

UK Newborn Screening Programme Centre (UKNSPC), October 2008

NHS Number Bar-coded Label for Newborn Blood Spot Screening

Standard Operating Procedure

Withdrawn on 26 August 2021



UK Newborn Screening
Programme Centre



NHS Sickle Cell & Thalassaemia
Screening Programme

Using NHS Number Bar-coded Label for Newborn Screening

Date effective: October 2008 – October 2010

Version: Supersedes previous version May 2004

Applicable to: All health professionals carrying out the newborn blood spot screening test

Review cycle: 2010

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NHS Numbers for Newborn Screening (NN4NS) - Extending the benefits of NHS number for babies to newborn screening, using the NHS number bar-coded label

Introduction

With the introduction of NHS Numbers for babies in October 2002, babies are given a unique identifier shortly after birth. Making use of the NHS Number as a unique identifier within the screening process will bring about significant benefits in the ability to track babies through the system.

This ability to correctly identify and track the progress of all babies is fundamental. Eliminating the risk of babies going untested or not being tested in a timely fashion (a 'near-miss' incident) and of an affected baby going untested or not being tested in a timely fashion (a 'critical' incident).

The UKNSPC has produced new standards and guidelines, August 2008.

- ◆ Standard 2: Enhanced tracking abilities, states as the developmental standard: 'By April 2010 – 95% of blood spot cards received by laboratory should have a label that includes the information standard board (ISB) approved bar-coded babies' NHS number.'
- ◆ Standard 6: Timely receipt of a repeat / second blood spot sample, where the core standard is '95 % of repeat samples should be taken within 72 hours of the laboratory request or specified date of sample' (Condition specific guidance is given see http://www.newbornbloodspot.screening.nhs.uk/download/UKNSPCstandards_guidelines_Aug2008.pdf).

How will this happen?

The NHS number that is obtained following delivery of the baby will be printed on labels in the form of a bar-code as well as eye-readable format, in addition to basic birth and demographic details. These labels will be affixed to the newborn screening blood spot card at the time the screening test is performed. Screening laboratories will be able to scan the bar-code into the laboratory information management system to uniquely identify the baby to the system for all blood spot samples received. Screening laboratories and Child Health Records Departments (CHRD) would then be able to track babies who have missed being tested or for whom a further sample is required using an accurate NHS number.

Procedure

1.0 Babies discharged home with mother

- 1.1 Following delivery of the baby and before any data is entered onto the maternity IT system, the following checks must be done:
 - ◆ Check name (baby's name on notification of birth should be same as the name that the parents intend to register), address and GP details with the mother
 - ◆ Check mother's details already entered on the maternity IT system in the antenatal period
 - ◆ Correct any information that has changed.
- 1.2 Enter details of the delivery (birth) onto the maternity IT system, and obtain the NHS number for the baby via the Central Issue System (CIS) or Patient Demographic System (PDS). The NHS number is usually obtained at the same time as the birth notification and is usually printed on the birth notification.
- 1.3 Midwife/clerk (depending on local arrangements) will then generate and print a page of approved NHS number bar-coded labels (minimum of 9).
- 1.4 At the point of delivery or transfer home, the labels must be given to the mother/parent with the Personal Child Health Record (PCHR). Check that the blood spot card is within expiry date. Ideally it should be given to the mother/parent with the PCHR.
DO NOT APPLY LABELS TO CARD PRIOR TO TEST
- 1.5 The midwife must check details on the labels with mother/parent, and should explain that when the midwife visits to perform the blood spot screening test, she/he will affix the labels on the newborn blood spot screening card. The mother/parent should be asked to please keep them secure with PCHR to avoid misplacing them at home.
- 1.6 When mother and baby are discharged from the hospital, the midwife must check that the mother has received a page of approved NHS number bar-coded labels (minimum of 9) with the PCHR and knows how they will be used.
- 1.7 Before the day of the test (day 0 – 4), ideally at the first visit, the midwife in the community must check with the mother/parent that they have received the labels, all details are correct and they have the national pre-screening booklet available. If labels/national booklets are not with mother/parent, local procedure should be in place on how to obtain them before performing the test and a contingency plan must be in place if unable to obtain them (refer to limitations on page 11).
- 1.8 On day 5, prior to the test, the midwife must ask for the labels, check the details with the mother/parent, affix the labels on the newborn screening blood spot card, explain the procedure for the blood spot screening and gain consent using national guidance.
- 1.9 Perform the newborn blood spot screening as per guidelines for newborn blood spot sampling 2008.
- 1.10 Send the card to the screening laboratory within 24 hours (as per national guidance, standard 4).

Refer to flowcharts pathways 1 & 2 on pages 12 & 13

2.0 Babies born at home, additional procedures

- 2.1 Midwife should check demographic and GP details with the mother/parent before leaving to go back to base to enter the delivery/birth details onto the maternity system (as per local policy).
- 2.2 Midwife should generate the bar-coded NHS label when she generates the NHS number. The midwife should then take the labels (and PCHR if not already given) to the mother on her next visit and check again the details on the labels with the mother/parent. The midwife must explain what the labels are to be used for before leaving the labels with the mother (local procedures to be in place on how the labels will reach the mother if the midwife who delivered the baby is not going to be the one visiting the mother).

