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Newborn Metabolic Screening Programme (NMSP)

Biannual Monitoring Report Number 9

1 January to 30 June 2013

National Screening Unit

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Contents

List of Tables

List of Figures

Executive summary

This is the ninth monitoring report for the Newborn Metabolic Screening Programme (NMSP) since the completion of the NMSP Monitoring Framework in November 2010. Regular analysis of data against agreed national programme indicators is a key monitoring and evaluation tool of the NMSP. The first eight reports were quarterly. This is the first biannual report. 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 developmental potential.

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 Technical Group has reviewed this monitoring report, and considered key findings and made recommendations for ongoing monitoring and initiatives to improve the programme, which are included in the recommendations below.

Key points and recommendations

This report, as a biannual report, provides information on indicators 2 to 6, and 9.

Indicator 2: Timing of sample taking

Overall, 71.8% of samples were collected within the recommended timeframe of 48 to 72 hours. No district health board (DHB) met the standard of 95% of samples taken within the timeframe (range 51–89%). It is impossible to calculate this indicator for about 4% of samples because they did not have the date and time of both birth and collection. The standard was not met for any ethnic group (range 63–76%) or NZ Deprivation Index (NZDep) group (range 64–78%).

This data is similar to that presented in earlier reports.

Recommendations: The NSU should continue working with DHBs, with a particular focus on those achieving under 60%: – Bay of Plenty and Waikato DHBs.

Indicator 3: Quality of blood samples

There has been improvement in this indicator since the first report. Nine DHBs met or exceeded the standard of 99% of samples being satisfactory for testing. All remaining DHBs achieved 97% or above.

Recommendations: The NSU should continue to monitor and provide feedback to DHBs.

Indicator 4: Sample dispatch and delivery

Overall, 72.8% of samples met the standard of receipt in the laboratory of within four days after collection. No DHB met the standard of 95%. All DHBs have significantly improved transit times since the provision of postage-paid envelopes, and 93% were received in seven days or less.

Recommendations: The NSU should continue working with DHBs, with a particular focus on those achieving under 60%: – Hawke's Bay and Nelson Marlborough 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 amino acid breakdown disorders, which had a low percentage (96.5%).

Recommendations: No recommendations are necessary.

Indicator 6: Timeliness of reporting: notification of screen positives

No disorder met the standard of 100% of reports notified in the specified timeframe. Between 48% and 91% of reports met the standard. All clinical critical results were notified within the timeframe. Note that this indicator is based on calendar days, which may affect reporting.

Recommendations: Notification by phone and notification by mail should be split. Clarification between notification of screen positives and those needing rescreening is also required. It is recommended that testing and reporting times be harmonised in 2014.

Indicator 9: Blood spot card storage and return

Ninety-nine percent of 304 requests for card return met the standard of within 28 days of completion of screening.

Recommendations: No recommendations are necessary.

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 ninth 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 first 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 130 such samples out of approximately 29,400 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, 71.8% (DHB range 51–89%) samples were taken within the recommended timeframe of 48 to 72 hours, which is similar to previous reports.

