

20 March 2019

[REDACTED]
[REDACTED]
[REDACTED]

Ref: H201900866

Dear [REDACTED]

Response to your request for official information

I refer to your request under the Official Information Act 1982 (the Act), transferred from all District Health Boards (DHBs) to the Ministry of Health (the Ministry) on 20 February 2019 for:

*“Can you please tell me all instances of court orders seeking access to Guthrie heel prick test samples, and all instances of police search warrants to the above made to the DHB since records began in 1969 until 2018? All information relating to each request - who, when, where, why. * Should the DHB decide to withhold this information on privacy grounds, Stuff asks you to please redact the name only so we can still report on this issue.*

Copies of all reports or advise the DHB has been given/received on the legality or ethics in accessing these tests

The number of people who opt-out of the Guthrie heel prick test - broken down by the number of people per year, for each year, since records began

Can you please advise what the Guthrie heel prick is used to test exactly under the DHB

Can you please advise where the DHB stores Guthrie heel prick test cards, and the length of time these cards are stored

Can you please advise what your process is in advising parents about the test. What official information are they given, and when does this occur? Is this written, verbal?

How shortly before or after birth does the heel prick test happen, and how shortly before or after birth can parents opt-out? What are parents told about what the sample is used for and how it is stored?”

Information held by the Ministry relating to your request is itemised in Appendices One and Two of this response.

I trust this information fulfils your request. You have the right, under section 28 of the Act, to ask the Ombudsman to review any decisions made under this request.

Please note this response (with your personal details removed) may be published on the Ministry of Health website.

Yours sincerely



Deborah Woodley
**Deputy Director-General
Population Health and Prevention**

Appendix One

<p><i>Can you please tell me all instances of court orders seeking access to Guthrie heel prick test samples, and all instances of police search warrants to the above made to the DHB since records began in 1969 until 2018?</i></p> <p><i>All information relating to each request - who, when, where, why.</i></p> <p><i>* Should the DHB decide to withhold this information on privacy grounds, Stuff asks you to please redact the name only so we can still report on this issue.</i></p>	<p>The National Screening Unit (NSU) assumed responsibility for the Newborn Metabolic Screening Programme (NMSP) in 2005. Itemised in Appendix Two, Table 1 of this response is information in respect to the release of (or request for release of) Guthrie cards to NZ Police. The Ministry has identified 27 requests between 1995 and 2016.</p> <p>The Ministry is unable to find any information on court orders or search warrants outside this time period. As such, this part of your request is partially refused under section 18(e) of the Act, as part of the requested information does not exist.</p>
<p><i>Copies of all reports or advise the DHB has been given/received on the legality or ethics in accessing these tests</i></p>	<p>The NSU website provides information on how the samples are stored and how safeguards are put in place and includes several links as below:</p> <ol style="list-style-type: none">1. Link to the 2003 report by the former Privacy Commissioner Bruce Slane on the release of metabolic screening test samples: www.privacy.org.nz/assets/Files/70989185.pdf2. The Privacy Act 1993 and the Health Information Privacy Code (HIPC) 1994 cover the blood spot cards. Further information on these Acts can be viewed at: www.privacy.org.nz/ and www.legislation.govt.nz
<p><i>The number of people who opt-out of the Guthrie heel prick test - broken down by the number of people per year, for each year, since records began</i></p>	<p>Reports on monitoring of the NMSP against national indicators have been published since 2011. These are accessible at the following link: www.nsu.govt.nz/health-professionals/newborn-metabolic-screening-programme/procedures-guidelines-and-reports-2. Please note earlier data is not held by the Ministry.</p> <p>National information on the number of people who opt-out of the Guthrie heel prick test – broken down by the number of people per year, for each year, since records began is not available, as there is no formal requirement that opt-outs are notified to the laboratory database. This part of your request is refused under section 18(e) of the Act, as the requested information does not exist.</p>

