



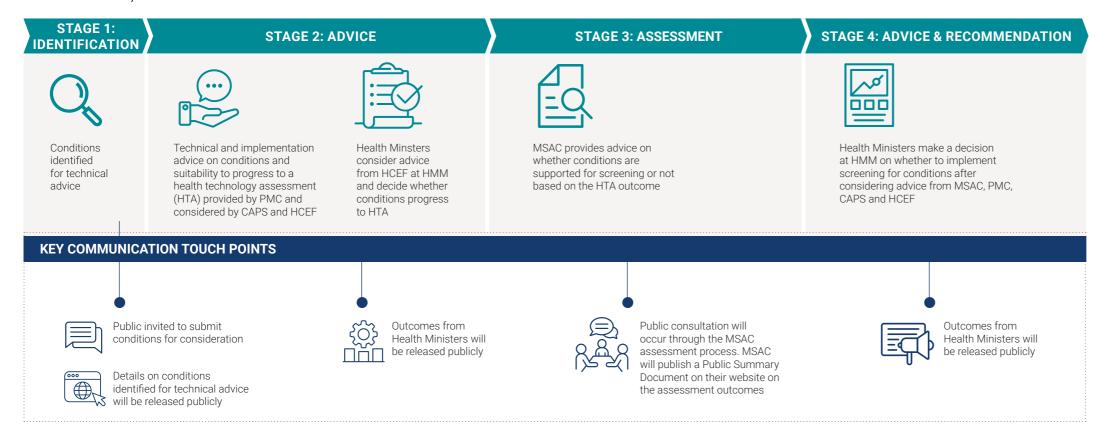
NEWBORN BLOODSPOT SCREENING

Our national decision-making pathway

The expansion of the newborn bloodspot screening (NBS) programs will see an increase in the number of conditions screened and support consistency of screening across Australia. NBS programs are delivered independently by states and territories, however all jurisdictions and the Australian Government work in partnership to consider which conditions are screened. The national decision-making pathway has been developed to support expanding the programs. For the first time in the history of Australia's NBS programs, we have a clear pathway that promotes transparency, collaboration and efficiency, while maintaining the safety of the programs and high quality screening that families trust.

NBS decision-making pathway

The national decision-making process for the addition of new conditions to Australian NBS programs and consideration of implementation involves a range of stakeholders and takes place over stages of condition identification, advice, assessment, and recommendation.



Roles and responsibilities

PMO

The NBS Program Management Committee (PMC) is an advisory body that provides technical advice to ensure the quality and consistency of newborn bloodspot screening in Australia. PMC will also provide implementation advice on a condition.

PMC comprises technical experts including senior clinical and laboratory scientists, clinicians, program managers and policy makers and may include additional experts as required.

CAPS Committee

The Cancer and Population Screening (CAPS) Committee provides strategic policy direction for national population screening and cancer control. Committee members are deputy chief executives of health departments and have strategic oversight of population screening and cancer in their jurisdictions, including decision-making authority. CAPS progresses a recommendation, based on PMC advice, to HCEF and HMM.

HCEF

The Health Chief Executives Forum (HCEF) is an intergovernmental forum for joint decision-making and strategic policy discussions that helps to efficiently deliver health services in Australia. It is made up of the health department chief executive officer from each state and territory and the Australian Government.

HMM

The Health Minister's Meeting (HMM) works to progress health issues of national importance which require cross-border collaboration. It is made up of all Australian Health Ministers.

MSAC

The Medical Services Advisory Committee (MSAC) is an independent non-statutory committee that provides advice to the Australian Government Minister for Health and Aged Care on whether a medical service, health technology or health program should be publicly funded, based on the outcomes of a health technology assessment.

Key improvements in the new national approach

01

Transparency and openness

There are clear, agreed steps for identifying, assessing and approving conditions, and agreed communication points to publicly share where a condition under consideration is up to on the pathway. Families, clinicians and other experts with an interest in a condition will be kept up to date on the status of conditions through updates to the NBS webpages.

