National Screening Unit

Newborn Metabolic Screening Programme

Newborn Metabolic Screening Programme (NMSP)

Quarterly Monitoring Report

Number 8

1 October to 31 December 2012

Disclaimer

This publication reports on information provided to the Ministry of Health by Auckland District Health Board. The purpose of this publication is to inform discussion and assist ongoing NMSP development. All care has been taken in the production of this report, and the data was deemed to be accurate at the time of publication. However, the data may be subject to slight changes over time as further information is received. Before quoting or using this information, it is advisable to check the current status with the Ministry of Health.

Acknowledgements

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Executive Summary

This is the eighth 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. Seven indicators are covered by this report and two will be reported in the annual 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 report four the age of the baby is reported in hours unless the date and time of birth and sample collection are not provided. The improvement in the quality of data to monitor this indicator is a significant achievement for the NMSP.

The NMSP is overseen nationally by the National Screening Unit (NSU) of the Ministry of Health. Almost all babies born in New Zealand have been screened since the NMSP began in 1969, and as a result, approximately 45 babies are identified with and treated for a metabolic disorder each year. When a baby is diagnosed with a metabolic disorder in early infancy, treatment can commence immediately, preventing life-threatening illness and limiting the impact on the baby's development potential.

The NMSP is monitored and evaluated by the NSU to ensure it continuously meets high standards. A multi-disciplinary advisory group provides expert leadership and advice for the programme. The NMSP Technical Group has reviewed this Monitoring Report and considered key findings and made recommendations for on-going monitoring and initiatives to improve the programme which are included in the recommendations below.

Key points and recommendations:

Indicator 2 Timing of sample-taking

Overall 72.3% of samples were collected between 48-72 hours. No DHB met the standard of 95% of samples taken in the timeframe (range 50-90%). It is not possible to calculate this indicator for about 4% of samples since they do not have the date and time of both birth and collection. The standard was not met for any ethnic group (range 61-76%) or NZDep group (range 63-79%).

This data is similar to that in reports 4 - 7. There has been a notable improvement in the percentage of samples taken in the correct timeframe for babies born in Tairawhiti DHB. Key senior members of the NSMP team delivered a series of education sessions in this DHB in early April and this has been sustained.

Recommendations:

NSU to follow up with DHBs who have under 70% of samples taken between 48-72 hours, focusing on the four under 65% as a priority, as per the recommendations in the previous report (July – September 2012).

Indicator 3 Quality of blood samples

There has been significant improvement in this indicator since the first report. Thirteen DHBs met or exceeded the standard of 99% of samples satisfactory for testing with Nelson Marlborough achieving 100%. All remaining DHBs achieved between 98-99%.

During 2011-2012 the quarter performance for blood sample quality was been overall 98.6%, 98.5%, 98.7%, 98.8%, 99.1%, 99.2%, 99.2% and this quarter 99.1%. This improvement may be due to the supply of high-quality lancets to LMCs.

Recommendations:

No recommendation.

Indicator 4 Sample dispatch and delivery

Overall 76% 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, 70% in October – December, 68% in January – March 2012, 69% April – June 2012, 72% July – September 2012 and 76% in this report). 95% are received in 7 days or less.

Recommendations:

NSU to follow up with DHBs who have under 70% of samples received by the laboratory within four days.

Indicator 5 Laboratory testing timeframes

The standard of 100% was not met for any disorder however most timeframes were very close to this being between 99.8 and 99.9%. The exception is screening for fatty acid oxidation and aminoacid breakdown disorders which has a low percentage (97.8%) meeting the turnaround time due to instrument breakdowns.

Recommendations:

The testing timeframe for congenital hypothyroidism to be discussed with the *Human Genetics Society of Australasia / Royal Australasian College of Physicians Division of Paediatrics Joint Newborn Screening Subcommittee* (HGSA/RACP Subcommittee).

Indicator 6 Timeliness of Reporting – Notification of Screen Positives

Only screening for galactosemia met the standard of 100% of reports notified in the specified timeframe. For other disorders 0-90% of reports met the standard. All clinical critical results were notified in the timeframe. Because this indicator is in calendar days and Indicator 5 in working days results can meet the testing timeframe but not the reporting standard.

Recommendations:

This indicator is to be discussed with HGSA/RACP Subcommittee and then reviewed at the July Technical Group meeting.

Indicator 7 Collection and Receipt of Second Samples

Overall 42.3% of requested second samples were received in ten days or less, up from 36.9% in 2011. Followup was complete in 11 DHBs, up from 5 in 2011.

Recommendations:

This indicator to be reviewed in 2013.

Indicator 9 Blood spot card storage and return.

99% of 171 requests for card return met the standard of within 28 days of completion of screening. The outstanding request was to return to a Post Office Box which cannot be done by tracked courier. No response has been received to a request to supply a street address.

Recommendations:

Continue to monitor and review annual data for 2011.

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 eighth 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 NHIs. 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 2012 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 67 such samples from approximately 15,300 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 report 4 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			X	
8. Diagnosis and commencement of treatment by disorder: • Biotinidase deficiency • Cystic fibrosis • Congenital hypothyroidism • Congenital adrenal hyperplasia • Galactosaemia • Amino acid disorders • Fatty acid oxidation disorders			X	
9. Blood spot card storage and return	X	X	X	

Indicator 2 – Timing of sample taking

2: TIMING OF SAMPLE –TAKING
DESCRIPTION 1. The proportion of eligible babies who have a newborn metabolic screening sample taken. 2. The proportion of eligible babies who have a newborn metabolic screening sample taken between 48 and 72 hours of birth.
RATIONALE Timely sample collection leads to the best possible chance of a baby receiving early diagnosis and treatment where necessary. Severe forms of some of the disorders screened for can be fatal within seven to ten days. Many may not show any signs or symptoms of disease until irreversible damage has occurred. However, the baby must have been independent of their mother long enough for their indicator biochemicals to show an abnormality. Therefore the optimum window for sample collection is between 48 and 72 hours of birth.
RELEVANT OUTCOME Babies screened should have a newborn metabolic screening sample taken between 48 and 72 hours of birth.
STANDARD 95% of first samples are taken between 48 and 72 hours of birth.
METHODOLOGY ***Indicator 2*** Numerator: Number of babies who have a newborn metabolic screening sample taken between 48 and 72 hours of birth. Denominator: Number of babies who have a newborn metabolic screening sample taken.
NOTES • Samples for screening must be taken in accordance with Programme Guidelines and Policy and Quality requirements. • Reporting by: ➢ DHB ➢ Ethnicity ➢ Deprivation status

Timing of Sample Taking

Overall 72.3% (range 50-90%) of samples were taken in the recommended timeframe of 48-72 hours, similar to previous reports.