Refer to flowcharts pathways 2 & 3 on pages 13 & 14

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3.0 Babies transferred to SCBU/NICU/PICU within or out of area hospital

- 3.1 Following delivery of the baby and before any data is entered onto the maternity IT system; the following checks must be done:
 - ◆ Check name (baby's name on notification of birth should be same as the name that the parents intend to register), address and GP details with the mother
 - ◆ Check mother's details already entered on the maternity IT system in the antenatal period
 - ◆ Correct any information that has changed.
- 3.2 Enter details of the delivery (birth) onto the maternity IT system, and obtain the NHS number for the baby via the Central Issue System (CIS) or Patient Demographic System (PDS). The NHS number is usually obtained at the same time as the birth notification and is usually printed on the birth notification.
- 3.3 Midwife/clerk (depending on local arrangements) will then generate and print a page of approved NHS number bar-coded labels (minimum of 9).
- 3.4 Insert labels in the case notes or PCHR to go with baby to NICU or with information that is going with the baby to the hospital she/he is being transferred.
- 3.5 Midwife should inform nurse/health professional in charge of the baby's care in NICU/hospital where baby has been transferred, to use those labels on the newborn screening blood spot card when carrying out the blood spot test.
- 3.6 If baby is discharged before that, the labels must be given to the mother/parent to take home and informed about their use for the newborn screening blood spot test as outlined in points 1.6 to 1.10, babies discharged home with mother on page 5.
- 3.7 If baby is in hospital on the day of the test, the nurse/health professional should explain the test, gain informed consent and check details on the labels with the mother/parent. The labels should be affixed on the newborn screening blood spot card, complete the rest of the details on the card and check the information with the mother/ parent.
- 3.8 On day 5, prior to the test, the midwife must ask for the labels, check the details with the mother/parent, affix the labels on the newborn screening blood spot card, explain the procedure for the blood spot screening and gain consent using national guidance.
- 3.9 Perform the newborn blood spot screening as per guidelines for newborn blood spot sampling 2008.
- 3.10 Send the card to the screening laboratory within 24 hours (as per national guidance standard 4).

Refer to flowcharts pathways 2 & 3 on pages 13 & 14

4.0 Babies delivered in private hospital and independent birth centres

Current process:

- ◆ All babies are issued an NHS number from the Child Health Records Department (CHRD) following receipt of birth notification from the private hospital
- ◆ CHRD send a copy of the birth notification with the NHS number to the health visitor.

As private hospitals are not connected to NHS net, with the introduction of NN4NS the following process will need to be put in place in order for parents to have access to their baby's bar-coded labels at the time of the newborn screening blood spot test.

- 4.1 Following delivery of the baby, birth notification will be sent to CHRD.
- 4.2 CHRD will obtain the NHS number for the baby and print a set of the specific baby labels with the bar-coded NHS number as well as eye readable details (CHRDs will need to have the resources to enable them to print these labels).
- 4.3 The midwife should arrange for the NHS bar-coded labels to be available in the PCHR.
- 4.4 Bar-coded labels to be used for blood spot screening.
- 4.5 These baby labels could be sent to the hospital and given to the mother before she is discharged home or if she is in hospital at time of newborn screening blood spot test, then these labels should be used.

Local areas to decide how these labels will be sent to the private hospitals in order for them to reach the mother and baby before the blood spot sample is obtained. Possible suggestions: courier service may be required depending on average hospital stay.

It is advisable not to use the postal service as delays may occur which may mean mothers and babies go home without NHS bar-coded labels.

- 4.6 At the point of delivery or transfer home, labels must be given to the mother/parent with the PCHR. Check that the blood spot card is within expiry date. Ideally it should be given to the other/parent with the PCHR, **DO NOT APPLY LABELS TO CARD PRIOR TO TEST.**
- 4.7 The midwife must check details on the labels with mother/parent, and should explain that when the midwife visits to perform the blood spot screening test, she/he will affix the labels on the newborn blood spot screening card. The mother/parent should be asked to please keep them secure with PCHR to avoid misplacing them at home.
- 4.8 When mother and baby are discharged from the hospital, the midwife must check that the mother has received a page approved NHS number bar-coded labels (minimum of 9) with the PCHR and knows how they will be used.
- 4.9 Before the day of the test (day 0-4), ideally at the first visit, the midwife in the community must check with the mother/parent that they have received the labels, all details are correct, and they have the national pre-screening booklet available. If labels/national booklets are not with mother/parent, local procedure should be in place on how to obtain them before performing the test and a contingency plan must be in place if unable to obtain them.
- 4.10 On day 5, prior to the test, the midwife must ask for the labels, check the details with the mother/parent, affix the labels on the newborn screening blood spot card,

explain the procedure for the blood spot screening and gain consent using national guidance.

- 4.11 Perform the newborn blood spot screening as per guidelines for newborn blood spot sampling 2008.
- 4.12 Send the card to the screening laboratory within 24 hours (as per national guidance, standard 4).

Refer to flowcharts pathways 2 & 3 on pages 13 & 14

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5.0 Babies delivered by independent midwives at home

Current Process:

- ◆ Child Health Records Departments (CHRD) obtains the NHS Number for the baby after receiving the Birth notification from the independent midwife
- ◆ CHRD then sends a copy of the birth notification with the NHS number to the Health Visitor.

With the introduction of NN4NS, independent midwives will require the specific baby labels for newborn screening blood spot test. The following procedure needs to be in place so that baby labels are available for use on the newborn screening test card at the time of the bloodspot test.

- 5.1 Following delivery of the baby, the birth notification will be sent to CHRD as per current practice.
- 5.2 CHRD would obtain the NHS number for the baby and print a set of the specific baby labels with the bar-coded NHS number as well as eye readable details.
- 5.3 These baby labels will be sent to the independent midwife or the mother for use on the newborn screening test card.

Local areas to decide how these labels will be sent to the private hospitals in order for them to reach the mother and baby before the blood spot sample is obtained.

Possible suggestions: courier service may be required depending on average hospital stay.

It is advisable not to use the postal service as delays may occur which may mean mothers and babies go home without NHS bar-coded labels.

