our specially-designed kits contain the child's saliva swab and instructions, then function as reply-paid return mailers.

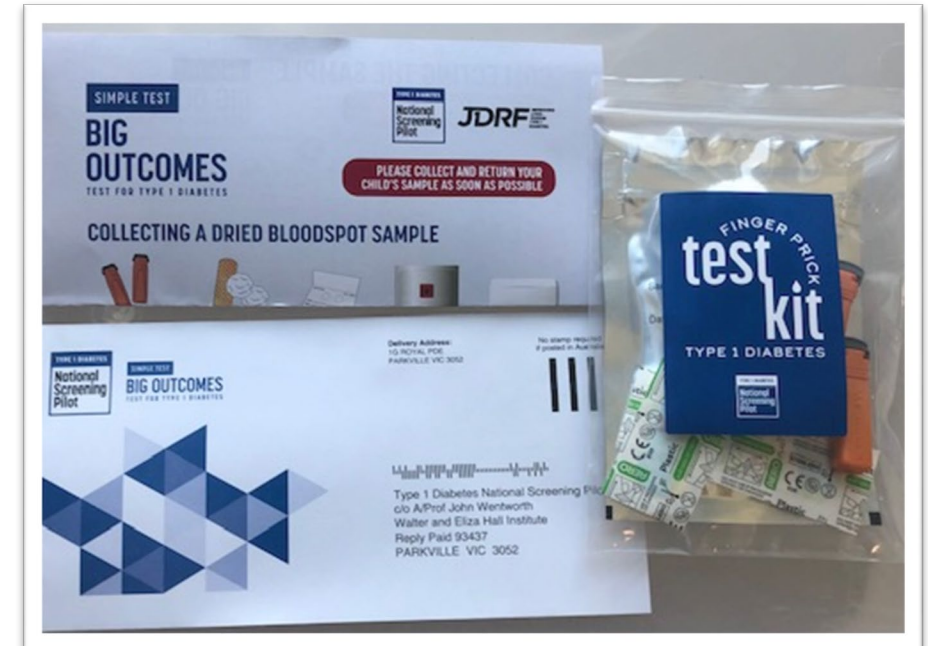




# Dried Bloodspot Kits



Our pilot-branded finger prick dried bloodspot kits are mailed out to families with custom 2-spot screening cards and reply-paid branded envelopes.



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# Dedicated Screening Helpline

# 1800 505 909

Monday – Friday, 9am to 4pm AEST

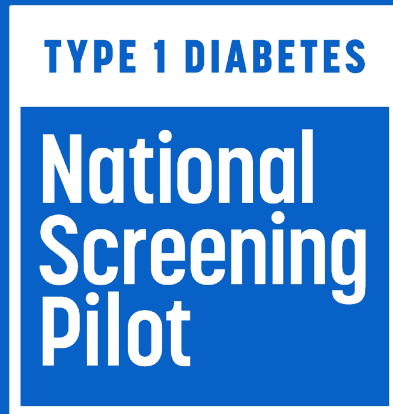
Staffed by: Paediatric CDE, Genetic Counsellor  
& Research Staff



**Alternatively:**

**Request a call back via website OR**

**Email: [info@KidsDiabetesScreen.com.au](mailto:info@KidsDiabetesScreen.com.au)**






# Preliminary Results







# Screening Update

As of 24<sup>th</sup> Oct 2023

**Note:** Cohorts have had staged rollouts, not all running identical durations.

	Cohort 1 	Cohort 2 	Cohort 3 	Total
<b>Registered Children</b>	<b>2,287</b> <i>Screening Closed</i>	<b>2,095</b> <i>Available to Dec '23</i>	<b>2,025</b> <i>Available to Dec '23</i>	<b>6,407</b>
<b>Consented Children</b> <i>% of registered</i>	<b>94%</b>	<b>84%</b>	<b>82%</b>	<b>87%</b>
<b>Samples Collected/Received</b> <i>% of consented</i>	<b>92%</b>	<b>70%</b>	<b>50%</b>	<b>73%</b>
<b>Screening Results Returned</b> <i>% of samples received/collected</i>	<b>12%</b> <i>Returned at ≥ 11mo</i>	<b>50%</b> <i>Returned at ≥ 10mo</i>	<b>95%</b>	<b>41%</b>
<b>Genetic - Increased Chance</b> <i>% of returned results</i>	<b>8%</b>	<b>9%</b>	<b>N/A</b>	<b>9%</b>
<b>Antibody Positive (1+ IAb)</b>	<b>0</b>	<b>1</b>	<b>2</b> <i>+3 pending</i>	<b>0.2-0.3%</b>

# Preliminary: Demographics

	Cohort 1 (Newborns)	Cohort 2 (Infants)	Cohort 3 (Children)
 Sex (M/F)	51%/49%	52%/48%	52%/47%
 Age			2yo: 34% 6yo: 31% 10yo: 35%
 T1D Fam Hx	Yes: 11% Unsure: 14%	Yes: 16% Unsure: 16%	Yes: 14% Unsure: 16%
 Ethnicity	Oceanian/European: 56% South/East Asian: 24% Middle Eastern: 6% South American: 5% African/ATSI/Other: 10%	Oceanian/European: 66% South/East Asian: 23% Middle Eastern: 4% South American: 3% African/ATSI/Other: 4%	Oceanian/European: 69% South/East Asian: 22% Middle Eastern: 2% South American: 2% African/ATSI/Other: 6%

