MINISTRY OF HEALTH
MANATŪ HAUORA
newzealand.govt.nz

Newborn Metabolic Screening Programme (NMSP)

Biannual Monitoring Report

Number 10

1 July to 31 December 2013

National Screening Unit

Copyright

Disclaimer

This publication reports on information provided to the Ministry of Health by Auckland District Health Board. The purpose of this publication is to inform discussion and assist ongoing Newborn Metabolic Screening Programme development. All care has been taken in the production of this report, and the data was deemed to be accurate at the time of publication. However, the data may be subject to slight changes over time as further information is received. Before quoting or using this information, it is advisable to check the current status with the Ministry of Health.

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 10, 1 July to 31 December 2013. Wellington: Ministry of Health.

Published in July 2014
by the Ministry of Health
PO Box 5013, Wellington 6145, New Zealand

ISBN 978-0-478-42856-8 (online)
HP 5940

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

Contents

List of Tables

List of Figures

Executive summary

This is the tenth 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 second 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 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 72.8% 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 61-79%). 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. Eight DHBs met or exceeded the standard of 99% of samples satisfactory for testing. All remaining DHBs achieved between 96-99%.

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

Indicator 4 Sample dispatch and delivery

Overall 70.4% of samples met the standard of receipt in the laboratory by four days after collection. No DHB met the standard. All DHBs have significantly improved transit times since the provision of postage-paid envelopes. 93.5% 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 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 fatty acid oxidation and aminoacid breakdown disorders which has a low percentage (98.2%) meeting the turnaround time due to instrument breakdowns and screening for congenital adrenal hyperplasia which is low (97.5%) due to reagent supply problems.

Recommendations: There were no recommendations.

Indicator 6 Timeliness of Reporting – Notification of Screen Positives

No disorder met the standard of 100% of reports notified in the specified timeframe. Between 63.2-100% 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 August 2014.

Indicator 9 Blood spot card storage and return.

98.2% of 271 requests for card return met the standard of within 28 days of completion of screening. Four samples have not been returned as the requests came separately from the samples and without photo ID and no response has been received to the request for this. The return of one sample was delayed waiting for a replacement form and the form was lost in the laboratory.

Recommendations: There were no recommendations.

Introduction

Purpose of report

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. Reports will be published on the NSU website.

This is the tenth 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 second six-monthly 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 developmental potential.

Newborn metabolic screening involves collecting a blood sample from the baby's' heel (the 'heel prick test') onto a blood spot card (a 'Guthrie card'). Blood samples must be collected between 48 and 72 hours of the 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 multidisciplinary advisory group provides expert leadership and advice for the programme. The NMSP Governance Team and the Technical Group review 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 72.8% (range 54 to 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 72.8 at 48-72 hours.

