

Australian Nursing and Midwifery Federation submission

**Australian Government
Department of Health and
Aged Care
Expansion of Newborn
Bloodspot Screening
Public Consultation**

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Australian
Nursing &
Midwifery
Federation



Australian Nursing and Midwifery Federation submission

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INTRODUCTION

The Australian Nursing and Midwifery Federation (ANMF) is Australia's largest national union and professional nursing and midwifery organisation. In collaboration with the ANMF's eight state and territory branches, we represent the professional, industrial and political interests of more than 322,000 nurses, midwives and carers across the country.

Our members work in the public and private health, aged care and disability sectors across a wide variety of urban, rural and remote locations. We work with them to improve their ability to deliver safe and best practice care in each and every one of these settings, fulfil their professional goals and achieve a healthy work/life balance.

Our strong and growing membership and integrated role as both a professional and industrial organisation provide us with a complete understanding of all aspects of the nursing and midwifery professions and see us uniquely placed to defend and advance our professions.

Through our work with members we aim to strengthen the contribution of nursing and midwifery to improving Australia's health and aged care systems, and the health of our national and global communities.

The ANMF welcomes the opportunity to provide response to the *Expansion of Newborn Bloodspot Screening* public consultation.

We offer the following feedback in response to the consultation questions in the survey.



NEWBORN BLOODSPOT SCREENING CONSULTATION SURVEY RESPONSE

This consultation seeks your thoughts on what is important to think about when expanding NBS programs, against five key areas:

1. The aims and objectives of the programs
2. National consistency
3. Assessment of conditions
4. Readiness
5. Measuring success.

It is intended that a report of findings from this consultation will be developed and shared publicly. Do you consent to your responses to these questions being shared?

- Yes – response can be published in full
- Yes – anonymise content
- No

Please select the category that best describes you:

- Technical expert (e.g., clinician, paediatrician, laboratory worker)
 - Midwife
 - Scientist
 - Pathologist
 - Nurse
 - General Practitioner
 - Community health worker
 - Researcher
 - Medical Specialist (specialty area optional)
 - Public health practitioner
 - Ethicist
 - Academic
 - Laboratory scientist
 - Other – please include details



If so, where do you work or practice?

- General public
 - Parent
 - Guardian
 - Family member
 - Other
 - If so,
 - Are you of Aboriginal or Torres Strait Islander origin
 - Are you from a culturally or linguistically diverse background
- Consumer peak body or advocacy group
- Rare disease group
 - If so, which? Please name the group.
- Professional peak body
 - Australian Nursing and Midwifery Federation
- State or Territory Government Health Department
- Other
 - Please provide further details



1. Where we are going (two questions)

This section describes the commitment to expand the programs, and then reflects on the existing aim and objectives of the programs.

Australia's newborn bloodspot screening (NBS) programs are well regarded and trusted by the Australian communities they also have a strong international reputation. Like all screening programs, NBS programs need regular updating to keep up with new science and evidence.

The Australian Government is committed to increasing the number and consistency of conditions screened across NBS programs. This expansion project aims to:

- ensure every baby born in Australia will be screened for the same conditions and have access to the same high-quality care no matter where they live
- ensure Australian babies are screened for more conditions in a safe and high-quality matter where recommended
- assess new conditions in a more streamlined and efficient way
- monitor emerging interventions, and technologies to test for conditions that could be screened through the programs
- help states and territories implement NBS for additional conditions that have been recommended for inclusion
- ensure that equity of access and outcomes are considered and incorporated into the design of the programs.



Aim and objectives of NBS

We are keen to understand if you have any comments or reflections on the current aim and objectives for the programs

Box 1: Nationally agreed aim and objectives for newborn bloodspot screening¹

The aim of newborn bloodspot screening is to improve the health of babies by identifying those at risk of developing a serious condition early, generally before symptoms present, thereby enabling earlier intervention.

The objectives are that newborn bloodspot screening programs:

- provide quality, timely and evidence-informed screening to all newborns in Australia
- enable early detection of individuals at risk of conditions screened to reduce the morbidity and mortality associated with the relevant conditions
- support referral to enable early diagnosis and management of conditions identified through screening
- maximise program participation and public trust
- encourage strong partnerships across health systems that are focused on the delivery of high-quality newborn bloodspot screening
- support timely communication of high-quality information to families on all aspects of newborn bloodspot screening
- develop and learn through continuous improvement processes that assess short- and long-term program performance.

