National Screening Unit

Newborn Metabolic Screening Programme

Newborn Metabolic Screening Programme (NMSP)

Quarterly Monitoring Report

Number 4

1 October to 31 December 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

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.

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Executive Summary

This is the fourth quarterly and second biannual 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. Eight indicators are covered by this report, including the quarterly and biannual indicators as well as the annual indicator for screening coverage. One indicator, diagnosis and commencement of treatment by disorder, was not reported as data was not available for the completion of 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. From this report 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 1 Newborn Metabolic Screening Coverage

Between 1 January 2011 and 31 December 2011 61,847 babies were screened and 62,487 babies were born, giving a coverage of approximately 99%.

Indicator 2 Timing of sample-taking

Overall 65.2% of samples were collected between 48-72 hours. No DHB met the standard of 95% of samples taken in the timeframe (range 48-88%). It is not possible to calculate this indicator for about 12% 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 44-73%) or NZDep group (range 58-70%). This report is the first in which this indicator is reported in hours so no trend analysis is possible.

Recommendations:

Continue to monitor this indicator.

Indicator 3 Quality of blood samples

Six DHBs (Waitemata, Counties Manukau, Taranaki, Hawkes Bay, Wairarapa and Canterbury) met or exceeded the standard of 99% satisfactory and a further 11 achieved 98-99%. Overall

98.8% 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 70% 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, 73% in July-September and 70% in this report). The decline may be due to two four day holidays in this period.

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 97.9 and 99.9%. Screening for fatty acid oxidation and aminoacid breakdown disorders has the lowest percentage meeting the turnaround time due to instrument breakdowns.

Recommendations:

Progress purchase of a backup tandem mass spectrometer.

Indicator 6 Timeliness of reporting

The standard of 100% meeting the timeframe was achieved for only biotinidase deficiency and galactosemia screening. The range was from 23-100%. The reasons for this include that this measure is in calendar days and written reports are not generated until all test results on a sample are available. All results where it was likely the condition was present and there is clinical urgency about commencement of treatment were notified in the timeframe.

Recommendations:

That this indicator be reviewed and that testing and reporting timeframes be harmonised.

Indicator 7 Collection and receipt of second samples

Overall 37% of second samples were received within ten days. Follow up was completed for 96% of infants however the data may not be complete due to the timing of this report.

Recommendations:

Include this indicator in annual reporting not quarterly.

Review resource and processes for notification and chase up of outstanding second samples.

Indicator 8 Diagnosis and commencement of treatment by disorder

This indicator is not reported here as data is not complete (February 2012) for babies screened in 2011. A supplementary report will be provided when the data is available.

Recommendations:

That this indicator be included in annual reporting.

Indicator 9 Blood spot card storage and return.

99% of 152 requests for card return met the standard of within 28 days of completion of screening. One of the two requests had insufficient information (which has not yet been received) and the other was returned in 33 days (the request was made over the holiday period).

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 fourth 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 NZ Dep 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 72 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. From this report the age of the baby is reported in hours unless the date and time of birth and sample collection are not provided.

A proportion of samples do not give the time of collection. The percentage meeting the standard is calculated from the total number of infants but would be higher if it 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 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 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.

Newborn Metabolic Screening Coverage

Overall samples were received from 61,856 newborns between January and December 2011. The number of newborns screened is determined by the number of unique NHI numbers for each DHB. Some instances of the same NHI number used for more than one infant in a DHB have been found which explains why the total number of infants counted in this way is slightly less than when counted by other parameters.

The numbers screened by DHB are given in Table 2, by ethnicity in Table 3 and by NZDep in Table 4.

Data from National Maternity Collection of the Ministry of Health shows 62,487 babies were born in 2011. The numbers given are babies screened and there may be a different number if the count was of screens done on babies born in the timeframe. Approximately 99% of babies were screened.

Table 2: Number of babies screened by DHB, January – December 2011

DHB region	No.
Northland	2287
Waitemata	7820
Auckland	6576
Counties Manukau	8663
Waikato	5368
Lakes	1590
Bay of Plenty	2887
Tairawhiti	694
Taranaki	1563
Hawkes Bay	2249
Whanganui	837
Mid Central	2321
Hutt Valley	2054
Capital and Coast	3861
Wairarapa	535
Nelson Marlborough	1671
West Coast	420
Canterbury	6094
South Canterbury	563
Southern	3697
Not recorded	97
Total	61847

Table 3: Number of babies screened by Group 1 and Group 2 Ethnicity, January to December 2011

Ethnicity (*Group 1 Group 2)*	**No. of babies**
Maori	*13,940*
Pacific	*6,859*
Cook Island Maori	1,008
Fijian	481
Niuean	361
Samoan	3,023
Tokelauan	123
Tongan	1,563
Other Pacific	300
Asian	*7,148*
Chinese	2,481
Indian	2,230
Southeast Asian	750
Other Asian	1,687
European	*32,611*
NZ European	28,595
Latin American / Hispanic	229
Other European	3,787
Other	*1,298*
African	418
Middle Eastern	435
Other/not known	445
Total	**61,856**

Table 4: Number of babies screened by NZDep, January to December 2011

NZ Dep	**No. of babies**
1	3,886
2	4,840
3	4,624
4	4,808
5	5,760
6	5,787
7	6,628
8	7,882
9	8,538
10	8,992
Not recorded	111
Total	61,856

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

This data is now available in hours. Overall 65.2% of samples were taken in the recommended timeframe of 48-72 hours. As expected this shows an increase over the 40% collected at 2 days as given in previous reports.

For this period no DHB region met the standard of 95% of samples taken between 48 and 72 hours. Table 5 shows the percentage of samples taken between 48-72 hours, as well as those outside of this timeframe, by DHB. Figure 1 shows the percentage of samples taken 48-72 hours by DHB compared with the overall average of 65.2% at 2 days.

In comparison with previous reports there is a significantly higher proportion where it is not possible to calculate the age of the baby at sampling because data (time of birth, date and time of sample collection) have not been provided on the test card. This seriously impacts the ability of the programme to correctly interpret test results and probably underestimates the percentage of samples taken in the correct timeframe. For example, ADHB has 52.4% collected in the timeframe, but if those samples for which the time is not available are excluded 84.1% are collected at 48-72 hours.

Table 5: Percentage of samples taken at 2 days, by DHB, October to December 2011

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	345	61.4	3	0.5	171	30.4	43	7.7	562
Waitemata	1,197	60.8	10	0.5	382	19.4	381	19.3	1,970
Auckland	847	52.4	7	0.4	153	9.5	608	37.6	1,615
Counties Manukau	1,259	58.8	15	0.7	615	28.7	251	11.7	2,140
Waikato	734	56.2	14	1.1	451	34.5	108	8.3	1,307
Lakes	266	64.6	4	1.0	120	29.1	22	5.3	412
Bay of Plenty	319	48.0	1	0.2	309	46.5	35	5.3	664
Tairawhiti	86	56.2		0.0	56	36.6	11	7.2	153
Taranaki	295	80.6	3	0.8	58	15.8	10	2.7	366
Hawkes Bay	420	77.3	1	0.2	93	17.1	29	5.3	543
Whanganui	119	60.1	2	1.0	69	34.8	8	4.0	198
Mid Central	414	74.3	5	0.9	116	20.8	22	3.9	557
Hutt Valley	277	52.2	1	0.2	228	42.9	25	4.7	531
Capital and Coast	697	74.3	6	0.6	185	19.7	50	5.3	938
Wairarapa	95	70.9	1	0.7	33	24.6	5	3.7	134
Nelson Marlborough	325	81.9	0	0.0	62	15.6	10	2.5	397
West Coast	75	83.3	1	1.1	13	14.4	1	1.1	90
Canterbury	1,278	88.2	5	0.3	117	8.1	49	3.4	1,449
South Canterbury	113	87.6	0	0.0	14	10.9	2	1.6	129
Southern	650	74.0	7	0.8	180	20.5	41	4.7	878
Not recorded	6	18.2	0	0.0	10	30.3	17	51.5	33
Total	9,817	65.2	86	0.6	3,435	22.8	1,728	11.5	15,066

Figure 1: Percentage of samples taken 48-72 hours, by DHB, October to December 2011

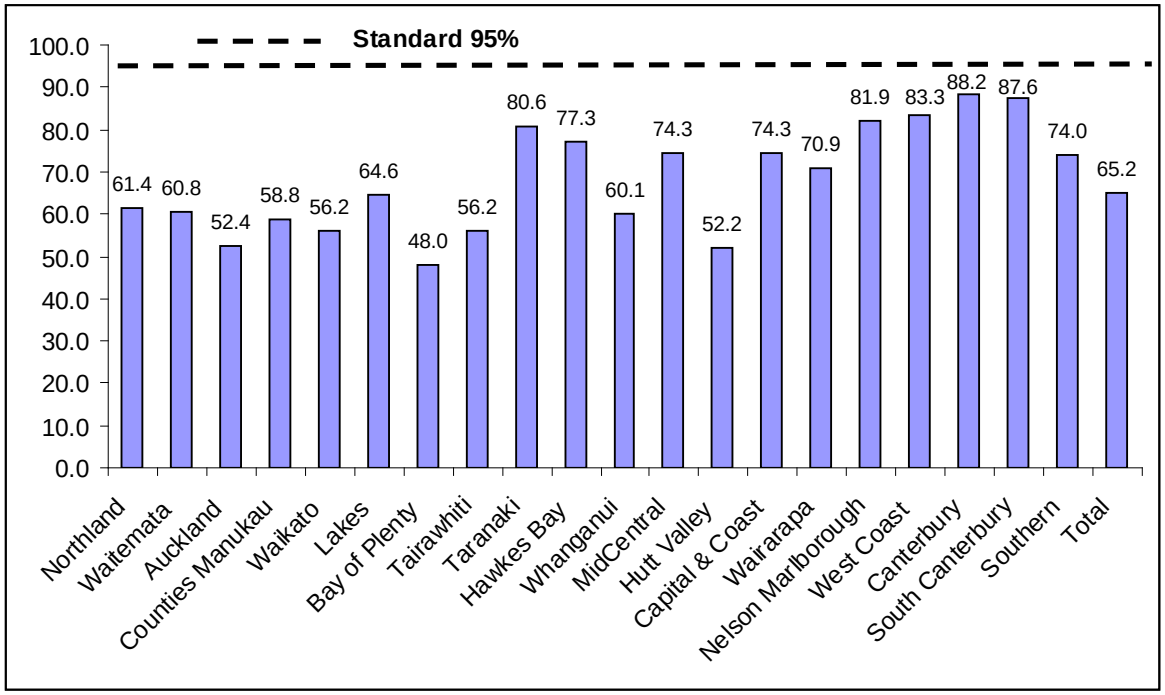


Figure 2 below and Table 6 identify some small differences between ethnic groups. While no ethnic group met the standard of 95% the percentages for European and Other appear higher than for the remaining ethnic groups. This is similar to the previous three reports.

