National Screening Unit

Newborn Metabolic Screening Programme

Newborn Metabolic Screening Programme (NMSP)

Quarterly Monitoring Report

Number 5

1 January to 31 March 2012

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 NMSP 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 ADHB staff; Dr Dianne Webster and Keith Shore.

Contents

Lists of tables and figures

Executive Summary

This is the fifth quarterly 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. Five indicators are covered by this report.

Timing of sample taking (Indicator 2) was reported in days for the first three monitoring reports. This was due to data collection issues which did not enable time of birth data to be collected in hours and therefore previous monitoring reports underestimated the number of samples meeting the standard. This is the second report where the age of the baby is reported in hours unless the date and time of birth and sample collection are not provided. The improvement in the quality of data to monitor this indicator is a significant achievement for the NMSP.

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 70.9% of samples were collected 48-72 hours. No DHB met the standard of 95% of samples taken in the timeframe (range 50-88%). 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 63-75%) or NZDep group (range 63-79%). These figures are similar to those in Report 4.

Recommendations:
Continue to monitor this indicator.

Indicator 3 Quality of blood samples

Fourteen DHBs met or exceeded the standard of 99% satisfactory and a further 5 achieved 98-99%. Overall 99.1% of samples were suitable for testing. This indicator is showing improvement over time which may be due to the provision of high quality lancets.

Recommendations:
Continue to monitor the effect of lancet provision on this indicator.

Indicator 4 Sample dispatch and delivery

Overall 68% of samples met the standard of receipt in the laboratory by 4 days after collection. No DHB met the target for this standard. All DHBs have significantly improved

transit times since the provision of postage-paid envelopes but this improvement has not been built on in Reports 4 & 5.

Recommendations:
Continue to monitor the effect of postage-paid envelopes on transit times.

Indicator 5 Laboratory testing timeframes

The standard of 100% was not met for any disorder however timeframes were very close to this being between 98.9 and 99.8%.

Recommendations:
Continue to monitor this indicator.

Indicator 9 Blood spot card storage and return.

97% of 183 requests for card return met the standard of within 28 days of completion of screening. Two requests did not have all the required information (one without a signature and one without photo identification), these have not been received and the cards not returned. One card was returned in 31 days.

Recommendations:
No recommendation.

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 fifth report of the NMSP following the development of national indicators and completion of the NMSP Monitoring Framework in November 2010.

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 through high-quality screening that facilitates 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 development potential impacted 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 MS 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 NHI's. This method follows a matching and data retrieval process that is defined within 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 October to 31 December 2011 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 would be counted twice.

Ethnicity and NZ Deprivation 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.

DHB reporting

While 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.
- Timing of 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 by 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 done 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 NHI. There were 101 such samples from approximately 15,400 in this reporting period. This number is small and the analysed data includes these babies. Where possible, identified errors (such as using mother's NHI number not 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 is reported in hours. If the date and time of birth and sample collection are not provided the data is shown as missing.

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 was calculated from the number in 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 around 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 above. They incorporate all tests required to screen for the named condition including any second-tier tests e.g. 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, hence 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 with their reporting frequency and detail. This report, as a quarterly report, provides information on indicators 2-5 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 monitoring frequency

Indicators	Quarterly	Biannually	Annually	Detail
1. Newborn Metabolic Screening Coverage			X	• DHB • Ethnicity • Deprivation status
2. Timing of sample taking	X	X	X	• DHB • Ethnicity • Deprivation status
Laboratory reporting				
3. Quality of Blood Samples	X	X	X	• DHB
4. Sample dispatch and delivery	X	X	X	• DHB
5. Laboratory testing timeframes	X	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	X	

Indicator 2 – Timing of sample taking

2: TIMING OF SAMPLE –TAKING

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 Programme Guidelines and Policy and Quality requirements.
- Reporting by:
  - DHB
  - Ethnicity
  - Deprivation status

Timing of Sample Taking

This data is now available in hours. Overall 70.9% of samples were taken in the recommended timeframe of 48-72 hours.

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.

It is not possible to calculate the age of the baby at sampling in about 4% of samples as the some of the date and time of birth and sample are not provided on the test card.

