



# Newborn Bloodspot Screening

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## Protocol for Repeats & Transfers in to NHS Borders

Version Control	Version	Summary
28 <sup>th</sup> June 2018	0.1	Original document circulated for comment and amendment.
30 <sup>th</sup> July 2018	0.2	Amendments from Child Health incorporated.
30 <sup>th</sup> August 2018	0.3	HV & MW contacts removed
30 <sup>th</sup> October 2020	0.4	Names & e-mail & phone number address updates

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## Responsibilities

It is the responsibility of NHS Borders, through the Screening Co-ordinator Julieann Brennan and the Director of Public Health Dr Tim Patterson, to ensure that robust systems are in place locally to confirm that every newborn child up to the age of 1 year old, resident in NHS Borders, is invited to participate in Bloodspot screening.

## Failsafe Requirements

NHS Borders must implement failsafe measures that ensure that:

- all babies that are transferred have their screening status notified
- all eligible babies are identified and offered screening
- all babies whose parents accept screening are tested
- all samples arrive at the laboratory in a timely manner
- all positive babies receive timely treatment within national standard
- Child Health Records Departments should also perform regular checks to identify babies that might have missed screening.

## National Bloodspot Protocol & Guidance Documents

**All staff involved with the Bloodspot Screening Programme are responsible for ensuring they have read and adhere to the: National Protocols (v1 March 2018) and the Newborn Screening Sampling Guidelines (v1.0 March 2018) provided below:**



2018 Newborn  
Bloodspot Sampling G



2018 - Newborn  
bloodspot Screening I



2018 Newsletter -  
Changes to the newb

**Public Health Screening Co-ordinator Julieann Brennan (07493882128) & Director of Public Health Dr Tim Patterson 01896 825560 must be notified immediately of any adverse incidents in the bloodspot screening programme.**

## **Adverse Events**

Any screening programme has the potential for significant adverse incidents to occur at any stage in the screening process and for complaints and issues about the service to attract significant public, political and media attention. It is therefore important that robust risk management and audit systems are established to minimise the occurrence and impact of any adverse incidents and to facilitate continuous quality improvement. All adverse incidents should be managed appropriately to minimise the risks to, and effects on those involved and participating Boards.

### **An adverse incident can be any of the following:**

**Administrative:** Failsafe procedures not instigated; Parent / carer or requesting midwife/ GP not notified of result.

**Laboratory:** Assay errors, Interpretation errors.

**Clinical:** Misdiagnosis, Long waiting times through the pathway from positive screening test to confirmed diagnosis.

### **Nationally agreed guidance on escalation procedures for the screening programmes should be followed.**

Any healthcare professional involved in the NHS Scotland newborn bloodspot screening programme who becomes aware of a suspected problem should follow agreed local Board clinical governance procedures. Local clinical governance procedures may vary from one Board to another but commonly involve an initial period of local investigation and establishment of extent of problem followed by external independent peer review when appropriate. In all cases associated with the screening programme, there will be a thorough investigation and National Services Division (NSD) will be notified early in the process – at the time of internal investigation. In view of the sensitivities of national screening programmes and the public interest in them, NSD may require an external peer review even if local Board management decide not to invoke this. If necessary NSD and the Board will meet to discuss and agree what action, if any, is required. NSD will notify the Scottish Government Health Directorates (SGHD) and decide if action is needed in other NHS Boards.

**NB: These protocols are in addition to, and do not replace, NHS Borders Clinical / Adverse Incident Reporting Procedures.**

**Public Health Screening Co-ordinator Julieann Brennan (07493882128) & Director of Public Health Dr Tim Patterson 01896 825560 must be notified immediately of any adverse incidents in the bloodspot screening programme.**