Questions

We are keen to understand if the existing aim and objectives of the program (**Box 1**) remain current

1.1 Do you have any comments or reflections on the aim of NBS above?

The ANMF supports the aim of the NBS program. It is imperative the program continues to deliver health benefits to babies, without causing avoidable harm and is universally accessible regardless of geographical location.

¹ From the NBS National Policy Framework



1.2 Do you have any comments or reflections on the objectives?

The objectives of the NBS program are clear and support achievement of the aim.

The ANMF recommends that the Program objectives also include the need to support parents' informed decision making as to whether to proceed with newborn screening tests, based on the benefits and risks.

It should be noted that the objectives require a well-resourced and cohesive health system. Midwives, and at times nurses, provide the bulk of newborn bloodspot screening counselling and blood sample collection. Ensuring midwives and nurses have access to resources to provide quality, evidence-based information and the time required to counsel and perform the test is essential for these objectives to be met.

Consideration should be given to the decreased length of stay of women as inpatients in maternity units and the resultant requirement of additional extended postnatal care/hospital in the home resourcing as detailed below.



2. Achieving national consistency (two questions)

This relates to commitments to achieve national consistency, and then how this consistency is maintained throughout the expansion process.

What have we heard through our consultation so far

- There has been a strong positive response to the intention to achieve national consistency in the conditions screened.
- There was recognition that all governments have agreed to the NBS National Policy Framework, which looks to support a level of national consistency across the program. However, more can be done to support consistency across Australia of conditions screened.
- The Australian Government's commitment responds to this need and in collaboration with the efforts of states and territories, provides a unique opportunity to ensure consistency in the programs.
- NBS programs across Australia should add conditions at the same time, to ensure consistency of screening.

Questions

2.1. Noting the above, please provide any reflections, suggestions or comments on progress to achieve national consistency.

A plan to achieve national consistency is imperative to improve health outcomes for all Australians particularly those living in rural and remote areas.

2.2 What do you consider to be the key issues when considering national consistency, for example equity of access to screening, follow-up services, consumer information and education?

Delivering nationally consistent programs and services requires additional supports and funding to be invested in the health system particularly in areas poorly serviced and with significant health workforce shortfalls.

The ANMF recommends investing in the midwifery and nursing workforce to expand access for women, infants and families to newborn blood spot screening and associated services consistent with the objectives of the program. This may include, but is not limited to:

- *Recognising and utilising the skills and expertise of midwives and nurses to allow them to work to their full scope of practice through midwife-led and nurse-led programs in maternity and early intervention services;*



- *Continuing to invest in telehealth services that enable specialists to liaise and consult with families supported by midwives and nurses in their local community;*
- *Addressing broader midwifery and nursing workforce issues such as:*
 - *ensuring funding models recognise the time required to care for newborn babies, including counselling and blood spot sampling for the newborn screening program;*
 - *providing training in the collection of bloodspot screening. Currently there is no training in the collection of blood for bloodspot screening. Midwives reports that some collections fail due to insufficient blood being collected for testing. If training standards were developed and implemented, this would assist in increasing consistency of collection and help to reduce failure rates of screening;*
 - *if a re-test needs to be conducted, this often falls to community health services that may not have received adequate education;*
 - *providing incentives and strategies to increase access to midwifery and nursing care in regional, rural and remote areas such as increased support for structured clinical placement opportunities for students of midwifery and nursing and newly graduated midwives and nurses in rural and remote healthcare facilities, additional leave entitlements to address isolation and burnout, financial support to undertake professional development; and*
- *Continuing national and state government support for health services designed and led by Aboriginal and Torres Strait Islander peoples, such as the Waminda Birthing on Country program.*



3. Assessment (seven questions)

'Assessment' refers to the process by which a condition is identified and assessed prior to being included in NBS programs. The [NBS National Policy Framework](#) includes criteria for assessing conditions (section 6).

What we have heard from consultation so far

- There is ongoing support for the criteria within the [NBS – National Policy Framework](#) to be used to assess conditions for inclusion in the program.
- Feedback has been clear that there is a continued need for a detailed assessment process, that considers evidence, and the benefits and harms of screening.
- It was recognised that there may not always be the level of evidence or local data to comprehensively assess the full range of benefits and harms, with a lack of Australian data for specific conditions or evidence relating to cost effectiveness provided as examples.