- 5.4 Midwife should check details on the baby's labels with the mother; explain that they are to be used for the newborn screening bloodspot test. If labels are not with mother/parent, a procedure should be in place on how to obtain these labels before performing the test and a contingency plan to be in place if unable to obtain labels.
- 5.5 At the point of delivery or transfer home, the labels must be given to the mother/parent with the Personal Child Health Record (PCHR). Check that the blood spot card is within expiry date. Ideally it should be given to the mother/parent with the PCHR.

DO NOT APPLY LABELS TO CARD PRIOR TO TEST.

- 5.6 Before the day of the test (day 0-4), ideally at the first visit, the midwife in the community must check with the mother/parent that they have received the labels, all details are correct, and they have the national pre-screening booklet available. If labels/national booklet are not with mother/parent, local procedure should be in place on how to obtain them before performing the test and a contingency plan must be in place if unable to obtain them.
- 5.7 On day 5, prior to the test, the midwife must ask for the labels, check the details with the mother/parent, affix the labels on the newborn screening blood spot card, explain the procedure for the blood spot screening and gain consent using national guidance.
- 5.8 Perform the newborn blood spot screening as per guidelines for newborn blood spot sampling 2008.
- 5.9 Send the card to the screening laboratory within 24 hours (as per national guidance, standard 4).

Refer to flowcharts pathways 1, 2 & 3 on pages 12, 13 & 14

Limitations:

If there are no labels available due to being misplaced or being lost:

- ◆ The midwife should try to get another set of labels printed (local process to be in place on how this is to be done)
- ◆ If unable to obtain another set of labels, then the midwife should handwrite the information on the newborn screening card and must include the NHS number of the baby.

If the NHS number is unobtainable at the time the labels require printing, then one of the following must be done according to local process:

- ◆ Labels should be printed and given to parents if going home before the NHS number is obtained and midwife must handwrite the NHS number at the time of the test
- ◆ Wait until NHS number is obtained then print the labels and give to the parents to take home
- ◆ Inform the local CHRDR, who can obtain the NHS number and print a set of labels with the NHS number.

However if this option is chosen, arrangements must be made between maternity unit and CHRDR on how these labels will reach the parents before the day of the test.

Prerequisites:

Labels must consist of a bar-coded NHS number label that complies with the Output Based Specification for the blood spot card label (version 2.0 Final, 21st July 2008).

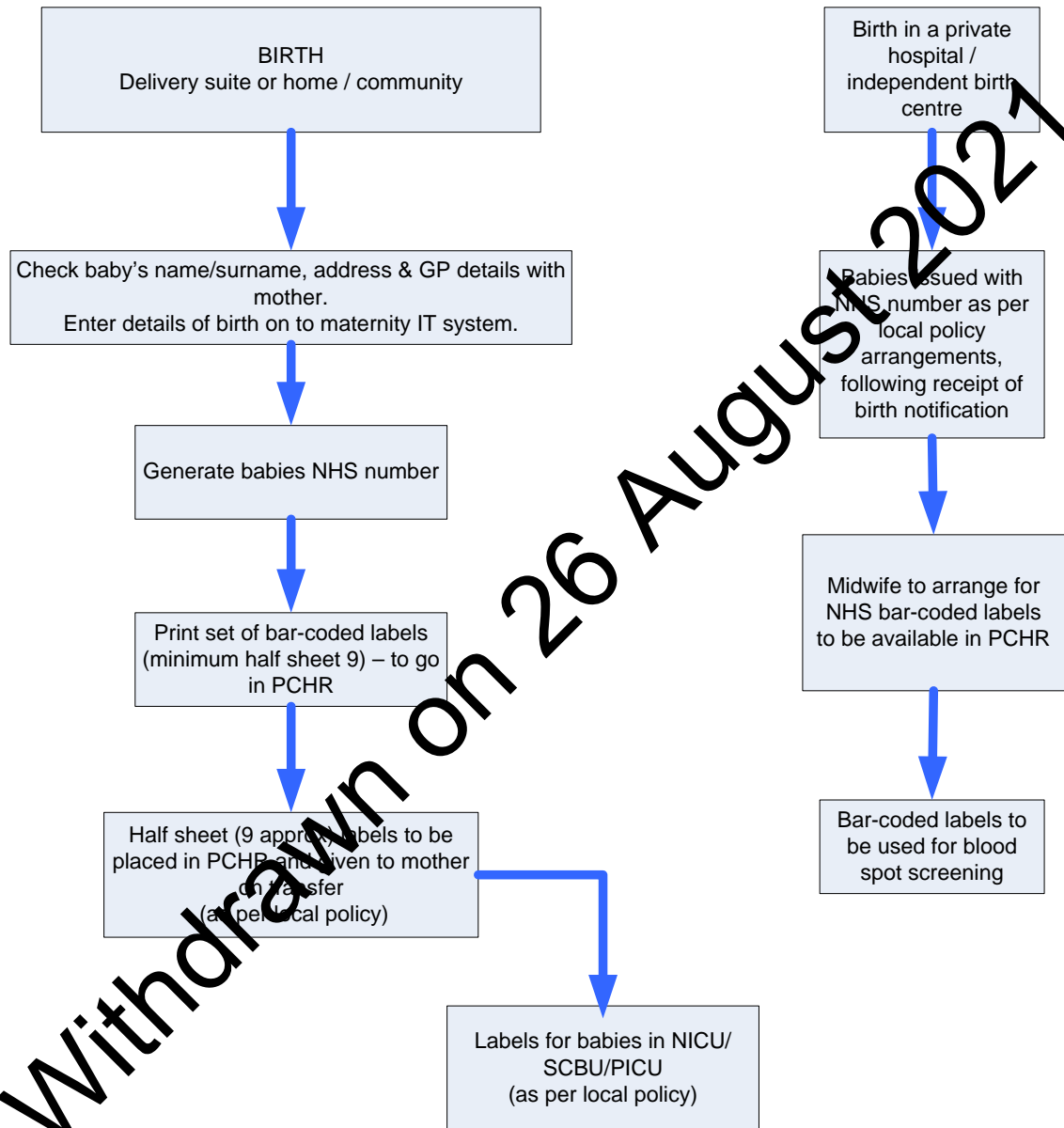
Precautions:

- ◆ Check details on the labels are correct
- ◆ Any information required for the card that is not printed should be handwritten
- ◆ Label details to be checked with parent before affixing onto the blood spot screening card
- ◆ Labels **should not** be affixed onto the card before the day of the test. They must be stuck on at the time of the test, in the presence of the parent, after checking the details again with the parent.