Figure 2: Percentage of samples taken at 48-72 hours, by ethnicity, October to December 2011

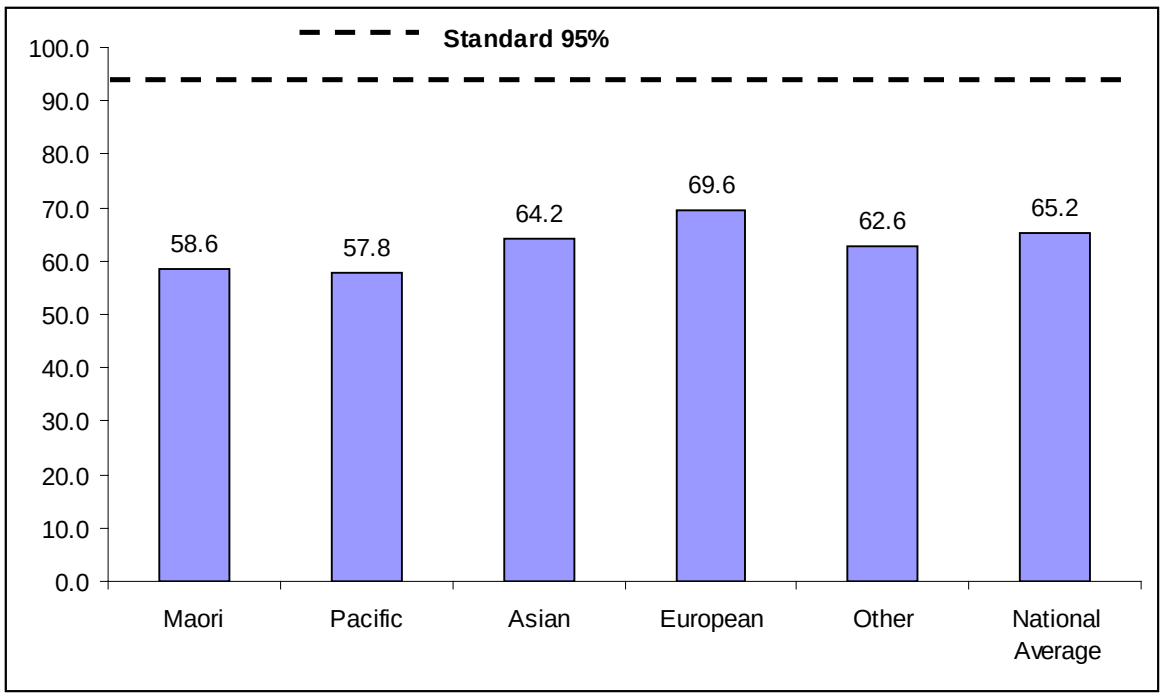


Table 6: Percentage of samples taken at 48-72 hours days, by Group 1 and Group 2 Ethnicity, October to December 2011

