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Newborn Metabolic Screening Programme (NMSP)

Biannual Monitoring Report

Number 11

1 January to 30 June 2014

National Screening Unit

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Acknowledgements

We would like to thank all those people involved in producing this report. We would particularly like to acknowledge those who have collected this information, those who have entered the data and those who have facilitated the analysis of the data; in particular, Auckland District Health Board staff and Dr Dianne Webster and Keith Shore.

Citation: Ministry of Health. 2014. Newborn Metabolic Screening Programme (NMSP): Biannual Monitoring Report Number 11, 1 January to 30 June 2014. Wellington: Ministry of Health.

Published in March 2015
by the Ministry of Health
PO Box 5013, Wellington 6145, New Zealand

ISBN 978-0-478-44450-6 (online)

HP 6077

This document is available at www.nsu.govt.nz

Contents

Executive summary **v**
Key points and recommendations: v

Introduction **1**
Background 1
NMSP aim and objectives 1
Data 2

NMSP monitoring indicators **4**
Indicator 2: Timing of sample taking 5
Indicator 3: Quality of blood samples 10
Indicator 4: Sample dispatch and delivery 12
Indicator 5: Laboratory testing timeframes 14
Indicator 6: Timeliness of reporting – notification of screen positives 15
Indicator 9: Blood spot card storage and return 17
Appendix 1 18

List of Tables

Table 1: NMSP indicators and their monitoring frequency 4
Table 2: Percentage of samples taken earlier than, between and after 48–72 hours, by DHB, January to June 2014 6
Table 3: Percentage of samples taken earlier than, between and after 48–72 hours, by Group 1 and Group 2 ethnicity, January to June 2014 8
Table 4: Percentage of samples taken earlier than, between and after 48–72 hours, by NZDep, January to June 2014 9
Table 5: Percentage of blood samples that met the quality standards, by DHB, January to June 2014 11
Table 6: Percentage of samples received by the laboratory within four days, by DHB, January to June 2014 13
Table 7: Percentage of results available within specified timeframes, by disorder, January to June 2014 14
Table 8: Percentage of results reported within specified timeframes, by disorder, January to June 2014 16

List of Figures

Figure 1: Percentage of samples taken between 48 and 72 hours, by DHB, January to June 2014 6

Figure 2: Number of samples taken at different ages, January to June 2014 7

Figure 3: Percentage of samples taken between 48 and 72 hours, by ethnicity, January to June 2014 7

Figure 4: Percentage of samples taken at 48–72 hours, by NZDep, January to June 2014 9

Figure 5: Percentage of blood samples that met quality standards, by DHB, January to June 2014 11

Figure 6: Percentage of samples received by the laboratory within four days, by DHB, January to June 2014 13

Executive summary

This is the eleventh monitoring report for the Newborn Metabolic Screening Programme (NMSP) since the completion of the NMSP Monitoring Framework in November 2010.The first eight reports were quarterly. This is the third biannual report. Regular analysis of data against agreed national programme indicators is a key monitoring and evaluation tool of the NMSP. Six indicators are covered by this draft report.

The NMSP is overseen nationally by the National Screening Unit (NSU) of the Ministry of Health. Almost all babies born in New Zealand have been screened since the NMSP began in 1969, and as a result, approximately 45 babies are identified with and treated for a metabolic disorder each year. When a baby is diagnosed with a metabolic disorder in early infancy, treatment can commence immediately, preventing life-threatening illness and limiting the impact on the baby's development potential.

The NMSP is monitored and evaluated by the NSU to ensure it continuously meets high standards. A multi-disciplinary advisory group provides expert leadership and advice for the programme. The NMSP Technical Group has reviewed this Monitoring Report and considered key findings and made recommendations for on-going monitoring and initiatives to improve the programme which are included in the recommendations below.

Key points and recommendations:

Indicator 2 Timing of sample-taking

Overall 73.5% of samples were collected between 48-72 hours. No DHB met the standard of 95% of samples taken in the timeframe (range 54-89%). It is not possible to calculate this indicator for about 4% of samples since they do not have the date and time of both birth and collection. The standard was not met for any ethnic group (range 65-79%) or NZDep group (range 58-89%).

This data is similar to that in earlier reports.

Recommendations: The NSU is recommended to continue working with DHBs, with a particular focus on those under 60%, namely Bay of Plenty and Waikato DHBs.

Indicator 3 Quality of blood samples

There was improvement in this indicator since the first report but this has not been sustained. Four DHBs met or exceeded the standard of 99% of samples satisfactory for testing. All remaining DHBs achieved between 97-99%.

Recommendations: The recommendation is to continue to monitor and provide feedback to DHBs.

Indicator 4 Sample dispatch and delivery

Overall 63.8% of samples met the standard of receipt in the laboratory by four days after collection. No DHB met the standard. All DHBs had significantly improved transit times since

the provision of postage-paid envelopes however this has not been sustained. 93% were received in 7 days or less.

Recommendations: The NSU is recommended to continue working with DHBs, with a particular focus on those under 60%, namely Tairawhiti, Hawkes Bay, Nelson Marlborough and South Canterbury DHBs.

Indicator 5 Laboratory testing timeframes

The standard of 100% was not met for any disorder however all timeframes were greater than 99% except screening for cystic fibrosis with 98.9% meeting the turnaround time due to delays in receiving CF mutation results.

Recommendations: There were no recommendations.

Indicator 6 Timeliness of Reporting – Notification of Screen Positives

The single positive test for biotinidase deficiency met the standard of 100% of reports notified in the specified timeframe. For the other disorders, between 52-91% of reports met the standard. All clinical critical results were notified in the timeframe. Because this indicator is in calendar days and Indicator 5 in working days results can meet the testing timeframe but not the reporting standard.

Recommendations: It is recommended that testing and reporting times be harmonised and this should be discussed at the next meeting in December 2014.

Indicator 9 Blood spot card storage and return.

99.6% of 285 requests for card return met the standard of within 28 days of completion of screening. One sample was unsuitable for testing and returned with the followup sample within 28 days of receiving the second sample.

Recommendations: There were no recommendations.

Introduction

The purpose of this Monitoring Report is to assess the performance of specific components of the NMSP against the agreed set of national indicators.

Regular analysis of data against programme indicators is a key monitoring and evaluation tool of the NMSP. The development of quarterly, biannual and annual reports is a priority for the NMSP. Reports will be published on the NSU website.

This is the eleventh report of the NMSP following the development of national indicators and completion of the NMSP Monitoring Framework in November 2010. The first eight reports covered quarter years. This is the third half-year report.

Background

The NMSP is overseen nationally by the National Screening Unit (NSU) of the Ministry of Health. Almost all babies born in New Zealand have been screened since the NMSP began in 1969, and as a result, approximately 45 babies are identified with and treated for a metabolic disorder each year. When a baby is diagnosed with a metabolic disorder in early infancy, treatment can commence immediately, preventing life-threatening illness and limiting the impact on the baby's development potential.

Newborn metabolic screening involves collecting blood samples from babies' heels (the 'heel prick test') onto a blood spot card (a 'Guthrie card'). Blood samples must be collected between 48 and 72 hours of baby's age for maximum utility. The blood samples are screened for over 20 metabolic disorders.