Table 2 Percentage of samples taken at 2 days, by DHB, January to March 2012

DHB region	Sampled 48-72 hours		Sampled less than 48 hours		Sampled greater than 72 hours		No Collection Date/ Time or no time of birth		Total babies
	No.	%	No.	%	No.	%	No.	%	No.
Northland	384	64.9	5	0.8	180	30.4	23	3.9	592
Waitemata	1,439	73.9	10	0.5	451	23.2	48	2.5	1,948
Auckland	1,322	80.1	20	1.2	221	13.4	87	5.3	1,650
Counties Manukau	1,365	62.6	11	0.5	669	30.7	134	6.1	2,179
Waikato	738	55.7	11	0.8	490	37.0	85	6.4	1,324
Lakes	210	61.0	1	0.3	117	34.0	16	4.7	344
Bay of Plenty	361	50.0	4	0.6	325	45.0	32	4.4	722
Tairawhiti	103	54.2	3	1.6	73	38.4	11	5.8	190
Taranaki	349	85.1	2	0.5	52	12.7	7	1.7	410
Hawkes Bay	420	76.2	7	1.3	108	19.6	16	2.9	551
Whanganui	154	66.1		0.0	71	30.5	8	3.4	233
Mid Central	409	75.0	1	0.2	107	19.6	28	5.1	545
Hutt Valley	284	54.6	4	0.8	216	41.5	16	3.1	520
Capital and Coast	738	75.8	7	0.7	196	20.1	33	3.4	974
Wairarapa	105	72.9		0.0	30	20.8	9	6.3	144
Nelson Marlborough	304	81.9	3	0.8	51	13.7	13	3.5	371
West Coast	89	79.5	5	4.5	16	14.3	2	1.8	112
Canterbury	1,337	88.4	10	0.7	125	8.3	40	2.6	1,512
South Canterbury	127	83.6	2	1.3	19	12.5	4	2.6	152
Southern	648	73.3	3	0.3	201	22.7	32	3.6	884
Not recorded	14	56.0	1	4.0	6	24.0	4	16.0	25
Total	10,900	70.9	110	0.7	3,724	24.2	648	4.2	15,382

Figure 1 **Percentage of samples taken 48-72 hours, by DHB, January to March 2012**

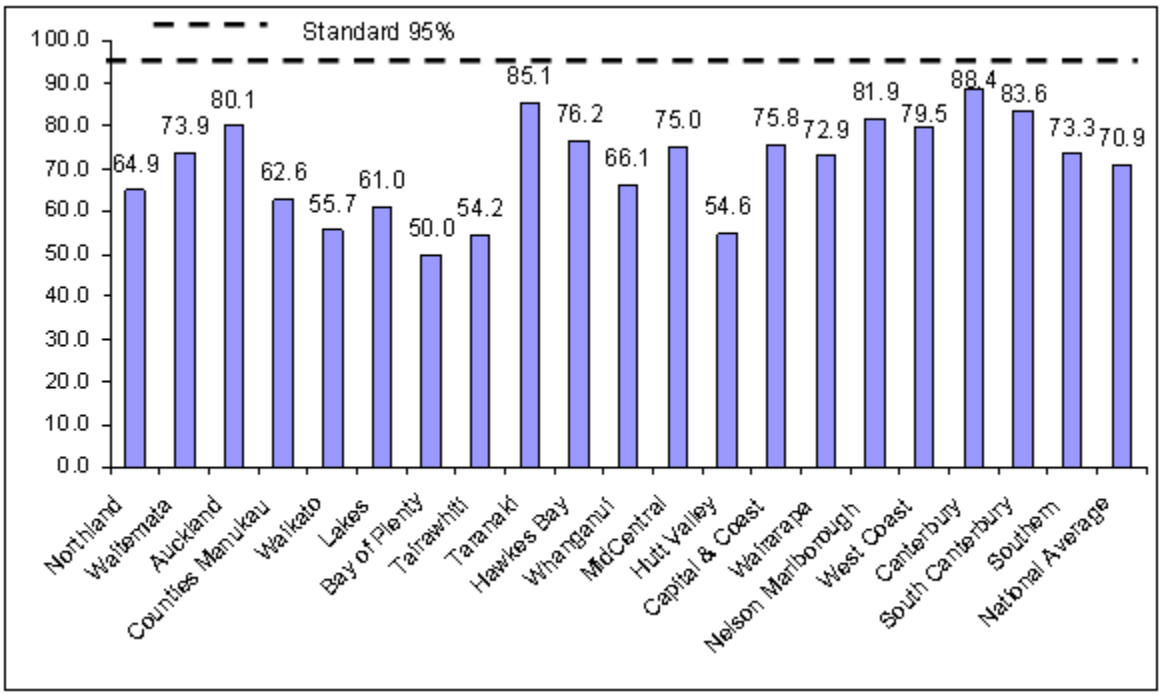


Figure 2 below and Table 3 identify some small differences between ethnic groups. While no ethnic group met the standard of 95% the percentages for European appear higher than for the remaining ethnic groups. This is similar to the previous five reports.