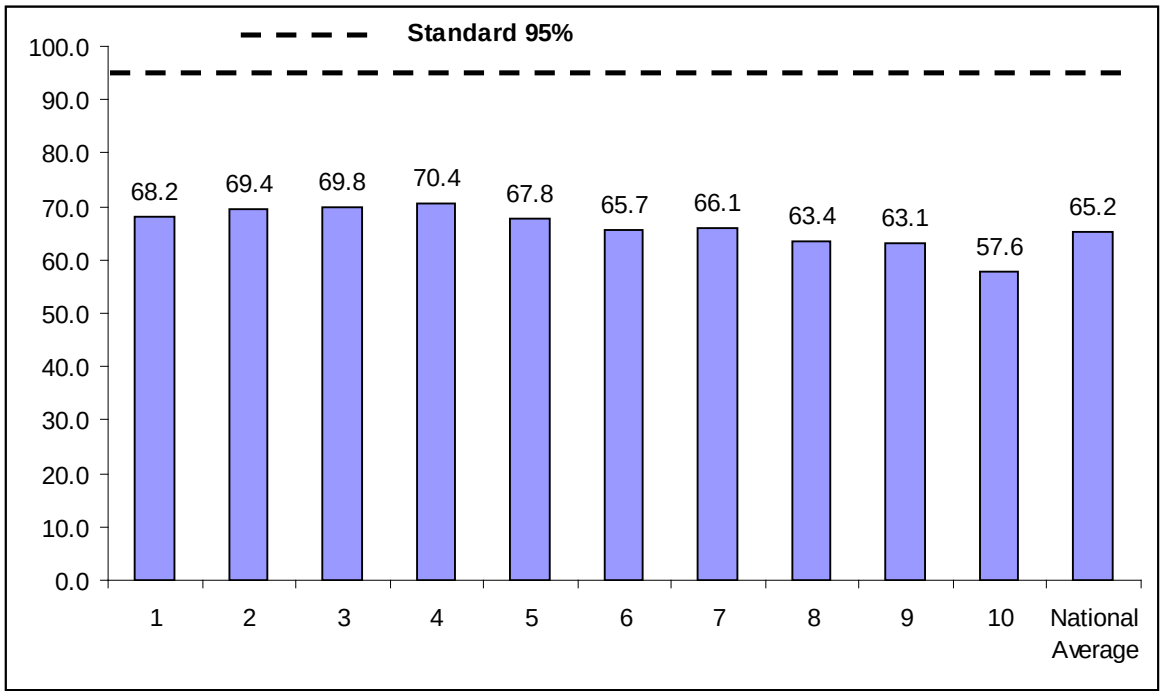
Ethnicity (*Group 1 Group 2)*	Sampled at 48-72 hrs		Sampled less than 48 hrs		Sampled over 72 hrs		No collection date and / or time		Total babies
	No.	%	No.	%	No.	%	No.	%	No.
Maori	*1,925*	*58.6*	*27*	*0.8*	*998*	*30.4*	*333*	*10.1*	*3,283*
Pacific	*940*	*57.8*	*8*	*0.5*	*419*	*25.8*	*258*	*15.9*	*1,625*
Cook Island Maori	121	53.3	4	1.8	64	28.2	38	16.7	227
Fijian	71	62.8	1	0.9	30	26.5	11	9.7	113
Niuean	45	57.0	1	1.3	18	22.8	15	19.0	79
Samoan	446	61.9	2	0.3	171	23.7	102	14.1	721
Tokelauan	16	44.4	0	0.0	15	41.7	5	13.9	36
Tongan	189	50.7	0	0.0	105	28.2	79	21.2	373
Other Pacific	52	68.4	0	0.0	16	21.1	8	10.5	76
Asian	*1,157*	*64.2*	*5*	*0.3*	*342*	*19.0*	*299*	*16.6*	*1,803*
Chinese	395	66.2		0.0	94	15.7	108	18.1	597
Indian	336	59.7	3	0.5	127	22.6	97	17.2	563
Southeast Asian	127	63.8	1	0.5	33	16.6	38	19.1	199
Other Asian	299	67.3	1	0.2	88	19.8	56	12.6	444
European	*5,594*	*69.6*	*43*	*0.5*	*1,608*	*20.0*	*789*	*9.8*	*8,034*
NZ European	4,900	69.9	34	0.5	1,414	20.2	663	9.5	7,011
Latin American / Hispanic	31	64.6		0.0	4	8.3	13	27.1	48
Other European	663	68.0	9	0.9	190	19.5	113	11.6	975
Other	*201*	*62.6*	*3*	*0.9*	*68*	*21.2*	*49*	*15.3*	*321*
African	57	55.9	1	1.0	25	24.5	19	18.6	102
Middle Eastern	75	73.5	0	0.0	14	13.7	13	12.7	102
Other/not known	69	59.0	2	1.7	29	24.8	17	14.5	117
Total	*9,817*	*65.2*	*86*	*0.6*	*3,435*	*22.8*	*1,728*	*11.5*	*15,066*

Table 7 and Figure 3 below show the number of samples taken between 48 and 72 hours 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 7: Percentage of samples taken at 48-72 hours by NZDep, October to December 2011

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	659	68.2	3	0.3	192	19.9	112	11.6	966
2	844	69.4	5	0.4	199	16.4	169	13.9	1,217
3	783	69.8	4	0.4	207	18.5	127	11.3	1,121
4	811	70.4	2	0.2	203	17.6	136	11.8	1,152
5	963	67.8	9	0.6	300	21.1	148	10.4	1,420
6	924	65.7	10	0.7	296	21.1	176	12.5	1,406
7	1,084	66.1	6	0.4	370	22.5	181	11.0	1,641
8	1,208	63.4	11	0.6	478	25.1	209	11.0	1,906
9	1,281	63.1	19	0.9	513	25.3	216	10.6	2,029
10	1,252	57.6	17	0.8	666	30.7	237	10.9	2,172
Not recorded	8	22.2	0	0.0	11	30.6	17	47.2	36
Total	9,817	65.2	86	0.6	3,435	22.8	1,728	11.5	15,066

Figure 3: Percentage of samples taken at 48-72 hours, by NZDep, October to December 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

