National Screening Unit

Newborn Metabolic Screening Programme

Newborn Metabolic Screening Programme (NMSP)

Quarterly Monitoring Report

Number 1

1 January to 30 March 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 first quarterly monitoring report for the Newborn Metabolic Screening Programme (NMSP) and it is for the period 1 January to 31 March 2011. Five quarterly indicators are covered by the report, the findings of which are summarised below.

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

Key points and recommendations:

Indicator 2 Timing of sample-taking

This indicator is currently reported in days, however the standard aims to report the proportion of eligible babies who have a newborn metabolic screening sample taken between 48 and 72 hours of birth. This measurement discrepancy is due to data collection issues which do not currently enable time of birth data to be collected in hours. The current data collection underestimates the number of samples meeting the standard.

The current data indicates that 41% of samples were taken at day 2, which is significantly less than the standard of 95% of sample taken between 48 and 72 hours. The standard was not met by any District Health Board (DHB) region, ethnic group or deprivation level.

Recommendations:

1. Age of baby at sampling should be expressed in hours as soon as possible.
2. Further analysis of the underestimation issue is required.
3. All opportunities to educate Lead Maternity Carers (LMCs) about the importance of taking the sample at the correct time should be utilised.

Indicator 3 Quality of blood samples

Four of twenty DHB regions (Counties Manukau, Hutt Valley, Nelson-Marlborough and South Canterbury) met the standard of 99% of blood samples being of satisfactory quality. Overall 98.6% of samples were satisfactory for testing.

The NMSP recently started to provide high-quality lancets to LMCs for the collection of newborn screening samples. This initiative began in April 2011, outside the period of this report, and may impact on this indicator in the future.

Recommendation:

4. Monitor this indicator over time to gauge the effect of provision of lancets to LMCs.

Indicator 4 Sample dispatch and delivery

Overall 56.4% of samples were received within four days of collection. No DHB region met the standard of 95%. The NMSP has recently started to provide postage-paid envelopes to LMCs, included in the provision of lancets initiative as noted above. The provision of postage paid envelopes may improve this indicator.

Recommendation:

5. Monitor this indicator over time to gauge the effect of provision of envelopes to LMCs.

Indicator 5 Laboratory testing timeframes

More than 98% of tests have first results reported within the timeframe expected for the disorder.

Recommendation:

6. This indicator and standard should be clarified, then reviewed in conjunction with indicator 6 (not reported in this report).

Indicator 9 Blood spot card storage and return.

The majority of cards (159 of 160) requested by families of babies who had their first test in this quarter were returned by tracked courier within the expected timeframe 28 days.

Recommendation: No recommendations for this indicator.

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 first 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 New Zealand Deprivation decile (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 January to 30 March 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 New Zealand 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.

The deprivation index is the average level of deprivation of people living in an area at a particular point in time, relative to the whole of New Zealand. Deprivation refers to areas (based on New Zealand Census meshblocks) rather than individuals. Nine indicators are combined to give the deprivation index. The indicators reflect aspects of material and social deprivation, and the nine indicators are:

- income derived from benefits
- unemployment
- low income earning
- access to car
- access to telephone
- sole-parent families
- lack of formal educational qualifications
- level of home ownership
- living space within a home.

In the deprivation index system used by the health sector, areas classified as Decile 1-2 have the least deprivation and areas classified as Decile 9-10 have the most deprivation. This is opposite to some other systems of classification such as that used by education, where level 10 is the least disadvantaged and level 1 the most disadvantaged.

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 <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 48 such samples from approximately 15,600 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

With the data at this time, there is no reliable way to differentiate Amino acid disorders from Fatty acid oxidation disorders, they are therefore 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. (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 41% of samples were taken at 2 days of age. As noted previously 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.

For this period no DHB region met the standard of 95% of samples taken at 2 days. Under the current measure 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 show the percentage of samples taken at 2 days by DHB, compared with the overall average of 41%.

