



## NEWBORN BLOODSPOT SCREENING

# Progress towards consistency and expansion

The Australian Government is investing \$64 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. \$25.3 million of this investment is being provided directly to states and territories.

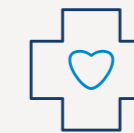
### How is this different?

- ✓ 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



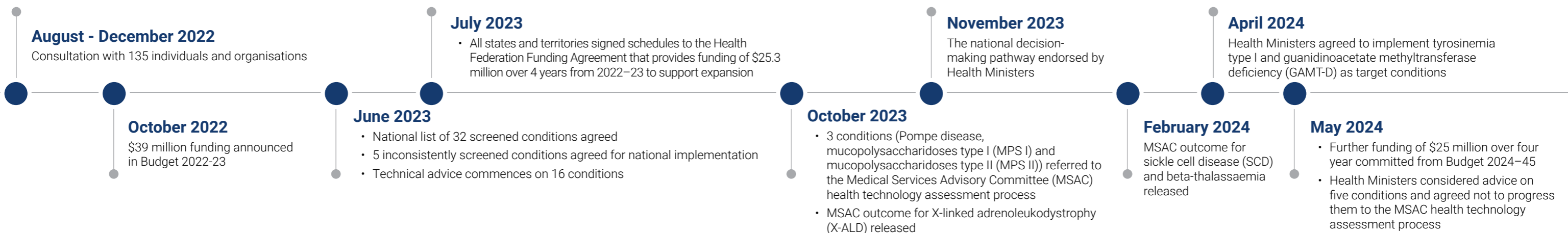
Monitoring emerging technology, new treatments and learnings, locally and overseas



Ongoing identification and assessment 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:



### What's coming up

**01** Health Ministers to consider advice on conditions being considered for screening

**02** MSAC health technology assessment for Pompe disease, MPS I and MPS II

**03** Establish open call for identification of new conditions.



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# Program Expansion

## Top FAQs



### 1 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.

### 2 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 are taking steps to achieve consistency against this national list, supported by funding from the Australian Government to help achieve consistency and expand conditions
- A nationally agreed streamlined process to assess new conditions.

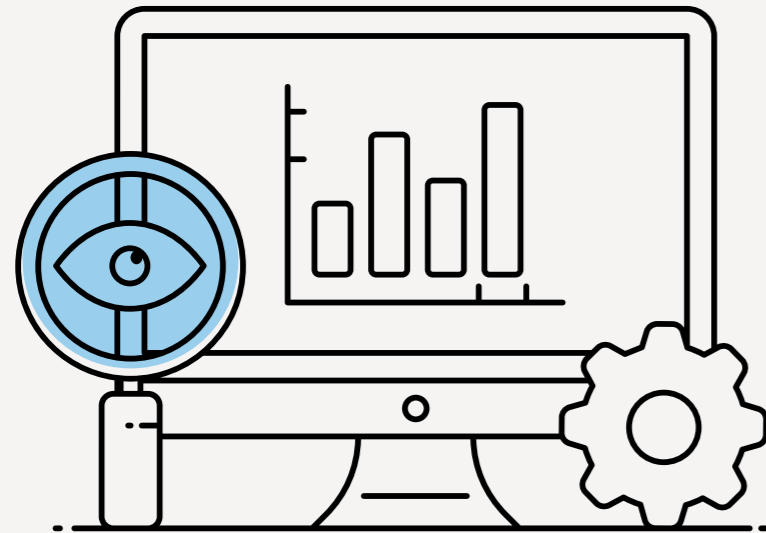
- There are 51 conditions that are either being screened or are under consideration for screening.

This includes:

- 34 target conditions agreed for screening across Australia.
- Announcement of outcomes of 3 conditions from MSAC (X-ALD, sickle cell disease, beta thalassemia).
- MSAC is considering a further 3 conditions (Pompe, MPSI and MPSII).
- And more conditions are being considered for screening.

To see the latest updates on the status of conditions visit the [NBS webpages](#).



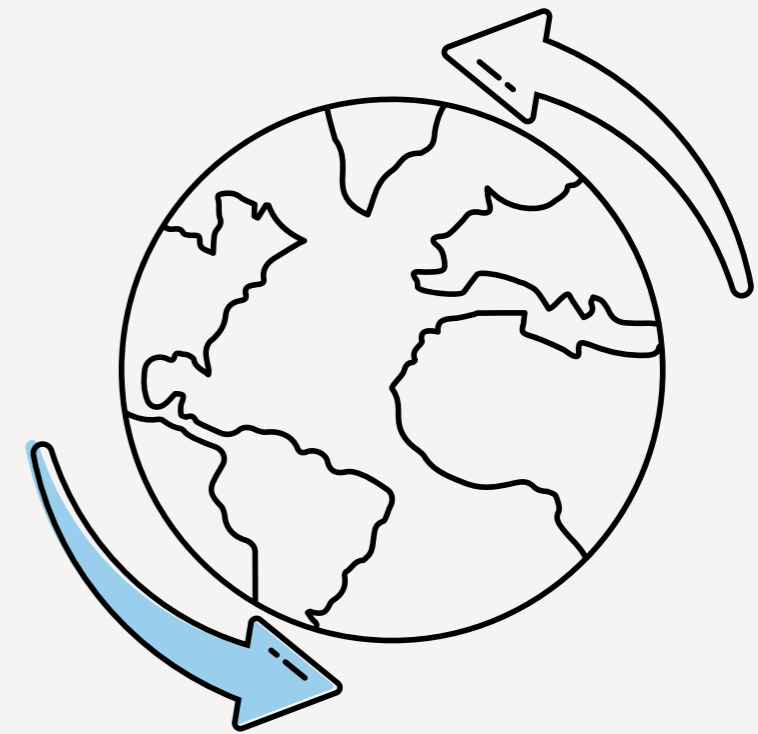
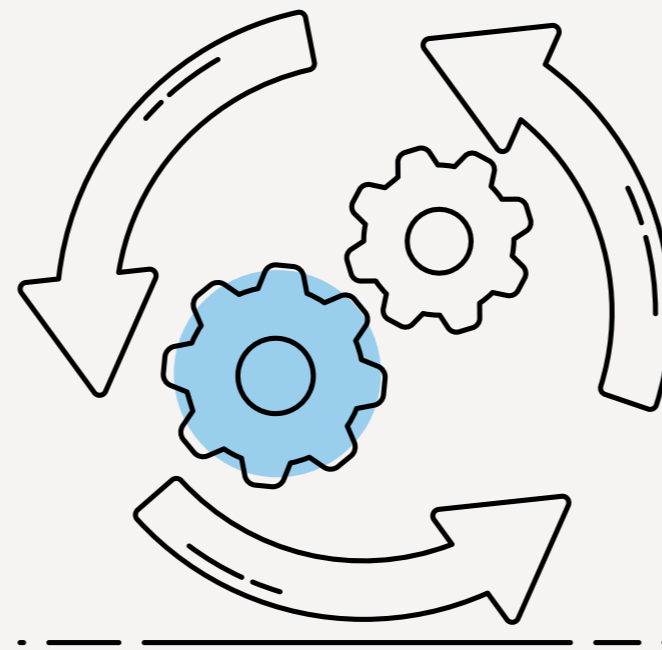


**3** What plans are there to make sure Australia's NBS programs continue to lead the way?

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).

**4** 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 83. This includes 33 target conditions (conditions for which screening provides the most benefit to newborns and families) and 50 non-target conditions (which are not the primary target of a screening test, not detected with the same level of accuracy, and treatments or interventions may not be available).