## **NHS Borders Adverse Event Policy**



Adverse Event Policy  
v7 Final APPROVED\_1

Screening Programme	Failsafe Measures	Responsible Person
<p><b>Repeat Bloodspot Sample Required</b></p> <p>Scottish Newborn Screening Laboratory (SNSL) informs Child Health Team that a repeat is required. <b>Target: Avoidable Repeats ≤ 2.0%.</b></p> <p>New Babies with no screening result recorded by day 18 must be offered bloodspot testing/retesting within 1 week of identification.</p> <p><b>The Community Midwife is responsible for obtaining the repeat test.</b> Child Health telephone the Midwife Team in the relevant locality (see appendix 3), who arrange for a community midwife to obtain a repeat sample. All contacts are recorded on the labs result letter requesting a repeat sample. Child Health continually monitor until resolution. Child Health contact the lab, several days after notifying the community midwife, to check the repeat sample has been received at the lab if result not yet received.</p> <p>Any babies in SCBU/Ward when their sample was taken, if still an in-patient would be retested there, but once discharged the community midwife would take the bloodspot sample.</p> <p><b>Scottish National Screening Lab (SNSL)</b> processes the sample and reports results.</p>	<ul style="list-style-type: none"> <li>Repeat samples should be taken as soon as possible, or at the age directed by the screening laboratory. Tick the 'repeat sample' box on the blood spot card.</li> <li>It is critical that time limits are strictly adhered to if a repeat is required for Cystic Fibrosis purposes.</li> <li><b>The Cystic Fibrosis screen is not reliable for babies over 8 weeks</b></li> <li><b>A bloodspot card must be completed &amp; sent to SNSL, for all babies even if the offer of repeat screening has been declined.</b></li> <li><b>A declined offer of screening</b> must be added to the comment section. Parents are given the option to take up screening at a later date and are provided with a copy of the information sheet <b>"When the blood spot screening test has not been undertaken"</b>. The information sheet lists the possible signs and symptoms of the conditions that are screened for. This information is also given to the family's GP, so that the GP can also look out for these signs and symptoms</li> <li>SNSL confirm receipt of a "refusal of consent" bloodspot card with a letter and ensure that the family is not contacted for a missed screen in error. Child Health adds this to EMIS &amp; SIRS.</li> <li>Written informed consent must be obtained for the repeat test using official form (appendix 3) &amp; parent/carer should be informed of the reason for the repeat.</li> <li>Accuracy in recording time of birth &amp; calculating age of baby is crucial. The bloodspot card has two new fields added: time of birth and time specimen taken - to ensure the bloodspot has been taken within the correct timescales.</li> <li>Check the expiry date on the card.</li> <li>All mandatory fields must be completed.</li> <li>Ensure the correct CHI number is on bloodspot card &amp; use a pre-printed label with baby's details if available</li> <li>Post bloodspot card to lab as soon as possible - avoid sending in batches.</li> </ul> <ul style="list-style-type: none"> <li>SNSL has its own failsafe measures.</li> <li>95% target for results ready within 2 working days</li> </ul>	<p>SNSL Child Health Team Community Midwife</p> <p>Ward midwife SCBU Child Health Team</p> <p>SNSL</p>

<p><b>Result sent to NHS Borders Child Health</b> Child Health monitors repeat bloodspot requests until actioned or consent refused.</p>	<ul style="list-style-type: none"> <li>• Results e-mailed to designated Child health account: <a href="mailto:bord-uhb.newbornscreening@borders.scot.nhs.uk">bord-uhb.newbornscreening@borders.scot.nhs.uk</a> which specific staff in Child Health can access and it is checked daily.</li> <li>• If a result is not available, the HV can ask Child Health team to contact SNSL to find results for babies born in Scotland. SNSL may also be able to assist in tracking down results for non-Scottish births.</li> <li>• Child Health communicate to Midwives any actions that are required such as repeat bloodspots. Child Health check responses to these task requests on a daily basis and chase up any outstanding until their completion.</li> <li>• In the event that a Midwife in a locality is unavailable to action this task in the required time period, due to absence etc, Child Health would escalate this to Ann Fernie (Senior Charge Midwife Community) and another Midwife in another locality would provide assistance to obtain the repeat bloodspot within the required timescale.</li> <li>• Child Health Team must check the SIRS “overdue bloodspot report” weekly, request notes and contact the relevant Midwife or Health Visitor to action to ensure all babies have a result by day 18.</li> </ul>	<p>Child Health Dept</p>
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Screening Programme Component	Failsafe Measures	Responsible Person
<p><b>Transfers in to NHS Borders</b> Policy is to ensure that all babies moving in to Scotland from elsewhere, who have not been screened or have not provided verifiable screening results should be offered newborn screening up to the age of 12 months.</p> <p>Child Health must establish whether or not the child has a bloodspot result or been offered screening.</p> <p>New Babies with no screening result recorded by day 18 must be offered bloodspot testing/retesting within 1 week of identification.</p> <p>In the case of travelling families or families who, for any reason, are not resident within a single NHS Board, the NHS Board where the child was born is responsible for offering screening and for following up results as necessary.</p>	<ul style="list-style-type: none"> <li>• Child Health run a weekly overdue bloodspot report to notify of any transfer-in to the Borders infants that do not have a bloodspot result and ensure notes are requested from their previous Health Board and monitor until it the bloodspot is done or consent refused.</li> <li>• If a result is not available, the Health Visitor can ask the Child Health team to contact SNSL to find results for babies born in Scotland. SNSL may also be able to assist in tracking down results for non-Scottish births.</li> </ul>	<p>SNSL Child Health Department Health Visitor Teams Ambulatory Care</p>

