

# Interagency Cooperation Improves Quality of Newborn Baby Metabolic Screening

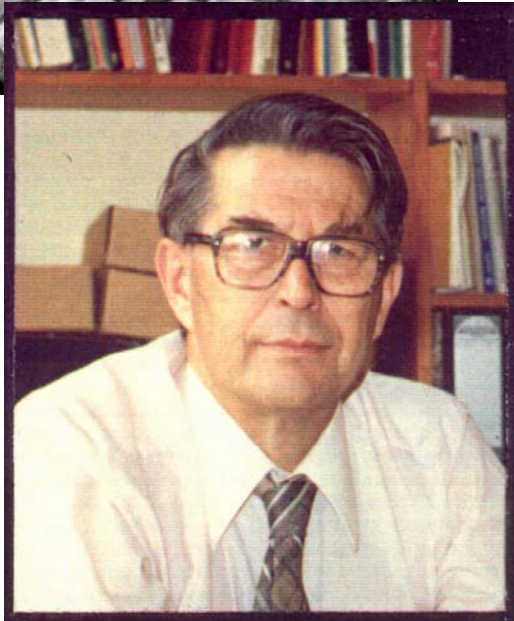
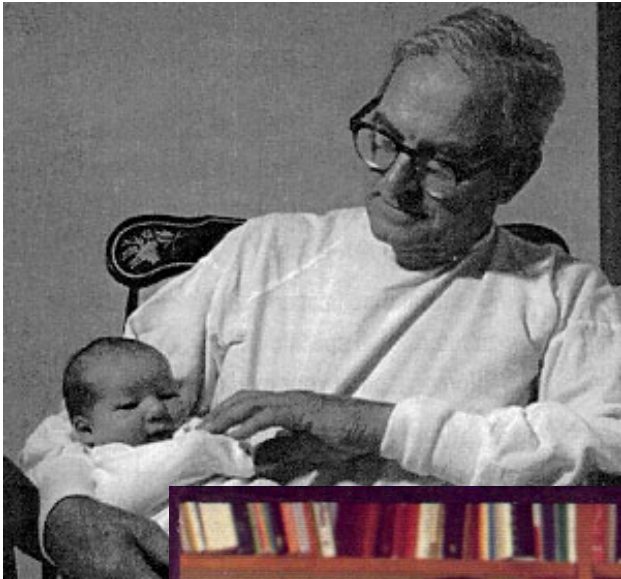
Dianne Webster  
Diane Casey  
Kathy Bendikson

# Outline



- Background – newborn screening in New Zealand
- Crisis
- Policy and Quality Standards
- Outcome

# Bob Guthrie (1916-1995) Arthur Veale (1925-1987)



- Worked together on a national screening programme – complete coverage from May 1969
- Funded by Medical Research Council of New Zealand
- Then Ministry of Health POBOC funding

# Along comes ...





- 4.4M people
- 65,000 births
- 20 Health Authorities

# Meanwhile ..

## **Cervical Cancer Audit Report**

Screening of Women with Cervical  
Cancer, 2000–2002

### **Executive Summary**

- Cervical cancer screening issue
- International review
- Recommendation setting up specialist screening unit within Ministry of Health

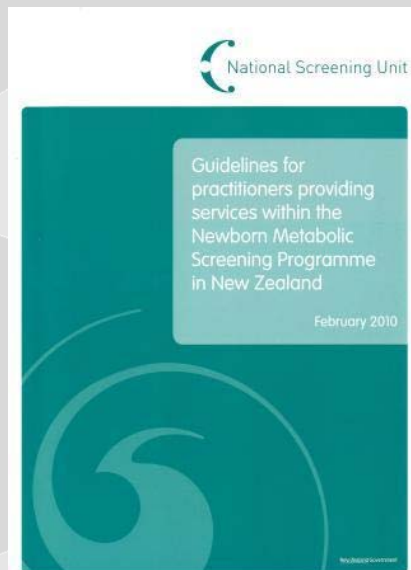
# 2005



- National Screening Unit
- Specialist unit within Ministry of Health
- Funds screening through contract with local hospital laboratory
- Takes care of policy, audit, funding
- Nb all screening and treatment government funded



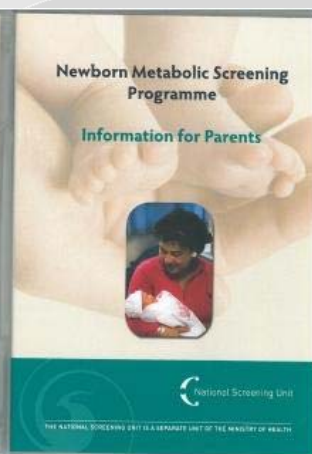
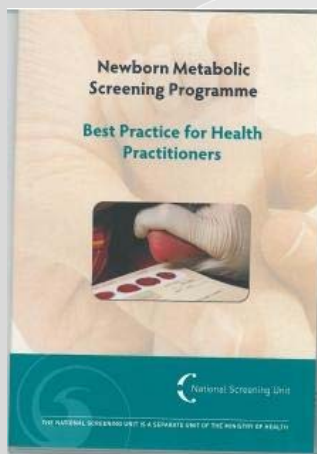
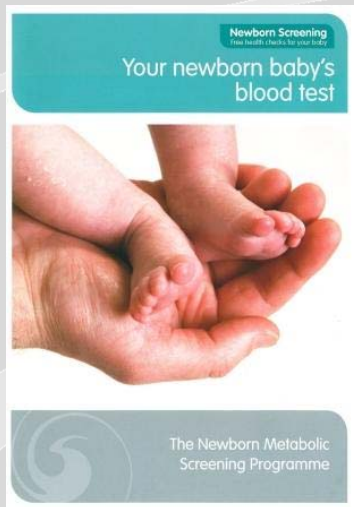
# Quality – informed workforce



- Best practice DVD for healthcare practitioners
- Guidelines
  - 77pp
  - Disorders, processes, more resources etc
- On-line learning 6 modules



# Quality – informed families



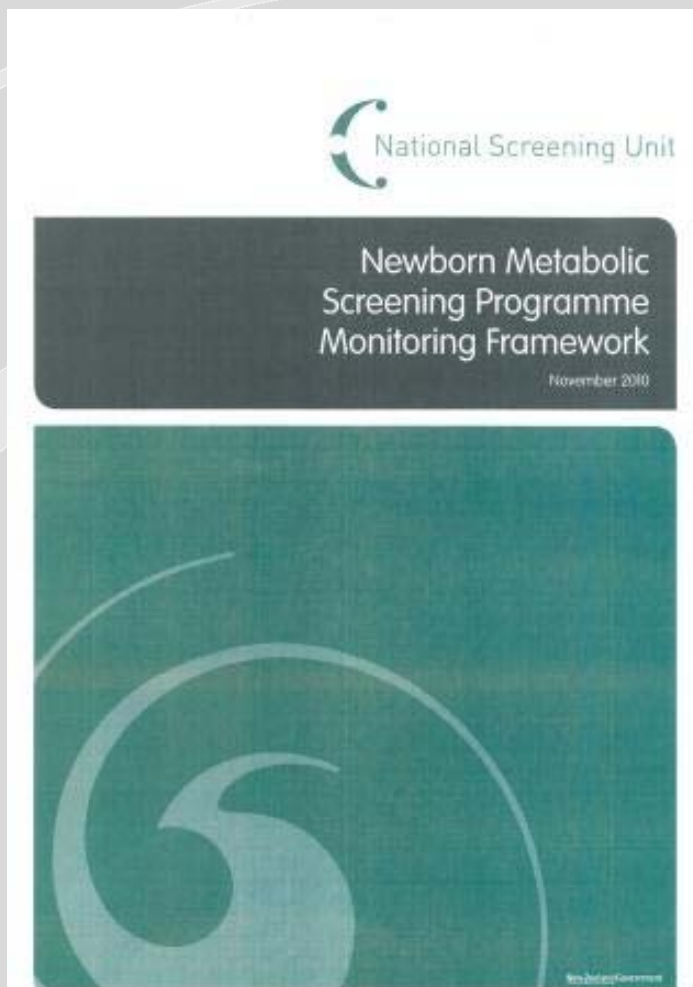
- New information sheet
- Disorder specific information following a positive test
- DVD for parents