Table 2 Percentage of samples taken at 2 days, by DHB, January to March 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	184	*33.8*	0	*0.0*	361	*65.3*	8	*1.4*	553
Waitemata	679	*37.9*	1	*0.1*	1,111	*61.7*	9	*0.5*	1,800
Auckland	1,004	*47.2*	9	*0.4*	1,114	*51.8*	24	*1.1*	2,151
Counties Manukau	491	*26.5*	2	*0.1*	1,359	*72.6*	20	*1.1*	1,872
Waikato	387	*28.9*	3	*0.2*	948	*69.8*	21	*1.5*	1,359
Lakes	128	*35.7*	0	*0.0*	231	*63.5*	5	*1.4*	364
Bay of Plenty	161	*19.4*	1	*0.1*	667	*78.6*	20	*2.4*	849
Tairawhiti	67	*30.6*	1	*0.5*	151	*68.6*	1	*0.5*	220
Taranaki	233	*58.0*	0	*0.0*	169	*41.8*	2	*0.5*	404
Hawkes Bay	293	*52.7*	1	*0.2*	262	*46.4*	9	*1.6*	565
Whanganui	69	*32.9*	1	*0.5*	140	*65.1*	5	*2.3*	215
Mid Central	271	*41.4*	3	*0.5*	381	*57.5*	8	*1.2*	663
Hutt Valley	69	*21.9*	0	*0.0*	246	*77.4*	3	*0.9*	318
Capital and Coast	567	*44.7*	3	*0.2*	699	*54.1*	22	*1.7*	1,291
Wairarapa	43	*39.1*	0	*0.0*	67	*60.9*	0	*0.0*	110
Nelson Marlborough	198	*45.1*	0	*0.0*	241	*53.8*	9	*2.0*	448
West Coast	40	*53.3*	0	*0.0*	35	*44.9*	3	*3.8*	78
Canterbury	1,135	*71.1*	4	*0.2*	458	*28.2*	28	*1.7*	1,625
South Canterbury	93	*61.2*	0	*0.0*	59	*38.8*	0	*0.0*	152
Southern	406	*45.0*	5	*0.5*	492	*53.7*	13	*1.4*	916
Not recorded	0	*0*	0	*0.0*	2	*100.0*	0	*0.0*	2
Total	**6,518**	***40.8***	**34**	***0.2***	**9,193**	***57.6***	**210**	***1.3***	**15,955**

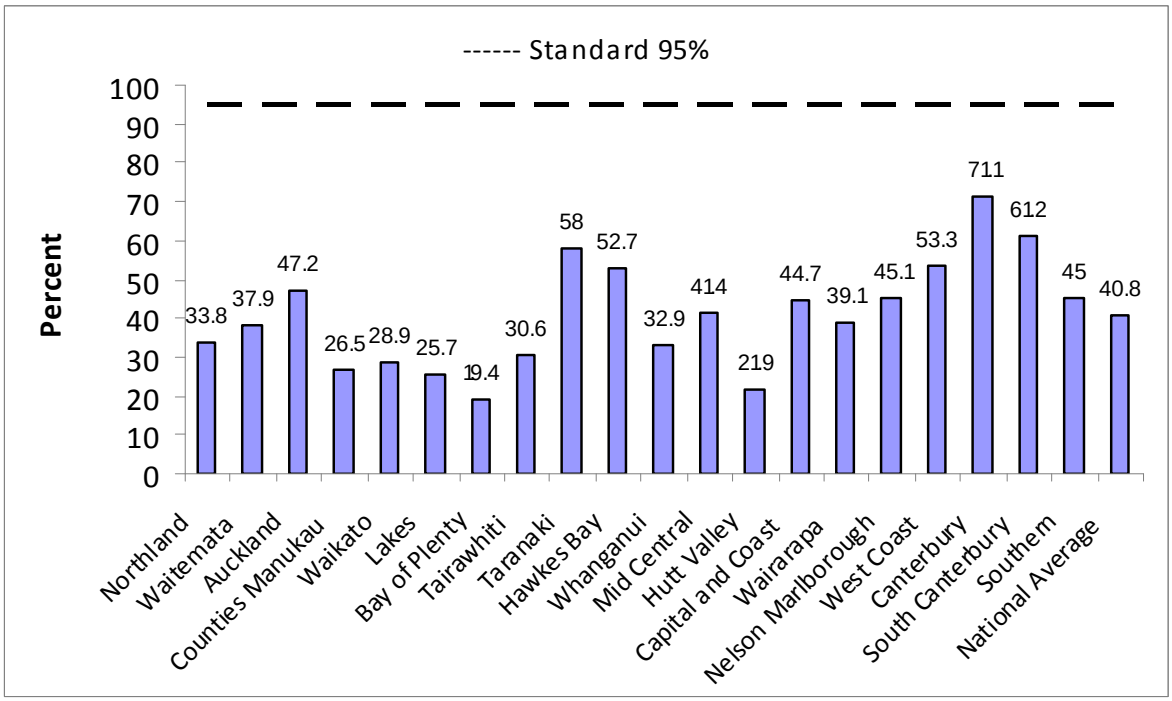

Figure 1 Percentage of samples taken at 2 days, by DHB, January to March 2011

No ethnic group met the standard of 95% of samples collected at 2 days. There may be some difference between the main ethnic groups as shown in Figure 2 and Table 3. A higher proportion of European and "Other" babies had a sample taken at 2 days.

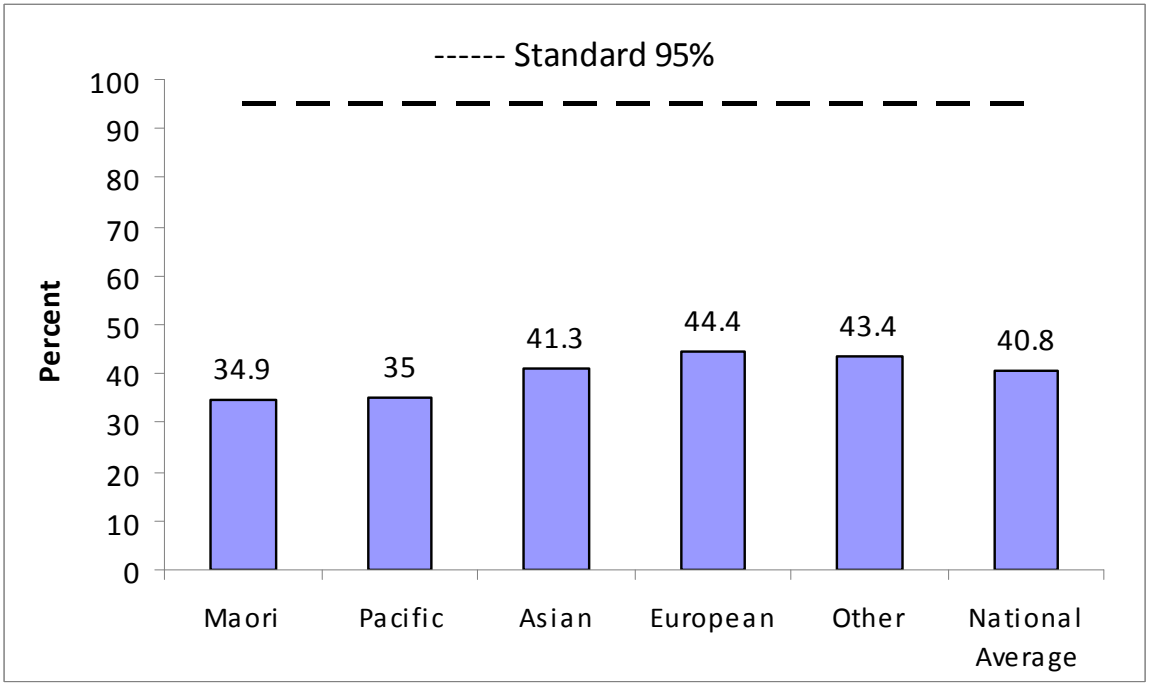

Figure 2 Percentage of samples taken at 2 days, by ethnicity, January to March 2011

