National Screening Unit

Newborn Metabolic Screening Programme

Newborn Metabolic Screening Programme (NMSP)

Quarterly Monitoring Report

Number 6

1 April to 30 June 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 sixth quarterly and third 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. Six indicators (the quarterly and biannual indicators) are covered by this report.

Timing of sample taking (Indicator 2) was reported in days for the first three monitoring reports. This was due to data collection issues which did not enable time of birth data to be collected in hours and therefore previous monitoring reports underestimated the number of samples meeting the standard. 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 70.8% of samples were collected between 48-72 hours. No DHB met the standard of 95% of samples taken in the timeframe (range 54 - 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 62 - 84%) or NZDep group (range 64 - 77%). 93% of samples were collected between 48 hours and 5 days.

This data is similar to that in reports 4 and 5. 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.

Recommendations:

- NSU to follow up with DHBs who have under 70% of samples taken between 48-72 hours
- Investigate data for larger DHBs under 60% with multiple sites and offer education and training support.

Indicator 3 Quality of blood samples

There has been significant improvement in this indicator. Fourteen DHBs (Waitemata, Auckland, Counties Manukau, Waikato, Lakes, Bay of Plenty, Taranaki, Hawkes Bay, Capital and Coast, Wairarapa, Canterbury, West Coast, South Canterbury and Southern) met or exceeded the standard of 99% of samples satisfactory for testing and a further three achieved 98-99%. All samples (100%) from South Canterbury were satisfactory for testing.

During 2011-2012 the quarter performance for blood sample quality was been overall 98.6%, 98.5%, 98.7%, 98.8%, and 99.1%. This quarter is 99.2%. The number of DHBs meeting the target over the year is 4, 3, 3, 6, 14 and this quarter 14. This improvement may be due to the supply of high-quality lancets to LMCs.

Recommendations:

Continue to monitor.

Indicator 4 Sample dispatch and delivery

Overall 69% 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 and 69% in this report). The decline may be due to four day holiday periods in the timeframes of reports 4, 5 and 6.

Recommendations:

NSU to provide specific feedback to DHB outliers for targeted intervention.

Indicator 5 Laboratory testing timeframes

The standard of 100% was not met for any disorder however timeframes were very close to this being between 98.9 and 99.8%. Screening for fatty acid oxidation and aminoacid breakdown disorders has a low percentage (99.5%) meeting the turnaround time due to instrument breakdowns and for cystic fibrosis (98.9%) due to delayed genetic test results.

Recommendations:

The process for a new Tandem Mass Spectrometer (TMS) and replacement needs to be expedited.

Indicator 6 Timeliness of reporting

The standard of 100% meeting the timeframe was achieved for only biotinidase deficiency screening. The range was from 36-100%. 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:

Review by the Technical Group at the next meeting.

Indicator 9 Blood spot card storage and return.

99% of 164 requests for card return met the standard of within 28 days of completion of screening. The outstanding request had insufficient information (which has not yet been received).

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 sixth 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 April to 30 June 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 NZDep Status.
- Timing of sample taking is separated into three time periods <48 hours, 48-72 hours and >72 hours.
- For quality of blood sample the presence/absence of the INAD tests is used to classify samples as either Satisfactory' or Non-satisfactory.
- Transit time for sample dispatch and delivery is categorised as <=4 days and > 4 days. Missing data is recorded as such.
- Lab testing timeframes are captured though they vary by different diseases being tested for. The analysis takes this into account.
- Data is analysed to determine whether or not cards that are requested to be returned are done within the 28 days required.

Data Quality and Limitations

Data cleansing process

The full data cleansing process is included in separate business rules. An exception report identifies those samples where the date of birth against an NHI number from the LabPLUS information system differs from that held by NHI. There were 74 such samples from approximately 15,200 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 Galactosaemia positive tests, mutation analysis for cystic fibrosis screening.

Disorder	**Working days from receipt of sample**
Congenital Adrenal Hyperplasia	2
Galactosaemia	2
Amino acid disorders	2
Fatty acid oxidation disorders	2
Biotinidase deficiency	5
Cystic fibrosis	5
Congenital hypothyroidism	5

Amino acid disorders and Fatty acid oxidation disorder analyses are run at the same time on the same instrument in the same analysis, hence the results are available at the same time and the disorders are combined into a single category to calculate the testing time.

NMSP Monitoring Indicators

Table 1 summarises all the NMSP indicators used in regular monitoring with their reporting frequency and detail. This report, as a quarterly report, provides information on indicators 2-5 and 9. These indicators have been developed following consultation with key NMSP stakeholders. Indicators will be further refined as data is collected over time, and will be subject to regular review by the NMSP Advisory Group.

Table 1 NMSP indicators and monitoring frequency

Indicators	Quarterly	Biannually	Annually	Detail
1. Newborn Metabolic Screening Coverage			X	• DHB • Ethnicity • Deprivation status
2. Timing of sample taking	X	X	X	• DHB • Ethnicity • Deprivation status
Laboratory reporting				
3. Quality of Blood Samples	X	X	X	• DHB
4. Sample dispatch and delivery	X	X	X	• DHB
5. Laboratory testing timeframes	X	X	X	
6. Timeliness of reporting - notification of screen positives		X	X	
7. Collection and receipt of second samples			X	• DHB
Incidence			X	
8. Diagnosis and commencement of treatment by disorder: • Biotinidase deficiency • Cystic fibrosis • Congenital hypothyroidism • Congenital adrenal hyperplasia • Galactosaemia • Amino acid disorders • Fatty acid oxidation disorders			X	
9. Blood spot card storage and return	X	X	X	

Indicator 2 – Timing of sample taking

2: TIMING OF SAMPLE –TAKING

DESCRIPTION

1. The proportion of eligible babies who have a newborn metabolic screening sample taken.
2. The proportion of eligible babies who have a newborn metabolic screening sample taken between 48 and 72 hours of birth.