# Quality – Screening processes



- Background
- Programme policy
- Responsibilities
  - Provider
  - Lead Maternity Carer
  - Laboratory
- Return of residual blood spots
- New technologies
- Changes to disorder panel

# Quality monitoring



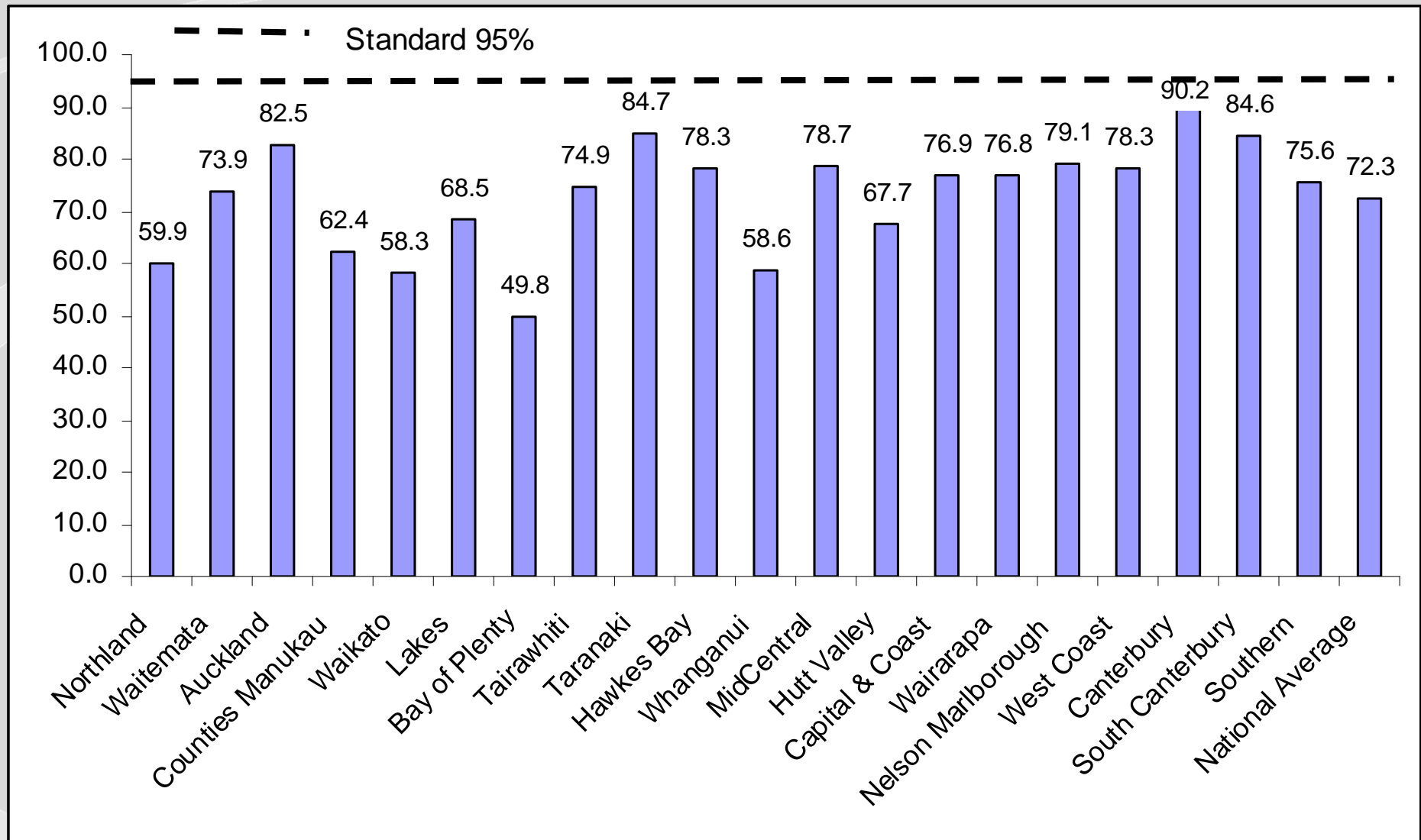
- Coverage
- Timing of sample taking
- Quality of samples
- Despatch and delivery
- Lab testing
- Reporting
- Second samples
- Diagnosis and treatment
- Card storage and return