Figure 2 **Percentage of samples taken at 48-72 hours, by ethnicity, January to March 2012**

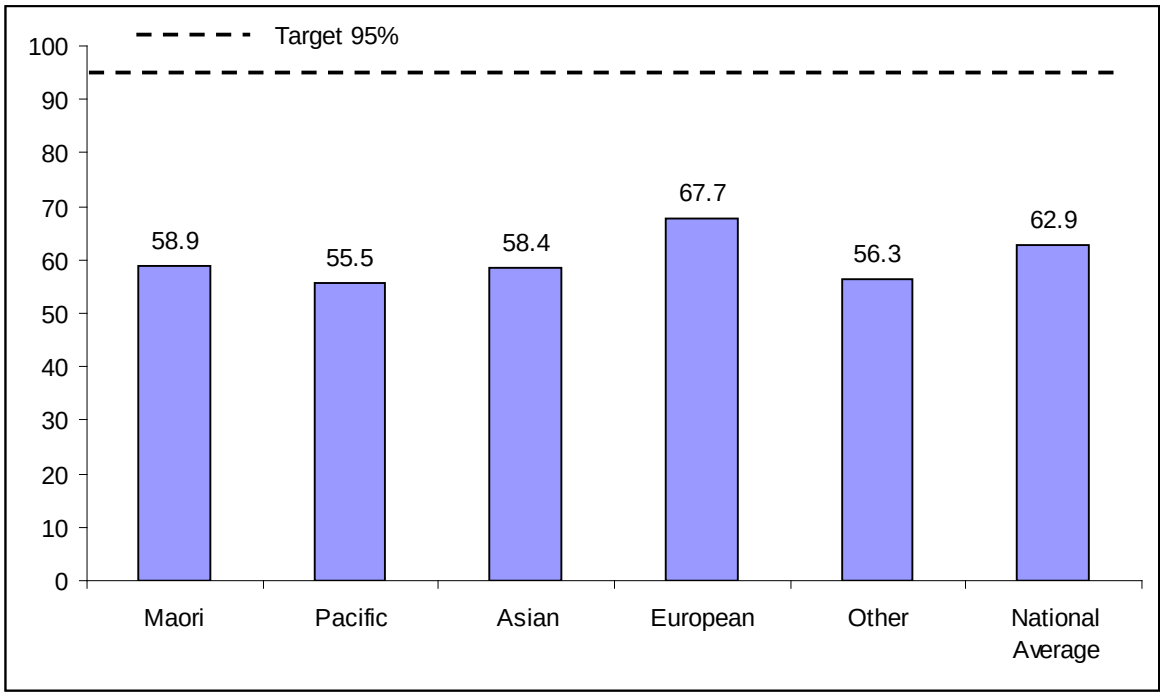


Table 3 Percentage of samples taken at 48-72 hours days, by Group 1 and Group 2 Ethnicity, January to March 2012