Changes to practice that may be required:

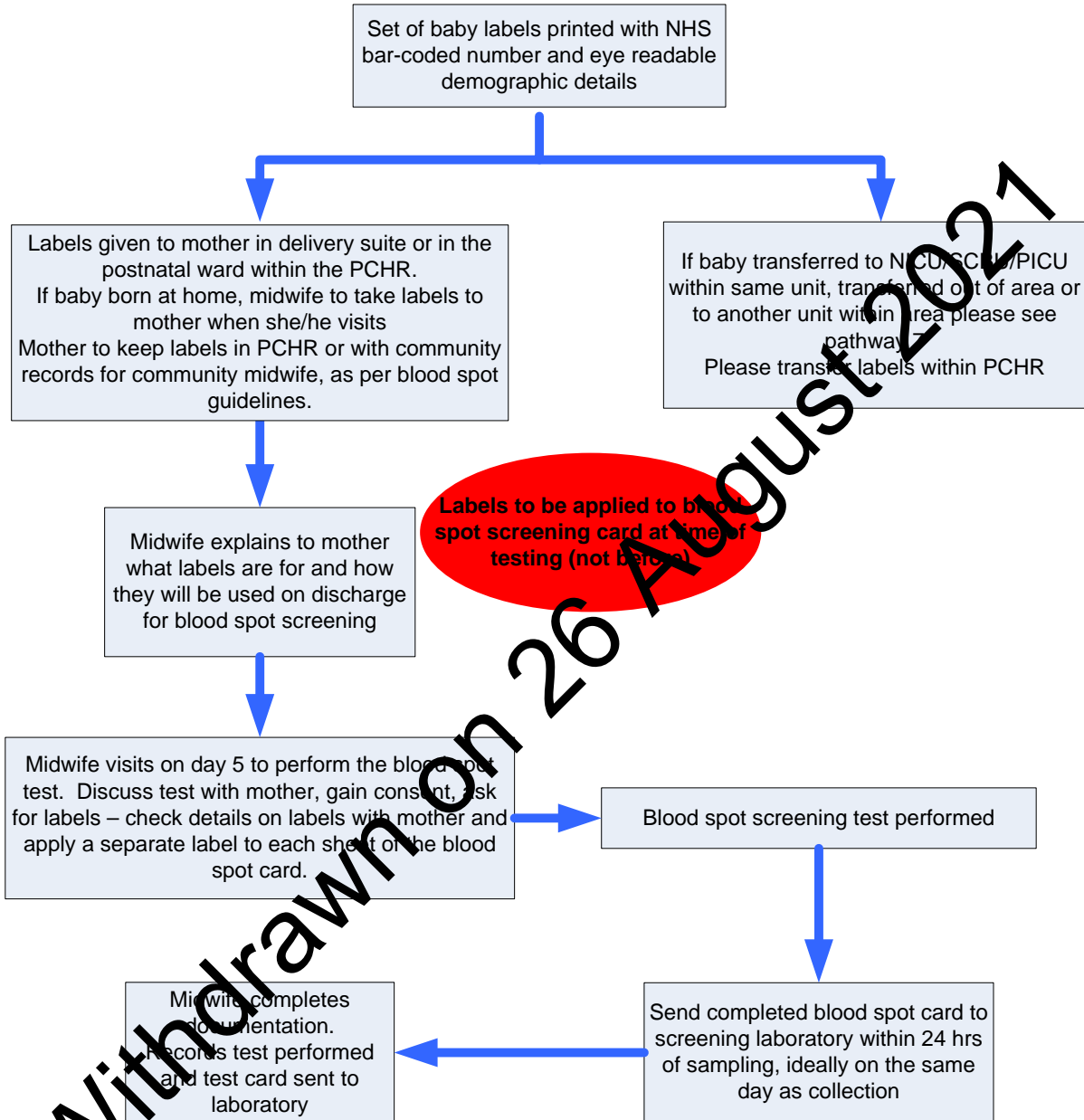
- ◆ PCR given to parents before discharge home so labels can be stored safely