# Quality parameters

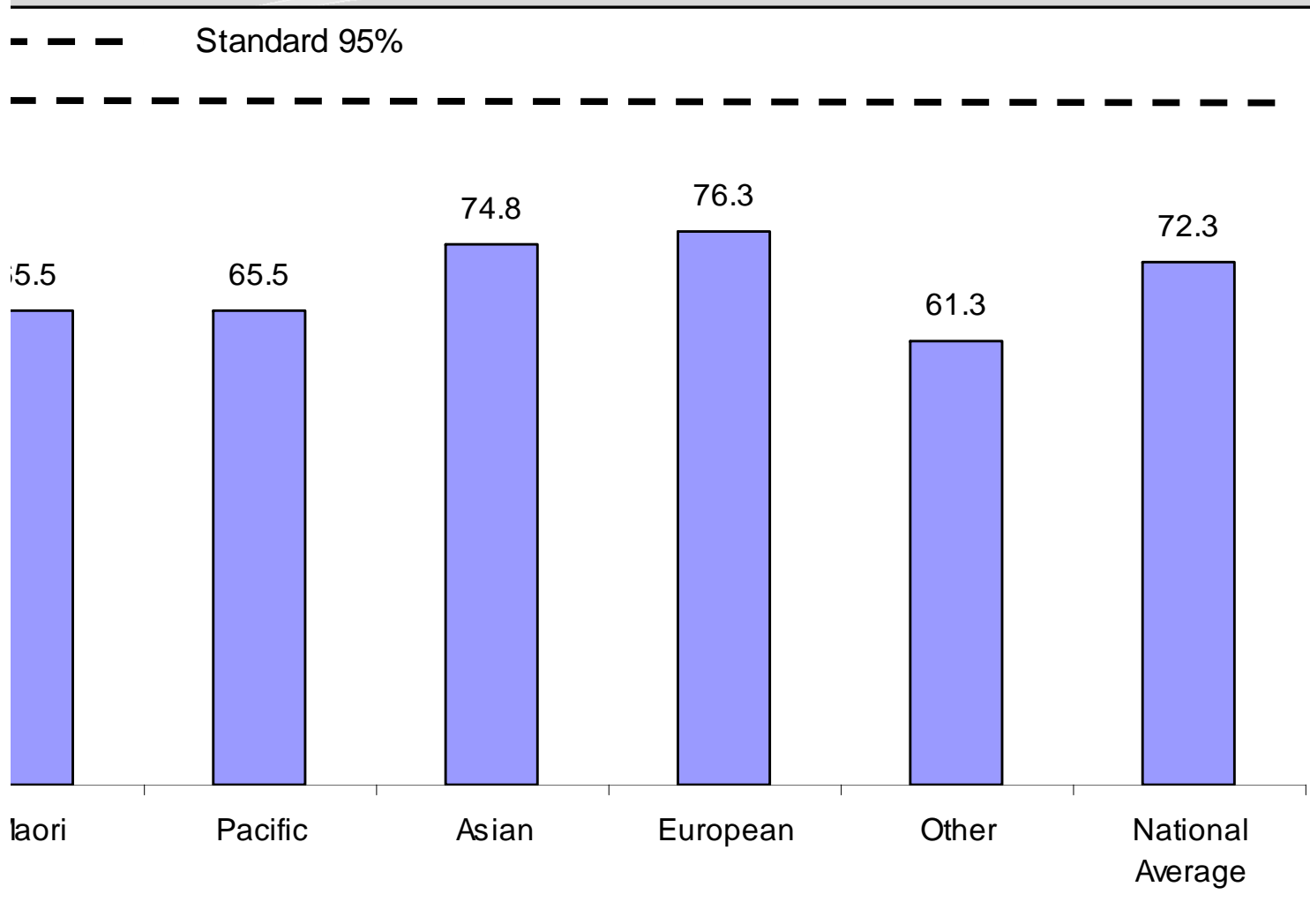


- Frequency of reporting (1, 2 or 4x yearly)
- Variables
- Standard
  
- Eg Timing of blood sample.
  - Reported quarterly
  - Against DHB region, ethnicity and socio-economic status
  - Standard 95% taken 48-72 hours