For this period no DHB region met the standard of 95% of samples taken between 48 and 72 hours. Table 2 shows the percentage of samples taken between 48-72 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 72.3 at 48-72 hours.

The notable improvement in the percentage of samples taken in the correct timeframe for babies born in Tairawhiti DHB reported in April-June 2012 had been sustained (see figure 2).

Overall there has been little change in this indicator over Reports 6-8 (April to December 2012) as shown in Figure 2.

The number of samples in which it is not possible to calculate the age of the baby at sampling because data (time of birth, date and time of sample collection) have not been provided on the test card is about 4%. This impacts the ability of the programme to correctly interpret test results and may underestimate the percentage of samples taken in the correct timeframe.

Table 2 Percentage of samples taken at 48-72 hours, by DHB, October to December 2012

DHB region	Sampled 48-72 hours		Sampled less than 48 hours		Sampled greater than 72 hours		No Collection Date/ Time or no time of birth		Total babies
	No.	%	No.	%	No.	%	No.	%	No.
Northland	336	59.9	4	0.7	205	36.5	16	2.9	561
Waitemata	1,534	73.9	15	0.7	470	22.7	56	2.7	2,075
Auckland	1,464	82.5	25	1.4	234	13.2	51	2.9	1,774
Counties Manukau	1,353	62.4	16	0.7	678	31.3	121	5.6	2,168
Waikato	777	58.3	12	0.9	482	36.2	61	4.6	1,332
Lakes	265	68.5		0.0	104	26.9	18	4.7	387
Bay of Plenty	363	49.8	6	0.8	326	44.7	34	4.7	729
Tairawhiti	134	74.9	1	0.6	34	19.0	10	5.6	179
Taranaki	333	84.7	6	1.5	42	10.7	12	3.1	393
Hawkes Bay	436	78.3	2	0.4	106	19.0	13	2.3	557
Whanganui	143	58.6		0.0	97	39.8	4	1.6	244
MidCentral	437	78.7	5	0.9	95	17.1	18	3.2	555
Hutt Valley	325	67.7	4	0.8	137	28.5	14	2.9	480
Capital & Coast	761	76.9	11	1.1	184	18.6	34	3.4	990
Wairarapa	86	76.8	1	0.9	24	21.4	1	0.9	112
Nelson Marlborough	311	79.1	1	0.3	68	17.3	13	3.3	393
West Coast	83	78.3		0.0	19	17.9	4	3.8	106
Canterbury	1,382	90.2	8	0.5	108	7.0	34	2.2	1,532
South Canterbury	132	84.6		0.0	23	14.7	1	0.6	156
Southern	697	75.6	7	0.8	193	20.9	25	2.7	922
Not Recorded	12	19.4		0.0	9	14.5	41	66.1	62
National Average	11,364	72.3	124	0.8	3,638	23.2	581	3.7	15,707

Figure 1 Percentage of samples taken 48-72 hours, by DHB, October to December 2012

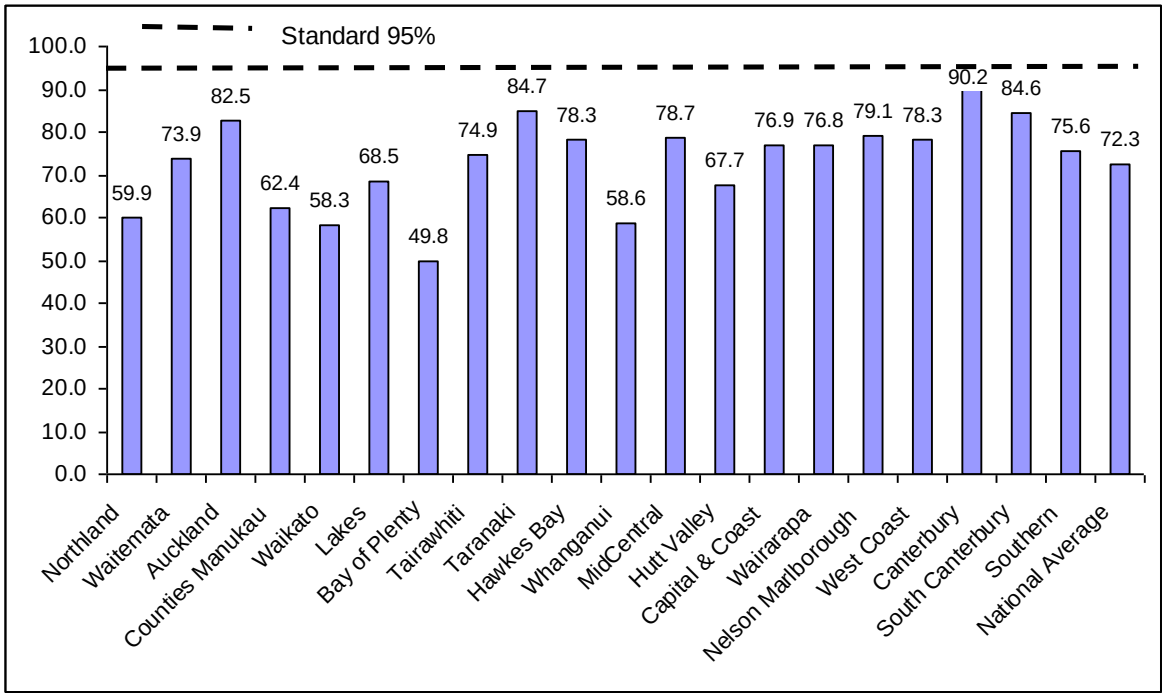
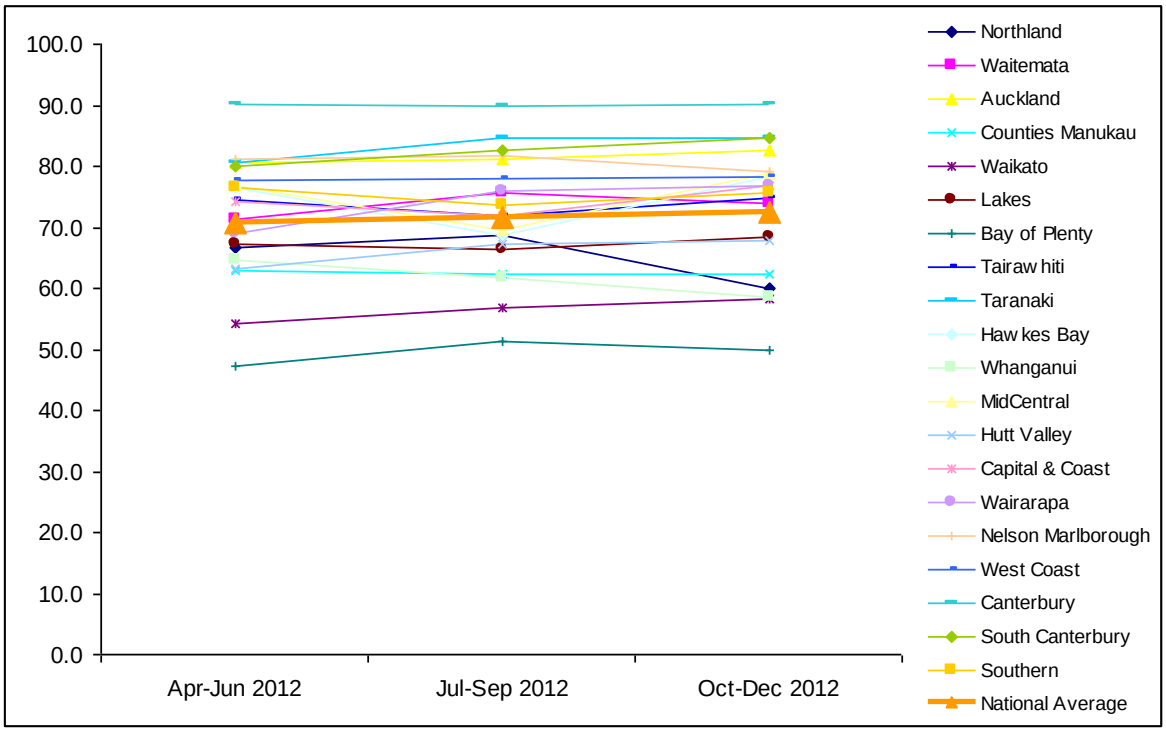


