Digital Child Health: Blood Spot Messaging Implementation

Review

Draft 23rd November 2020 v0.4

**Document Management**

**Revision History**

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| **Version** |  | **Status** | **Date** | **Author** | **Summary of Changes** |
| 0.1 |  | Draft | 16/09/20 | Alison Golightly, Head of Implementation and Business Change, Digital Child Health Programme | First draft |
| 0.2 |  | Draft | 01/10/20 | Alison Golightly, NHS Digital | Addition of Section 6 and 7 text, ready for external review/input |
| 0.3 |  | Draft | 19/10/20 | Alison Golightly, NHS Digital | Incorporating PHE/UKSLN comments from review call 15th October plus additional comments received from CHIS who are implemented/implementing. |
| 0.4 |  | Final for acceptance | 23/11/20 | Alison Golightly, NHS Digital | Introducing issue on ‘movers in from abroad’, revision of Summary and Recommendations (now Next Steps) |

**Further Information**

For further information on the Digital Child Health Programme, please see the Digital Child Health web pages <https://digital.nhs.uk/services/digital-child-health>

For questions about this document, please email [dch@nhs.net](mailto:dch@nhs.net)

# Purpose

The purpose of this paper is to set out a brief review of blood spot messaging over NEMs outlining issues and questions which have been raised with the Digital Child Health (DCH) programme team at NHS Digital (NHSD) by provider organisations during implementation.

This version of the paper has been reviewed by Public Health England (PHE), public health commissioners, the UK Screening Laboratory Network (UKSLN) and the providers and suppliers who have implemented/are considering implementing the message.

# Objective of the data flow and message

The objective of the DCH Blood Spot Outcome message was to reduce the burden on Child Health Information Services (CHIS) in re-keying results into their records and to provide a means for parents to receive results electronically via a digital version of the Personal Child Health (DPCHR) which is being made available to all parents in England in January 2021.It additionally made it possible to distribute the results to Health Visitors and GPs, again reducing the burden on CHIS, and resulting in a more complete child health record being available to health professionals.

At this stage of implementation, this outcome message is not intended to be a replacement of the laboratory outcome reports which CHIS receive and CHIS will continue to receive these in parallel.

# Solution Design

The original solution design agreed by the Professional Records Standards Body for Blood Spot results was for three messages to be received by CHIS:

* Blood Spot Sample Taken – to be sent from Maternity systems
* Blood Spot Sample Received – to be sent from Laboratory systems
* Blood Spot Outcome – to be sent from Laboratory systems

Due to budget and time constraints only one of these messages – Outcome – was developed and put into Live and it was sourced from the national Blood Spot Failsafe System (NBSFS) and not direct from the thirteen laboratories.

This was a pragmatic decision taken by NHSD and PHE to deliver rapid benefits to CHIS and derive additional value from the files the laboratories were providing to Northgate for NBSFS and which are subsequently processed by PHE/Northgate in the National Screening Store (NSS). It should be noted these files are provided manually by the screening laboratories in various Excel and CSV formats and require further processing before the enter the NSS.

Using the NSS as the source of data being passed to NEMs had a couple of other advantages:

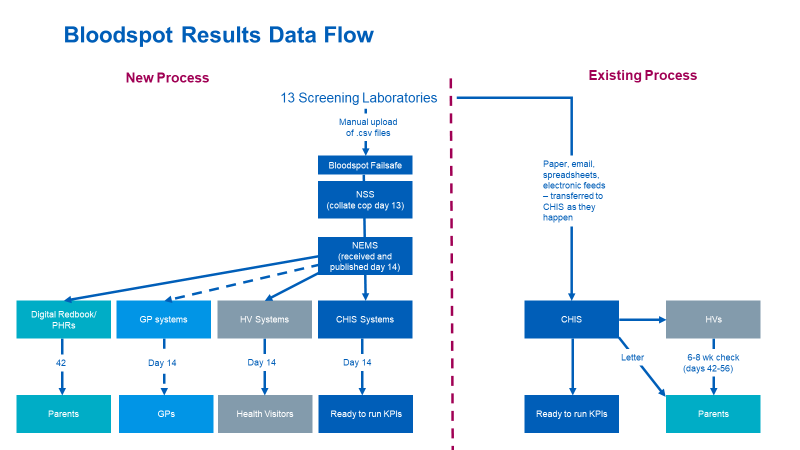
* It made blood spot results available nationally in one single implementation, rather than thirteen implementations one for each laboratory. This reduced the complexity and time taken to get the data flow live
* NSS is also the source of NIPE and Hearing Results, so that all newborn screening results can be made available to CHIS/DPCHRs in the same implementation.