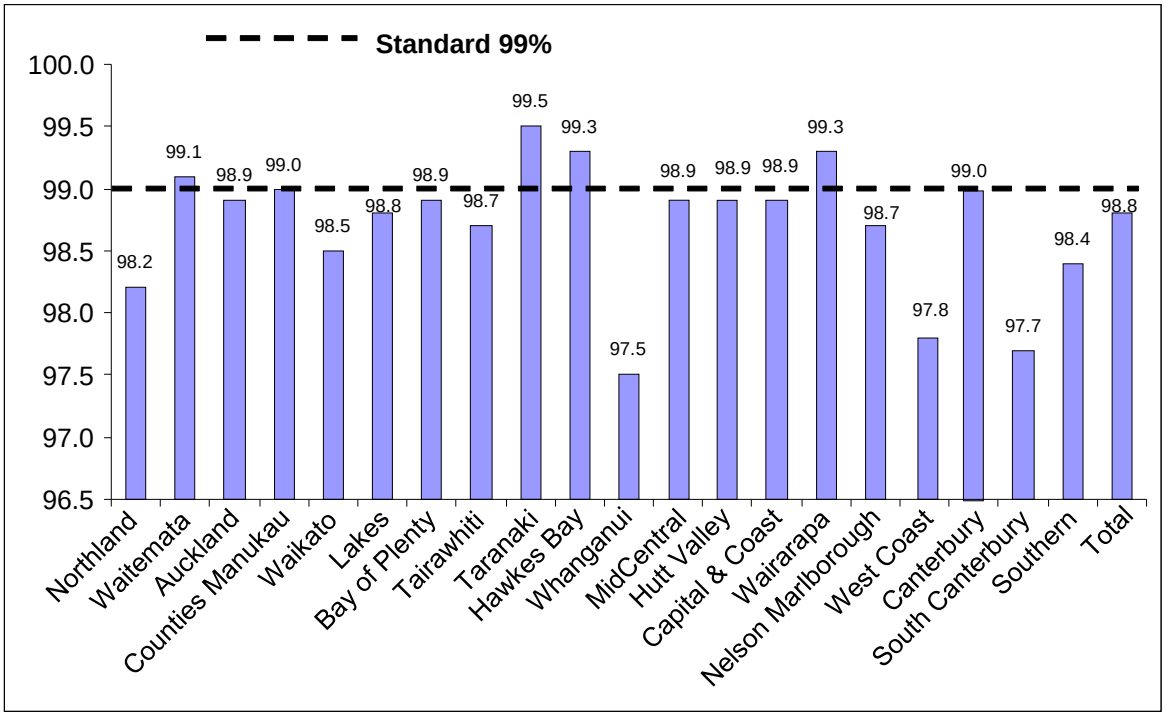
Six DHBs (Waitemata, Counties Manukau, Taranaki, Hawkes Bay, Wairarapa and Canterbury) met or exceeded the standard of 99% of samples satisfactory for testing and a further 11 achieved 98-99%.

During 2011 the quarter performance for blood sample quality has been overall 98.6%, 98.5%, 98.7% and this quarter 98.8%. The number of DHBs meeting the target over the year is 4, 3, 3 and this quarter 6. This may represent an improvement due to the supply of high-quality lancets to LMCs.

Table 8: Percentage of blood samples that meet quality standards by DHB, October to December 2011

DHB region	Satisfactory		Unsatisfactory		Total samples
	No.	%	No.	%	No.
Northland	552	98.2	10	1.8	562
Waitemata	1,953	99.1	17	0.9	1,970
Auckland	1,598	98.9	17	1.1	1,615
Counties Manukau	2,118	99.0	22	1.0	2,140
Waikato	1,287	98.5	20	1.5	1,307
Lakes	407	98.8	5	1.2	412
Bay of Plenty	657	98.9	7	1.1	664
Tairawhiti	151	98.7	2	1.3	153
Taranaki	364	99.5	2	0.5	366
Hawkes Bay	539	99.3	4	0.7	543
Whanganui	193	97.5	5	2.5	198
Mid Central	551	98.9	6	1.1	557
Hutt Valley	525	98.9	6	1.1	531
Capital and Coast	928	98.9	10	1.1	938
Wairarapa	133	99.3	1	0.7	134
Nelson Marlborough	392	98.7	5	1.3	397
West Coast	88	97.8	2	2.2	90
Canterbury	1,434	99.0	15	1.0	1,449
South Canterbury	126	97.7	3	2.3	129
Southern	864	98.4	14	1.6	878
Not recorded	32	97.0	1	3.0	33
Total	14,892	98.8	174	1.2	15,066

Figure 4: Percentage of blood samples that meet quality standards by DHB, October to December 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

No DHB met the standard of 95% of samples received in four days or less. The significant improvement seen in Quarter 3 has not been sustained although this is quite possibly due the holiday period. 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 9: Percentage of samples received by the laboratory within four days by DHB, October to December 2011

DHB region	Less than or equal to 4 days		Greater than 4 days		Unknown		Total samples
	No.	%	No.	%	No.	%	No.
Northland	388	69.0	164	29.2	10	1.8	562
Waitemata	1,457	74.0	483	24.5	30	1.5	1,970
Auckland	1,272	78.8	321	19.9	22	1.4	1,615
Counties Manukau	1,538	71.9	575	26.9	27	1.3	2,140
Waikato	908	69.5	379	29.0	20	1.5	1,307
Lakes	304	73.8	103	25.0	5	1.2	412
Bay of Plenty	403	60.7	247	37.2	14	2.1	664
Tairawhiti	69	45.1	80	52.3	4	2.6	153
Taranaki	263	71.9	100	27.3	3	0.8	366
Hawkes Bay	357	65.7	176	32.4	10	1.8	543
Whanganui	144	72.7	52	26.3	2	1.0	198
Mid Central	354	63.6	195	35.0	8	1.4	557
Hutt Valley	310	58.4	210	39.5	11	2.1	531
Capital and Coast	658	70.1	263	28.0	17	1.8	938
Wairarapa	100	74.6	33	24.6	1	0.7	134
Nelson Marlborough	275	69.3	120	30.2	2	0.5	397
West Coast	58	64.4	31	34.4	1	1.1	90
Canterbury	939	64.8	495	34.2	15	1.0	1,449
South Canterbury	75	58.1	54	41.9		0.0	129
Southern	542	61.7	324	36.9	12	1.4	878
Not recorded	7	21.2	23	69.7	3	9.1	33
Total	10,421	69.2	4,428	29.4	217	1.4	15,066