**When Child Health is notified of a child transferring in to NHS Borders where a bloodspot result is not documented or known then for :**

**Child aged 14 days or under at transfer-in:**

**Community Midwife is responsible for obtaining the bloodspot.**

Child Health requests the child's notes from their previous UK health authority to establish the child's screening status (appendix 2)

If Child Health cannot confirm bloodspot screening has been done, then they contact the community Midwife team to arrange for a midwife to contact parent/carer to discuss the child's screening status.

Only verifiable evidence of a child's bloodspot test result should be accepted i.e. a result letter written in English. If this is unobtainable, offer screening.

Verbal results and Red Book type records with a date on which a bloodspot was taken cannot be accepted as evidence of a result.

Midwife should send a copy of the bloodspot result letter to Child Health for recording on SIRS and EMIS.

**Child aged 15 days - 12 months at transfer-in:**

**Health Visitor is responsible for obtaining the screening status & arranging the referral to ward 15 Ambulatory Care for a bloodspot screening appointment where applicable.**

Child Health requests, from the Child's previous UK Health Authority, notes for any child transferring in to NHS Borders, to establish the child's screening status. All contacts are recorded by Child Health.

If Child Health cannot confirm if bloodspot screening has been completed for a child, less than 12 months of age, then Child Health contact the Health Visitor by sending a task on EMIS to contact the parent(s)/carer(s) to ascertain the screening status of the child and offer bloodspot screening. (See letter appendix 4)

Only verifiable evidence of child's bloodspot screening result should be accepted i.e. a result letter written in English.

- Child Health communicates to Health Visitors any actions that are required such as repeat bloodspots. Child Health check responses to these task requests on a daily basis and chase up any outstanding until their completion.
- In the event that a Health Visitor in a locality is unavailable to action this task, in the required time period due to leave/absence etc, Child Health would escalate this to Fiona Houston the Community Nurse Manager and another Health Visitor in another locality would provide assistance to obtain the repeat bloodspot within the required timescale.