Research was carried out with Northgate that showed that 85% of all children had a set of final results for each of the nine tests by the time they were 13 days old. The solution was therefore designed to pass all children with a full result set on day 13 to NEMs each evening, plus any final results sets for children older than 13 days. These results pass into NEMs and onward to CHIS, GP or HV systems on the morning of the 14th day.

PHE confirmed they were happy with Day 14 solution as this would still enable CHIS to meet the KPI NBS-S02 which asks for timely identification of babies with a null or incomplete result recorded on the CHIS, giving the example of a system which does a daily check of babies equal to or more than 17 days of age and equal to or less than 364 days of age.

PHE also confirmed that the responsibility for Failsafing blood spot results up to and including Day 14 was with midwifery services rather than CHIS and that the NBSFS was being used for this purpose. CHIS were therefore only required to Failsafe the blood spot pathway once the child had reached 14 days and did not have a full set of results.

The diagram below shows the solution design:



# Implementation History

NHSD presented the solution design to a UKSLN meeting in November 2019 and there were no objections to implementation proceeding. However, the decision to pass data to the DPCHR (digital personal child health record) was held back as the day results should be passed to parents could not be agreed, it was subsequently set to 42 days.

Implementation of all three newborn screening messages began at North East London Foundation Trust (NELFT) who run both a CHIS hub and a Health Visiting service both of whom would receive the results. Discussions were held with the CHIS and the London antenatal and newborn screening lead on how the messages would work with their current Failsafe practices and how their KPIs might be affected. It was agreed in January 2021 that NHSD Digital would provide a review of the findings from NELFT back to London public health commissioning (this paper).

The blood spot screening message has subsequently been implemented in:

* Birmingham Community Healthcare NHS Foundation Trust, using System C – Careplus
* Central Surrey Health, CSH, using System C – Careplus
* South Central West CSU, using System C – Careplus
* Health Intelligence, using System C - Careplus

This review also includes issues raised from these areas.

# Issues Raised

In this section we present the issues raised, along with resolutions or mitigations and where the decisions for further work or mitigation lie.

## 5.1 CHIS Failsafing

On hearing that with NEMs a results message is not received into their CHIS system until Day 14, many CHIS raise concerns that they will either not meet their Failsafing obligations under national KPIs or different KPIs set by their local public health commissioner, below we present the issues raised:

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| --- | --- | --- |
| Issue Raised | Response | Owner |
| If we do not get a result into our system until the child is 14 days old, we will not be able to identify children without a result in line with the national KPI | The national KPI NBS-S02 asks a CHIS to report whether they have a system in place that meets the standard for identifying babies with a null or incomplete NBS result for any of the 9 conditions in a timely way. An example is given of a system that performs a daily check of babies equal to or more than 17 days of age and equal to or less than 364 days of age.  As the NEMS system populates the CHIS record on the morning of the 14-day, daily checks can be run for any child of 14 days or over who is missing a result.  **Conclusion: The NEMS message enables a CHIS to meet the national standard.** | Not required, there is no issue to resolve |
| If we do not get a result into our system until the child is 14 days old, we will not be able to identify children without a result in line with local KPIs set by our local public health commissioner which ask that we chase missing records before 14 days of age | It is the responsibility of midwifery services to Failsafe a child up to 14 days of age using the national Blood Spot Failsafe system, CHIS are not required to chase results before this date age unless they have made additional agreements with their local public health commissioner.  All CHIS should have access to the NBSFS, PHE guidance is available on its use here: <https://www.gov.uk/government/publications/newborn-blood-spot-screening-failsafe-solution-user-guide/nbsfs-operational-level-agreements-for-chrd-users>  Analysis has shown that 85% of children will have all nine results present at 13 days of age. It is thus not efficient for a CHIS service to chase earlier than this as 1) this is duplication of effort as the midwifery service has the responsibility until and 2) 85% of children will have a result by Day 14 so earlier chasing is not needed.  Where public health commissioners are contracting their CHIS specifically to do earlier chasing of missing results because they are worried about the quality of maternity failsafing, this is still possible as a) NBSFS caters for it and b) the reporting feeds from the laboratory are not being stopped[[1]](#footnote-2).  **Conclusion:** **CHIS should review the timing of their failsafing practices with their commissioners ahead of implementation to decide the best approach once they are receiving a NEMs message** | CHIS and their commissioners to review the effectiveness of early Failsafing. |
| We are worried that we will not have time to identify and chase results for a ‘moved in’ child from another area. | Usually it would take additional time for a result to come through/be chased down for a child moving into a new CHIS area with a blood spot initiated from an out of area maternity service and being processed in an out of area laboratory.  This is not the case when a service moves onto NEMS as the CHIS also receives demographic changes as they happen and the NEMS automatically routes the results message from the National Screening Store to the correct CHIS based on the child’s GP practice/postcode irrespective of which laboratory is processing the test[[2]](#footnote-3).  The CHIS will thus automatically receive a result on Day 14 for a child who has moved into their area after the blood spot was taken and before the result was processed irrespective of which laboratory is doing the processing.  **Conclusion:** **automatic demographic updates and routing of blood spot results to the correct CHIS based on GP practice and postcode means the burden of chasing down ‘moved in’ children’s results is reduced** | Not required, there is no issue to resolve |
| The NEMs message does not contain the laboratory card number so we cannot query a result with the laboratory easily as part of failsafing obligations | By waiting until the 14th day, when 85% of children have a final set of results for all nine tests, use of the NEMs message aims to reduce unnecessary queries from the CHIS to the laboratory.  Where a final result is not present by Day 14 and the CHIS need to query what has gone wrong in the pathway, they will still be receiving the sample received results from the laboratory[[3]](#footnote-4) as well as the full results, so the card number is available to aid querying.  **Conclusion:** **the majority of CHIS who do not already use a direct electronic feed continue to receive laboratory reports and so can a) use these to facilitate queries based on laboratory card number or b) use NBSFS**  **Commissioners and laboratories need to consider the long-term approach for passing results to CHIS, see section of Failsafe Responsibilities.** | Commissioners and laboratories to consider long term approach to passing results given the new interoperability available |
| NEMS does not seem to pass results for children who have moved in from abroad, we are worried we cannot failsafe adequately. | This is a result of the way NBSFS/NSS handle demographic updates currently and is being prioritised for change.  **Conclusion: Until the change is made, CHIS can failsafe these children as they continue to receive laboratory reports and so can a) use these to facilitate queries based on laboratory card number or b) use NBSFS**  **An update will be provided once the technical change is in place.** | PHE/Northgate to provide timeline for change |

## 5.2 Failsafe Roles and Responsibilities

Since the introduction of the national Blood Spot Failsafe System (NBSFS) over five years ago for midwifery services, the responsibilities for and timeline for failsafing the pathway have become confused and it would be useful for roles and responsibilities to be clarified nationally and cascaded locally. Specific issues are:

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| Issue Raised | Response | Owner |
| Who is the NBSFS used by and for what purpose? Can a CHIS have access to it to help with their Failsafe enquiries? | The NBSFS was introduced primarily to alert midwives to an early failure in the pathway such as a sample card not being received in the laboratory so that the midwifery service could take responsibility for rectifying this. This therefore changed the responsibility of the CHIS in the early part of the pathway, CHIS should not need to perform the check for sample received except for moved in children. However, this change of responsibility does not seem to be implemented extensively or well understood.  NBSFS later evolved to receiving all results from the laboratories and access was available to CHS to check NBSFS.  **Conclusion: Clarification on use of NBSFS has been provided by PHE. Clarification may be needed from commissioners as to which agencies are responsible for failsafing which part of the pathway.** | Commissioners |
| What is the purpose of the CHIS receiving laboratory results a) from the laboratory and b) from the NEMs? What are they obliged to do with results under their contracts | What CHIS is commissioned to do, varies locally. Some CHIS do send letters to all parents of children, some only send the negative results.  The original reason that CHIS were passed laboratory results was that there was no other way to inform health visitors and parents of the results as the laboratory could not pass these results directly to them. CHIS were the necessary intermediary and CHIS were also the only agency capable of failsafing the pathway before the NBSFS was introduced.  Before the introduction of NBSFS, CHIS was also the only agency who could provide KPIs for a local population. There are now other possibilities for KPIs, for example, via the NBSFS.  Additionally, at the inception of the NEMs project, it was understood that laboratories/laboratory system suppliers would not want to participate in a beta project, based on the experience of asking them to contribute to NBSFS. Now that the infrastructure has matured and is out of its beta phase, this may no longer be the case.  It is clear that we are in transition period, given the new interoperability and systems becoming available. It would seem sensible to review the end to end data flow for laboratory results and what PHE/commissioners/laboratories want to achieve in the blood spot pathway.  **Conclusion:** **PHE, UKSLN, commissioners and NHSHx to conduct review of end to end data flows for the blood spot pathway, NHS Digital to support with technical options if required.** | PHE , UKSLN, Commissioners, NHSx, NHSD |

