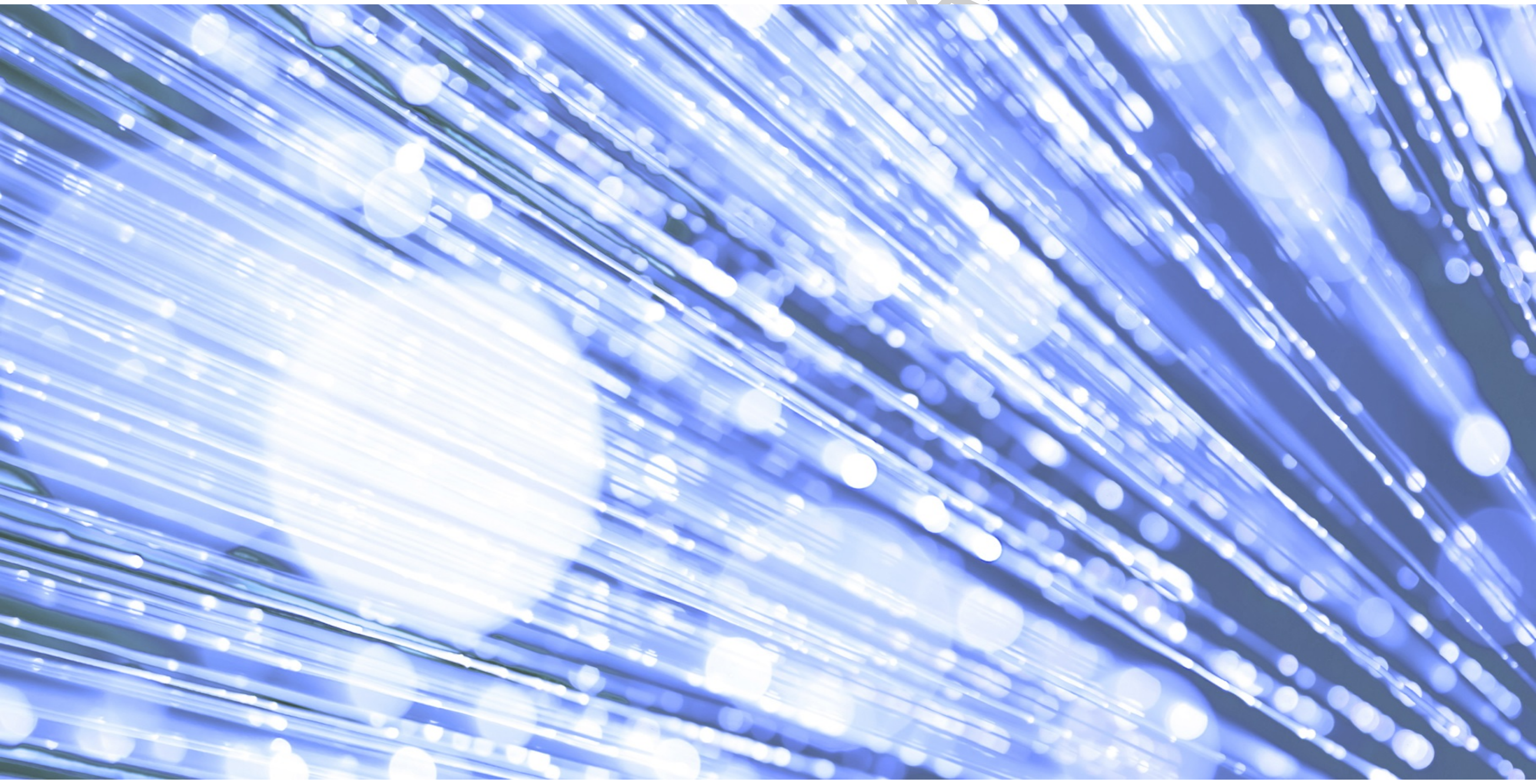
DCB3009 Healthy Child Record Standard

Implementation Guidance

Published 13 December 2018



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Data Coordination Board

This information standard (DCB3009) has been approved for publication by the Department of Health and Social Care 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 Coordination Board (DCB), a sub-group of the Digital Delivery Board.

This information standard comprises the following documents:

- Specification
- Implementation Guidance
- Record Specification
- Event Specification.

An Information Standards Notice (DCB3009 Amd 32/2017) has been issued as a notification of use and implementation timescales. Please read this alongside the documents for the standard.

