

TYPE 1 DIABETES

National
Screening
Program

Australian Type 1 Diabetes National Screening Pilot

5th Childhood Diabetes Prevention Symposium:
General Population Screening for T1D

11th November 2022

Dr Kirstine Bell

Principal Research Fellow – Type 1 Diabetes National Screening
Pilot

University of Sydney



Pilot Objectives & Aims

Overarching Objective:

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



Aim 1

Pilot Study Comparing Feasibility & Acceptability of 3 Screening Models



Aim 2

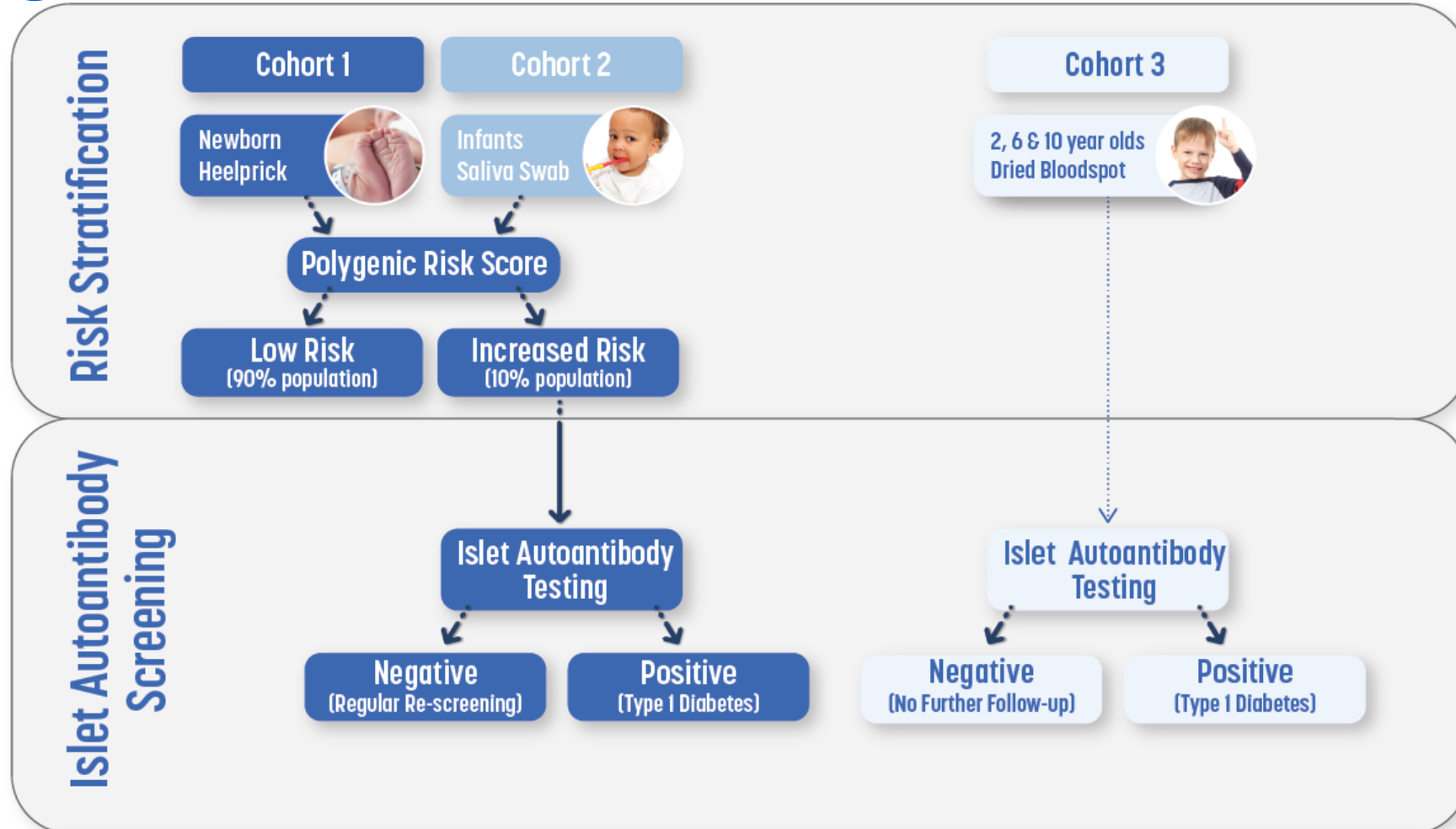
Health Technology Assessment & Economic Modelling