## 5.3 Key Performance Indicators (KPIs)

Changing over to a different method of processing blood spot results into the CHIS system raises concerns as to whether the CHIS’s performance on national and local KPIs will change, especially as PHE specify using only the PKU result to stand as a proxy for receipt of all results.

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| Issue Raised | Response | Owner |
| NEMS only sends a message on Day 14 or later when all results have been received. We currently get results from the lab as they happen and so get the PKU result through as soon as it happens, will this affect our performance against the KPI | KPI NBS-S01a is specified as ‘The proportion of babies registered within the CCG both at birth and on the last day of the [reporting period](https://www.gov.uk/government/publications/nhs-population-screening-glossary-of-terms/glossary-of-terms#reporting-period) who are [eligible](https://www.gov.uk/government/publications/nhs-population-screening-glossary-of-terms/glossary-of-terms#eligible) for newborn blood spot (NBS) screening and have a conclusive result for phenylketonuria (PKU) recorded on the child health information service system (CHISS) ≤ 17 days of age’  As NEMS passes a message for all nine test results when they are complete on Day 14 and 85% of children have a full set of results by day 13, there should not be a large change in performance against this KPI. However, in instances where there is a late result on one or more of the conditions but the PKU result is final NEMs does not pass this, so CHIS will likely see a small decrease in performance.  The likelihood of this happening should be discussed with the CHIS commissioner ahead of implementation so it is expected. The decrease in performance needs to be balanced by the fact that all results being present is now being measured, not just PKU and that the CHIS will have greater accuracy of who is in the local population due to the NEMs demographic messages.  **Conclusion: Small decrease in performance which should be discussed with the commissioner ahead of implementation** | CHIS/ Local Commissioner |

## 5.4 Existing electronic feeds from laboratories

At least 3 of the 13 screening laboratories are providing a direct HL7 feed into CHIS systems. Where this is happening, the recommendation is that the CHIS continue to take the HL7 feed in preference to NEMS. Your CHIS supplier should be able to suppress the feed so it does not register into the record.

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| Issue Raised | Response | Owner |
| Pros of introducing the NEMs feed | The NEMs feed routes results from all 13 laboratories to the correct CHIS for a child based on GP/postcode. It reduces the need to chase down results from non-local laboratories, helping to ensure there is a valid result recorded by 17 days.  Measuring the availability of all results being received rather than just PKU as a proxy is a truer guide to performance.  Reduced level of manually providing blood spot information to other CHIS (also using NEMs) as this is automated. | CHIS and Lab |
| Cons of introducing the NEMs feed | Necessitates a review of Failsafing processes which may need to change in the light of NEMS not passing results until Day 14.  Small decrease in KPI NBS-S01a | CHIS and Lab |
| Pros of retaining the existing lab electronic feed | No disruption of current business processes/failsafing practices  Performance against KPI NBS-S01a remains the same | CHIS and Lab |
| Cons of retaining the existing lab electronic feed | Will not automatically receive results from other laboratories for children moving into the area after day 5.  Will continue current level of manually providing result information to other CHIS when a child moves out. | CHIS and Lab |

## 5.5 Format of the NEMs Message

At least 3 of the 13 screening laboratories are providing a direct HL7 feed into CHIS systems.