The controlled versions 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: 13 December 2018

Glossary of Terms

Term / Abbreviation	What it stands for
DCH	Digital Child Health
PRSB	Professional Record Standards Body
ISN	Information Standards Notice
PDS	Personal Demographic Service
CHO	Child Health Organisation, also referred to as a Child Health Records Department/Child Health Information Service
SNOMED CT	Structured clinical vocabulary for use in an electronic health record. It is the most comprehensive and precise clinical health terminology product in the world
PCHR	Personal Child Health Record (commonly known as the 'red book'
ePCHR	Electronic version of the Personal Child Health Record
HCP	Healthy Child Programme
PHE	Public Health England
RCPCH	Royal College for Paediatrics and Child Health
FHIR	Fast Healthcare Interoperability Resource. A method for exchanging healthcare information electronically
DCB	Data Coordination Board

Contents

1. Introduction

Background context

This standard is to facilitate uniform data for children under the *Healthy Child Programme* (0-5 years and 5-19 years) and ensure that all clinical providers and systems involved in that programme use the same data. The purpose of this to provide a foundation for the future sharing of that data between all child health providers so they have a complete view of the child's health under the Healthy Child Programme.

In November 2016 NHS England published *Healthy Children: Transforming Child Health Information,* a digital strategy describing how making child health information more accessible can 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:

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.

The first step in the journey toward modern, responsive services is to ensure that key health information can be shared by **introducing standards**.

This Healthy Child Record standard, co-produced by the Professional Record Standards Body (PRSB) and NHS Digital in consultation with a comprehensive range of health and care professionals, is that first step.

2. Purpose

The purpose of this document is to provide guidance on the implementation of the Healthy Child Record standard. This will prepare systems to be in a position to begin sharing information in the future via mechanisms currently under development by NHS Digital. This Implementation Guidance is to be read alongside the Requirements Specification.

Further implementation guidance describing how the data will be exchanged will be available in a future standard - DCB3009 Phase 2 – *Interoperability and Portability.*

3. Implementation Checklist

The following is a sequence of steps, set-out to help organisations understand the implementation process and supporting in asking the right questions and engaging the right people within the organisation.

Step 1: Read the Information Standard Notice (ISN)

This is the official notification of the Information Standard, published by the Data Coordination Board (DCB). 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.

This is available to download from 13/12/2018, and will provide an implementation period of 12 months

Step 2: Read the Healthy Child Standard (Healthy Child Record and Event Specification)

This provides a more detailed description of the Information Standard and will be published at the same time as the ISN.

These provide the detailed information and explanation about the data items in the data set, definitions, formats and values which can be recorded.

Step 3: Identify and discuss with stakeholders

It is essential to engage with those who are involved in recording, collecting and using the data in/or for the organisation.

Step 4: Plan implementation

Step 5: Check current state of readiness

IT Systems (Software)

- Many of the elements in the Healthy Child Standard may already be recorded electronically
- Check what changes are required to meet the new elements

Processes:

- Are there any changes to process required?
- Additional training needs

Step 6: Talk with current IT Systems Supplier

If a commercial system is in use, speak with the supplier to confirm the timescale for any necessary changes to the system. In most cases these changes will be part of your Service Level Agreement (SLA).

Similarly, healthcare organisations must talk with their software suppliers to agree dates for roll-out of their systems and local updates

4. Implementation Plan

Compliance with the standard must be achieved no later than 01/12/2019. This is the agreed implementation date. Compliance is a criterion for the supplier receiving DCB3009 Phase 2 – *Interoperability and Portability* standard.

If support in implementing the standard is required, please email dch@nhs.net. PRSB can offer support for putting standards into practice and can be contacted at info@theprsb.org

5. Overview

The Healthy Child Record standard supports the Healthy Child Programme (Healthy Child Programme 0-5 and 5-19 years) the universal preventative service, providing families with a programme of screening, immunisation, health and development reviews, supplemented by advice around health, wellbeing and parenting. This programme is offered to all families with a child in England and they are supported in understanding and documenting the care received by a booklet they are given known as the Personal Child Health Record (PCHR), sometimes known as the ‘red book’. Currently, the scope of the PCHR is greater than the Healthy Child Programme as it is a record for the parents/carers of everything that has happened to the child, including hospital visits and any allergies or reactions.

The Healthy Child Record standard covers the scope of the Healthy Child Programme and the way in which this programme is recorded in the PCHR. It includes any child seen within a community setting as part of the Healthy Child Programme. It is the set of information that is currently exchanged between professionals and parents to support care of a child.

This standard is being issued so that providers of Healthy Child Programme services including screening services, health visiting services, primary care services, school health services, child health organisations (CHOs) and all other providers offering part of the Healthy Child Programme must ensure that the systems they use are conformant to the PRSB standards and will therefore be able to transition to an interoperable model of care, that is, move towards a standardised electronic exchange of information.

