



Cabinet Social Policy Committee

SOC Min (11) 15/7

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Minute of Decision

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Newborn Metabolic Screening Programme Blood Spot Cards: New Policy and Governance Arrangements

Portfolio: Health

On 3 August 2011, the Cabinet Social Policy Committee (SOC):

- 1 **noted** that in July 2010, SOC:
 - 1.1 agreed to the permanent retention of newborn blood spot cards, with a strengthened policy framework, and improved Ministry of Health (MoH) and Advisory Group governance arrangements;
 - 1.2 invited the Minister of Health to report to SOC in March 2011 on the new policy and governance arrangements, including protections and limitations;

[SOC Min (10) 16/4]
- 2 **noted** that the Newborn Metabolic Screening Programme Policy Framework, attached to the paper under SOC (11) 51, brings all of the policies, governance, and provider responsibilities together in one place for the first time in the Newborn Metabolic Screening Programme's (the Programme) history, which will help to make the policy and governance arrangements more transparent and widely known;
- 3 **noted** the two key changes to existing Programme policies and procedures are:
 - 3.1 governance arrangements have been clearly documented, and the roles and responsibilities between MoH, Programme operations, and the Governance Team have been clarified;
 - 3.2 a research applications pathway has been developed to clarify the requirements for requesting blood spot cards for research:
 - 3.2.1 individual written consent is required for population research on samples collected prior to June 2011;

- 3.2.2 for cards collected after June 2011, parents will be properly informed of the potential primary and secondary uses of the card before consenting to long-term storage of the card. Any proposal for research that will require release of cards collected after June 2011 must first be approved by an Ethics Committee and reviewed by the Governance Team.



Saphron Powell
Committee Secretary

Reference: SOC (11) 51

Present:

Hon Bill English (part of item)
Hon Simon Power
Hon Tony Ryall (Chair)
Hon Dr Nick Smith
Hon Judith Collins
Hon Anne Tolley
Hon Steven Joyce
Hon Paula Bennett
Hon Phil Heatley
Hon Hekia Parata
Hon Dr Pita Sharples
Hon Tariana Turia

Officials present from:

Office of the Prime Minister
Officials Social Policy Committee
Office of the Privacy Commissioner
Ministry of Health

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