<p>Health Visitor should send a copy of the bloodspot result letter to Child Health for recording on SIRS &amp; EMIS.</p> <p>If the family is difficult to contact by telephone or has not produced the bloodspot results after being prompted, the letter from Public Health (appendix 6) may be used to encourage a response.</p> <p><b>Verbal results and Red Book type records with a date on which a bloodspot was taken cannot be accepted as evidence of a result.</b></p> <p>If verifiable evidence is unobtainable, as may be the case if transferred in from abroad, then offer screening if the bloodspot can be taken before the child reaches 12 months of age.</p> <p>If parent(s)/carer(s) decide not to accept the offer of screening or the baby is over 12 months of age this should be recorded on EMIS by the Health Visitor and added to SIRS.</p>		
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Screening Programme Component	Failsafe Measures	Responsible Person
<p><b>Eligibility &amp; Referral</b></p> <p>To determine if the child is eligible for a bloodspot screen referral, the Health Visitor must calculate the exact age of the child and ensure the child is under 12 months of age at referral and able to be tested before it reaches that age.</p> <p>Health Visitor makes a referral to Ambulatory Care Ward 15 using the Bloodspot referral form (appendix 5). This is e-mailed to the Child Health team generic e-mail <a href="mailto:bord-uhb.newbornscreening@borders.scot.nhs.uk">bord-uhb.newbornscreening@borders.scot.nhs.uk</a></p> <p>Child Health will take a copy of this referral and add to the child's EMIS records.</p> <p>Child Health then hand the referral directly to Ambulatory Care on the same day as it is received. It must be handed to someone who can make the appointment for the bloodspot test, confirming that the appointment date will be before the child reaches 12 months of age.</p>	<p><b>If the child does not attend the appointment for the bloodspot:</b></p> <ul style="list-style-type: none"> <li>Ambulatory Care will inform Child Health, on the day of the appointment, if the child DNA's. Details of any related communication from the parents must be recorded by the clinic and communicated to Child Health who will record this information on the Child's SIRS/EMIS records.</li> <li>Ambulatory Care will also contact the Health Visitor who will contact</li> </ul>	<p>Ward 16 Ambulatory Care BGH Child Health Health Visitor</p>



<p>Ambulatory Care will provide Child Health with a copy of the appointment letter which they will add to the Child's EMIS records. When Child Health uploads the appointment letter to EMIS they will task the Health Visitor to notify them of this appointment.</p> <p>If parent(s)/carer(s) decide not to accept the offer of bloodspot screening at this stage, this should be recorded in the Health Visitors notes and added to the child's SIRS/EMIS records.</p> <p><b>A labelled blank bloodspot card should be sent to the SNSL so there is a national record of the declined offer of screening.</b></p>	<p>the Child's parent(s)/carer(s) to establish why they did not attend and whether another appointment is required. This information must be added to the Child's SIRS/EMIS records.</p>	
<p><b>National Programme Failsafe Arrangements</b></p> <p>A range of failsafe arrangements are in place at various stages within the screening pathway. These are the responsibility of the relevant department and monitored and reported through local governance systems and processes.</p> <ul style="list-style-type: none"> <li>• Offer of screening - Requirement for a newborn blood spot card to be completed for all babies, regardless of whether the offer of screening has been declined.</li> <li>• Each quarter the Registrar General's Office provides the SNSL with data on a random selection of 10% of all births registered in Scotland. The SNSL compares this information with its own records to ensure that each baby has had a report issued. All anomalies are investigated and appropriate arrangements are made to follow up.</li> <li>• Referred cases - SNSL telephone the nominated clinical specialist on the day the positive screening result is known and follows the referral up in writing. The clinical specialist is asked to provide written confirmation by way of a reply slip supplied with the referral letter that the child has been assessed. A system is in place within the SNSL to follow up any cases where written confirmation is not provided.</li> </ul>		<p>SNSL  Child Health Team  Hospital Midwives  SCBU  Community Midwives  Health Visitors</p>

## Appendix 1

## Programme Contacts

Midwife Team	Location	Designation	Phone Numbers	E-Mail
Kirsteen Guthrie	BGH	Senior Charge Midwife BGH	01896 826735	kirsteen.guthrie@borders.scot.nhs.uk
Ann Fernie	Galashiels HC	Senior Charge Midwife Community	01896 661369	ann.fernie@borders.scot.nhs.uk

  

Health Visitor Team	Location	Designation	Phone Numbers	E-Mail
Fiona Houston	Hawick Community Hospital	Community Nurse Manager	01450 361001	fiona.houston@teviot.borders.scot.nhs.uk
	Hay Lodge Hospital	HV Team Leader	01721 722080	

  

Public Health Team	Location	Designation	Phone Numbers	E-Mail
Board Screening Co-ordinator	Education Centre BGH	Julieann Brennan	01896 825548 07493882128	Julieann.Brennan@borders.scot.nhs.uk
Screening Business Manager	Education Centre BGH	Karen McKay	01896 830559 0758 449 1177	Karen.McKay@borders.scot.nhs.uk
Dept of Public Health	Education Centre BGH	Admin Office	01896 828278	