RATIONALE

Timely sample collection leads to the best possible chance of a baby receiving early diagnosis and treatment where necessary. Severe forms of some of the disorders screened for can be fatal within seven to ten days. Many may not show any signs or symptoms of disease until irreversible damage has occurred. However, the baby must have been independent of their mother long enough for their indicator biochemicals to show an abnormality. Therefore the optimum window for sample collection is between 48 and 72 hours of birth.

RELEVANT OUTCOME

Babies screened should have a newborn metabolic screening sample taken between 48 and 72 hours of birth.

STANDARD

95% of first samples are taken between 48 and 72 hours of birth.

METHODOLOGY

Indicator 2

Numerator: Number of babies who have a newborn metabolic screening sample taken between 48 and 72 hours of birth.

Denominator: Number of babies who have a newborn metabolic screening sample taken.

NOTES

- Samples for screening must be taken in accordance with Programme Guidelines and Policy and Quality requirements.
- Reporting by:
  - DHB
  - Ethnicity
  - Deprivation status

Timing of Sample Taking

Overall 70.8% of samples were taken in the recommended timeframe of 48-72 hours, similar to the data in Reports 4 & 5.

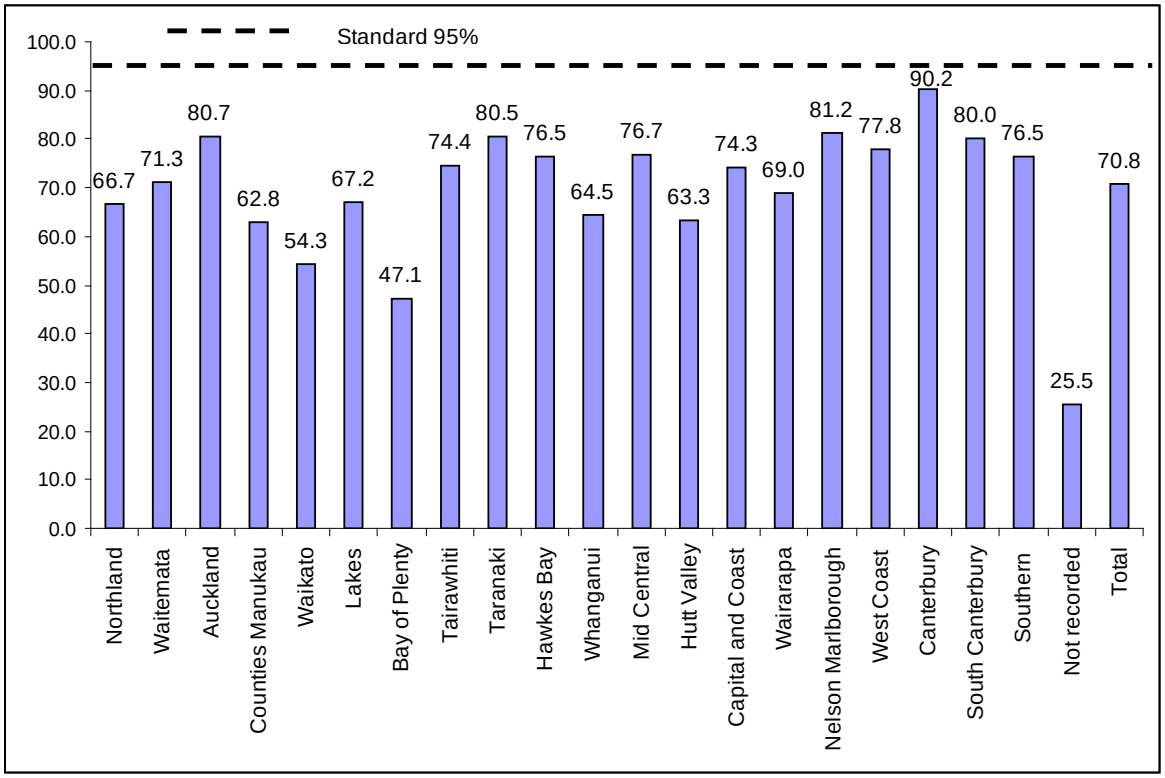
For this period no DHB region met the standard of 95% of samples taken between 48 and 72 hours. Table 2 shows the percentage of samples taken between 48-72 hours, as well as those outside of this timeframe, by DHB. Figure 1 shows the percentage of samples taken 48-72 hours by DHB compared with the overall average of 70.8% at 48-72 hours.

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 also given in Table 2. This seriously impacts the ability of the programme to correctly interpret test results. The data in the table has been amended due to a data error causing the time of birth to be dropped from the laboratory information system and the new data shows ADHB now has only 4.1% of samples do not have the information required and 80.7% of samples are collected at 48-72 hours.

