Professional Record Standards Body

Better records for better care

RECORD STANDARDS FOR THE HEALTHY CHILD PROGRAMME:

FINAL REPORT

OCTOBER 2017

Document Management

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Name	Signature	Date
Project Board	Signed off	26.10.17
PRSB Assurance Committee	Signed off	24.10.17

Planned Review Date and Route for User Feedback

The next maintenance review of this document is planned for November 2020, subject to agreement with NHS Digital as the commissioning body.

Please direct any comments or enquiries related to the project report and implementation of the standard to support@theprsb.org.

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1. Introduction and Background

1.1 Purpose

The objective of the project was to develop an initial standard for sharing information on events taking place as part of the Department of Health's 'Healthy Child Programme'. The Professional Record Standards Body (PRSB) was commissioned by NHS Digital to consult with parents, healthcare professionals, suppliers and public health professionals to ensure that the standard meets their needs. Clinical leadership was provided by the Royal College of Paediatrics and Child Health (RCPCH), the Royal College of General Practitioners (RCGP), and NHS Digital subject matter experts. The work has been conducted in partnership with the Royal College of Physicians (RCP) Health Informatics Unit (HIU). The PRSB work was undertaken in three 'work packages', comprising:

1. Events around the birth, up to and including initial six to eight week GP screening check.
2. Routine health visitor, school nurse and primary care events (including immunisations).
3. Developmental checks, developmental firsts and personal information.

Through the consultation the project has developed recommendations for the structure and content of a child health record and information sharing requirements related to events taking place as part of the 'Healthy Child Programme'. The aim of the project has been to enable all types of users to record information that is important to them in a standardised way. The aim is also to enable parents/carers and children to view and record information in the Electronic Personal Child Health Record (ePCHR). The structure is intended to be flexible to accommodate multiple uses and changes in practice. Whilst the focus has been the Healthy Child Programme, the information models developed may support recording for other purposes within a child health record. NHS Digital are producing information models based on the recommendations made by the PRSB and are producing technical specifications which can be implemented on NHS IT systems. It is anticipated that NHS IT system suppliers will develop solutions for implementation in the NHS based on the following NHS Digital deliverables:

- **Healthy Child Record Specification (a separate document. See** https://theprsb.org/standards/healthychildrecord)
  This contains the format of an electronic care record supporting the Healthy Child Programme and specifies the clinical headings and information model which provide the standardised structure for that record.
- **Healthy Child Events Specification (a separate document. See** https://theprsb.org/standards/healthychildrecord)
  This provides the information models setting out the detailed content for the events, including values and business rules used to support the creation of the FHIR Events Catalogue. The events will be used to populate the healthy child record and so the information models also provide the standardised values and business rules needed for the care record.
- **Healthy Child Fast Healthcare Interoperability Resources (FHIR) Events Catalogue (a separate document)** – this provides the technical specification to allow the events to be exchanged as an electronic message.

In addition to these deliverables NHS Digital are developing an implementation guide to support implementers and suppliers with implementation of the Healthy Child Record standard.

This document is the PRSB final project report, describing the methods used, outputs from the consultation, the recommended record structure and associated recommendations to NHS Digital.

1.2. Children's Health Digital Strategy

Children's services are currently provided by a number of different professions and organisations using different IT systems, which are not currently interoperable. Some parents and carers have access to an ePCHR, but this is not interoperable with NHS IT systems.

NHS England has produced Healthy Children: Transforming Child Health Information, which aims to implement interoperability between NHS IT systems to enable more integrated services, which better support children and their families. Two key objectives are:

a) knowing where every child is and how healthy they are, and
b) appropriate access to information for all involved in the care of children, including parents and carers through ePCHR.

The strategy includes plans to provide online access to parents, carers and young people to enable them to contribute their goals, manage information sharing and view information in the ePCHR format. Health and care professionals will be able to have a complete record of the child's interventions and associated data within their current IT systems and up to date population data will be available for public health analysis. Key to achieving these strategic aims is the electronic sharing of child health data.

1.3. Healthy Child Record Specification and Healthy Child Events Specification

The Healthy Child Record standard supports the Healthy Child Programme: 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'.

The Healthy Child Record standard covers, at a summary level, the scope of the Healthy Child Programme and the PCHR. It is the set of information that it is currently exchanged between professionals and parents to support direct care of a child.

The standard is provided in two documents:

• **Healthy Child Record Specification (a separate document)** – this contains the format of an electronic care record supporting the Healthy Child Programme and specifies the clinical headings and information model which provide the standardised structure for that record.

• **Healthy Child Events Specification (a separate document)** – this provides the data models and detailed content for the care record.

NHS Digital are building a National Events Management Solution (NEMS) to provide a 'subscribe and publish' service which will enable information on the Healthy Child Programme (e.g. screening reviews, immunisations etc) to be published and consumed by those involved in the care of the child and their parents. Technical Specifications for these events will be documented in the Healthy Child FHIR Events Catalogue and published on GitHub. This catalogue will reflect the Healthy Child Record Specification and Healthy Child Events Specification, and will be updated during the Alpha and Beta development period.