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

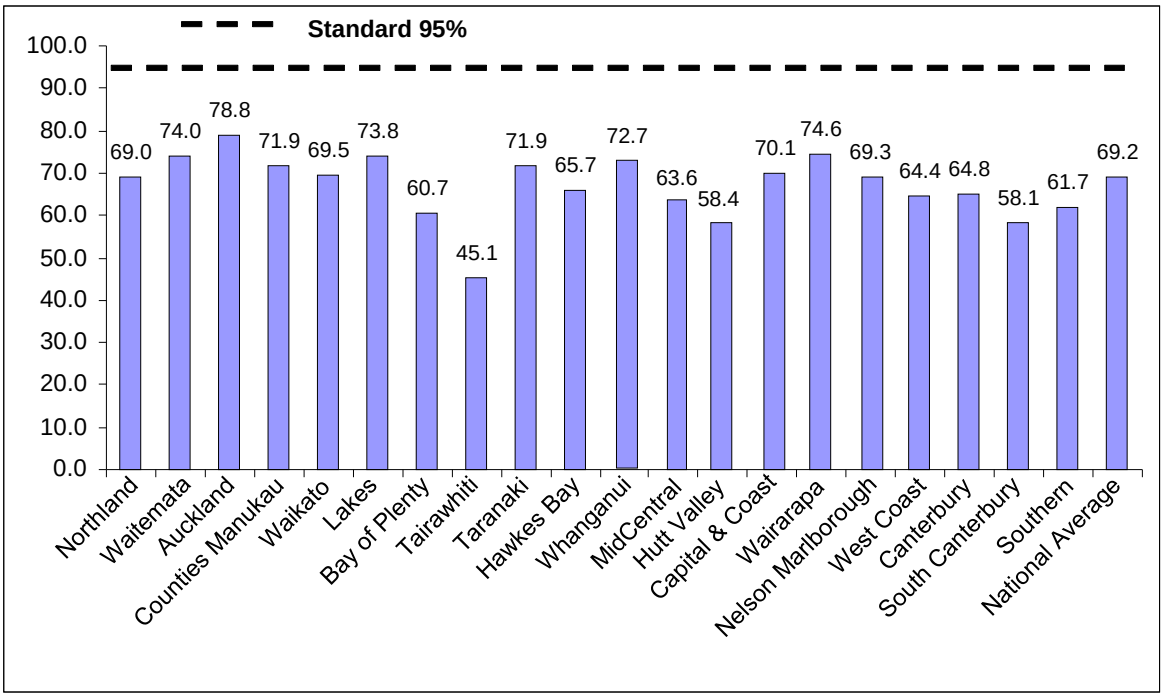
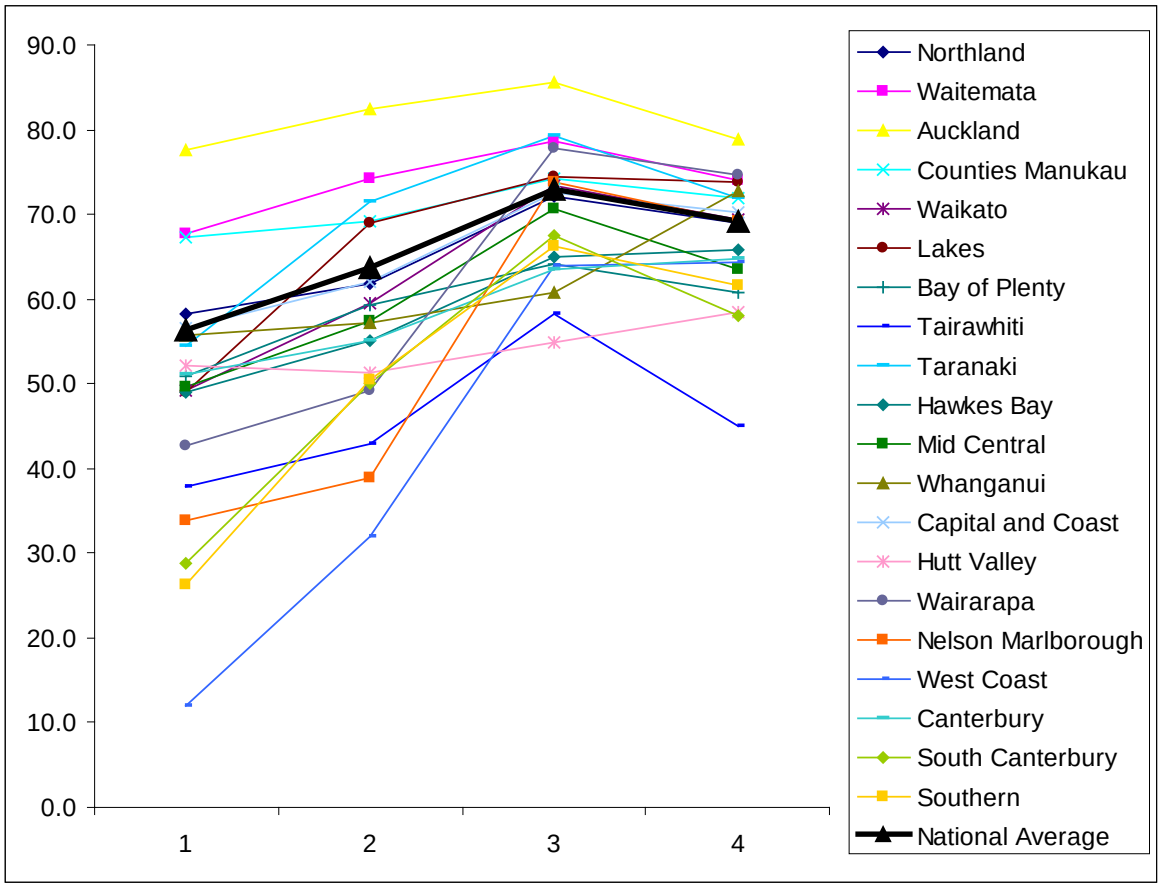


