14 March 2011

National Health Board
Ministry of Health
P O Box 92522, Wellesley Street
AUCKLAND 1141

Re: Newborn Metabolic Screening Programme Policy Framework: Storage and use of blood spot samples

Introduction
Thank you for the opportunity to comment on the policy framework document. The blood spot samples may be of value in identification of bodies. Accordingly, I suggest that this possibility is drawn to the parents' attention when they are deciding whether to ask for the return of the sample. Similarly, should parents request the return of the sample they should be recommended to retain the sample in a safe place.

Written consent
Paragraph 6.1.1
The Code of Health and Disability Services Consumers' Rights (the Code) does not require a person who is requesting the return or disposal of any body parts to do so in writing.[1] Accordingly the requirement that it be a written communication including the name, signature, address and relationship of the person requesting the sample, before the sample is returned exceeds what is required under the law.

Additionally, I suggest thought is given to the steps that will be taken in the event that that the parents disagree. In this context I draw your attention to the decision in *S v T*.[2] From that case it appears that one parent may uplift the card despite the opposition of the other parent.

It is important to make it clear that once a child is competent, whether or not they have reached the age of 16 years, they have a right to make decisions about the sample.

Secondary uses
I acknowledge that there may be social benefit from secondary use of the blood samples, for example, testing for long QT syndrome in the case of a deceased child for the benefit of the remaining family. In that case, consent to the research is likely to be given.

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[1] Right 7(9).
[2] [2003] NZFL 223 (HC).

However, it is important that the possibility of secondary uses does not have a chilling effect and undermine the primary purpose of the programme, especially as research uses are likely to be infrequent.

In addition, there is anecdotal evidence that some people fear the use of the samples for a criminal investigation and consider that the existence of a memorandum of understanding is insufficient protection for the samples, as the protections are not embodied in law.

Samples collected prior to June 2011
As the policy requires individual consent for research use from the person authorised to give consent, this may result in very limited use of the samples for research because the parents of a minor (or the child once competent) may be difficult to contact. The details collected at birth will frequently not be correct at that stage.

Samples collected after July 2011
It is unclear whether parents will be informed of the possibility of future unspecified research use at the time the sample is taken or whether any consent will be required to the use. It appears that Right 7(10) of the Code will be relied upon and the use will be unconsented.

It is unclear why samples collected after July 2011 will be treated differently from those collected previously. As informed consent is the cornerstone of the Code, parents should be made aware that this use is possible before consenting to the collection of the heel prick sample.

Any research on these samples will require approval from an ethics committee and the NMSP Governance Team and the Ministry (presumably the Ministry of Health). It is unclear what those bodies will take into account when making decisions on whether or not to allow the research to go ahead.

Refusal by child
Although a parent or parents may give consent for future unspecified use of the blood spots for research presumably that consent could be overridden by a refusal of the child once the child is competent.[3] I suggest some thought is given to how the child will know how such research consent was given and how they may take steps to refuse once they are able to do so, other than uplifting the sample.

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[3] Right 7(7) Every consumer has the right to refuse services and to withdraw consent to services.