Table 3 Percentage of samples taken at 2 days, by Group 1 and Group 2 Ethnicity, January to March 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	1,248	*34.9*	8	*0.2*	2,272	*63.5*	52	*1.5*	3,580
Pacific	608	*35.0*	5	*0.3*	1108	*63.8*	17	*1.0*	1,738
Cook Island Maori	85	*31.8*	1	*0.4*	177	*66.3*	4	*1.5*	267
Fijian	46	*39.3*	0	*0.0*	70	*59.8*	1	*0.9*	117
Niuean	37	*36.6*	0	*0.0*	63	*62.4*	1	*1.0*	101
Samoan	277	*34.7*	3	*0.4*	510	*63.9*	8	*1.0*	798
Tokelauan	10	*45.5*	0	*0.0*	12	*54.5*	0	*0.0*	22
Tongan	136	*37.3*	0	*0.0*	226	*61.9*	3	*0.8*	365
Other Pacific	17	*25.0*	1	*1.5*	50	*73.5*	0	*0.0*	68
Asian	762	*41.3*	2	*0.1*	1,064	*57.6*	18	*1.0*	1,846
Chinese	313	*48.8*	1	*0.2*	326	*50.9*	1	*0.2*	641
Indian	191	*31.5*	1	*0.2*	407	*67.1*	8	*1.3*	607
Southeast Asian	74	*43.0*	0	*0.0*	96	*55.8*	2	*1.2*	172
Other Asian	184	*43.2*	0	*0.0*	235	*55.2*	7	*1.6*	426
European	3,774	*44.4*	18	*0.2*	4,597	*54.1*	113	*1.3*	8,502
NZ European	3,327	*44.4*	16	*0.2*	4,055	*54.1*	93	*1.2*	7,491
Latin American / Hispanic	30	*46.9*	0	*0.0*	33	*51.6*	1	*1.6*	64
Other European	417	*44.0*	2	*0.2*	509	*53.7*	19	*2.0*	947
Other	125	*43.4*	1	*0.3*	152	*52.8*	10	*3.5*	288
African	49	*48.0*	0	*0.0*	50	*49.0*	3	*2.9*	102
Middle Eastern	39	*37.9*	0	*0.0*	61	*59.2*	3	*2.9*	103
Other/not known	38	*45.2*	1	*1.2*	41	*49.4*	4	*4.8*	84
Total	**6,518**	***40.8***	**34**	***0.2***	**9,193**	***57.6***	**210**	***1.3***	**15,955**

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.

Table 4 Percentage of samples taken at 2 days by NZDep, January to March 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	460	*46.6*	1	*0.1*	527	*52.4*	17	*1.7*	1,005
2	542	*44.9*	5	*0.4*	660	*54.2*	10	*0.8*	1,217
3	547	*45.6*	2	*0.2*	651	*53.3*	21	*1.7*	1,221
4	629	*48.8*	2	*0.2*	657	*50.3*	18	*1.4*	1,306
5	683	*45.4*	3	*0.2*	820	*53.9*	16	*1.1*	1,522
6	621	*41.8*	5	*0.3*	858	*57.2*	15	*1.0*	1,499
7	686	*41.7*	2	*0.1*	956	*57.4*	22	*1.3*	1,666
8	782	*39.6*	5	*0.2*	1,190	*59.3*	31	*1.5*	2,008
9	795	*36.7*	4	*0.2*	1,370	*62.3*	30	*1.4*	2,199
10	767	*33.9*	5	*0.2*	1,488	*65.1*	27	*1.2*	2,287
Not recorded	6	*27.3*	0	*0.0*	16	*64.0*	3	*12.0*	25
Total	**6,518**	***40.8***	**34**	***0.2***	**9,193**	***57.6***	**210**	***1.3***	**15,955**

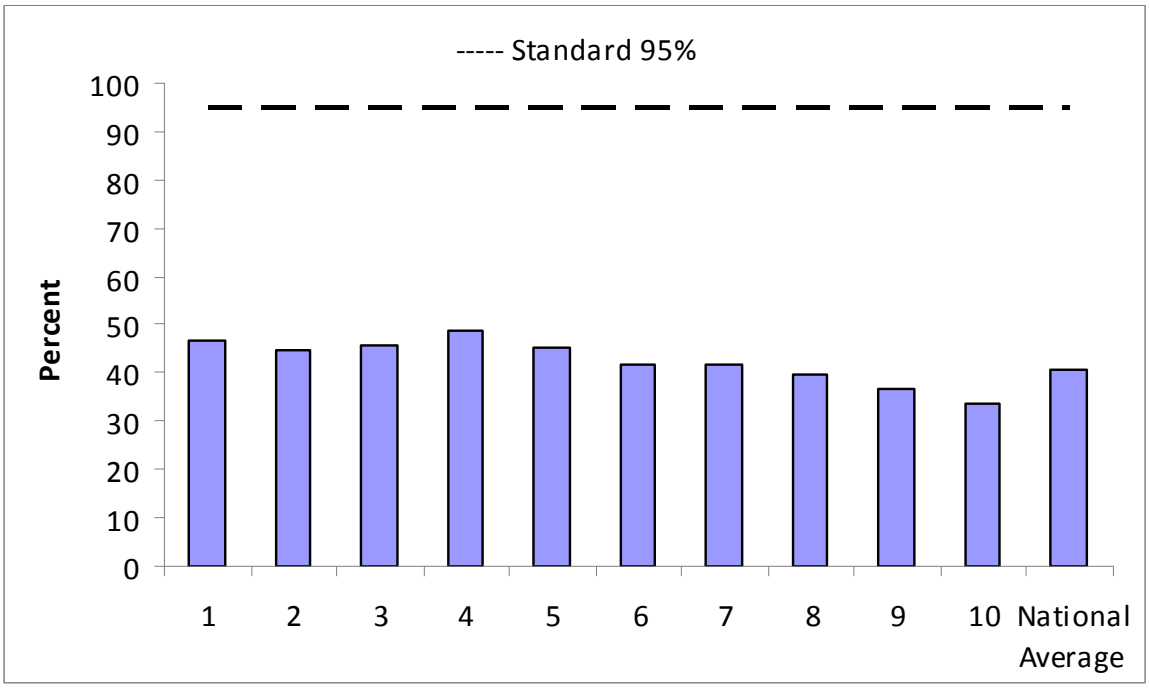

Figure 3 **Percentage of samples taken at 2 days, by NZDep, January to March 2011**

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

Overall 98.6% of samples taken between 1 January and 31 March 2011 met the quality standards for testing. Four out of the twenty DHB regions met the target of 99% of blood spot samples of satisfactory quality - Counties Manukau, Hutt Valley, Nelson-Marlborough and South Canterbury. Eleven additional DHB regions were over 98%, therefore fifteen out of the twenty DHB regions were above or within 1% of the 99% target.

Table 5 Percentage of blood samples that meet quality standards by DHB, January to March 2011

DHB region	Satisfactory		Unsatisfactory		Total samples
	No.	%	No.	%	No.
Northland	539	*97.5*	14	*2.5*	553
Waitemata	1,770	*98.3*	30	*1.7*	1,800
Auckland	2,124	*98.7*	27	*1.3*	2,151
Counties Manukau	1,855	*99.1*	17	*0.9*	1,872
Waikato	1,336	*98.3*	23	*1.7*	1,359
Lakes	360	*98.9*	4	*1.1*	364
Bay of Plenty	837	*98.6*	12	*1.4*	849
Tairawhiti	215	*97.7*	5	*2.3*	220
Taranaki	399	*98.8*	5	*1.2*	404
Hawkes Bay	557	*98.6*	8	*1.4*	565
Whanganui	209	*97.2*	6	*2.8*	215
Mid Central	656	*98.9*	7	*1.1*	663
Capital and Coast	1,264	*97.9*	27	*2.1*	1,291
Hutt Valley	317	*99.7*	1	*0.3*	318
Wairarapa	107	*97.3*	3	*2.7*	110
Canterbury	1,605	*98.8*	20	*1.2*	1,625
Nelson Marlborough	444	*99.1*	4	*0.9*	448
West Coast	77	*98.7*	1	*1.3*	78
South Canterbury	152	*100.0*	0	*0.0*	152
Southern	900	*98.3*	16	*1.7*	916
Not recorded	2	*100.0*	0	*0.0*	2
Total	**15,725**	***98.6***	**230**	***1.4***	**15,955**

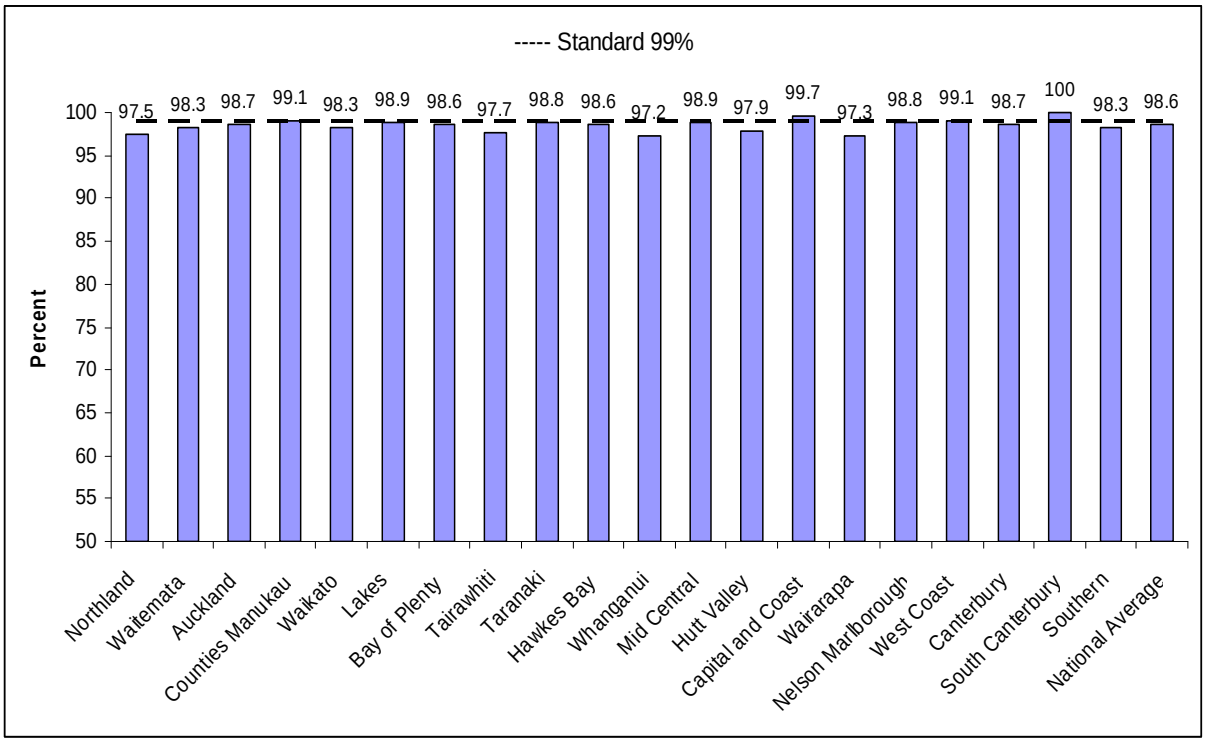

Figure 4 **Percentage of blood samples that meet quality standards by DHB, January to March 2011**

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

During the period 1 January to 31 March 2011 56.4% of samples were received within the standard of four days of collection. At this time no DHB region met the standard of 95% for this indicator. Results ranged from 77.5 % of samples from the Auckland DHB region to just 12% of samples from the West Coast being received within four days

Table 6 Percentage of samples received by the laboratory within four days by DHB, January to March 2011

DHB region	Less than or equal to 4 days		Greater than 4 days		Unknown		Total samples
	No.	*%*	No.	*%*	No.	*%*	No.
Northland	318	*58.3*	227	*41.7*	8	*1.4*	553
Waitemata	1,210	*67.6*	581	*32.4*	9	*0.5*	1,800
Auckland	1,649	*77.5*	480	*22.5*	22	*1.0*	2,151
Counties Manukau	1,246	*67.3*	606	*32.7*	20	*1.1*	1,872
Waikato	660	*49.3*	678	*50.7*	21	*1.5*	1,359
Lakes	176	*49.0*	183	*51.0*	5	*1.4*	364
Bay of Plenty	421	*50.8*	408	*49.2*	20	*2.4*	849
Tairawhiti	83	*37.9*	136	*62.1*	1	*0.5*	220
Taranaki	219	*54.5*	183	*45.5*	2	*0.5*	404
Hawkes Bay	273	*49.1*	283	*50.9*	9	*1.6*	565
Mid Central	325	*49.6*	330	*50.4*	8	*1.2*	663
Whanganui	117	*55.7*	93	*44.3*	5	*2.3*	215
Capital and Coast	718	*56.6*	551	*43.4*	22	*1.7*	1,291
Hutt Valley	164	*52.1*	151	*47.9*	3	*0.9*	318
Wairarapa	47	*42.7*	63	*57.3*	0	*0.0*	110
Nelson Marlborough	149	*33.9*	290	*66.1*	9	*2.0*	448
West Coast	9	*12.0*	66	*88.0*	3	*3.8*	78
Canterbury	818	*51.2*	779	*48.8*	28	*1.7*	1,625
South Canterbury	44	*28.9*	108	*71.1*	0	*0.0*	152
Southern	237	*26.2*	666	*73.8*	13	*1.4*	916
Not recorded	0	*0.0*	2	*100.0*	0	*0.0*	2
Total	**8,883**	***56.4***	**6,864**	***43.6***	**208**	***1.3***	**15,955**