Pathway 1: Production of newborn blood spot bar-coded label

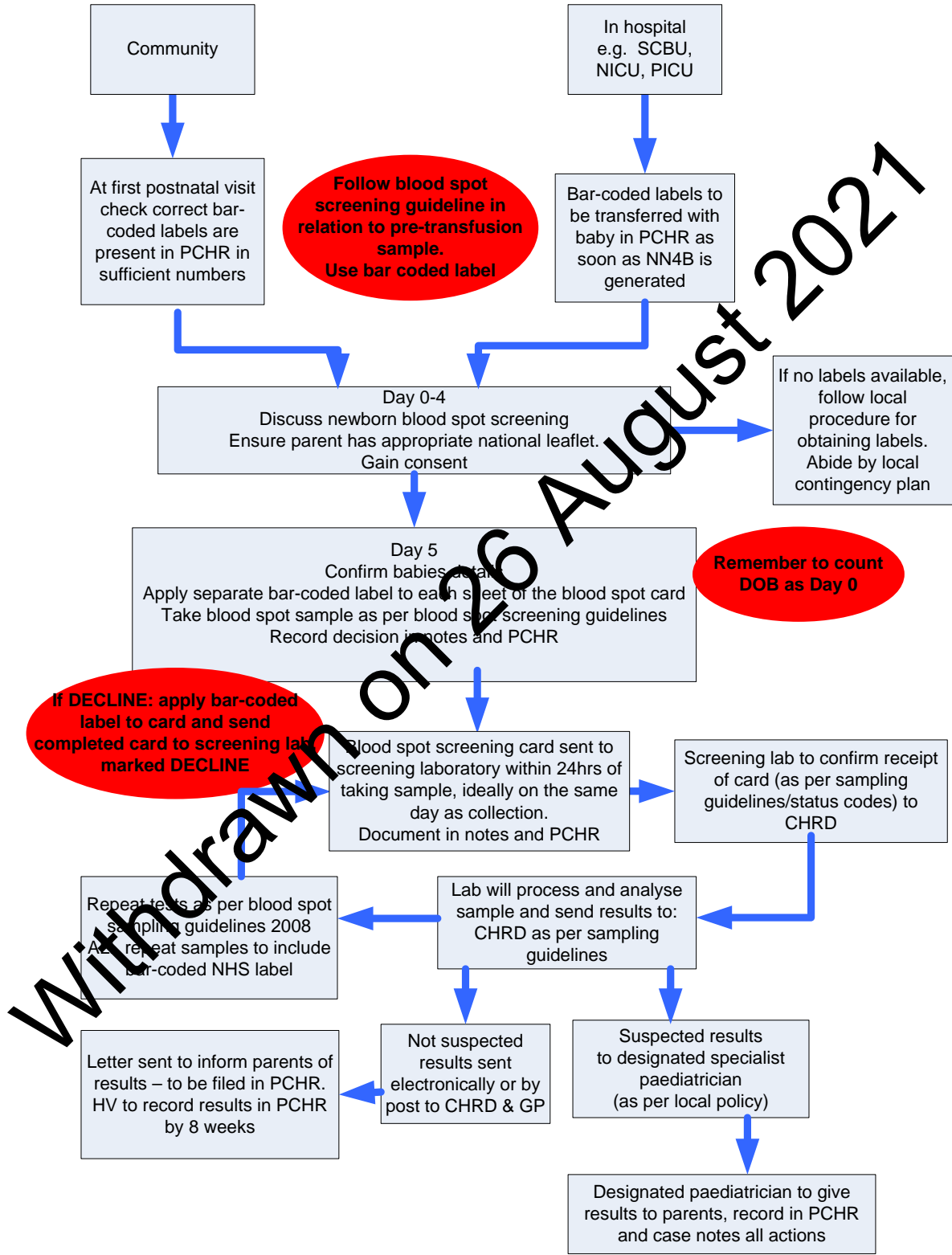


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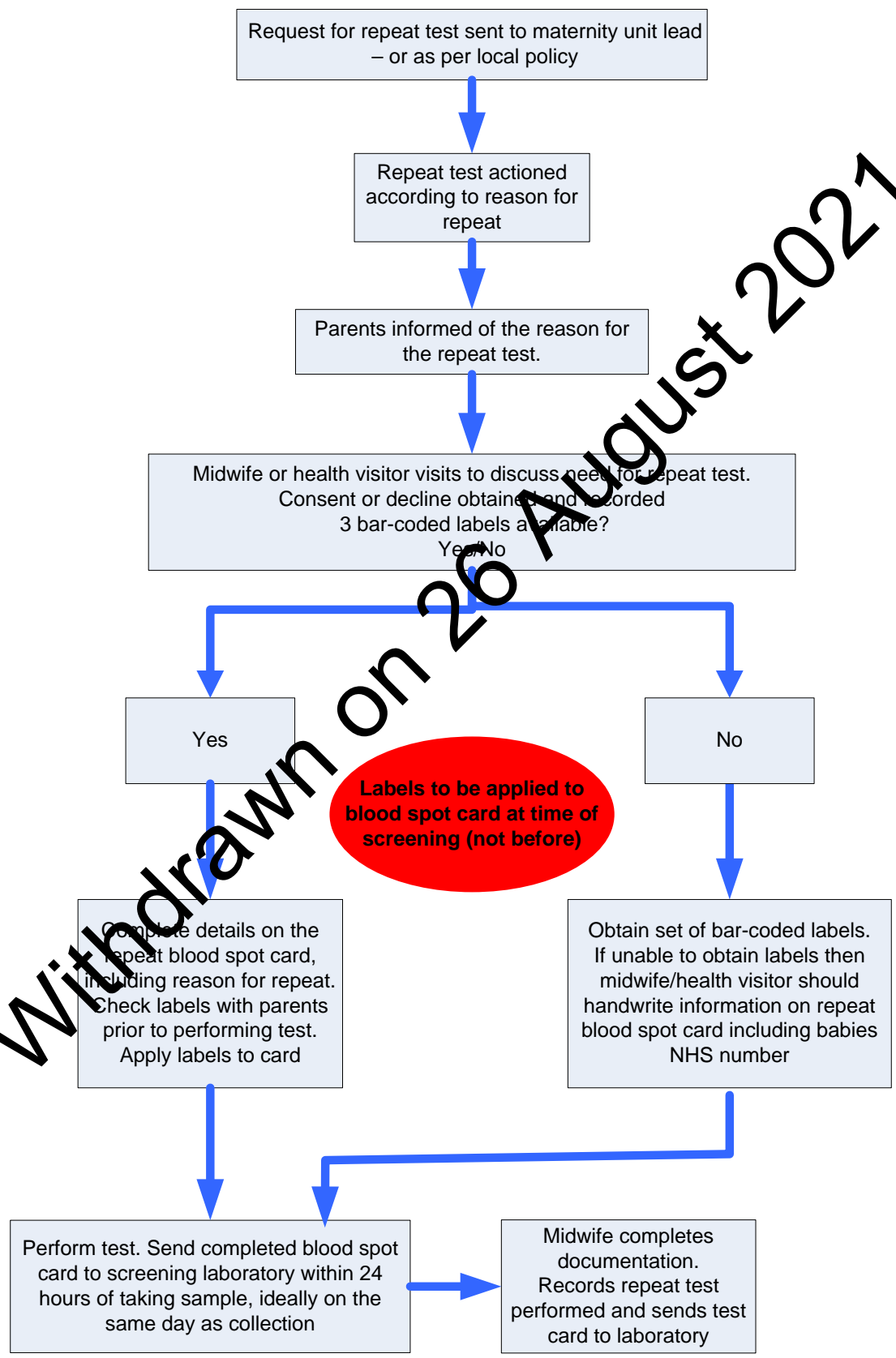
Pathway 2: Midwife pathway