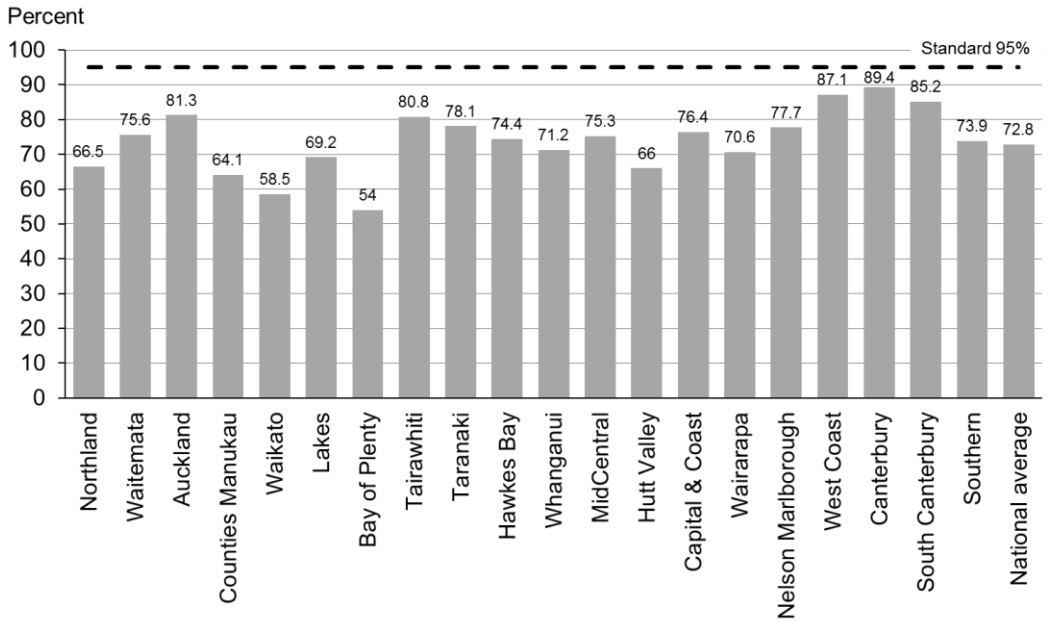
The number of samples in which it is not possible to calculate the age of the baby at sampling because data (time of birth, date and time of sample collection) have not been provided on the test card is about 4%. This impacts the ability of the programme to correctly interpret test results and may underestimate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

Table 2: Percentage of samples taken earlier than, between and after 48–72 hours, by DHB, July to December 2013

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.
Northland	726	66.5	5	0.5	331	30.3	30	2.7	1092
Waitemata	2951	75.6	20	0.5	813	20.8	118	3.0	3902
Auckland	2600	81.3	30	0.9	437	13.7	131	4.1	3198
Counties Manukau	2592	64.1	21	0.5	1175	29.1	253	6.3	4041
Waikato	1544	58.5	17	0.6	986	37.4	91	3.4	2638
Lakes	505	69.2	4	0.5	189	25.9	32	4.4	730
Bay of Plenty	754	54.0	8	0.6	581	41.6	54	3.9	1397
Tairawhiti	270	80.8	0	0.0	57	17.1	7	2.1	334
Taranaki	619	78.1	5	0.6	150	18.9	19	2.4	793
Hawkes Bay	839	74.4	6	0.5	259	23.0	23	2.0	1127
Whanganui	304	71.2	3	0.7	110	25.8	10	2.3	427
Mid Central	811	75.3	8	0.7	217	20.1	41	3.8	1077
Hutt Valley	639	66.0	3	0.3	294	30.4	32	3.3	968
Capital & Coast	1351	76.4	11	0.6	343	19.4	64	3.6	1769
Wairarapa	178	70.6	0	0.0	63	25.0	11	4.4	252
Nelson Marlborough	611	77.7	4	0.5	148	18.8	23	2.9	786
West Coast	162	87.1	2	1.1	19	10.2	3	1.6	186
Canterbury	2642	89.4	13	0.4	227	7.7	72	2.4	2954
South Canterbury	259	85.2	2	0.7	39	12.8	4	1.3	304
Southern	1339	73.9	12	0.7	393	21.7	68	3.8	1812
Not Recorded	37	60.7	2	3.3	10	16.4	12	19.7	61
National Average	21,733	72.8	176	0.6	6841	22.9	1098	3.7	29,848

*Total includes babies who have had more than one screen

Figure 1: Percentage of samples taken between 48 and 72 hours, by DHB, July to December 2013



Although overall only 72.8% of samples were collected in the timeframe 93.8% (27997) were collected 2-5d and 0.5% (155) at 10d or older. Data is shown in figure 2.