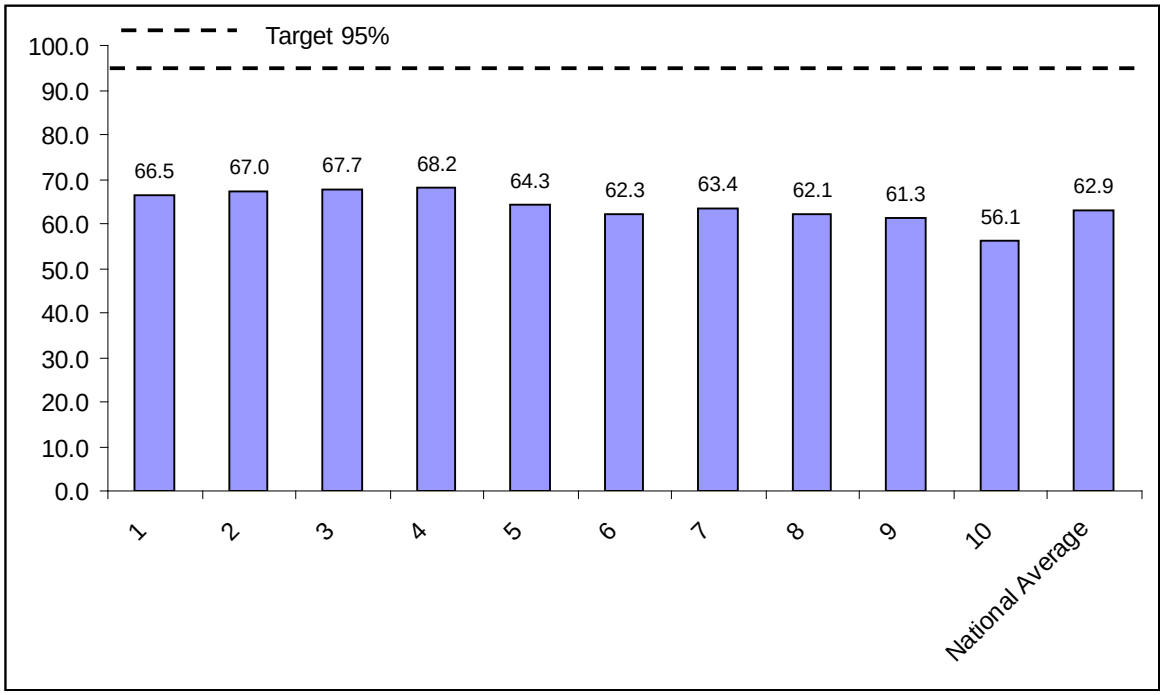
Ethnicity (*Group 1 Group 2)*	Sampled at 48-72 hrs		Sampled less than 48 hrs		Sampled over 72 hrs		No collection date and/or time		Total babies
	No.	%	No.	%	No.	%	No.	%	No.
Maori	2,026	58.9	23	0.7	1,082	31.4	311	9.0	3,442
Pacific	936	55.5	10	0.6	417	24.7	324	19.2	1,687
Cook Island Maori	133	53.6	0	0.0	74	29.8	41	16.5	248
Fijian	67	56.3	2	1.7	31	26.1	19	16.0	119
Niuean	36	48.6	0	0.0	18	24.3	20	27.0	74
Samoan	433	58.7	8	1.1	185	25.1	112	15.2	738
Tokelauan	14	46.7	0	0.0	11	36.7	5	16.7	30
Tongan	209	51.5	0	0.0	82	20.2	115	28.3	406
Other Pacific	44	61.1	0	0.0	16	22.2	12	16.7	72
Asian	1,100	58.4	10	0.5	319	16.9	454	24.1	1,883
Chinese	419	57.6	1	0.1	107	14.7	201	27.6	728
Indian	321	56.1	4	0.7	114	19.9	133	23.3	572
Southeast Asian	104	56.5	2	1.1	34	18.5	44	23.9	184
Other Asian	256	64.2	3	0.8	64	16.0	76	19.0	399
European	5,458	67.5	35	0.4	1,631	20.2	965	11.9	8,089
NZ European	4,748	67.7	29	0.4	1,436	20.5	805	11.5	7,018
Latin American / Hispanic	50	63.3	0	0.0	13	16.5	16	20.3	79
Other European	660	66.5	6	0.6	182	18.3	144	14.5	992
Other	180	56.3	2	0.6	59	18.4	79	24.7	320
African	57	64.8	0	0.0	15	17.0	16	18.2	88
Middle Eastern	57	58.2	0	0.0	17	17.3	24	24.5	98
Other/not known	66	49.3	2	1.5	27	20.1	39	29.1	134
Total	9,700	62.9	80	0.5	3,508	22.7	2,133	13.8	15,421

Table 4 and Figure 3 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 of 95%. 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 at 48-72 hours by NZDep, January to March 2012**

NZ Dep	Sampled at 48-72 hrs		Sampled less than 48 hrs		Sampled over 72 hrs		No collection date and/or time		Total babies
	No.	%	No.	%	No.	%	No.	%	No.
1	664	66.5	5	0.5	200	20.0	130	13.0	999
2	836	67.0	4	0.3	188	15.1	219	17.6	1,247
3	795	67.7	6	0.5	212	18.1	161	13.7	1,174
4	803	68.2	9	0.8	217	18.4	148	12.6	1,177
5	907	64.3	4	0.3	310	22.0	190	13.5	1,411
6	900	62.3	5	0.3	319	22.1	220	15.2	1,444
7	1,045	63.4	9	0.5	371	22.5	223	13.5	1,648
8	1,200	62.1	8	0.4	473	24.5	251	13.0	1,932
9	1,289	61.3	14	0.7	545	25.9	256	12.2	2,104
10	1,245	56.1	13	0.6	658	29.7	302	13.6	2,218
Not recorded	16	23.9	3	4.5	15	22.4	33	49.3	67
Total	9,700	62.9	80	0.5	3,508	22.7	2133	13.8	15,421

Figure 3 **Percentage of samples taken at 48-72 hours, by NZDep, January to March 2012**



Indicator 3 – Quality of blood samples

3: QUALITY OF BLOOD SAMPLES
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, page 21-22 of Programme Guidelines. • Reporting by DHB