The NMSP is monitored and evaluated by the NSU to ensure it continuously meets high standards. A multi-disciplinary advisory group provides expert leadership and advice for the programme. The NMSP Governance Team and the Technical Group reviews Monitoring Reports and makes recommendations.

NMSP aim and objectives

The aim of the NMSP is to reduce newborn morbidity and mortality by utilising high-quality screening that facilitates the early detection and treatment of specific metabolic disorders in pre-symptomatic babies.

The objectives of the programme are to:

- enable early detection of pre-symptomatic newborns
- ensure appropriate early referral to treatment of newborns
- ensure babies born with congenital metabolic disorders have their developmental potential affected as little as possible from the disorder
- facilitate early diagnosis, appropriate treatment and continuous monitoring of specific metabolic disorders
- maintain high uptake of screening, community participation and trust
- facilitate continuous quality improvement through the development of quality assurance, reporting, education and the strategic planning framework

- inform the community of all aspects of newborn screening, including the storage and use of blood spot cards.

Data

Data source and extraction

Data is first obtained from the LabPLUS Delphic laboratory information system (Delphic). The extracted data is then placed in a temporary table on the Delphic Data Warehouse and imported into a Microsoft Access database for analysis.

Data on DHB, ethnicity and NZDep is obtained from the Ministry of Health national collections and merged with the LabPLUS data, based on NHIs (National Health Index numbers). This method follows a matching and data retrieval process that is defined by the business rules.

Samples selected for inclusion in this report are based on the date they are received at the laboratory. For this reporting period, only valid samples from 1 January to 30 June 2013 are included. Samples are only included if they are a first sample received from a baby. Follow-up samples are excluded, because if a baby is screened in one reporting period and has follow-up in the next period, they will be counted twice.

Ethnicity and NZDep decile

Ethnicity is prioritised based on the NHI ethnicity information. All reporting by NZDep decile is based on the extraction against the NHI associated with residential addresses. Decile 1 is the highest and decile 10 is the lowest decile rating of socioeconomic status.

DHB reporting

Although many lead maternity carers (LMCs) are not directly responsible to a particular DHB, data is reported by DHB region, as this is the most usual way of comparing health information across New Zealand.

Analysis

The full process for analysis is documented in separate business rules and is summarised here.

- Analysis is provided by DHB region, ethnicity (Classification 1 and 2) and NZDep status.
- The timing of the sample taking is separated into three time periods: < 48 hours, 48–72 hours and > 72 hours.
- For quality of blood sample, the presence/absence of the INAD tests is used to classify samples as either satisfactory or non-satisfactory.
- Transit time for sample dispatch and delivery is categorised as ≤ 4 days and > 4 days. Missing data is recorded as such.
- Lab testing timeframes are captured, though they vary due to the different diseases being tested for. The analysis takes this into account.
- Data is analysed to determine whether or not cards that are requested to be returned are in fact returned within the 28 days required.

Data quality and limitations

Data cleansing process

The full data cleansing process is included in separate business rules. An exception report identifies those samples where the date of birth against an NHI number from the LabPLUS information system differs from that held by the NHI. There were 122 such samples out of approximately 29,700 in this reporting period. This number is small, and the analysed data in this report includes the data as originally extracted. Where possible, identified errors (such as using the mother's NHI number, not the baby's) will be corrected and the annual report will include the cleansed data.

Timing of test

Ideally, the testing for babies occurs after 48 hours and before 72 hours. From report 4, the age of the baby has been reported in hours, unless the date and time of birth and sample collection are not provided.

A proportion of samples do not give the time of collection. The percentage meeting the standard is calculated from the total number of infants but would be higher if it were calculated from the number for which the information is available.

Laboratory testing timeframes

The number of days the laboratory is expected to perform testing differs by disease, and the analysis takes into account the individual timeframes when producing the output for lab-testing timeframes. The standard definition of laboratory turnaround time is the time from receipt of sample to a reportable result, and this has been used for the laboratory testing times below. They incorporate all tests required to screen for the named condition, including any second-tier tests (eg, transferase enzyme for galactosaemia positive tests, mutation analysis for cystic fibrosis screening).

Disorder	Working days from receipt of sample
Congenital adrenal hyperplasia	2
Galactosaemia	2
Amino acid disorders	2
Fatty acid oxidation disorders	2
Biotinidase deficiency	5
Cystic fibrosis	5
Congenital hypothyroidism	5

Amino acid disorders and fatty acid oxidation disorder analyses are run at the same time on the same instrument in the same analysis, and so the results are available at the same time and the disorders are combined into a single category to calculate the testing time.

NMSP monitoring indicators

Table 1 summarises all the NMSP indicators used in regular monitoring, along with their reporting frequency and detail. Indicators 1 and 2 are reported by DHB, ethnicity and deprivation status. Indicators 3, 4 and 7 are reported by DHB. This report, as a biannual report, provides information on indicators 2 to 6 and 9. These indicators have been developed following consultation with key NMSP stakeholders. Indicators will be further refined as data is collected over time and will be subject to regular review by the NMSP Advisory Group.

Table 1: NMSP indicators and their monitoring frequency

Indicators		Biannually	Annually	Detail
1	Newborn metabolic screening coverage		X	DHB Ethnicity Deprivation status
2	Timing of sample taking	X	X	DHB Ethnicity Deprivation status
Laboratory reporting				
3	Quality of blood samples	X	X	DHB
4	Sample dispatch and delivery	X	X	DHB
5	Laboratory testing timeframes	X	X	
6	Timeliness of reporting – notification of screen positives	X	X	
7	Collection and receipt of second samples		X	DHB
Incidence			X	
8	Diagnosis and commencement of treatment by disorder: • biotinidase deficiency • cystic fibrosis • congenital hypothyroidism • congenital adrenal hyperplasia • galactosaemia • amino acid disorders • fatty acid oxidation disorders.		X	
9	**Blood spot card storage and return**	X	X	

Indicator 2: Timing of sample taking

Summary

Description

1 The proportion of eligible babies who have a newborn metabolic screening sample taken.

2 The proportion of eligible babies who have a newborn metabolic screening sample taken between 48 and 72 hours of birth.

Rationale

Timely sample collection leads to the best possible chance of a baby receiving early diagnosis and treatment, where necessary. Severe forms of some of the disorders screened for can be fatal within seven to ten days. Many may not show any signs or symptoms of disease until irreversible damage has occurred. However, the baby must have been independent of their mother long enough for their indicator biochemicals to show an abnormality. Therefore the optimum window for sample collection is between 48 and 72 hours of birth.

Relevant outcome

Babies screened should have a newborn metabolic screening sample taken between 48 and 72 hours of birth.

Standard

95% of first samples are taken between 48 and 72 hours of birth.

Methodology – Indicator 2

Numerator: Number of babies who have a newborn metabolic screening sample taken between 48 and 72 hours of birth.

Denominator: Number of babies who have a newborn metabolic screening sample taken.

Notes

Samples for screening must be taken in accordance with the *Programme Guidelines* and policy and quality requirements.

Reporting is by:

- DHB
- ethnicity
- deprivation status.