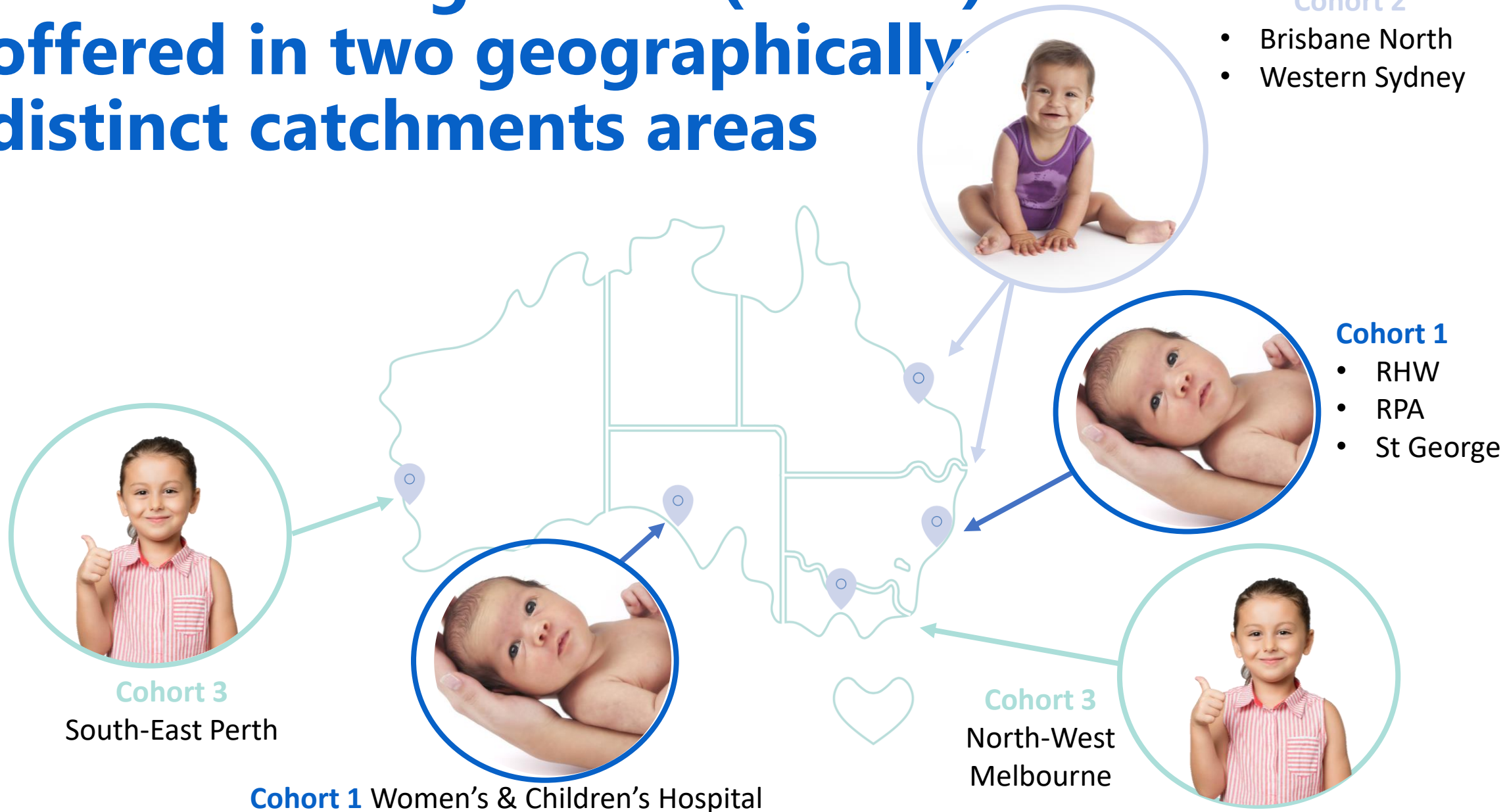
Aim 3

Stakeholder Mapping and Engagement

Aim 1: Implementation Pilot of 3 Screening Models



Each screening model (cohort) offered in two geographically distinct catchments areas



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National
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The Campaign