Figure 2 Percentage samples taken 48-72 hours, by DHB, April – December 2012 (data from reports 6, 7 and Table 1.



Although overall only 72.3% of samples were collected in the timeframe 93.3% (14648) were collected 2-5 days and 0.5% (86) at 10 days or older. Data is shown in figure 3.

Figure 3 Numbers of samples taken at different ages October to December 2012.

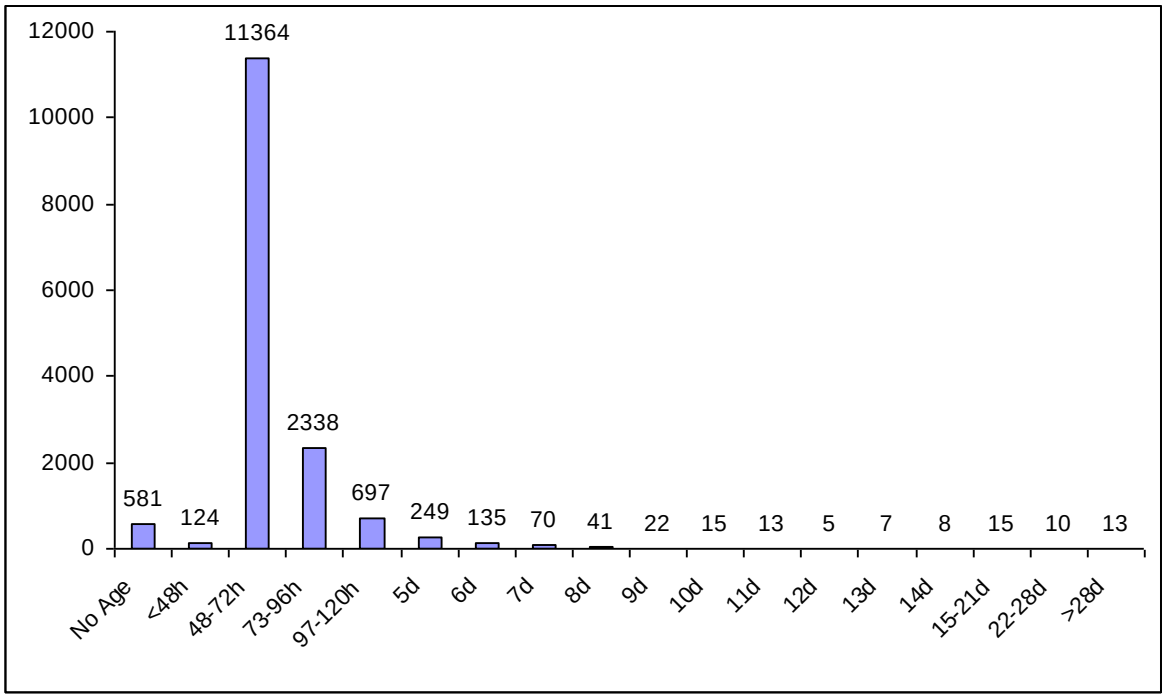


Figure 4 below and Table 3 identify some small differences between ethnic groups. While no ethnic group met the standard of 95% the percentages for European, Asian and Other appear higher than for the remaining ethnic groups. This is similar to the previous seven reports.

Figure 4 Percentage of samples taken at 48-72 hours, by ethnicity, October to December 2012