Table 2 Amended Percentage of samples taken at 48-72 hours, by DHB, April to June 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	372	66.7	7	1.3	166	29.7	13	2.3	558
Waitemata	1,375	71.3	15	0.8	487	25.2	52	2.7	1,929
Auckland	1,308	80.7	18	1.1	229	14.1	66	4.1	1,621
Counties Manukau	1,333	62.8	12	0.6	627	29.5	151	7.1	2,123
Waikato	758	54.3	11	0.8	542	38.8	85	6.1	1,396
Lakes	272	67.2	2	0.5	115	28.4	16	4.0	405
Bay of Plenty	369	47.1	3	0.4	368	47.0	43	5.5	783
Tairawhiti	131	74.4	1	0.6	38	21.6	6	3.4	176
Taranaki	323	80.5	3	0.7	59	14.7	16	4.0	401
Hawkes Bay	416	76.5	3	0.6	108	19.9	17	3.1	544
Whanganui	142	64.5	5	2.3	68	30.9	5	2.3	220
Mid Central	418	76.7	3	0.6	106	19.4	18	3.3	545
Hutt Valley	319	63.3	2	0.4	156	31.0	27	5.4	504
Capital and Coast	675	74.3	7	0.8	188	20.7	38	4.2	908
Wairarapa	87	69.0	1	0.8	31	24.6	7	5.6	126
Nelson Marlborough	311	81.2	3	0.8	57	14.9	12	3.1	383
West Coast	63	77.8	2	2.5	14	17.3	2	2.5	81
Canterbury	1,323	90.2	9	0.6	107	7.3	28	1.9	1,467
South Canterbury	128	80.0	2	1.3	27	16.9	3	1.9	160
Southern	686	76.5	4	0.4	190	21.2	17	1.9	897
Not recorded	14	25.5	3	5.5	19	34.5	19	34.5	55
Total	10,823	70.8	116	0.8	3,702	24.2	641	4.2	15,282

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



Although only 70.8% of samples were collected 48-72 hours, 92.7% were collected between 2-5 days (48 hours-5 days) as shown in Figure 2. 97 samples (0.7%) were collected at 10 days of age or older.

Figure 2 Age at which samples were collected April – June 2012.

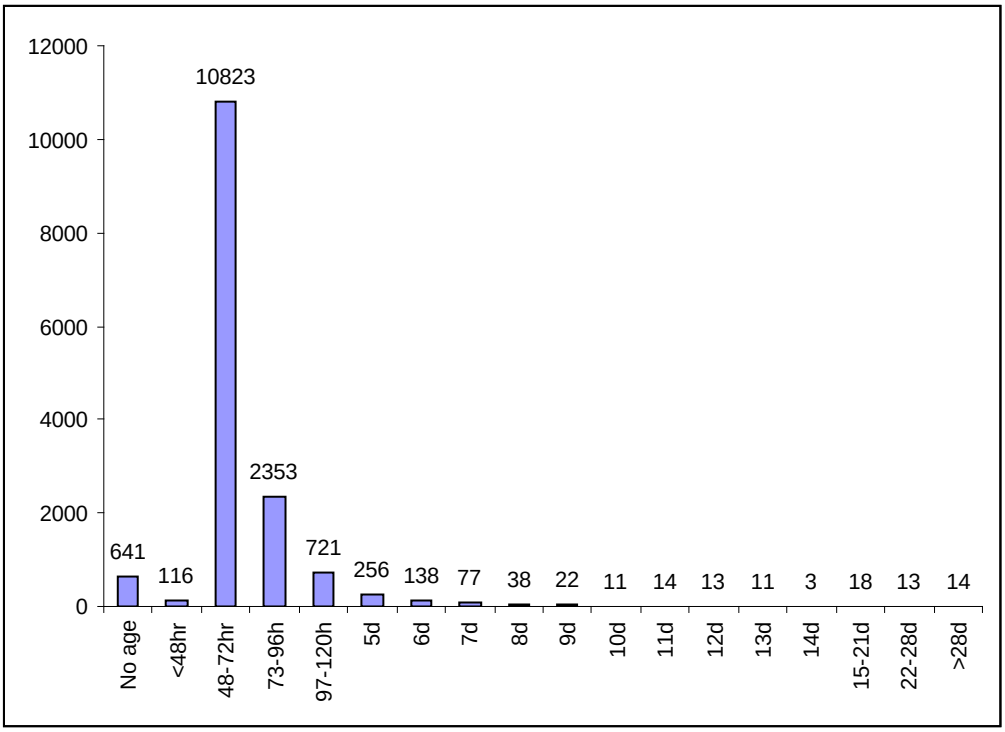


Figure 3 below and Table 3 identify some small differences between ethnic groups. While no ethnic group met the standard of 95% the percentages for European and Asian appear higher than for the remaining ethnic groups. This is similar to the previous five reports.

Figure 3 Percentage of samples taken at 48-72 hours, by ethnicity, April to June 2012

