National Screening Unit

Newborn Metabolic Screening Programme

Newborn Metabolic Screening Programme (NMSP)

Quarterly Monitoring Report

Number 3

1 July to 30 September 2011

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

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Executive Summary

This is the third 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 quarterly 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 41% of samples are taken at two days but this is likely to be an underestimate since time is collected in whole days only. No DHB met the standard of 95% (range 21.1-68.9%). The standard was not met for any ethnic group (range 34.0-44.0%) or NZDep group (range 33.0-46.3%).

Recommendations:

Reassess performance when time is available in hours, which will be from Report 4.

Indicator 3 Quality of blood samples

Three DHBs, Bay of Plenty, Nelson-Marlborough and Southern met the standard of 99% satisfactory and 13 other DHBs came close. Overall 98.7% of samples were satisfactory.

Recommendations:

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

Indicator 4 Sample dispatch and delivery

Overall 72.9% 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 (56% met the standard in January-March 2011; 64% in April-June and 73% in this report).

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 98.3 and 99.9%.

Recommendations:

No recommendation.

Indicator 9 Blood spot card storage and return.

98% of 157 requests for card return met the standard of within 28 days of completion of screening. The two requests that did not had insufficient information e.g. no address and returns were made within 28 days of receipt of the missing information.

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 third 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 July to 30 September 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 NZ Dep Status.
- Timing of sample taking is separated into three time periods <2 days, 2 days, >2 days (see data issues below for discussion re timing of sample taking).
- 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 87 such samples from approximately 15,700 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 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. Current data collections systems do not allow collection of the age of the baby in hours as the laboratory management system used cannot collect the time of birth. Therefore the age of the baby at collection is given in days; less than 48 hours equates to less than 2 days; 48-72 hours equates to 2 days, and over 72 hours equates to over 2 days.

This way of counting in days will underestimate the number of babies for whom the sampling time met the standard. Babies born less than 48 hours are correctly identified, but for example when a sample is collected at 70 hours (which is within the 48-72 hour timeframe) this will often be included in the "over 2 days" category.

A proportion of samples do not give the time of collection. The percentage meeting the standard is calculated from the percentage of those infants in which this 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 Galactosemia 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				
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. (see data limitations above, the measure used in this report is the number of babies screened at 2 days)

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

Overall 40.5% of samples were taken at two days of age. As noted above, this is likely to be an underestimate as babies with a sample taken around 60-72 hours after birth will appear in the over 2 days category. Time of birth is now able to be collected by the laboratory and this information will be given in hours in future reports.

For this period no DHB region met the standard of 95% of samples taken at 2 days. Under the current measure of using days rather than hours, achieving the 95% standard would be difficult. Table 2 shows the percentage of samples taken at 2 days, as well as those outside of this timeframe, by DHB. Figure 1 shows the percentage of samples taken at 2 days by DHB compared with the overall average of 40.5% at 2 days.

In comparison with the data in Reports 1&2, the percentage of samples taken at 2 days has not changed.