Data on timing of sample taking

Overall 73.5% (DHB range 58-89%) samples were taken in the recommended timeframe of 48-72 hours, similar to previous reports.

For this period no DHB region met the standard of 95% of samples taken between 48 and 72 hours. Table 2 shows the percentage of samples taken between 48-72 hours, as well as those outside of this timeframe, by DHB. Figure 1 shows the percentage of samples taken 48-72 hours by DHB compared with the overall average of 73.5 at 48-72 hours.

Overall there has been little change in this indicator since it became possible to report time in hours (ie from Report 5 January to June 2012).

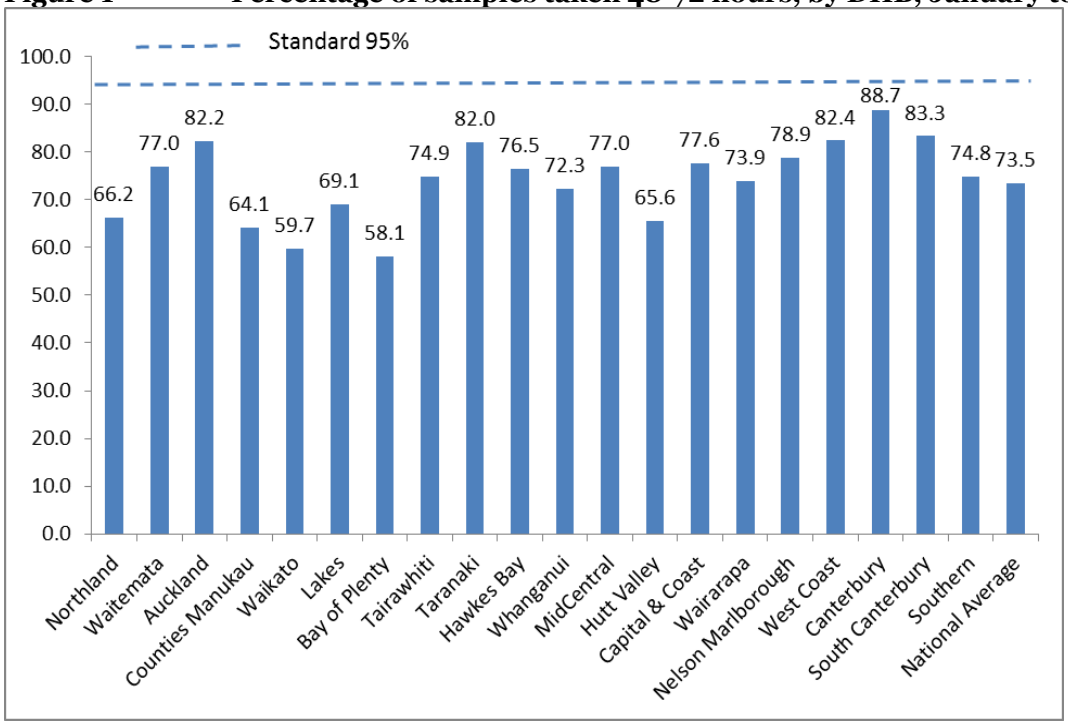
The number of samples in which it is not possible to calculate the age of the baby at sampling because data (time of birth, date and time of sample collection) have not been provided on the test card is about 4%. This impacts the ability of the programme to correctly interpret test results and may underestimate the percentage of samples taken in the correct timeframe.

Table 2 Percentage of samples taken at 48-72 hours, by DHB, January to June 2014

DHB region	Sampled at 48–72 hours		Sampled at less than 48 hours		Sampled at greater than 72 hours		No collection date/time or no time of birth		Total number of screens
	No.	%	No.	%	No.	%	No.	%	No.
	No.	%	No.	%	No.	%	No.	%	No.
Northland	695	66.2	7	0.67	314	29.9	34	3.2	1050
Waitemata	2878	77.0	32	0.86	759	20.3	67	1.8	3736
Auckland	2515	82.2	20	0.65	402	13.1	121	4.0	3058
Counties Manukau	2553	64.1	23	0.58	1161	29.2	245	6.2	3982
Waikato	1529	59.7	17	0.66	913	35.7	101	3.9	2560
Lakes	457	69.1	5	0.76	178	26.9	21	3.2	661
Bay of Plenty	745	58.1	5	0.39	483	37.6	50	3.9	1283
Tairawhiti	256	74.9	1	0.29	79	23.1	6	1.8	342
Taranaki	606	82.0	5	0.68	104	14.1	24	3.2	739
Hawkes Bay	802	76.5	8	0.76	216	20.6	23	2.2	1049
Whanganui	271	72.3	3	0.80	95	25.3	6	1.6	375
MidCentral	808	77.0	5	0.48	201	19.1	36	3.4	1050
Hutt Valley	617	65.6	2	0.21	294	31.2	28	3.0	941
Capital & Coast	1397	77.6	13	0.72	339	18.8	51	2.8	1800
Wairarapa	176	73.9	2	0.84	55	23.1	5	2.1	238
Nelson Marlborough	538	78.9	7	1.03	117	17.2	20	2.9	682
West Coast	150	82.4	1	0.55	22	12.1	9	4.9	182
Canterbury	2600	88.7	16	0.55	236	8.0	80	2.7	2932
South Canterbury	285	83.3	1	0.29	53	15.5	3	0.9	342
Southern	1229	74.8	9	0.55	353	21.5	51	3.1	1642
Not Recorded	39	29.1	0	0.00	16	11.9	79	59.0	134
National Average	21146	73.5	182	0.63	6390	22.2	1060	3.7	28778

*Total includes babies who have had more than one screen

Figure 1 Percentage of samples taken 48-72 hours, by DHB, January to June 2014



Although overall only 73.5% of samples were collected in the timeframe 93.7% (26952) were collected 2-5d and 0.5% (158) at 10d or older. Data is shown in figure 2.

