

**Newborn Metabolic Screening Programme Advisory
Group**

**Recommendations to the National Screening Unit for
the retention period and secondary use of Guthrie
(‘blood spot’) cards**

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Acknowledgments

Newborn Metabolic Screening Programme Advisory Group Members

Joanne Dixon (Chair)	Clinical Leader, Central and Southern Regional Genetic Service
Norma Campbell	Midwife, College of Midwives
Catherine Donaldson	Midwife, College of Midwives
Paul Hofman	Endocrinologist, Auckland District Health Board
John Forman	Director, New Zealand Organisation for Rare Disorders
Richard MacKay	Chemical Pathologist, Canterbury Health Laboratory
Fiona McCrimmon	Lawyer, McCrimmon Law
Deb Rowe	Maori Advisor
Mereana Ruri	Office of the Children's Commissioner
Mina Timutimu	Maori Advisor
Pat Tuohy	Chief Advisor Child and Youth Health, Ministry of Health
Dianne Webster	Clinical Director, National Testing Centre
Bridget Wilcken	Metabolic Physician, New South Wales Biochemical Genetics and Newborn Screening Service
Callum Wilson	Metabolic Physician, Auckland District Health Board

National Screening Unit Secretariat

Brendon Gray	Public Health Medicine Registrar
Kathy Bendikson	Programme Manager

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Executive Summary

Following public consultation on consent, storage and use of blood spot cards in 2007, the Newborn Metabolic Screening Programme Advisory Group makes the following recommendations to the National Screening Unit:

1. That consent for participation in the Newborn Metabolic Screening Programme and consent for storage be distinct processes, but obtained at the same time.
2. That verbal consent is adequate.
3. That consent/decline is recorded in clinical notes.
4. That the National Screening Unit funds an education programme targeted at lead maternity carers to raise awareness of the Newborn Metabolic Screening Programme and the importance of gaining informed consent.
5. That newborn blood spot cards are available for the primary use of the Newborn Metabolic Screening Programme.
6. That investigation of morbidity and mortality is acknowledged as a secondary use of newborn blood spot cards.
7. That victim identification is acknowledged as a secondary use of residual newborn blood spot cards.
8. That assay improvement and validation for disorders currently in the Newborn Metabolic Screening Programme panel is acknowledged as a secondary use of de-identified newborn blood spot cards.
9. That validation of assays for potential new disorders to be added to the newborn metabolic screening panel is acknowledged as a secondary use of de-identified newborn blood spot cards.
10. That research (with appropriate consents and approvals) is acknowledged as a secondary use of identified newborn blood spot cards.
11. That research (with appropriate consents and approvals) is acknowledged as a secondary use of de-identified newborn blood spots cards.
12. That following completion of testing, newborn blood spot cards are to be retained for a minimum of 16 years (for primary usage). The Advisory Group recommends retention beyond 16 years for the identified secondary uses, but is unable to identify a maximum retention time.
13. That a guardianship group is established to control third party access to residual newborn blood spot cards.
14. That the Memorandum of Understanding with the Police be strengthened to ensure that Police access to the blood spot card collection is only possible with a court order or the requisite consent of a person legally entitled to give such consent.

1. Introduction

Following public consultation on consent, storage and use of blood spot cards in 2007, the Newborn Metabolic Screening Programme Advisory Group (the Advisory Group) wishes to make recommendations to the National Screening Unit (NSU) in relation to the consent, retention and uses of residual newborn blood spot cards acquired by the Newborn Metabolic Screening Programme (NMSP).

Specifically, this paper sets out recommendations to the NSU in relation to:

1. Consent
 - a. Process
 - b. Timing
 - c. Responsibility
2. Usage
 - a. Primary
 - b. Secondary
3. Research
4. Retention time
5. Guardianship
6. Police and Court orders

2. Background

Newborn metabolic screening has been available as a national service in New Zealand since the 1960's. It commenced with screening for phenylketonuria and the programme now screens for over 20 metabolic disorders. Metabolic screening is highly recommended for every baby.

Screening involves collecting a blood sample from the newborn baby at 48 hours of age, or as soon as possible thereafter. The blood is obtained from a heel prick and is placed on a blood spot card. The card records information about the baby, mother and the lead maternity carer (LMC).