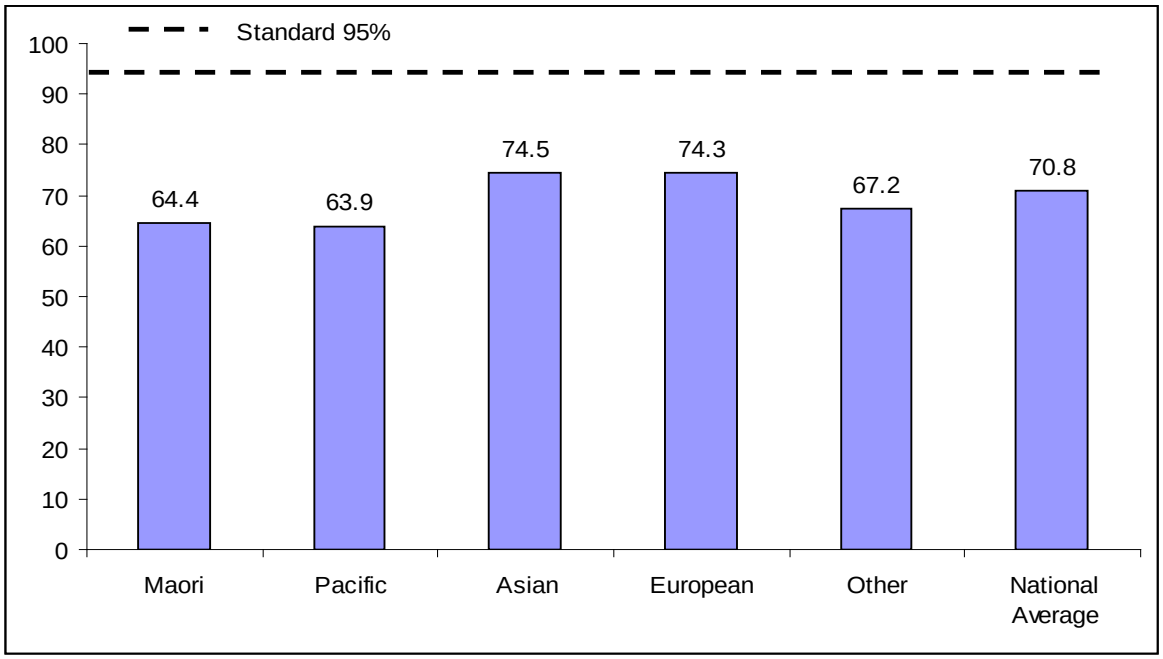


Table 3 Percentage of samples taken at 48-72 hours days, by Group 1 and Group 2 Ethnicity, April to June 2012

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	2,214	64.4	1,043	30.3	28	0.8	153	4.5	3,438
Pacific	1,055	63.9	502	30.4	10	0.6	84	5.1	1,651
Cook Island Maori	150	60.5	92	37.1	0	0.0	6	2.4	248
Fijian	76	70.4	27	25.0	1	0.9	4	3.7	108
Niuean	59	67.0	25	28.4	0	0.0	4	4.5	88
Samoan	454	63.9	216	30.4	7	1.0	33	4.6	710
Tokelauan	27	84.4	5	15.6	0	0.0	0	0.0	32
Tongan	246	62.0	115	29.0	0	0.0	36	9.1	397
Other Pacific	43	63.2	22	32.4	2	2.9	1	1.5	68
Asian	1,484	74.5	407	20.5	14	0.7	86	4.3	1,991
Chinese	592	78.2	130	17.2	3	0.4	32	4.2	757
Indian	404	67.3	155	25.8	4	0.7	37	6.2	600
Southeast Asian	134	76.6	34	19.4	2	1.1	5	2.9	175
Other Asian	354	77.1	88	19.2	5	1.1	12	2.6	459
European	5,847	74.3	1,676	21.3	57	0.7	290	3.7	7,870
NZ European	5,127	74.2	1,472	21.3	53	0.8	257	3.7	6,909
Latin American / Hispanic	52	75.4	13	18.8	0	0.0	4	5.8	69
Other European	668	74.9	191	21.4	4	0.4	29	3.3	892
Other	223	67.2	74	22.3	7	2.1	28	8.4	332
African	59	69.4	21	24.7	1	1.2	4	4.7	85
Middle Eastern	89	78.1	18	15.8	2	1.8	5	4.4	114
Other/not known	75	56.4	35	26.3	4	3.0	19	14.3	133
Total	10,823	70.8	3,702	24.2	116	0.8	641	4.2	15,282

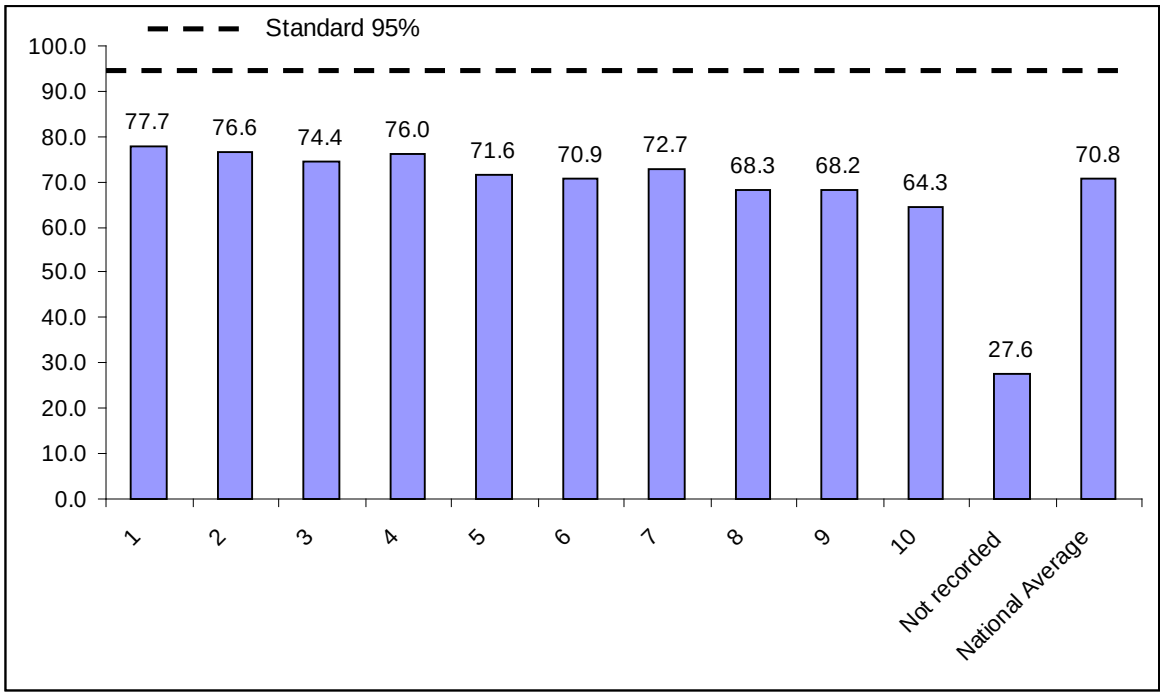
Table 4 and Figure 4 below show the number of samples taken between 48 and 72 hours by NZ Deprivation index. There was no NZDep level that reached the target. The data

