



Public consultation on the expansion of newborn bloodspot screening

June 2023

From 11 November to 12 December 2022, we published a consultation paper seeking people's views to inform the expansion of newborn bloodspot screening (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 better understand what is important to support the successful expansion of these programs.



The paper was built on work the government is already doing with patient and advocacy groups, peak bodies, technical and clinical experts, and state and territory governments to understand what is needed to expand these life changing programs.

Overview

We have developed an [infographic that outlines the key findings from our publication consultation](#).

We received 105 responses to the survey from a range of stakeholders:

- technical experts (35%)
- advocacy groups (17%)
- general public (15%)
- professional peak bodies (11%)
- rare disease groups (5%)
- state or territory departments (3%)
- other (14%).

What we heard

The consultation focused on 5 key areas:

- Aims and objectives of the programs
- National consistency
- Assessment of conditions
- Readiness
- Measuring success

Aims and objectives of the programs

Consultation findings showed respondents had either positive (70%) or neutral (20%) sentiment towards the aims and objectives of the NBS programs. Findings also showed support for the current goals that focus on delivering benefits to the newborn. The aims and objectives of NBS are outlined in the [NBS National Policy Framework](#) (pg. 9).

Consultation feedback also confirmed the expansion should include:

- a focus on equity of access
- the timeliness of intervention
- achieving national consistency between the states and territories
- long-term equity of health outcomes of babies and their families.

National consistency

There was strong support for having a consistent process for adding new conditions and screening/testing procedures in the NBS program across states and territories.

Responses outlined the need to address the inconsistency of funding and implementation approaches across Australia.

Assessment of conditions

There was support for clear governance pathways, engaging consumers throughout the assessment process, and the provision of information about NBS programs that is accessible and easy to understand.

Consultation findings confirmed ongoing support for the robust assessment process articulated in the NBS National Policy Framework and the criteria that underpin this assessment.

Responses highlighted that the major benefit of the NBS program is early detection and diagnosis of newborn conditions that allow for timely intervention. This ultimately improves health outcomes of newborns in Australia.

When considering the evidence for a new condition, respondents recognised the need to consider evidence to help understand and communicate the full benefits of screening. This includes the positive impact on the baby, through enabling earlier diagnosis.

Respondents also recommended focusing on emerging treatments and promoting access to clinical trials when assessing the interventions available for conditions. Respondents reflected that this may require updating the NBS National Policy Framework in the future.

Respondents were asked to identify potential harms that should be considered when thinking about adding a condition. They identified the impacts on families who may receive a false positive test, which may lead to unnecessary interventions, parental stress, and anxiety.

Readiness

'Readiness' relates to what is needed 'on the ground' to make sure the NBS programs, clinicians and services are best able to provide expanded screening and support families following an abnormal result. In terms of readiness, respondents suggested the activities anticipated to be most impacted by the expansion of NBS programs are:

- diagnostic testing
- data collection
- the ability of families to access supportive services.

Responses from the general public highlighted a desire for clear information on newborn bloodspot screening that is easy to find. This includes information on the importance of screening and how screening works. It also included information being made available in a range of languages to support inclusivity.

Measuring success

Equity of access was the most highlighted measure of success. Respondents indicated that having equity of access is impacted by differences in funding and access to health services by state and territory.

The responses also outlined other measures of success including:

- improved newborn health outcomes (decreased mortality and morbidity)
- continually screening around 99% of babies every year

- equitable participation and access regardless of location.

In addition to these key measures of success, another measure of success proposed was aligning Australia's programs with the conditions screened internationally. There was also a recommendation for a once off immediate review or inclusion of additional diseases currently screened in California.

What we are doing

Our programs save the lives of Australian babies and offer screening for a comprehensive range of conditions in line with international programs. We are committed to maintaining our world leading status and support future growth of the program. We look to international programs, literature, emerging evidence and Australian experts, including families, to identify further conditions and inform the expansion.



In response to the consultation results, we will be progressing the expansion of NBS programs. This will be achieved through:

- ongoing consultation with families, advocates and clinical and technical experts
- working closely with states and territories to directly fund the expansion and explore how best to support equity of outcomes
- instituting an ongoing review of evidence to identify new conditions for assessment
- a national, detailed assessment process to make sure the benefits of the expanded screening outweigh the harms
- removing the burden on civil society to drive the nomination and assessment process and making sure the assessment process is fit for purpose and timely
- considering the information and support needs of families and clinicians to enable equity of outcomes for families whose baby has an abnormal result.