  

Child Health Team	Location	Designation	Phone Numbers	E-Mail
Child Health Generic e-mail	Child Health Dept BGH	Department Office	01896 826672 / 826678 / 826694	bord-uhb.childhealth- admin@borders.scot.nhs.uk
Muriel Grzybowski	Child Health Dept BGH	Information Team Manager	01896 826682	muriel.grzybowski @borders.scot.nhs.uk
Rachel Patterson	Child Health Dept BGH	Information Team Supervisor	01896 826672	Rachel.Patterson@borders.scot.nhs.uk
Kirsty Hunter	Child Health Dept BGH	Information Team Supervisor	01896 826694	Kirsty.Hunter@borders.scot.nhs.uk

  

Laboratory	Location	Designation	Phone Numbers	E-Mail
Scottish Newborn Screening Laboratory (SNSL)	Queen Elizabeth University Hospital,, Glasgow	Laboratory	0141 354 9277	<a href="mailto:sarah.smith2@ggc.scot.nhs.uk">sarah.smith2@ggc.scot.nhs.uk</a> Sarah Smith Consultant Scientist Department Head & Director of Newborn Screening

## Transfer of Records

**NHS Borders  
Child Health Department**

Borders General Hospital  
Melrose  
Roxburghshire  
TD6 9BS  
[www.nhsborders.org.uk](http://www.nhsborders.org.uk)



Direct Fax : 01896 826785

Enquiries to:  
Direct Line:  
Email:  
Date:

Surname	Forename	Sex	DOB	CHI

Previous Address	Present Address
Previous School	Present School

We have been notified that the above child/children have moved to our area. Can you please send records as indicated below?

- Child Health Record – if the child is aged 12 months and under, please ensure a Neonatal Hearing result and Newborn bloodspot screening result are included.
- Immunisation Record

Please be aware that NHS Borders School Nursing and Health Visiting Service now use electronic patient records therefore we would be grateful where possible to receive the record either via e-mail to [bord-uhb.childhealth-admin@borders.scot.nhs.uk](mailto:bord-uhb.childhealth-admin@borders.scot.nhs.uk) or on disk to the above address.

Please let us know if you do not hold records for these children.

Yours sincerely,

Name  
Title

## Consent for Newborn Blood Spot Screening

### Consent for Newborn Blood Spot Screening for Congenital Hypothyroidism (CHT), Cystic Fibrosis (CF), Sickle Cell Disorders (SCD) and 6 Inherited Metabolic Disorders (IMDs):

[Phenylketonuria (PKU),  
Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCADD),  
Maple Syrup Urine Disease (MSUD),  
Homocystinuria (HCU),  
Isovaleric Acidaemia (IVA)  
Glutaric aciduria type 1 (GA1)]

I have received and read the national patient information leaflet and have had an opportunity to discuss the tests I am being offered with a health professional. I understand the reasons for the tests and the consequences of the results. I also understand the significance of not having these tests performed. I am aware that my decision whether or not to have these tests will not affect the quality of care delivered by healthcare professionals.

Baby's Name..... Date of birth .../.../...

CHI Number.....

- I wish  I do not wish my baby to be tested for Congenital Hypothyroidism
- I wish  I do not wish my baby to be tested for Cystic Fibrosis
- I wish  I do not wish my baby to be tested for Sickle Cell Disorders
- I wish  I do not wish my baby to be tested for the 6 IMDs

I understand that the Newborn Blood Spot Screening Programme needs to obtain my permission to store the newborn blood spot card beyond the initial 12 month testing period and to use any of the blood spots left over after testing is complete for anonymised research, such as the development of new screening tests. If any research was proposed in which the researcher would be able to identify me or my baby, a member of staff from the Newborn Bloodspot Screening Programme would always contact me again to seek my approval.

- I agree  I do not agree for the storage of my baby's blood spot sample beyond the initial 12 month testing period.
- I agree  I do not agree to the use of any leftover blood spots for anonymised research.

Signature:..... (Parent/Guardian) Date ...../...../.....