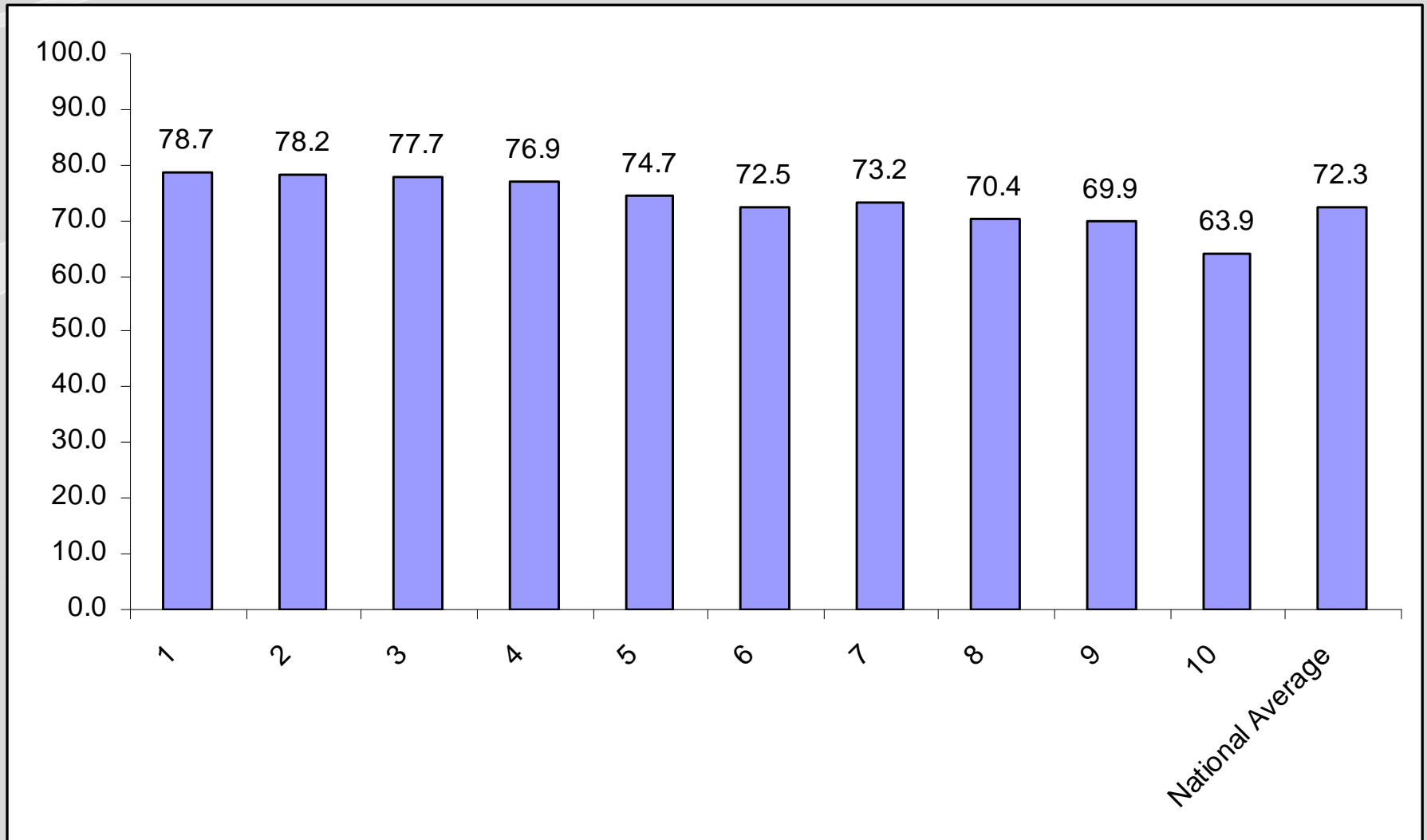
# Samples taken 48-72h Oct-Dec 2012



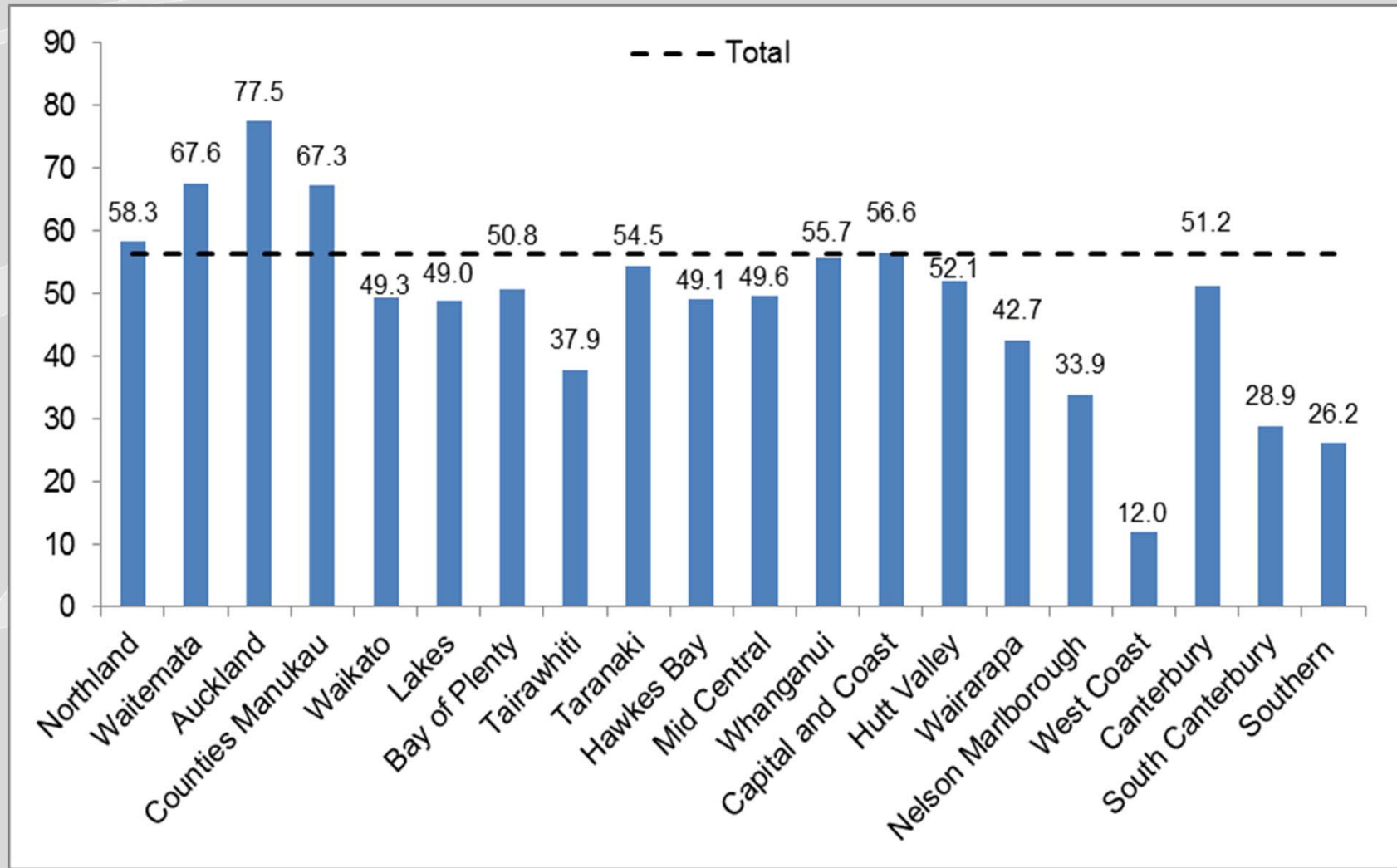
# Samples taken 48-72hrs Oct-Dec 2012



# Samples taken 48-72hrs Oct-Dec 2012