Figure 2: Number of samples taken at different ages, January to June 2014

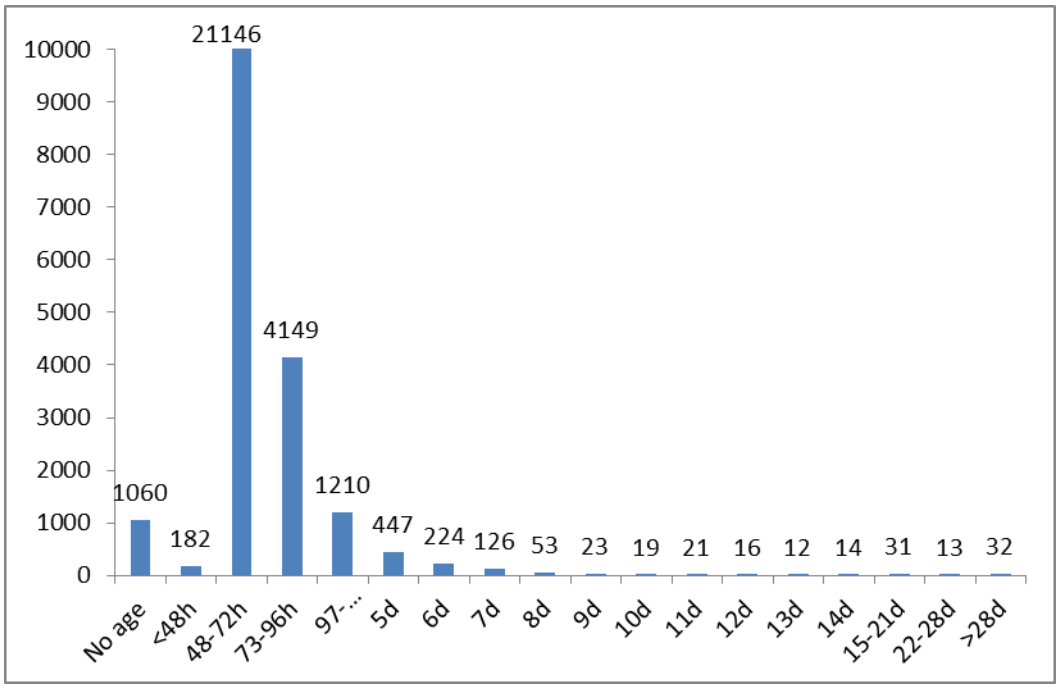


Figure 3 below and Table 3 identify some small differences between ethnic groups. While no ethnic group met the standard of 95% the percentages for European and Asian appear higher than for the remaining ethnic groups. This is similar to the previous ten reports.

Figure 3: Percentage of samples taken between 48 and 72 hours, by ethnicity, January to June 2014

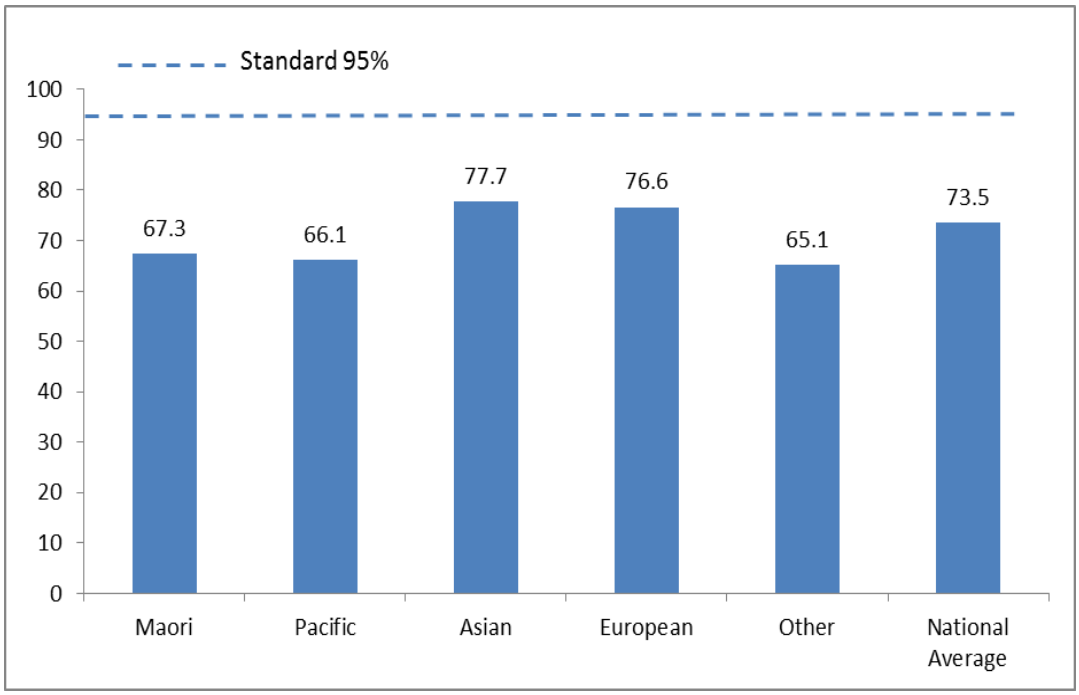


Table 3: Percentage of samples taken earlier than, between and after 48–72 hours, by Group 1 and Group 2 ethnicity, January to June 2014

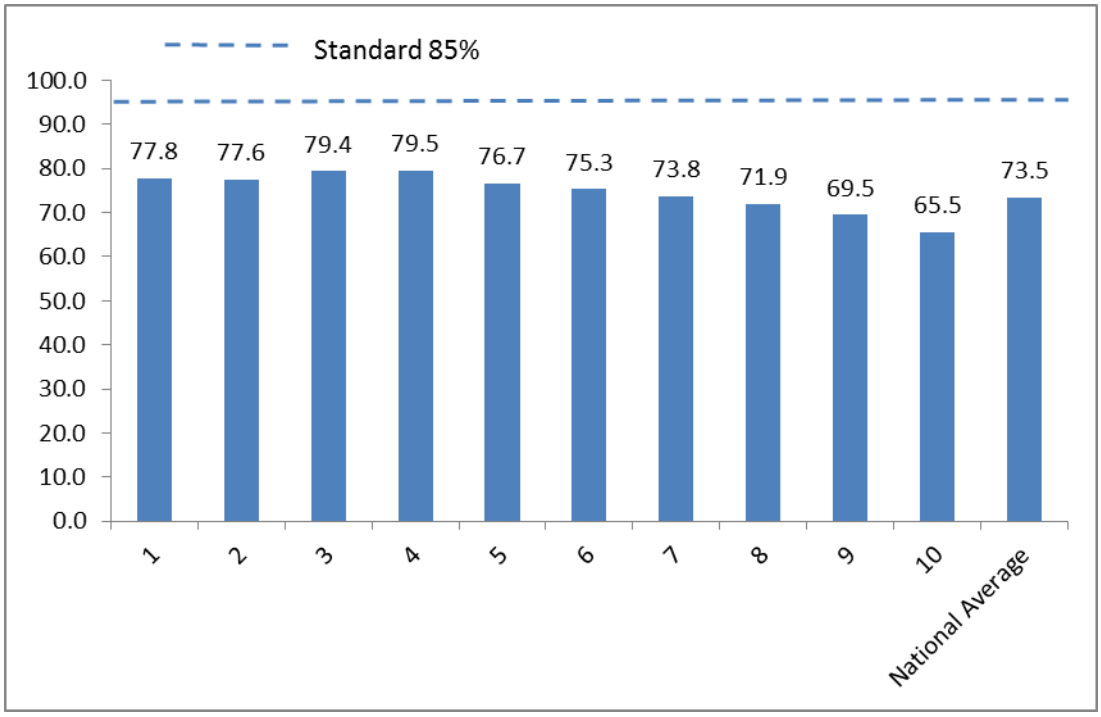
Ethnicity (Group 1 and Group 2)	Sampled at 48–72 hours		Sampled at less than 48 hours		Sampled at over 72 hours		No collection date and/or time		Total no of screens
	No.	%	No.	%	No.	%	No.	%	No.
	No.	%	No.	%	No.	%	No.	%	No.
Maori	4042	67.3	45	0.7	1703	28.4	215	3.6	6005
Pacific	1941	66.1	25	0.9	822	28.0	150	5.1	2938
Cook Island Maori	287	63.5	2	0.4	139	30.8	24	5.3	452
Fijian	155	71.1		0.0	51	23.4	12	5.5	218
Niuean	96	66.2	2	1.4	41	28.3	6	4.1	145
Samoan	778	65.2	13	1.1	342	28.6	61	5.1	1194
Tokelauan	39	76.5		0.0	10	19.6	2	3.9	51
Tongan	480	67.1	6	0.8	194	27.1	35	4.9	715
Other Pacific	106	65.0	2	1.2	45	27.6	10	6.1	163
Asian	3289	77.7	24	0.6	781	18.4	141	3.3	4235
Chinese	1263	81.0	8	0.5	247	15.8	41	2.6	1559
Indian	955	73.0	8	0.6	282	21.6	63	4.8	1308
Southeast Asian	392	77.5	4	0.8	100	19.8	10	2.0	506
Other Asian	679	78.8	4	0.5	152	17.6	27	3.1	862
European	11468	76.6	85	0.6	2962	19.8	461	3.1	14976
NZ European	9798	76.7	74	0.6	2510	19.6	399	3.1	12781
Latin American / Hispanic	122	79.2	1	0.6	27	17.5	4	2.6	154
Other European	1548	75.8	10	0.5	425	20.8	58	2.8	2041
Other	406	65.1	3	0.5	122	19.6	93	14.9	624
African	140	82.4	1	0.6	27	15.9	2	1.2	170
Middle Eastern	150	69.4	1	0.5	59	27.3	6	2.8	216
Other/not known	116	48.7	1	0.4	36	15.1	85	35.7	238
National Average	21146	73.5	182	0.6	6390	22.2	1060	3.7	28778

