# Newborn Blood Spot Data and Reporting Specification for CHIS

# Version 1.0 / February 2015

About the NHS Newborn Blood Spot Screening Programme

The NHS Newborn Blood Spot (NBS) Screening Programme screens newborn babies for a number of rare but serious conditions: sickle cell disease (SCD), cystic fibrosis (CF), congenital hypothyroidism (CHT) and six inherited metabolic diseases: phenylketonuria (PKU), medium-chain acyl-CoA dehydrogenase deficiency (MCADD), maple syrup urine disease (MSUD), isovaleric acidaemia (IVA), glutaric aciduria type 1 (GA1) and homocystinuria (pyridoxine unresponsive) (HCU).

Public Health England (PHE) is responsible for the NHS Screening Programmes. PHE is an executive agency of the Department of Health and works to protect and improve the nation's health and wellbeing, and reduce health inequalities.

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Glossary of terms

|  |  |
| --- | --- |
| **Acronym** | **Definition** |
| CCG | Clinical Commissioning Group |
| CHIS | Child Health Information System/Service |
| CHRD | Child Health Records Department |
| KPI | Key Performance Indicator |
| NBS | Newborn Blood Spot |
| PDS | Personal Demographics Service |
| UK NSC | United Kingdom National Screening Committee |

References

|  |  |
| --- | --- |
| **No.** | **Document Title, Reference, Date, Source** |
| 1 | Output-Based Specification for Child Health Information Systems, Gateway reference 18067 Oct 2012  <https://www.gov.uk/government/publications/output-based-specification-for-child-health-information-systems> |
| 2 | Information Requirements for Child Health Information Systems, Gateway reference 17232, 30 April 2012  <https://www.gov.uk/government/publications/information-requirements-for-child-health-information-systems> |
| 3 | UK NSC KPI Definitions 14-15 v1.14, July 2014: <http://screening.nhs.uk/kpi> |
| 4 | NBS CHRD KPI Submission Template 2014-15 |
| 5 | UK NSC KPI Indicator Submission Process Year 14-15, v1.4 |
| 6 | IMPLEMENTATION GUIDELINES FOR THE EDIFACT MESSAGE NHSDAT:0:1:NH:NHS001, v1.3, 08 Nov 2002 |
| 7 | NHS Newborn Blood Spot Screening Programme Newborn Blood Spot Status Codes v4.2, Oct 2014 |
| 8 | HSCIC Newborn Blood Spot Status Code Mapping v0.9, 18Dec 2014 |

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1. Introduction

This document contains the data and reporting specifications for the NHS Newborn Blood Spot (NBS) Screening Programme, which are based on the NBS national screening standards. The primary audience are the System Suppliers of Child Health Information Systems (CHIS) in England. Child Health Information Service Providers will also find this document useful as it explains which data items need to be recorded within their systems and how this data is used in order to produce the data for statutory returns.

## Terminology

The acronym ‘CHIS’ occurs in a number of different publications and, depending on the publication, can either mean ‘Child Health Information Systems’ or ‘Child Health Information Service’ and thus the acronym ‘CHIS’ alone can be ambiguous. Throughout this document the acronym CHIS will not be used on its own and will always be supplemented by ‘Suppliers’, ‘Systems’ or ‘Providers’.

CHIS Providers are the organisations who are commissioned by NHS England until 2020 to deliver Child Health Services. CHIS Suppliers are the commercial companies (or equivalent) who provide CHIS Systems for CHIS Providers to use to help them deliver their services.

## Background

CHIS Providers have been required to provide statutory data returns (eg KPIs, Annual Data Returns) for a number of years. KPIs have been issued with documentation to define each KPI, to describe the submission process and with Excel spreadsheets to enter the data onto for submission. Annual Reports are issued as an Excel spreadsheet. Each CHIS Provider has to determine how best to use their CHIS System in order to obtain the data to populate their data returns. This can be a protracted process on some systems requiring a user to run many tens of reports in order to complete a simple dataset on a return.

## Purpose

The purpose of this document is to provide a specification to CHIS Suppliers so that they can (a) understand what data is required to be output, (b) understand how that data is derived or calculated and (c) provide a set of standard KPI and Annual Data Return reports which will generate the required data for each return.

## Document scope

The scope of this document is limited to the recording of Newborn Blood Spot Screening data and reporting on that data. It includes specific sections on producing aggregate data items required to be included in CHIS Provider quarterly and annual returns. All the data items required should exist in all CHIS systems and it should therefore be possible for a CHIS Supplier to generate the required data items in a single report per KPI. The KPI returns covered by this document are:

* KPI NB1: Newborn Blood Spot Screening Coverage
* KPI NB3: Newborn Blood Spot Screening Timeliness of Result Availability
* KPI NB4: Newborn Blood Spot Screening Coverage (Movers-in)
* Annual Return: Standard 1a – Completeness of coverage (reg’d with CCG at birth)
* Annual Return – Standard 1b - Completeness of coverage (movers in)
* Annual Return - Standard 2 - Timely identification of untested babies (see Note)
* Annual Return – Standard 12 - Timeliness of results to parents

Note: Standard 2 is supported by provision of general reporting functionality rather than a standard report.