Quality of blood samples

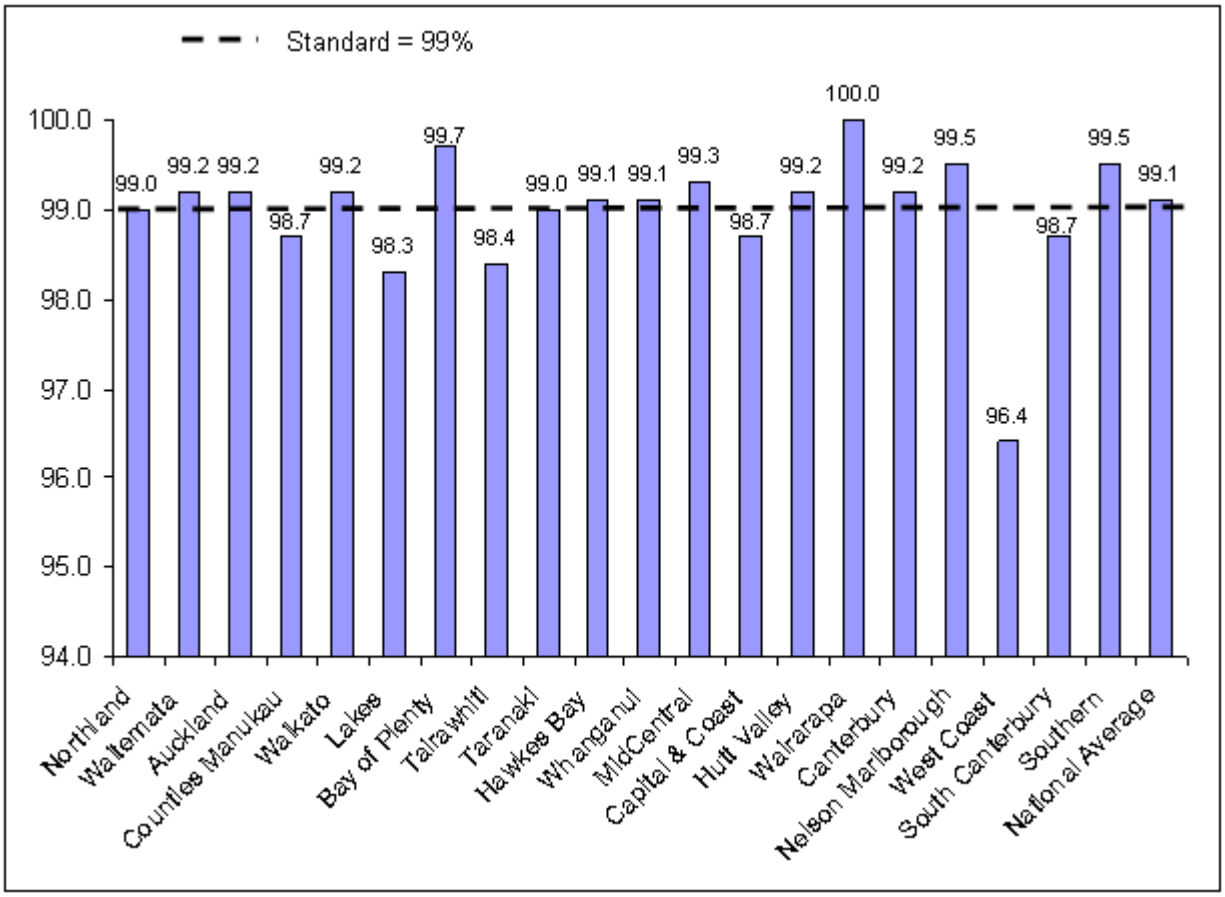
There has been significant improvement in this indicator since the last quarter. Fourteen DHBs (Northland, Waitemata, Auckland, Waikato, Bay of Plenty, Taranaki, Hawkes Bay, Whanganui, MidCentral, Hutt, Wairarapa, Canterbury, Nelson Marlborough and Southern) met or exceeded the standard of 99% of samples satisfactory for testing and a further five achieved 98% or greater

During 2011 the quarter performance for blood sample quality was 98.6%, 98.5%, 98.7%, 98.8% respectively for the past four quarters. This quarter it is 99.1%. The number of DHBs meeting the target over 2011 by quarter was 4, 3, 3 and 6 and this quarter it is 14. This improvement may be impacted by the supply of high-quality lancets to LMCs.