Figure 6: Percentage of samples received by laboratory within 4 days by DHB, for January to March, April to June and July to September 2011 (Data from Monitoring Reports 1-3)



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 10 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. The conditions for which the testing is done on the tandem mass spectrometer have the lowest percentage turnaround time meeting the timeframe due to breakdowns of the instrument and backup being sending samples to Australia.

Table 10: Percentage of results available within specified timeframes, by disorder, October to December 2011 (n=15,066 samples)

Disorder	Expected timeframe (days)	Number met timeframe	% met timeframe
Congenital Adrenal Hyperplasia	2	15,006	99.6
Galactosaemia	2	15,027	99.7
Amino acid disorders	2	14,742	97.9
Fatty acid oxidation disorders	2	14,742	97.9
Biotinidase deficiency	5	15,047	99.9
Cystic fibrosis	5	14,914	99.0
Congenital hypothyroidism	5	15,047	99.9

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
Congenital Adrenal Hyperplasia	3
Galactosaemia	3
Congenital hypothyroidism	4
Biotinidase deficiency	9
Cystic fibrosis	12

METHODOLOGY

Indicator 6

Numerator: Number of babies who are notified to their referrer for further testing for a particular disorder within the number of calendar days specified for that disorder.

Denominator: Number of babies who receive a positive screening result for a particular disorder.

Timeliness of Reporting Notification of Screen Positives

Most screening tests have a two-tier reporting system. Where results are highly likely to indicate the disorder is present, the results are telephoned to the LMC and referral made to an appropriate subspecialist paediatrician. All results in this category were reported inside the timeframes.

Marginal test results are reported by mail, and in this case the written report is not generated until all the screening test results are available. The results are available and will be phoned if there is a clinical reason to do so (as above). Of 86 reports which did not meet the turnaround time, 38 were due to waiting for cystic fibrosis gene testing or biotinidase deficiency screening results (all the delayed cystic fibrosis screen reporting was due to delayed gene results); 19 were due to waiting for aminoacid and fatty acid oxidation screening results delayed due to breakdowns in the tandem mass spectrometer; 21 delayed due to a delay in signout (which reflects the availability of senior staff) and 9 for other reasons.

In many cases where reporting does not meet the timeframe the testing time for that specimen does meet the timeframe because testing turnaround times are specified in working days but reporting times in calendar days e.g. CAH is two days for test result being available and three days for reporting. A sample which arrives on Friday and has a test result available and reported on Monday meets the testing timeframe but not the reporting timeframe.

It is recommended that the testing and reporting timeframes be harmonised.

Table 11: Percentage of results reported within specified timeframes, by disorder, October to December 2011 (n=15,066 samples)

Reason for report	Calendar days (from receipt in lab to report)	Number of positive test reports	Number met timeframe	% met timeframe
Amino acid & fatty acid oxidation disorders	3	195	146	74.9
Congenital Adrenal Hyperplasia	3	57	34	59.6
Galactosaemia	3	4	4	100
Congenital Hypothyrodism	4	30	29	96.7
Biotinidase deficiency	9	1	1	100
Cystic fibrosis	12	32	19	59.4

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.

Collection and receipt of second samples

Second samples are requested when samples are not suitable for testing or there are minor elevations of screened metabolites. Table 12 details:

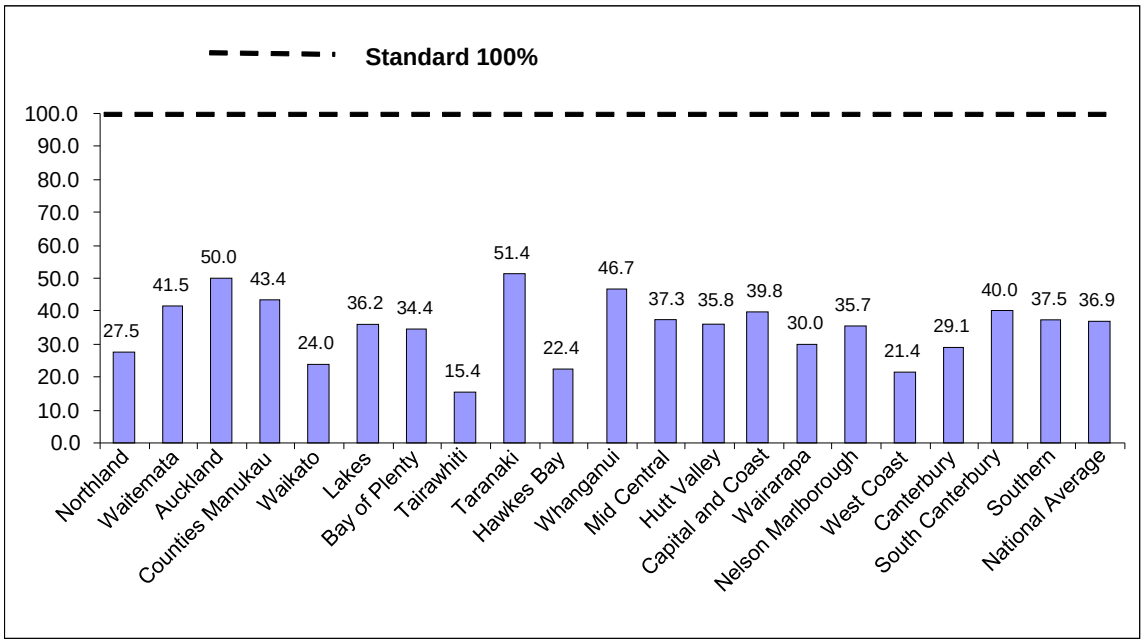
- the timeframe for receipt of second samples (less than or equal to 10 days or greater than 10 days),
- whether other follow up occurred (e.g. notification of decline of resampling, follow up thyroid testing in the community; note the dates of notification of other follow up are recorded but not easily accessible),
- the number with no follow up, and
- whether follow up is complete.

This data was collated mid-February 2012 and second samples and follow up notification was still being received at that time, hence individual DHB figures for completed follow up may change. However data for second samples received within ten days is complete, and no DHB meets the standard of 100%.

Table 12: Follow-up of requested second samples by DHB, January to December 2011

DHB region	Less than or equal to 10 days		Greater than 10 days		Other follow up		No follow up		Follow up complete		Total samples
	No.	%	No.	%	No.	%	No.	%	No.	%	No.
Northland	22	27.5	52	65.0	2	2.5	4	5.0	76	95.0	80
Waitemata	85	41.5	104	50.7	7	3.4	9	4.4	196	95.6	205
Auckland	86	50.0	73	42.4	5	2.9	8	4.7	164	95.3	172
Counties Manukau	124	43.4	148	51.7	5	1.7	9	3.1	277	96.9	286
Waikato	40	24.0	109	65.3	14	8.4	4	2.4	163	97.6	167
Lakes	17	36.2	25	53.2	3	6.4	2	4.3	45	95.7	47
Bay of Plenty	22	34.4	40	62.5	1	1.6	1	1.6	63	98.4	64
Tairawhiti	4	15.4	19	73.1	0	0.0	3	11.5	23	88.5	26
Taranaki	19	51.4	13	35.1	2	5.4	3	8.1	34	91.9	37
Hawkes Bay	13	22.4	42	72.4	0	0.0	3	5.2	55	94.8	58
Whanganui	14	46.7	16	53.3	0	0.0	0	0.0	30	100.0	30
Mid Central	22	37.3	31	52.5	3	5.1	3	5.1	56	94.9	59
Hutt Valley	19	35.8	31	58.5	2	3.8	1	1.9	52	98.1	53
Capital and Coast	39	39.8	55	56.1	0	0.0	4	4.1	94	95.9	98
Wairarapa	6	30.0	13	65.0	0	0.0	1	5.0	19	95.0	20
Nelson Marlborough	10	35.7	18	64.3	0	0.0	0	0.0	28	100.0	28
West Coast	3	21.4	11	78.6	0	0.0	0	0.0	14	100.0	14
Canterbury	44	29.1	102	67.5	3	2.0	2	1.3	149	98.7	151
South Canterbury	6	40.0	8	53.3	1	6.7	0	0.0	15	100.0	15
Southern	36	37.5	55	57.3	3	3.1	2	2.1	94	97.9	96
Not recorded	2	25.0		0.0	0	0.0	6	75.0	2	25.0	8
Total	633	36.9	965	56.3	51	3.0	65	3.8	1649	96.2	1714

Figure 7: Follow-up of requested samples by DHB, for January to December 2011



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
Congenital hypothyroidism	10
Congenital Adrenal Hyperplasia	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.

Diagnosis and commencement of treatment by disorder

This data is incomplete at the time of reporting (February 2012) because not all diagnoses arising from samples collected in December are complete. It will be supplied as part of the annual report.

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 152 requests for card returns during the reporting period 1 October to 31 December 2011, 150 (98.7%) were returned in the timeframe. One card has not been returned as the request for return was not signed and the mother has been contacted but no reply received. In the other case the card was returned in 33 days the request being made during the holiday period. In general samples are returned very quickly with a median time over this period of 1.3 days. This has been consistent for the whole of 2011.