## Document overview

The Background section provides a brief history an overview of KPI reports and Annual Data Returns.

The CHIS System Requirements section includes requirements that are related to the recording of NBS national data standards and various demographic data that will enable the KPIs and Annual Data Returns to be readily generated. The section covers:

* Configuration – CCGs and their GP Practices supported by the system
* Registration – data associated with determining the child’s responsible CCG, registration periods, types, etc
* Organisation Links – electronic receipt of demographic changes from NHAIS systems
* NBS result recording – the different status codes, multiple results, new sub-status codes
* NBS reporting – general reporting requirements to help track children
* NBS statutory reporting – detailed descriptions of how to produce the statutory reports

## Definitions

Where used in this document set, the keywords MUST, SHOULD and MAY are to be interpreted as follows:

**MUST**: This word, or the terms "**REQUIRED**" or "**SHALL**", means that the definition is an absolute requirement of the specification.

**SHOULD**: This word, or the adjective "**RECOMMENDED**", means that there may exist valid reasons in particular circumstances to ignore a particular item, but the full implications **MUST** be understood and carefully weighed before choosing a different course.

**MAY**: This word, or the adjective “**OPTIONAL**”, means that an item is truly optional. One implementer may choose to include the item because a particular implementation requires it or because the implementer feels that it enhances the implementation while another implementer may omit the same item. An implementation which does not include a particular option **MUST** be prepared to interoperate with another implementation which does include the option, though perhaps with reduced functionality. In the same vein an implementation which does include a particular option **MUST** be prepared to interoperate with another implementation which does not include the option (except, of course, for the feature the option provides).

2. Background

KPIs provide a relatively simple method for measuring certain aspects of NBS services and CHIS Providers are required to submit their KPI returns quarterly and annually as part of their Child Health Services contract. They are also required to submit an Annual Data Return which contain more detailed information than the quarterly returns, incorporating the various result codes of screening for analyse by PHE. KPIs and Annual Returns are one of the mechanisms used to monitor the quality of service delivery. The quarterly returns provide a high level indication of the current service levels, typically focusing on cohort management and enable significant deviations from the norm to be quickly identified and investigated.

In August 2013 the newborn screening standards were revised (see <http://newbornbloodspot.screening.nhs.uk/standards>). The annual returns were previously referred to as Standard 8 and 9 Core and Developmental, but were revised to become Standards 1a, 1b and 2 as outlined in the table below. Standard 1a and 2 remained identical to previous measures.

Standard 1b was introduced to collect the data for ‘Movers in’ with an additional timeframe of 21 calendar days. This was introduced as a result of several Serious Incidents being reported which resulted in ‘mover in’ babies not being tested. It is a key priority of the programme to prevent this reoccurring.

|  |  |
| --- | --- |
| **Revised standards 2013** | **Previous standard 2008** |
| Standard 1a: Completeness of coverage (CCG responsibility at birth) | Standard 9a : Completeness of uptake - Born and registered |
| Standard 1b: Completeness of coverage (movers in) | Standard 9b : Completeness of uptake - Movers in |
| Standard 2: Timely identification of babies with a null or incomplete result recorded on the child health information system | Standard 8 : Timely identification of babies for whom the child health records department has not received notification of specimen received in laboratory, screening test result or decline |
| Standard 12: Timely delivery of conclusive negative results of all 5 conditions to parents. | n/a |

The pilot for Standard 1b (NB4) ran for 12 months and identified several problems around identifying movers-in in a timely manner and also around collation of the required data for the return. This specification is intended to address some of these issues by enabling movers-in to be clearly identified and by specifying the KPI reports themselves in greater detail.

The KPI identifiers are related to the standards as follows:

|  |  |
| --- | --- |
| **Standard** | **KPI** |
| Standard 1a: Completeness of coverage (CCG responsibility at birth) | NB1: Completeness of coverage (CCG responsibility at birth) |
| Standard 1b: Completeness of coverage (movers in) | NB4: Completeness of coverage (movers in) |
| Standard 2: Timely identification of babies with a null or incomplete result recorded on the child health information system | NB3: Timely identification of babies with a null or incomplete result recorded on the child health information system |
| Standard 12: Timely delivery of conclusive negative results of all 5 conditions to parents. | n/a |

Note: NB2: ‘Newborn blood spot screening – avoidable repeat tests’ is applicable to Maternity Units and their systems and is therefore not included within this specification.

The disorders screened for in 2014-15 are:

* phenylketonuria (PKU)
* congenital hypothyroidism (CHT)
* cystic fibrosis (CF)
* sickle cell disease (SCD)
* medium chain acyl CoA dehydrogenase deficiency (MCADD)

The following disorders will also be screening for in 2015-16:

* homocystinuria (HCU)
* maple syrup urine disease (MSUD)
* glutaric aciduria type 1 (GA1)
* isovaleric acidaemia (IVA)

The status and result of each condition is indicated by a status code. These have been a two digit status code from ‘01’ to ‘10’ but new 4 digit sub-status codes have been introduced to further refine these, eg along with an ‘03’ code some labs will also send an ‘03xx’ sub-code to provide further detail. At the time of writing Laboratories are in the process of making these changes and so there is currently no requirements for systems to report on them. These are documented in Status Codes V4.2 document (Ref 7).

