



# Newborn bloodspot screening open call – condition identification form



## What is this form for?

Australia's newborn bloodspot screening (NBS) programs provide screening to babies for rare conditions in the first few days of life. A list of the conditions screened for in NBS programs is on the [department's website](#).

The Australian Government, in collaboration with states and territories, invites the public to identify conditions that may be suitable for NBS through an open call process (open call).

This form is used to identify conditions during the open call for potential inclusion in Australian NBS programs. Anyone can complete this form, including, but not limited to, the general public, consumers, family members, researchers, scientists, and clinicians.

This form and the open call is one of several ways the government will identify conditions. The Department of Health, Disability and Ageing (the department) will also review emerging evidence, international programs, new treatments and technologies to identify any other relevant conditions for consideration.

## How to complete this form:

*If you have questions or need help with the form, please contact the department at [NBS@health.gov.au](mailto:NBS@health.gov.au).*

### **STEP ONE: Review the considered and screened conditions listed here on the [department's website](#)**

You do not need to submit a condition that has already been considered for screening in Australian NBS programs. If a condition appears in **any table** on the website, you do not need to submit a form.

The department will monitor developments in treatments, technology and international screening programs. If sufficient new evidence becomes available for a previously considered condition, it will be reconsidered.

If you would like to share evidence relevant to a condition that has already been considered, you can email it to [NBS@health.gov.au](mailto:NBS@health.gov.au).

### **STEP TWO: Complete the form (one form per condition)**

Using the form below, please complete questions 1, 2, 3 and 4 to the best of your ability.

### **STEP THREE: Email the form**

Once complete, email the form to [NBS@health.gov.au](mailto:NBS@health.gov.au).



## How are conditions considered?

All Australian governments have agreed a [national decision-making pathway](#) to consider conditions for including in Australia's NBS programs. The pathway has four main stages:

1. Condition identification
2. Technical advice
3. Assessment
4. Advice and recommendation.

Using this form to identify a condition through open call is part of the first stage - **condition identification**.

For all conditions identified through this form, the department will gather the best available evidence to support consideration of the condition.

Evidence gathered for each condition will be considered against the NBS decision-making criteria in the [NBS National Policy Framework](#) (see Policy area 5 on page 37). The criteria include that:

- the condition needs to be a serious health problem with a clear benefit from early diagnosis in the newborn period
- there is a suitable test available
- there is an acceptable and effective intervention or treatment available.

## What are the next steps for conditions identified via this form?

The conditions identified, and information on how well they align with the decision-making criteria, will be considered by the Cancer and Population Screening Committee.<sup>1</sup>

Conditions that have sufficient alignment with the criteria will move to the second stage in the decision-making pathway - **technical advice**. If a condition does not sufficiently align with the criteria, it will not proceed to technical advice at this time.

View our [factsheet](#) for more information on the pathway and the stages that follow technical advice.

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<sup>1</sup> The Cancer and Population Screening Committee provides strategic policy direction for national population screening and cancer control. Members are deputy chief executives of health departments in each jurisdiction.

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## When will I hear more about the condition?

**Confirmation email:** You will receive an email confirming receipt of your form within five business days of submission.

**Outcome notification email:** Once the Cancer and Population Screening Committee has considered your condition, you will receive an email advising whether the condition will progress to the next stage in the decision-making pathway (technical advice).

**Public outcomes:** A list of all conditions identified through the open call – and which ones will proceed to technical advice - will be published on the department's website and shared by email through our subscription service.

**Timing:** We anticipate outcomes will be available in mid-2026, depending on the number of conditions identified.

## Do you have more questions?

Please see other [Frequently Asked Questions and Answers](#).





# NBS Condition identification form

## 1. Contact information

<b>Your name</b>	
<b>Job title or position (if applicable)</b>	
<b>Organisation (if applicable)</b>	
<b>Email address</b>	
<b>Phone number</b>	
<b>Mobile number</b>	
<b>Can the department contact you for further information regarding this submission?</b>	<input type="checkbox"/> <b>Yes:</b> what is your preferred method of contact: <input type="checkbox"/> Email <input type="checkbox"/> Phone <input type="checkbox"/> Mobile <input type="checkbox"/> <b>No:</b> Go to next question
<b>Are you submitting this form for a group of people or organisation/s?</b>	<input type="checkbox"/> <b>Yes:</b> If yes, please add below the organisation/s or group you are identifying the condition on behalf of <b>Organisation/s, group and/or affiliations represented:</b>  <input type="checkbox"/> <b>No:</b> Go to next question

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Do you wish to sign up to our subscription service to receive email updates about NBS programs and condition outcomes?

☐ **Yes:** If yes, please add email addresses below

Email address/es to receive the subscription service updates:

☐ **No:** Go to Question 2

## 2. Condition name

**What is the condition you would like to identify?**

Please add any known name/s of the condition that you are aware of. A condition is sometimes known by several names and it would be helpful to list these.