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, April to June 2012

NZDep	Sampled at 48-72 hrs		Sampled less than 48 hrs		Sampled over 72 hrs		No collection date and/or time		Total babies
1	720	77.7	4	0.4	170	18.3	33	3.6	927
2	892	76.6	8	0.7	226	19.4	38	3.3	1,164
3	863	74.4	9	0.8	251	21.6	37	3.2	1,160
4	873	76.0	8	0.7	230	20.0	37	3.2	1,148
5	988	71.6	12	0.9	322	23.4	57	4.1	1,379
6	1,018	70.9	15	1.0	350	24.4	53	3.7	1,436
7	1,211	72.7	5	0.3	393	23.6	56	3.4	1,665
8	1,297	68.3	18	0.9	496	26.1	89	4.7	1,900
9	1,503	68.2	16	0.7	586	26.6	98	4.4	2,203
10	1,442	64.3	18	0.8	658	29.3	124	5.5	2,242
Not recorded	16	27.6	3	5.2	20	34.5	19	32.8	58
Total	10,823	70.8	116	0.8	3,702	24.2	641	4.2	15,282

Figure 4 Percentage of samples taken at 48-72 hours, by NZDep, April to June 2012



Indicator 3 – Quality of blood samples

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

Quality of blood samples

There has been significant improvement in this indicator. Fourteen DHBs (Waitemata, Auckland, Counties Manukau, Waikato, Lakes, Bay of Plenty, Taranaki, Hawkes Bay, Capital and Coast, Wairarapa, Canterbury, West Coast, South Canterbury and Southern) met or exceeded the standard of 99% of samples satisfactory for testing and a further three achieved 98-99%. All samples (100%) from South Canterbury were satisfactory for testing.

During 2011-2012 the quarter performance for blood sample quality was been overall 98.6%, 98.5%, 98.7%, 98.8%, and 99.1%. This quarter is 99.2%. The number of DHBs meeting the target over the year is 4, 3, 3, 6, 14 and this quarter 14. This improvement may be due to the supply of high-quality lancets to LMCs.

Table 5 Percentage of blood samples that meet quality standards by DHB, April to June 2012

DHB region	Satisfactory		Unsatisfactory		Total samples
	No.	%	No.	%	No.
Northland	552	98.9	6	1.1	558
Waitemata	1,913	99.2	16	0.8	1,929
Auckland	1,612	99.4	9	0.6	1,621
Counties Manukau	2,107	99.2	16	0.8	2,123
Waikato	1,384	99.2	11	0.8	1,395
Lakes	402	99.3	3	0.7	405
Bay of Plenty	780	99.6	3	0.4	783
Tairawhiti	174	98.9	2	1.1	176
Taranaki	397	99.0	4	1	401
Hawkes Bay	542	99.4	3	0.6	545
Whanganui	213	96.8	7	3.2	220
Mid Central	537	98.5	8	1.5	545
Hutt Valley	498	98.8	6	1.2	504
Capital and Coast	899	99.0	9	1	908
Wairarapa	125	99.2	1	0.8	126
Canterbury	380	99.2	3	0.8	383
Nelson Marlborough	79	97.5	2	2.5	81
West Coast	1,459	99.5	8	0.5	1,467
South Canterbury	160	100		0	160
Southern	891	99.3	6	0.7	897
Not recorded	53	96.4	2	3.6	55
Total	15,157	99.2	125	0.8	15,282

Figure 5 **Percentage of blood samples that meet quality standards by DHB, April to June 2012**

