

Expansion of Newborn Bloodspot Screening Public Consultation

NACCHO Response submitted via Online portal 12 December 2022

Please select the category that best describes you:

General public

Technical expert (e.g. clinician, paediatrician, laboratory worker)

Consumer peak body or advocacy group

Rare disease group

Professional peak body

State or Territory Government Health Department

Other – please include details

Please name the Consumer peak body or Advocacy group

NACCHO (National Aboriginal Community Controlled Health Organisation)

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We are keen to understand if the existing aim and objectives of the program (shown in box 1 above) remain current.

1.1 Please provide any **comments or reflections on the aim of NBS** above.

1.2 Please provide any **comments or reflections on the objectives**.

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1.1 Aim: The aim should include explicit reference to equity as well as culture and cultural safety in line with the National Agreement on Closing the Gap. Although it may be implicit in “improve the health of babies” that this aim refers to **all babies**, the current reality is that not all babies have equitable or culturally safe access to NBS. The National Agreement specifically identifies the target that *Aboriginal and Torres Strait Islander children thrive in their early years* and that “*by 2031, increase the proportion of Aboriginal and Torres Strait Islander children assessed as developmentally on track in all five domains of the Australian Early Development Census (AEDC) to 55 per cent.*” The NBS program has the potential to positively contribute towards this stated target but only if screening is culturally safe and accessible for all Aboriginal and Torres Strait Islander children and their families.

1.2 Objectives: Culturally safe partnerships: it is imperative that the objectives acknowledge the need for culturally safe approaches, and the key role that the ACCHO sector and individuals such as Aboriginal and Torres Strait Islander Liaison Officers can play in mainstream birthing centres and children’s hospitals. The objective “encourage strong partnerships across health systems...” has potential to align with Priority 1 of the National Agreement (Formal Partnerships and Shared Decision Making) but genuine partnerships are only possible if there is meaningful movement to ensuring the cultural safety of children and their families, and the ACCHO sector workforce.

Language: the objectives should also acknowledge need for NBS informational resources and processes that are well placed to support mothers and families for whom English is not the first language

Develop research agenda - It is essential to:

- **Learn more about those who decline NBS** - more information is required to better understand who declines NBS currently and why. NACCHO suggests that the Department consider specific efforts that could be taken to reduce number of parents who decline NBS.
- **Learn more about the lived experiences of families through the NBS Program** – active steps must be taken to ensure the Program is

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working well for all Australians with a particular focus on Aboriginal and Torres Strait Islander peoples.

- **Shared Access to Data and Information at a Regional Level** – as per Priority Reform 4 of the National Agreement, it is vital that the Department provide communities and organisations with access to the same data and information they use to make decisions

Implement non-punitive processes to safe-guard babies of families who decline NBS – avoid punitive approaches and consider options for structural reform. For instance, consider systems that could be established to safeguard babies when screening is declined (for eg a letter to GP; information sharing with families on what symptoms / signs to look out for / what to do if they have concerns in coming weeks / written advice on later testing (and effectiveness) should they change their mind/ number they can call for more information etc. Such systems should be developed in partnership with key stakeholders such as the ACCHO sector in line with the National Agreement (priority reforms 1 and 2)

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

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?

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2.1 NACCHO supports **meaningful** commitment to achieve national consistency, this includes reassessing funding models, increasing the transparency of processes by which decisions are made to include certain tests and identifying and eliminating racism in strategic and operational frameworks in line with the National Agreement (*Priority Reform 3*).

2.2 Key issues

An equity lens approach **must** be applied to achieve national consistency. This may necessitate making additional resources available to different jurisdictions in consultation with the ACCHO sector and other stakeholders as required to achieve this goal. Only by genuinely shared decision making, building the ACCHO sector and increasing accountability of the Department for equitable delivery of the NBS (*Priority Reforms 1,2 and 3*) will national consistency be achieved.

A person and community-centred approach to NBS is needed. The Program must consider the lives of children and families beyond diagnosis. For instance, this could include investment in support groups, informational resources, communication platforms and other structures that can help families and children living with chronic conditions enjoy the highest quality of life possible¹. A more holistic focus would have the added advantage of supporting consumer education and informational resource development.

1. <https://www.mdpi.com/2409-515X/6/4/76/htm>

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<p>Questions</p> <p>3.1 What do you view as the benefits of NBS?</p> <div data-bbox="233 391 808 509" style="border: 1px solid black; height: 73px;"></div> <p>3.2. What do you view as the harms of NBS?</p> <div data-bbox="233 602 808 721" style="border: 1px solid black; height: 73px;"></div> <p>3.3 How important do you think it is to consider the:</p> <table data-bbox="233 820 940 938"><thead><tr><th></th><th>Not at all important</th><th>Slightly important</th><th>Moderately important</th><th>Very important</th><th>Extremely important</th></tr></thead><tbody><tr><td>Benefits of screening</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr><tr><td>Harms of screening</td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td><td><input type="radio"/></td></tr></tbody></table>		Not at all important	Slightly important	Moderately important	Very important	Extremely important	Benefits of screening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Harms of screening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<p>3.1 Benefits of NBS:</p> <p>The potential for equity with strong, culturally safe systems and processes in line with the National Agreement on Closing the Gap</p> <p>The potential to reduce preventable mortality and morbidity</p> <p>3.2 Harms of NBS:</p> <p>The failure to achieve equity (with systems that are not culturally safe) and risk of systematic discrimination and exclusion, particularly where social and cultural determinants of health are not addressed.</p> <p>There is also a risk of trauma to families if new diagnosis of severe and chronic conditions of childhood are not communicated in an appropriate and culturally safe way.</p> <p>3.3 Importance of considering: Benefits: <i>extremely important</i> Harms: <i>extremely important</i></p>
	Not at all important	Slightly important	Moderately important	Very important	Extremely important														
Benefits of screening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>														
Harms of screening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>														

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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
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What does an accepted intervention look like?