Table 4 and Figure 4 below show the number of samples taken between 48 and 72 hours by NZ Deprivation index. There was no NZDep level that reached the target. The data does seem to indicate a slightly lower percentage of samples taken by the recommended time for babies in the five groups with the highest levels of deprivation. There has been no significant change in this indicator.

Table 4: Percentage of samples taken earlier than, between and after 48–72 hours, by NZDep, January to June 2014

NZDep	Sampled at 48–72 hours		Sampled at less than 48 hours		Sampled at over 72 hours		No collection date and/or time		Total no of babies screened
	No.	%	No.	%	No.	%	No.	%	No.
1	1428	77.8	11	0.6	350	19.1	47	2.6	1836
2	1760	77.6	16	0.7	425	18.7	68	3.0	2269
3	1784	79.4	8	0.4	395	17.6	61	2.7	2248
4	1750	79.5	19	0.9	369	16.8	62	2.8	2200
5	2048	76.7	17	0.6	538	20.1	67	2.5	2670
6	2104	75.3	21	0.8	582	20.8	87	3.1	2794
7	2330	73.8	22	0.7	693	21.9	113	3.6	3158
8	2637	71.9	21	0.6	885	24.1	123	3.4	3666
9	2655	69.5	25	0.7	970	25.4	169	4.4	3819
10	2609	65.5	22	0.6	1166	29.3	184	4.6	3981
Not Known	41	29.9	0	0.0	17	12.4	79	57.7	137
National Average	21146	73.5	182	0.6	6390	22.2	1060	3.7	28778

Figure 4: Percentage of samples taken at 48–72 hours, by NZDep, January to June 2014



Indicator 3: Quality of blood samples

Summary
Description
The quality of the blood spot sample.
Rationale
Accurate testing of blood spot samples is reliant on the quality of the sample. Unsatisfactory samples require a repeat sample, which could have been avoided.
Relevant outcome
Blood spot samples are of sufficient quality for laboratory testing for screened disorders.
Standard
99% of blood spot samples are of satisfactory quality.
Methodology – Indicator 3
Numerator: Number of samples of satisfactory quality as reported by the laboratory.
Denominator: Number of samples taken.
Notes
Requirements for a satisfactory sample are detailed in Chapter 7, pages 21–22 of the *Programme Guidelines*.
Reporting by DHB.

Data on quality of blood samples

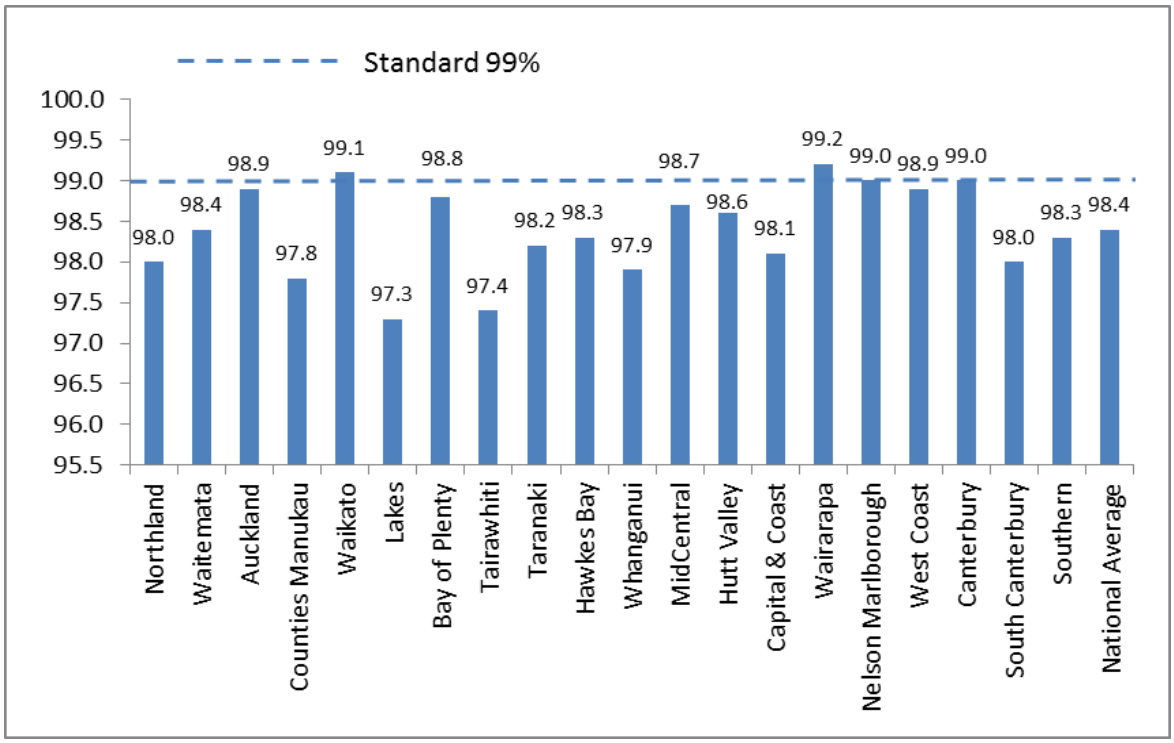
Only four DHBs met or exceeded the standard of 99% of samples satisfactory for testing. This is shown in Table 5 and Figure 5.

During 2011-2013 the quarter performance for blood sample quality was been overall 98.6%, 98.5%, 98.7%, 98.8%, 99.1%, 99.2%, 99.1% and 98.8%. For the half year July-December it was 98.8% and this half year 98.4% of samples were satisfactory. The number of DHBs meeting the target for the quarterly reports 1-10 was 4, 3, 3, 6, 14, 8, 13, 9 and 8. For this half-year 4 DHBs met the target.