Consultation so far has suggested several opportunities to enhance, improve and streamline the assessment process. These include:

- Instituting an ongoing review of evidence to identify new conditions for assessment
- Removing the reliance on families and civil society to drive the nomination and assessment process, to ensure that no undue burden is placed on families
- Ensuring a consumer input at relevant stages of the assessment process
- Ensuring that the assessment process is fit for purpose, timely and ensures robust assessment.

Questions

3.1. What do you view as the benefits of NBS?

The NBS provides benefit where it identifies a condition that can be treated prior to it causing irreversible harm to the infant.

3.2. What do you view as the harms of NBS?

The NBS has the potential to cause harm when a family receives a positive screening result but subsequently tests negative for the condition. The emotional distress experienced by parents awaiting diagnostic testing can cause long term parental anxiety and affect infant parent attachment. The impact of false negatives needs to be considered both for its effect on families and also on the overall success of the program.

There is also a risk of harm if an identified condition has no treatment. The ethics of an individual's right to choose if they want to know about an untreatable life-limiting condition needs to be considered as a potential risk of harm when evaluating new conditions for inclusion in the program.



3.3. How important do you think it is to consider the:

- Benefits of screening – not at all important, slightly important, moderately important, **very important**, extremely important
- Harms of screening – not at all important, slightly important, moderately important, **very important**, extremely important

3.4 The NBS National Policy Framework decision-making criteria are designed to assess the benefits and harms of screening. They focus on:

- 1) what we know about the condition,
- 2) how good the screening test is at finding the condition in a newborn,
- 3) what we know about how to best manage a condition, and
- 4) how screening can best be implemented in the health system.

The Policy Framework talks about ‘intervention’ rather than ‘treatment’ since some conditions that may be considered for NBS may respond to pharmaceutical as well as other (non-pharmaceutical) interventions.

In your view, how important is it that there is an intervention that can significantly improve the outcomes for the baby?

Not at all important, slightly important, moderately important, very important, **extremely important**

The value of the NBS program lies in its ability to detect a condition present from birth where early intervention can improve the health and wellbeing outcomes for the infant. It is very important conditions screened for have identified interventions that can significantly improve the outcomes for the newborn.

If the NBS program identifies conditions where early diagnosis offers no additional benefit to the health outcomes for the infant, the underlying premise of the program is not achieved. Testing for untreatable life limiting conditions involves different ethical parameters and counselling outside of the scope of the NBS programs’ aims and objectives.

What does an accepted intervention look like?

Determining an accepted intervention is complex where the broad spectrum of conditions screened for and subsequently diagnosed by the NBS program have varying degrees of severity and impacts on growth, development and health outcomes. The acceptability of an intervention can only be assessed by taking into consideration the infant’s individual presentation, diagnosed condition and in consultation with their parents/carers.



In view of this, broadly, an accepted intervention should:

- *improve the quality of life for the infant;*
- *consider the risk of harm to the infant of that intervention;*
- *consider family values and preferences.*

3.5 Please describe any other areas that should be a focus when considering the evidence for a new condition. You may wish to reflect on the NBS National Policy Framework criteria, although it is not essential for you to do so.

No additional feedback

3.6 Any assessment process will provide all stakeholders the opportunity to comment or seek information as conditions are considered for the programs. Noting the below simplified assessment process for illustrative purposes, are there any specific points along the assessment process at which the consumer input should be sought?

Stakeholder input should be sought at the point of gathering evidence. This may include:

- o *consultation with people and/or their carers who have lived experience with the identified condition;*
- o *consultation with the workforce regarding the necessary upskilling, if any, required to include the test.*





3.7 In your view, what would be the most appropriate way for you to be involved?

- **Consultation forums**
- Online approaches
- Surveys
- Consultation paper
- Other – please specify
- Not interested in being involved in consultation

3.8. How should the department best advise on consultation opportunities for conditions going through an assessment process?