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SIMPLE TEST

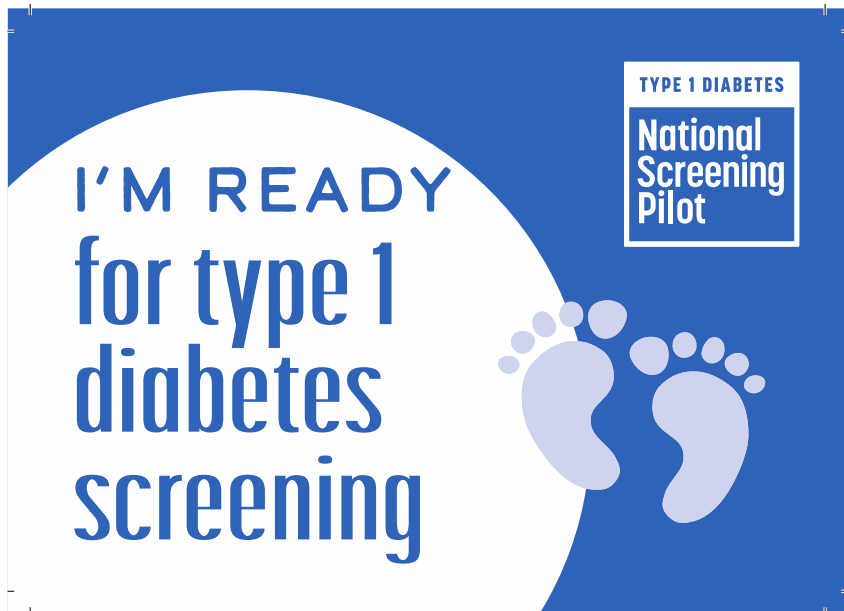
BIG OUTCOMES
TEST FOR TYPE 1 DIABETES

TYPE 1 DIABETES

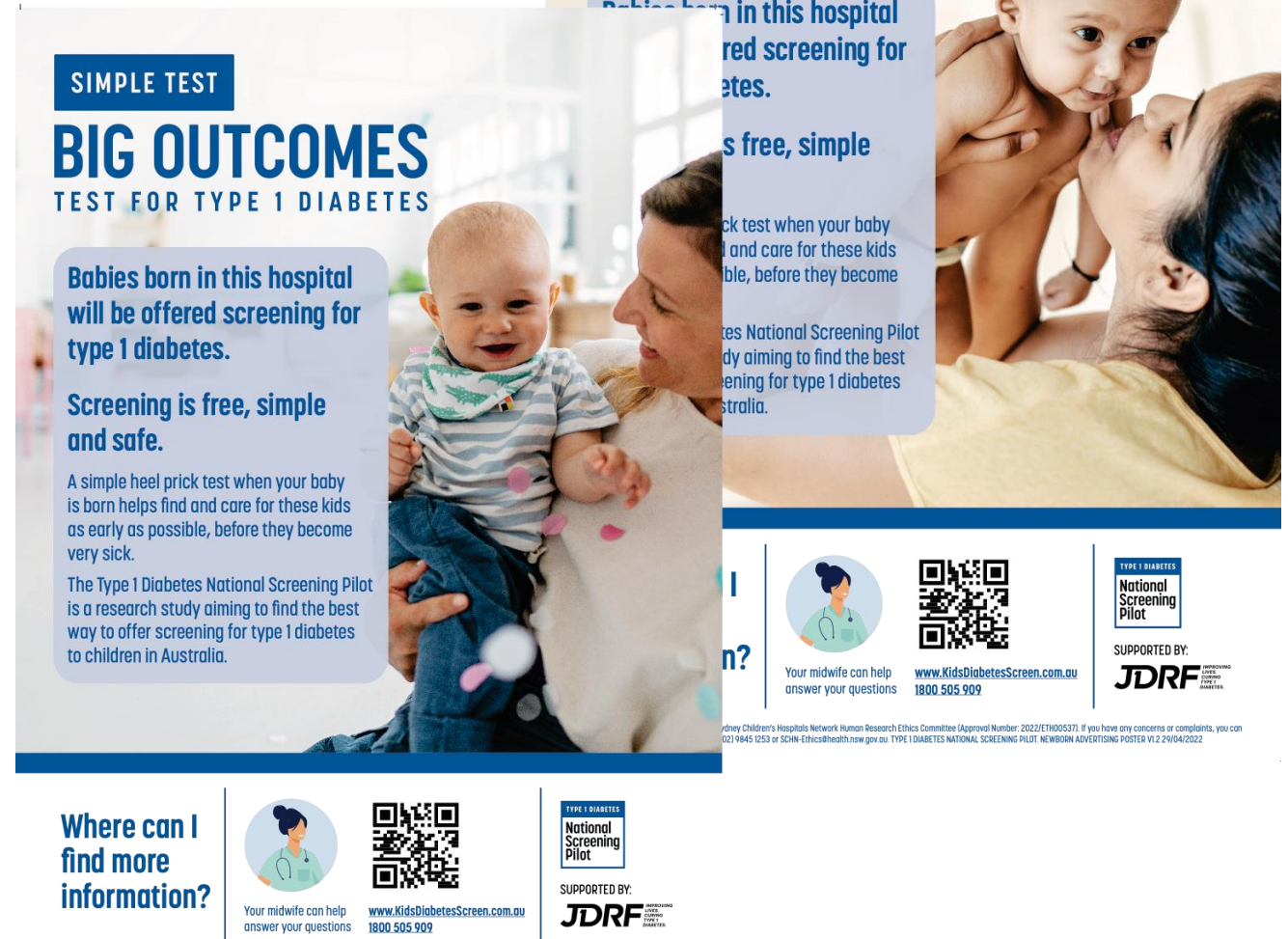
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Cohort 1 (Newborns)

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



Cards for hospital bassinets



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 24/04/2022

Cohorts 2 and 3

Parents of children in cohort 2 (6-12mo) and cohort 3 (2, 6 & 10 years) are mailed invitation letters and brochures by Services Australia. Prompted to visit website for self-directed registration

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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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



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

Website

www.KidsDiabetesScreen.com.au

- Website for community & health professionals directs user to cohort-specific information about T1D and screening
- Cohorts 2 & 3 -> Links to self-directed eligibility check and self-registration (*Cohort 1 newborns recruited through hospitals*)

TYPE 1 DIABETES
National
Screening
Pilot

SIMPLE TEST
BIG OUTCOMES
TEST FOR TYPE 1 DIABETES

Every day three children are diagnosed with type 1 diabetes in Australia.

With a simple test, the type 1 diabetes National Screening Pilot can help find these children as early as possible, avoid the trauma of a missed diagnosis, and support families in every way possible.

About type 1 diabetes

The Type 1 Diabetes National Screening Pilot is open for registrations, select your state to find opportunities in your area.