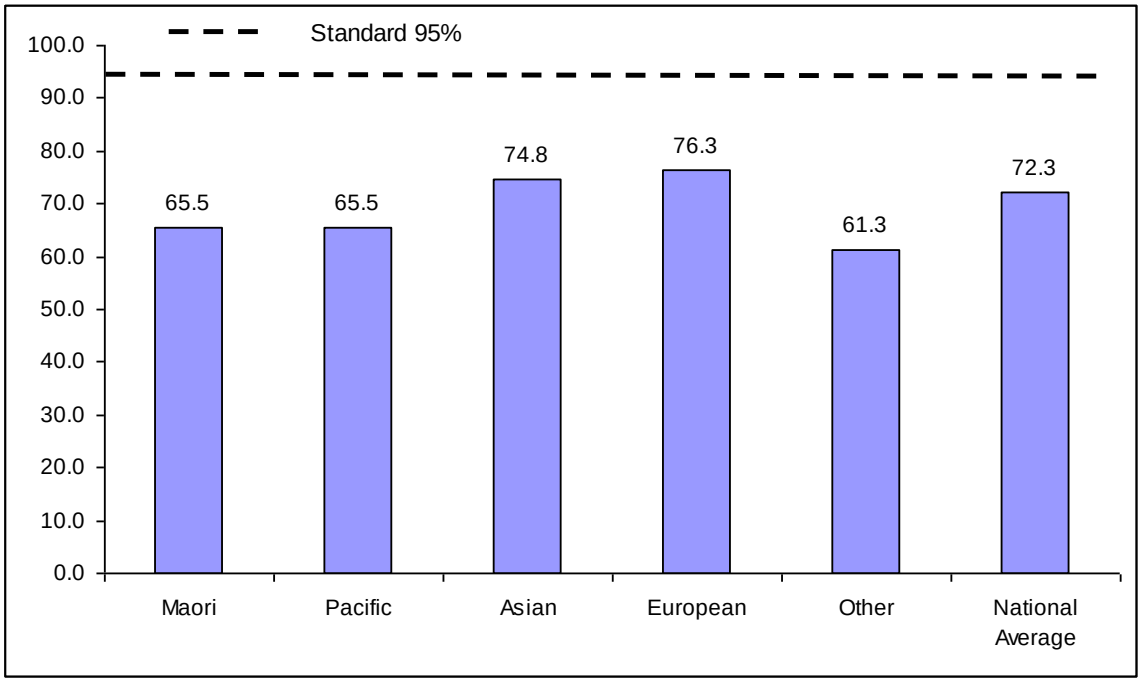


Table 3 Percentage of samples taken at 48-72 hours days, by Group 1 and Group 2 Ethnicity, October to December 2012

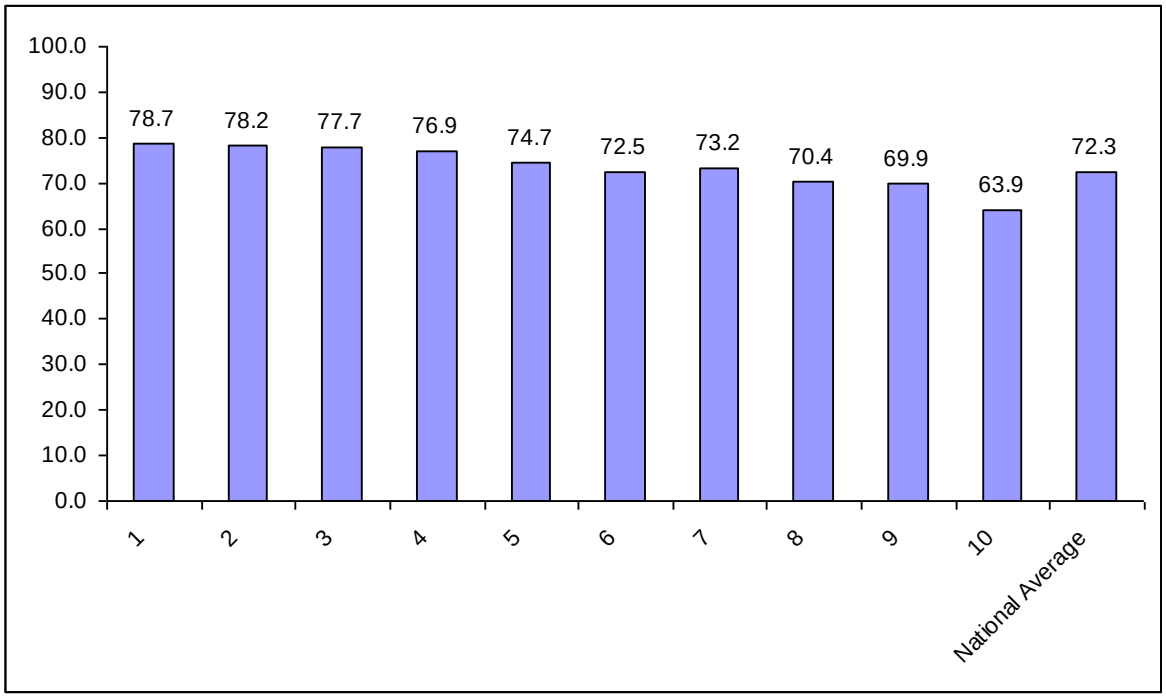
Ethnicity (*Group 1 Group 2)*	Sampled at 48-72 hrs		Sampled less than 48 hrs		Sampled over 72 hrs		No collection date and/or time		Total babies
	No.	%	No.	%	No.	%	No.	%	No.
Maori	2,181	65.5	20	0.6	999	30.0	132	4.0	3,332
Pacific	1,036	65.5	9	0.6	457	28.9	80	5.1	1,582
Cook Island Maori	129	62.3	1	0.5	67	32.4	10	4.8	207
Fijian	85	66.9	0	0.0	31	24.4	11	8.7	127
Niuean	67	69.8	1	1.0	23	24.0	5	5.2	96
Samoan	429	63.2	3	0.4	210	30.9	37	5.4	679
Tokelauan	18	75.0	0	0.0	5	20.8	1	4.2	24
Tongan	253	66.4	4	1.0	109	28.6	15	3.9	381
Other Pacific	55	80.9	0	0.0	12	17.6	1	1.5	68
Asian	1,769	74.8	26	1.1	496	21.0	74	3.1	2,365
Chinese	774	79.2	7	0.7	175	17.9	21	2.1	977
Indian	484	69.9	13	1.9	165	23.8	30	4.3	692
Southeast Asian	181	74.5	2	0.8	51	21.0	9	3.7	243
Other Asian	330	72.8	4	0.9	105	23.2	14	3.1	453
European	6,167	76.3	64	0.8	1,608	19.9	245	3.0	8,084
NZ European	5,326	76.1	56	0.8	1,403	20.0	213	3.0	6,998
Latin American / Hispanic	51	76.1	0	0.0	14	20.9	2	3.0	67
Other European	790	77.5	8	0.8	191	18.7	30	2.9	1,019
Other	211	61.3	5	1.5	78	22.7	50	14.5	344
African	71	69.6	0	0.0	27	26.5	4	3.9	102
Middle Eastern	83	69.7	4	3.4	26	21.8	6	5.0	119
Other/not known	57	46.3	1	0.8	25	20.3	40	32.5	123
National Average	11,364	72.3	124	0.8	3,638	23.2	581	3.7	15,707

Table 4 and Figure 5 below show the number of samples taken between 48 and 72 hours by NZ Deprivation index. There was no NZDep level that reached the target. The data does seem to indicate a slightly lower percentage of samples taken by the recommended time for babies in the five groups with the highest levels of deprivation. There has been no significant change in this indicator.