Pathway 3: Use of newborn blood spot bar-coded label

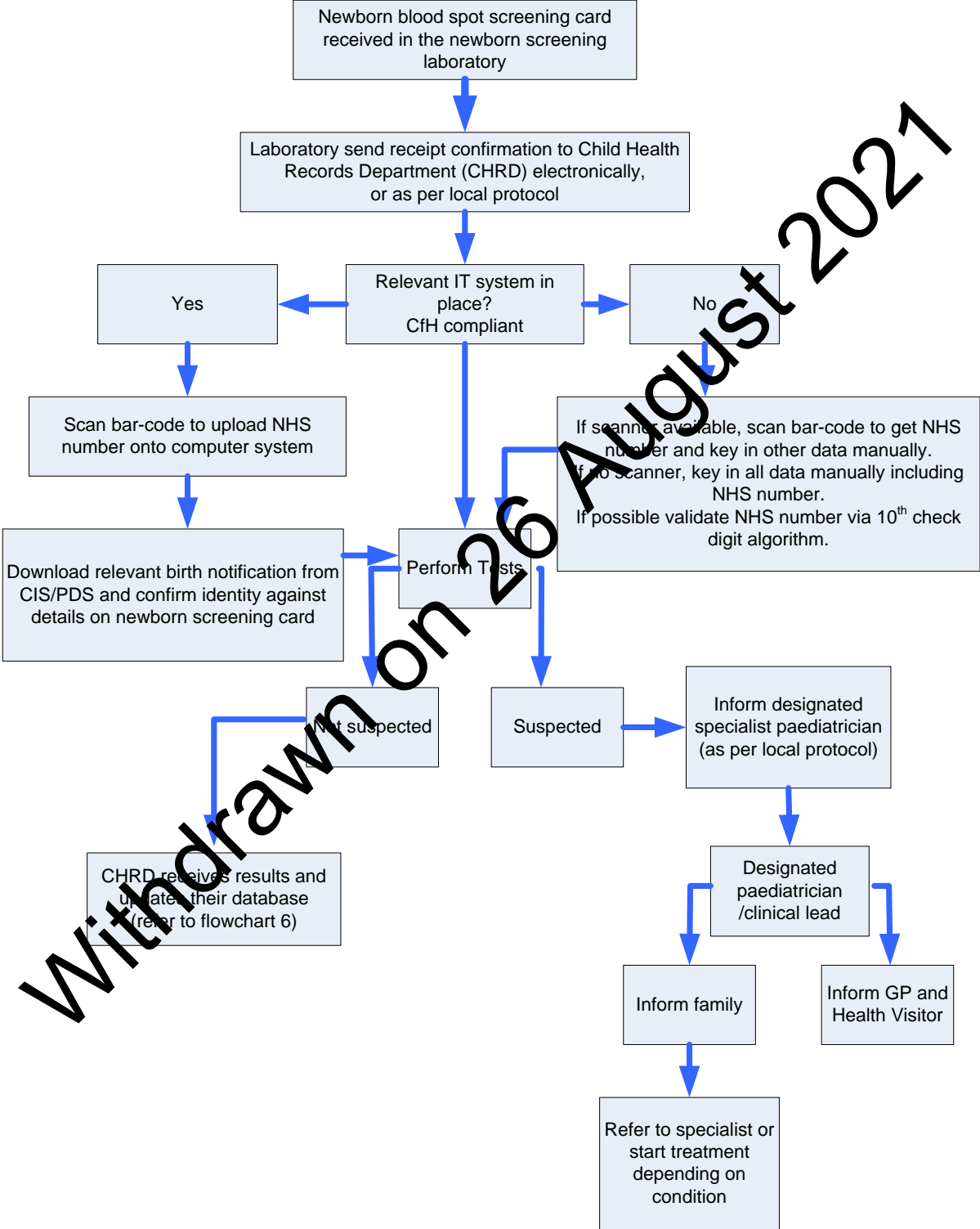


Pathway 4: Repeat test



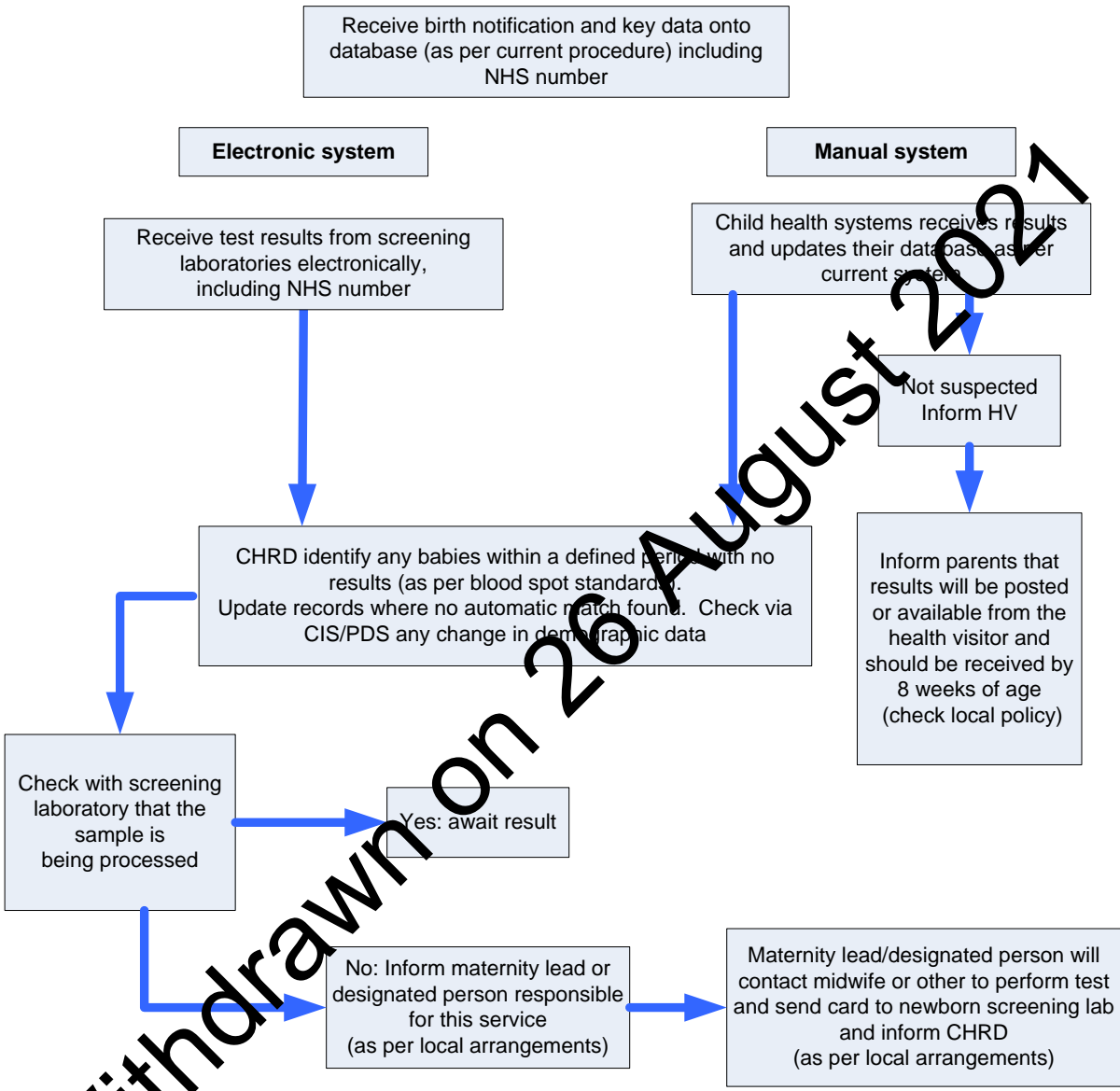
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Pathway 