Newborn Bloodspot Screening (NBS)

June 2023

As part of the 2022–23 Budget, the Australian Government committed $39.0 million over four years to expand newborn bloodspot screening (NBS) to include more conditions and ensure consistency of programs across Australia.

# Why is NBS so important?

NBS is a public health success story. Through small drops of blood taken from a baby’s heel, the programs have saved and improved the lives of thousands of Australian babies since newborn bloodspot screening began in the 1960s.

If a baby is found to have a condition, they can receive intervention earlier than would have otherwise been possible. This earlier intervention leads to better health outcomes for the baby and the family.

In Australia, more than 99 per cent of babies receive newborn bloodspot screening. This means that more than 300,000 babies are screened each year.

# Online consultation

From 11 November until 12 December 2022 the Australian Government Department of Health and Aged Care published a consultation paper, seeking people’s views to inform the expansion of NBS.

The consultation paper focused on what is needed to support families, carers, clinicians and others to benefit from expanded NBS. It also sought to further understand what is important for consumers, clinicians, and others, to support successful expansion of these life changing programs.

# Summary of key findings

The NBS programs have operated successfully for the past 60 years. Work is now needed to ensure the NBS programs’ continued success into the future.

Here are some high-level key findings confirmed through the online consultation:

* 90% of respondents had either positive or neutral views towards the aims and objectives of the NBS program.
* 75% of responses highlighted that improved outcomes for babies and their families as either very important or extremely important.
* Information on how decisions are made when it comes to the assessment of conditions is important.
* Opportunities for the public to provide input throughout the assessment process is important.
* Over 85% of survey respondents indicated that considering the benefits and harms of screening is extremely important.
* Information about NBS programs needs to be accessible and easily understood.
* In determining the readiness of NBS programs to achieve consistency and expansion, respondents voiced that the activities anticipated to be the most impacted by the expansion of NBS programs are diagnostic testing, data collection and the ability of families to access supportive services.

Ensuring equity of access was the most highlighted theme from the responses.

“Newborn bloodspot screening allows patients to be treated effectively, improving quality of life, and in some cases is life-saving. It not only helps alleviate the burden of disease on the patients, but also on the families.”

## Response demographics

There were 105 participants, grouped by these demographics:

* 37 technical experts
* 18 consumer peak body or advocacy group
* 16 general public
* 11 professional peak body
* 5 rare disease group
* 3 state or territory representative
* 15 others.

“National consistency is key to a successful national NBS program. The screening program and targets should be the same regardless of residence.”

“Information [relating to NBS] must be accurate, accessible and appropriate for First Nations people, culturally and linguistically diverse groups and other communities, and accessible for those who have an intellectual disability/impairment.”