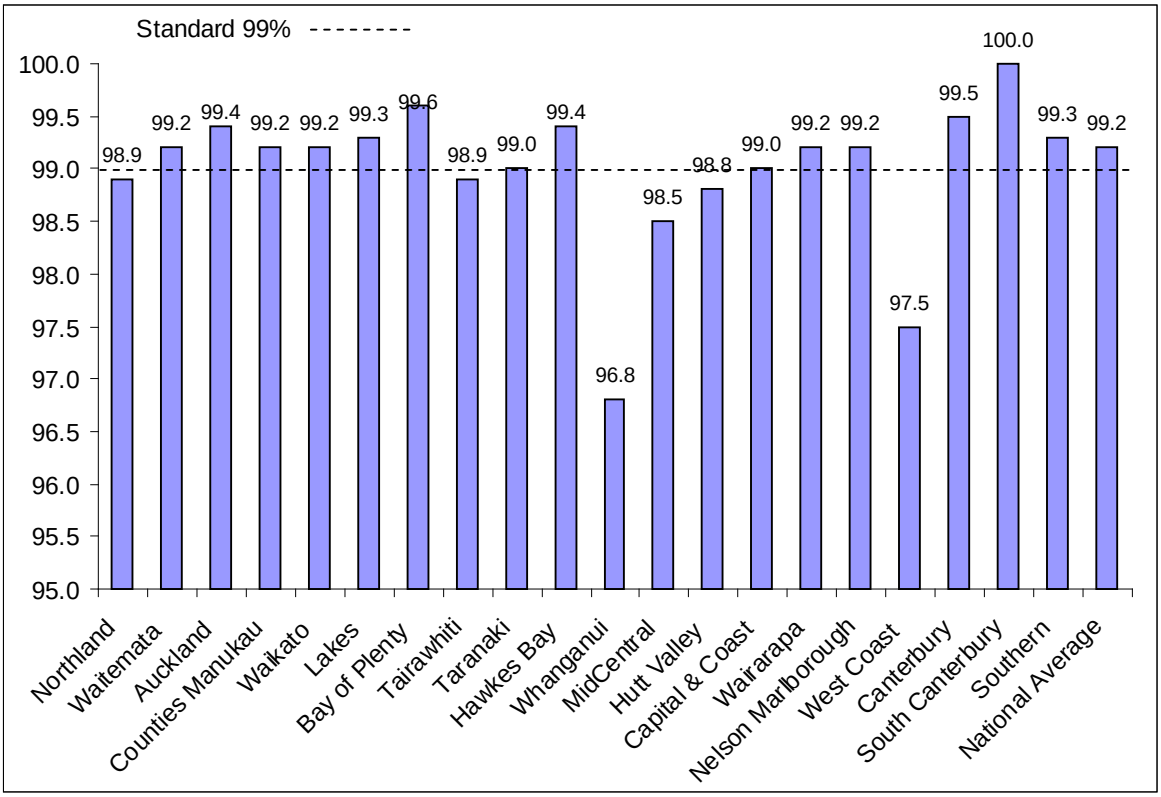
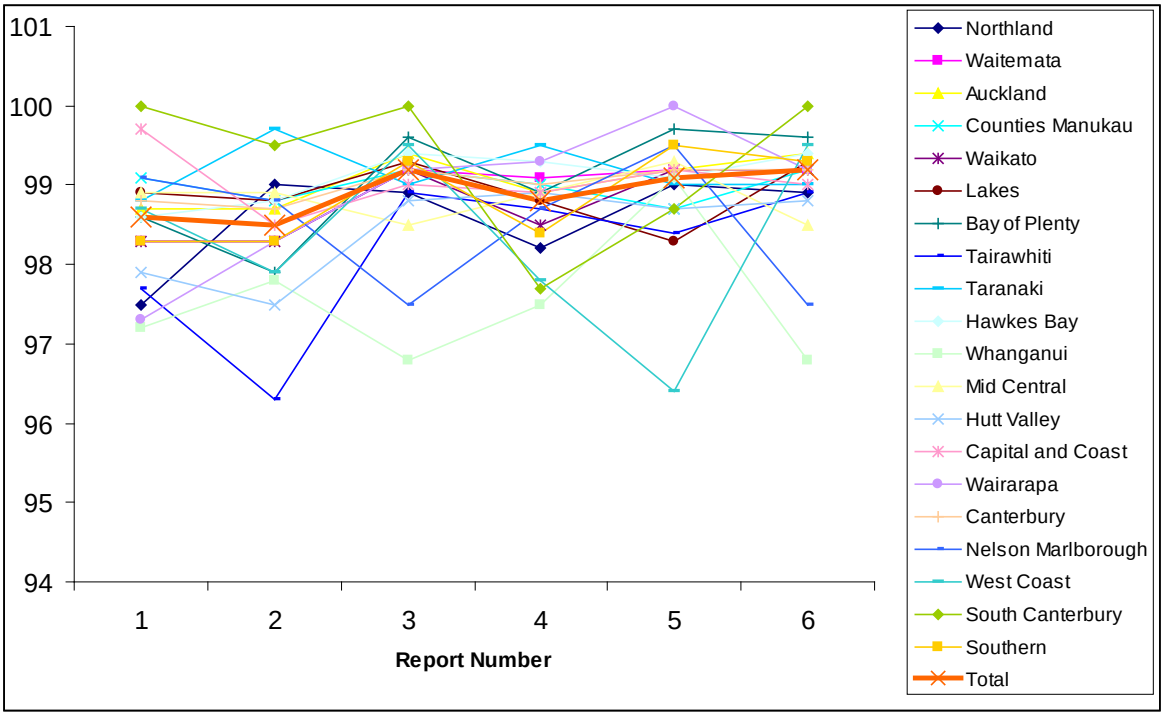


Figure 6 **Percentage of samples suitable for testing by DHB, for January to March, April to June, July to September, October to December 2011 and January – March, April – June 2012 (Data from Monitoring Reports 1-6).**



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 7, however there has been significant improvement since 2010 for all DHBs. The national average has moved from 56% in January-March 2011 to 69% in April – June 2012 as shown in Figure 8.

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

DHB region	Less than or equal to 4 days		Greater than 4 days		Unknown		Total samples
	No.	%	No.	%	No.	%	No.
Northland	404	72.4	148	26.5	6	1.1	558
Waitemata	1,448	75.1	455	23.6	26	1.3	1,929
Auckland	1,265	78.0	336	20.7	20	1.2	1,621
Counties Manukau	1,533	72.2	566	26.7	24	1.1	2,123
Waikato	992	71.1	383	27.5	20	1.4	1,395
Lakes	269	66.4	131	32.3	5	1.2	405
Bay of Plenty	536	68.5	236	30.1	11	1.4	783
Tairawhiti	90	51.1	83	47.2	3	1.7	176
Taranaki	282	70.3	114	28.4	5	1.2	401
Hawkes Bay	285	52.3	254	46.6	6	1.1	545
Mid Central	355	65.1	185	33.9	5	0.9	545
Whanganui	165	75.0	52	23.6	3	1.4	220
Capital and Coast	601	66.2	298	32.8	9	1.0	908
Hutt Valley	313	62.1	177	35.1	14	2.8	504
Wairarapa	83	65.9	40	31.7	3	2.4	126
Nelson Marlborough	271	70.8	107	27.9	5	1.3	383
West Coast	59	72.8	22	27.2	0	0.0	81
Canterbury	824	56.2	626	42.7	17	1.2	1,467
South Canterbury	111	69.4	49	30.6	0	0.0	160
Southern	629	70.1	259	28.9	9	1.0	897
Not recorded	15	27.3	37	67.3	3	5.5	55
Total	10,530	68.9	4,558	29.8	194	1.3	15,282