Table 5 **Percentage of blood samples that meet quality standards by DHB, January to March 2012**

DHB region	Satisfactory		Unsatisfactory		Total samples
	No.	%	No.	%	No.
Northland	586	99.0	6	1.0	592
Waitemata	1,933	99.2	16	0.8	1,949
Auckland	1,635	99.2	13	0.8	1,648
Counties Manukau	2,151	98.7	28	1.3	2,179
Waikato	1,313	99.2	11	0.8	1,324
Lakes	338	98.3	6	1.7	344
Bay of Plenty	720	99.7	2	0.3	722
Tairawhiti	187	98.4	3	1.6	190
Taranaki	406	99.0	4	1.0	410
Hawkes Bay	546	99.1	5	0.9	551
Whanganui	231	99.1	2	0.9	233
Mid Central	541	99.3	4	0.7	545
Capital and Coast	961	98.7	13	1.3	974
Hutt Valley	516	99.2	4	0.8	520
Wairarapa	144	100.0	0	0.0	144
Canterbury	1,500	99.2	12	0.8	1,512
Nelson Marlborough	368	99.5	2	0.5	370
West Coast	108	96.4	4	3.6	112
South Canterbury	150	98.7	2	1.3	152
Southern	880	99.5	4	0.5	884
Not recorded	62	93.9	4	6.1	66
Total	15,276	99.1	145	0.9	15,421

Figure 4 **Percentage of blood samples that meet quality standards by DHB, January to March 2012**



Indicator 4 – Sample dispatch and delivery

4: SAMPLE DESPATCH AND DELIVERY
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 laboratory within four calendar days of being taken. Denominator: Number of samples received by laboratory.
NOTES • Requirements for sending samples to the laboratory are detailed in Chapter 7, page 23 of Programme Guidelines • Reporting by DHB

Sample dispatch and delivery

No DHB met the standard of 95% of samples received in four days or less. Although no DHB met the standard of 95% of samples received in four days or less, there has been significant improvement over 2011 for all DHBs. The national average has moved from 56% in January-March 2011 to 68% in January-March 2012 as shown in Table 6 and Figure 6. Given this the significant improvement seen in Report 3 (72.9%) has not been sustained in this quarter.

Table 6 Percentage of samples received by the laboratory within four days by DHB, January to March 2012

DHB region	Less than or equal to 4 days		Greater than 4 days		Unknown		Total samples
	No.	%	No.	%	No.	%	No.
Northland	394	66.6	190	32.1	8	1.4	592
Waitemata	1,500	77.0	433	22.2	16	0.8	1,949
Auckland	1,290	78.3	341	20.7	17	1.0	1,648
Counties Manukau	1,538	70.6	619	28.4	22	1.0	2,179
Waikato	958	72.4	342	25.8	24	1.8	1,324
Lakes	239	69.5	100	29.1	5	1.5	344
Bay of Plenty	474	65.7	235	32.5	13	1.8	722
Tairawhiti	106	55.8	81	42.6	3	1.6	190
Taranaki	282	68.8	123	30.0	5	1.2	410
Hawkes Bay	332	60.3	213	38.7	6	1.1	551
Mid Central	325	59.6	199	36.5	21	3.9	545
Whanganui	188	80.7	42	18.0	3	1.3	233
Capital and Coast	604	62.0	358	36.8	12	1.2	974
Hutt Valley	303	58.3	211	40.6	6	1.2	520
Wairarapa	100	69.4	41	28.5	3	2.1	144
Nelson Marlborough	245	66.2	118	31.9	7	1.9	370
West Coast	71	63.4	39	34.8	2	1.8	112
Canterbury	873	57.7	619	40.9	20	1.3	1,512
South Canterbury	92	60.5	58	38.2	2	1.3	152
Southern	561	63.5	310	35.1	13	1.5	884
Not recorded	23	34.8	38	57.6	5	7.6	66
Total	10,498	68.1	4,710	30.5	213	1.4	15,421

Figure 5 **Percentage of samples received by laboratory within 4 days by DHB, January to March 2012**