Figure 2: Number of samples taken at different ages, July to December 2013

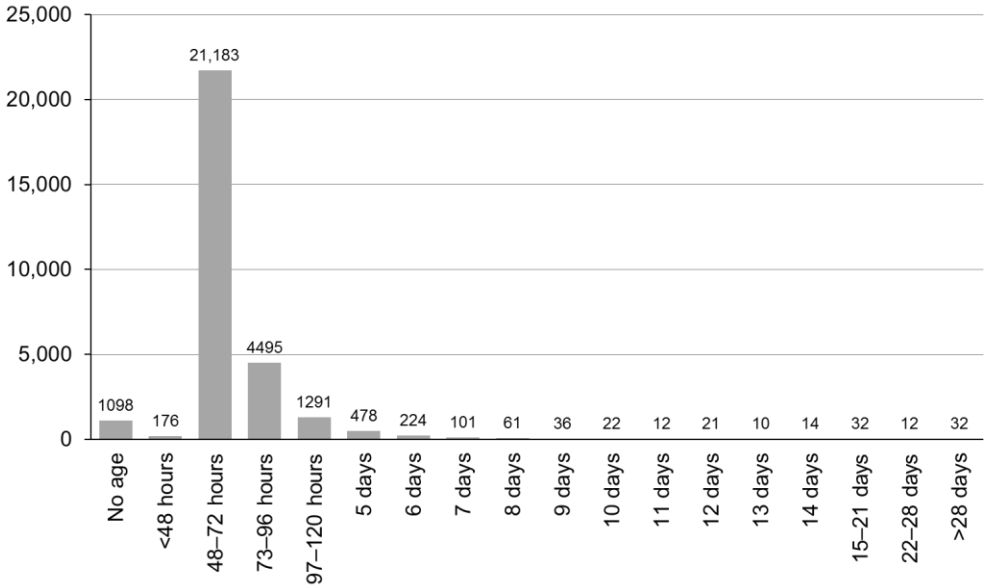


Figure 3 below and Table 3 identify some small differences between ethnic groups. While no ethnic group met the standard of 95% the percentages for European, Asian and Other appear higher than for the remaining ethnic groups. This is similar to the previous nine reports.

Figure 3: Percentage of samples taken between 48 and 72 hours, by ethnicity, July to December 2013

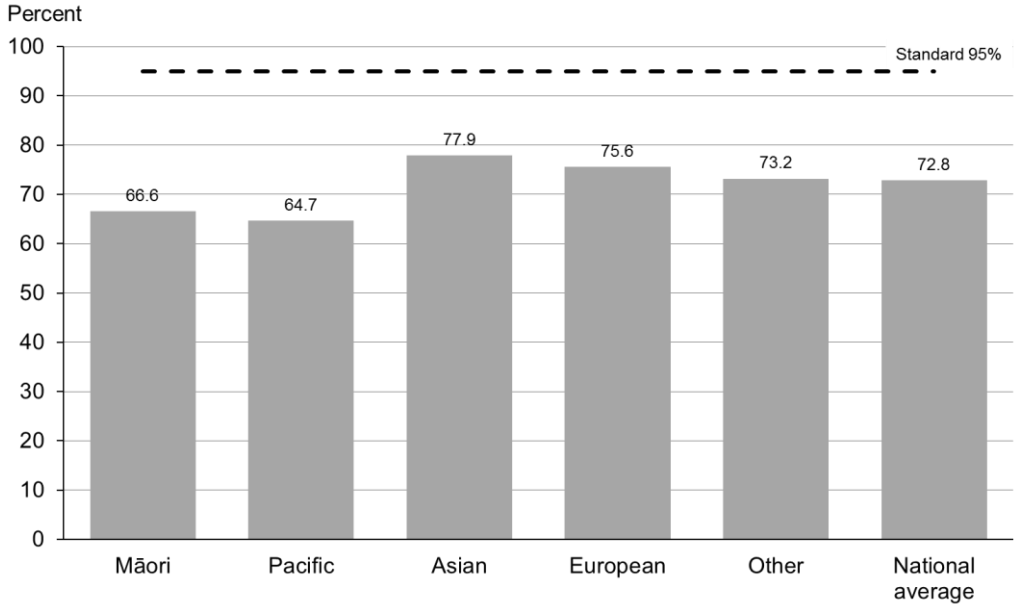


Table 3: Percentage of samples taken earlier than, between and after 48–72 hours, by Group 1 and Group 2 ethnicity, July to December 2013

