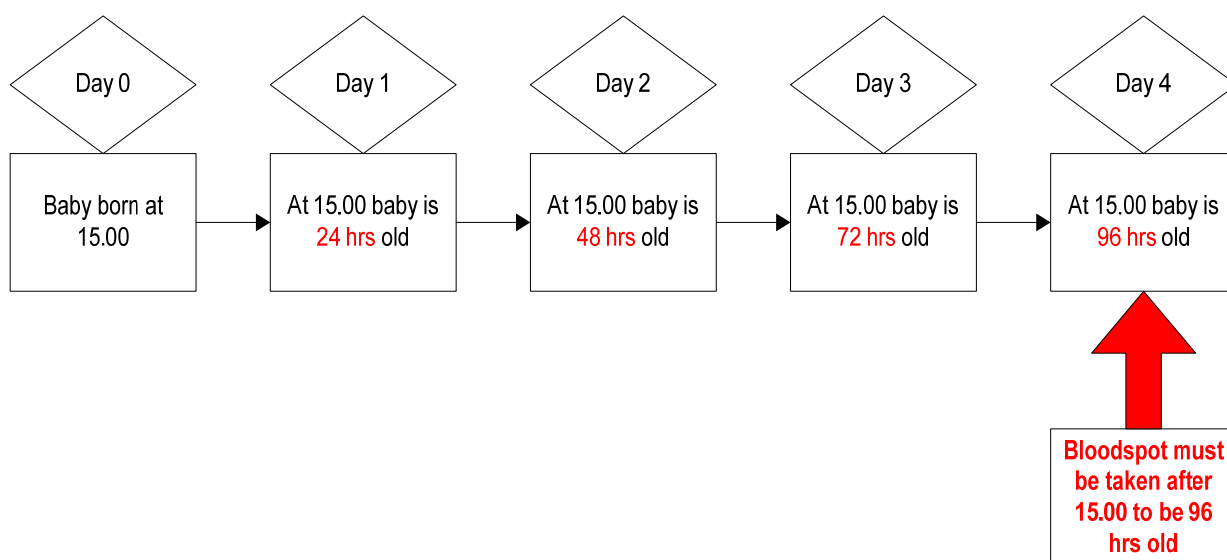


### Additional fields on the newborn bloodspot card to be used from 2 April 2017

The Scottish Newborn Screening Laboratory (SNSL) must ensure that a baby is over 96 hours old when a sample for Newborn Screening is taken. The earliest that Newborn Screening can be performed accurately is when the baby is over 96 hours old. It is important to take the sample as close to 96 hours as possible as the aim of newborn screening is to get babies on treatment as soon as possible if one of the nine disorders screened for is detected. The

timeliness of treatment is critical in many of the screened disorders and can make a significant difference to the morbidity and mortality.

Most midwives will count the age of the baby in days rather than hours. Using day of birth as day 0 they will take the sample on day 4 of life assuming that makes the baby 96 hours old. However this may not be the case depending on the time the baby was born, for example;



### Key Dates

Pregnancy & Newborn Coordinators' meeting

Pregnancy Screening Steering Group

Newborn Blood Spot Screening Steering Group

Clinical governance reference group

## Newborn Bloodspot Screening

To ensure the baby is over 96 hours old when the sample is taken the Newborn bloodspot sample cards have been modified to accommodate the time the baby was born and the time the sample was taken to be recorded. This will allow the SNSL to calculate the age of the baby in hours when the sample was taken. This information will become mandatory on Monday 2<sup>nd</sup> April 2018. After this date, if this information is not supplied, the screening sample will not be able to be processed until the

information is provided. A repeat sample will not be necessary unless the times are unable to be supplied (or the baby was less than 96 hours old when the sample was taken).

If an old style card is used after the 2<sup>nd</sup> April 2018 the Midwife is asked to supply the information in the comments box (remember to check the expiry date on the card before use).

DO NOT DETACH FOLD OR PLACE IN A POLYTHENE BAG.

Baby Surname \_\_\_\_\_ Date of Birth \_\_\_\_\_  
 Perkinsimer 226  
 Analom  
 Lab use only

1312701x 1312701x

**PLEASE PRINT IN BLOCK CAPITALS**

Baby's CHI Number - Mandatory \_\_\_\_\_ (label area)

Baby's Surname \_\_\_\_\_  
 Mother's or Baby's Alternative Surname (Not Maiden) \_\_\_\_\_  
 Baby's First Name \_\_\_\_\_  
 Address \_\_\_\_\_  
 Address \_\_\_\_\_  
 Post Code \_\_\_\_\_  
 Parent Contact Telephone Number \_\_\_\_\_  
 Hospital of Birth \_\_\_\_\_  
 G.P. Name \_\_\_\_\_  
 G.P. Address \_\_\_\_\_  
 G.P. Address \_\_\_\_\_  
 G.P. Practice Code \_\_\_\_\_

Baby's D.O.B. \_\_\_\_\_  
 Baby's Time of Birth \_\_\_\_\_  
 Gender (✓) \_\_\_\_\_  
 M ☐ F ☐ U ☐  
 Rank (See Over) \_\_\_\_\_ Gest Age at Birth \_\_\_\_\_  
 Weeks \_\_\_\_\_ Days \_\_\_\_\_  
 Birth Weight (g) \_\_\_\_\_  
 Baby's Ancestry (See Over) \_\_\_\_\_  
 Mother Born in UK (✓) \_\_\_\_\_  
 Yes ☐ No ☐  
 Mother's D.O.B. \_\_\_\_\_