5: Screening laboratory pathway



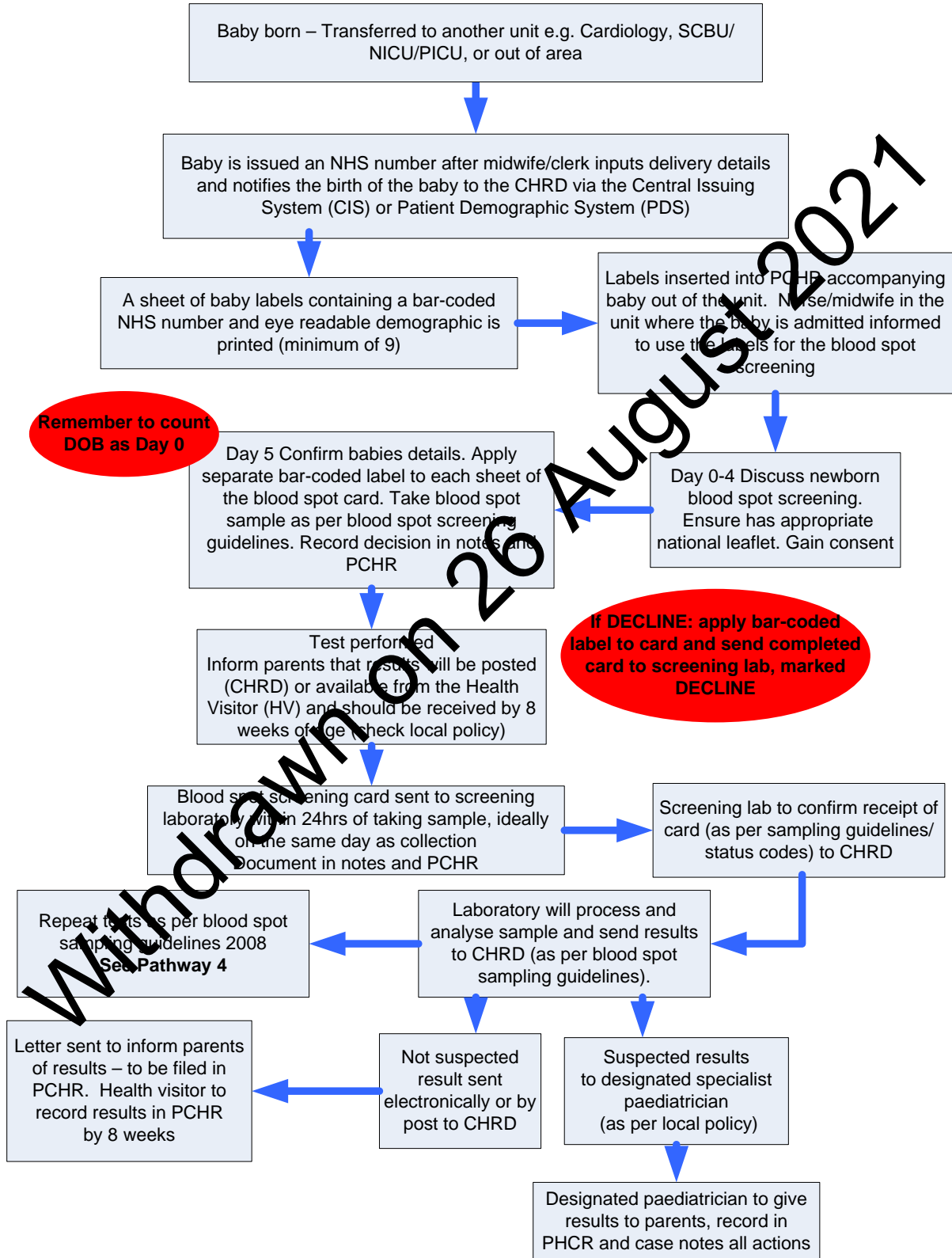
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Pathway 6: Child health record departments