# Transit time 4d Jan-Mar 2011





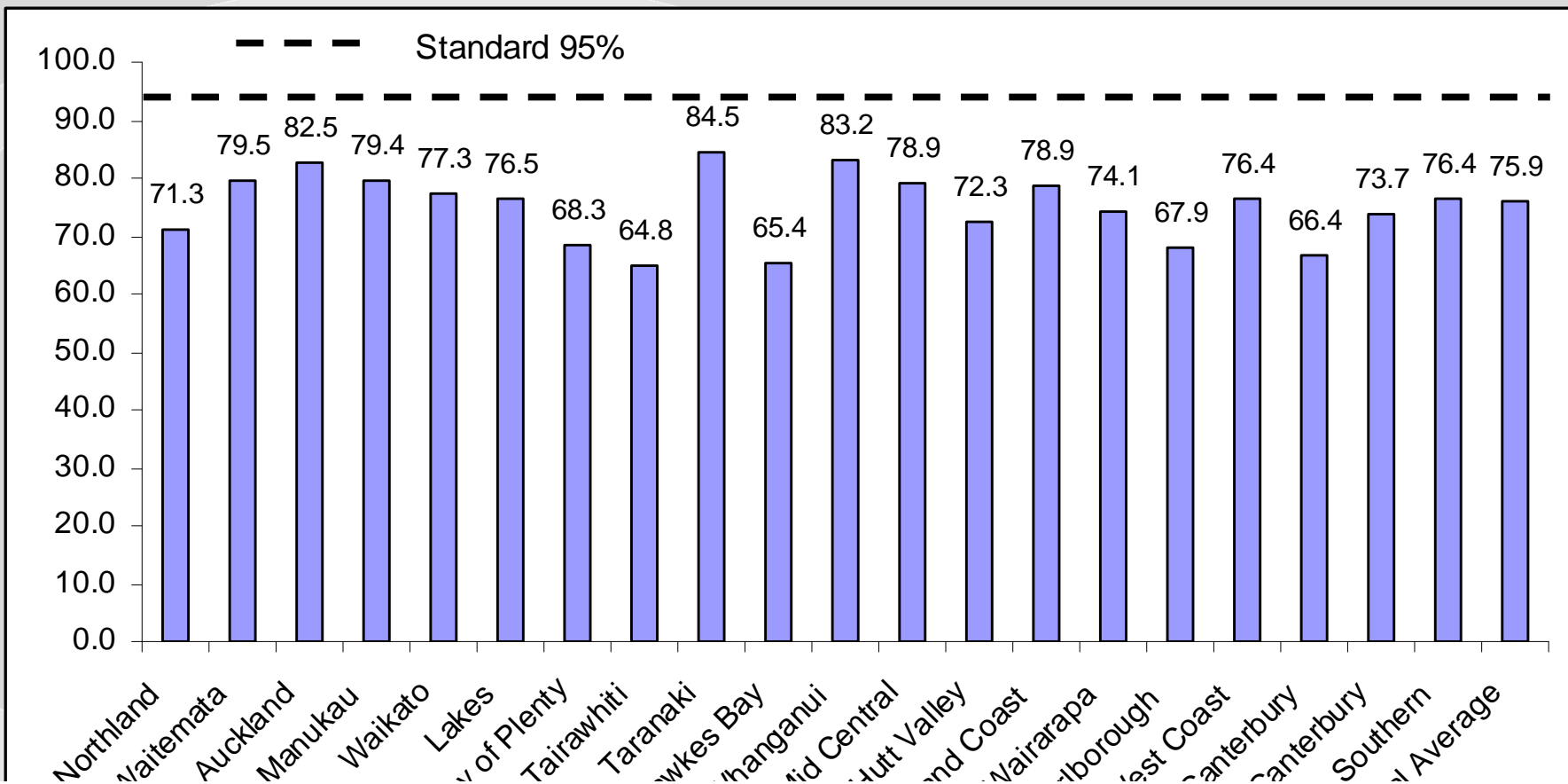
# Solution



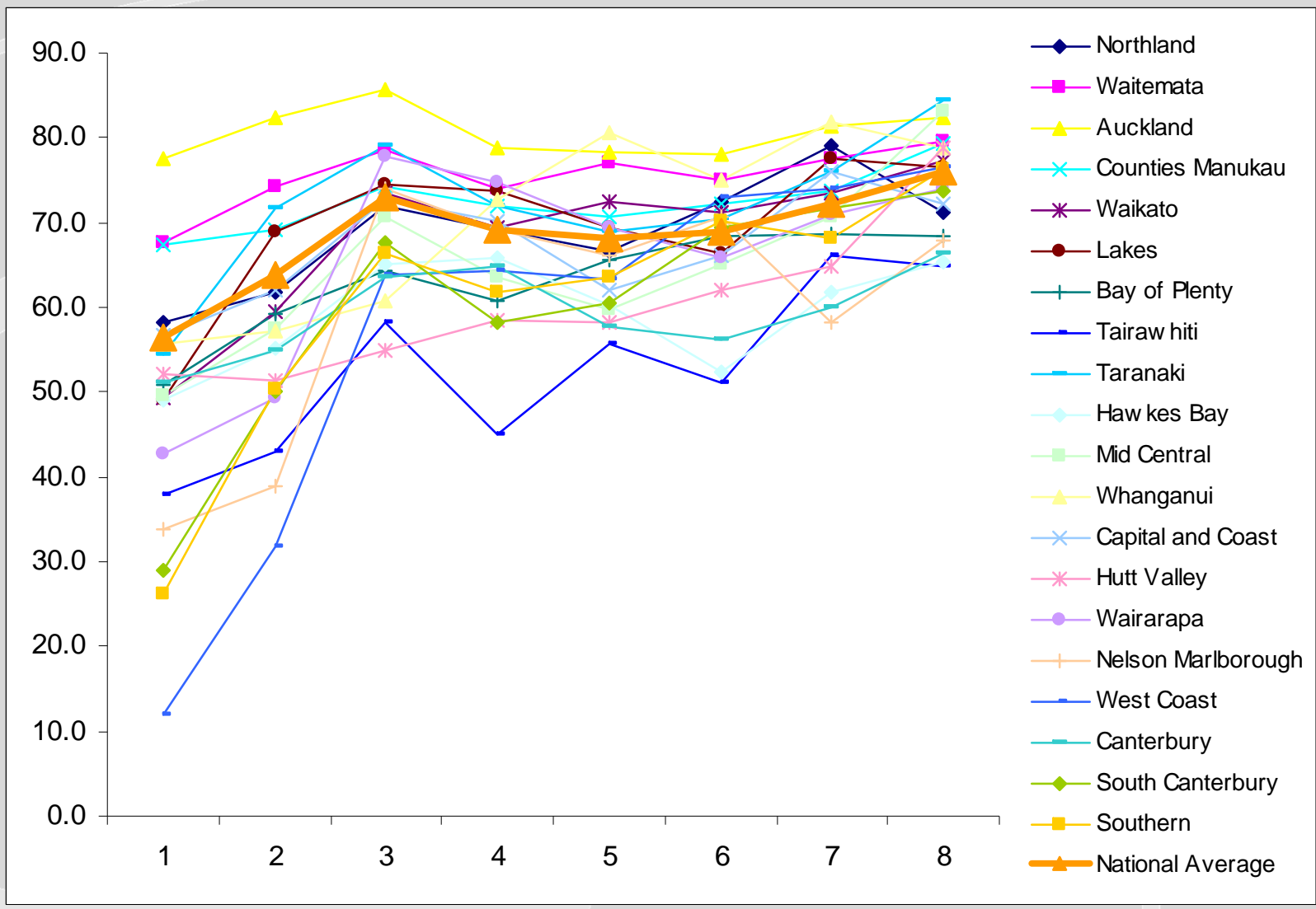
- Postage paid addressed envelopes supplied to all maternity caregivers