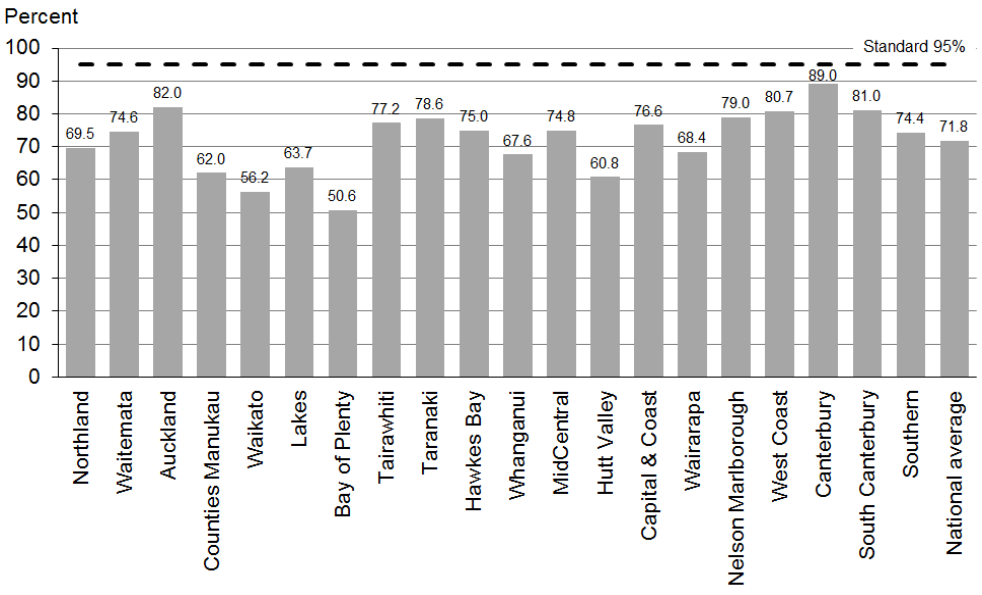
For this period, no DHB region met the standard of 95% of samples taken between 48 and 72 hours. Table 2 shows the percentage of samples taken between 48 and 72 hours, as well as those taken outside this timeframe, by DHB. Figure 1 shows the percentage of samples taken between 48 and 72 hours by DHB, compared with the overall average (71.8% between 48 and 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) has not been provided on the test card is about 4%. This affects the ability of the programme to correctly interpret test results and may underestimate the percentage of samples taken within the correct timeframe.

Table 2: Percentage of samples taken earlier than, between and after 48–72 hours, by DHB, January to June 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 babies
	No.	%	No.	%	No.	%	No.	%	No.
Northland	760	69.5	7	0.6	280	25.6	46	4.2	1093
Waitemata	2821	74.6	25	0.7	864	22.8	73	1.9	3783
Auckland	2544	82.0	28	0.9	406	13.1	124	4.0	3102
Counties Manukau	2581	62.0	22	0.5	1267	30.4	294	7.1	4164
Waikato	1440	56.2	29	1.1	974	38.0	118	4.6	2561
Lakes	438	63.7	11	1.6	216	31.4	23	3.3	688
Bay of Plenty	711	50.6	6	0.4	635	45.2	53	3.8	1405
Tairawhiti	267	77.2	1	0.3	69	19.9	9	2.6	346
Taranaki	593	78.6	6	0.8	139	18.4	16	2.1	754
Hawke's Bay	791	75.0	11	1.0	234	22.2	18	1.7	1054
Whanganui	288	67.6	4	0.9	121	28.4	13	3.1	426
MidCentral	800	74.8	9	0.8	218	20.4	42	3.9	1069
Hutt Valley	565	60.8	6	0.6	322	34.7	36	3.9	929
Capital & Coast	1423	76.6	14	0.8	343	18.5	77	4.1	1857
Wairarapa	167	68.4	1	0.4	68	27.9	8	3.3	244
Nelson Marlborough	606	79.0	3	0.4	142	18.5	16	2.1	767
West Coast	163	80.7	3	1.5	31	15.3	5	2.5	202
Canterbury	2622	89.0	17	0.6	241	8.2	65	2.2	2945
South Canterbury	273	81.0	2	0.6	58	17.2	4	1.2	337
Southern	1289	74.4	10	0.6	378	21.8	55	3.2	1732
Not recorded	41	66.1	2	3.2	11	17.7	8	12.9	62
National average	21,183	71.8	217	0.7	7017	23.8	1103	3.7	29,520

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



Although overall only 71.8% of samples were collected within the timeframe, 93.1% (27,496) were collected within two to five days and 0.7% (210) at 10 days or older (see Figure 2).