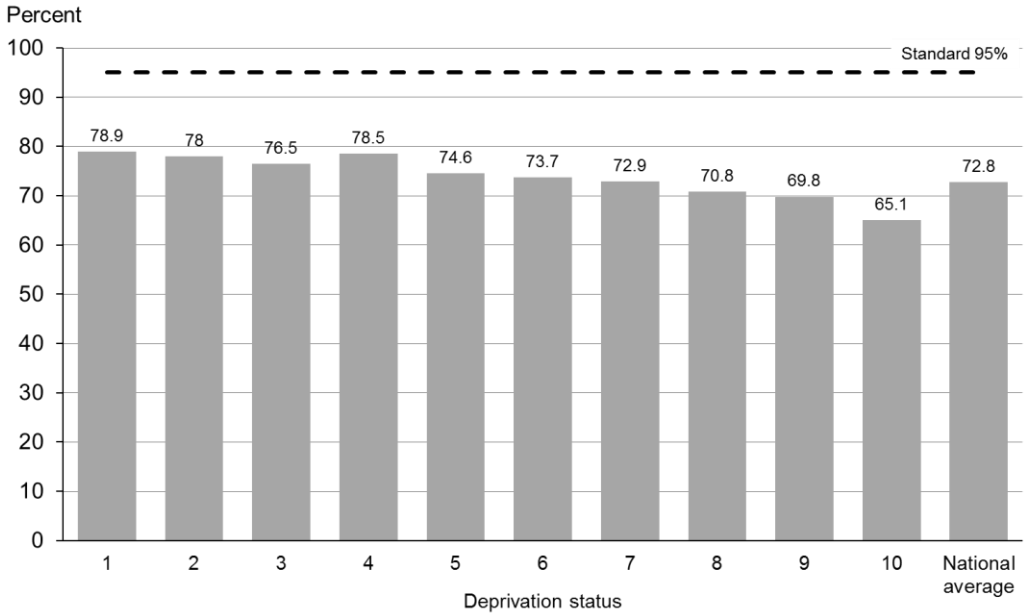
Ethnicity (Group 1 and Group 2)	Sampled at 48–72 hours		Sampled at less than 48 hours		Sampled at over 72 hours		No collection date and/or time		Total no of screens
	No.	%	No.	%	No.	%	No.	%	No.
Māori	4306	66.6	40	0.6	1886	29.2	232	3.6	6464
Pacific	1983	64.7	27	0.9	890	29.0	166	5.4	3066
Cook Island Māori	269	60.0	8	1.8	147	32.8	24	5.4	448
Fijian	155	67.4	4	1.7	56	24.3	15	6.5	230
Niuean	106	64.2	2	1.2	51	30.9	6	3.6	165
Samoan	803	64.6	5	0.4	364	29.3	71	5.7	1243
Tokelauan	41	60.3		0.0	23	33.8	4	5.9	68
Tongan	506	67.9	6	0.8	198	26.6	35	4.7	745
Other Pacific	103	61.7	2	1.2	51	30.5	11	6.6	167
Asian	3305	77.9	26	0.6	757	17.8	157	3.7	4245
Chinese	1258	82.4	7	0.5	215	14.1	47	3.1	1527
Indian	960	72.1	11	0.8	301	22.6	59	4.4	1331
Southeast Asian	385	79.1	7	1.4	77	15.8	18	3.7	487
Other Asian	702	78.0	1	0.1	164	18.2	33	3.7	900
European	11,707	75.6	82	0.5	3178	20.5	516	3.3	15,483
NZ European	10,014	75.6	74	0.6	2728	20.6	436	3.3	13,252
Latin American / Hispanic	122	73.5		0.0	36	21.7	8	4.8	166
Other European	1571	76.1	8	0.4	414	20.0	72	3.5	2065
Other	432	73.2	1	0.2	130	22.0	27	4.6	590
African	118	69.8	1	0.6	42	24.9	8	4.7	169
Middle Eastern	188	74.3		0.0	58	22.9	7	2.8	253
Other/not known	126	75.0		0.0	30	17.9	12	7.1	168
National average	**21,733**	**72.8**	**176**	**0.6**	**6841**	**22.9**	**1098**	**3.7**	**29,848**