It is important to understand the terminology that is used within the standard. This document frequently refers to a number of terms which are defined as below:

Term	Description
Record	A care record for a child that contains a list of sections such as diagnoses, medications and allergies.
Section	This is a label for a high-level **heading** within the record. For example, ‘medication and medical devices’ and ‘diagnoses’ are **sections**.
Entry	A single record **entry** within a section. For example, a medication item is an **entry** within the ‘medications and medical devices’ **section** or a diagnosis is an **entry** within the ‘diagnoses’ **section**. A **section** can have multiple entries.
Element	This is a label for sub-heading in relation to a specific record **section (heading)**. For example, a diagnosis **section (heading)** may be composed of the following **elements**: ‘diagnosis/symptom’, ‘stage of disease’, ‘comment’. Could be referred to as a ‘data item’.
Event	The definition of an Event as part of this document is based on Healthy Children; Transforming Child Health Information and is based on the sharing of information. An event is classed as a small set of data that is produced and shared post an intervention. One intervention could produce 1..* Events. 1..* indicates a cardinality of ‘1 to many’ . This means that at least 1 event *must* be created, but there is no maximum amount.

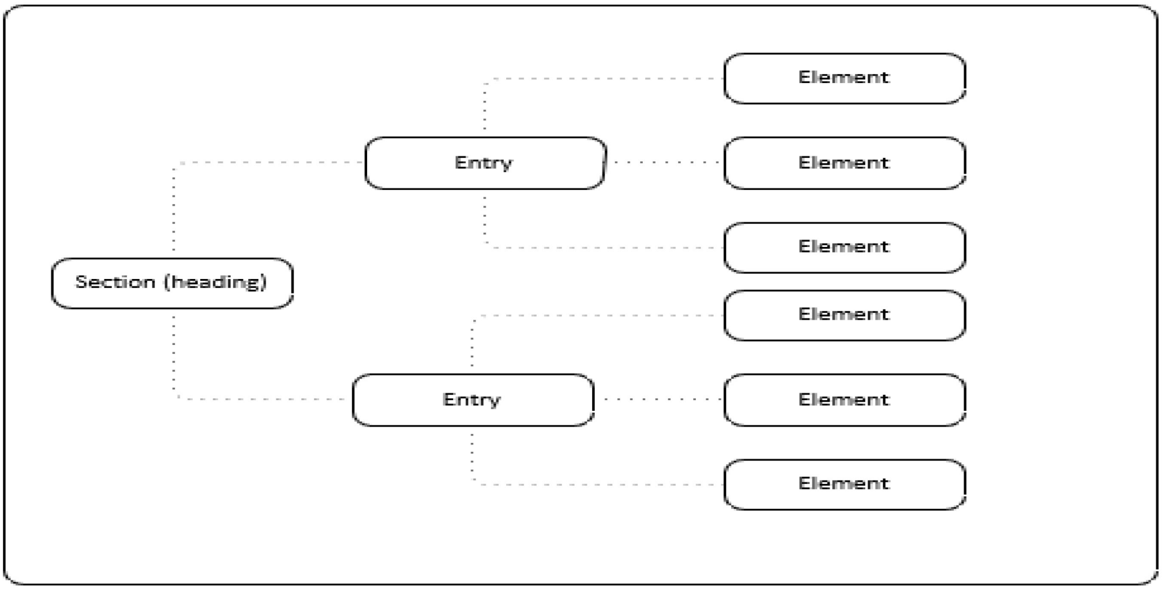


Figure 1: Record Specification Model

6. Healthy Child Record Standard Content

The content of the Healthy Child Record is aligned with the Professional Record Standards Body (PRSB)/Academy of Medical Royal Colleges (AoMRC) Record Standards where possible. Where PRSB/AoMRC sections (headings) did not exist, new sections (heading) were created to fulfil the Healthy Child Record requirements. To provide the context for this implementation guidance, the set of sections (headings) included in the Healthy Child Record is provided in the diagram below.