Figure 2: Number of samples taken at different ages, January to June 2013

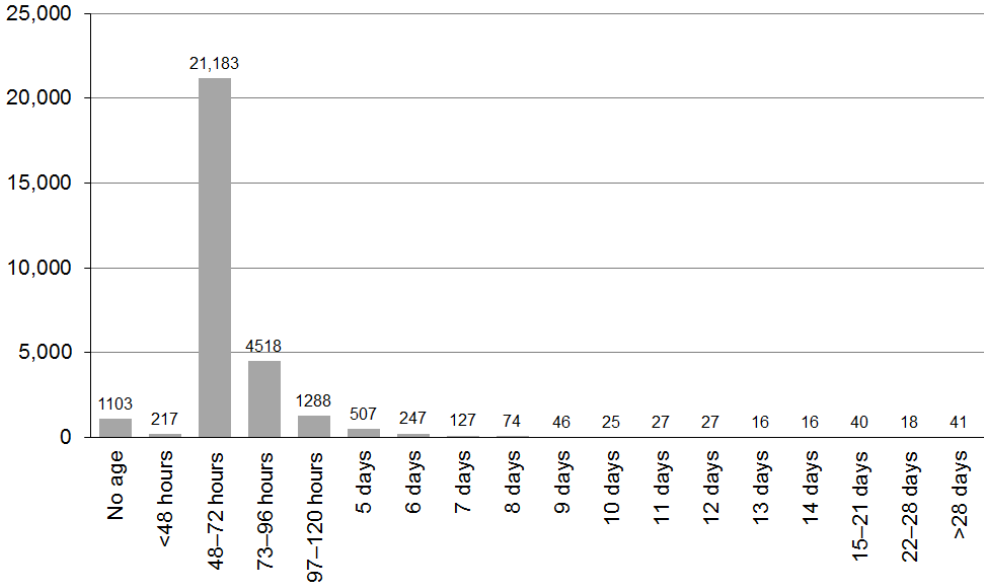


Figure 3 and Table 3 identify some small differences between ethnic groups. Although no ethnic group met the standard of 95%, the percentages for European, Asian and Other appear higher than for the remaining ethnic groups. This is similar to the previous eight reports.

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

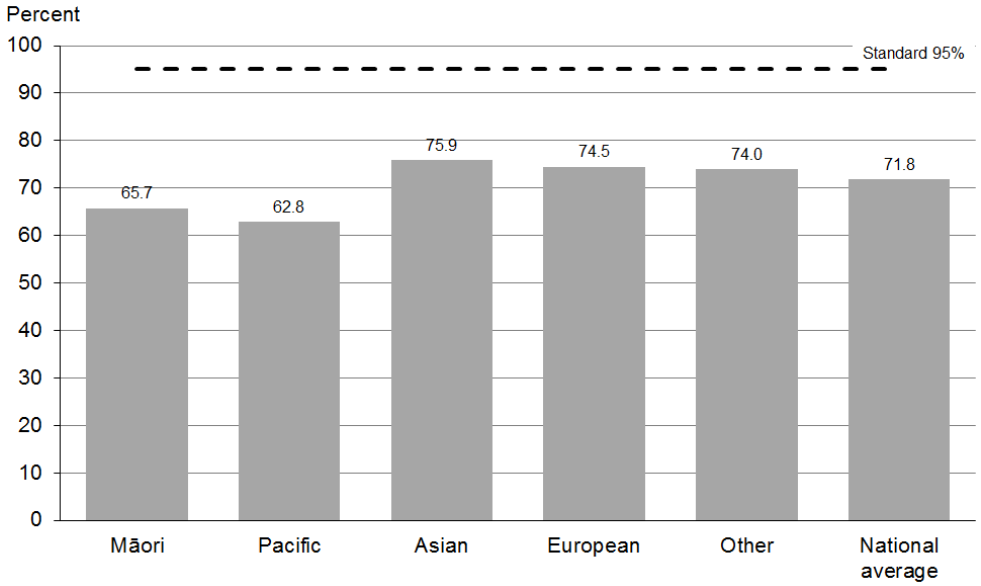


Table 3: Percentage of samples taken earlier than, between and after 48–72 hours, by Group 1 and Group 2 ethnicity, January to June 2013