# Transit time

## 4d Oct-Dec 2012



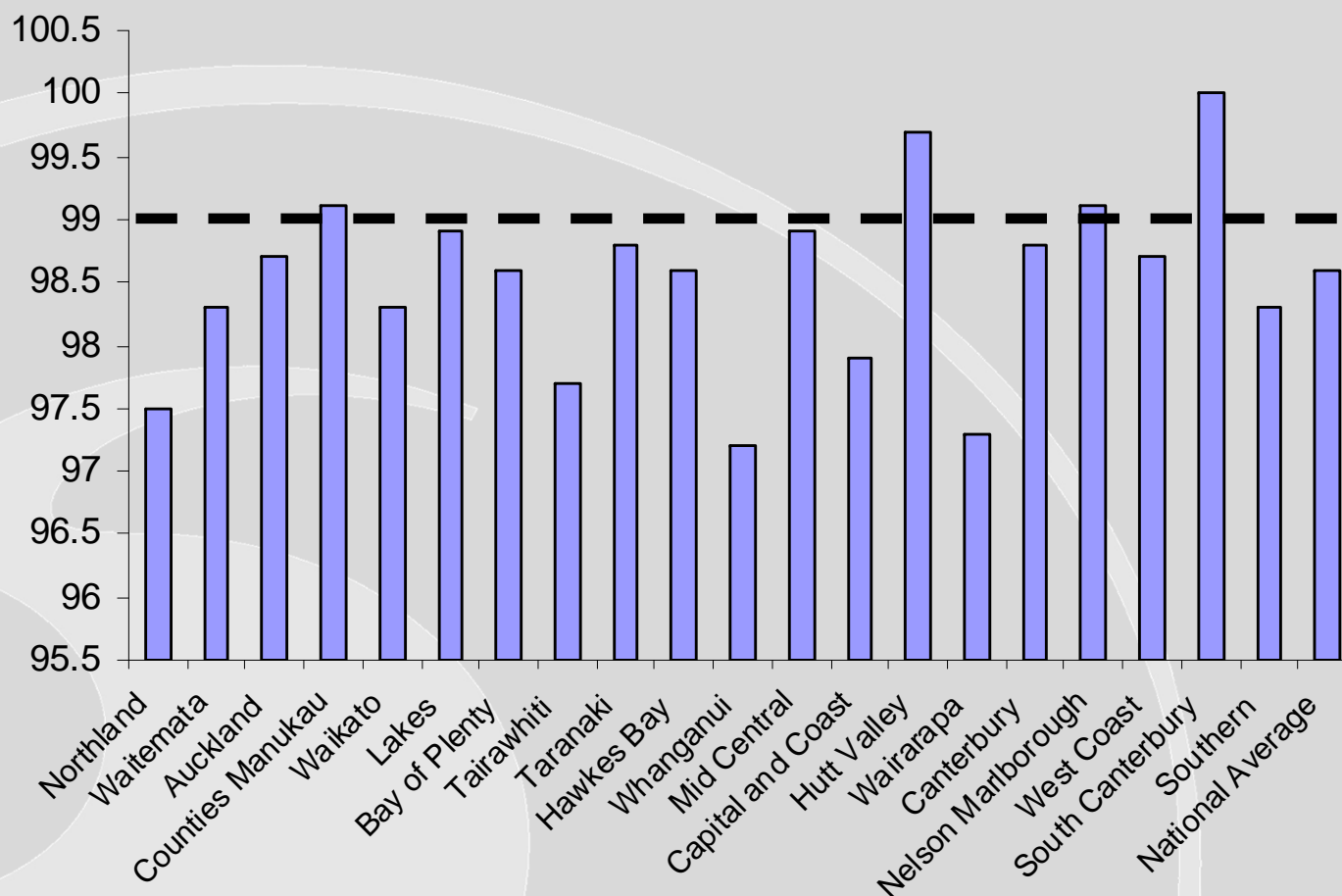
# 56% to 76% meet standard



# Adequate samples Standard 99%



## 4 regions meet standard Jan-Mar 2011

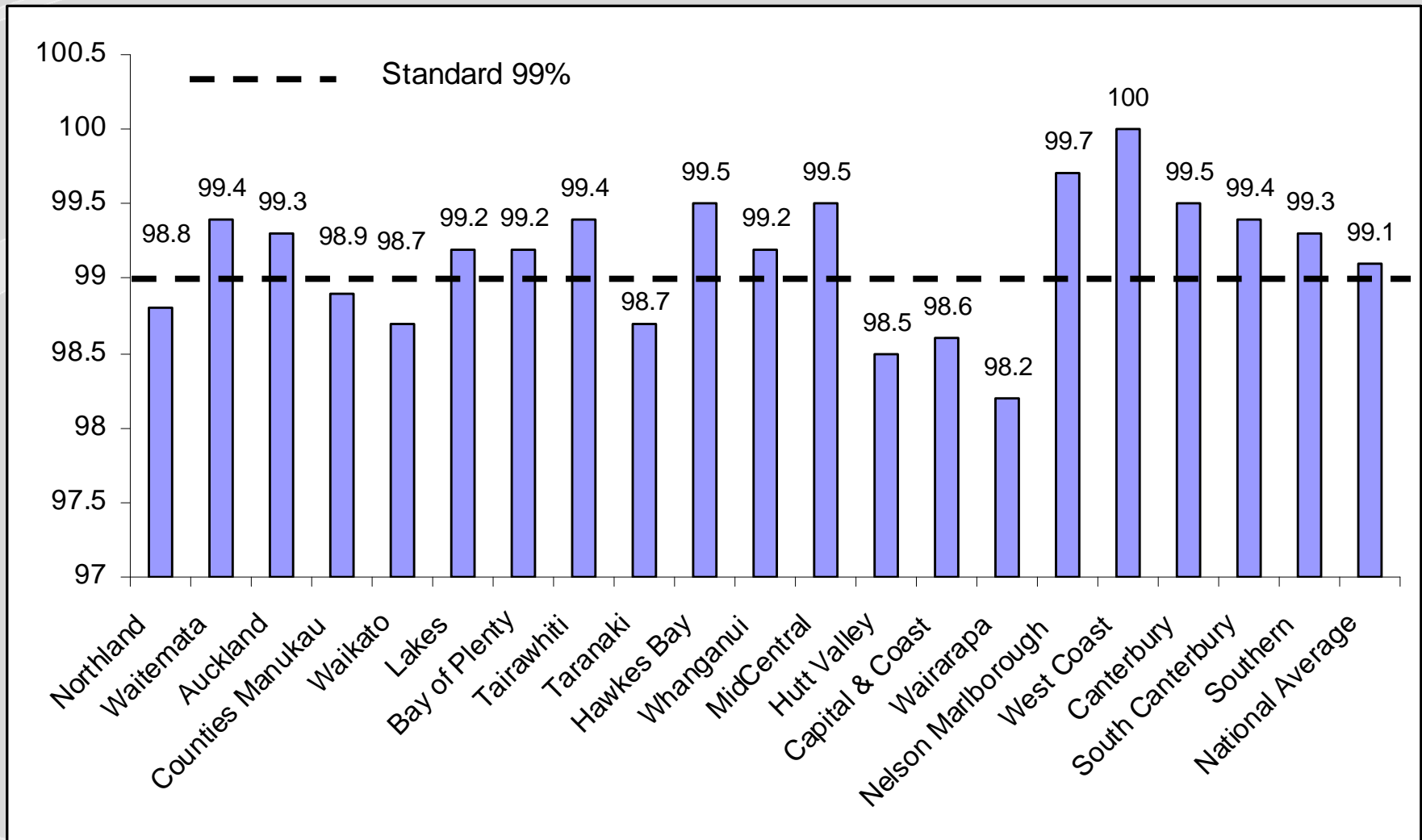


# Solution

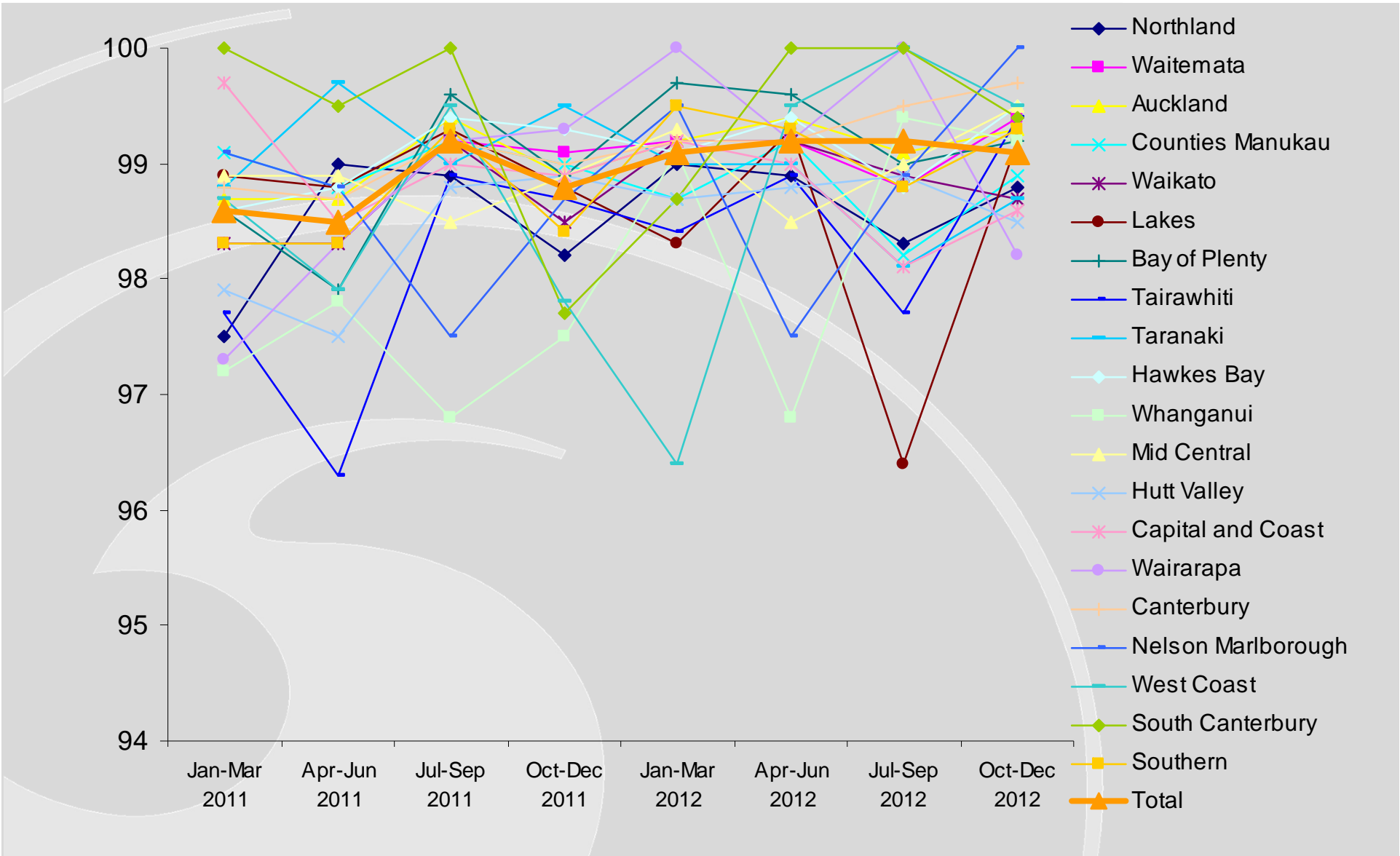


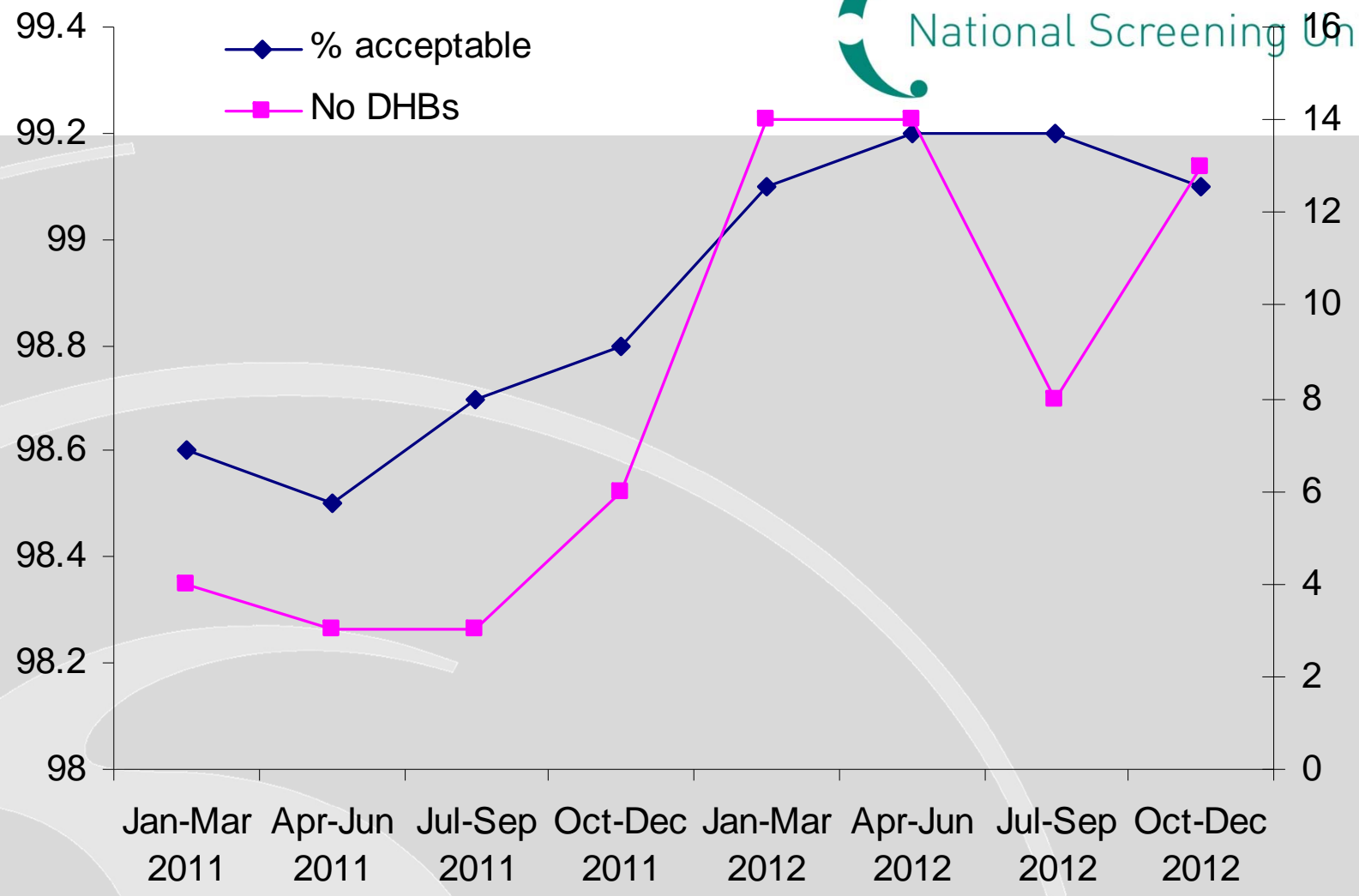
- Provision of high quality lancets free of charge to maternity caregivers mid 2011

# Suitable samples Oct-Dec 2012



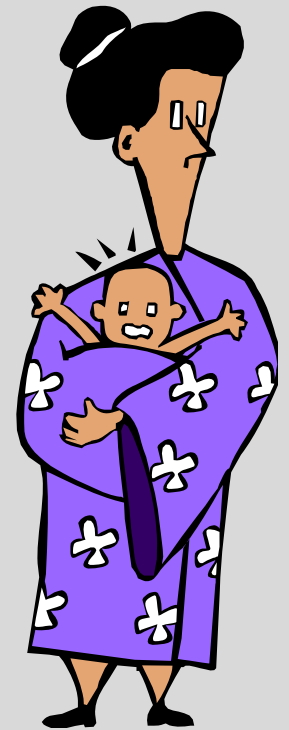
# % adequate samples Standard 99%







- 0.6% improvement in sample quality
- 390 babies / year don't need a repeat sample



# Laboratory Testing

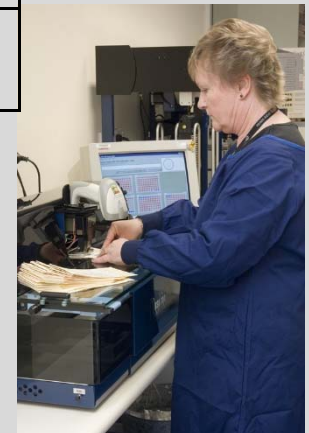


- 100% of testing complete by agreed timeframes per condition

# Oct-Dec 2012 n=15707



<b>Disorder</b>	<b>Days</b>	<b>% met timeframe</b>
CAH	2	99.9
Galactosaemia	2	99.8
AA and FAOD	2	97.8
Biotinidase def	5	99.9
Cystic fibrosis	5	98.9
CH	5	99.9