Signature:..... (Witness: Healthcare professional)

Print name:.....

Designation: ..... Date ...../...../.....

**NHS Borders  
Child Health Department**

Borders General Hospital  
Melrose  
Roxburghshire  
TD6 9BS



Telephone: 01896 826000

[www.nhsborders.org.uk](http://www.nhsborders.org.uk)

Date:

CHI:

Enquiries to:

Direct Line:

Direct Fax: 01896 826785

E-mail: [bord-uhb.childhealth-admin@borders.scot.nhs.uk](mailto:bord-uhb.childhealth-admin@borders.scot.nhs.uk)

**[Name & Address of Health Visitor]**

Dear **(Name)**

**[Childs Name, dob, Address]**

According to our records this child recently transferred into the area from abroad. Our current policy along with Public Health regarding children who transfer into the area and who are under 12 months of age is to ensure that these children have received newborn screening or been offered it.

As this child is under 12 months old and Child Health Department don't have a Bloodspot or Neonatal Hearing Result, I would be grateful if you would check your records or discuss with the parent/carer and send a copy of the results to Child Health.

However, if it appears that the child has not had a Bloodspot screen, can you please discuss with parents/carer and arrange for this to be carried out as soon as possible. If parents refuse consent for the Bloodspot screen, then please complete a blank Bloodspot card so that the SNSL can process this and send a confirmation letter to this effect.

If the child does not appear to have had a Hearing Screen, then please refer to Audiology.

Thank you for your help with this matter.

Yours sincerely,

Child Health Information Systems Administrator



## Bloodspot Referral

### Ambulatory Care Unit Ward 15



<b>Childs CHI Number:</b>	<b>Date of referral:</b>
<b>DOB:</b>	<b>Referrers Name:</b>
<b>Surname:</b>	<b>Referrers Designation &amp; Contact Tel No:</b>
<b>Forename:</b>	<b>Signature:</b>
<b>Address:</b>  Stick Label Here	<b>Time limit for the test? (please advise).</b>
<b>Telephone Number(s):</b>	<b>Reason for referral:</b>
<b>GP Name/Practice:</b>	

When completed please forward this form by e-mail to:

[bord-uhb.newbornscreening@borders.scot.nhs.uk](mailto:bord-uhb.newbornscreening@borders.scot.nhs.uk).

Any other documentation can be forwarded to Child Health:

**Child Health Department**  
**Borders General Hospital**  
**TD63 9BS**

**Tel: 01896 826672**



**Department of Public Health**

Education Centre  
Borders General Hospital  
TD6 9BS

Direct Line: 01896 825560  
julieann.brennan@borders.scot.nhs.uk

Date:

Parent(s)/Carer(s) of xxxxxxx  
address  
address  
address

**Re: Name, Chi Number, address of child**

Dear Parent(s)/Carer(s) of xxxxx

According to our records, xxxxx recently transferred in to the Scottish Borders from abroad. Recently your Health Visitor had contacted you in line with the current policy of the Department of Public Health, regarding children who transfer into the area and who are under 12 months of age to obtain a copy of xxxxx newborn blood spot screening results. I understand that you haven't been able to provide a copy of results at present.

As we currently do not hold a copy of the results for xxxxx newborn blood spot screening results, we cannot confirm the conditions tested for.

I am writing this letter as a reminder to you that under current policy and if you wish to do so, you still have the opportunity to have xxxxx tested under the Scottish Newborn Bloodspot Screening Programme; however, the test will need to be taken before xxxxx 1<sup>st</sup> Birthday. The test will be performed at the Borders General Hospital. I have included an information leaflet on the tests included in the Scottish programme and further information can be found at NHS Inform:

<https://www.nhsinform.scot/healthy-living/screening/newborn/newborn-screening>

If you do wish to take up this offer of screening, I would encourage you to please contact the Child Health Department on **01896 826672** as soon as possible so that a referral can be generated and screening test performed prior to xxxxx 1<sup>st</sup> Birthday.

Please feel free to contact me should you wish to discuss further

Yours sincerely

Julieann Brennan  
NHS Borders Board Screening Co-ordinator