Table 4 Percentage of samples taken at 48-72 hours by NZDep, October to December 2012

NZ Dep	Sampled at 48-72 hrs		Sampled less than 48 hrs		Sampled over 72 hrs		No collection date and/or time		Total babies
1	845	78.7	14	1.3	187	17.4	28	2.6	1,074
2	982	78.2	7	0.6	231	18.4	36	2.9	1,256
3	987	77.7	10	0.8	234	18.4	40	3.1	1,271
4	910	76.9	6	0.5	224	18.9	44	3.7	1,184
5	1,109	74.7	7	0.5	321	21.6	48	3.2	1,485
6	1,045	72.5	17	1.2	330	22.9	49	3.4	1,441
7	1,207	73.2	9	0.5	385	23.3	49	3.0	1,650
8	1,390	70.4	15	0.8	510	25.8	60	3.0	1,975
9	1,463	69.9	13	0.6	528	25.2	90	4.3	2,094
10	1,412	63.9	26	1.2	677	30.6	95	4.3	2,210
Not Known	14	20.9	0	0.0	11	16.4	42	62.7	67
National Average	11,364	72.3	124	0.8	3,638	23.2	581	3.7	15,707

Figure 5 Percentage of samples taken at 48-72 hours, by NZDep, October to December 2012



Indicator 3 – Quality of blood samples

3: QUALITY OF BLOOD SAMPLES
DESCRIPTION The quality of the blood spot sample.
RATIONALE Accurate testing of blood spot samples is reliant on the quality of the sample. Unsatisfactory samples require a repeat sample which could have been avoided.
RELEVANT OUTCOME Blood spot samples are of sufficient quality for laboratory testing for screened disorders.
STANDARD 99% of blood spot samples are of satisfactory quality.
METHODOLOGY ***Indicator 3*** Numerator: Number of samples of satisfactory quality as reported by the laboratory. Denominator: Number of samples taken.
NOTES • Requirements for a satisfactory sample are detailed in Chapter 7, page 21-22 of Programme Guidelines. • Reporting by DHB

Quality of blood samples

Thirteen DHBs met or exceeded the standard of 99% of samples satisfactory for testing.and the remainder achieved 98-99%. All samples (100%) from Nelson Marlborough were satisfactory for testing. This is shown in Table 5 and Figure 6.

During 2011-2012 the quarter performance for blood sample quality was been overall 98.6%, 98.5%, 98.7%, 98.8%, 99.1%, 99.2%. This quarter is 99.1%. The number of DHBs meeting the target over the year is 4, 3, 3, 6, 14, 8 and this quarter 13.

The trend in performance improvement is shown in Figure 7.

Table 5 Percentage of blood samples that meet quality standards by DHB, October to December 2012

DHB region	Satisfactory		Unsatisfactory		Total samples
	No.	%	No.	%	No.
Northland	554	98.8	7	1.2	561
Waitemata	2,063	99.4	12	0.6	2,075
Auckland	1,761	99.3	13	0.7	1,774
Counties Manukau	2,145	98.9	23	1.1	2,168
Waikato	1,315	98.7	17	1.3	1,332
Lakes	384	99.2	3	0.8	387
Bay of Plenty	723	99.2	6	0.8	729
Tairawhiti	178	99.4	1	0.6	179
Taranaki	388	98.7	5	1.3	393
Hawkes Bay	554	99.5	3	0.5	557
Whanganui	242	99.2	2	0.8	244
Mid Central	552	99.5	3	0.5	555
Hutt Valley	473	98.5	7	1.5	480
Capital and Coast	976	98.6	14	1.4	990
Wairarapa	110	98.2	2	1.8	112
Canterbury	392	99.7	1	0.3	393
Nelson Marlborough	106	100	0	0	106
West Coast	1,525	99.5	7	0.5	1,532
South Canterbury	155	99.4	1	0.6	156
Southern	916	99.3	6	0.7	922
Not recorded	58	93.5	4	6.5	62
Total	15,570	99.1	137	0.9	15,707

Figure 6 Percentage of blood samples that meet quality standards by DHB, October to December 2012