LMCs are responsible for offering newborn metabolic screening to parents/caregivers; obtaining informed consent from the parents/caregivers; ensuring the blood sample is taken and that all the necessary details are recorded on the sample card, and; sending the card to the National Testing Centre (a laboratory unit within LabPlus at Auckland City Hospital). The LMC is also responsible for any follow up requested by the laboratory.

At present, the NMSP screens over 60,000 New Zealand babies per year. The programme covers nearly 100 percent of the New Zealand newborn population. Approximately 45 newborns a year affected by one of the tested disorders are detected through the programme.

In New Zealand, blood spot cards are currently stored indefinitely after screening is completed. Storage is secure and physical access to these cards is limited to specific screening programme personnel with appropriate permission.

Currently, parents/caregivers or guardians (and ultimately the individuals themselves) have the right to have their newborn's blood spot card returned to them at any time. Each year, approximately 650 cards are returned to families at the request of parents/caregivers.

After screening, blood spot cards are currently used in the following circumstances:

- where there is direct benefit for the family/whānau;
- programme audit and quality control;
- forensic use;
- court orders.

Bruce Slane (2003), the former Privacy Commissioner, published a report following an inquiry into the collection, retention, use and release of residual newborn blood spot cards. In the report the Commissioner recommended:¹

1. *that the Ministry of Health allocate clear responsibility and authority for the operation of the newborn metabolic screening programme;*
2. *that the body appointed move urgently to develop clear rules for retention of the samples and any further use or third party access to those samples, consulting widely with stakeholders and with the Privacy Commissioner;*
3. *that these rules, and any permission-granting structures they involve, be incorporated in legislation in such a way that they are clear, robust and enforceable.*

In response to these recommendations, the Ministry of Health appointed responsibility for the funding, monitoring and strategic direction of the NMSP to the NSU in 2005.

Public consultation 2007

The NSU consulted with the public on future policies for the storage and use of blood spot cards, and the wider focus of the programme in 2007. This consultation involved an on-line questionnaire and focus group discussions. The on-line questionnaire received 184 responses from both individuals and organisations. Focus groups included 37 participants, representing different ethnic groups (Maori, Pacific, Asian and New Zealand Europeans). New parents and adults (18-37 years of age) with no children were also included.

Both consultation processes revealed a spectrum of perceptions and expectations of both the current programme and future policies.

Focus group participants were universally supportive of screening. However, for other matters (consent, storage and use) there was a wide range of different attitudes and beliefs. Most participants were supportive of using the blood spots for programme audit and quality control, to identify cause of death and court access. Retained knowledge of the consent process was generally limited to the screening aspect of the programme. Some participants favoured extending the programme to include as many disorders as possible. Others

¹ Slane, B. Guthrie tests. Wellington: Office of the Privacy Commissioner; 2003.

only wanted the programme extended to include new disorders that both present in infancy and can be treated. There were different views about storage time, ranging from support for indefinite storage to those who believed blood spots should be returned soon after screening. Some people supported use of the cards for research, others opposed this. Views towards Police access varied considerably.²

Responses to the on-line questionnaire demonstrated a similar spectrum of views towards storage time and Police access. Adding new disorders and research were not explored to the same extent in the questionnaire. However, the questionnaire did explore the concept of guardianship for the blood spot collection and 66% agreed that approval from the NSU, in addition to ethics committee approval, was an appropriate protective mechanism for research requests.³

From both consultation processes, many respondents supported greater clarification of programme policy, better access to accurate information and greater public awareness of the programme.

3. Recommendations

3.1 Consent

The NMSP operates under the Code of Health and Disability Services Consumers' Rights 1996 (the Code of Consumers' Rights) and the Health Information Privacy Code (HIPC) 1994.

Under Right 6 of the Code of Consumers' Rights, parents/guardians have a right to be fully informed before they decide to participate in newborn screening.

Right 7 of the Code of Consumers' Rights also stipulates that parents/guardians have a right to make an informed choice and give informed consent before participating in the programme.

The HIPC also has relevance to the programme. The HIPC provides a broad framework of controls for the management of information about identifiable individuals. The rules of particular note are:

- Rule 3: collection of health information from individuals;
- Rule 10: limits on use of health information;
- Rule 11: limits on disclosure of health information.