- Medical Services Advisory Committee website
- **Health website**
- ***Other – direct communication with key stakeholders such as support groups for people living with the identified condition and the health workforce administering the NBS program.***



4. Readiness (eleven questions)

'Readiness' relates to what is needed 'on the ground' to ensure that the NBS programs and clinicians and services are best able to provide expanded screening and support families following an abnormal result

What we have heard through consultation so far

- When expanding NBS, it is important not just think about the condition, or the screening test, but also any further testing needed, and the clinical and support services that families need to ensure the best possible outcomes following an abnormal result.
- Given this, expansion requires careful planning and engagement to ensure that all relevant sections of the health system are able to support expanded screening.
- Efforts are needed to ensure that follow up testing, services and care can be provided to the same degree of quality across Australia, regardless of where a person lives. This will ensure equity of outcomes and support across rural and remote regions, and metropolitan regions.
- There is a need for information that supports consumers throughout the screening process, and also information to support them during any further testing or care, focused on the needs of consumers.
- These materials should also be tailored to provide information to First Nations' families and culturally and linguistically diverse families. More work is needed to also understand what is needed to support these families throughout the screening and follow-up pathways.
- There may be the need for materials and information for clinicians to enable them to quickly understand the conditions added and clinical pathways.

The following material and questions seek to explore what is needed to support the expansion, building on what we have heard from the consultation.



Box 4.1. The screening pathway is supported by the following key activities

1. Information is provided to families, with an opportunity to discuss this information
2. All families are offered screening for their baby
3. Dried bloodspots are provided to the laboratory in a timely way
4. Accurate and timely testing of the bloodspot occurs
5. Every baby has a recorded screening result or refusal
6. The family of a baby with an abnormal result is contacted by the appropriate health care provider for diagnostic testing in a timely manner, and/or have further samples or testing
7. Diagnostic testing occurs and for those babies identified as being at increased risk of having a condition, results are provided to the newborn bloodspot screening laboratory for data collection
8. The family is offered care and intervention (specialist care, medications and other clinical support)
9. Families access other supportive services (consumer groups, counselling).

Note, further information on how the programs operate can be found in the [NBS National Policy Framework](#).

Questions

4.1. From your experience, which activities from Box 4.1 do you think will be most impacted by an expansion of the NBS programs, and why?

Expansion of the NBS programs will impact activity 1. If additional conditions are added to the NBS program, health practitioners, predominantly midwives, providing counselling and taking the blood sample will require additional education to continue to administer the test following principles of informed consent and to maintain public confidence in the value of the screening program. Written information provided to families and resources for further information will also need to be updated to reflect the changes.

Activity 4, accurate and timely testing of the bloodspot, may be impacted if the amount of blood sample taken is not sufficient to perform the required screening. The amount of blood required for the expanded screening will need to be considered.

Barriers currently exist to universal access to timely health care for people living in regional, rural and remote areas of Australia and/or with specific social, cultural and/or economic needs. Therefore, regardless of expansion of NBS programs, the health system needs to be redesigned to achieve activities 6, 8 and 9 for these people.



4.2 Thinking about your experience with NBS, or with maternal hospital services more broadly, please select any issues that may impact the likelihood of accessing screening services:

Select all that apply

- Language or communication barriers
- Cultural or religious beliefs
- Previous experiences with medical staff
- Staff who reflect the consumer's cultural background
- Staff who respect the consumer's cultural background
- Clear information about the screening process
- Clear information about the need for screening
- Fear of medical procedures
- Other, geographical location
- Not applicable

Follow up question for those who select any of the options above:

4.3. Thinking about the issues you selected above, please highlight how important you think they are for making a decision to access screening services, or discussing them with consumers:

Not at all important, slightly important, moderately important, very important, extremely important

Public/Consumer question 1.

4.4 Thinking about the consumer experience of care outside the hospital setting (this might include at a pathology service, with GPs, or specialist services) please select any issues that may impact the likelihood of attending these services if a baby had a positive NBS diagnosis:

Select all that apply

- Language or communication barriers
- Transport
- Location of services
- Cultural or religious beliefs
- Previous experiences with medical staff
- Staff who reflect the consumer's cultural background
- Staff who respect the consumer's cultural background



- Clear information about the screening process
- Clear information about the need for screening
- Fear of medical procedures
- Privacy
- Knowing where to go for screening
- Other, please specify
- N/A

Follow up question for those who select any of the options above:

4.5 Thinking about the issues you selected above, please highlight how important you think they are for making a decision to accessing follow up:

Not at all important, slightly important, moderately important, **very important**, extremely important

Public/Consumer question 2.

4.6 What else would you like to tell us about what is needed to make NBS and follow-up testing care accessible, and culturally safe?