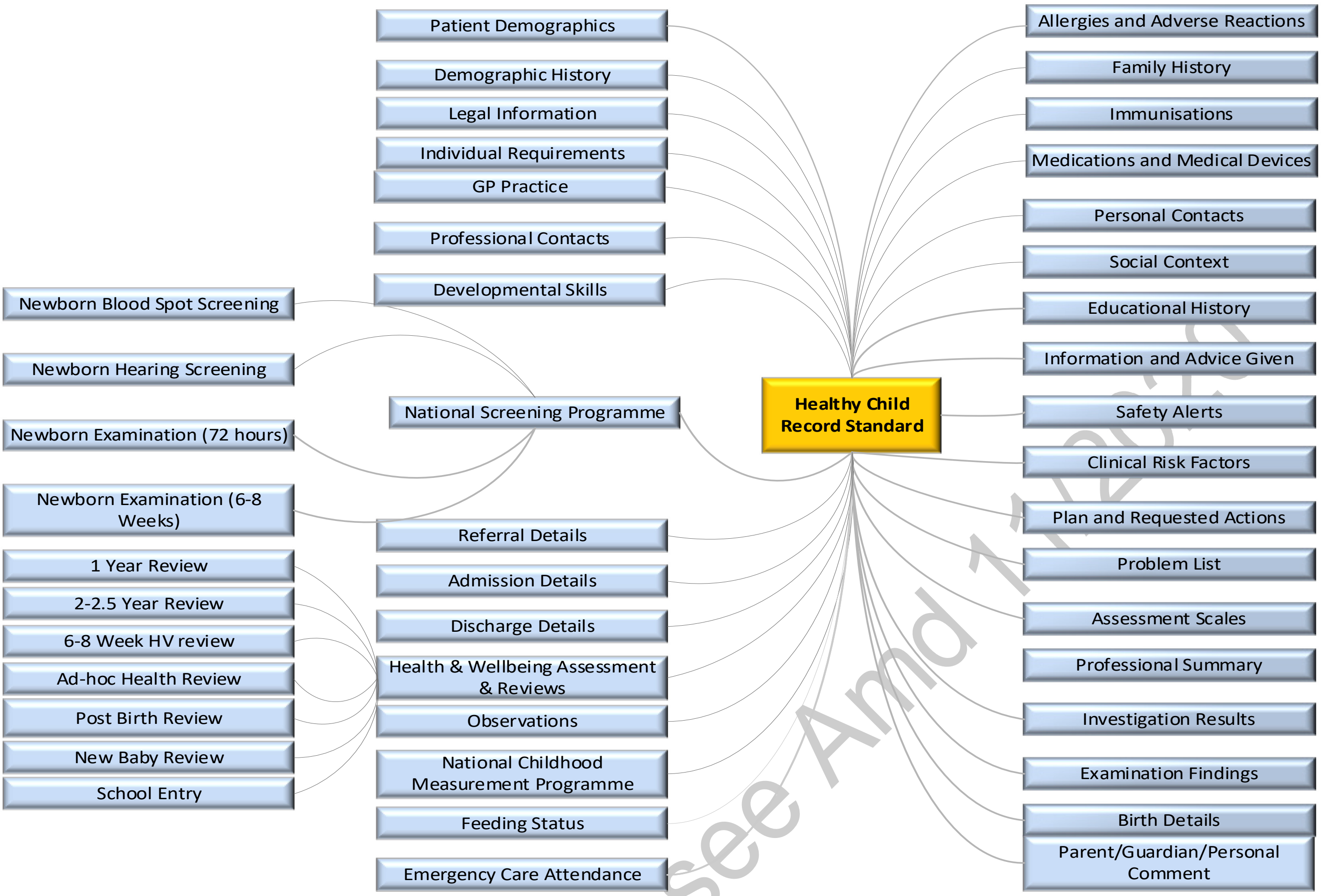


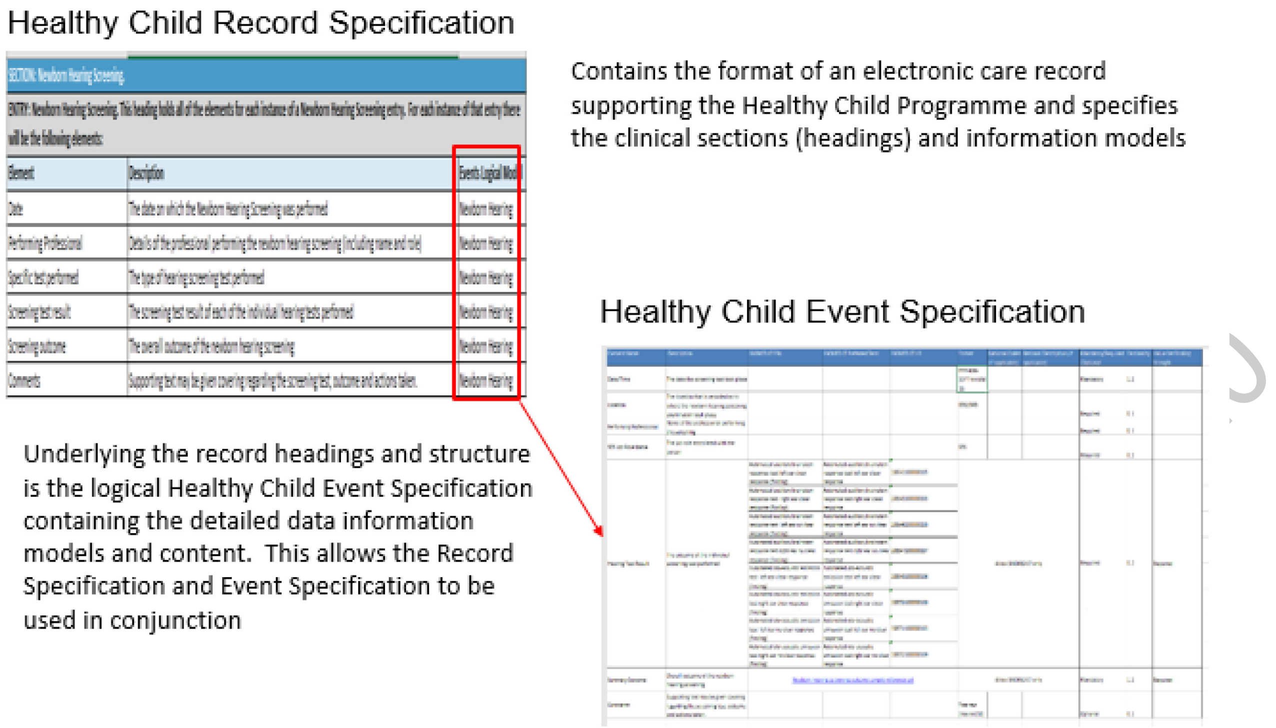
Figure 2: Healthy Child Record Specification sections (headings)