Select your State/Territory:

Check eligibility

Participating Organisations

The Royal Children's Hospital
The Sydney Children's Hospitals Network
NSW Health South Eastern Sydney Local Health District

Supported by
JDRF

Portal/Database

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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



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

About Me



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 - ...fSupport-APD

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[Dashboard](#) [My Personal Details](#) [Contact Us](#) Parent1

Welcome Parent1

[Add Another Child](#)

 rth hfshrw

- My child's details [Edit](#) [Withdraw](#)
- My details [Edit My Detail](#)
- Invite my child's other parent (optional)
- Find out about type 1 diabetes screening
- Consent for type 1 diabetes screening ☐ Not yet available
- Postal Address for Screening Kit ☐ Not yet available
- Nominate GP (optional) ☐ Not yet available
- Complete Survey ☐ Not yet available
- View Screening Result ☐ Not yet available
- Complete Survey ☐ Not yet available

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

Media & Social Media

Communication Strategy

- National launch for Australia's National Diabetes Week (July 11-15th 2022)
- Local print, radio & TV media for launch of each catchment area (staggered starts)
- Paid social media marketing through Mum's groups etc



TYPE 1 DIABETES SCREENING

ST GEORGE HOSPITAL PILOT PROGRAM HELPS IDENTIFY BABIES AT RISK

Channel 9 News (TV), 6th October 2022

Brisbane Mums Group
October 13 at 6:12 PM · 🌐

Are you a parent or carer of an infant aged between 6 and 12 months living in North Brisbane? If so, your child may be eligible for a free test to determine if they are at risk of developing type 1 diabetes.

The Type 1 Diabetes National Screening Pilot, led by a research team at the University of Sydney, offers infants aged 6-12 months a free, simple test that can be done from the comfort of your own home or with a local GP or participating pharmacy.

Type 1 diabetes is a lifelong autoimmune condition that affects 1 in 300 children in Australia, 90 per cent of whom have no family history of the condition.

The current challenge with type 1 diabetes is that it can be difficult to identify, often with symptoms being mistaken for other minor childhood concerns. As a result, children are not being diagnosed until they are very sick and require emergency care.

Find out more and order your test kit here:
<http://www.kidsdiabetesscreen.com.au/>

TYPE 1 DIABETES

National Screening Pilot

KIDSDIABETESSCREEN.COM.AU

Type 1 Diabetes National Screening Pilot

With a simple test, the Type 1 Diabetes National Screening ...

[Learn more](#)

thelader.com.au

Wednesday October 05, 2022 ST GEORGE & SUTHERLAND SHIRE LEADER 5

NEWS

Pilot launch to keep newborns in check

Type 1 diabetes screening



Kirstine Bell's son Harry was the first baby to have a Type 1 diabetes test done at St George Hospital. Dr Bell led the development of a screening program. Picture supplied

BY EVA KOLIMAR

ONE of the first newborn screening pilot programs for type 1 diabetes has been launched at St George Hospital.

The Type 1 Diabetes National Screening Pilot, funded by IDRF and led by a University of Sydney team, identifies children at risk of developing type 1 diabetes.

Parents of babies will be offered a simple heel prick test, done when the usual newborn bloodspot test is collected.

Experts say the challenge with type 1 diabetes is that it can be difficult to identify, often with symptoms being mistaken for other conditions.

Kirstine Bell from the university's Charles Perkins Centre, has been the lead researcher of the pilot since it started in 2020. With St George being the first hospital to offer the test, the goal is to expand, and become part of the national newborn screening program.



St George Hospital launches new screen test for bubs. Picture supplied

"The program has gone through a long development phase and we're excited to be launching at St George," Dr Bell said. "It's a common misconception that type 1 diabetes is an autoimmune condition, but we know that with nine out of 10 babies, there's no family history. For those families, it really comes out of the blue. When symptoms, such as thirst, tiredness, irritability, start appearing, they can escalate quickly, and by then a lot of

damage has been done. We can completely avoid that just by screening."