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**Has this condition already been considered for screening in Australia? See our [conditions](#).**

If the condition appears in any table on this page, you do not need to complete this form.

☐ **Yes:** If yes, you **do not** need to complete this form.

Developments in treatments, technology and international screening programs will be monitored. Where there is sufficient new evidence relating to a previously considered condition, it will be reconsidered.

If you would like to share information or evidence relevant to a previously considered condition you can email it to [NBS@health.gov.au](mailto:NBS@health.gov.au).

☐ **No:** Go to next question

**Would you like to identify more than one condition?**

☐ **Yes:** Please complete and submit a separate form for each condition (one condition per form)

☐ **No:** Please complete Question 3



## 3. Information about the condition

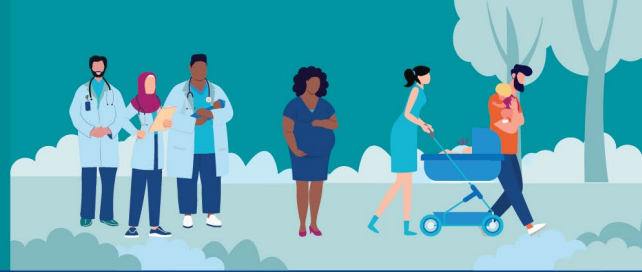
Decisions to add conditions to NBS programs must be made in line with agreed **decision-making criteria outlined in the NBS [National Policy Framework](#)**.

This includes criteria about the condition, the screening test, and the intervention/treatment. To the best of your knowledge, please indicate how the condition identified in this form meets the decision-making criteria in the section below.

The department, in collaboration with states and territories, will do a thorough review of the evidence for each condition. However, we understand that members of the public, families, clinicians, scientists, researchers and other experts may have extra information they wish to contribute.

The volume of information you provide **will not impact** how the condition progresses.

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## a) About the condition

**Guidance:** The National Policy Framework says the identified condition should be a **serious health problem** that leads to significant illness (morbidity) or death (mortality).

There should be a **benefit to screening in the newborn period**. While the baby must always be the primary consideration, benefits to the family may also be considered.

**Is the identified condition a serious health problem that leads to significant illness (morbidity) and/or death (mortality)?**

☐ **Yes:** Provide any known details below or go to next question

☐ **No**

☐ **Unsure**

**Is there a benefit to detecting this condition in the newborn period?**

☐ **Yes:** Provide any known details below or go to next question

☐ **No**

☐ **Unsure**

**If you replied 'Yes' to any of the above, you can provide any known details you would like to:**  
(up to 250 words)

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## b) The screening test

**Guidance:** The National Policy Framework says the identified condition should have a **suitable test method** that is able to be performed on a dried bloodspot to effectively identify the presence of the condition.

The test should be **simple and reliable**, and socially and ethically acceptable to health professionals and the public.

**Is there a test that identifies the presence of the condition?**

☐ **Yes:** Provide any known details below or go to next question

☐ **No**

☐ **Unsure**

**Is this condition currently screened in newborn screening programs outside of Australia?**

☐ **Yes**

☐ **No**

☐ **Unsure**

**If you replied 'Yes' to any of the above, you can provide any known details if you would like to:**  
(up to 250 words)



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## c) The intervention or treatment

**Guidance:** The National Policy Framework says identified conditions should have an **accepted intervention** or treatment for newborns diagnosed with the condition, that is approved for use in Australia. There should also be **health services to manage** the condition.

**Is a treatment or intervention for the condition available?**

☐ **Yes:** Provide any known details below or go to next question

☐ **No**

☐ **Unsure**

**Is the intervention or treatment currently available in Australia or elsewhere?**

☐ **Yes**   ☐ **No**   ☐ **Unsure**

**If you replied 'Yes' to any of the above, you can provide any known details if you would like to:**  
(up to 250 words)

## Newborn bloodspot screening open call – condition identification form



### **d) OPTIONAL: Do you have anything else to add to this form?**

This may include other information relevant to decision making that has not been captured elsewhere.  
This could include, but is not limited to:

- the names of any clinicians the department could approach for further information
- any evidence or personal experience of the condition you wish to contribute.

(Up to 250 words)

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## 4. Privacy statement and acknowledgment

Your personal information is protected by law, including the *Privacy Act 1988* and the Australian Privacy Principles, and is being collected by the Australian Government Department of Health, Disability and Ageing (the department) for the primary purpose of notifying you on the progress of your condition at communication points.

The department will not disclose your personal information to any overseas recipients.

If you do not provide this information the department will be unable to notify you at future communication points.

You can get more information about the way in which the department will manage your personal information, including our privacy policy, at [www.health.gov.au/resources/publications/privacy-policy](http://www.health.gov.au/resources/publications/privacy-policy)

By providing your sensitive information to us, you consent to the department collecting your contact information, including your contact name, job title or position (if applicable), organisation (if applicable), email address, and phone/mobile number for the purposes indicated above.

Please tick the box below:

☐ **I acknowledge I have read the privacy statement.**

**END**