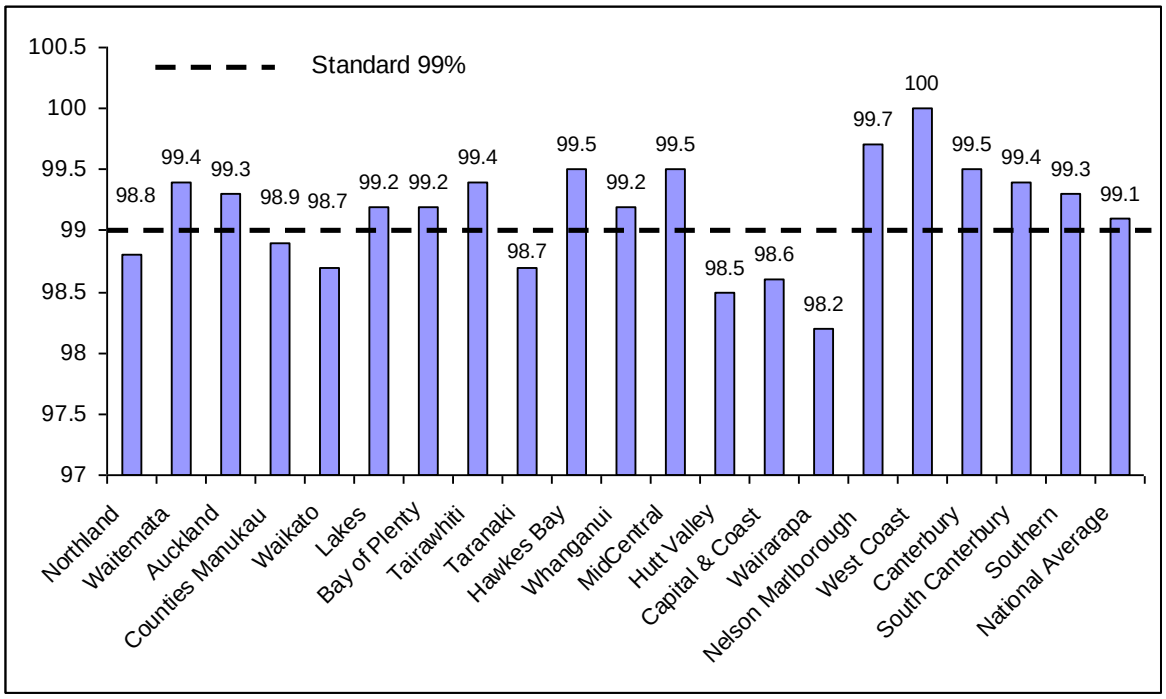
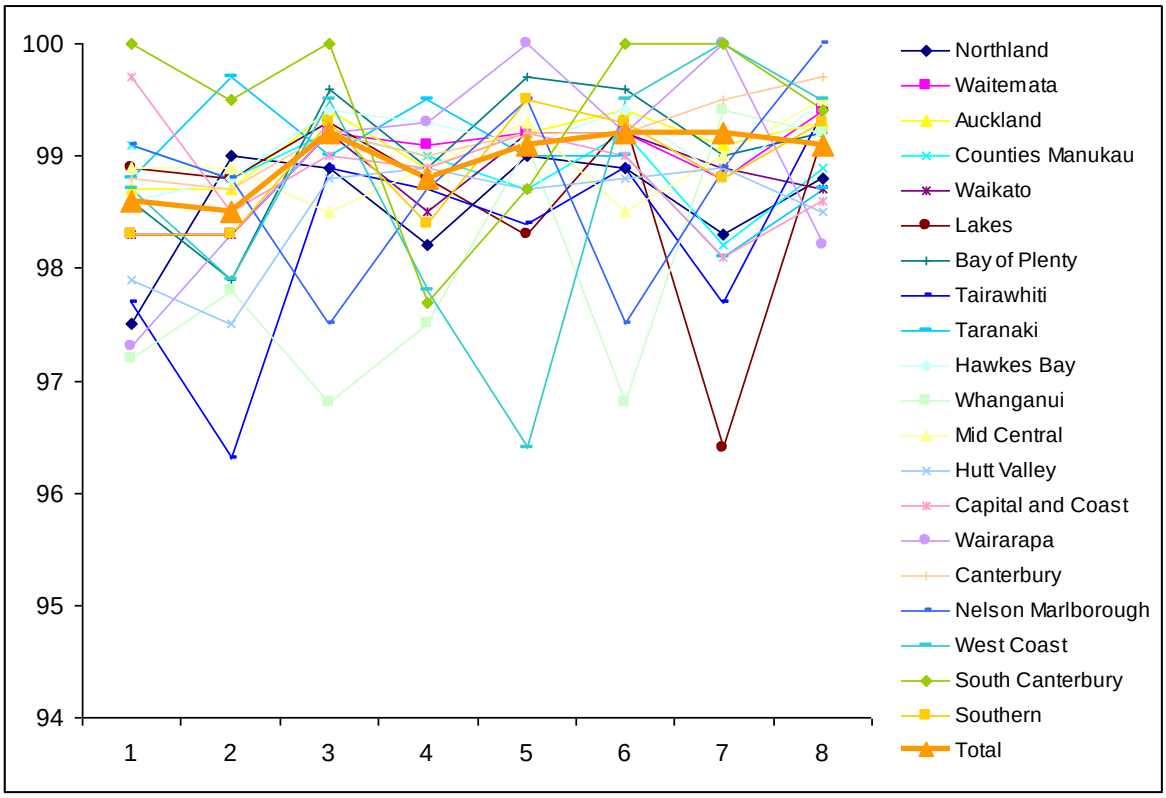


Figure 7 Percentage of samples suitable for testing by DHB, for January to March, April to June, July to September, October to December 2011 and January – March, April – June, July – September and October-December 2012 (Data from Monitoring Reports 1-7 and Table 5).



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, as shown in Table 6 and Figure 8, however there has been significant improvement since 2010 for all DHBs. The national average has moved from 56% in January-March 2011 to 76% in October – December 2012 as shown in Figure 9. The range of values reduced (12-78% January – March 2011 to 65-85% October – December 2012.

Overall 75.9% of samples were received in 4 days or less; 95.1% in 7 days or less and 98.2% in 14 days or less,

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

DHB region	Less than or equal to 4 days		Greater than 4 days		Unknown		Total samples
	No.	%	No.	%	No.	%	No.
Northland	400	71.3	159	28.3	2	0.4	561
Waitemata	1,650	79.5	404	19.5	21	1.0	2,075
Auckland	1,463	82.5	298	16.8	13	0.7	1,774
Counties Manukau	1,721	79.4	431	19.9	16	0.7	2,168
Waikato	1,030	77.3	286	21.5	16	1.2	1,332
Lakes	296	76.5	80	20.7	11	2.8	387
Bay of Plenty	498	68.3	220	30.2	11	1.5	729
Tairawhiti	116	64.8	61	34.1	2	1.1	179
Taranaki	332	84.5	57	14.5	4	1.0	393
Hawkes Bay	364	65.4	189	33.9	4	0.7	557
Mid Central	203	83.2	38	15.6	3	1.2	244
Whanganui	438	78.9	112	20.2	5	0.9	555
Capital and Coast	347	72.3	125	26.0	8	1.7	480
Hutt Valley	781	78.9	199	20.1	10	1.0	990
Wairarapa	83	74.1	28	25.0	1	0.9	112
Nelson Marlborough	267	67.9	123	31.3	3	0.8	393
West Coast	81	76.4	23	21.7	2	1.9	106
Canterbury	1,018	66.4	497	32.4	17	1.1	1,532
South Canterbury	115	73.7	41	26.3	0	0.0	156
Southern	704	76.4	211	22.9	7	0.8	922
Not recorded	16	25.8	44	71.0	2	3.2	62
Total	11,923	75.9	3,626	23.1	158	1.0	15,707

Figure 8 Percentage of samples received by laboratory within 4 days by DHB, October to December 2012

