Public Health Screening Programmes

Annual Report

TO 31 MARCH 2007

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INTRODUCTION

This annual report presents information about the following screening programmes offered to residents across NHS Greater Glasgow and Clyde:

- Cervical Screening
- Breast Screening
- Communicable Diseases in Pregnancy
- Down’s Syndrome and Neural Tube Defects
- Newborn Bloodspot
- Universal Newborn Hearing
- Diabetic Retinopathy screening
- Pre-School Vision Screening

In addition, plans for the implementation of bowel screening are highlighted.

Screening is a public health service offered to specific population groups to detect potential health conditions before symptoms appear. Screening has the potential to save lives and improve quality of life through early diagnosis of serious conditions.

In NHS Greater Glasgow and Clyde, the co-ordination of all screening programmes is the responsibility of the Public Health Screening Unit led by a Consultant in Public Health Medicine. Multidisciplinary Steering Groups for the programmes have been set up to monitor performance, uptake and quality assurance. Figure 1 illustrates the reporting and accountability lines.

Figure 1
Each year, approximately 250,000 NHS Greater Glasgow and Clyde residents are eligible for screening (see Table 1).

**Table 1 Approximate Eligible Target Population**

<table>
<thead>
<tr>
<th>Screening Programme</th>
<th>Approximate Eligible Target Population GGC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cervical Screening</td>
<td>119,000</td>
</tr>
<tr>
<td>Breast Screening</td>
<td>47,000</td>
</tr>
<tr>
<td>Communicable Diseases in Pregnancy</td>
<td>15,500</td>
</tr>
<tr>
<td>Down’s Syndrome and Neural Tube Defects</td>
<td>15,500</td>
</tr>
<tr>
<td>Newborn Bloodspot Screening</td>
<td>14,000</td>
</tr>
<tr>
<td>Universal Newborn Hearing Screening</td>
<td>14,000</td>
</tr>
<tr>
<td>Diabetic Retinopathy Screening</td>
<td>50,500</td>
</tr>
<tr>
<td>Pre-School Vision Screening</td>
<td>15,000</td>
</tr>
</tbody>
</table>
SUMMARY

CHAPTER 6: NEWBORN BLOODSPOT SCREENING

- The newborn bloodspot screening programme offers tests to detect certain congenital metabolic abnormalities which can cause problems in growth and development and for which there is effective management or treatment. The conditions screened for are phenylketonuria (PKU), congenital hypothyroidism (CHT) and cystic fibrosis (CF).

- Screening is offered to all newborn babies resident in Greater Glasgow and Clyde.

- Newborn Screening for phenylketonuria (PKU) and congenital hypothyroidism (CHT) has been in progress since 1965 and 1979 respectively. Newborn screening for cystic fibrosis (CF) was added in Scotland in February 2003.

- A heel prick sample of blood is taken by the community midwife on the baby’s fifth day of life and posted to the National Newborn Screening Laboratory in Yorkhill where it is analysed for markers of the three conditions.

- Excellent communication and co-ordination between the hospital and community midwifery service, the National Newborn Screening Laboratory at Yorkhill, the screening department at Gartnavel and the paediatric service is required to be able to meet the NHS QIS pregnancy and newborn screening clinical standards of 95% of cases of CHT and PKU to have started treatment by 14 days age and of CF within 35 days age.

- Normally 95% of samples arriving at the National Laboratory are reported within two working days as required by the clinical standards. However in 2006 for Scotland this fell to 91% due to equipment problems and staff shortage. National Services Division appointed two new members of staff in early 2007 and the equipment problems have been resolved.

- The number of babies of NHS Greater Glasgow and Clyde residents screened in 2006 - 2007 was 13,458, 96% of the total eligible population of 14015.

- From 1 April 2006 to 31 March 2007 one case of PKU, 7 cases of CHT and 13 cases of CF were detected. All received appropriate management within the timescale set.

- An integrated bloodspot screening programme has been developed across Greater Glasgow and Clyde adhering to the principles of the NHS QIS standards. Steps are being taken to ensure all the standards are met.
CHAPTER 6: NEWBORN BLOODSPOT SCREENING

Background

Newborn bloodspot screening is offered to parents/guardians of all live infants resident in Greater Glasgow, Clyde and Argyll and Bute.

Newborn Screening for phenylketonuria (PKU) and congenital hypothyroidism (CHT) has been in progress since 1965 and 1979 respectively. Newborn screening for cystic fibrosis was added in Scotland in February 2003.

Aim of screening programme

The aim of the screening programme is to identify, as early as possible, abnormalities of body chemistry (metabolism) in newborn babies which can lead to problems with growth and development, so that they may be offered appropriate management for the condition detected. The diseases screened for are phenylketonuria (PKU), which is found in around 1 in 8,000 babies born; congenital hypothyroidism (CHT), which affects approximately 1 in 3,500; and cystic fibrosis (CF), an inherited condition affecting 1 in 2,500 babies born in Scotland.