Figure 7 Percentage of samples received by laboratory within 4 days by DHB, April to June 2012

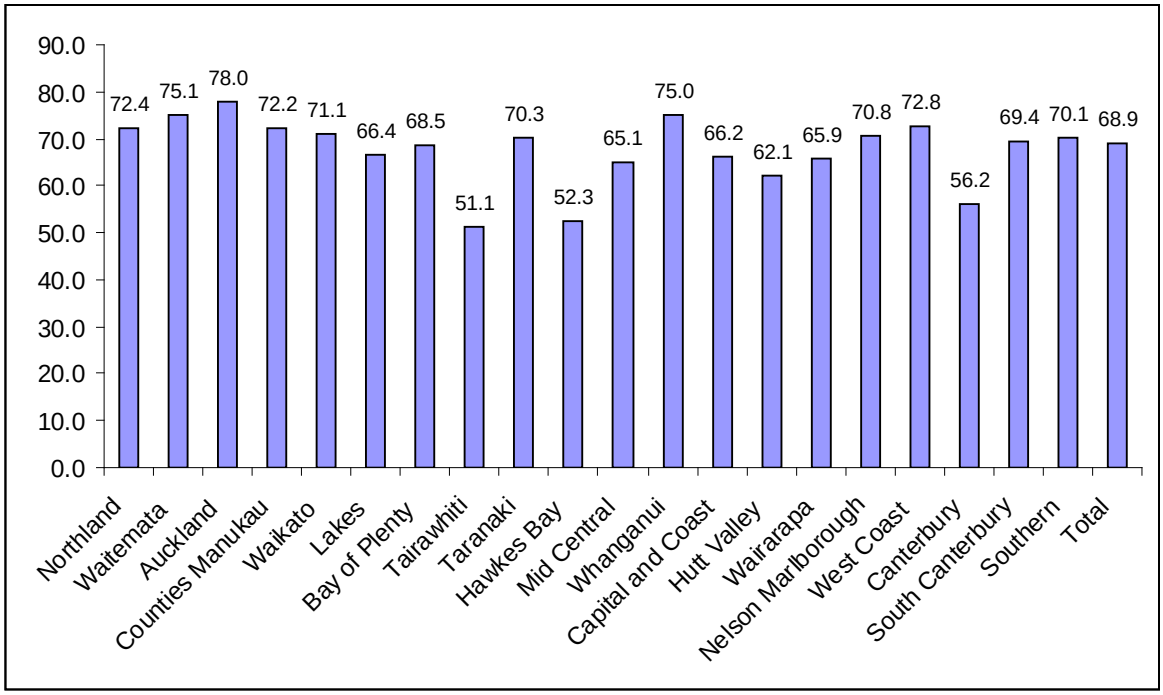
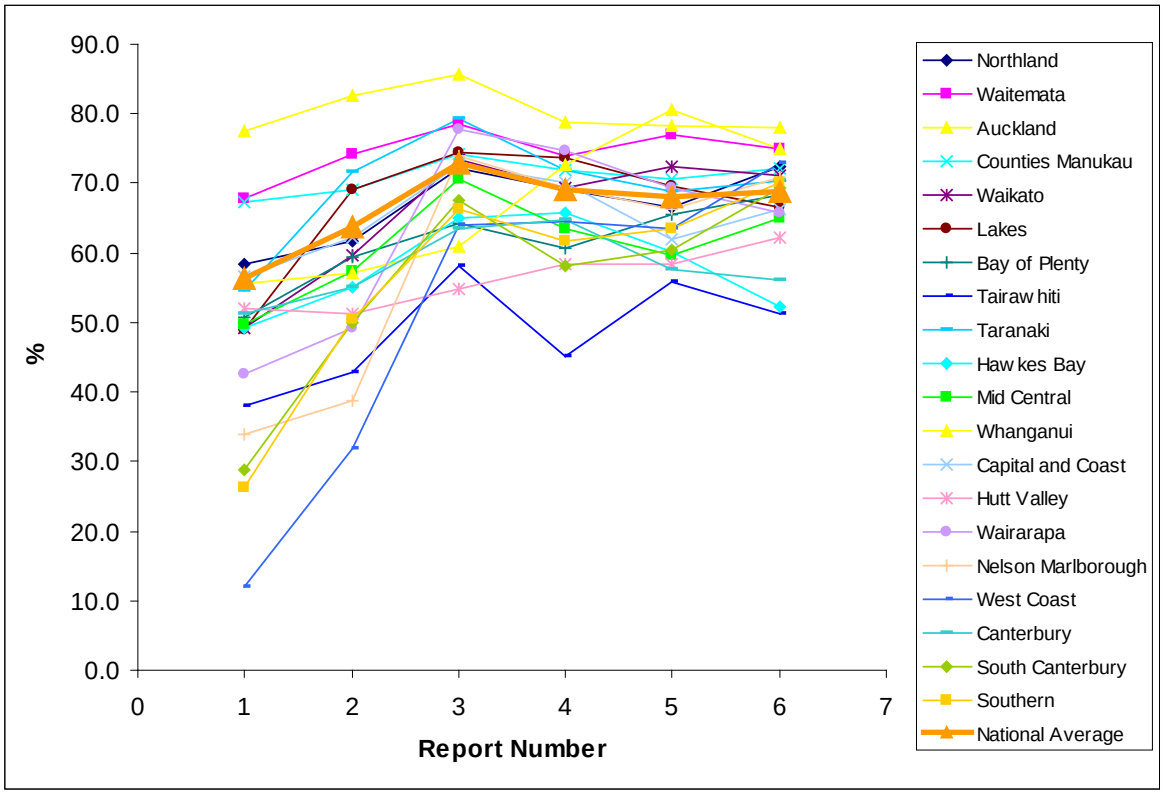