If this is a REPEAT Specimen (✓) ☐

Type of Feed at Blood Spot Collection (✓) \_\_\_\_\_  
 Breast ☐ Milk Formula ☐ Other ☐

Current Hospital and Ward if Applicable \_\_\_\_\_

Has Baby Had a Transfusion (✓) \_\_\_\_\_ If yes, Date of Transfusion \_\_\_\_\_  
 Yes ☐ No ☐ Blood ☐ Other ☐

Comments: family history e.g. mother's carrier status \_\_\_\_\_

Date Specimen Taken \_\_\_\_\_ Time Specimen Taken \_\_\_\_\_  
 Specimen Taken by \_\_\_\_\_  
 Contact Telephone Number \_\_\_\_\_  
 Lab use only

Expires 2020-07-31

**Avoidable repeat samples** can cause anxiety for parents, distress to babies and delays in the screening process (for example a baby might miss CF screening because it can only be screened for accurately up to eight weeks of age). They are also a waste of healthcare resources (**each repeat costs the NHS around £100**). In some cases, parents may refuse to consent to a repeat – this means that the baby will have incomplete screening and an opportunity to identify a condition in an effective timeframe to prevent irreversible serious health consequences may be missed. Always check the expiry date on the card before use and check all fields on the card are completed before returning the completed card to the laboratory.

## Scottish Pregnancy and Newborn Screening news

- Ministers have asked the Chair of the Scottish Screening Committee to undertake a review of how screening programmes are managed and delivered in Scotland. The primary aim of the review is to provide recommendations on improving the effectiveness of the national screening programmes in Scotland, ensuring sustainability of services that meet the needs of the Scottish population and better contribute to improving population health, and setting out the implications of new models of service to optimise both clinical and cost effectiveness.
- Health Improvement Scotland are currently revising the pregnancy and newborn screening programme standards. The draft standards should be out for consultation in the Spring with publication of the finalised standards scheduled for publication in the summer.
- The screening leaflets 'You're pregnant' and 'Your baby' were among the winners in the Plain English Campaign Awards. Congratulations to Health Scotland colleagues and all the stakeholders involved in developing the leaflets. <http://www.plainenglish.co.uk/campaigning/awards/2017-awards/plain-english-awards.html>
- At the request of the Scottish Screening Committee a business case has been prepared for the potential implementation of Non Invasive Prenatal Testing as a second line screening test following a higher chance screening result for Down's syndrome and also for expanding first trimester screening for Down's syndrome to also screen for Edwards syndrome (Trisomy 18 ) and Patau syndrome (Trisomy 13). This is now being consulted on with the relevant stakeholders before a final decision is reached by the Scottish Screening Committee. The service and NHS Boards would be kept informed of the outcomes.

## National Screening Committee News

- The consultation on guidance development documents prepared by the UK NSC Task and Finish group on Informed Choice closed on the 16th November. A report would be brought to the February UKNSC meeting and the Scottish Screening Committee in March 2018.
- A recently published HTA paper considered the provisions of information about newborn screening antenatally. Further information can be found at; [www.journalslibrary.nihr.ac.uk/hta/hta21550/#/abstract](http://www.journalslibrary.nihr.ac.uk/hta/hta21550/#/abstract)
- The Ethics task group's first meeting was held in September with the aim to agree terms of reference for the group. It is anticipated that a draft report would be available in time for the February UK NSC meeting.

## Useful Resources

### NHS Scotland websites.

- **Health Professionals**  
<http://www.pnsd.scot.nhs.uk/>
- **Public**  
<https://www.nhsinform.scot/healthy-living/screening/pregnancy-screening/introduction-to-pregnancy-screening>  
<https://www.nhsinform.scot/healthy-living/screening/newborn-screening/introduction-to-newborn-screening>

### NHS England websites.

- **Health Professionals**  
The NHS England main site for screening programmes can be found here for:  
<https://www.gov.uk/topic/population-screening-programmes>
- The English screening programme centres are no longer producing newsletters. Instead you can sign up for the PHE screening blog alert service here  
<https://phescreening.blog.gov.uk/>

### Patient Information

Health Scotland  
<http://www.healthscotland.com/topics/health/screening/pregnancynewborn.aspx>

Ready steady Baby  
<http://www.readysteadybaby.org.uk/>

## Useful resources



## Networks

### Networks related to the pregnancy and newborn screening programmes

- **SPAIIIN**—Scottish Paediatric & Adolescence Infection & Immunology Network  
<http://www.spaiin.scot.nhs.uk/>
- **Paediatric Cystic Fibrosis**  
<http://www.knowledge.scot.nhs.uk/child-services/communities-of-practice/cystic-fibrosis.aspx>
- **Scottish Managed Clinical Network for Inherited Metabolic Disorders in Scotland (IMD Scotland)**  
<http://www.imd.scot.nhs.uk/>
- **Scottish Paediatric and Adult Haemoglobinopathy network (SPAH)**  
<http://www.spah.scot.nhs.uk/>

## Supporting resources...

- Service specifications
- Protocols
- Laboratory handbook
- Bloodspot sampling guidance
- Child Health Records guidance
- Patient information leaflets



NHS National Services Scotland  
Address

Tel: 01234 567 890 Fax: 01234 567 8901 Web: [www.nhsnss.org](http://www.nhsnss.org)

NHS National Services Scotland is the common name of the Common Services Agency for the Scottish Health Service