02

Opportunities for public involvement

Governments are reducing the burden on civil society to drive expansion by establishing a transparent, systematic process, to identify, assess and select new conditions for screening on a regular basis. The public will be invited to contribute at the identification and assessment stages as new conditions progress through the pathway, providing the opportunity to contribute lived experience and expertise.

03

Collaboration across Australian governments

A collaborative approach across states and territories and the Australian Government 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.

04

Efficiency

From the point a condition is identified for technical advice, the pathway is expected to deliver a decision on screening within two years (depending on the complexity of the condition), with implementation to follow.

05

Funding to add new conditions

For the first time, the Australian Government has offered direct funding of \$25.3 million over four years from 2022–23 to states and territories for their NBS programs. An additional \$43.3 million was announced through MYEFO 2024–25 for states and territories. This funding will help support implementation of new conditions.





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Top FAQs

How can the public contribute to identifying and assessing conditions?

As part of condition identification, the public is invited to submit conditions for consideration for assessment (invitation dates to be confirmed).

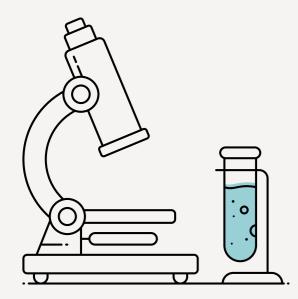
The public can also submit comments and feedback through the MSAC process on conditions that are being assessed for their suitability for screening. More information is available on the <u>MSAC webpages</u>.





Will there be an ongoing proactive approach to identify conditions?

As well as considering public submissions, all governments will identify conditions via ongoing reviews looking at emerging evidence, technology, and international screening programs. This includes reviewing scientific journal articles, monitoring the accuracy of screening tests, and results from completed clinical trials investigating the effectiveness of interventions or treatments.



What does the NBS
Program Management
Committee consider in its
technical advice?

The Program Management Committee (PMC) considerations of a condition are guided by the NBS National Policy Framework decision-making criteria. Consideration is given to the health benefits and harms to newborns, screening tests available, benefits of early detection and therapeutic intervention, clinical impacts and broader impacts on the programs.

PMC considers the available clinical, scientific and technical evidence and provides advice on the suitability of the condition to be screened for and to progress for a health technology assessment through the MSAC process.

4

What does MSAC assessment involve?

MSAC provides advice on new conditions proposed for NBS programs.

MSAC's advice is based on an assessment of comparative safety, clinical effectiveness, cost-effectiveness and total cost using the best available evidence. This helps ensure Australian healthcare funding is used to support the best health outcomes for Australians.

The <u>NBS National Policy Framework</u> also provides context to support MSAC's consideration.

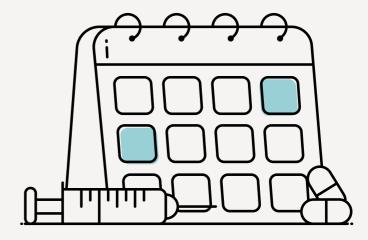
After assessing a condition, MSAC will provide advice on whether a condition is supported for screening or not.

A Public Summary Document outlining MSAC's advice for each condition assessed is published on the MSAC website.



What's the process for conditions that don't progress along the pathway?

Conditions that are considered but do not progress to an MSAC assessment or are not supported by MSAC are added to a registry for future review. The Department will monitor developments in treatments, technology and international screening programs relevant to the conditions on the registry. Experts and advocates are able to bring new information forward to the Australian Government for consideration.



6

What are the next steps once conditions are approved?

Once conditions are recommended for implementation by Health Ministers, states and territories will ready their laboratories and workforce to implement conditions and will take the necessary steps to achieve consistency and ensure smooth implementation.

Following Health Ministers' endorsement of a condition for screening, families can be assured that a condition will be implemented.

There may be slight variances in implementation time-frames for each state and territory in the short-term, once Health Ministers agree to add a condition.