Figure 8 Percentage of samples received by laboratory within 4 days by DHB, for January to March, April to June, July to September, October to December 2011 and January – March, April – June 2012 (Data from Monitoring Reports 1-6).



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 Hypothyroidism	5

METHODOLOGY

Indicator 5

Numerator: Number of samples tested and reported within specified timeframes.

Denominator: Number of samples tested.

Laboratory testing timeframes

Table 7 identifies the percentage of samples that met the specified laboratory testing timeframes. While not quite 100% (98.9 – 99.8%) the rates are very close to this for all disorders. The most frequent cause of delays in cystic fibrosis screening is delayed genetic test results and in screening for fatty acid oxidation and amino acid breakdown disorders is instrument (tandem mass spectrometer) malfunction.

Table 7 Percentage of results available within specified timeframes, by disorder, April to June 2012 (n=15,282 samples)

Disorder	Expected timeframe (days)	Number met timeframe	% met timeframe
Congenital Adrenal Hyperplasia	2	15,248	99.8
Galactosaemia	2	15,257	99.8
Amino acid disorders	2	15,212	99.5
Fatty acid oxidation disorders	2	15,212	99.5
Biotinidase deficiency	5	15,271	99.9
Cystic fibrosis	5	15,111	98.9
Congenital hypothyroidism	5	15,271	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 as shown in Table 8a. 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). Table 8 shows the reporting timeframes of all positive tests. Of the 105 reports which did not meet the turnaround time, 34 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); 35 were due to waiting for aminoacid and fatty acid oxidation screening results delayed due to breakdowns in the tandem mass spectrometer; 22 delayed due to a delay in sign-out (which reflects the availability of senior staff) and 14 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 8 Percentage of positive test results reported within specified timeframes, by disorder, 1 January to 30 June 2012 (n=15,282 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	183	112	61
CAH	3	64	36	56
Galactosaemia	3	3	2	67
CH	4	20	15	75
Biotinidase deficiency	9	1	1	100
Cystic fibrosis	12	22	8	36

Table 8a Percentage of urgent clinical critical positive results reported within specified timeframes, by disorder, 1 January to 30 June 2012

Reason for report	Calendar days (from receipt in lab to report)	Number of urgent critical positive test reports	Number met timeframe	% met timeframe
Amino acid and fatty acid oxidation disorders	3	26	26	100
CAH	3	0	0	
Galactosaemia	3	0	0	
CH	4	5	5	100
Biotinidase deficiency	9	0	0	
Cystic fibrosis	12	0	0	

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 164 requests for the return of cards collected during the reporting period 1 April to 30 June 2012, 163 (99.4%) were returned in the timeframe. The remaining card has not been returned – the request for return was not signed and the mother has been contacted but no reply received. In general samples are returned very quickly with a median time over this period of 2.1 days.

Appendix – Indicators Not Reported Biannually

Indicator 1 – Newborn Metabolic Screening Coverage

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

Indicator 6 Timeliness of Reporting – Notification of Screen Positives

6: TIMELINESS OF REPORTING – NOTIFICATION OF SCREEN POSITIVES

DESCRIPTION

The time taken for a baby with a positive screening result to be referred for diagnostic testing.

RATIONALE

The NMSP relies on early detection and treatment. This ensures babies with congenital metabolic disorders have their development potential impacted as little as possible from the disorder.

RELEVANT OUTCOME

All babies with positive screening results are referred for further testing within the specified timeframes after results become available.

STANDARD

100% of babies with positive results are notified to their LMC / referring practitioner by the laboratory within the following timeframes:

Reason for report	Calendar days (from receipt in lab test result)
Amino acid disorders	3
Fatty acid oxidation disorders	3
CAH	3
Galactosaemia	3
CH	4
Biotinidase deficiency	9
Cystic fibrosis	12

METHODOLOGY

Indicator 6

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

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

Indicator 7 Collection and Receipt of Second Samples

7: COLLECTION AND RECEIPT OF SECOND SAMPLES

DESCRIPTION

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

RATIONALE

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

RELEVANT OUTCOME

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

STANDARD

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

METHODOLOGY

Indicator 7.1

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

Denominator: Number of second samples requested.

Indicator 7.2

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

Denominator: Total number of second samples received and declined.

NOTES

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

Indicator 8 – Diagnosis and Commencement of Treatment by Disorder

8 DIAGNOSIS AND COMMENCEMENT OF TREATMENT BY DISORDER

DESCRIPTION

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

RATIONALE

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

RELEVANT OUTCOME

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

STANDARD

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

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

METHODOLOGY

Indicator 8

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

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

NOTES

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