3. CHIS system requirements

This section details the CHIS Systems requirements that relate to the capture and processing of child demographic data and Newborn Blood Spot Screening data that are required in order for CHIS Providers to produce statutory returns for each of their CCGs which in turn inform the Public Health Outcome Frameworks (PHOF) and NHS England Outcome Frameworks.

## Existing requirements

There are two recently produced documents which contain comprehensive sets of requirements for CHIS systems, these are the Output Based Specification for Child Health Information Systems (Ref 1) and the Information Requirements for Child Health Information Systems (Ref 2). Both of these documents are currently being revised and may ultimately be merged into a single document, however, the latest versions do not indicate any changes to areas that affect this document.

Suppliers should be familiar with these documents and may have customers who refer to them in their contracts. The intention of this document is to reference sections and requirements within these documents, repeating or elaborating on them where required, in order to provide a clear statement of the data items that are required to be held in order to produce and/or derive the data in the data returns.

The main sections of relevance in each of these two documents are:

CHIS OBS

* Section 4.3: ‘Registration’
* Section 4.6: ‘Newborn Blood Spot’

CHIS information requirements

* Section 5: ‘Registration and Scope of Responsibility’, specifically 5.1 and 5.2
* Section 8: ‘Newborn Blood Spot Screening’

Reference may also be made to other documents contained in the References section at the beginning of this document. In particular suppliers are recommended to be familiar with:

* UK NSC KPI Definitions 14-15 v1.14, July 2014 (Ref 3)
* NBS CHRD KPI Submission Template 2014-15 (Ref 4)
* UK NSC KPI Indicator Submission Process Year 14-15, v1.4 (Ref 5)

2015-16 versions of the above documents will be issued shortly. All known changes have been incorporated into this document.

Example KPI and Annual Report Templates can be found in Appendix A.

## Responsible population

There has often been confusion over which patients (children) are the responsibility of a CCG and this section will remove that confusion by providing a clear definition of which children are the responsibility of a CCG in respect of the provision of Child Health Services.

The CHIS Information Requirements document (Ref 2) states in section 5 ‘Registration and Scope of Responsibility’ (2014 revision in italics):

5.2.1 The PCO should ensure that their database includes all children for whom they have a statutory responsibility. Currently the PCO responsibility is determined foremost by whether the child has a registration at a GP practice that is associated with the PCO, or, in the event that the child is not registered with a GP, *by the mother’s GP Practice and if she is not registered then* by the child’s postcode of usual address placing them inside the geographic area of the PCO footprint.

5.2.2 The list of which GP practices and residential postcodes are associated with each PCO are maintained centrally on a national basis and published through [Technology Reference Data Update Distribution Service](https://isd.hscic.gov.uk/trud3/user/guest/group/0/pack/1/subpack/61/releases) (TRUD).

Note:

At the time if writing (Jan 2015) ‘PCO’ should be regarded as a CCG.

**Definitions**

1. The children for whom a CCG has statutory responsibility are those who are registered with a GP Practice that is a member of the CCG, or, in the event that the child is not registered with a GP, by determining their CCG from their mother’s GP Practice, and if she is not registered, then by the postcode of the child’s usual address.
2. A child is defined as a person under the age of 20, ie between 0 days old and 19 years 364 days old inclusive. A child’s records must be kept until the child is 25 years old.

## System configuration

|  |  |  |
| --- | --- | --- |
| Req ID | Requirement Text | Type |
| 3.3.1 | The system MUST record which CCGs it is supporting within its configuration. Each CCG MUST be identified by its national code (see ODS). | MUST |
| 3.3.2 | The national codes and names of CCGs MUST be obtained from an authoritative source such as ODS or TRUD. | MUST |
| 3.3.3 | For each CCG that the system is supporting, it SHOULD indicate whether any other CHIS systems also support the CCG or whether only this system supports the CCG (ie whether this system is the source of all Child Health data for the CCG). | SHOULD |

## 

## Sensitive records

Systems that are connected with PDS should respect any sensitive records and control access to location related data items. Systems that are not directly connected to PDS which support the same sensitive record flag, should behave in the same manner.

|  |  |  |
| --- | --- | --- |
| Req ID | Requirement Text | Type |
| 3.4.1 | The system MUST provide adequate controls to restrict access to data items associated with PDS records that are flagged as ‘sensitive’, eg by provided specific access rights (eg via National RBAC mechanisms) to control access to such data. | MUST |
| 3.4.2 | The minimum data items which MUST be restricted are:   * Address * Post code * Registered GP Practice * GP (if present) * Related Persons | MUST |
| 3.4.3 | Sensitive record restricted items MAY, provided the user has the appropriate access rights, be displayed on screen but MUST NOT be otherwise output (eg printed, included in a message, etc). | MUST |