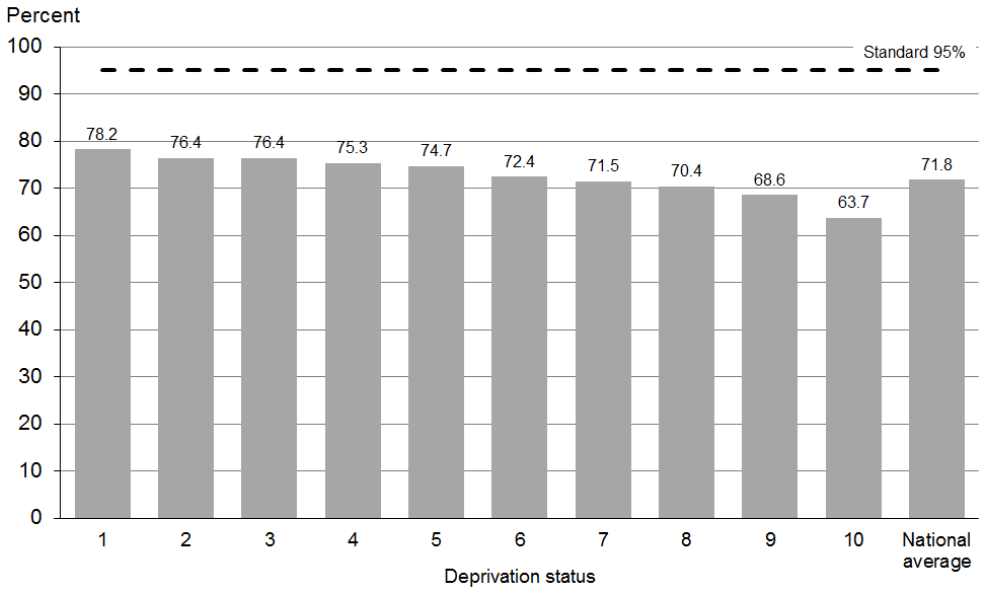
Ethnicity (Group 1 and Group 2)	Sampled at 48–72 hours		Sampled at less than 48 hours		Sampled at over 72 hours		No collection date and/or time		Total babies
	No.	%	No.	%	No.	%	No.	%	No.
Māori	4180	65.7	44	0.7	1893	29.7	249	3.9	6366
Pacific	1934	62.8	23	0.7	881	28.6	141	4.6	3081
Cook Island Māori	297	62.8	4	0.8	145	30.7	27	5.7	473
Fijian	146	63.8	3	1.3	69	30.1	11	4.8	229
Niuean	114	69.1	1	0.6	44	26.7	6	3.6	165
Samoan	810	63.9	11	0.9	391	30.8	56	4.4	1268
Tokelauan	31	60.8	2	3.9	17	33.3	1	2.0	51
Tongan	481	66.3	2	0.3	203	28.0	39	5.4	725
Other Pacific	111	65.3	0	0.0	55	32.4	4	2.4	170
Asian	3100	75.9	31	0.8	798	19.5	155	3.8	4084
Chinese	1156	79.3	11	0.8	249	17.1	42	2.9	1458
Indian	931	71.9	11	0.8	288	22.2	65	5.0	1295
Southeast Asian	390	78.3	6	1.2	87	17.5	15	3.0	498
Other Asian	623	74.8	3	0.4	174	20.9	33	4.0	833
European	**11,503**	**74.5**	**114**	**0.7**	**3287**	**21.3**	**531**	**3.4**	**15,435**
NZ European	9858	74.4	104	0.8	2833	21.4	449	3.4	13,244
Latin American / Hispanic	111	75.0	2	1.4	33	22.3	2	1.4	148
Other European	1534	75.1	8	0.4	421	20.6	80	3.9	2043
Other	**410**	**74.0**	**5**	**0.9**	**115**	**20.8**	**24**	**4.3**	**554**
African	145	77.1	1	0.5	37	19.7	5	2.7	188
Middle Eastern	159	75.0	2	0.9	42	19.8	9	4.2	212
Other/not known	106	68.8	2	1.3	36	23.4	10	6.5	154
National average	**21,183**	**71.8**	**217**	**0.7**	**7017**	**23.8**	**1103**	**3.7**	**29,520**