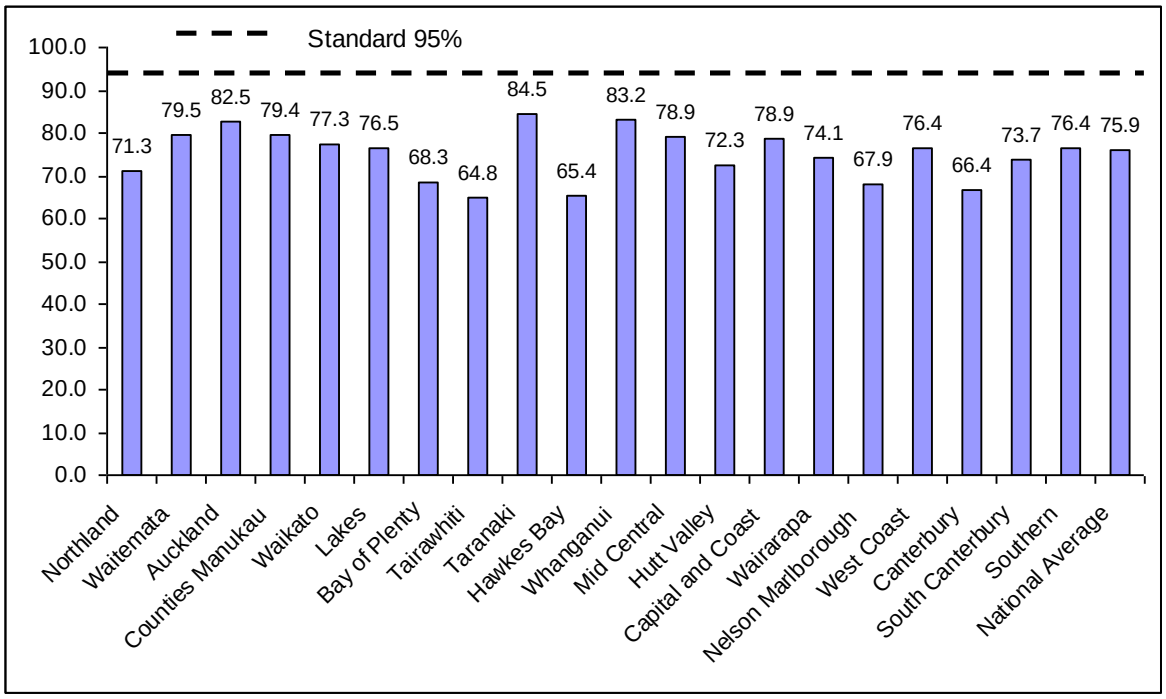
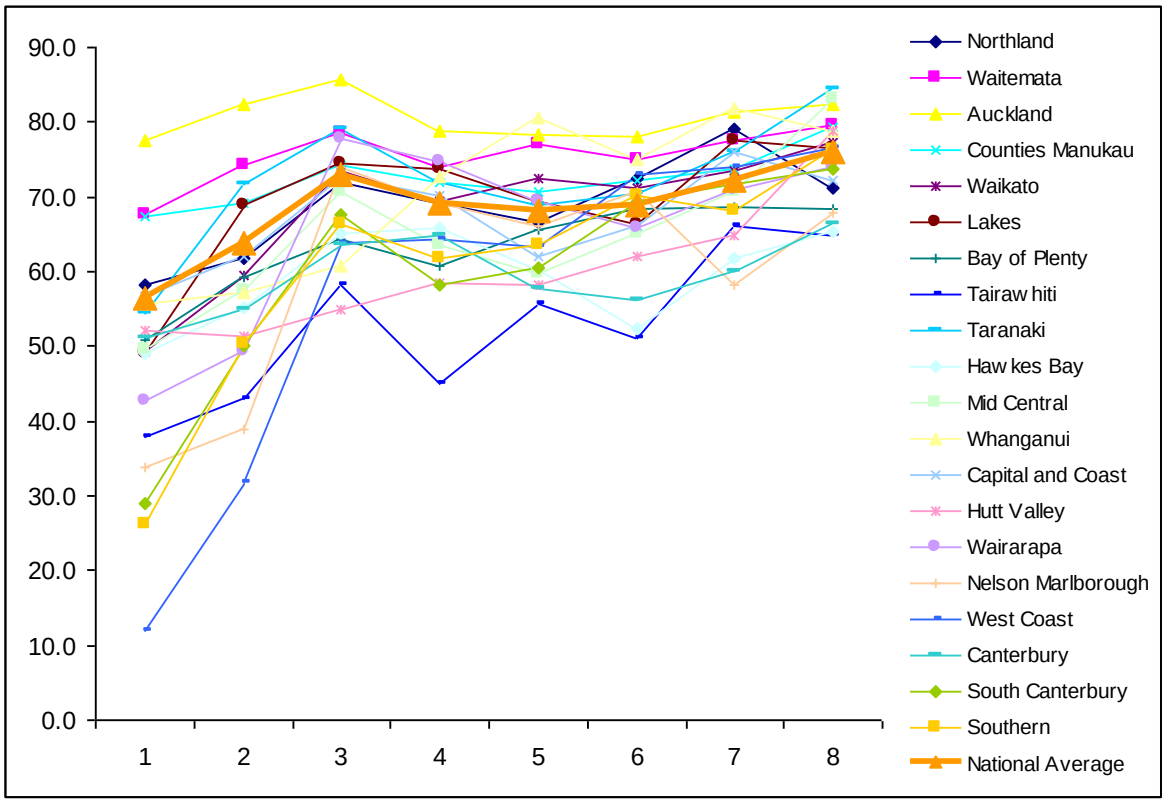


Figure 9 Percentage of samples received by laboratory within 4 days by DHB, for January to March, April to June, July to September, October to December 2011 and January – March, April – June 2012, July – September 2012 (Data from Monitoring Reports 1-7) and October – December 2012 (Table 6)



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% (98.9 – 99.9%) the rates are very close to this for disorders other than those tested using the tandem mass spectrometer which has had additional instrument malfunction this quarter (detailed in a separate report). The most frequent cause of delays in cystic fibrosis screening is delayed genetic test results.

Table 7 Percentage of results available within specified timeframes, by disorder, July to September 2012 (n=15,707 samples)

Disorder	Expected timeframe (days)	Number met timeframe	% met timeframe
Congenital Adrenal Hyperplasia	2	15,577	99.9
Galactosaemia	2	15,673	99.8
Amino acid disorders	2	15,362	97.8
Fatty acid oxidation disorders	2	15,362	97.8
Biotinidase deficiency	5	15,694	99.9
Cystic fibrosis	5	15,539	98.9
Congenital hypothyroidism	5	15,694	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
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.

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.

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

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 89 reports which did not meet the turnaround time, 7 were due to waiting for cystic fibrosis gene testing, 56 were due to waiting for aminoacid and fatty acid oxidation screening results, 16 waiting for specific 17-hydroxyprogesterone results and for 18 delayed signout was either the reason for, or contributory to, the delay. For tests with a 3 day reporting timeframe, if a sample is received on Thursday or Friday the normal testing schedule will make results available on Monday or Tuesday hence about 20% of positive tests will not be reported in the timeframe.

