

Consultation Survey on MSAC Application 1737

Nomination for

- Sickle Cell Disorders
- β -Thalassemia
- Haemoglobin E- β -Thalassemia
- Delta-beta thalassemia

to be added to Newborn Bloodspot Screening programs

Please note: The original nomination was for Sickle Cell Disease only. This survey links to sections of this nomination form.

During the initial review stage, the Sickle Cell Disease expert Working Group recommended that β -thalassemia, Haemoglobin E- β -Thalassemia and Delta-beta thalassemia also be considered.

This survey has been expanded to include all of the above conditions, noting that β -thalassemia, Haemoglobin E- β -Thalassemia and Delta-beta thalassemia do not link to a nomination form.

MSAC welcomes feedback on MSAC applications for public funding from individuals, organisations representing health professionals or consumers and/or carers, and from other stakeholders. Please use this template to prepare your feedback. You may also attach additional information if you consider it may be useful in informing MSAC and its sub-committees.

Sharing consultation feedback

Submitted consultation feedback will be shared with the Applicant and with MSAC and its sub-committees.

- The applicant will receive a summary of comments from individuals, with the individual's name and other identifying information removed.
- MSAC and its sub-committees will receive both the summary and copies of the comments, with the name of the individual and other identifying information removed.
- Consultation feedback from groups or organisations will be provided in a complete form to both the Applicant and to MSAC and its sub-committees.

Please do not include information in your feedback that you do not want shared as outlined above. In addition, to protect privacy, do not include identifying personal (e.g. name) or sensitive (e.g. medical history) information about third parties, such as medical professionals or friends/relatives.

How consultation feedback is used

MSAC and its sub-committees consider consultation feedback when appraising an application, including to better understand the potential impact of the proposed medical technology/service on consumers, carers, and health professionals. A summary of consultation feedback will be included in the Public Summary Document (PSD) published on the MSAC website once MSAC has completed its appraisal. The PSD may also cite feedback from groups/organisations, including the name of the organisation. As such, organisations should not include information or opinions in their feedback that they would not wish to see in the public domain.

Consultation deadlines.

Please ensure that feedback is submitted by the pre-PASC or pre-MSAC consultation deadline for this application. Consultation deadlines for each PASC and MSAC meeting are listed in the PASC and MSAC and ESC calendars available on the [MSAC website](#). They are also published in the MSAC Bulletin. Feedback received after the respective deadlines may not be considered.

For further information on the MSAC consultation process please refer to the MSAC Website or contact the Consumer Evidence and Engagement Unit on email: commentsMSAC@health.gov.au. Thank you for taking the time to provide your feedback.

Please return your completed survey to:

Email: commentsMSAC@health.gov.au

Mail: MSAC Secretariat,
MDP 960, GPO Box 9848,
ACT 2601.

PART 1 – PERSONAL AND ORGANISATIONAL INFORMATION

1. Respondent details

Name:

Email:

Phone No:

2. Is the feedback being provided on an individual basis or by a collective group?

- Individual
 Collective Group

If individual, specify the name of the organisation you work for

If collective group, specify the name of the group

3. How would you best identify yourself?

- General Practitioner
 Specialist
 Researcher
 Consumer
 Care giver
 Other

If other, please specify

PART 2 – CLINICAL NEED AND PUBLIC HEALTH SIGNIFICANCE

- 4. Describe your experience with the disease/s listed on this application and/or the proposed intervention and/or services.**

- 5. What do you see as the benefit(s) of newborn bloodspot screening in particular for the person involved and/or their family and carers?**

- 6. What do you see as the disadvantage(s) of newborn bloodspot screening in particular for the person involved and/or their family and carers?**

- 7. What other benefits can you see from having this intervention publicly funded?**

- 8. What other services do you believe need to be delivered before or after this intervention, eg Haematology, Pathology etc? (Please be clear which disease/s the intervention refers to).**

PART 3 – INDICATION(S) FOR THE PROPOSED MEDICAL SERVICE AND CLINICAL CLAIM

9. Do you agree or disagree with the proposed population(s) for the proposed medical service – which is all babies born in Australia?

- Strongly Agree
 Agree
 Disagree
 Strongly Disagree

Specify why or why not:

10. Do you have any additional information regarding the test protocol outlined in Part 2 of the nomination form for Sickle Cell Disease? (e.g. the number of testing tiers and type of tests proposed)

11. Do you have any information regarding the test protocol for β -Thalassemia, Haemoglobin E- β -Thalassemia, and Delta-beta thalassemia? (e.g. the number of testing tiers and type of tests proposed)

12. Do you agree or disagree that the comparator(s) to the proposed medical service – which is no screening – is correct?

- Strongly Agree
 Agree
 Disagree
 Strongly Disagree

Please explain:

13. Have all the associated interventions for Sickle Cell Disease been adequately captured in Part 3 of the nomination form?

- Yes
 No

Please explain:

14. Do you have any information about the associated intervention for β -Thalassemia, Haemoglobin E- β -Thalassemia and/or Delta-beta thalassemia?

PART 4 – COST INFORMATION FOR THE PROPOSED MEDICAL SERVICE

15. Do you have any comments or additional details regarding the proposed cost effectiveness as per Part 4 of the nomination form, or Part 8 of the Rapid Review?

PART 5 – ADDITIONAL COMMENTS

16. Do you have any additional comments on the proposed intervention and/or disease relating to newborn bloodspot screening?

17. Please include any ethical considerations raised by screening for these conditions.

18. Do you have any comments on this feedback survey? Please provide comments or suggestions on how this process could be improved.

Again, thank you for taking the time to provide valuable feedback.