The standard to be implemented is provided in two documents;

- **Healthy Child Record Specification** – this specifies 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. The record specification in this standard is to support the collecting and recording of information within in source system.

- **Healthy Child Event Specification** – this provides the information models setting out the detailed content, format, structure and rules needed for a system supplier to implement the standard.

To begin implementation, it is important to understand how the Event Specification links into the Record Specification. The diagram below is to aid understanding



Healthy Child Record Specification

SECTION: Newborn Hearing Screening.

ENTRY: Newborn Hearing Screening. This heading holds all of the elements for each instance of a Newborn Hearing Screening entry. For each instance of that entry there will be the following elements:

Element	Description	Events Logical Model
Date	The date on which the Newborn Hearing Screening was performed	Newborn Hearing
Performing Professional	Details of the professional performing the newborn hearing screening (including name and role)	Newborn Hearing
Specific test performed	The type of hearing screening test performed	Newborn Hearing
Screening test result	The screening test result of each of the individual hearing tests performed	Newborn Hearing
Screening outcome	The overall outcome of the newborn hearing screening	Newborn Hearing
Comments	Supporting text may be given covering regarding the screening test, outcome and actions taken.	Newborn Hearing

Contains the format of an electronic care record supporting the Healthy Child Programme and specifies the clinical sections (headings) and information models

Underlying the record headings and structure is the logical Healthy Child Event Specification containing the detailed data information models and content. This allows the Record Specification and Event Specification to be used in conjunction

Healthy Child Event Specification

Figure 3: Link between Record and Event Specification

For example, the Newborn Hearing section (heading) has 6 elements that make up each entry. The 6 elements (e.g screening outcome) highlighted in the red box are shown in more detail in the Healthy Child Event Specification within the Newborn Hearing *event*.

The Healthy Child Record Specification and the Healthy Child Event Specification are found on the NHS Digital website and are available in Microsoft Excel.

7. Healthy Child Event Specification Content

This section of the document is designed to be read alongside the Healthy Child Event Specification spreadsheet and gives more context to the information that is contained within it to support implementing the standard.

The spreadsheet contains 37 clinical events. For simplicity, in this standard these can be thought of as information models.

Element Name and Description

Columns A and B give the name of the element and a detailed definition of what should be recorded against each.

SNOMED CT

NHS Digital are using SNOMED CT coding where appropriate in the Healthy Child Record. Where this is not possible or practical, national coding from the NHS Data Model and

Dictionary has been used. The recording supplier system must be compliant with the SNOMED CT codes set out within the Healthy Child Event Specification. Compliancy is based on the scope of the standard SNOMED CT SCCI0034.

Further information on SNOMED CT, including mapping can be found in the SNOMED CT Editorial Guide.

To aid understanding of how it is used within the Healthy Child Event Specification some examples are illustrated in Annex A.

Format

If national codes have been defined, then the format will match that of the NHS Data Model and Dictionary and this will be shown in column F. The field describes the valid formats that must be accepted in this field. For dates and times, it specifically refers to the exact formatting. For other fields it describes the data type required and the max/min field lengths.

If SNOMED CT is expected to be entered, then this column will state that only SNOMED CT is allowed.

Where ODS has been referenced within the specification further guidance is shown below:

Organisation Identifier (code of provider)

Organisation Site Identifier (of Treatment)

Organisation Identifier (Educational Establishment)

Organisation Identifier (Reporting Laboratory)

National Codes

If no SNOMED CT has been identified, then certain elements provide a list of the valid codes that can be accepted in this field (if there are any). For example, a field may only allow values of "Y", "N" and "X", which equate to "Yes", "No", "Don't Know".

The National Code definition describes the meaning of the code in the previous "National Code" column.

For ease, the detailed information models will contain a hyperlink to the Data Dictionary in columns G and H.

Mandatory/Required/Optional

This section defines what is meant by ‘Mandatory’, ‘Required’ and ‘Optional’ in a Healthy Child Record standard, as detailed in the Healthy Child Event Specification.

The Healthy Child Record Specification does not include mandatory, required and optional information at the individual record section (heading) level. Systems adopting the standard need to be capable of being able to record all elements under each of the overall record sections (headings).