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, July to December 2013

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	1472	78.9	11	0.6	342	18.3	41	2.2	1866
2	1793	78.0	9	0.4	410	17.8	87	3.8	2299
3	1819	76.5	13	0.5	470	19.8	77	3.2	2379
4	1831	78.5	13	0.6	413	17.7	76	3.3	2333
5	2132	74.6	13	0.5	603	21.1	109	3.8	2857
6	2141	73.7	10	0.3	645	22.2	110	3.8	2906
7	2354	72.9	19	0.6	750	23.2	108	3.3	3231
8	2673	70.8	20	0.5	958	25.4	125	3.3	3776
9	2752	69.8	26	0.7	1007	25.5	160	4.1	3945
10	2725	65.1	40	1.0	1231	29.4	193	4.6	4189
Not known	41	61.2	2	3.0	12	17.9	12	17.9	67
National average	21,733	72.8	176	0.6	6841	22.9	1098	3.7	29,848

Figure 4: Percentage of samples taken at 48–72 hours, by NZDep, July to December 2013



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

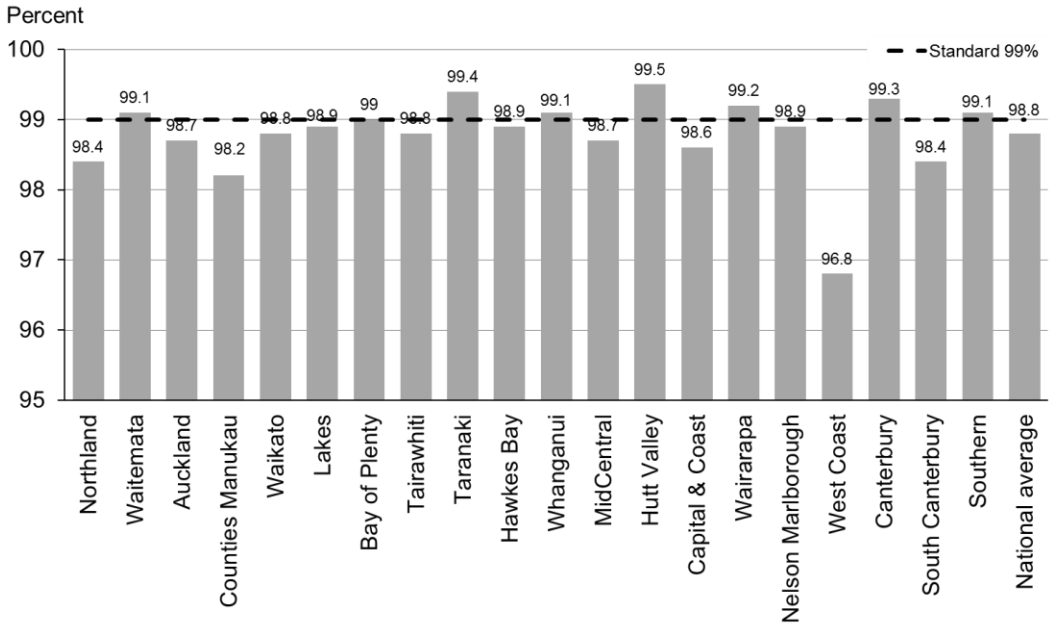
Only eight DHBs met or exceeded the standard of 99% of samples satisfactory for testing. This is shown in Table 5 and Figure 5.