Table 5: Percentage of blood samples that met the quality standards, by DHB, January to June 2014

DHB region	Satisfactory		Unsatisfactory		Total samples
	No.	%	No.	%	No.
Northland	1029	98.0	21	2	1050
Waitemata	3675	98.4	61	1.6	3736
Auckland	3023	98.9	35	1.1	3058
Counties Manukau	3893	97.8	89	2.2	3982
Waikato	2536	99.1	24	0.9	2560
Lakes	643	97.3	18	2.7	661
Bay of Plenty	1267	98.8	16	1.2	1283
Tairawhiti	333	97.4	9	2.6	342
Taranaki	726	98.2	13	1.8	739
Hawkes Bay	1031	98.3	18	1.7	1049
Whanganui	367	97.9	8	2.1	375
MidCentral	1036	98.7	14	1.3	1050
Hutt Valley	928	98.6	13	1.4	941
Capital & Coast	1766	98.1	34	1.9	1800
Wairarapa	236	99.2	2	0.8	238
Nelson Marlborough	675	99.0	7	1.0	682
West Coast	180	98.9	2	1.1	182
Canterbury	2903	99.0	29	1.0	2932
South Canterbury	335	98.0	7	2.0	342
Southern	1614	98.3	28	1.7	1642
Not Recorded	132	98.5	2	1.5	134
National Average	28328	98.4	450	1.6	28778

Figure 5: Percentage of blood samples that met quality standards, by DHB, January to June 2014



Indicator 4: Sample dispatch and delivery

Summary
Description
The time taken for the sample to be received by the laboratory after being taken.
Rationale
The NMSP relies on timeliness. Samples must be sent to the laboratory as soon as they are dry. Samples must be received by the laboratory as soon as possible after they are taken.
Relevant outcome
Samples are received by the laboratory within four days of being taken.
Standard
95% of samples are received by the laboratory within four calendar days of being taken.
Methodology – Indicator 4
Numerator: Number of samples received by the laboratory within four calendar days of being taken.
Denominator: Number of samples received by the laboratory.
Notes
Requirements for sending samples to the laboratory are detailed in Chapter 7, page 23 of the *Programme Guidelines*.
Reporting by DHB.

Data on sample dispatch and delivery

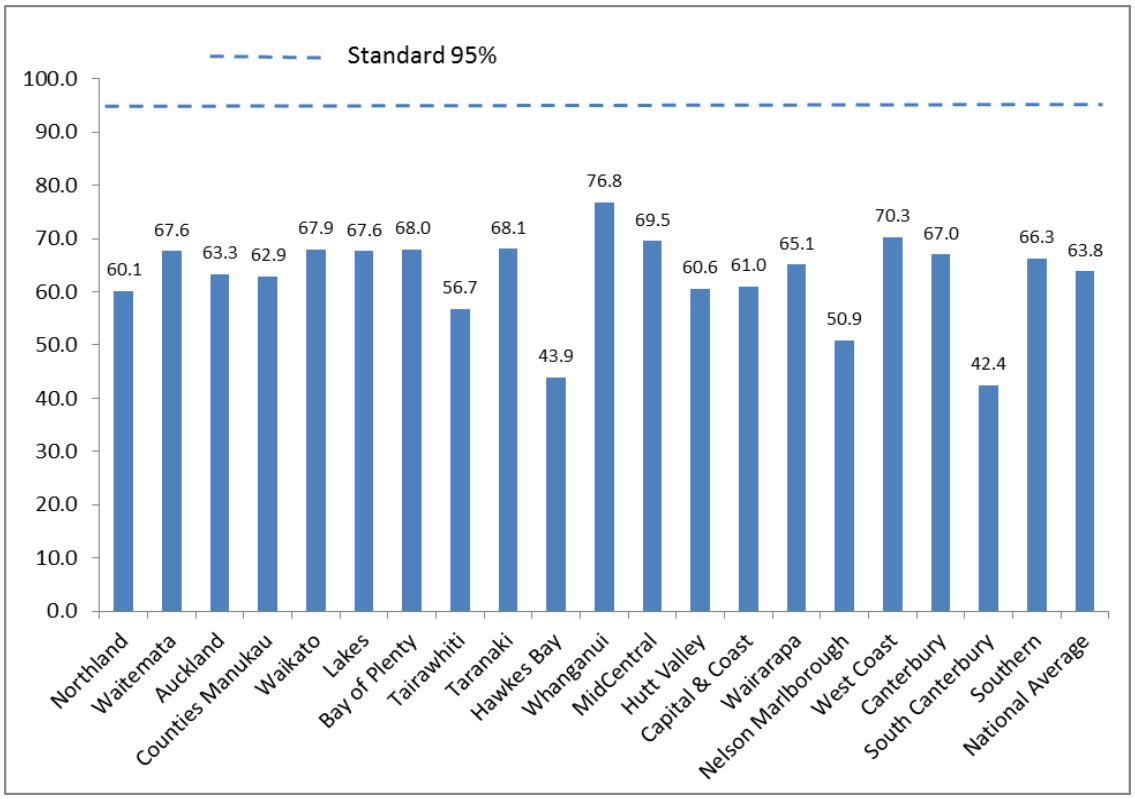
No DHB met the standard of 95% of samples received in four days or less, as shown in Table 6 and Figure 6. The national average has moved from 56% in January-March 2011 to 73% in January – June 2013, was 70% in July to December 2013 and has fallen to 64% in January – June 2014 as shown in Figure 9. The range of values reduced (12-78% January – March 2011 to 54 - 83% in January – June 2013, 40-84% for July to December 2013 and is 42-77% this period. The Ministry of Health National Screening Unit is working with NZ Post to identify reasons for the longer transit times.

Overall 63.8% of samples were received in 4 days or less; 93.1% in 7 days or less and 99.0% in 14 days or less, Further details of timing of samples from DHBs is given in Appendix 1.

Table 6: Percentage of samples received by the laboratory within four days, by DHB, January to June 2014

DHB region	Less than or equal to 4 days		Greater than 4 days		Unknown		Total samples
	No.	%	No.	%	No.	%	No.
	No.	%	No.	%	No.	%	No.
Northland	631	60.1	404	38.5	15	1.4	1050
Waitemata	2526	67.6	1188	31.8	22	0.6	3736
Auckland	1937	63.3	1074	35.1	47	1.5	3058
Counties Manukau	2504	62.9	1397	35.1	81	2.0	3982
Waikato	1739	67.9	785	30.7	36	1.4	2560
Lakes	447	67.6	201	30.4	13	2.0	661
Bay of Plenty	872	68.0	392	30.6	19	1.5	1283
Tairawhiti	194	56.7	146	42.7	2	0.6	342
Taranaki	503	68.1	225	30.4	11	1.5	739
Hawkes Bay	461	43.9	575	54.8	13	1.2	1049
Whanganui	288	76.8	83	22.1	4	1.1	375
MidCentral	730	69.5	300	28.6	20	1.9	1050
Hutt Valley	570	60.6	356	37.8	15	1.6	941
Capital & Coast	1098	61.0	683	37.9	19	1.1	1800
Wairarapa	155	65.1	81	34.0	2	0.8	238
Nelson Marlborough	347	50.9	325	47.7	10	1.5	682
West Coast	128	70.3	53	29.1	1	0.5	182
Canterbury	1964	67.0	924	31.5	44	1.5	2932
South Canterbury	145	42.4	197	57.6		0.0	342
Southern	1088	66.3	530	32.3	24	1.5	1642
Unspecified	44	32.8	88	65.7	2	1.5	134
National Average	18371	63.8	10007	34.8	400	1.4	28778

Figure 6: Percentage of samples received by the laboratory within four days, by DHB, January to June 2014



Indicator 5: Laboratory testing timeframes

Summary

Description

The time taken by the laboratory to test each sample for each of the specified disorders (turnaround time).

Rationale

Samples should be tested as soon as possible to ensure that screen positives can be acted on as quickly as possible to reduce/minimise avoidable harm.

Relevant outcomes

All samples are tested within the specified timeframes.

Samples received before 7:30 am are tested the same day.

Standard

100% of samples meet the following laboratory turnaround times:

Disorder	Working days (from receipt by laboratory)
Congenital adrenal hyperplasia	2
Galactosaemia	2
Amino acid disorders	2
Fatty acid oxidation disorders	2
Biotinidase deficiency	5
Cystic fibrosis	5
Congenital hypothyroidism	5

Methodology – Indicator 5

Numerator: Number of samples tested and reported within the specified timeframes.

Denominator: Number of samples tested.

Data on laboratory testing timeframes

Table 7 identifies the percentage of samples that met the specified laboratory testing timeframes. While not quite 100% (98.9 – 99.9%) the rates are very close to this. The most frequent cause of delays in cystic fibrosis screening is delayed genetic test results.

Table 7: Percentage of results available within specified timeframes, by disorder, January to June 2014 (n = 28,778 samples)

Disorder	Expected timeframe (days)	Number met timeframe	% met timeframe
Congenital Adrenal Hyperplasia	2	28639	99.5
Galactosaemia	2	28709	99.8
Amino acid disorders	2	28578	99.3
Fatty acid oxidation disorders	2	28578	99.3
Biotinidase deficiency	5	28752	99.9
Cystic fibrosis	5	28450	98.9
Congenital hypothyroidism	5	28751	99.9

Indicator 6: Timeliness of reporting – notification of screen positives

Summary

Description

The time taken for a baby with a positive screening result to be referred for diagnostic testing.

Rationale

The NMSP relies on early detection and treatment. This ensures babies with congenital metabolic disorders have their developmental potential affected as little as possible from the disorder.

Relevant outcome

All babies with positive screening results are referred for further testing within the specified timeframes after results become available.

Standard

100% of babies with positive results are notified to their LMC / referring practitioner by the laboratory within the following timeframes:

Reason for report	Calendar days (from receipt in lab test result)
Amino acid disorders	3
Fatty acid oxidation disorders	3
Congenital adrenal hyperplasia	3
Galactosaemia	3
Congenital hypothyroidism	4
Biotinidase deficiency	9
Cystic fibrosis	12

Methodology – Indicator 6

Numerator: Number of babies who are notified to their referrer for further testing for a particular disorder within the number of calendar days specified for that disorder.

Denominator: Number of babies who receive a positive screening result for a particular disorder.

Data on timeliness of reporting notification of screen positives

Most screening tests have a two-tier reporting system. Where results are highly likely to indicate the disorder is present, the results are telephoned to the LMC and referral made to an appropriate subspecialist paediatrician. All results in this category were reported inside the timeframes.

The numbers and percentages of reports meeting the timeframes are given in Table 8.

Marginal test results are reported by mail, and in this case the written report is not generated until all the screening test results are available. The results are available and will be phoned if there is a clinical reason to do so (as above). 79 reports did not meet the turnaround time, 15 were due to waiting for cystic fibrosis gene testing, 37 were due to waiting for the particular test result (32/37 aminoacid and fatty acid oxidation screening results), 6 waiting for the results of another test and for 21 delayed signout or reporting was either the reason for, or contributory to, the delay. Generally the delays were only 1-2 days over the standard however there was one significant outlier, a CF result reported at 36 days, due to a laboratory error.

For tests with a 3 day reporting timeframe, if a sample is received on Thursday or Friday the normal testing schedule will make results available on Monday or Tuesday hence about 20% of positive tests will not be reported in the timeframe.

In many cases where reporting does not meet the timeframe the testing time for that specimen does meet the timeframe because testing turnaround times are specified in working days but reporting times in calendar days eg CAH is two days for test result being available and three days for reporting. A sample which arrives on Friday and has a test result available and reported on Monday meets the testing timeframe but not the reporting timeframe.

It is recommended that the testing and reporting timeframes be harmonised.

Table 8: Percentage of results reported within specified timeframes, by disorder, January to June 2014

Reason for report	Calendar days (from receipt in lab to report)	Number of positive test reports	Number met timeframe	% met timeframe
Amino acid and fatty acid oxidation disorders	3	108	56	51.9
CAH	3	26	14	54.0
Galactosaemia	3	2	1	50.0
CH	4	23	21	91.3
Biotinidase deficiency	9	1	1	100
Cystic fibrosis	12	31	19	61.3

Indicator 9: Blood spot card storage and return

Summary

Description

The time taken for the laboratory to return requested blood spot cards to parents/guardians/individuals.

Rationale

Where requested, blood spot cards should be returned within:

- 28 days of completion of screening
- 28 days of valid (fully completed) request for return.

Relevant outcome

All blood spot cards are returned to parents/guardians/individuals by tracked courier within 28 days.

Standard

1 Where requested, 100% of blood spot cards are returned to parents/guardians within 28 days of completion of screening.

2 100% of blood spot cards are returned to the authorised person by tracked courier within 28 calendar days of a valid request.

Methodology – Indicator 9

Numerator: Number of blood spot cards returned within 28 days.

Denominator: Number of blood spot cards requested by parents/guardians/individuals.

Notes

Complete information is required by the laboratory in order to process requests for return of blood spot cards, as per Chapter 11 of the *Programme Guidelines*.

Data on blood spot card storage and return

All samples are returned by tracked courier. Of 285 requests for the return of cards collected during the reporting period 1 January to 30 June 2014, 284 (99.62%) were returned in the timeframe. The outlier request was for the return of an inadequate sample and in line with policy this sample was returned with the followup sample, the day after the followup sample was received by the laboratory. In general samples are returned very quickly with a median time over this period of 2.1 days.

Appendix 1

No DHB meets Standard 4 (95% of samples received in four days or less after the sample is taken). More detailed information about transit times from DHBs is given in Figures 1 and 2 and the Table. No data is available when the date of specimen collection is omitted from the test card.

Figure 1 Transit times for samples from DHBs, January to June 2014, percentage received in timeframes.