Table 2: Percentage of samples taken at 2 days, by DHB, July to September 2011

DHB region	Sampled at 2 days		Sampled less than 2 days		Sampled greater than 2 days		No Collection Date		Total babies
	No.	%	No.	%	No.	%	No.	%	No.
Northland	211	36.5	0	0.0	353	61.1	14	2.4	578
Waitemata	803	39.4	5	0.2	1,211	59.4	19	0.9	2,038
Auckland	809	46.8	2	0.1	885	51.2	31	1.8	1,727
Counties Manukau	662	29.6	4	0.2	1,557	69.5	16	0.7	2,239
Waikato	391	28.8	3	0.2	939	69.1	25	1.8	1,358
Lakes	121	31.5	0	0.0	258	67.2	5	1.3	384
Bay of Plenty	161	23.0	3	0.4	525	75.0	11	1.6	700
Tairawhiti	56	28.0	0	0.0	139	69.5	5	2.5	200
Taranaki	231	57.5	2	0.5	164	40.8	5	1.2	402
Hawkes Bay	256	44.4	4	0.7	309	53.6	8	1.4	577
Whanganui	66	33.0	0	0.0	134	67.0	0	0.0	200
Mid Central	240	44.0	3	0.5	289	52.9	14	2.6	546
Hutt Valley	107	21.9	2	0.4	376	76.9	4	0.8	489
Capital and Coast	425	44.8	4	0.4	511	53.8	9	0.9	949
Wairarapa	52	41.3	0	0.0	70	55.6	4	3.2	126
Nelson Marlborough	209	45.9	0	0.0	240	52.7	6	1.3	455
West Coast	70	58.3	0	0.0	49	40.8	1	0.8	120
Canterbury	1,045	69.4	6	0.4	425	28.3	28	1.9	1,504
South Canterbury	69	52.3	0	0.0	62	47.0	1	0.8	132
Southern	384	39.8	2	0.2	566	58.7	13	1.3	965
Not recorded	4	13.8	0	0.0	22	75.9	3	10.3	29
Total	6,372	40.5	40	0.3	9,084	57.8	222	1.4	15,718

Figure 1: Percentage of samples taken at 2 days, by DHB, July to September 2011

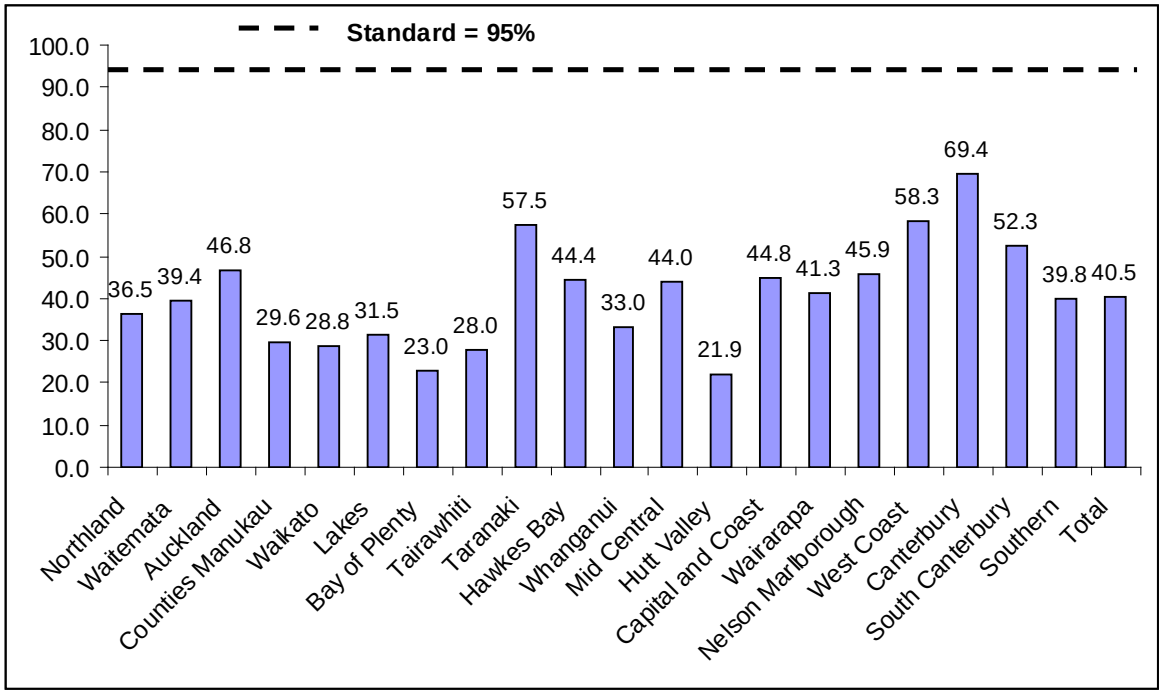


Figure 2 below and Table 3 identifies some small differences between ethnic groups. While no ethnic group met the standard of 95% the percentages for European and Other appear higher than for the remaining ethnic groups. This is similar to the previous two reports.