² National Screening Unit. Newborn blood spot cards: consent, storage and use – a public consultation; responses to the public consultation document. Wellington: Ministry of Health; 2007.

³ National Screening Unit. Newborn blood spot cards: consent, storage and use – a public consultation; focus groups. Wellington: Ministry of Health; 2007.

*RIGHT 6 of the Code of Consumers' Rights
Right to be Fully Informed*

- 1) Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive, including -
 - a) An explanation of his or her condition; and
 - b) An explanation of the options available, including an assessment of the expected risks, side effects, benefits, and costs of each option; and
 - c) Advice of the estimated time within which the services will be provided; and
 - d) Notification of any proposed participation in teaching or research, including whether the research requires and has received ethical approval; and
 - e) Any other information required by legal, professional, ethical, and other relevant standards; and
 - f) The results of tests; and
 - g) The results of procedures.
- 2) Before making a choice or giving consent, every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, needs to make an informed choice or give informed consent.
- 3) Every consumer has the right to honest and accurate answers to questions relating to services, including questions about -
 - a) The identity and qualifications of the provider; and
 - b) The recommendation of the provider; and
 - c) How to obtain an opinion from another provider; and
 - d) The results of research.
- 4) Every consumer has the right to receive, on request, a written summary of information provided.

RIGHT 7

Right to Make an Informed Choice and Give Informed Consent

- 1) Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise.
- 2) Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent.
- 3) Where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence.
- 4) Where a consumer is not competent to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where -
 - a) It is in the best interests of the consumer; and
 - b) Reasonable steps have been taken to ascertain the views of the consumer; and
 - c) Either, -
 - i. If the consumer's views have been ascertained, and having regard to those views, the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if he or she were competent; or
 - ii. If the consumer's views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.
- 5) Every consumer may use an advance directive in accordance with the common law.
- 6) Where informed consent to a health care procedure is required, it must be in writing if -
 - a) The consumer is to participate in any research; or
 - b) The procedure is experimental; or
 - c) The consumer will be under general anaesthetic; or
 - d) There is a significant risk of adverse effects on the consumer.
- 7) Every consumer has the right to refuse services and to withdraw consent to services.
- 8) Every consumer has the right to express a preference as to who will provide services and have that preference met where practicable.
- 9) Every consumer has the right to make a decision about the return or disposal of any body parts or bodily substances removed or obtained in the course of a health care procedure.
- 10) No body part or bodily substance removed or obtained in the course of a health care procedure may be stored, preserved, or used otherwise than
 - (a) with the informed consent of the consumer; or
 - (b) For the purposes of research that has received the approval of an ethics committee; or
 - (c) For the purposes of 1 or more of the following activities, being activities that are each undertaken to assure or improve the quality of services:
 - (i) a professionally recognised quality assurance programme;
 - (ii) an external audit of services;
 - (iii) an external evaluation of services.

LMCs have a contractual obligation under the Primary Maternity Services Notice 2007, issued pursuant to Section 88 of the New Zealand Public Health and Disability Act 2000, to offer parents of newborns the opportunity to have their child screening for metabolic disorders. Other LMC obligations are:

- to ensure informed consent under the Code of Consumers' Rights highlighted above;
- to document in either the mother's or baby's medical record that there has been a discussion about newborn metabolic screening;

- to ensure the heel prick test is performed if consent is given;
- to ensure any follow-up is completed where necessary.

The newborn screening pamphlet, which provides information to parents to support the consent process, should be given to parents prior to delivery and should be available for review after the baby's birth. The pamphlet has been in use for several years and was revised in 2006 to include new expanded screening. From the number of pamphlets requested by LMCs and maternity units, it is believed that the brochure is provided to parents but focus group discussions suggest that the brochure is not well read, nor is information retained or understood.

It is reasonable to include the concept of use for quality assurance purposes when consent to participate in the screening programme is given. An effective newborn metabolic screening programme must have access to stored blood spot cards in cases of reported false negative results. If an infant whose newborn screening test was negative is later diagnosed with one of the disorders that were screened for, it may be necessary to go back to the blood spot cards for all babies tested on that day to recheck the analysis and results.