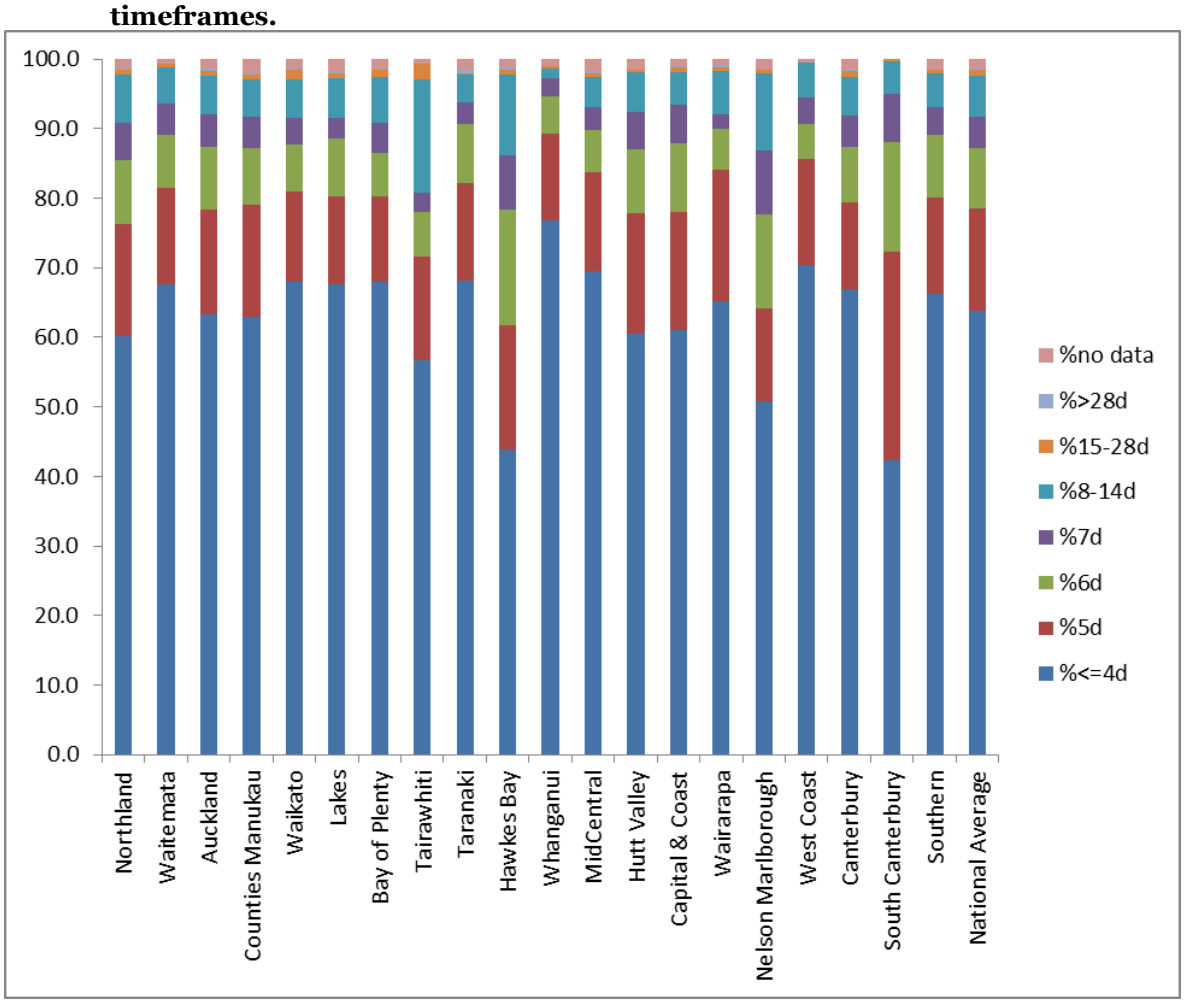


Table 1 Detailed transit times for DHBs, January to June 2014

DHB_Name	<=4d	%<=4d	5d	%5d	6d	%6d	7d	%7d	8-14d	%8-14d	15-28d	%15-28d	>28d	%>28d	No data	% no data	Total
Northland	631	60.1	170	16.2	97	9.2	55	5.2	73	7.0	8	0.8	1	0.1	15	1.4	1,050
Waitemata	2526	67.6	517	13.8	286	7.7	166	4.4	198	5.3	20	0.5	1	0.0	22	0.6	3,736
Auckland	1,937	63.3	460	15.0	276	9.0	143	4.7	166	5.4	25	0.8	4	0.1	47	1.5	3,058
Counties Manukau	2,504	62.9	646	16.2	323	8.1	180	4.5	212	5.3	25	0.6	11	0.3	81	2.0	3,982
Waikato	1,739	67.9	332	13.0	176	6.9	98	3.8	142	5.5	32	1.3	5	0.2	36	1.4	2,560
Lakes	447	67.6	83	12.6	56	8.5	19	2.9	38	5.7	4	0.6	1	0.2	13	2.0	661
Bay of Plenty	872	68.0	158	12.3	79	6.2	56	4.4	85	6.6	13	1.0	1	0.1	19	1.5	1,283
Tairawhiti	194	56.7	51	14.9	22	6.4	9	2.6	56	16.4	8	2.3	0	0.0	2	0.6	342
Taranaki	503	68.1	104	14.1	63	8.5	23	3.1	29	3.9	2	0.3	4	0.5	11	1.5	739
Hawkes Bay	461	43.9	187	17.8	174	16.6	81	7.7	123	11.7	7	0.7	3	0.3	13	1.2	1,049
Whanganui	288	76.8	47	12.5	20	5.3	10	2.7	5	1.3	1	0.3	0	0.0	4	1.1	375
MidCentral	730	69.5	150	14.3	63	6.0	35	3.3	45	4.3	6	0.6	1	0.1	20	1.9	1,050
Hutt Valley	570	60.6	162	17.2	87	9.2	50	5.3	54	5.7	3	0.3	0	0.0	15	1.6	941
Capital & Coast	1,098	61.0	307	17.1	176	9.8	102	5.7	84	4.7	11	0.6	3	0.2	19	1.1	1,800
Wairarapa	155	65.1	45	18.9	14	5.9	5	2.1	15	6.3	1	0.4	1	0.4	2	0.8	238
Nelson Marlborough	347	50.9	90	13.2	93	13.6	62	9.1	76	11.1	4	0.6	0	0.0	10	1.5	682
West Coast	128	70.3	28	15.4	9	4.9	7	3.8	9	4.9	0	0.0	0	0.0	1	0.5	182
Canterbury	1,964	67.0	362	12.3	238	8.1	130	4.4	160	5.5	29	1.0	5	0.2	44	1.5	2,932
South Canterbury	145	42.4	102	29.8	54	15.8	24	7.0	16	4.7	1	0.3	0	0.0	0	0.0	342
Southern	1,088	66.3	228	13.9	147	9.0	66	4.0	79	4.8	9	0.5	1	0.1	24	1.5	1,642
Unspecified	44	32.8	7	5.2	10	7.5	11	8.2	30	22.4	19	14.2	11	8.2	2	1.5	134
National Average	18,371	63.8	4,236	14.7	2,463	8.6	1,332	4.6	1,695	5.9	228	0.8	53	0.2	400	1.4	28,778