Figure 2: Percentage of samples taken at 2 days, by ethnicity, July to September 2011

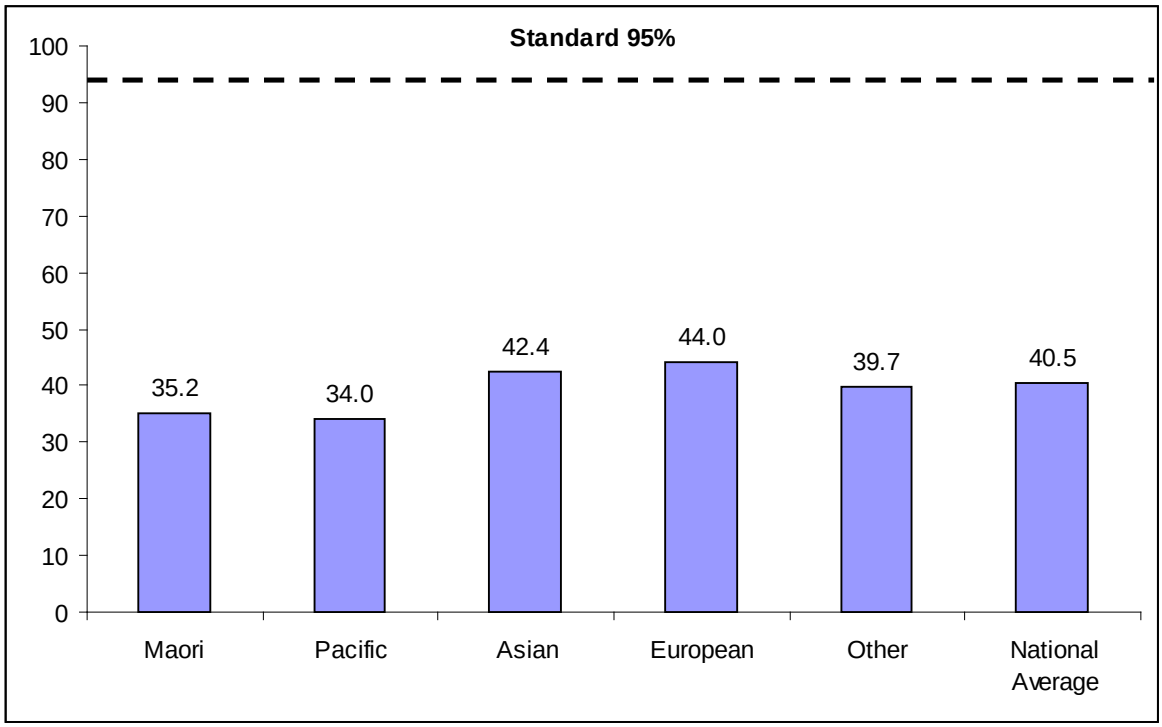


Table 3: Percentage of samples taken at 2 days, by Group 1 and Group 2 Ethnicity, July to September 2011