Table 4 and Figure 4 show the number of samples taken between 48 and 72 hours, by NZDep. There was no NZDep category 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 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 babies
	No.	%	No.	%	No.	%	No.	%	No.
1	1495	78.2	14	0.7	325	17.0	78	4.1	1912
2	1770	76.4	13	0.6	453	19.6	80	3.5	2316
3	1767	76.4	16	0.7	452	19.6	77	3.3	2312
4	1766	75.3	23	1.0	483	20.6	74	3.2	2346
5	2042	74.7	22	0.8	575	21.0	95	3.5	2734
6	1961	72.4	16	0.6	635	23.5	95	3.5	2707
7	2288	71.5	24	0.7	792	24.7	97	3.0	3201
8	2682	70.4	29	0.8	962	25.2	138	3.6	3811
9	2748	68.6	34	0.8	1051	26.3	170	4.2	4003
10	2622	63.7	24	0.6	1278	31.1	191	4.6	4115
Not known	42	66.7	2	3.2	11	17.5	8	12.7	63
National average	21,183	71.8	217	0.7	7017	23.8	1103	3.7	29,520

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

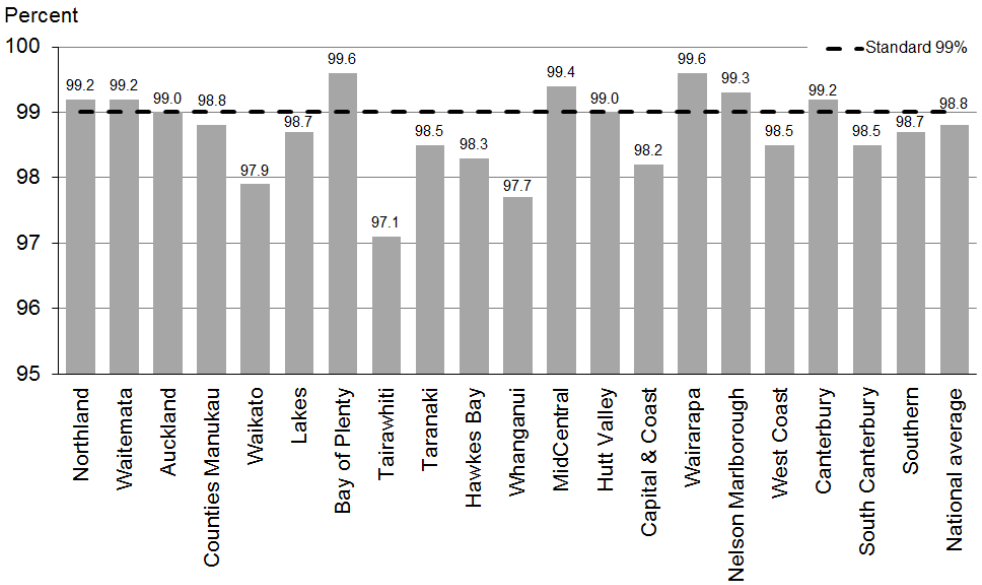
Only nine (down from 13 in Report 8) DHBs met or exceeded the standard of 99% of samples satisfactory for testing. This is shown in Table 5 and Figure 5.