During 2011-2013 the quarter and six-monthly 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 this half year 98.8% of samples were satisfactory. The number of DHBs meeting the target for the quarterly reports 1-9 was 4, 3, 3, 6, 14, 8, 13 and 9. For this half-year eight DHBs met the target.

Table 5: Percentage of blood samples that met the quality standards, by DHB, July to December 2013

DHB region	Satisfactory		Unsatisfactory		Total samples
	No.	%	No.	%	No.
Northland	1075	98.4	17	1.6	1092
Waitemata	3865	99.1	37	0.9	3902
Auckland	3157	98.7	41	1.3	3198
Counties Manukau	3967	98.2	74	1.8	4041
Waikato	2606	98.8	32	1.2	2638
Lakes	722	98.9	8	1.1	730
Bay of Plenty	1383	99.0	14	1	1397
Tairawhiti	330	98.8	4	1.2	334
Taranaki	788	99.4	5	0.6	793
Hawkes Bay	1115	98.9	12	1.1	1127
Whanganui	423	99.1	4	0.9	427
MidCentral	1063	98.7	14	1.3	1077
Hutt Valley	963	99.5	5	0.5	968
Capital & Coast	1744	98.6	25	1.4	1769
Wairarapa	250	99.2	2	0.8	252
Nelson Marlborough	777	98.9	9	1.1	786
West Coast	180	96.8	6	3.2	186
Canterbury	2933	99.3	21	0.7	2954
South Canterbury	299	98.4	5	1.6	304
Southern	1796	99.1	16	0.9	1812
Not Recorded	55	90.2	6	9.8	61
National Average	29,491	98.8	357	1.2	29,848

Figure 5: Percentage of blood samples that met quality standards, by DHB, July to December 2013



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

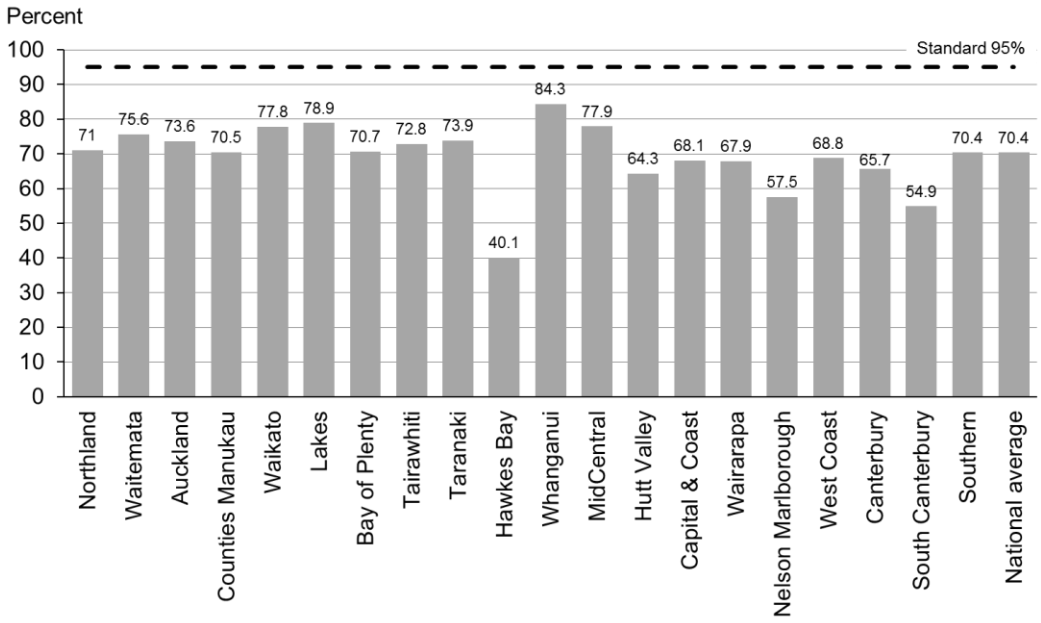
No DHB met the standard of 95% of samples received in four days or less, as shown in Table 6 and Figure 6. The national average has moved from 56% in January-March 2011 to 73% in January – June 2013 and is now 70% in July to December 2013 as shown in Figure 9. The range of values reduced (12-78% January – March 2011 to 54 - 83% in January – June 2013 and is 40-84% for this period.

