

### NEWBORN BLOODSPOT SCREENING

## Delivering consistency and expansion

The Australian Government is investing \$107.3 million from 2022–23 to 2027–28 to support expansion of the newborn bloodspot screening (NBS) programs and achieve national consistency in partnership with states and territories. \$68.6 million of this investment is for states and territories.

### How is this different?

- For the first time, all governments have agreed to a nationally consistent list of target conditions and committed to achieve and maintain consistency.
- In an Australian first, states and territories are receiving specific funding from the Australian Government to support expansion.
- Conditions are identified through an efficient decision-making pathway.
- Following Health Ministers' endorsement of a condition for screening, families can be assured that screening for a condition will be implemented.

### What does successful expansion look like?

- Opportunities for the public to contribute to the process, without significant evidence gathering and navigating the health technology assessment (HTA) process.
- A collaborative approach across states and territories that brings all Australian Health Ministers together at the right points to consider the evidence and make joint decisions on assessing or implementing new conditions.
- A more open, transparent and accessible process to identify and consider conditions.
- Equitable screening and access regardless of location.
- An expanded, consistent program that families can continue to trust.
- Maintaining the existing 99% participation rate in NBS.

# What has the government committed to?



Maintaining safe and high quality screening and services for newborns and families



Ongoing consultation with families, advocates, clinicians and other experts



Monitoring emerging technology, new treatments and learnings, locally and overseas



Ongoing identification and consideration of conditions

### **Timeline**

Since the election commitment to end the newborn postcode lottery was made in April 2022, the Australian Government alongside states and territories have made significant progress:

#### August-December 2022

Consultation with 135 individuals and organisations

#### **July 2023**

All states and territories signed schedules to the Health Federation Funding Agreement that provides initial funding of \$25.3 million over 4 years from 2022–23 to support expansion

#### November 2023

The national decision-making pathway endorsed by Health Ministers

#### April 2024

Health Ministers agreed to add tyrosinemia type I and guanidinoacetate methyltransferase deficiency as target conditions

#### September 2024

Health Ministers agreed to add sickle cell disease as a target condition

#### May 2024

- Further funding of \$25 million over 4 years committed from Budget 2024–25
- Health Ministers considered advice on 5 conditions and agreed not to progress them to the MSAC HTA process

#### October-November 2024

Technical advice commences on an additional 23 conditions Consistency of 32 conditions is achieved

#### December 2024

- Health Ministers agreed to add X-ALD as a target condition for male newborns, and commissioned further work in relation to screening female newborns
- Further funding of \$43.3 million over 4 years for provision to states and territories through MYEFO 2024-25
- Health Ministers considered advice on Gaucher disease and agreed for it not to progress to the MSAC HTA process

### February 2025

Health Ministers agreed to add biotinidase deficiency as a target condition

#### October 2022

\$39 million funding announced in Budget 2022-23

#### **June 2023**

- National list of 32 screened conditions agreed
- 5 inconsistently screened conditions agreed for national implementation
- Technical advice commences on 16 conditions

#### October 2023

3 conditions (Pompe disease, MPS I and MPS II) referred to the Medical Services Advisory Committee (MSAC) HTA process



# NEWBORN BLOODSPOT SCREENING

# Program Expansion

### Top FAQs



How do we ensure consistency of conditions across jurisdictions, especially as new conditions are added?

All states and territories have agreed to implement conditions approved for screening by Health Ministers. Funding has been allocated to support implementation and Health Ministers will review implementation progress to ensure the addition of new conditions are on track.

Some variation is likely to arise in the short-term as states and territories ready their laboratories and workforces to add conditions. However, achieving consistency across the country is core to the programs' expansion, and the dedicated funding will support expansion and achieve consistency.

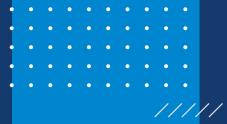
## What expansion progress has been so made so far?

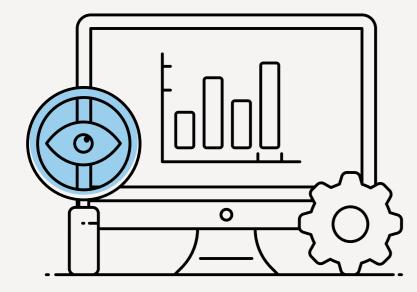
This is huge reform, and we must get it right for our babies and their families. To date, the following progress has been made:

- A nationally agreed list of conditions
- States and territories have achieved consistency against this national list, supported by funding from the Australian Government
- A nationally agreed streamlined process to assess new conditions
- There are now 76 conditions either being screened, agreed for screening, being considered or have been considered for screening in Australia.

To see the latest updates on the status of conditions visit the NBS webpages.







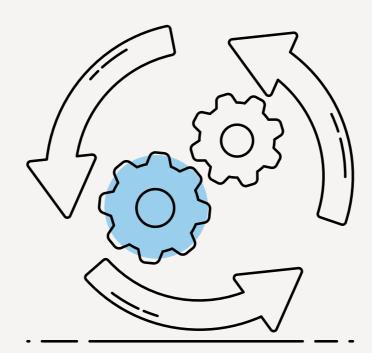
What plans are there to make sure Australia's NBS programs continue to lead the way?

We will monitor program developments, emerging evidence and literature to gather insights from across the globe on an ongoing basis, as well as complete regular horizon scanning. Additionally, the public will be invited to submit conditions for consideration for assessment through an open call process (published on the NBS webpages once available).



# Will families have to do anything differently?

No. The NBS test remains the same and is part of the routine care offered to all families for their baby within the first few days after birth. There is no change to the bloodspot collection process, or the support provided by midwives or health care professionals. Families can find out more about the condition assessment process and the conditions screened via the NBS webpages.





5

# How do our programs compare globally?

Australian NBS programs are safe, effective and aligned with global best practice for universal screening programs. There is no 'global standard' set of conditions for NBS programs internationally, each country has a unique approach based on local needs and circumstances. International review identifies that California's NBS program screens for the most conditions at 85 (including 35 target and 50 non-target conditions). As at December 2024, all conditions<sup>1</sup> in the California NBS program are either being screened, have been considered or are being considered for screening in Australia through the decision-making pathway.

<sup>1</sup> Please note, due to differences in condition naming, counting conventions and classification, the 85 conditions in the California program is counted as 76 conditions in the Australian programs.