During 2011/12, the quarterly performance for blood sample quality was 98.6%, 98.5%, 98.7%, 98.8%, 99.1%, 99.2% and 99.1%. For this half year, 98.8% of samples were satisfactory. The number of DHBs meeting the target for quarterly reports 1–8 was four, three, three, six, fourteen, eight and thirteen. For this half-year, nine DHBs met the target.

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

DHB region	Satisfactory		Unsatisfactory		Total samples
	No.	%	No.	%	No.
Northland	1084	99.2	9	0.8	1093
Waitemata	3753	99.2	30	0.8	3783
Auckland	3072	99.0	30	1.0	3102
Counties Manukau	4115	98.8	49	1.2	4164
Waikato	2508	97.9	53	2.1	2561
Lakes	679	98.7	9	1.3	688
Bay of Plenty	1400	99.6	5	0.4	1405
Tairawhiti	336	97.1	10	2.9	346
Taranaki	743	98.5	11	1.5	754
Hawke's Bay	1036	98.3	18	1.7	1054
Whanganui	416	97.7	10	2.3	426
MidCentral	1063	99.4	6	0.6	1069
Hutt Valley	920	99.0	9	1.0	929
Capital & Coast	1824	98.2	33	1.8	1857
Wairarapa	243	99.6	1	0.4	244
Nelson Marlborough	762	99.3	5	0.7	767
West Coast	199	98.5	3	1.5	202
Canterbury	2920	99.2	25	0.8	2945
South Canterbury	332	98.5	5	1.5	337
Southern	1710	98.7	22	1.3	1732
Not recorded	59	95.2	3	4.8	62
National average	29,174	98.8	346	1.2	29,520

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

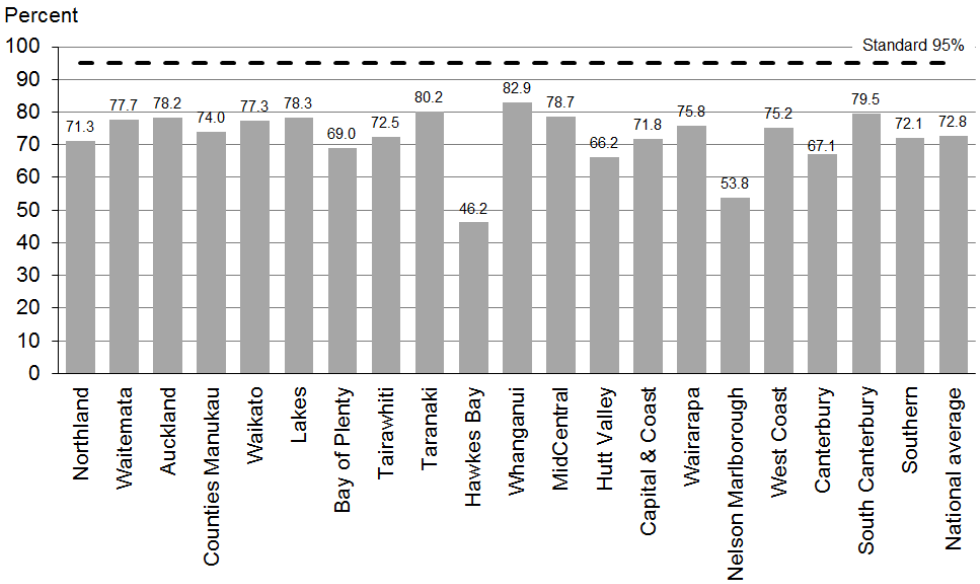
No DHB met the standard of 95% of samples received in four days or less, as shown in Table 6 and Figure 6. However, there has been significant improvement since 2010 for all DHBs.

Overall, 72.8% of samples were received in four days or less, 92.8% in seven days or less and 97.7% in 14 days or less.