In many cases where reporting does not meet the timeframe the testing time for that specimen does meet the timeframe because testing turnaround times are specified in working days but reporting times in calendar days eg 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 8 Percentage of results reported within specified timeframes, by disorder, October to December 2012 (n=15,707 samples)

Reason for report	Calendar days (from receipt in lab to report)	Number of positive test reports	Number met timeframe	% met timeframe
Amino acid and fatty acid oxidation disorders	3	167	100	59.9
CAH	3	46	29	63
Galactosaemia	3	5	5	100
CH	4	19	17	89.5
Biotinidase deficiency	9	1	0	0
Cystic fibrosis	12	27	22	81.5

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

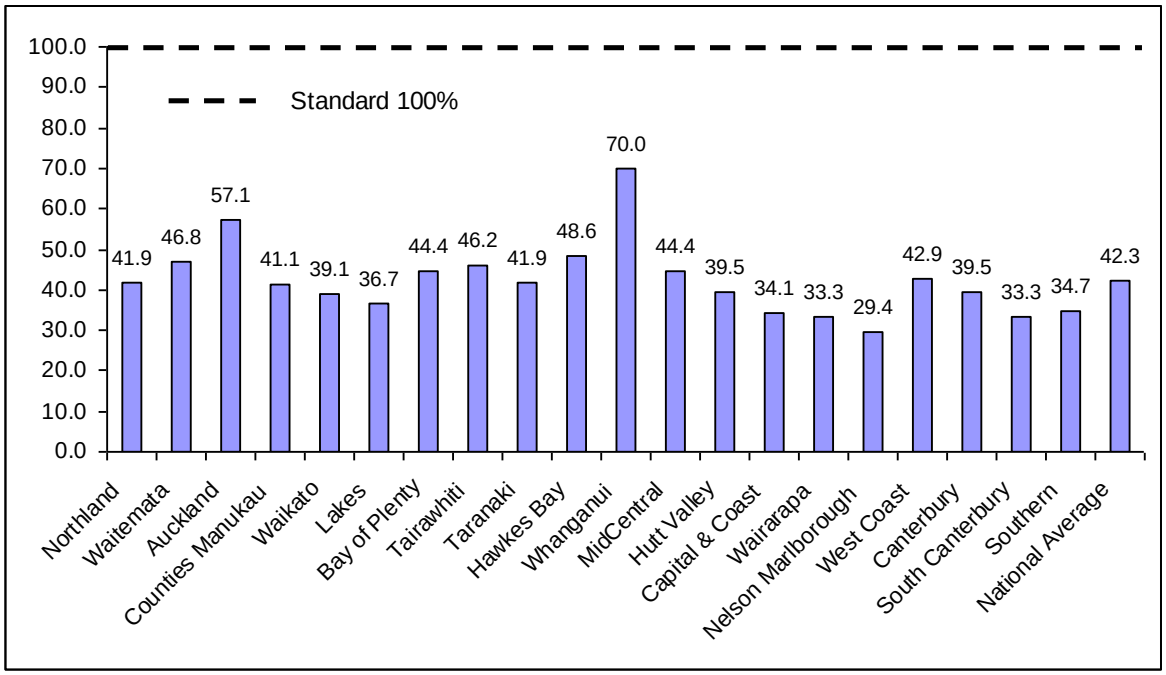
Second samples are requested when samples are not suitable for testing or there are minor elevations of screened metabolites. Table 9 details the timeframe for receipt of second samples (less than or equal to 10 days or greater than 10 days), whether other follow-up occurred (e.g. notification of decline 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 early March 2013 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%. Overall 42.3% of follow-up met the standard compared to 36.9% in 2011 as shown in Figure 10.

Table 9 Follow-up of requested second samples by DHB, January to December 2012

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	18	41.9	21	48.8	4	9.3	0	0.0	43	100.0	43
Waitemata	52	46.8	54	48.6	2	1.8	3	2.7	108	97.3	111
Auckland	56	57.1	36	36.7	6	6.1	0	0.0	98	100.0	98
Counties Manukau	76	41.1	98	53.0	5	2.7	6	3.2	179	96.8	185
Waikato	34	39.1	49	56.3	3	3.4	1	1.1	86	98.9	87
Lakes	11	36.7	17	56.7	2	6.7	0	0.0	30	100.0	30
Bay of Plenty	16	44.4	18	50.0	1	2.8	1	2.8	35	97.2	36
Tairawhiti	6	46.2	6	46.2	0	0.0	1	7.7	12	92.3	13
Taranaki	13	41.9	17	54.8	1	3.2	0	0.0	31	100.0	31
Hawkes Bay	17	48.6	18	51.4	0	0.0	0	0.0	35	100.0	35
Mid Central	14	70.0	6	30.0	0	0.0	0	0.0	20	100.0	20
Whanganui	16	44.4	19	52.8	1	2.8	0	0.0	36	100.0	36
Capital and Coast	15	39.5	21	55.3	1	2.6	1	2.6	37	97.4	38
Hutt Valley	29	34.1	50	58.8	1	1.2	5	5.9	80	94.1	85
Wairarapa	2	33.3	4	66.7	0	0.0	0	0.0	6	100.0	6
Nelson Marlborough	5	29.4	11	64.7	0	0.0	1	5.9	16	94.1	17
West Coast	3	42.9	4	57.1	0	0.0	0	0.0	7	100.0	7
Canterbury	30	39.5	40	52.6	3	3.9	3	3.9	73	96.1	76
South Canterbury	2	33.3	4	66.7	0	0.0	0	0.0	6	100.0	6
Southern	17	34.7	31	63.3	1	2.0	0	0.0	49	100.0	49
Not recorded	1	7.1	3	21.4	7	50.0	3	21.4	11	78.6	14
Total	433	42.3	527	51.5	38	3.7	25	2.4	998	97.6	1,023

Follow-up is complete in 11 DHBs, up from 5 in 2011 (from Monitoring Report 4).

Figure 10 Follow-up of requested samples by DHB, January to December 2012



Indicator 9 – 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 171 requests for the return of cards collected during the reporting period 1 October to 31 December 2012, 170 (99.4%) were returned in the timeframe. For the remaining sample the address given for the return of the card was a post office box. Cards cannot be returned to boxes because of the requirement for a signature on receipt. There has been no response to a request to supply a street address. In general samples are returned very quickly with a median time over this period of 2.1 days.