## Child registration

Child registrations on CHIS systems arise from a number of different situations including receipt of an electronic birth notification from PDS, processing of a manual birth notification, notification of a new child registration at a GP Practice or notification of a child moving into the area (without any known GP registration details). It is important to maintain an up-to-date list of all children who are the responsibility of each CCG in order that appropriate child services are delivered in a timely manner. It is therefore important for a CHIS system to receive notifications electronically (where they exist) and for users to be able to clearly identify the registration status and type of all children at any time. The requirements in this section support these principals.

|  |  |  |
| --- | --- | --- |
| Req ID | Requirement Text | Type |
| 3.5.1 | The system MUST record for each child record held in the system:   * Date of Birth * The registration Start date * The registration End date * Registered GP Practice (identified by a national GP Practice code) * Mother’s registered GP Practice * Usual address and post code * Responsible CCG.   Note: Date of registration should not default to the date of data entry and should be left to the user to enter the appropriate date (eg date of receipt of mover-in notification). | MUST |
| 3.5.2 | The system MUST be capable of recording multiple periods of registration for a child to support children moving away and back again. | MUST |
| 3.5.3 | The system MUST determine each child’s Responsible CCG using definition 1 above and MUST indicate whether such responsibility is by:   * ‘registration’ * ‘mother’s registration’ * ‘residence’ | MUST |
| 3.5.4 | The system MUST use GP Practice CCG membership tables and CCG post code lookup tables to determine a responsible CCG. These tables MUST be kept up to date and MUST be obtained from an authoritative source such as ODS or TRUD. | MUST |
| 3.5.5 | The system MUST record the type of registration as one of:   * birth (ie upon receipt of a birth notification from PDS) * mover in - from another CCG * mover in - immigrant | MUST |
| 3.5.6 | Upon entry of a registration end date the system MUST regard the child as no longer the statutory responsibility of the CCG. | MUST |
| 3.5.7 | The system MUST support the following registration end types:   * transfer to another CCG * moved abroad/emigrated * death | MUST |
| 3.5.8 | If a child transfers to another CCG or emigrates the system MUST support the recording of the child’s new address, new GP Practice and new CCG (as appropriate). | MUST |
| 3.5.9 | The system MUST support the recording of the child’s previous address, previous GP Practice and previous CCG | MUST |
| 3.5.10 | The system MUST support the receipt of Birth Notifications from PDS and upon receipt MUST create a new child record and associated registration. | MUST |
| 3.5.11 | The system SHOULD synchronise child records with PDS in order to detect changes in a child’s address and/or GP Practice so that children moving out of the area or registering with another GP Practice which results in the child no longer being the responsibility of the CCG can be proactively detected. | SHOULD |

## Organisation links

The Organisation Links system can be configured to send daily notifications of any changes to demographic data for any person under a specified age and registered with any GP Practice within a defined set of Practices. The Org Links system can either send an EDIFACT message to a DTS mailbox for a system to receive and process or to a specified email address, usually a CHIS system user, who can place the file in an appropriate location for the CHIS system to import and process. A further option allows a user to interactively collect a CSV file from a secure FTP site and place that in a location for the system to import and process.

These various options have been evaluated and the best option is for all CHIS systems to support receipt of the EDIFACT file over DTS and subsequent processing.

|  |  |  |
| --- | --- | --- |
| Req ID | Requirement Text | Type |
| 3.6.1 | The system MUST be able to receive and process a demographic changes file produced by the ‘Organisation Links’ system contained in a ‘NHSDAT’ EDIFACT message (Ref 6) over DTS. | MUST |
| 3.6.2 | The system MUST conform to the DTS specifications and use DTS Client v5. | MUST |
| 3.6.3 | Upon receipt and processing of changes for an existing child record to their registered GP Practice the system MUST, if connected to PDS, validate the received data by synchronising with PDS and if ok, as appropriate:   * create an end date for the current registration * determine whether the new GP Practice is within a CCG supported by the system and if so create a new registration start date * if the child is not registered with a GP Practice (ie is the responsibility of the CCG by residency alone) AND the child’s address has changed, the system shall determine whether the child remains within the geographic area of the CCG and either end or continue the registration as appropriate | MUST |
| 3.6.4 | If the changes result in a registration ending the system MUST produce appropriate notifications/reports to inform users. | MUST |
| 3.6.5 | If the change file contains details of children not present on the system, the system MUST, if connected to PDS, validate the received data by synchronising with PDS and if ok create a new record with an appropriate registration type as follows:   * ‘birth’ if the NHAIS registration type is ‘birth’ * ‘mover-in – from another CCG’ if the child’s previous GP details are provided and these are from a practice not in the CCG * ‘mover-in – immigrant if the NHAIS registration type is ‘immigrant’ | MUST |

## Newborn blood spot screening data recording

CCGs have a statutory requirement to ensure that all of the children for whom they are responsible, up to their first birthday, have had or are offered a newborn blood spot screen. This includes children who have moved into the area from other parts of England, the other home countries, and from other countries.

For children with a registration type of ‘birth’ the person registering the birth (on PDS) will have offered NBS screening to the mother and completed the Blood Spot Card whereupon the CHIS Provider will receive the results (including a declined offer) from the Laboratory. The CHIS Provider is not responsible for offering screening in this situation. For children with a registration status of ‘mover in – from other CCG’ the CHIS Provider must determine whether NBS screening has been offered and whether previous results are available, if not the Provider must offer NBS screening to the mother and arrange for sample collection and reporting. For children with a registration status of ‘mover in – immigrant’ it is assumed that NBS screening has not occurred and the mother is offered screening.

Note that for electronic results two (or more) messages will be received for each sample tested. The first is a ‘sample received’ message with status ‘01’ and the second contains the test results. There may be multiple test result messages if tests are reported at different times or tests have to be repeated, in the latter case using a new sample.. Note that from April 2015 new 4 digit sub codes will be rolled out and will be included along with the original 2-digit status code.

For paper based reporting the laboratory receiving the sample may send a ‘sample received – status 01’ notification by mail or email a PDF equivalent, however, some laboratories do not send an equivalent and therefore some CHIS Providers just receive results which can cause problems with ‘01’ counts on statutory reports.

|  |  |  |
| --- | --- | --- |
| Req ID | Requirement Text | Type |
| 3.7.1 | For children with a registration type of ‘mover in – other CCG’ the system MUST indicate whether the NBS results have:   * been requested from the previous CCG’s CHRD * been received from the previous CCG’s CHRD * previous CCG’s CHRD has no results for NBS | MUST |
| 3.7.2 | For children with a registration type of ‘mover in – other CCG’ and ‘previous CCG’s CHRD has no results for NBS’ the system MUST record the date an offer of NBS screening was made to the mother and whether the offer was accepted or declined. | MUST |
| 3.7.3 | For children with a registration type of ‘mover in – immigrant’ the system MUST record the date an offer of NBS screening was made to the mother and whether the offer was accepted or declined. | MUST |
| 3.7.4 | The system MUST support the electronic receipt of NBS reports from Laboratories and/or from the National Screening Store (see Electronic Results Messaging section below). | MUST |
| 3.7.5 | The system MUST support the manual entry of an NBS reports from a Laboratory into the system. | MUST |
| 3.7.6 | The system MUST record the results for each of the conditions tested.  Note: in 2014-15 there were 5 conditions tested; in 2015-16 there will be 9 conditions tested. | MUST |
| 3.7.7 | The system MUST record multiple reports for each test in order to record any ‘failed’ tests prior to a successful test. | MUST |
| 3.7.8 | For each test the system MUST record the following data items:   * the ‘01’ status (“sample received”) report together with   + report date   + date sample taken   + date sample received   + sample ID   + date entered into the system (see Notes below) * the “result” status (format NN) code together with   + report date   + sample ID   + date entered into the system (see Notes below)   Notes  The ‘date entered into the (CHIS) system’ MUST be system generated and not able to be changed by a user.  Reports contain many other data items which need to be recorded – those above are mentioned as they have relevance to KPI reporting. | MUST |
| 3.7.9 | If paper reporting is being used and results are being added (ie codes 03 to 10), the system SHOULD prompt the user to add a sample received 01 entry. The system MAY offer to create such an entry using the same date as the results report. (See Notes) | SHOULD |
| 3.7.10 | The system MUST use sample ID to determine whether multiple tests were requested and for matching results to each test request. Note that test results may be reported more than once if some results are sent before others – the final report will contain the results for all tests including those reported earlier. | MUST |
| 3.7.11 | The system MUST record the date that the child’s parents were informed of the screening results AND the method used as one of:   * letter sent * Health Visitor informed (to convey results to parents) | MUST |
| 3.7.12 | The system MUST record the new 4-digit status sub-codes (format NNNN) (see Status Codes v4.2 (Ref 7)) in addition to the existing 2-digit format codes. | MUST |

Notes

3.7.9: If an ‘01’ date is not enforced the system MUST use the report/result data as a proxy for the 01 date when generating the annual data returns.

## Electronic results messaging

At the present time there are a number of different messages used by Laboratories to convey screening results to CHIS - HL7 2.4 (used by a number of laboratories in London and the South East), HL7 v3 National Blood Spot Screening (HSCIC) message used in Leeds, and a different HL7 v3 proprietary message used in Birmingham.

During 2014 a new Child Screening Domain Message Specification was developed jointly by UK NSC and the ITK team at HSCIC based on HL7 v3 CDA. Version 2 currently supports the Hearing Screening, Newborn Infant Physical Examination (NIPE) and Newborn Blood Spot screening outcomes. The message was developed as a combined newborn screening message for use between Laboratories and the National Screening Store (NSS), Laboratories and Provider systems and the National Screening Store and Provider Systems. In this context Provider systems include Maternity systems, Child Health systems, National Hearing Screening system, National NIPE system and the National Screening Store. The NBS messages are currently in User Acceptance Testing (UAT) by the Sheffield NBS Laboratory and a Northampton CHIS system.

The strategic direction for all UK NSC screening messages is to use the NHS standard ITK Child Screening Domain Message Specification. Details of these can be found on TRUD (<https://isd.hscic.gov.uk>). The full messaging documentation can only be downloaded by registering as a user. Supplier staff are allowed to be TRUD users.

The currently published ITK Child Screening DMS messages, version 2.0, supports the 5 conditions tested in 2014-15 and the original 2 digit status codes. An updated set of message specifications, version 3.0, is expected to be published in April 2015 which will include the 4 new ‘expanded’ metabolic conditions (making 9 conditions in total),the new 4-digit sub-codes as well as the associated SNOMED codes for Hearing & Blood Spot Screening. All 2 and 4-digit status codes have an associated SNOMED CT code together with mappings to Read2 and CTV3 codes. (See Ref 8 for current draft (not for implementation)). The messages are populated with these SNOMED codes and any code translations required between local coding systems and the message contents must (a) use the mappings provided and (b) be undertaken automatically by the system.

The requirements below are necessarily future requirements. Note that systems are not required to support version 2.0 of these specifications.

|  |  |  |
| --- | --- | --- |
| Req ID | Requirement Text | Type |
| 3.8.1 | The system MUST support the Newborn Blood Spot sub-domain of the Child Screening Domain Message Specification v3.0 as published by HSCIC under the ITK set of standards. | MUST |

## Newborn blood spot screening reporting

It is important for CHIS system users to be able to identify all children who have not received Newborn Blood Spot Screening and those who have been offered screening and are awaiting a response. This activity is undertaken frequently (eg daily) in order to ensure screening is provided in a timely manner.

|  |  |  |
| --- | --- | --- |
| Req ID | Requirement Text | Type |
| 3.9.1 | The system MUST provide an on-screen report that lists all children under the age of 1 year old for whom no NBS reports have been received. The report MUST be broken down into those children who have been offered a test but are awaiting a response and those who have not been offered a test yet. The report MUST indicate for all children included in the report, how many days have elapsed since their birth AND since their registration date. | MUST |
| 3.9.2 | It MUST be possible for a user to select any child in the report and display demographic details of them and their mother/parents, including as a minimum:   * child forename & surname * date of birth * child’s usual address & post code * child’s telephone numbers * child’s registered GP Practice and usual GP name * mother’s/parent’s forename & surname * mother’s/parent’s address and post code (if different) * mother’s/parent’s telephone numbers (if different) | MUST |
| 3.9.3 | It MUST be possible for a user to select any or all of the children in the report and print the demographic details of them and their mother/parents, including as a minimum:   * child forename & surname * date of birth * child’s usual address & post code * child’s telephone numbers * child’s registered GP Practice and usual GP name * mother’s/parent’s forename & surname * mother’s/parent’s address and post code (if different) * mother’s/parent’s telephone numbers (if different) | MUST |

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## Newborn blood spot screening statutory reports

CHIS Providers need to submit two KPI reports for 2015-16: NB1 and NB4 on both a quarterly and annual basis. NB3 still needs to be reported for 2014-15. The KPI reports provide statistics on the numbers of children screened (standards 1a and 1b).

CHIS Providers also need to submit an Annual Data Return which provides data on additional standards 2 and 12 (new for 2015-16) and a more detailed breakdown of screening results.

To summarise the reporting requirements:

In Year 2014-15: 5 disorders are tested for and reported via

* KPI NB1
* KPI NB3
* Annual Data Return Standards 1a, 1b and 2

In Year 2015-16: 9 disorders are tested for and reported via

* KPI NB1
* KPI NB4
* Annual Data Return Standards 1a, 1b, 2 and 12

Provided all the raw data exists in the system (as defined in previous sections of this document) the system can produce the required KPI and Annual Data Return data items for users to enter on their returns. This section details the data processing required to generate the required information for each return.

The system is only required to produce data for the NB1 and NB4 quarterly and annual submissions for 2015-16. (Note: KPI NB3 will not be reported in 2015-16)

The Quarterly KPI reporting periods are:

* Q1: 1st April to 30th June
* Q2: 1st July to 30th September
* Q3: 1st October to 31st December
* Q4: 1st January to 31st March

Quarterly reports are submitted during the 3rd month following the reporting period, ie Q1 (Apr-Jun) reports are submitted between 1st August to 31st August.

Annual KPI Reports and Annual Data Returns are for the period 1st April to 31st March and must be submitted between 1st and 30th June along with the Q4 KPI report.

**Important notes – annual data returns**

When generating numerator data it is important to count the correct reports/results. Each child who is screened will, if electronic messaging is in place, get a sample arrived status (code 01) set of data once the lab has reported the sample arriving. If paper-based reporting is in place the CHIS Provider may or may not receive a paper equivalent to the sample received 01 report (see 3.6 recreating an artificial 01 entry).

If screening is declined the child will get a screening declined status (code 02). If a test has to be repeated (status code 03) and a further sample is taken and tested, a further sample received report (status 01) will be received. The system needs to support receipt of multiple 01 status codes each condition tested.

For individual test results (eg PKU, CHD, etc), a test result may be sent before all results are available and subsequent reports for the late tests also include the earlier test result and thus the earliest conclusive test outcome (status codes 04,05,06,07,08 or 10) are to be used in the timeframe numerator in the Annual Data Return reports.

Standard 2 on the Annual Data Return requires no data producing.

In **summary**: A child offered screening will have for each of the 5 (in 2014-15) or 9 (in 2015-16) disorders:

EITHER one or more 01 status codes OR one 02 status code

AND if not 02 above, one or more 03,04,05,06,07,08,09 or 10status codes

An **algorithm** for determining which numerator for each disorder tested a child falls under is as follows:

IF a 02 code exists THEN add it to 02 numerator

ELSE IF a 01 code exists THEN

Add it (once) to the 01 numerator

IF a conclusive code (04,05,06,07,08,10) also exists THEN

BEGIN

Add it (once) to the appropriate 04/05/06/07/08/10 numerator

IF the date of the earliest conclusive code is within the 17/21 day

from birth timeframe

THEN Add to the timeframe numerator

ENDIF

ELSE if a 03 code exists add to the 03 numerator

ELSE if a 09 code exists add to the 09 numerator

ELSE do not count the child in any numerator.

Note: when determining if within x days, the time of the event (birth/report) must not be used.

| Req ID | Requirement Text | Type |
| --- | --- | --- |
| 3.10.1 | The system MUST provide the following KPI reports as pre-defined, unalterable (apart from selection of the CCG and reporting period parameters), standard reports:   * NB1 Quarterly Report * NB4 Quarterly Report * NB1 Annual Report * NB4 Annual Report * Annual Data Return |  |
| 3.10.2 | Upon selection of a report the user MUST be prompted to select:   * the CCG for whom the report will be run * the reporting period * the reporting year |  |
| 3.10.3 | The list of quarterly reporting periods MUST be:   * Q1: 1st April to 30th June * Q2: 1st July to 30th September * Q3: 1st October to 31st December * Q4: 1st January to 31st March |  |
| 3.10.4 | For the annual KPI reports and the Annual Data Return the reporting period MUST be :   * 1st April to 31st March   and the reporting year MUST be:   * 20nn-nn (eg 2015-16) |  |
| 3.10.5 | The submission periods are:   * for Q1 reports: 1st September to 31st September * for Q2 reports: 1st December to 31st December * for Q3 reports: 1st March to 31st March * for Q4 and Annual reports: 1st June to 30th June |  |
| 3.10.6 | If a quarterly or annual report is not being run during the submission period the system SHOULD inform the user that the data within the report cannot be included within their statutory return. |  |
| 3.10.7 | When analysing data the system MUST use all report/result data available up to and including the last day before the submission period (ie for Q4 or annual reports all report/result data up to and including 31st May). This allows the results of children born towards the end of March to be reported. |  |
| 3.10.8 | All report data MUST be available to view on screen AND to be able to be printed. |  |
| 3.10.9 | All reports MUST clearly indicate the reporting period and the date on which the report was run. |  |
| 3.10.10 | All data for a selected report MUST be available in a single report, ie a user MUST NOT have to run multiple reports in order to obtain the required data. |  |
| **Quarterly KPI – NB1 (Standard 1a): Newborn blood spot screening – coverage (CCG responsibility at birth)** | | |
| 3.10.11 | The system MUST generate the numerator and denominator as per the example quarterly KPI template (see Appendix A). |  |
| 3.10.12 | Further to the definitions contained in the quarterly KPI template:   * ‘CCG responsibility at birth’ means include only those with a ‘birth’ registration type and excludes those with one of the ‘mover –in’ registration types or who died before age 8 days * a ‘conclusive screening result for PKU’ is one with a report status of 04,05,06,07,08 or 10. * within an ‘effective timeframe’ means that a conclusive result was present in the CHIS system within 17 days from birth (ie if born on the 3rd then the result must be present in the system no later than the 20th ). Note that this does not mean the date of the report but the date the reports results were entered into the system. |  |
| **Quarterly KPI – NB4 (Standard 1b): Newborn blood spot screening – coverage (movers-in only)** | | |
| 3.10.13 | The system MUST generate the numerator and denominator in as per the example quarterly KPI template (see Appendix A). |  |
| 3.10.14 | Further to the definitions contained in the quarterly KPI template:   * ‘mover in’ means include only those with a registration types of ‘mover in – from other CCG’ and ‘mover in – immigrant’ and excludes those with one of the ‘birth’ registration type or who died before age 8 days * with the registration start date within the reporting period and with no registration end date within the reporting period * a ‘conclusive screening result for PKU’ is one with a report status of 04,05,06,07,08 or 10. * within an ‘effective timeframe’ means that a conclusive result was present in the CHIS system within 21 days from birth (ie if born on the 3rd then the result must be present in the system no later than the 24th ). Note that this does not mean the date of the report but the date the reports results were entered into the system. |  |
| **Annual Data Return – Standard 1a: Newborn blood spot screening – coverage (CCG responsibility at birth)** | | |
| 3.10.15 | The system MUST generate the numerators and denominators as per the example Annual Data Return template (see Appendix A - ‘Standard 1a’ section). |  |
| 3.10.16 | The system MUST generate the denominator (See cell C27/28 in example Annual Data Return template (see Appendix A)) as follows:  ‘Total number of babies the CCG is responsible for at birth and remain responsible for on the last day of the reporting period’  means include only those with a ‘birth’ registration type and exclude those with one of the ‘mover –in’ registration types or if the child died before age 8 days. |  |
| 3.10.17 | A child MUST only be counted once, or not at all, in either the 01 or 02 numerators. |  |
| 3.10.18 | A child MUST only be counted once, or not at all, in one of the 03 to 10 numerators. |  |
| 3.10.19 | The system MUST generate the ‘***Number of samples received in laboratory notifications (status code 01)’*** numerator. |  |
| 3.10.20 | The system MUST generate the ‘***Number of babies declined (status code 02)’*** numerator. |  |
| 3.10.21 | The system MUST generate the ‘***Number of babies screening incomplete (status code 03) Repeat sample required’*** numerator. |  |
| 3.10.22 | The system MUST generate the ***‘Number where screening is incomplete (status code 09) if recorded on your system’*** numerator. |  |
| 3.10.23 | The system MUST generate the ***‘Number of babies tested (status codes 04,05,06,07,08,10)’*** numerator. |  |
| 3.10.24 | The system MUST generate the ‘***Number of babies tested and recorded on the child health system at 17 days’*** numerator by getting the date of the earliest 04,05,06,07,08 or 10 status code and counting it if the date is with 17 days of birth. |  |
| **Annual Data Return – Standard 1b: Newborn blood spot screening – coverage (movers-in only)** | | |
| 3.10.25 | The system MUST generate the numerators and denominators as per the example Annual Data Return template (see Appendix A - ‘Standard 1b’ section). |  |
| 3.10.26 | The system MUST generate the denominator (See cell C40/41 in example Annual Data Return template (see Appendix A)) as follows:  ‘Total number of babies the CCG is responsible for at birth and remain responsible for on the last day of the reporting period’  means include only those with one of the ‘mover –in’ registration types and exclude those with a ‘birth’ registration type or if the child died before age 8 days. |  |
| 3.10.27 | A child MUST only be counted once, or not at all, in either the 01 or 02 numerators. |  |
| 3.10.28 | A child MUST only be counted once, or not at all, in one of the 03 to 10 numerators. |  |
| 3.10.29 | The system MUST generate the ‘***Number of samples received in laboratory notifications (status code 01)’*** numerator. |  |
| 3.10.30 | The system MUST generate the ‘***Number of babies declined (status code 02)’*** numerator. |  |
| 3.10.31 | The system MUST generate the ‘***Number of babies screening incomplete (status code 03) Repeat sample required’*** numerator. |  |
| 3.10.32 | The system MUST generate the ***‘Number where screening is incomplete (status code 09) if recorded on your system’*** numerator. |  |
| 3.10.33 | The system MUST generate the ***‘Number of babies tested (status codes 04,05,06,07,08,10)’*** numerator. |  |
| 3.10.34 | The system MUST generate the ‘***Number of babies tested (status codes 04,05,06,07,08, 10) equal to or less than 21 calendar days of movement in being recorded on the child health information system***’ numerator by getting the date of the earliest 04,05,06,07,08 or 10 status code and counting it if the date is with 21 days of birth.. |  |
| **Annual Data Return – Standard 12: Newborn blood spot screening - timeliness of result availability** | | |
| 3.10.35 | The system MUST generate the numerators and denominators as per the example Annual Data Return template (see Appendix A – Standard 12 section). |  |
| 3.10.36 | The system MUST generate the denominator (Babies screen negative for all 5/9 conditions) as follows:  ‘babies screen negative for all 5/9 conditions (denominator) is the total number of babies born within the reporting period:  • for whom the CCG were responsible at birth and still responsible on the last day of the reporting period.  • for whom a conclusive screen negative status code 04 (condition not suspected) result is available on all five.  means include only those with a current ‘birth’ registration type (ie exclude those with one of the ‘mover –in’ registration types or if the child died before age 8 days ) AND who also have a status code of ‘04’ for ALL conditions tested (ie all 5/9).  Note: ‘on the last day of the reporting period’ removed from 2nd bullet above to allow accurate reporting of babies born in February/March. |  |
| 3.10.37 | The system MUST generate the numerator (Results available for communication by 6 weeks) as follows:  ‘results available for communication by 6 weeks (numerator) is the number of babies screen negative for all five conditions for whom screening results are available on the Child Health Information System (CHIS) for access by health visitors within 6 weeks (42 days) of birth.’  means that the ‘child’s parents informed’ date (ie letter sent or Health Visitor informed) (see 3.6) is within 36 days of the child’s date of birth.  Note: In the absence of a ‘child’s parents informed’ date field the system MUST use the earliest date that ALL 5/9 conditions have ‘04’ status codes (NB. Results can be reported on different dates). |  |