One objective of newborn metabolic screening must be to maximise the uptake of this public health programme. A more structured consent process that details storage options could alleviate many of the concerns associated with storage of the blood spot cards. It is recognised that discussion with parents/caregivers to ensure informed consent must include providing details about storage, retrieval and secondary uses of the cards. It is anticipated that the newborn screening pamphlet will be revised to include further details on storage and future uses of blood spot cards once the future policies have been endorsed.

Recommendations: consent

1. That consent for participation in the NMSP and consent for storage be distinct processes, but obtained at the same time.
2. That verbal consent is adequate.
3. That consent/decline is recorded in clinical notes.
4. That the NSU funds an education programme targeted at LMCs to raise awareness of the NMSP and the importance of gaining informed consent.

3.2 Use of the blood spot cards

Blood spots are collected for the purpose of testing newborn blood for over 20 metabolic disorders in order to reduce morbidity and mortality from these disorders. Because residual newborn blood spot cards contain only a very limited amount of blood, their further use after screening has to be prioritised to ensure that enough blood is left to serve the most important purposes. In making its recommendations, the Advisory Group has taken into account a

prioritisation schedule developed for the Danish newborn metabolic screening programme.⁴

Priority of use

The Advisory Group consider the most important uses (in order) are:

1. Use of the newborn blood spot card for the benefit of child and family/whānau.
2. Maintenance of a quality screening programme.
3. Gaining new knowledge through research and development

3.2.1 Primary use

The aim of the NMSP is to:

- to ensure early detection and appropriate treatment of newborns with congenital metabolic disorders.

To meet this aim, the newborn blood spot cards are required for the initial screening test, occasionally for repeat testing (e.g. confirmatory testing) and rarely to investigate false negative results. The cards are also required for professionally recognised quality assurance programmes and laboratory audits. These uses are considered primary uses related to the screening programme and consent for these uses is included when consent to participate in the programme is obtained.

The cards must be available for the primary use of the NMSP. The Advisory Group expects that cases of disorders not detected by the screening programme will show symptoms and come to the attention of health practitioners by 14 years of age. A further 2 years allows the programme to investigate any missed cases. Primary use must have highest priority for residual use and a sufficient sample must be retained for primary purposes.

For these reasons (all pertaining to primary use), newborn blood spot cards must be stored and retained for a minimum period of 16 years.

Recommendation: use of blood spot cards

5. That newborn blood spot cards are available for the primary use of the NMSP.

⁴ Norgaard-Pedersen, B. & Hougaard, D.M. Storage policies and use of the Danish newborn screening biobank. *Journal of Inherited Metabolic Disease*. 2007;30(4):530-36.

3.2.2 Secondary use

3.2.2.1 Investigation of morbidity and mortality

Access to the blood spot cards of family members who have died can provide important information unobtainable through testing living relatives. For example, if the child died, the child's blood spot card may be used after death to determine whether the cause of death was a harmful genetic condition that may affect other family/whānau members. Such testing may benefit parents who wish to make reproductive choices about having further children. Siblings may also benefit in respect to making their own future reproductive choices. For conditions such as "long QT", parents and siblings may wish to undertake additional testing to determine whether they would benefit from preventative medical treatment.

Blood spot cards may also be used to detect infection. If a congenital infection is suspected, blood spots can be analyzed for specific IgM antibodies and for nucleic acid sequences or antigens from the suspected micro-organism. This may be important in investigating mortality. It may also be important in some investigations of morbidity.

Release of a blood spot card to investigate morbidity and mortality would only occur in situations where the additional consent from the dead or affected child's family/whānau has been given. This use is primarily for the benefit of the child and family/whānau.

For the investigation of morbidity and mortality in families, long term retention of the cards would provide the maximum benefit.

Recommendation: investigation of morbidity and mortality
6. That investigation of morbidity and mortality is acknowledged as a secondary use of newborn blood spot cards.

3.2.2.2 Victim identification

Newborn blood spot cards may be useful to identify human remains or tissue (including blood) where no other means of identification exist. Such use may benefit family/whānau members of victims through the appropriate identification of a loved one's remains. This is likely to occur as part of a legal process.