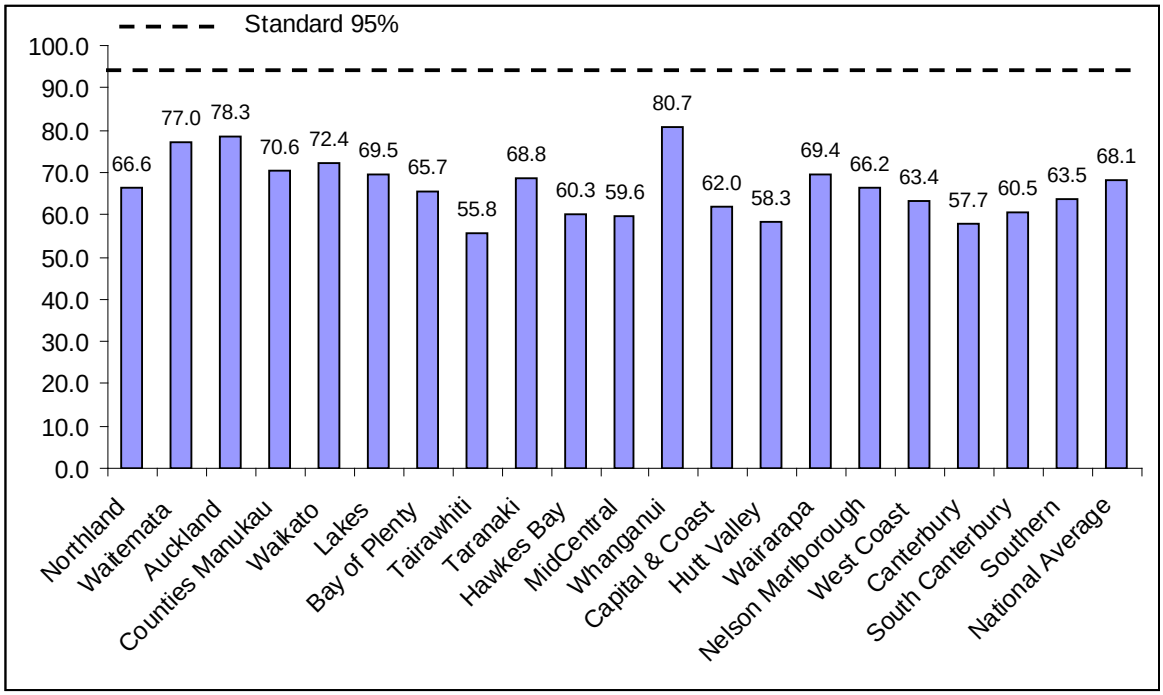
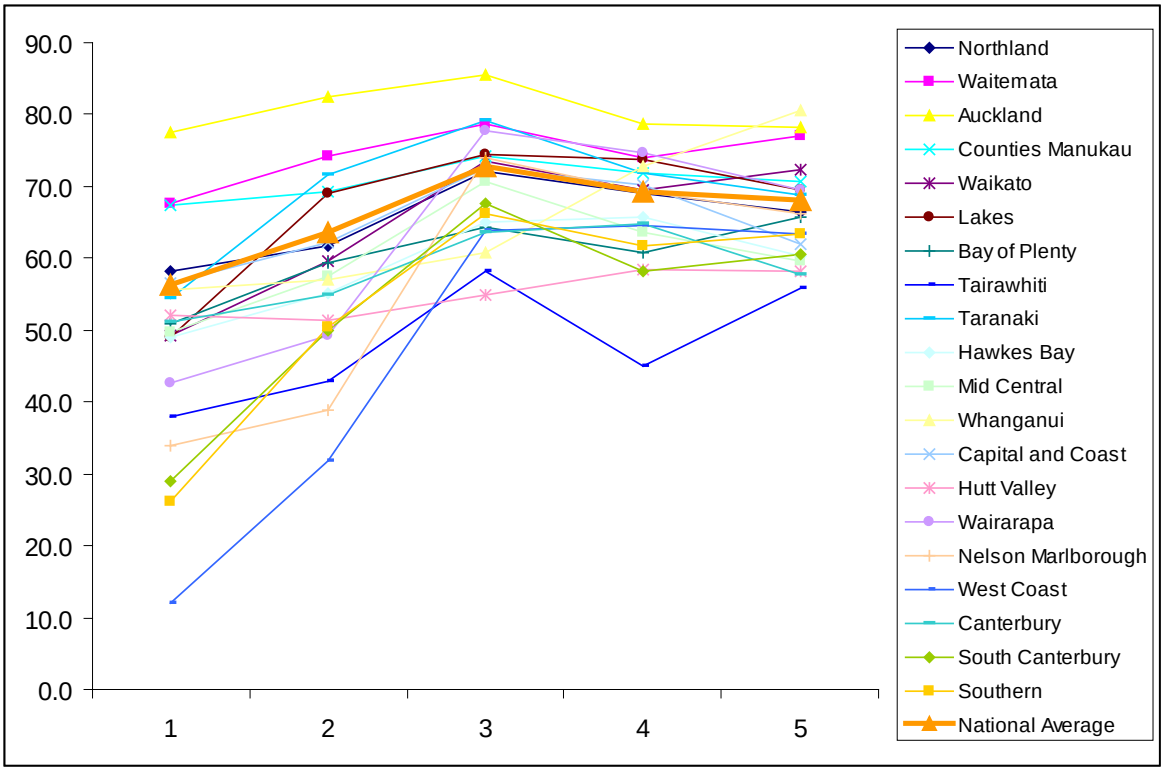


Figure 6 **Percentage of samples received by laboratory within 4 days by DHB, for January to March, April to June, July to September and October to December 2011 and January to March 2012 (Data from Monitoring Reports 1-5).**



Indicator 5 – Laboratory testing timeframes

5: LABORATORY TESTING TIMEFRAMES

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 07:30am 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 specified timeframes.

Denominator: Number of samples tested.