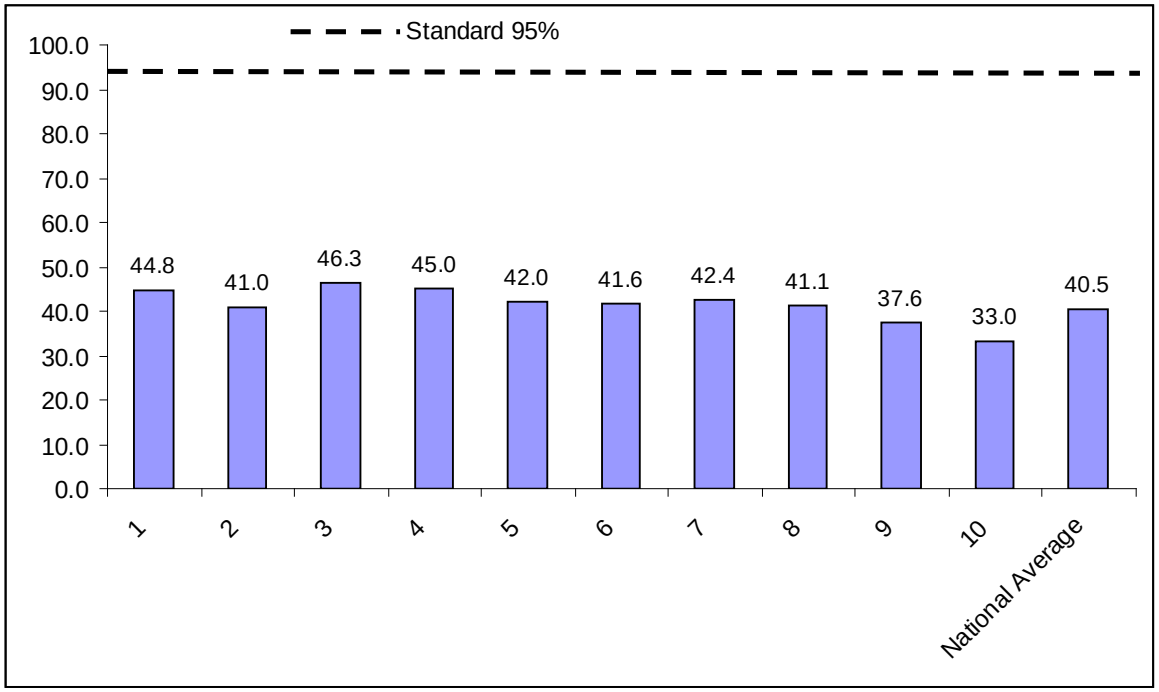
Ethnicity (*Group 1 Group 2)*	Sampled at 2 days		Sampled less than 2 days		Sampled greater than 2 days		No Collection Date		Total babies
	No.	%	No.	%	No.	%	No.	%	No.
Maori	*1,252*	*35.2*	*7*	*0.2*	*2,247*	*63.1*	*54*	*1.5*	*3,560*
Pacific	*630*	*34.0*	*4*	*0.2*	*1,201*	*64.7*	*20*	*1.1*	*1,855*
Cook Island Maori	99	34.0	0	0.0	186	63.9	6	2.1	291
Fijian	39	31.5	0	0.0	85	68.5	0	0.0	124
Niuean	35	37.6	1	1.1	56	60.2	1	1.1	93
Samoan	245	31.6	2	0.3	524	67.6	4	0.5	775
Tokelauan	15	38.5	0	0.0	24	61.5	0	0.0	39
Tongan	167	37.3	1	0.2	272	60.7	8	1.8	448
Other Pacific	30	35.3	0	0.0	54	63.5	1	1.2	85
Asian	*770*	*42.4*	*4*	*0.2*	*1,024*	*56.4*	*19*	*1.0*	*1,817*
Chinese	296	45.7	1	0.2	344	53.1	7	1.1	648
Indian	228	40.6	1	0.2	327	58.2	6	1.1	562
Southeast Asian	80	40.2	0	0.0	117	58.8	2	1.0	199
Other Asian	166	40.7	2	0.5	236	57.8	4	1.0	408
European	*3,573*	*44.0*	*23*	*0.3*	*4,404*	*54.2*	*121*	*1.5*	*8,121*
NZ European	3,123	43.9	22	0.3	3,858	54.3	103	1.4	7,106
Latin American / Hispanic	28	47.5	0	0.0	31	52.5	0	0.0	59
Other European	422	44.1	1	0.1	515	53.9	18	1.9	956
Other	*145*	*39.7*	*2*	*0.6*	*210*	*57.5*	*8*	*2.2*	*365*
African	37	35.9	1	1.0	64	62.1	1	1.0	103
Middle Eastern	51	41.8	1	0.8	68	55.7	2	1.6	122
Other/not known	57	40.7	0	0.0	78	55.7	5	3.6	140
Total	6,370	40.5	40	0.3	9,086	57.8	222	1.4	15,718