This use is primarily for the benefit of the child and family/whānau.

For the investigation of victim identification, long term retention of the blood spot cards would provide the maximum benefit.

Recommendation: victim identification
7. That victim identification is acknowledged as a secondary use of residual newborn blood spot cards.

3.2.2.3 New and existing test assessment, and development

Blood spot cards are required for developing and validating laboratory testing methods for disorders included in the programme screening panel. Similarly, samples are needed to develop and validate new testing methods. Without access to de-identified samples, laboratories are unable to evaluate or validate new technologies or tests, or determine screening cut-off points, resulting in unacceptably inaccurate screening results. De-identified samples (samples with all identifying information removed) may be used for these purposes; however, information obtained cannot be traced back to an individual.

This use is for maintaining a high quality screening programme.

For the purposes of improving and validating laboratory testing, blood spot cards need to be stored for up to six months.

Recommendations: test assessment and development

8. That assay improvement and validation for disorders currently in the NMSP panel is acknowledged as a secondary use of de-identified newborn blood spot cards.
9. That validation of assays for potential new disorders to be added to the NMSP panel is acknowledged as a secondary use of de-identified newborn blood spot cards.

3.2.2.4 Research

Right 7 (10) (b) of the Code of Consumers' Rights allows for the use of specimens without specific consent provided that ethics committee approval has been given. In addition, for research to be carried out by a hospital or tertiary institution, both institutional and ethics committee approval will be required. Maori ethics committee approval is often also required.

Research may involve identified residual newborn blood spot cards where the cards are selected on the basis of a known disease state, condition or predisposition. Such research must be conducted with specific consent from the relevant individual or family/whānau. To date, no samples have been released for research without the consent of the individual/family/whānau.

Other research may be population-based and rely on de-identified blood samples from the card collection (e.g. disease prevalence studies). The justification of such research is that it contributes to the public good through increased scientific knowledge. A related use might be to monitor the outcome of other public health programmes. The use of de-identified blood spots cards does not require additional consent of individuals (as per Right 7(10)), but does require institutional and ethics committee approval. In addition, the Advisory Group proposes that the approval of a guardianship group (see section 3.4) should be required.

Storage time of the programme should not be determined by the use of blood spots for research.

Recommendations: research

10. That research (with appropriate consents and approvals) is acknowledged as a secondary use of identified newborn blood spot cards.
11. That research (with appropriate consents and approvals) is acknowledged as a secondary use of de-identified newborn blood spots cards.

3.3 Retention

Cards are currently stored indefinitely in New Zealand. Retention times for residual cards vary widely around the world. In Australia, cards are stored for 18 years in New South Wales, two years in Western Australia, and indefinitely in Victoria and South Australia.

Determining an appropriate storage time is inextricably linked to a decision about whether secondary use of blood spots cards should be permitted and the question of whose consent is operative during the storage period. For example, while parents may consent to secondary use of their child's card, such use may be less appropriate when the child becomes an adult and is capable of giving their own consent to secondary use of the sample (i.e. when the child reaches "the age of consent" or becomes "Gillick competent").

Possible retention times include:

1. 16 years
 - Parental consent is considered operative and the sample is available for primary and secondary use.
2. 17 – 25 years
 - Secondary use possible and cards held into young adulthood giving individuals time to determine what they want done with their card.
3. Long term retention
 - The cards are currently stored indefinitely and long term retention would be similar to the status quo. Long term retention allows for primary and secondary uses as outlined in this document. Some families will benefit from long term retention. It is noted that long term retention is not to the benefit of the screening programme aim of early detection and treatment of certain metabolic disorders.

The Advisory Group has considered the question of long term retention and has discussed retaining the cards for up to 100 years. The Advisory Group recommends retention beyond 16 years in order to maximise the potential benefit of secondary uses. However, the Advisory Group is unable to settle on an agreed maximum retention time.

Recommendation: retention time

12. That following completion of testing, newborn blood spot cards are to be retained for a minimum of 16 years (for primary usage). The Advisory Group recommends retention beyond 16 years for the identified secondary uses, but is unable to identify a maximum retention time.