Barriers currently exist to universal access to timely health care for people living in regional, rural and remote areas of Australia and/or with specific social, cultural and/or economic needs. The ANMF recommends investing in the midwifery and nursing workforce to expand women, infants and families access to NBS and follow up testing and care. This may include, but is not limited to:

- *Recognising and utilising the skills and expertise of midwives and nurses to allow them to work to their full scope of practice through midwife-led and nurse-led programs in maternity and early intervention services;*
- *Continuing to invest in telehealth services that enable specialists to liaise and consult with families supported by midwives and nurses in their local community;*
- *Providing incentives and other strategies to increase access to midwifery and nursing care in regional, rural and remote areas such as increased support for structured clinical placement opportunities for students of midwifery and nursing and newly graduated midwives and nurses in rural and remote health facilities, additional leave entitlements to address isolation and burnout, financial support to undertake professional development;*
- *Continuing national and state government support for health services designed and led by Aboriginal and Torres Strait Islander peoples, such as the Waminda Birthing on Country program.*



The following questions help us to understand where program information is currently accessed and what further information is needed to support families and clinicians for the expanded programs.

4.7 Where do you currently access information about the NBS program? Select all that apply

- Department of Health and Aged Care website
- State based websites
- Local GP
- Health Care Provider (website, fact sheets, pamphlets, in person advice)
- Facebook or social media
- Word of mouth
- Google/search engine
- Friends or family
- Other health professional
- Other please specify
- N/A

Public/Consumer question 3.

4.8 What national information is needed to support consumers, such as parents, families and carers, along the NBS pathway?

- Printed materials
- Information modules
- One stop shop for information
- National phone line
- Publicly available clinical care guidelines or pathways
- Other – online information or information embedded in existing health services smart phone apps
- N/A

Technical expert question 1.

4.9 What could be done nationally to support clinicians to help provide informed and timely support to families following NBS?

- Modules
- One stop shop for information
- National phone line
- Clinical care pathways



- Clinical guidelines
- Other
- N/A

Technical expert question 2.

4.10 What could be done at a state or territory level to support clinicians to help provide informed and timely support to families following NBS?

- Modules
- One stop shop for information
- National phone line
- Clinical care pathways
- Clinical guidelines
- Other
- N/A

Technical expert question 3.

4.11 What else can be done to support clinicians to deliver safe and effective care at the following levels:

- National
 - *Development of national clinical care pathways and guidelines to assist all health practitioners involved in a family's care to understand their role in supporting that family and provide consistent care across service providers;*
 - *Increased utilisation of digital health technologies to support health practitioners, particularly those in rural and remote areas, to liaise and consult with specialised services and provide local support to families;*
 - *Access to free, nationally consistent professional development programs;*
 - *Investment in programs to address barriers to universal health care access such as Aboriginal and Torres Strait Islander peoples-led services.*
- State
 - *Ensuring that funding of the workforce reflects the time that is required to provide the care;*
 - *Establishment of a liaising clinician or care coordinator in each jurisdiction who oversees the care of infants who have received a positive newborn screening result from the first communication with parents/carers regarding the positive result through to referral and ongoing treatment.*



- Local/clinical level
 - *Allocated time to complete professional development activities in work time;*
 - *Implementation of digital health technologies within local services that support inter-organisational and inter-professional collaboration as well as data and information sharing across health service providers involved in a family's care.*

5. What does success look like? (one question)

5.1 In your view, once the programs are successfully expanded, what do you consider will be the three most important signs of success and how should they be measured?

- *Continued public engagement and confidence with the program measured by the percentage of infants born in Australia participating in the test;*
- *Early detection and management of conditions screened for by the program measured by number of infants experiencing harm related to a screened for condition as a result of delayed or missed diagnosis; and*
- *Consistency of experience with the program across all health services in all geographical locations.*

6. Next Steps

Thank you for responding to this consultation paper. Stakeholder input is and will continue to be essential to expanding NBS programs.

The information collected will be analysed and inform the next steps for the national expansion project.



CONCLUSION

Thank you for the opportunity to provide response to the *Expansion of Newborn Bloodspot Screening Program* public consultation. The ANMF supports the expansion of the national program that ensures that every baby born in Australia will be screened for the same conditions and have access to the same high-quality care no matter where they live. It is essential that there is adequate training and resourcing for midwives and nurses for the success and consistency of the expanded newborn bloodspot screening programs.