Table 4 and Figure 3 below show the number of samples taken by 2 days by NZ Deprivation index. There was no NZ Dep 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 at 2 days by NZDep, July to September 2011

NZ Dep	Sampled at 2 days		Sampled less than 2 days		Sampled greater than 2 days		No Collection Date		Total babies
	No.	%	No.	%	No.	%	No.	%	No.
1	438	44.8	3	0.3	518	53.0	18	1.8	977
2	506	41.0	5	0.4	708	57.4	15	1.2	1,234
3	527	46.3	2	0.2	590	51.8	20	1.8	1,139
4	534	45.0	4	0.3	640	53.9	9	0.8	1,187
5	612	42.0	2	0.1	824	56.6	19	1.3	1,457
6	605	41.6	4	0.3	824	56.6	22	1.5	1,455
7	711	42.4	2	0.1	940	56.1	24	1.4	1,677
8	837	41.1	3	0.1	1,173	57.6	24	1.2	2,037
9	837	37.6	9	0.4	1,357	61.0	22	1.0	2,225
10	758	33.0	6	0.3	1,488	64.8	46	2.0	2,298
Not recorded	5	15.6	0	0.0	24	75.0	3	9.4	32
Total	6,370	40.5	40	0.3	9,110	58.0	222	1.4	15,718

Figure 3: Percentage of samples taken at 2 days, by NZDep, July to September 2011



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.