# Outcome

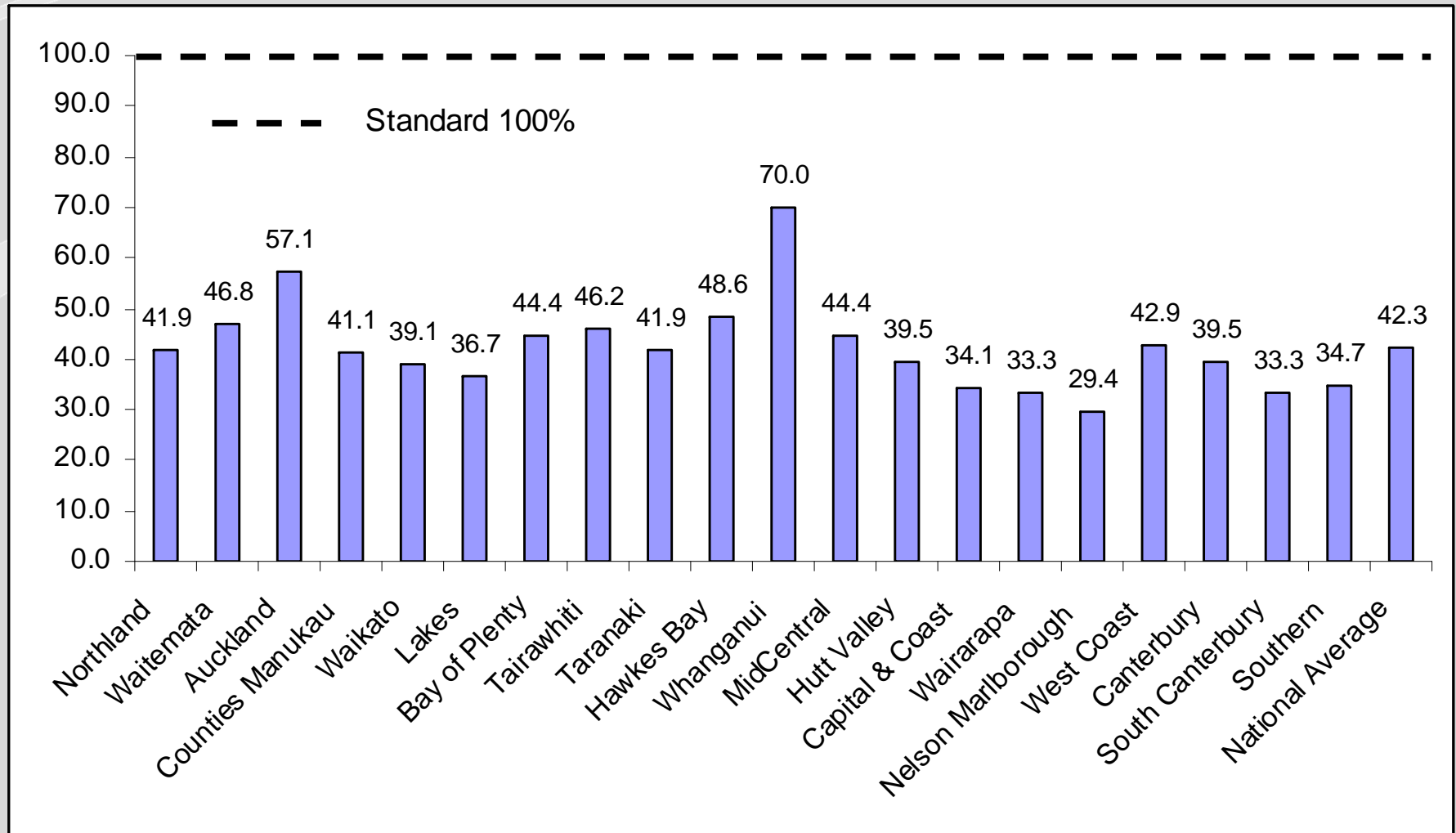
- 2 new tandems in 2013
- CF – revise methodology or target

# Followup

- Reported 6-monthly
- By DHB region
- Standard 100% of requested second samples be received by the laboratory, or decline notified, by 10 calendar days from request



# Followup Jul-Dec 2012



# What happens to reports?



- Laboratory to National Screening Unit
- Reviewed by Advisory Committee
- Sent to maternity services in each DHB region
  
- Reporting has improved awareness of, and engagement with, maternity health professionals

All resources free downloadable from  
<http://www.nsu.govt.nz/index.aspx>

The screenshot shows the National Screening Unit website. The header is teal with the logo and a search bar. A navigation menu includes 'About Us', 'Pregnancy & Newborn Screening', 'Breast Screening', 'Cervical Screening', and 'For Health Professionals'. The breadcrumb trail reads: Home Page > Antenatal and Newborn Screening Programmes > Newborn Metabolic Screening Programme - heel prick test.

**Antenatal HIV Screening**  
Antenatal Screening for Down syndrome and other conditions

**Newborn Metabolic Screening Programme - heel prick test**

- > About the programme
- > How the process works
- > Taking the blood sample
- > Your baby's screening test results
- > Storage and uses of leftover blood spots

**Universal Newborn Hearing Screening Programme**

## Newborn Metabolic Screening Programme



The Newborn Metabolic Screening Programme screens for rare but potentially serious disorders such as phenylketonuria (PKU), cystic fibrosis, and congenital hypothyroidism.

A blood sample is taken from your baby's heel at or as soon as possible after 48 hours of age (the 'heel prick' or 'Guthrie' test). If a disorder is found, early treatment can prevent permanent damage or death.

### Did you know that...

- While most babies look healthy, there are some disorders that aren't visible
- Early treatment of these disorders can prevent potentially serious complications which can cause permanent damage to the baby or even death
- To screen for these disorders, a sample of blood is collected from the baby's heel
- The screening is free to babies born in New Zealand (<http://www.health.govt.nz/new-zealand-health-system/eligibility-publicly-funded-health-and-disability-services>)

### How to get your baby screened

### The Screening Process



Find out how the screening process works »

### Resources



Access information pamphlets and other resources »

### Suggested links

- Eligibility for Publicly Funded Health and Disability Services
- Frequently asked questions



And



- F

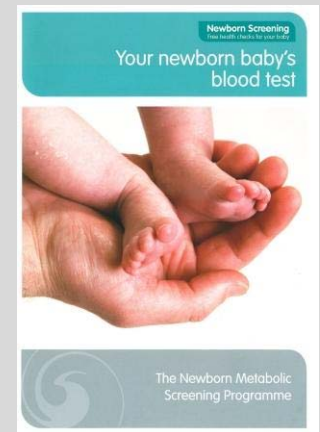
# And



- Funded longterm followup study on congenital hypothyroidism

# Summary

- Better resourced maternity professionals and families
- NSU oversight of screening system invaluable
- Policy framework gives structure to programme changes eg addition of new tests
- Monitoring framework and action following unsatisfactory results improves screening performance



# Thank-you



# NSU



- <http://www.nsu.govt.nz/index.aspx>
- <http://www.nsu.govt.nz/health-professionals/3810.aspx> (learn on line, national screening unit)
- Resources guidelines and information sheets from HealthEd  
[www.healthed.govt.nz](http://www.healthed.govt.nz)
- Cards lancets envelopes from  
[newbornscreeningresources@adhb.govt.nz](mailto:newbornscreeningresources@adhb.govt.nz)

You are here: [Home](#) > [Course Catalogue](#) > **National Screening Unit**

[« Back to parent](#)

## National Screening Unit



Educational resources for health practitioners who provide services within the national screening initiatives managed by the National Screening Unit (NSU).  
Note: these resources are planned for upgrade in 2013. Some links to external web resources may be outdated at present.

### Courses in this category (6)

 [Newborn Hearing Screening Competency Assessment](#)

 [Screening: Principles and Practice](#) ←

 [Quality Improvements in Antenatal Screening for Down Syndrome and Other Conditions \(QIASD\)](#)

 [Antenatal HIV Screening Programme \(AHIV\)](#)

 [Newborn Metabolic Screening Programme \(NMSP\)](#) ←

 [Universal Newborn Hearing Screening and Early Intervention Programme \(UNHSEIP\)](#)