<p><i>Can you please advise what the Guthrie heel prick is used to test exactly under the DHB</i></p>	<p>Blood spot samples are screened for 25 metabolic disorders. Please refer to Appendix A of the NMSP monitoring reports, which are available at the following link: www.nsu.govt.nz/health-professionals/newborn-metabolic-screening-programme/procedures-guidelines-and-reports-2.</p>
<p><i>Can you please advise where the DHB stores Guthrie heel prick test cards, and the length of time these cards are stored</i></p>	<p>The Guthrie heel prick cards from the immediate past 12 months are held securely at Auckland District Health Board with PIN access to the storage room. After 12 months the cards are stored indefinitely in a secure storage facility area.</p>
<p><i>Can you please advise what your process is in advising parents about the test.</i></p>	<p>The process is as follows:</p> <ol style="list-style-type: none"> 1. Lead Maternity Carers (LMCs) are responsible for talking to parents about the NMSP as part of their antenatal and postnatal care, and ensuring consent before the test is taken. 2. The blood sample is taken by the LMC, hospital midwife, or trained blood taker (phlebotomist) at the hospital or birthing centre, at home, or in some areas, at certain laboratories. 3. The LMC will receive negative results within a week to 10 days of sending away the baby's blood sample. Positive results are notified to the LMC within two to three days of sending the sample away. 4. The LMC advises the parents of the test results.

<p><i>What official information are they given, and when does this occur? Is this written, verbal?</i></p>	<p>Parents are given written and verbal information about the tests by their LMC as part of their antenatal and postnatal care (www.nsu.govt.nz/system/files/resources/your-newborn-babys-blood-text-oct17.pdf).</p> <p>The LMC must make it clear to parents/caregivers that they have two distinct decisions to make, and assist parents/caregivers to make an informed choice for both decisions:</p> <ol style="list-style-type: none"> 1. Whether they agree to their baby being screened for metabolic disorders. 2. If they agree to screening, whether they agree to their baby's residual blood spot samples being stored for future uses; or want the residual blood spot samples returned to them after testing. <p>Parents who want the residual blood spot samples returned to them after testing are provided with the following information: www.nsu.govt.nz/system/files/resources/request-form-return-of-card-final.doc.</p>
<p><i>How shortly before or after birth does the heel prick test happen, and how shortly before or after birth can parents opt-out? What are parents told about what the sample is used for and how it is stored?</i></p>	<p>The heel prick test happens 48 to 72 hours after birth. This is because newborn screening detects a range of markers present in dried blood, and the blood is most informative between 48 and 72 hours. A baby's metabolic system is not fully independent of its mother's until around 48 hours after birth. Some metabolites are normal at birth and rise; some rise shortly after birth and decline. Testing by day three is also important for identification of those conditions that, without management, can cause serious harm or death within 7 to 10 days.</p> <p>The Ministry of Health strongly recommends newborn metabolic screening. Parents can however opt-out of this screening at any time. Parents can request return of the blood spot card at any time using the form: www.nsu.govt.nz/resources/return-newborn-metabolic-screening-samples-guthrie-card-or-blood-spot-card-family-request-form.</p>

Appendix Two

Table 1. Requests made by NZ Police for release of Guthrie Cards

Information released to	Year of release	Reason for release
Police	1995	Information withheld under section 9(2)(a) of the Act, to protect the privacy of natural persons, including that of deceased natural persons.
Police	1996	
Police	1997	
Police	1998	
Police	1999	
Police	2000	
Police	2000	
Police	2001	
Police	2001	
Police	2001	
Police	2002	
Police	2003	
Police	2003	
Police	2003	
Police	2008	
Police	2008	
Police	2010	
Police	2011	
Police	2012	
Police	2015	
Police	2016	

Note: Information that may identify an individual (such as the exact date of information release, and reason for release) has been withheld under section 9(2)(a) of the Act, to protect personal privacy. All requests were facilitated by the Police, which may have included instances where the Police were providing assistance to the Coroner.