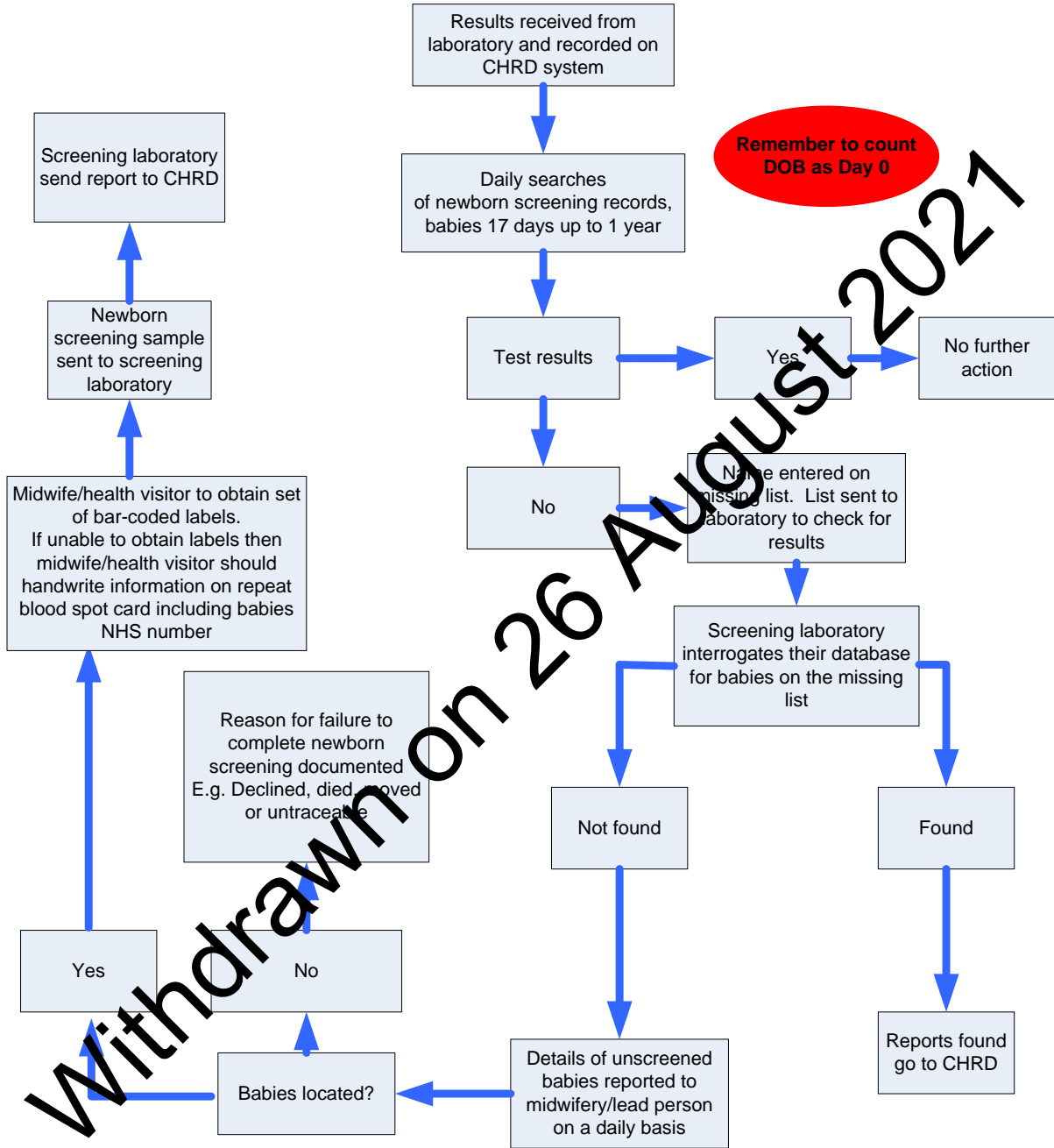


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Pathway 7: Baby transferred to another hospital 'in or out' of areas



Pathway 8: Missing results or babies who may have missed screening



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