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.

How important is it that there is an intervention that can significantly improve the outcomes for the baby? – *Extremely important*

3.4 What an accepted intervention looks like depends on how benefit is defined. If there is benefit to the parents and family, then there will be flow-on benefits to the baby and broader community. There needs to be cultural interpretation of benefits and harms considered, therefore it will be important to have Aboriginal and Torres Strait Islander people involved in highest level of governance of the expanded and improved NBS Program as per the National Agreement (*Priority Reforms 1 and 3*). Accepted interventions must be culturally safe – in addition to meeting gold standard biomedical guidelines and benchmarks.

3.5 The expanded NBS program must have structures in place to ensure equitable approaches at all times and avoid instances where it is only the most vocal and persistent lobbyists achieving their goals. This is best achieved through “*policy and place-based partnerships to respond to local priorities*” as laid out in the National Agreement (*Priority Reform 1*).

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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, please highlight any specific points along the assessment process at which consumer input should be sought?



3.6 - All stages

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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 – please specify

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3.7 All of the above. Must allow appropriate time for meaningful consultation.

3.8 Medical Services Advisory Committee (MSAC)

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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?

4.1 Most affected will include:

- 1) Information must be culturally appropriate and available in different languages, with the option to discuss with a culturally appropriate healthcare professional. This may require building capacity in some services/regions in line with Priority Reform 2 of the National Agreement.
- 2) Culturally appropriate approaches to communicating NBS to all families must be prioritised (see point 1).
- 5) More research is needed to understand why some families decline NBS, these findings then need to be shared at the regional level so that local services can respond in a culturally safe and appropriate manner as per Priority Reform 4 of the National Agreement.
- 6) Processes must be culturally appropriate. Resources will be needed to ensure equitable access to all.
- 7) Data relating to Indigeneity should be included and then reported back to the appropriate service at the regional level as per Priority Reform 4 of the National Agreement.
- 8) Culturally safe and appropriate care, with involvement of Aboriginal and Torres Strait Islander Liaison Officers needs to be prioritised. Translation services will be needed for some families. Transport support will be needed for some families.
- 9) Range of culturally safe services must be available.

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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.

Fear of medical procedures

Clear information about the need for screening

Cultural or religious beliefs

Language or communication barriers

Clear information about the screening process

Staff who reflect the consumer's cultural background

Staff who respect the consumer's cultural background

Previous experiences with medical staff

Other, please specify

Not applicable

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4.2 All of the above. Considerations specific to Aboriginal and Torres Strait Islander specific communities must be explicitly addressed.

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<p>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.</p> <p>4.3 Where do you currently access information about the NBS program?</p> <p>Select all that apply.</p> <p><input type="checkbox"/> Department of Health and Aged Care website</p> <p><input type="checkbox"/> State based websites</p> <p><input type="checkbox"/> Local GP</p> <p><input type="checkbox"/> Health Care Provider (website, fact sheets, pamphlets, in person advice)</p> <p><input type="checkbox"/> Facebook or social media</p> <p><input type="checkbox"/> Word of mouth</p> <p><input type="checkbox"/> Google/search engine</p> <p><input type="checkbox"/> Friends or family</p> <p><input type="checkbox"/> Other health professional</p> <p><input type="checkbox"/> Other please specify</p> <input type="text"/> <p><input type="checkbox"/> Not applicable</p> <p><input type="button" value="Back"/> <input type="button" value="Next"/></p>	<p>N/A</p>
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5. What does success look like?

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?

Measure of success one

Measure of success two

Measure of success three

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Success includes:




Equity of access – this includes identification of Indigeneity, shared decision making and partnerships that are accountable and representative, and appropriate resourcing of jurisdictions on a needs basis in line with the National Agreement.

Patient Reported Experience Measures (PREMs) and Patient Reported Outcome Measures (PROMs)

Longer-term health outcomes (noting NBS detects chronic health conditions) with specific consideration for proportion of Aboriginal and Torres Strait Islander children who are supported to thrive as per the National Agreement.

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 <p>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?</p> <p>Yes - my response can be published in full</p> <p>Yes - if steps are taken to anonymise content</p> <p>No</p> <p>Next steps</p> <p>Thank you for responding to this consultation paper. Stakeholder input is and will continue to be essential to expanding NBS programs.</p> <p>The information collected will be analysed and inform the next steps for the national expansion project.</p> <p>Please click <i>Submit</i> to finalise your response.</p> <p>Back Submit</p>	<p>Yes, can publish</p>
  <p>We thank you for your time spent taking this survey. Your response has been recorded.</p>	

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