Laboratory testing timeframes

Table 7 identifies the percentage of samples that met the specified laboratory testing timeframes. While not quite 100% the rates are very close to this for all disorders.

Table 7 Percentage of results available within specified timeframes, by disorder, January to March 2012 (n=15,421 samples)

Disorder	Expected timeframe (days)	Number met timeframe	% met timeframe
Congenital Adrenal Hyperplasia	2	15,365	99.6
Galactosaemia	2	15,375	99.7
Amino acid disorders	2	15,313	99.3
Fatty acid oxidation disorders	2	15,313	99.3
Biotinidase deficiency	5	15,391	99.8
Cystic fibrosis	5	15,245	98.9
Congenital hypothyroidism	5	15,391	99.8

Indicator 9 – Blood spot card storage and return

9: CARD STORAGE AND RETURN
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 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 Programme Guidelines in Chapter 11.

Blood spot card storage and return

All samples are returned by tracked courier. Of 183 requests for card returns during the reporting period 1 January to 31 March 2012, 178 (97.3%) were returned in the timeframe. Three of the five unreturned cards are explained below.

One card has not been returned as the request for return was not signed and the mother has been contacted but no reply received. Another has not been returned because the request was received separately from the card without photo identification, this has been requested but not received. One further card was returned in 31 days.

In general samples are returned very quickly with a median time over this period of 2.8 days.

Appendix – Indicators Not Reported Quarterly

Indicator 1 – Newborn Metabolic Screening Coverage

1: NEWBORN METABOLIC SCREENING COVERAGE
DESCRIPTION The proportion of babies who have had newborn metabolic screening.
RATIONALE All babies whose parents/guardians consent to screening should have screening.
RELEVANT OUTCOME All babies whose parents/guardians consent to newborn metabolic screening are screened.
STANDARD 100% of babies whose parents/guardians consent to screening are screened.
METHODOLOGY ***Indicator 1.1*** Numerator: Number of babies screened. Denominator: Number of live births.
NOTES • Denominator limitations to be explained in published reports • Reporting by: ➢ DHB ➢ Ethnicity ➢ Deprivation status

Indicator 6 Timeliness of Reporting – Notification of Screen Positives

6: TIMELINESS OF REPORTING – NOTIFICATION OF SCREEN POSITIVES

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 development potential impacted 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
CAH	3
Galactosaemia	3
CH	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.

Indicator 7 Collection and Receipt of Second Samples

7: COLLECTION AND RECEIPT OF SECOND SAMPLES

DESCRIPTION

The number of babies that have had second samples taken, sent, and received by the laboratory. **Note**: this indicator does not cover highly positive samples. It is for those around the cut-off who have letters sent to them.

RATIONALE

If a second sample is required it means that a baby has not been fully screened, or that his/her results were borderline. Second samples should be taken as soon as possible so that the baby can be treated early if he/she has a disorder.

RELEVANT OUTCOME

Second samples are taken, sent, and received by the laboratory as soon as possible.

STANDARD

100% of second samples are received by the laboratory, or declined, within ten calendar days of request.

METHODOLOGY

Indicator 7.1

Numerator: Total number of second samples collected, declined, or baby died.

Denominator: Number of second samples requested.

Indicator 7.2

Numerator: Number of second samples received within ten calendar days.

Denominator: Total number of second samples received and declined.

NOTES

- Requirements for repeat samples are detailed in Chapter 7, page 24-25 of Programme Guidelines.
- Reporting by DHB

Indicator 8 – Diagnosis and Commencement of Treatment by Disorder

8 DIAGNOSIS AND COMMENCEMENT OF TREATMENT BY DISORDER

DESCRIPTION

The number of babies with a positive screening result who receive a confirmed diagnosis and timely commencement of treatment.

RATIONALE

The NMSP relies on confirmed detection and timely treatment to ensure babies with congenital metabolic disorders have their development potential impacted as little as possible from the disorder.

RELEVANT OUTCOME

All babies with a metabolic disorder and a screen positive result receive a confirmed diagnosis and timely commencement of treatment.

STANDARD

100% of babies who receive a screen positive result are diagnosed and commence treatment by:

Disorder	Calendar days
Biotinidase deficiency	14
Cystic fibrosis	28
CH	10
CAH	10
Galactosaemia	10
Amino acid disorders	10
Fatty acid oxidation disorders	10

METHODOLOGY

Indicator 8

Numerator: Number of babies who are diagnosed and commence treatment within the timeframes specified.

Denominator: Number of babies who receive a screen positive result and are diagnosed with and treated for a metabolic disorder.

NOTES

- Clinically-diagnosed babies will be reported separately.
- Measurement may also be by case review or periodic audit / evaluation.