The Mandatory, Required and Optional are designed to support the sharing of information between systems, as and when national or local infrastructure becomes available. However it is essential when implementing this standard that any mandatory items could have validation on at the point of data entry to prevent a user from not completing a mandatory field.

- **Mandatory** = The information must be recorded, or a reason why missing, for future sharing of information
- **Required** = Where the information is recorded, it must be available in the future to be shared
- **Optional** = Where the information is recorded, a local provider can take a decision as to whether, in the future, to share it.

If an element is marked as optional a healthcare professional must still have the option of recording it, but when this information is available to be shared via national or local infrastructure a local provider can elect to share it.

For elements within the Healthy Child Event Specification, the Mandatory, Required, Optional status is only relevant if that section (heading) is being recorded. For example, in Allergies and Reactions, Causative Agent is shown as mandatory, but is only mandatory if an allergy or reaction is being recorded or updated.

Cardinality

All elements defined in the Healthy Child Event Specification have cardinality as defined by UML as part of their definition – a minimum number of required appearances and a maximum number. These numbers specify the number of times the attribute may appear against the individual element being recorded. This specification only defines the following cardinalities 0..1, 0..*, 1..1 and 1..*

In the example of Birth Details, Type of Delivery is set to 1..1. This means that only 1 type of delivery as a minimum, and as a maximum should be recorded by a healthcare professional, whereas Attempted Type of Delivery is 0..*. This implies that there could have been zero attempted deliveries (i.e. the first type of delivery attempted was the final type of delivery), but the * (many) allows a healthcare professional to record as many attempted deliveries as they believe are necessary.

Value Set Binding Strength

The Value Set Binding Strength column is populated when the Event Specification gives a specific set of values that can be attributed to that element either in the SNOMED CT I.D or National Codes. The purpose is to ensure that in the future when information is shared via FHIR that the supplier is already conformant with the standard.

The definitions are in the Instructions tab of the Event Specification, but here are three examples to aid understanding

This information is being provided now, in advance of DCB3009 Phase 2 – *Interoperability and Portability* standard to prevent any potential re-work.

Extensible example

In the Birth Details, the element ‘Physical Problems detected at Birth’ has a Value Set Binding Strength of ***extensible***. As part of the consultation and the subsequent surveys a list of options were collated, and SNOMED CT I.D assigned. The codes in the User

Guidance document on the PRSB website are for guidance for a supplier and are listed as 'starter for 10'. It was acknowledged that it would not be possible to list all potential SNOMED CT codes that a healthcare professional may want to attribute to the element. Therefore, the specification allows this field to be extensible, so a healthcare professional could use the 'starter for 10' list or enter any SNOMED CT from the Findings or Disorder hierarchy.

Required example

In the Birth Details event, the element 'Delivery Place Type Code' has a Value Set Binding Strength of required. To aid implementation and prepare for interoperability, users must only be offered the codes specified under *National Codes/National Descriptions.*

This will ensure that when information is being shared, all supplier systems are using a standardised set of codes and descriptions that in turn are aligned to the Maternity Services Data Set v2.0 to ensure there is no extra burden on providers to record the same element in different formats.

Preferred Example

Healthcare professionals should be encouraged to draw from the specified codes but are not required to do so.

8. Free Text Fields

Free text will be available where there is a clear clinical requirement. Free text field size will be appropriate to support the clinical requirement. All free text documentation should be completed in concordance with all professional record keeping standards, being clear and accurate, which are relevant. As part of *Phase 2 - Interoperability and Portability* free text fields will be contextually bound via the specific FHIR profile, or via an encounter type, and incorporated within a FHIR Bundle or composition.

9. Provider Guidance

This section explains, as a minimum, what sections (headings) each provider of all or part of the Healthy Child Programme must implement.

The standards will both allow the recording of information in a standardised format if deemed applicable and in future, act as a placeholder to receive information into as part of DCB3009 Phase 2 – *Interoperability and Portability.*

Where an X is marked in the table in Annex B: Provider Guidance on Sections (Headings) for a service, the system MUST implement this heading. This serves two purposes and a system supplier MUST allow a user to input information into each element if required. There will be situations where a heading is a MUST to implement for a service, but the expectation is that as per DCB3009 Phase 2 this heading (section) acts as a placeholder to store this information once it is shared.

For example, Primary Care, Heath Visiting and School Nursing Supplier Systems are expected to have this heading present within their systems. It will allow for either:

- Recording of the information by a healthcare professional

- In future, ‘ingest’ information into the record from a third party via National or Local Infrastructure

As part of this standard, a system supplier MUST cater for both.

This is defined in Annex B and covers the following services

- Child Health Record Departments
- School Nursing services
- Health Visiting services
- Immunisation only providers
- All Principal Clinical Service Suppliers (Primary Care Services)
- Screening providers

10. Future Changes

Release Cycles

In alignment with the PRSB, the Healthy Child Standard, including the Healthy Child Record Specification and Healthy Child Event Specification, will be updated as necessary.