Benefits of programme

The benefits of the programme are that serious conditions may be detected before symptoms appear and treatment is offered at an early stage when it is likely to be more effective. For example, babies born with PKU cannot metabolise an amino acid called phenylalanine which is a component of protein found in every day foods including milk. Toxic levels of phenylalanine may build up causing irreversible brain damage unless the baby is urgently started on a special diet. With prompt treatment the baby is very likely to develop normally.

Recommended Age to Perform Screen

The bloodspot sample should be taken on day 5 of life whenever possible. There are separate protocols in place for screening babies who are ill, transfused or born prematurely and when repeat testing is required.
**The screening test**

Blood is taken by the community midwife from the baby's heel using a blood letting device and collected on a bloodspot card consisting of special filter paper which is posted by freepost to the National Newborn Screening Laboratory in Glasgow. The blood is analysed for markers of the 3 conditions phenylketonuria, congenital hypothyroidism and cystic fibrosis.

**Eligible Population**

All newborn babies of residents in NHS Greater Glasgow and Clyde.

**Delivery of screening programme 2006/07**

Guidelines for newborn bloodspot Screening have been developed for use across NHS Greater Glasgow and Clyde.  (ref: NHS Greater Glasgow and Clyde Neonatal Guidelines: Neonatal Bloodspot Screening, 2007). These include:

- Informing the parents/carers
- Consent
- Timing of the test
- Repeat testing for sick and premature infants
- Requirements for the test
- Method for heel prick testing
- Documentation

The screening process requires excellent communication and co-ordination between the hospital and community midwifery service, the National Laboratory at Yorkhill, the screening department at Gartnavel and the paediatric service as is demonstrated in the following pathway (Figure 6.1) for PKU and CHT. There is a separate CF pathway as double testing is required.
Baby born → Information to Parents

Yes → Consent for Test

Yes → Blood spot collected

Blood spot collected → "Test declined" recorded

"Test declined" recorded → No further action unless clinical symptoms present. Refusal recorded at laboratory

Yes → Repeat specimen if necessary

Repeat specimen if necessary → High/persistently raised

High/persistently raised → Report

Report → Telephone call to Paediatrician plus Report

Report → Treatment if necessary and follow up

Result recorded → Notification to GP, Hospital, Child Health

Result recorded → Result notified

Result notified → Referred to Paediatrician

Referred to Paediatrician → Treatment if necessary and follow up

Coverage Monitored

Birth Notified

SCREENING DEPT, GARTNAVEL

HOSPITAL
A national leaflet explaining the tests is distributed soon after the birth. The heel prick blood sample is generally taken by the community midwife on the 5th day and the bloodspot card sent by freepost to the National Newborn Screening Laboratory in Yorkhill. Currently across NHS Greater Glasgow and Clyde there is a variation in the devices used to prick the heel. The costs and benefits of the devices are currently being reviewed and by early 2008 the steering group will recommend that all of NHS Greater Glasgow and Clyde uses the same type of device causing the least distress and the least unsatisfactory results so avoiding repeat testing for all babies.

There is an urgency to begin the management of all babies found to have any of the 3 conditions as soon as possible. The standards require 95% of positive cases of CHT and PKU to have started treatment by 14 days of age and of CF within 35 days of age. The delivery of the programme within the timescale is also dependent on the postal service delivering the bloodspot samples to the Newborn Screening Laboratory. Arrangements are in place to courier the samples to the laboratory if necessary.

Normally 95% of samples arriving at the National Laboratory are reported within two working days as required by the clinical standards. However in 2006 for Scotland this fell to 91%. This is the first year the laboratory has not managed to meet the standard. This was due to equipment problems and staff shortages at critical periods of the year. The equipment problems appear to be resolved and National Services Division is funding two new members of staff and therefore this should improve turn around times for 2007.

**Delivery of Screening Programme 2006/07**

The number of babies of NHS Greater Glasgow and Clyde residents screened in 2006 was 13,458, 96% of the total eligible population of 14,015. Figure 6.2 illustrates uptake rates and the results of the screening programme from 1 April 2006 to 31 March 2007.

Of the 4% (557) not screened, only 9 refused screening, 412 moved in or out of the area and 30 babies died. From 1 April 2006 to 31 March 2007 there was one positive case of PKU detected, 7 of CHT and 13 of cystic fibrosis. All received appropriate management within the timescale of the standard.
Figure 6.2

Summary of Bloodspot Screening Uptake and Results for babies born 1 April 2006 – 31 March 2007

