



**National Council of
Women of New Zealand**

Te Kaunihera
Wahine O Aotearoa

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**Submission to the Ministry of Health on the Consultation Document on
Newborn Blood Spot Cards: Consent Storage and Use**

NCWNZ is an umbrella organisation representing 42 Nationally Organised Societies. It has 31 branches throughout the country attended by representatives of those societies and some 150 other societies. The Council's functions are to serve women, the family and the community at local, national and international levels through research, study, discussion and action. NCWNZ welcomes the opportunity to consider this Consultation Document. The response has been prepared by the Public Issues Standing Committee following circulation of the questions to NCW members.

Question 1

Do you agree with the proposed content and availability of the parent/caregiver information brochure?

The membership supported the proposed content and availability of information, further comments received were that:

- Other information could be included such as safeguarding of the information; the length of time it is kept; where the cards are stored and for how long; who has access to them and disposal procedures.
- Information could also be available through Citizens Advice Bureau, parenting magazines such as Treasures; TV advertisements; Little Lobbies Magazine, Doctors rooms, Plunket rooms and Marae.

Question 2

Do you agree with the proposed guidelines for obtaining consent from parents/caregivers to participate in newborn metabolic screening?

The membership supported the proposed guidelines for obtaining consent from parents and caregivers. A further comment received was that parents should be notified whether defects have been found or not so that they know the tests have been completed.

Question 3

Do you agree with the proposed guidelines for recording newborn metabolic screening refusals?

The membership approves of the proposed guidelines for recording newborn metabolic refusals. Further comments received were:

- Privacy should be discussed and parents should know who sees the results; what happens if a problem is detected and where to go for help and advice.
- Guidelines should include any medical information that is topical at the time.
- "Right of Refusal" needs to be made in a more positive way
- The parents understand the conditions that are being screened for.
- Parents General Practitioner (GP) should be notified of refusal.



Question 4

Should parents/caregivers be asked to sign a form to confirm their refusal of newborn metabolic screening?

The membership approves of the statement that parents/caregivers sign a form to confirm their refusal to newborn metabolic screening. In addition the membership commented that:

- The form should include the statement: I/we have read, had explained and understand the information provided.
- If parents have signed a form it is clear that they understand.

Question 5

Do you agree with the proposed guidelines for requests of newborn metabolic screening repeat testing?

The membership approved of the proposed guidelines for requests of newborn metabolic screening repeat testing.

Question 6

The current New Zealand Police access is appropriate.

All the responses for this question agreed, although one comment was that it should be for specific reason but not in criminal cases.

Question 7

How long do you consider blood spot cards should be stored for?

Most respondents supported an indefinite period of storage because of its application for coronial use. The rest of the respondents supported other periods on the use:

- 10 years, because of storage problems.
- 18 years, when person is considered to have reached maturity.
- 21 years, not specified.
- At least 25 years, as are hospital records.

Question 8

Do you consider that the process of formal notification and approval from the NSU in addition to Ethics Committee regarding research requests for residual blood spots is an adequate safeguard for the programme?

The membership agreed to the process of formal notification and approval from the NSU in addition to Ethics Committee regarding research requests for residual blood spots is an adequate safeguard for the programme. In addition some members believed that if a card is needed for research purposes the parents should be notified and also have the right of refusal.

**Question 9**

Any other comments

- One responder able to represent a midwife's concern with test proposals is that at present there is no formal consent for what is an invasive test on a newborn and the emphasis appears to be on the refusal of a voluntary procedure which very few caregivers refuse to have done. The formal consent should be done ante-natally and kept with the client's notes, or a provision on the testing card for written (informed) consent. Timing is important, for example that the parents should not be in a stressful situation such as a short stay in hospital for delivery.
- Another responder commented that she has had a client whose infant had a positive Guthrie test for a particular disorder. The child was referred to Starship to confirm the disorder. Positive action, in time has allowed the child to live a normal life.
- Another responder commented that now that DNA testing is so widely known, the Guthrie test may be a deterrent for some people who may be pursuing custody battles (of the child in question) or filing for paternity under duress.

Conclusion

The general consensus is that it is good that the issue is being reviewed and current views sought. Also members believe that it is important that the test is carried out as widely as possible, and that the cards can be used for research than can benefit others.

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National President

Joan Macdonald
Convenor Public Issues Standing Committee