Overall 70.4% of samples were received in 4 days or less; 93.5% in 7 days or less and 97.9% in 14 days or less.

Table 6: Percentage of samples received by the laboratory within four days, by DHB, July to December 2013

DHB region	Less than or equal to 4 days		Greater than 4 days		Unknown		Total samples
	No.	%	No.	%	No.	%	No.
Northland	775	71.0	304	27.8	13	1.2	1092
Waitemata	2951	75.6	905	23.2	46	1.2	3902
Auckland	2354	73.6	798	25.0	46	1.4	3198
Counties Manukau	2847	70.5	1121	27.7	73	1.8	4041
Waikato	2053	77.8	559	21.2	26	1.0	2638
Lakes	576	78.9	136	18.6	18	2.5	730
Bay of Plenty	988	70.7	381	27.3	28	2.0	1397
Tairawhiti	243	72.8	88	26.3	3	0.9	334
Taranaki	586	73.9	194	24.5	13	1.6	793
Hawkes Bay	452	40.1	664	58.9	11	1.0	1127
Whanganui	360	84.3	64	15.0	3	0.7	427
MidCentral	839	77.9	219	20.3	19	1.8	1077
Hutt Valley	622	64.3	332	34.3	14	1.4	968
Capital & Coast	1204	68.1	543	30.7	22	1.2	1769
Wairarapa	171	67.9	78	31.0	3	1.2	252
Nelson Marlborough	452	57.5	329	41.9	5	0.6	786
West Coast	128	68.8	57	30.6	1	0.5	186
Canterbury	1940	65.7	975	33.0	39	1.3	2954
South Canterbury	167	54.9	135	44.4	2	0.7	304
Southern	1275	70.4	508	28.0	29	1.6	1812
Unspecified	37	60.7	18	29.5	6	9.8	61
National average	**21,020**	**70.4**	**8408**	**28.2**	**420**	**1.4**	**29,848**

Figure 6: Percentage of samples received by the laboratory within four days, by DHB, July to December 2013



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% (97.5 – 99.9%) the rates are very close to this for disorders other than those tested using the tandem mass spectrometer and congenital adrenal hyperplasia (due to reagent supply issues). 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, July to December 2013 (n = 29,848 samples)

Disorder	Expected timeframe (days)	Number met timeframe	% met timeframe
Congenital Adrenal Hyperplasia	2	29,112	97.5
Galactosaemia	2	29,799	99.8
Amino acid disorders	2	29,313	98.2
Fatty acid oxidation disorders	2	29,313	98.2
Biotinidase deficiency	5	29,826	99.9
Cystic fibrosis	5	29,621	99.2
Congenital hypothyroidism	5	29,828	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). 71 reports did not meet the turnaround time, 8 were due to waiting for cystic fibrosis gene testing, 37 were due to waiting for the particular test result (34/37 amino acid and fatty acid oxidation screening results), 14 waiting for the results of another test and for 12 delayed sign-out or reporting was either the reason for, or contributory to, the delay. 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, for example 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, July to December 2013

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	136	86	63.2
Congenital adrenal hyperplasia	3	42	29	69.0
Galactosaemia	3	1	1	100.0
Congenital hypothyroidism	4	28	21	75.0
Biotinidase deficiency	9	0	0	n/a
Cystic fibrosis	12	20	18	90.0

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

Of 271 requests for the return of cards collected during the reporting period 1 July to 31 December, 266 (98.2%) were returned in the timeframe. The request form for one sample was lost in the laboratory and the card returned in a timely way following receipt of a replacement form. The other four requests came separately from the card without photo ID. This has been requested but not received and the cards have not been returned. In general samples are returned very quickly with a median time over this period of 2.1 days.