"The Menai mother's newborn, Harry, was the first baby at St George to have the test."

"I jumped at the chance to have my bub screened," Dr Bell said. "There's no extra prick for the baby and it's reassuring."

Associate Professor Amanda Henry, an obstetrician at St George Hospital, said the free test gave parents the

advantage of early detection.

"Early signs of type 1 diabetes are often vague and can be missed or confused with other minor childhood concerns," she said.

"As a result, at least one in three Australian children with type 1 diabetes are not diagnosed until they require emergency medical care."

"Screening at birth has been shown to support earlier diagnosis before the child becomes seriously unwell."

"While there is no cure yet for the disease, early detection can prevent serious health problems and support a better prognosis and long-term management of the condition."

For the majority of babies, early screening will show a low chance of developing the condition.

Children who are identified as having an increased risk will be notified and invited for regular follow up testing to monitor for very early signs of the condition.

St George & Sutherland Shire Leader Newspaper, 5th October 2022 (Fun fact: My baby was the first newborn screened for T1D in Australia)

Cohort 2 Saliva Kits



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



Cohort 3 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.



Screening uptake for each cohort is the primary outcome, as a summary indicator of feasibility and acceptability. Therefore, targets represent maximums rather than required minimums for power. Study is an implementation study and is not powered for clinical outcomes.

Uptake to Date

Cohort	Launch Date	Uptake <i>as of 8th Nov 2022</i>	Target Uptake
Cohort 1 (Newborns)	4 th & 18 th October (2 of 4 hospitals to date)	129	n = 3,000
Cohort 2 (6-12mo)	11 th July 2022	697	n = 3,000
Cohort 3 (2, 6 & 10yo)	8 th August 2022	386	n = 3,000

National Multidisciplinary Scientific Team

*(plus many more invaluable team
members)*



Prof Bill Hagopian



Prof Richard Oram



Dr Kirstine Bell (PI)



Prof Maria Craig



Prof Jenny Couper



Prof Peter Colman



A/Prof John Wentworth



Prof Elizabeth Davis



Dr Christel Hendrieckx



Dr Gary Deed



Prof Natasha Nassar



A/Prof Amanda Henry



Dr Antonia Shand



Prof Adrienne Gordon

We are also part of the larger T1D screening & prevention research network in Australia

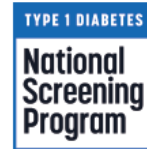
Type 1 Diabetes Screening & Prevention in Australia

Working together to identify those at-risk of type 1 diabetes to improve health and ultimately prevent type 1 diabetes

ENDIA Study
Finding the causes of type 1 diabetes



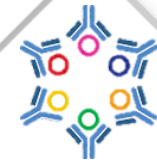
Type 1 Diabetes National Screening Program
Screening for the general community



Type1Screen
Screening for family members of those with type 1 diabetes



TrialNet ANZ
Clinical trials to prevent type 1 diabetes



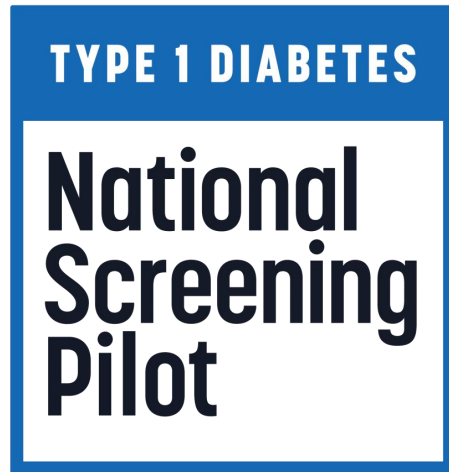
Immunotherapy Collaborative
Clinical trials to prevent type 1 diabetes



ADDN
Long-term follow-up of people with type 1 diabetes

Kindly supported
in part by JDRF





**Pilot Ongoing Until Mid-
2024**

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www.KidsDiabetesScreen.com.au