3.4 Guardianship

In order to maintain public confidence in the NMSP and to ensure the appropriate use of stored newborn blood spot cards, the Advisory Group believes that access to the cards should be approved and monitored by an independent “guardianship” or kaitiaki group. Such a group should have a range of membership, in addition to the programme Advisory Group members, to include additional legal, consumer and cultural representation. The representation of the group must ensure that there is public confidence in the protection of retained blood spot cards. The guardianship group’s terms of reference must ensure that there is not overlap with the responsibilities of ethics committees. The functions and membership of the group will require careful consideration.

It is also recognised by the Advisory Group that an enquiry process should be developed which allows researchers to request information from the NMSP regarding the potential uplift of blood spots from cards before beginning the work of preparing research applications.

The guardianship group's task would be to consider applications for the release of blood spots to all researchers (who will already have appropriate ethical approval and institutional scientific approval). The guardianship group would only be responsible for access to blood spots themselves, not other information held by the programme. The main purpose of the group would be to ensure that the programme is not harmed by research opportunities. This takes into account the main aim of the initial sample collection. A related purpose is to ensure that the blood spots are not consumed by the research. This would ensure that the maximum future benefit for families is preserved.

Recommendation: guardianship group

13. That a guardianship group is established to control third party access to residual newborn blood spot cards.

3.5 Court orders

The Advisory Group notes the inherent jurisdiction of the Courts to order a warrant granting access to the newborn blood spot cards by the police and other third parties. The High Court ordered such a warrant in the paternity case *H v G* (1999).⁵ Another card was uplifted by a mother following the Court ruling in *S v T* (2005).⁶

The Advisory Group does not intend that a guardianship group supersede or replace the inherent jurisdiction of the Court to order access to newborn blood spot cards. The guardianship group would not have any power to hear applications for access to the cards where this has been ordered by the Courts.

⁵ *H v G* (14 May 1999) High Court Auckland M 1868/98.

⁶ *S v T* [2003] NZFLR 223.

3.6 Police access and use

The Advisory Group notes that the New Zealand Police may request access to a specified residual newborn blood spot card under the conditions of the Memorandum of Understanding. The Memorandum states that such requests will be made to identify a deceased or missing person and to assist with other coronial inquiries. Generally, written consent is required from a person entitled to give consent on behalf of the individual. However, the Memorandum states that such consent may not be required in all situations, though the Police must provide sufficient information to explain why it is considered that authorisation is not necessary in terms of Rule 11(2) (l) (i) of the Health Information Privacy Code 1994 (prejudice to the maintenance of law by any public sector agency), or why some other ground for non-compliance with Rule 11 of the Code applies.

It is recognised that the Memorandum of Understanding was a temporary solution when it was signed. However, the Advisory Group believes that the Police should be required to obtain a Court warrant to uplift a card in all situations where written consent is not available and that Police access to the collection should not be possible without a Court order or specific consent.

Recommendation: Police access

14. That the Memorandum of Understanding with the Police be strengthened to ensure that Police access to the blood spot card collection is only possible with a court order or the requisite consent of a person legally entitled to give such consent.

4. Conclusion

The Advisory Group expects that the recommendations contained in this report will be taken for consultation with selected external stakeholders and will inform policy recommendations to the Minister of Health.

It is noted by the Advisory Group that there are a number of organisations in New Zealand and Australia that have now reported on storage and use of blood spot cards and other human tissue – notably the Australian Law Reform Commission,⁷ the Victorian Newborn Screening Review Committee⁸ and the Human Genome Research Project.⁹

Finally, the Advisory Group recommends that the NSU and the Ministry of Health involve the Privacy Commissioner and the Health and Disability Commissioner in discussions about whether legislative change is necessary in relation to the consent, storage and uses of newborn blood spot cards.

⁷ Australian Law Reform Commission - Australian Health Ethics Committee. Essentially yours: the protection of human genetic information in Australia. Sydney: Australian Law Reform Commission; 2003.

⁸ Victorian Newborn Screening Review Committee. Victorian Newborn Screening Review Committee: final report for the Minister for Health. Melbourne: Victorian Government Department of Human Services; 2006.

⁹ Human Genome Research Project. Genes, Society and the Future: Volume 1. Dunedin: University of Otago; 2007.