# *Preliminary: Top Reasons for Screening*

## Reason %

My child may benefit from knowing the results of this screening test 26

Other families and children can benefit from the results of this pilot in the future 16

It is easy to have my child screened 14

The screening test is free 10

To contribute to research 10



# *Preliminary: Top Hesitations*

## Reason

%

None of these apply

30

I am too busy/don't have enough time

15

I have concerns about the test (e.g., could be painful for my child)

10

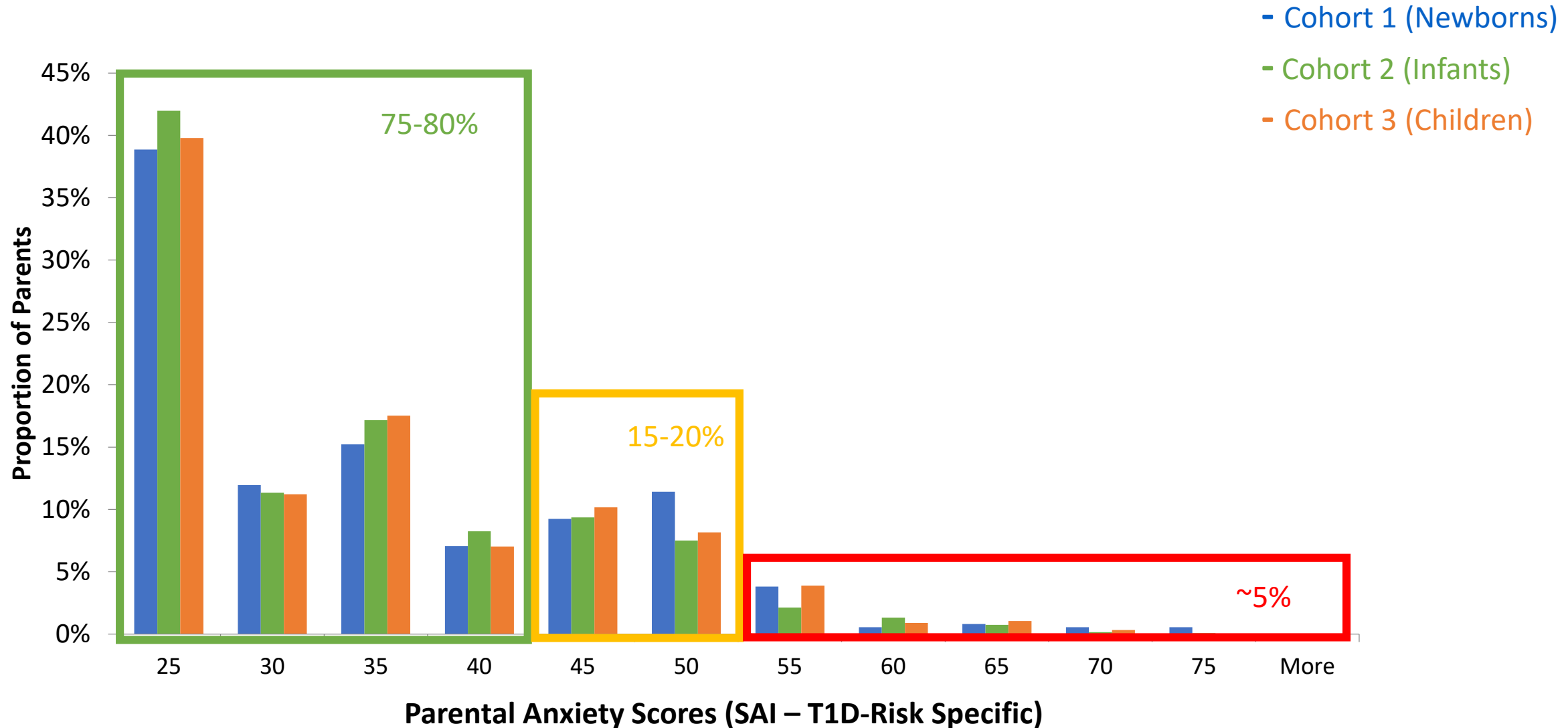
I am not worried about my child's risk of type 1 diabetes

8

Completion of surveys is too demanding

7

# *Preliminary: Parental Anxiety is Low*



# What's Next?

- Nov 2023** Launch in School Screening Program (C3)  
Final media & social media advertising (C2-3)
- Dec 2023** Screening closes (C2-3)
- Jan 2024** HTA & Economic modelling commences
- June 2024** First follow up of genetically at-risk children closes (C1-2)
- Nov 2024** Final results of Pilot due



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# Multidisciplinary Collaborating Team



Bill Hagopian



Richard Oram



Kirstine Bell (PI)



Maria Craig



Jenny Couper



Peter Colman



John Wentworth



Liz Davis



Christel Hendrieckx



Gary Deed



Natasha Nassar



Antonia Shand



Adrienne Gordon



Amanda Henry



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