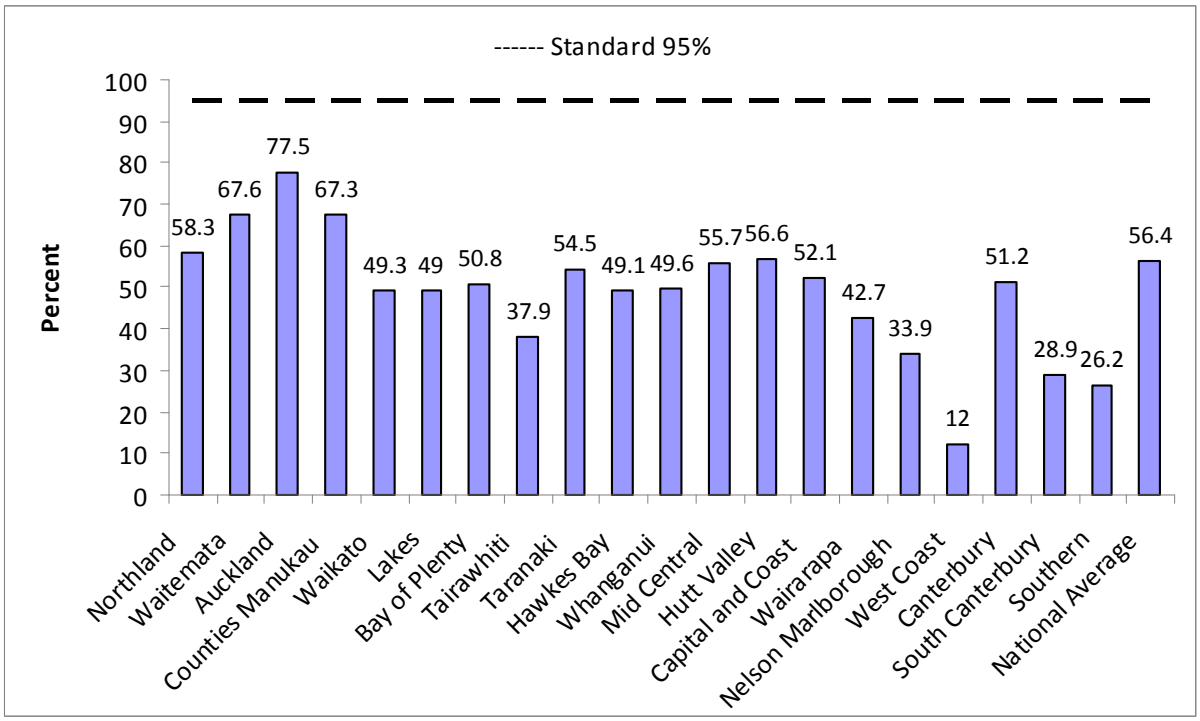

Figure 5 **Percentage of samples received by laboratory within 4 days by DHB, January to March 2011**

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, January to March 2011 (n=15,955 samples)

Disorder	Expected timeframe (days)	Number met timeframe	% met timeframe
Congenital Adrenal Hyperplasia	2	15920	99.8
Galactosaemia	2	15922	99.8
Amino acid disorders	2	15862	99.4
Fatty acid oxidation disorders	2	15852	99.4
Biotinidase deficiency	5	15937	99.9
Cystic fibrosis	5	15784	98.9
Congenital hypothyroidism	5	15937	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 160 requests for card returns during the reporting period 1 January to 31 March 2011, 159 (99.4%) were returned in the timeframe. In general samples are returned very quickly with a median time over this period of 1.3 days.

One sample has not been returned since the request was received separately from the sample without appropriate identification. This has been reported here as requested but not yet received.

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.