This could be based on clinical safety feedback, INTEROPen feedback or supplier implementation findings for example.

Future Standard

As referenced in section 2, NHS Digital is currently building national central infrastructure to support the sharing of information. Further implementation guidance describing how the data will be exchanged will be available in a future standard - DCB3009 *Phase 2 – Interoperability and Portability.*

A supplier and/or provider must be conformant to DCB3009 Phase 1 to be able to work with the national central infrastructure.

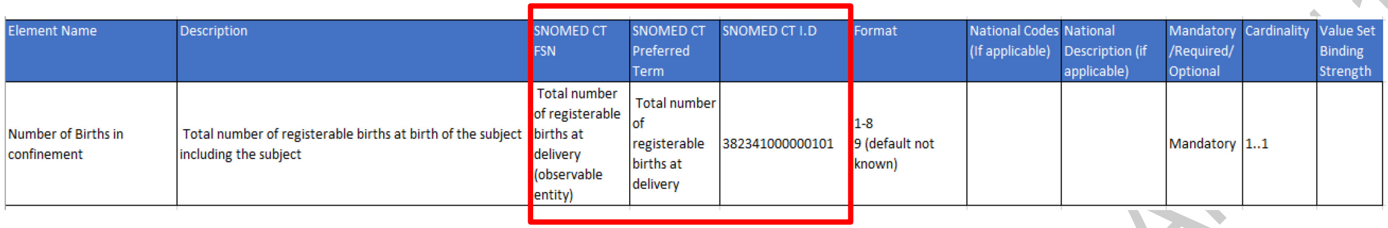
Within this standard there will be data that will be exchanged as ‘events’.

- The definition of an Event is based on Healthy Children; Transforming Child Health Information and is based on the sharing of information. An event is classed as a small set of data that is produced and shared post an intervention. One intervention could produce 1..* Events.

11. Annexes

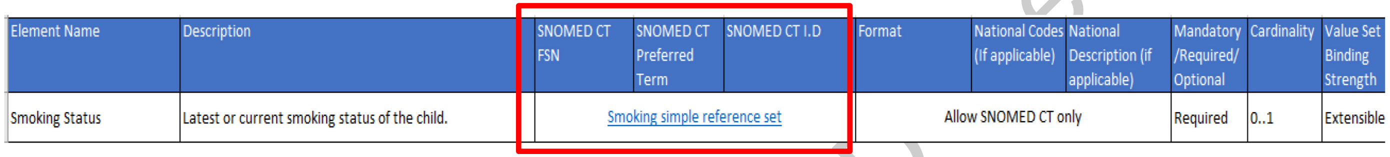
Annex A: SNOMED examples

Within Birth Details, the element ‘Number of Births in Confinement’ is measured using numerical values between 1-9, but the Observable entity highlighted below must be used to represent what the numerical value relates to.



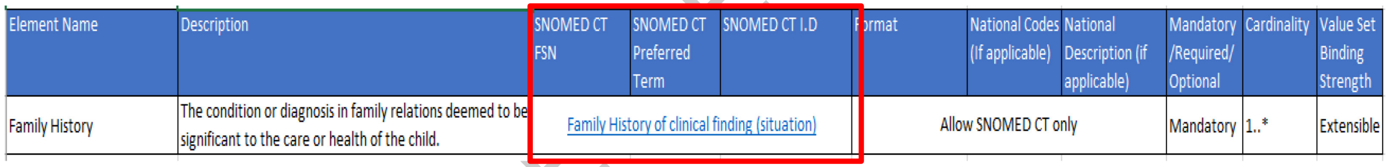
Element Name	Description	SNOMED CT FSN	SNOMED CT Preferred Term	SNOMED CT I.D	Format	National Codes (If applicable)	National Description (if applicable)	Mandatory /Required/ Optional	Cardinality	Value Set Binding Strength
Number of Births in confinement	Total number of registerable births at birth of the subject including the subject	Total number of registerable births at delivery (observable entity)	Total number of registerable births at delivery	382341000000101	1-8 9 (default not known)			Mandatory	1..1	

Where a suitable assured and maintained reference set (commonly known as a refset) has been identified this will be referenced as a hyperlink in columns C -E.