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| Issue Raised | Response | Owner |
| The NEMS message does not provide the same level of information as we get from the laboratory | This is correct, the NEMs message does not contain the ID for the sample card, nor does it contain the date the maternity unit took the sample or the sample received date. The format of the message was agreed with PHE.  THE NEMs message was not designed as a replacement for the laboratory message but rather to pass results information in electronic form to CHIS, HVs and GPs to reduce any re-keying or dissemination burden for those CHIS still doing this. It also provides a means for parents to access results in a digital redbook when these become more widely available in January 2021.  If there is now a need to replace the laboratory reporting systems and redesign the NEMS message, PHE, NHSx and commissioners can agree a programme of work with NHS Digital to facilitate this.  **Conclusion: The message meets the purpose for which it was designed. Should it be agreed that the purpose now needs to change along with the message contents, this can be agreed as a new programme of work.** | PHE, NHSx, Commissioners |

# Summary

The Blood Spot Outcome message is working as designed and agreed with Public Health England. In tandem with the demographics messages delivered over NEMs, the Blood Spot Outcome message provides an accurate means of establishing which children in a local population have/do not have a result by Day 14 and reduces the need for any CHIS to manually re-key the bulk of results received.

The specific benefits are:

* Results are passed to the CHIS from any laboratory that a child’s test has been processed in, reducing the need for chasing these down
* Movers-in are notified to the CHIS as soon as PDS registers the change of address/GP
* CHIS are able to meet KPI NBS-S01 without having to manually re-key information. (‘The proportion of babies registered within the CCG both at birth and on the last day of the [reporting period](https://www.gov.uk/government/publications/nhs-population-screening-glossary-of-terms/glossary-of-terms#reporting-period) who are [eligible](https://www.gov.uk/government/publications/nhs-population-screening-glossary-of-terms/glossary-of-terms#eligible) for newborn blood spot (NBS) screening and have a conclusive result for phenylketonuria (PKU) recorded on the child health information service system (CHISS) ≤ 17 days of age’).
* Only a full set of results are passed to the CHIS, so service performance being measured is more accurate that just taking PKU as a proxy for all results.
* Using a Day 14 result as the basis for initiating Failsafe measures in CHIS, reduces unnecessary, labour intensive chasing of results as analysis has shown that 85% of children have a final set of results by Day 14.
* As manual reporting from laboratories is not being withdrawn (paper results, emailed spreadsheet of results, etc), CHIS are still free to commence Failsafing earlier than Day 14 if their public health commissioners require it.

There remain several issues for providers to consider when implementing the Blood Spot Outcome message over NEMS:

* The format of the message does not contain the laboratory unique identifier or dates for sample taken or received in the laboratory, so any CHIS automated processes (reporting) using these fields will need to be reviewed. This information will still be available from the laboratories as existing laboratory reporting to CHIS is not being withdrawn.
* Where a CHIS has an HL7 feed directly into their system from the laboratory, they should choose to keep that feed and not implement NEMs..
* Implementing the NEMs measure may cause the KPI to decrease slightly as there will be no ‘early’ reporting of PKU results ahead of the full set of results being available. The possibility of this happening should be discussed with local public health commissioners ahead of implementation.

# Next Steps

The Blood Spot Outcome message is safe, effective and efficient for CHIS to use and offers a number of benefits. Implementation of this message and the change in working practice for some CHIS has, however, raised a number of questions around the end to end screening process that require clarification and further consideration from PHE, NHSX and commissioners. These are:

* Should the KPI continue to use PKU as a proxy for all results once all CHIS are capable of receiving results over NEMs?
* What are the purposes in providing laboratory results to CHIS – failsafing, communicating results to health visitors/other professionals, communicating results to parents – and how might these change now that interoperability is available?
* If there are changes in end to end processing and/or responsibilities, would the message structure need to change or other messages be implemented, for example a message for the sample being taken or the card being received in the laboratory?
* Is there an aspiration longer term (2+ years) that laboratories should provide results to NEMs direct for onward distribution to CHIS, health professionals and parents or will NEMs continue to use the National Blood Spot Failsafe System as a source?

This paper has now been passed to NHSx to manage further discussions on how to evolve blood spot messaging.

1. Where a CHIS has a direct electronic feed from a laboratory already, they have a choice as to whether to continue with this feed or use the NEMs feed. The pros and cons of this are discussed in the section on Existing Electronic Feeds. [↑](#footnote-ref-2)
2. This is only true for English screening laboratories, Welsh and Scottish laboratories are not providing results via Northgate into NEMS. [↑](#footnote-ref-3)
3. This is an issue for CHIS already receiving direct electronic feeds, see Section on this. [↑](#footnote-ref-4)