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 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

Northland: 59.9
Waitemata: 73.9
Auckland: 82.5
Counties Manukau: 62.4
Waikato: 58.3
Lakes: 68.5
Bay of Plenty: 49.8
Tairawhiti: 74.9
Taranaki: 84.7
Hawkes Bay: 78.3
Whanganui: 58.6
MidCentral: 67.7
Hutt Valley: 76.7
Capital & Coast: 76.9
Whanganui: 76.8
Nelson Marlborough: 79.1
West Coast: 78.3
Canterbury: 90.2
South Canterbury: 84.6
Southern: 75.6
National Average: 72.3

Samples taken 48-72h Oct-Dec 2012

National Screening Unit
Samples taken 48-72hrs
Oct-Dec 2012

<table>
<thead>
<tr>
<th>Category</th>
<th>Average</th>
<th>Standard 95%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maori</td>
<td>65.5</td>
<td></td>
</tr>
<tr>
<td>Pacific</td>
<td>65.5</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>74.8</td>
<td></td>
</tr>
<tr>
<td>European</td>
<td>76.3</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>61.3</td>
<td></td>
</tr>
<tr>
<td>National Average</td>
<td>72.3</td>
<td></td>
</tr>
</tbody>
</table>
Samples taken 48-72hrs
Oct-Dec 2012

National Average
Transit time 4d
Jan-Mar 2011

[Bar chart showing transit times for various regions, with Northland at 58.3, Waitemata at 67.6, Auckland at 77.5, Counties Manukau at 67.3, Waikato at 49.3, Bay of Plenty at 49.0, Tauranga at 50.8, Taranaki at 54.5, Hawkes Bay at 49.6, Mid Central at 55.7, Whanganui at 56.6, Capital and Coast at 52.1, Hutt Valley at 42.7, Wairarapa at 33.9, Nelson Marlborough at 28.9, West Coast at 26.2, Canterbury at 12.0, South Canterbury at 12.0, Southern at 26.2, and Total at 51.2.]
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
% adequate samples
Standard 99%
% acceptable

No DHBs
• 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
<table>
<thead>
<tr>
<th>Disorder</th>
<th>Days</th>
<th>% met timeframe</th>
</tr>
</thead>
<tbody>
<tr>
<td>CAH</td>
<td>2</td>
<td>99.9</td>
</tr>
<tr>
<td>Galactosaemia</td>
<td>2</td>
<td>99.8</td>
</tr>
<tr>
<td>AA and FAOD</td>
<td>2</td>
<td>97.8</td>
</tr>
<tr>
<td>Biotinidase def</td>
<td>5</td>
<td>99.9</td>
</tr>
<tr>
<td>Cystic fibrosis</td>
<td>5</td>
<td>98.9</td>
</tr>
<tr>
<td>CH</td>
<td>5</td>
<td>99.9</td>
</tr>
</tbody>
</table>
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

Northland: 41.1
Waitemata: 46.8
Auckland: 57.1
Waikato: 41.1
Lakes: 39.1
Bay of Plenty: 36.7
Tairawhiti: 44.4
Taranaki: 46.2
Hawkes Bay: 41.9
Whanganui: 48.6
MidCentral: 70.0
Hutt Valley: 44.4
Capital & Coast: 39.5
Wairarapa: 34.1
West Coast: 33.3
Canterbury: 29.4
South Canterbury: 42.9
Southern: 39.5
National Average: 34.7
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
And

- Funded long term 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/health-professionals/3810.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)
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 (QASD)
- Antenatal HIV Screening Programme (AHIV)
- Newborn Metabolic Screening Programme (NMSP)
- Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP)