

# **DAPB3009 (Amd 16/2022)**

## **Healthy Child Record Standard**

### **Phase 2.1**

## **Interoperability Specification and Implementation Guidance**

Current Version : Version 1.0  
Version Date: 14/07/2022



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# Data Alliance Partnership Board

The Data Alliance Partnership Board (DAPB), which holds delegated authority from the Secretary of State for Health and Social Care, has approved a change to an existing information standard for publication under [section 250 of the Health and Social Care Act 2012](#).

Assurance that this information standard meets the requirements of the Act and is appropriate for the use specified in the specification document has been provided by the Data Standards Assurance Service (DSAS) and endorsed by the Data Alliance Partnership Sub Board (DAPSB).

This information standard comprises the following documents:

- Interoperability Specification and Implementation Guidance
- Collaborative Requirements Catalogue
- Record Specification.


An Information Standards Notice (DAPB3009 Amd 16/2022) has been issued as a notification of use and implementation timescales. Please read this alongside the documents for the standard.

The controlled copies of these documents can be found on the [NHS Digital website](#). Any copies held outside of that area, in whatever format (e.g. paper, email attachment), are considered to have passed out of control and should be checked for currency and validity.

Date of publication: 14 July 2022

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## Glossary of Terms

*Describe terms that are relevant to this document, to help readers understand what is meant throughout.*

Term / Abbreviation	Description
API	Application Programming Interface is a set of functions and procedures allowing the creation of applications that access the features or data of an operating system, application, or other service.
BGL	Business Go Live is the point at which new provider system supplier functionality has been rolled out and available for providers to use.
Child	<p>The term Child or Children is used interchangeably throughout the document to ease reading.</p> <p>A Child or Young Person (Community Services) is a PERSON.</p> <p>For the purpose of this standard, this relates to all Children or Young People from birth up to the day before their 19th birthday, with the exception of young adults who remain in paediatric services after their 19th birthday and are included until their transition to adult services is completed.</p>
CHIS	Child Health Information Services
CHO	Child Health Organisation
DCB	Data Coordination Board (now replaced by DAPB – see below)
DAPB	Data Alliance Partnership Board
DCH	Digital Child Health
DIP	Digital Interoperability Platform
Direct Care	“A clinical, social or public health activity concerned with the prevention, investigation and treatment of illness and the alleviation of suffering of individuals. It includes supporting individuals’ ability to function and improve their participation in life and society. It includes the assurance of safe and high quality care and treatment through local audit, the management of untoward or adverse incidents, person satisfaction including measurement of outcomes undertaken by one or more registered and regulated health or social care professionals and their team with whom the individual has a legitimate relationship for their care” <sup>1</sup>
DPCHR	Digital Personal Child Health Record is to replace the paper redbook where the Parent(s)/Carer(s) have access to and signed up to digital versions. This should make it easier to hold online records for their children and access them via smartphones, laptops and tablets.
DVP	Deployment Verification Period starts 14 days after Business Go Live (BGL) and runs for 6 weeks (42 days). During this period provider system suppliers <b>MUST</b> demonstrate the new functionality is fit for purpose and there have been no service incidents raised, as a result of the new functionality having been deployed

<sup>1</sup> <https://digital.nhs.uk/services/national-data-opt-out/operational-policy-guidance-document/appendix-2-definitions>

<b>Term / Abbreviation</b>	<b>Description</b>
EMS	Event Management Service
FHIR	Fast Healthcare Interoperability Resources. A method for exchanging healthcare information electronically.
HCP	Healthy Child Programme
HVS	Health Visiting Services
ICT	Information and Communication Technologies
ISN	Information Standards Notice
LEMS	Local Event Management Service
LHCR	Local Health and Care Record
LRL	Local Record Locator
MIMO	Movers in Movers Out
NEMS	National Event Management Service
NIPE	Newborn and Infant Physical Examination (NIPE) consists of 4 screens to aid early identification of conditions which can impact on babies' lives, these include: <ol style="list-style-type: none"> <li>1. Eyes - to detect congenital cataracts,</li> <li>2. Heart - to detect congenital heart disease,</li> <li>3. Hips - to detect dislocated or dislocatable hips,</li> <li>4. Testes - to detect cryptorchidism (undescended testes).</li> </ol>
NRL	National Record Locator
PDS	Personal Demographics Service
Portability Solution	A portability solution is one provided by system suppliers to enable access to Healthy Child records via portable devices e.g. DPCHR.
PRSB	Professional Record Standards Body
Publisher	The publisher is the provider undertaking the intervention, publishes the fact that it has happened and its outcome shortly after it has happened.
RLS	Record Location Services
SCAL	Supplier Conformance Assessment List
Spine	Spine supports the IT infrastructure for health and social care in England, joining together over 23,000 healthcare IT systems in 20,500 organisations.
Subscriber	A subscriber wishes to receive information about an intervention for a specific event, for example, an HVS wishing to receive vaccination administration information for a specific Patient.

# 1. Introduction

## 1.1 Change request

NHS Digital were asked by our commissioners to make changes to National Event Management Service (NEMS) messages to support flowing of Bacillus Calmette-Guérin vaccine (BCG) and Severe Combined Immunodeficiency (SCID) information to and from NEMS Publishers and to NEMS Subscribers respectively.

There are currently nine approved events which are flowing through NEMS. Two of these have been updated to include additional information for BCG and SCID. Additionally a new requirement has been added. The changes are summarised below.

### SCID – Change to existing requirement

The SCID bloodspot test outcome has been added to the “Blood Spot Test Outcome” event message.

This has been added as an optional ‘Procedure’ resource within the event message, in the same manner blood spot test outcomes are already included in the event message.

### BCG Eligibility – Change to existing requirement

BCG eligibility has been added to the “NIPE” event message.

These changes to phase two came into effect from 1st September 2021 and are actively being flowed through NEMS.

### New requirement

Requirement DCH-710 has been added to the standard, highlighting that organisations need to be compliant with the SNOMED CT reference set as used in the latest version of the supporting FHIR profile, in line with the NEMS (DCH) specification.

## 1.2 Background context

The purpose of this information standard is to facilitate the sharing of standardised data between health care providers, parent(s) and carer(s) for all children, as described by the Healthy Child Programme. This will ensure that all appropriate stakeholders have access to consistent data structure and content to aid direct care decision making.

In November 2016, NHS England published *Healthy Children: Transforming Child Health Information*, a digital strategy describing how child health information can be made more accessible to support parents and professionals in their care for children and young people, and how that same information can be used to promote their health and wellbeing.

The central theme of the strategy is to improve interoperability and exchange of key pieces of health information to support two main objectives<sup>2</sup>:

- 1) Knowing where every child is and how healthy they are, and
- 2) Appropriate access to information for all involved in the care of children.

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<sup>2</sup> NHS England National Information Board, *Healthy Children: Transforming Child Health Information*, Nov 16

This uplifted Phase 2 release of this standard was preceded by DCB3009 Amd 32/2017 Healthy Child Programme Record Standard, Phase 1<sup>3</sup> (published 13-Dec-2018 and updated 09-Jan-2020).

This provided instructions on standardising child health data in readiness to be shared via interoperability capabilities developed by NHS Digital (via this Phase 2 release). The Phase 1 Healthy Child Record Specification was co-produced by the Professional Record Standards Body (PRSB) and NHS Digital in consultation with a comprehensive range of health and care professionals. This specification has been re-reviewed for Phase 2 to ensure the content still reflects the required data elements for the Healthy Child Programme and agreed with the PRSB. As a result of this work, a number of changes to data elements have been agreed with the PRSB and these have been reflected in both the Record Specification and Event Specification documents. Providers should therefore use the Phase 2 version of these documents to implement the standard. Both Record Specification and Event Specification documents have been appended with a change log to identify areas of change.

This has been further uplifted to reflect changes to include event information about SCID and BCG.

## 2. Phases

The aim of the programme is to support uptake and delivery of the Healthy Child Programme in England by enabling greater automated information exchange between health professionals, parents and those involved in public health initiatives and to provide a foundation for the introduction of a digital personal child health record. This is being achieved in 2 Phases:

Phase 1 of the information standard, developed by the Professional Record Standards Body (PRSB), in collaboration with NHS Digital, supported the move to sharing of child health information by setting out the Healthy Child Record specification that care providers should comply with, on a local basis, to ensure that all providers and their suppliers are using the same data in a standardised format.

Phase 2 introduces the mechanisms for sharing of this standardised data across providers.

It is a 'building block' model: the information events – which may or may not be recorded in an encounter – are aggregated to form the summary of the encounter and are then available for publication and retrieval by parents (via a digital personal child health record) or by health professionals using their native systems.

Making accurate information more freely available at the point of care and enfranchising parents in the information sharing will help in efforts to improve health outcomes and reduce health inequalities in the child population.

## 3. Key Dates

Providers will be expected to be compliant with uplifted Phase 2 requirements by 31 December 2022. Compliance with Phase 1 was preparation and readiness for delivery of Phase 2 and future phases of Digital Child Health delivery.

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<sup>3</sup> <https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dcb3009-healthy-child-programme>

## 4. Purpose

This document is aimed at health providers or providers of health data for children to enable the sharing of standardised child health data, thereby allowing clinicians to provide the optimal care for patients using the most recent information. The purpose of this document is to:

- provide implementation checklist/guidance
- signpost the reader to the record and event specifications, including change history
- signpost the reader to the Digital Child Health Collaborative Requirements Catalogue
- signposts the reader to the conformance approach which will be achieved via the SCAL
- outline instructions on handling sensitive data.

The data sharing capabilities of the Phase 2 standard have been developed using the structured messaging standard Fast Healthcare Interoperability Resources (FHIR). These messages have already been developed and assured by NHS Digital along with partners/suppliers. These messages, shown below, underwent a period of stability and successfully completed NHS Digital's Deployment Verification Period (DVP).

- Demographics
  - Personal Demographics Service (PDS) Change of Address
  - PDS Change of GP
  - PDS Birth Notification
  - PDS Death Notification.
- Screening
  - Newborn and Infant Physical Examination (NIPE) Outcome
  - Newborn Hearing
  - Bloodspot Test Outcome.
- Generic Messages
  - Vaccinations
  - Professional Contacts.

Additional information on these message sets is contained within Section 9 of this document.

## 5. Key, Supporting and Guidance Documents

The table below outlines the purpose of each document to support implementation of this standard.

Ref	Title	Purpose
1	Phase 2 - Interoperability Specification and Implementation Guidance	This document is aimed at health providers or providers of health data for children to enable the sharing of standardised child health data, thereby allowing clinicians to provide the optimal care for patients using the most recent information.
2	Information Standards Notice	Provides formal notification of the information standard.

3	Healthy Child Record Specification	Provides the format of an electronic healthy child record supporting the Healthy Child Programme, including the sections (headings) and elements which provide the standardised structure for that record.
4	Digital Child Health Collaborative Requirements Catalogue	Provides the details of system enhancements suppliers are to implement in support of Phase 2 of the standard.
5	Healthy Child Event Specification	Provides the information models setting out the detailed content, format, structure and rules needed for a system supplier to implement the standard.
6	National Events Management Service Onboarding Guide	Provides guidance for both new and existing health and social care organisation wishing to publish and/or subscribe to the National Events Management Service (NEMS) from initial engagement, build and test through to implementation into live.
7	Supplier Conformance Assessment List (SCAL)	Provides guidance on demonstrating technical conformance of this standard. This is a key aspect of the NEMS onboarding guide.

## 6. Scope

This standard applies to the following key groups and organisations who provide health care to children:

- All Primary Care Services
- All Child Health Organisations
- All Community services
- All School Nursing services
- All Maternity Services
- All Health Visiting services
- All Screening Laboratories
- All organisations providing NHS England and NHS Improvement commissioned immunisation services for children.

Providers through local contractual arrangements shall work with their system suppliers to implement the changes needed to facilitate this standard.

- All Principal Clinical Suppliers (GP / Primary Care Services)

- All Child Health Information system suppliers
- All community system suppliers for example Health Visitor and School Nursing system suppliers
- All Screening Service Suppliers (supporting Public Health England’s national screening programme for children)
- Any system supplier providing solutions for NHS England commissioned immunisation services
- DPCHR (digital Personal Child Health Record) suppliers.

## 7. Requirements definition

The requirements within this specification are assigned prioritisation levels using MoSCoW method, namely:

- **MUST** – This word, or the term “SHALL”, means that a requirement is mandatory, and business and project objectives cannot be met without it
- **SHOULD** – This word means that a requirement is mandatory, but the system will have short-term value without it and development can therefore wait until a later increment
- **COULD** – This word means that a requirement is beneficial if time or funds allow, but it is not central to project objectives
- **WOULD LIKE (or WANT TO HAVE)** – These words indicate that a requirement will not be met in this delivery increment, but may be included in the future

## 8. Implementation Checklist and Conformance

The following is a sequence of steps, set out to help organisations understand the implementation process. Further information can be found within Digital Child Health Implementation Guides<sup>4</sup>.

### Step 1: Read the Information Standards Notice (ISN)

This is the official notification of the Information Standard, published by the Data Alliance Partnership Board (DAPB). Providers **MUST** read this notice as it provides an outline of the approved standard and timeframe for compliance. Compliance with ISNs will normally be included in contracts between NHS Providers and their system suppliers.

### Step 2: Read this document and other supporting documents

There are two phases of the Healthy Child Standard.

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<sup>4</sup> Digital Child Health Implementation Guides:  
<https://digital.nhs.uk/services/digital-child-health/digital-child-health-implementation-guides>

For new or existing providers who are not compliant with Phase 1 or 2, please ensure you have completed the instructions within DCB3009 (Amd 32/2017) Healthy Child Programme Record Standard, Phase 1 (published 13-Dec-2018 and updated 09-Jan-2020)<sup>5</sup>.

For existing providers who have already submitted the Phase 1 compliance letter, you **MUST** proceed with the instructions set out in this document, to implement the requirements for Phase 2.

Providers **MUST** instruct their suppliers to review the latest version of the Record Specification and Event Specification documentation and the change log therein, before proceeding with the instructions in this document.

### **Step 3: Identify and discuss with your stakeholders**

Providers **MUST** engage with those who are involved in recording, collecting, sharing and using the data in/or for the organisation.

Provider **MUST** check the current state of readiness for the following:

#### IT Systems (Software)

- Many of the elements in the Healthy Child Standard may already be recorded electronically within your systems. Where this is not the case, providers **MUST** work with suppliers to understand changes required.

#### Processes:

- Are there any changes to process required?
- Providers must work with their user base and system suppliers to determine appropriate guidance and/or training material where changes have been applied to local systems.

### **Step 4: Talk with current IT Systems Supplier**

Providers **MUST** speak with their system supplier(s) to ensure the timescales for any necessary changes, documented within the Digital Child Health Collaborative Requirements Catalogue, to their local system are achievable as per their local contractual agreements and the dates specified within Section 3 above. In most cases these changes will be part of their Service Level Agreement (SLA).

### **Step 5: Conformance**

Providers **MUST** demonstrate they have implemented changes to local systems to enable the flow of information between services in line with the Phase 2 Healthy Child Standard DAPB3009 Amd 16/2022 by completing the Supplier Conformance Assessment List (SCAL) process (SCAL version 2.3), as defined within Section 3 above.

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<sup>5</sup> DCB3009 Amd 32/2017 Healthy Child Record Standards ISN (published 13-Dec-2018 and updated 09-Jan-2020)

<https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dcb3009-healthy-child-programme>

When ready to commence formal assurance and testing direct engagement with the Solutions Assurance team ([itkconformance@nhs.net](mailto:itkconformance@nhs.net)) is required, this team will provide guidance through the process.

Upon request, the Live Services team will via [interop.mgmt@nhs.net](mailto:interop.mgmt@nhs.net) issue the SCAL that is tailored to reflect any previous conformance testing undertaken with NHS Digital.

## 9. Interoperability Overview

This section signposts providers and system suppliers to supporting documentation on how child health data/messages, under the *Healthy Child Programme* will be exchanged using the National Events Management Service (NEMS)<sup>6</sup> capability.

### 9.1 National Events Management Service (NEMS)

NEMS is a national capability implemented on the Spine, allowing for patient event messages to be published and distributed from one system to another. NEMS however is not part of this standard but a technical capability that allows delivery of Phase 2.

NEMS is designed to allow a “publisher” to share that an event has occurred for a patient, without knowing who might be interested in that information “subscriber”. A subscriber, subscribes in advance to allow the timely receipt of information from a publishing provider, as illustrated in Figure 1 below.

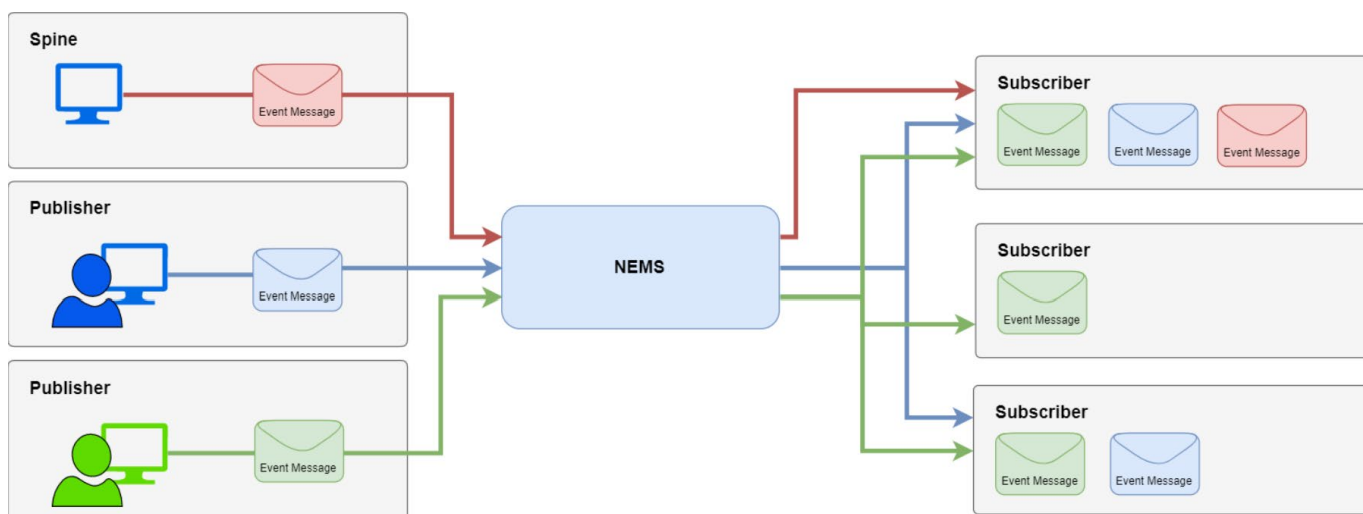


Figure 1 - High Level NEMS flow

### 9.2 Technical Specification

Detailed technical information for NEMS messaging can be found at: [https://developer.nhs.uk/apis/ems-beta/overview\\_supported\\_events.html](https://developer.nhs.uk/apis/ems-beta/overview_supported_events.html)

<sup>6</sup> Find out more about NEMS via: <https://digital.nhs.uk/services/digital-child-health/national-events-management-service>

## 9.2.1 Supported Messages

The following tables detail both the Demographic, Screening and Generic messages and their corresponding FHIR profiles for those messages defined for the Healthy Child Programme supported by the NEMS for either publication and/or subscription by provider's system suppliers.

## 9.2.2 Supported Demographics Messages

The Demographic messages and FHIR profile links supported by the NEMS are outlined in the following table.

Event	Event Code	FHIR Profile Link
<b>PDS Birth Notification</b>	pds-birth-notification-1	<a href="https://developer.nhs.uk/apis/ems-beta/pds_birth_notification.html">https://developer.nhs.uk/apis/ems-beta/pds_birth_notification.html</a>
<b>PDS Change of Address</b>	pds-change-of-address-1	<a href="https://developer.nhs.uk/apis/ems-beta/pds_change_of_address.html">https://developer.nhs.uk/apis/ems-beta/pds_change_of_address.html</a>
<b>PDS Change of GP</b>	pds-change-of-gp-1	<a href="https://developer.nhs.uk/apis/ems-beta/pds_change_of_gp.html">https://developer.nhs.uk/apis/ems-beta/pds_change_of_gp.html</a>
<b>PDS Death Notification</b>	pds-death-notification-1	<a href="https://developer.nhs.uk/apis/ems-beta/pds_death_notification.html">https://developer.nhs.uk/apis/ems-beta/pds_death_notification.html</a>

Table 1: Generic NEMS Event Messages

## 9.2.3 Supported Screening and Generic Messages

The Screening and Generic messages and FHIR profile links that are supported by the NEMS are outlined in the following table.

Event	Event Code	Event Maturity
<b>Blood Spot Test Outcome</b>	blood-spot-test-outcome-1	<a href="https://developer.nhs.uk/apis/ems-beta/blood_spot_test_outcome_1.html">https://developer.nhs.uk/apis/ems-beta/blood_spot_test_outcome_1.html</a>
<b>Newborn Hearing</b>	newborn-hearing-1	<a href="https://developer.nhs.uk/apis/ems-beta/newborn_hearing_1.html">https://developer.nhs.uk/apis/ems-beta/newborn_hearing_1.html</a>
<b>NIPE Outcome</b>	nipe-outcome-1	<a href="https://developer.nhs.uk/apis/ems-beta/nipe_outcome_1.html">https://developer.nhs.uk/apis/ems-beta/nipe_outcome_1.html</a>
<b>Professional Contacts</b>	professional-contacts-1	<a href="https://developer.nhs.uk/apis/ems-beta/professional_contacts_1.html">https://developer.nhs.uk/apis/ems-beta/professional_contacts_1.html</a>
<b>Vaccinations</b>	vaccinations-1	<a href="https://developer.nhs.uk/apis/ems-beta/vaccinations_1.html">https://developer.nhs.uk/apis/ems-beta/vaccinations_1.html</a>

Table 2: DCH Specific Event Messages

## 9.3 Handling Sensitive Data

Special Category data under GDPR is personal data consisting of information of racial or ethnic origin, political opinions, religious or philosophical beliefs, genetic data, biometric data, data concerning health or data concerning a natural person's sex life or sexual orientation. The Digital Child Health full message set contains some of these items and they are part of the scope. They are necessary for the purposes of preventative medicine, for assessing the, medical diagnosis, the provision of health or social care or treatment or management of health or social care systems and services.

This data is processed under Article 6 and Article 9 of GDPR.

<https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/special-category-data/>

The DPIA and Transparency Notice for the Digital Child Health Programme can be found:

<https://digital.nhs.uk/about-nhs-digital/our-work/keeping-patient-data-safe/gdpr/gdpr-register/digital-child-health-dch>

## 10. Benefits

Overall benefits include efficiency gains from reducing re-keying of information as well as increased robustness, completeness, and timeliness of data available to Health Professionals, commissioners and parents/carers supporting decision making, improved health outcomes and delivery of care.

Early benefits from the first set of messages in Private Beta are summarised below as an illustration.

Additional benefit details and templates are provided as part of the [Provider Implementation Guidance for different care settings](#).

## 10.1 Private beta benefits - PDS and Screening messages

To inform the Phase 2 ISN, a Private Beta has been underway since April 2019 to prove the technical functionality of the NEMS. As part of this, Child Health Information Services (CHIS) providers covering 15% of the 0-5 age range population were live with PDS and screening messages at end May 2020.

Commenting on the first week's live running in April 2019, one of the private beta providers made the following observation:

*"The results so far have been very encouraging. Within the first couple of days we achieved a 20% increase in the timeliness of new birth notifications from out of area maternity units, enabling our health visitors to see new families sooner." "We also received 2000 address changes on the first day, which means we're picking up children new to (...) services much quicker; ensuring those children moving out of area are rapidly notified to their new service provider. Based on these early improvements, we expect to be targeting health resources much more accurately in the coming year."*<sup>7</sup>

**PDS Messages** provide the foundation for **"knowing where every child is"** and more accurate CHIS population cohorts and records through pro-active and timely information on address and GP changes. This increases robustness and timeliness of data and efficiency.