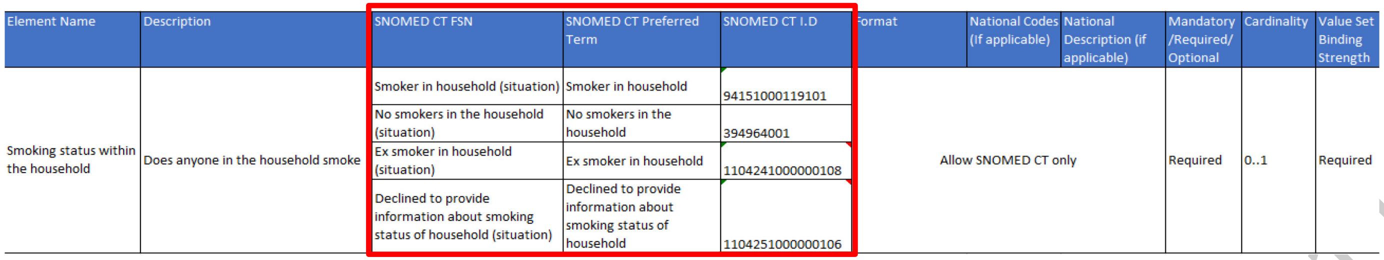
Element Name	Description	SNOMED CT FSN	SNOMED CT Preferred Term	SNOMED CT I.D	Format	National Codes (If applicable)	National Description (if applicable)	Mandatory /Required/ Optional	Cardinality	Value Set Binding Strength
Smoking Status	Latest or current smoking status of the child.	Smoking simple reference set			Allow SNOMED CT only			Required	0..1	Extensible

If it has been agreed that the element is within scope of SNOMED CT, but there has not been a suitable refset identified, then the information models will specify a hierarchy that is relevant but will not constraint the SNOMED CT just to this hierarchy, to ensure that other unusual concepts can also be used.



Element Name	Description	SNOMED CT FSN	SNOMED CT Preferred Term	SNOMED CT I.D	Format	National Codes (If applicable)	National Description (if applicable)	Mandatory /Required/ Optional	Cardinality	Value Set Binding Strength
Family History	The condition or diagnosis in family relations deemed to be significant to the care or health of the child.	Family History of clinical finding (situation)			Allow SNOMED CT only			Mandatory	1..*	Extensible

If applicable singular SNOMED CT terms are being refenced, column C will contain the SNOMED CT FSN (fully specified name) and column D has the SNOMED CT Preferred Term.



Element Name	Description	SNOMED CT FSN	SNOMED CT Preferred Term	SNOMED CT I.D	ormat	National Codes (If applicable)	National Description (if applicable)	Mandatory /Required/ Optional	Cardinality	Value Set Binding Strength
Smoking status within the household	Does anyone in the household smoke	Smoker in household (situation)	Smoker in household	94151000119101	Allow SNOMED CT only			Required	0..1	Required
		No smokers in the household (situation)	No smokers in the household	394964001						
		Ex smoker in household (situation)	Ex smoker in household	1104241000000108						
		Declined to provide information about smoking status of household (situation)	Declined to provide information about smoking status of household	1104251000000106						

Annex B: Provider Guidance on Sections (Headings)

	Service					
Healthy Child Record Section	**Primary Care**	**Health Visiting Provider**	**School Nursing Provider**	**Screening Provider**	**Child Health Information Service**	**Immunisation only Provider**
Patient Demographics	x	X	X	x	x	x
Demographic History	x	X	X	x	x	x
GP Practice	x	X	X	x	x	x
Individual Requirements	x	X	X	x		x
Birth Details	x	X	X	x	x	
National Screening Programme	x	X	X	x	x	
Newborn Blood Spot Screening	x	X	X	x	x	
Newborn Hearing Screening	x	X	X	x	x	
Newborn and Infant Physical Examination (72 hours)	x	X	X	x	x	
Newborn and Infant Physical Examination (6-8 Weeks)	x	X	X		x	
Referral Details	x	X	X			
Admission Details	x	X	X		x	
Discharge Details	x	X	X		x	
Observations	x	X	X			
National Childhood Measurement Programme			X			
Feeding Status	x	X	X		x	
Allergies and Adverse Reactions	x	X	X			x
Family History	x	X	X			
Vaccinations	x	X	X		x	x
Medications & Medical Devices	x	X	X			x
Emergency Care Attendance	x	X	X		x	
Personal Contacts	x	X	X	x		x
Professional Contacts	x	X	X	x		x
Social Context	x	X	X			
Educational History		X	X		x	
Information and Advice Given	x	X	X			
Safety Alerts	x	X	X	x		x
Legal Information	x	x	X	x		x
Clinical Risk Factors	x	X	X			x

	Service					
Healthy Child Record Section	**Primary Care**	**Health Visiting Provider**	**School Nursing Provider**	**Screening Provider**	**Child Health Information Service**	**Immunisation only Provider**
Plan and Requested Actions	x	X	X			
Parent/Guardian Comment		X	X			
Professional Summary	x	X	X			
Assessment Scales		X	X			
Examination Findings	x	X	X			
Developmental Skills		X	X			
Health & Wellbeing Assessment & Reviews		X	X			
Post Birth Review		X	X			
New Baby Review		X	X			
6-8 Week HV Review		X	X			
1 Year Review		X	X			
2-2.5 Year Review		X	X			
School Entry Review		X	X			
Ad Hoc Health Review		X	X			
Investigation Results	x	X	X			
Problem List	x	X	X	x		x

Figure 4: Headings (sections) to be implemented by provider