<table>
<thead>
<tr>
<th>Total Eligible for Screening</th>
<th>14015 (100%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live Births to NHSGGC resident</td>
<td>13422 (95.8%)</td>
</tr>
<tr>
<td>Babies who moved into the area</td>
<td>593 (4.2%)</td>
</tr>
<tr>
<td>Screened</td>
<td></td>
</tr>
<tr>
<td>YES</td>
<td></td>
</tr>
<tr>
<td>13458 (96%)</td>
<td></td>
</tr>
<tr>
<td>Live Births to NHSGGC resident</td>
<td>13316</td>
</tr>
<tr>
<td>Babies who moved into the area</td>
<td>142</td>
</tr>
<tr>
<td>NO</td>
<td>557 (4%)</td>
</tr>
<tr>
<td>Refused</td>
<td>9</td>
</tr>
<tr>
<td>Babies moved into area, but not born here</td>
<td>451</td>
</tr>
<tr>
<td>Babies died after birth</td>
<td>30</td>
</tr>
<tr>
<td>Babies move out after birth</td>
<td>61</td>
</tr>
<tr>
<td>To be investigated</td>
<td>6</td>
</tr>
</tbody>
</table>

Results

<table>
<thead>
<tr>
<th>PKU</th>
<th>THY</th>
<th>CF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive</td>
<td>Negative</td>
<td>Positive</td>
</tr>
<tr>
<td>1</td>
<td>13457</td>
<td>7</td>
</tr>
</tbody>
</table>

*1 total to include 2 Incomplete screens and 1 verified
*2 Total to include 9 carriers, 39 incompletes and 2 verified

Source: SIRS
Information systems

Information on Pregnancy and Newborn screening tests is provided by the National Laboratory’s Information Management System. The results of the Bloodspot test are recorded against the individual child’s record held within the Scottish Immunisation and Recall System (SIRS).

Since June 2006 there has been a national requirement for all medical samples to be marked with the Community Health Index (CHI) number. A national audit (see Figure 6.3) over several weeks during the summer 2007 shows marked variation in the use of CHI on bloodspot cards across Health Boards. The low percentage of CHI marked cards in NHS Greater Glasgow and Clyde (less than 20%) is unacceptable. It is currently being monitored by the Steering group and will be addressed by the appropriate Service Managers.

Figure 6.3

% CHI on Blood Spot Card on Random dates in May/Juli/Aug 2007

Source: National Newborn Screening Laboratory
Challenges and future priorities

- To ensure the programme meets the pregnancy and newborn screening clinical standards
- To standardise the heel prick device used across Greater Glasgow and Clyde
- To ensure the CHI number is used on all bloodspot samples
- To ensure the bloodspot samples are delivered to the laboratory in the most efficient and timely way recognising the tight timescales required.

Conclusion

An overarching principle of newborn screening as described in the pregnancy and newborn screening clinical standards states

“The aim is to offer treatment at an early stage when it is likely to be more effective. The emphasis should be on performing high quality blood spot and hearing tests, with rapid reporting, as key components of the programme so that repeat tests are minimised and parents have confidence in the value of the process.” (NHS Quality Improvement Scotland, Clinical Standards – October 2005, Pregnancy and Newborn, p12)

The Newborn Bloodspot Steering Group (Appendix 6.1) and all involved in the NHS Greater Glasgow and Clyde bloodspot programme have worked hard to achieve this and are continuing to address the few areas of the programme where the clinical standards are not met.
Appendix 6.1

Members of Newborn Bloodspot Screening Steering Group
(as at January 2007)

Mrs Donna Athanasopolous  PERL Resources Co-ordinator
Ms Dorothy Cafferty  Planning Officer
Mrs Jacquie Campbell  General Services Manager
Mrs Diane Paterson  Lead Midwife
Dr Anne Devenny  Consultant Paediatrician
Mrs Fiona Gilchrist  Screening Manager
Mrs Annie Hair  CHP Children’s Services Lead
Dr Margaret Lachlan  Consultant in Public Health Medicine
Miss Denise Lyden  Project Officer
Mrs Joan MacKenzie  Newborn Laboratory
Ms Marie-Elaine McClair  Lead Midwife PRM
Miss Jacqueline McFadden  Information Analyst
Ms Julie Mullin  Deputy Screening Manager
Dr Andrew Powls  Consultant Neonatologist
Ms Jo Scobie  Clinical Lead Midwife
Ms Audrey Taggart  Lead Midwife
Marion McLoone  Quality and Effectiveness Manager (until Nov 06)
Mrs Janice Winter  Clinical Effectiveness Manager (from Jan 07)
Acknowledgments

This annual report was prepared by the Public Health Screening Unit in collaboration with members from the screening programmes steering groups, Public Health Protection Unit, Jacqueline McFadden, Annette Little, Ann Boyle, Mark Menzies and Frances Paton from Information Services.

Also a special thank you to Screening Department staff at Gartnavel Royal.

Many thanks go to all the healthcare professionals and support staff for helping to deliver the screening services across NHS Greater Glasgow and Clyde.

The programmes have also benefited from the close links held with the Child Health Surveillance Programme (CHSP), Maternity Services Strategy Group, Regional Cancer Advisory Group and the Diabetes Managed Care Network.