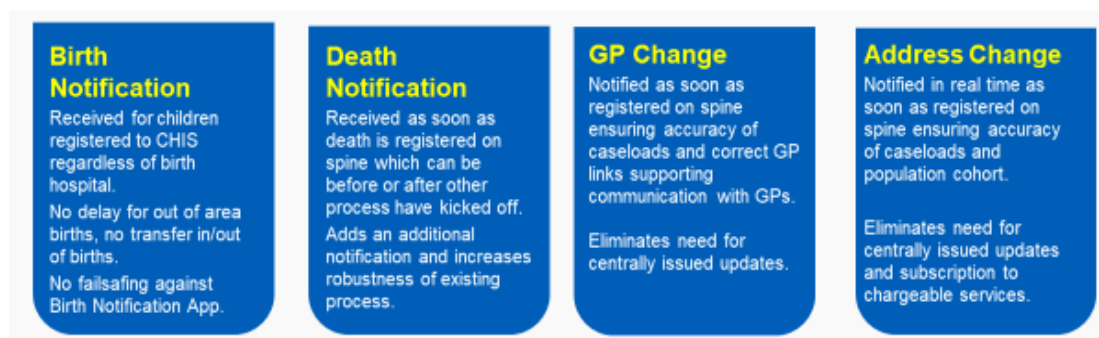


Figure 2 - Summary of PDS Messages

- Child Health Organisation (CHO) and Health Visiting population records and the degree of movement in/out of area are more accurate:
  - Supports discussions with commissioners and better planning and targeting of health resources.
  - Ad hoc population validation exercises will no longer be necessary in future.
  - Centrally provided demographics updates (e.g. Movers in Movers Out report) will no longer have to be created.
- CHO and Health Visiting Services (HVS) will no longer have to wait for out of area births, removing any delay from scheduling key early interventions like New Birth Visits.

**Screening messages** provide the foundation for **"knowing how healthy they are"** and **"appropriate information for all involved in the care of children"** by providing health professionals with the relevant information in their clinical system at the point of care, supporting decision making as well as eliminating the need for re-keying/re-processing data.

<sup>7</sup> <https://pharmafield.co.uk/uncategorized/digital-child-health-information-to-be-made-available-to-nhs-staff-patients/>

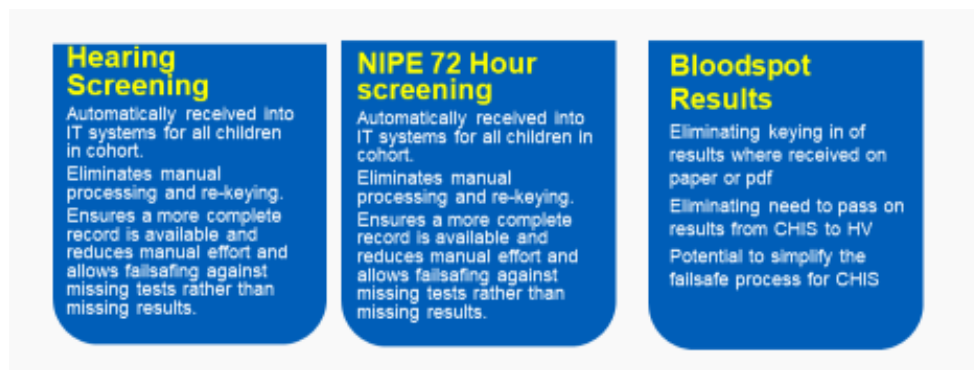


Figure 3 - Summary of Screening Messages

- DCH eliminates the need for manually loading or rekeying results and eliminates need for CHIS to pass on results to HVS.
- HVS and CHO receive results directly into their IT system for children in their cohort/caseloads: Some HVS do not currently receive bloodspot or newborn screening results into their system so may have to look them up in another system before or the paper redbook during the visit DCH provides:
  - Increased completeness of child’s record supporting early interventions
  - Increased efficiency through eliminating the need to look at information in other systems
  - Time will also be saved when collating a child’s information for Child Protection Case Conference Reports and Looked After Children’s health reviews.