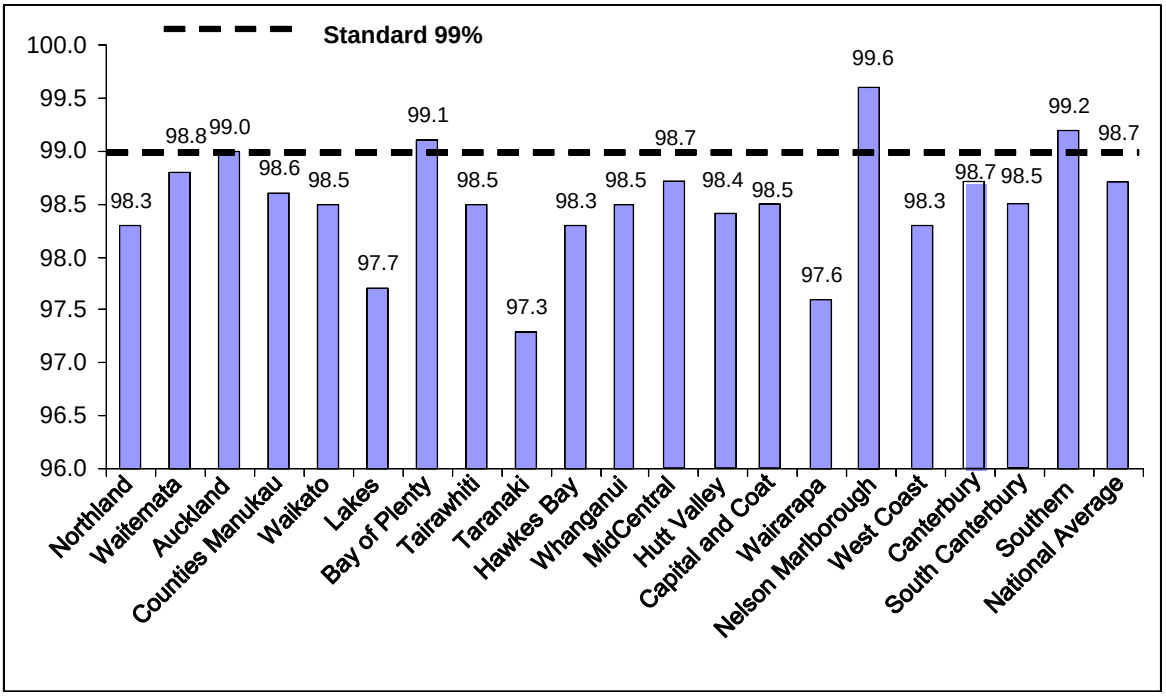
Quality of blood samples

Four DHBs, Auckland, Bay of Plenty, Nelson-Marlborough and Southern met or exceeded the standard of 99% satisfactory. Thirteen DHBs achieved between 98-99% of samples meeting the standard while three DHBs, Lakes, Taranaki and Wairapa between 97-98% of samples meeting the standard. There has been no significant change in the overall level of this indicator.

Table 5: Percentage of blood samples that meet quality standards by DHB, July to September 2011

DHB region	Satisfactory		Unsatisfactory		Total samples
	No.	%	No.	%	No.
Northland	568	98.3	10	1.7	578
Waitemata	2,013	98.8	25	1.2	2,038
Auckland	1,709	99.0	18	1.0	1,727
Counties Manukau	2,208	98.6	31	1.4	2,239
Waikato	1,338	98.5	20	1.5	1,358
Lakes	375	97.7	9	2.3	384
Bay of Plenty	694	99.1	6	0.9	700
Tairawhiti	197	98.5	3	1.5	200
Taranaki	391	97.3	11	2.7	402
Hawkes Bay	567	98.3	10	1.7	577
Whanganui	197	98.5	3	1.5	200
Mid Central	539	98.7	7	1.3	546
Hutt Valley	481	98.4	8	1.6	489
Capital and Coast	935	98.5	14	1.5	949
Wairarapa	123	97.6	3	2.4	126
Nelson Marlborough	453	99.6	2	0.4	455
West Coast	118	98.3	2	1.7	120
Canterbury	1,485	98.7	19	1.3	1,504
South Canterbury	130	98.5	2	1.5	132
Southern	957	99.2	8	0.8	965
Not recorded	28	96.6	1	3.4	29
Total	15,506	98.7	212	1.3	15,718

Figure 4: Percentage of blood samples that meet quality standards by DHB, July to September 2011



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

Although no DHB met the standard of 95% of samples received in four days or less, there has been significant improvement over the year for all DHBs. The national average has moved from 56% in January-March 2011 to 64% in April-June 2011 and 73% for July-September 2011. The highest percentage achieved was again from Auckland and this is not surprising since the testing laboratory is situated close to where the majority of births occur. All DHBs have improved markedly over the period since January 2011 as shown in Figure 6, The biggest improvement has been by West Coast (up by 52% to 64% from January-March to July-September 2011) followed by Nelson-Marlborough and Southern (both up 40% in the same period).

Table 6: Percentage of samples received by the laboratory within four days by DHB, July to September 2011

DHB region	Less than or equal to 4 days		Greater than 4 days		Unknown		Total samples
	No.	%	No.	%	No.	%	No.
Northland	426	73.7	138	23.9	14	2.4	578
Waitemata	1629	79.9	390	19.1	19	0.9	2,038
Auckland	1469	85.1	227	13.1	31	1.8	1,727
Counties Manukau	1699	75.9	524	23.4	16	0.7	2,239
Waikato	997	73.4	336	24.7	25	1.8	1,358
Lakes	280	72.9	99	25.8	5	1.3	384
Bay of Plenty	448	64.0	241	34.4	11	1.6	700
Tairawhiti	112	56.0	83	41.5	5	2.5	200
Taranaki	309	76.9	88	21.9	5	1.2	402
Hawkes Bay	381	66.0	188	32.6	8	1.4	577
Whanganui	125	62.5	75	37.5	0	0.0	200
Mid Central	388	71.1	144	26.4	14	2.6	546
Hutt Valley	274	56.0	211	43.1	4	0.8	489
Capital and Coast	711	74.9	229	24.1	9	0.9	949
Wairarapa	99	78.6	23	18.3	4	3.2	126
Nelson Marlborough	333	73.2	116	25.5	6	1.3	455
West Coast	85	70.8	34	28.3	1	0.8	120
Canterbury	945	62.8	531	35.3	28	1.9	1,504
South Canterbury	97	73.5	34	25.8	1	0.8	132
Southern	643	66.6	309	32.0	13	1.4	965
Not recorded	4	13.8	23	79.3	2	6.9	29
Total	11,454	72.9	4,043	25.7	221	1.4	15,718

Figure 5: Percentage of samples received by laboratory within 4 days by DHB, July to September 2011

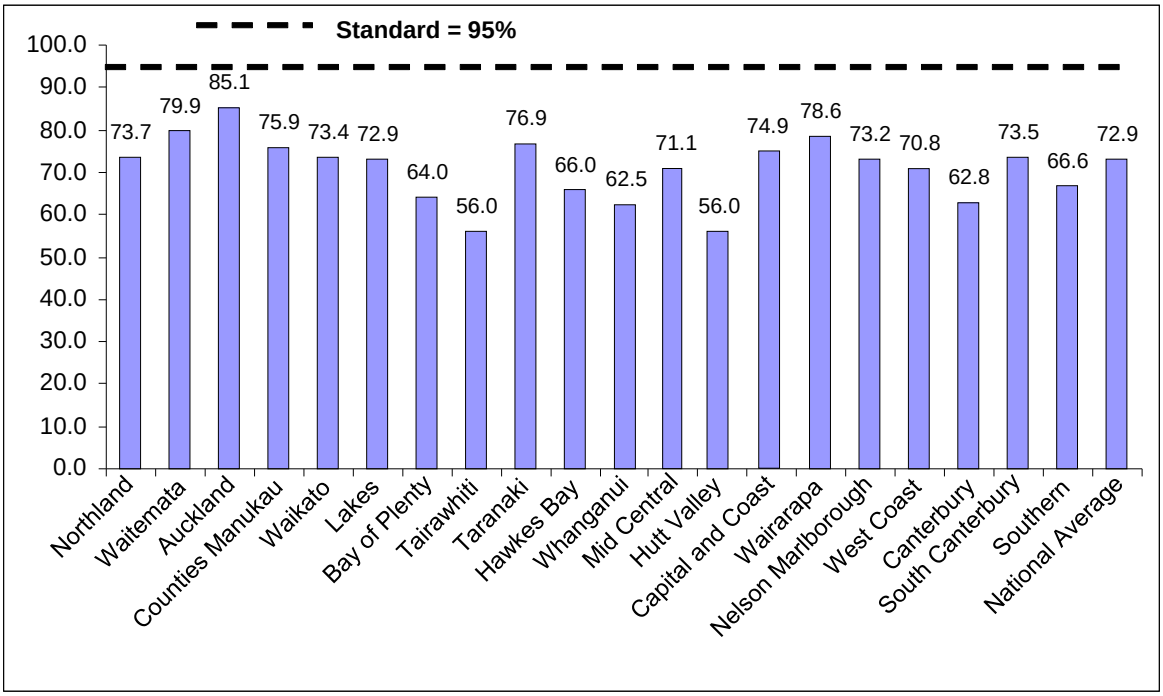
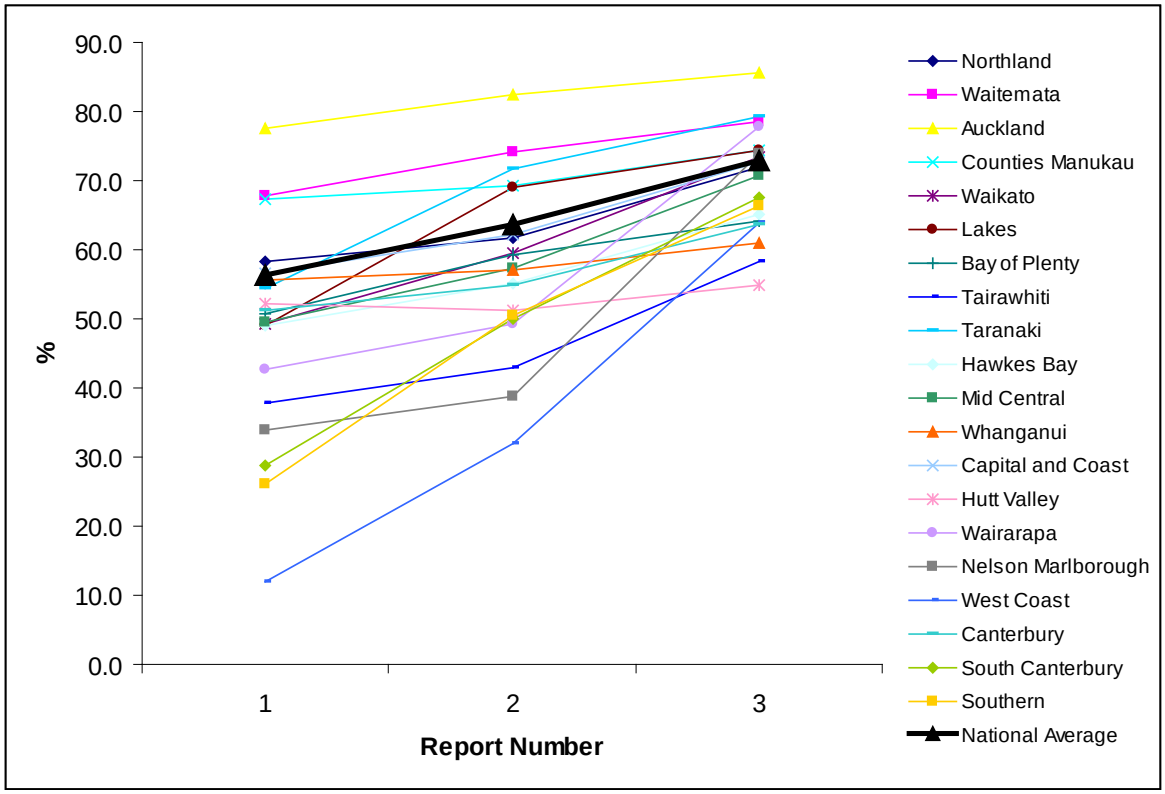


Figure 6: Percentage of samples received by laboratory within 4 days by DHB, for January to March, April to June and July to September 2011 (Data from Monitoring Reports 1-3)



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 Hypothyrodism	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, July to September 2011 (n=15,718 samples)

Disorder	Expected timeframe (days)	Number met timeframe	% met timeframe
Congenital Adrenal Hyperplasia	2	15,677	99.7
Galactosaemia	2	15,696	99.9
Amino acid disorders	2	15,611	98.3
Fatty acid oxidation disorders	2	15,611	99.3
Biotinidase deficiency	5	15,701	99.9
Cystic fibrosis	5	15,452	98.3
Congenital hypothyroidism	5	15,700	99.9

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 157 requests for card returns during the reporting period 1 July to 30 September 2011, 155 (98.7%) were returned in the timeframe. In both the cases where cards were returned outside the timeframe the requests had insufficient information with the request and the cards were returned within the timeframe after receiving the additional information. In general samples are returned very quickly with a median time over this period of 1.3 days. The same as for previous periods.

Appendix 1: Indicators not reported on quarterly

The following tables describe each of the other indicators not reported on quarterly.

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.

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.

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.

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.