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

DHB region	Less than or equal to 4 days		Greater than 4 days		Unknown		Total samples
	No.	%	No.	%	No.	%	No.
Northland	779	71.3	289	26.4	25	2.3	1093
Waitemata	2938	77.7	813	21.5	32	0.8	3783
Auckland	2426	78.2	637	20.5	39	1.3	3102
Counties Manukau	3082	74.0	1016	24.4	66	1.6	4164
Waikato	1980	77.3	543	21.2	38	1.5	2561
Lakes	539	78.3	134	19.5	15	2.2	688
Bay of Plenty	969	69.0	414	29.5	22	1.6	1405
Tairawhiti	251	72.5	92	26.6	3	0.9	346
Taranaki	605	80.2	141	18.7	8	1.1	754
Hawke's Bay	487	46.2	560	53.1	7	0.7	1054
MidCentral	353	82.9	65	15.3	8	1.9	426
Whanganui	841	78.7	208	19.5	20	1.9	1069
Capital & Coast	615	66.2	301	32.4	13	1.4	929
Hutt Valley	1334	71.8	497	26.8	26	1.4	1857
Wairarapa	185	75.8	56	23.0	3	1.2	244
Nelson Marlborough	413	53.8	350	45.6	4	0.5	767
West Coast	152	75.2	49	24.3	1	0.5	202
Canterbury	1976	67.1	929	31.5	40	1.4	2945
South Canterbury	268	79.5	67	19.9	2	0.6	337
Southern	1249	72.1	461	26.6	22	1.3	1732
Not recorded	45	72.6	15	24.2	2	3.2	62
Total	**21,487**	**72.8**	**7637**	**25.9**	**396**	**1.3**	**29,520**

Figure 6: Percentage of samples received by the laboratory within four days, by DHB, January to June 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 shows the percentage of samples that met the specified laboratory testing timeframes. While not quite reaching 100% (99.0–99.8%), the rates are very close to this for disorders other than those tested using the tandem mass spectrometer, which has had additional instrument malfunction this quarter (detailed in a separate report). 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 2013 (n = 29,523 samples)

Disorder	Expected timeframe (days)	Number met timeframe	% met timeframe
Congenital adrenal hyperplasia	2	29,425	99.7
Galactosaemia	2	29,454	99.8
Amino acid disorders	2	28,486	96.5
Fatty acid oxidation disorders	2	28,486	96.5
Biotinidase deficiency	5	29,480	99.9
Cystic fibrosis	5	29,217	99.0
Congenital hypothyroidism	5	29,477	99.8

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 is made to an appropriate subspecialist paediatrician. These results are not separated out in the data below, but all results where it is likely a disorder is present were reported inside the timeframes.

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). For this period, there were 70 reports that did not meet the turnaround time, due to the following reasons:

- 21 were waiting for cystic fibrosis genetic testing
- 40 were waiting for amino acid and fatty acid oxidation screening results
- two were waiting for specific 17-hydroxyprogesterone results
- for the remaining 19, delayed signout or reporting was either the reason for, or contributory to, the delay.

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

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

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, congenital adrenal hyperplasia is two days for the test result being available and three days for reporting). A sample that arrives on Friday and has a test result available and reported on Monday meets the testing timeframe but not the reporting timeframe.

Table 8: Percentage of results reported within specified timeframes, by disorder, January to June 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	108	68	63.0
Congenital adrenal hyperplasia	3	31	15	48.4
Galactosaemia	3	3	2	66.7
Congenital hypothyroidism	4	21	19	90.5
Biotinidase deficiency	9	0	0	0
Cystic fibrosis	12	27	16	59.3

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 304 requests for the return of cards collected during the reporting period 1 January to 30 June, 302 (99.3%) were returned within the timeframe. One of the other two samples was unsuitable for testing, and it was returned with the follow-up sample within the timeframe for the return of the follow-up sample. No address for the return was available for the remaining sample, and it has not been received following a request to the family made via the LMC. In general, samples are returned very quickly, with a median time over this period of 2.1 days.