1.4. PRSB Consultation

NHS Digital commissioned the PRSB to help with the implementation of Healthy Children: Transforming Child Health Information. The PRSB has done this by helping with the definition of requirements for the Healthy Child Record Specification and the Healthy Child Events Specification, to enable information about health and care events in a child's life to be shared, as appropriate, with health and social care professionals and with parents/carers through an ePCHR. The scope of this collaborative project between the PRSB and NHS Digital included:

- Reviewing data collection to ensure that the information model underpinning the Healthy Child Record Specification and the Healthy Child Events Specification was fit for purpose and compatible with the PRSB headings.
- Setting up a process for citizen and multi-professional health and care consultation/engagement in the child health events catalogue.
- Collaborating on requirements definition for an initial set of event types (supporting the healthy child programme).
- Collaborating on the establishment of a requirements development process that can be used on an on-going basis.
- The programme could be extended to older children with ongoing developmental problems.

2. Methodology

This section describes the approach taken to consult with parents and health and care professionals on the child health events.

2.1. First Draft Information Models

The NHS Digital Business Analyst team developed draft information and process models drawing upon existing data sets. The PRSB project team reviewed the documents and provided feedback on the items at meetings with NHS Digital. This informed a set of draft headings and questions to consult on at the multi-professional workshops.

2.2. Consultation Workshops

Three consultation workshops were held for the respective work packages:

- Birth details/screening workshop: 05 April 2017
- Routine health visitor, school nurse and primary care workshop: 05 June 2017
- Developmental checks and personal information workshop: 03 July 2017

These meetings were attended by parents, healthcare professionals, suppliers, public health professionals and other stakeholders (attendees are listed in Appendix A).

2.3. Online Survey Consultations

Following the consultation workshops, the outputs were discussed at meetings involving the NHS Digital and PRSB project teams. These meetings identified a number of issues to be explored further.

The PRSB project team designed two online surveys, to obtain the views of healthcare professionals, parents and suppliers (see Appendix A for a breakdown of the respondents):

1. The first survey focused on work package 1 and ran from 11 April – 22 May 2017. In total 947 individuals responded to the survey.
2. The second survey focused on work packages 2 and 3 and ran from 24 July – 24 August 2017. In total 1202 individuals responded to the survey.

Quantitative and qualitative analysis of the survey results was conducted and reviewed with the project clinical leads (a summary of the online survey results and analysis are provided in Appendix B). The analysis was used in conjunction with the workshop outputs to inform the recommendations provided in section three.

2.4. Expert Reference Group

An expert reference group meeting was held on 05 October 2017 to inform decisions on several outstanding issues identified in the earlier stages of the consultation (attendees are listed in Appendix A). A summary of the outputs from the meeting are detailed in Appendix C.

3. Recommendations

This section provides the PRSB recommendations to NHS Digital following the consultation with parents and health and care professionals.

3.1. General Recommendations

1. The Healthy Child Record standard covers, at a summary level, the scope of the Healthy Child Programme and the PCHR. There are other areas that are delivered in community child health which are not covered by this scope and have thus not been fully considered in this project. It is strongly recommended that additional work is carried out to cover these aspects in order to create a complete community child health record standard.

2. Where information models have already been developed by the PRSB for record structures or communications, these should be used for the child health events, to provide industry with consistent requirements. Similarly, where SNOMED CT subsets have been developed (e.g. RCPCH diagnosis subset) these should be used.

3. There are a number of previously developed PRSB standards,which will enable information to be shared between professionals and with parents. (See www.theprsb.org/standards)These include the standards for the structure and content of acute medical records and subsequent PRSB projects (e.g. the emergency care discharge summary, hospital discharge summary, outpatient letter standard etc.). Rather than replicating the information models developed for these projects in the current document, the project team recommends that these standards are used for these specific use cases, but are reviewed to incorporate relevant standards (both new and amended) from the Healthy Child Record and Events Specifications. The RCPCH has made a strong recommendation that these information standards are amalgamated with the standards for the structure and content of acute medical records to create a unified standard for child health records.

4. The consultation recommended lists of common terms to use to record specific conditions (e.g. maternal problems during pregnancy). These terms will be implemented on NHS IT systems using SNOMED CT. The purpose of the lists of terms is to aid quick, consistent and accurate data entry for common conditions. These lists are not comprehensive and it is recommended that if the condition is not represented by one of these terms, NHS IT systems provide a SNOMED CT browser so that clinicians can identify an appropriate term. Common lists of terms have to be subject to change over time and so it is important that they are not hard wired into systems. The UK Terminology Centre (UKTC) should explore ways in which term lists can be created, maintained and disseminated around the NHS, so that changes to these lists can be made on a national basis without individual systems requiring reconfiguration.

5. Some information from the maternity record forms an essential part of the child health record. This information has been identified by this project, but it is recognised that the primary source of much of this information will be from maternity systems, for which standards are about to be developed. It is recommended that the information models which relate directly to maternity practice are considered in the related maternity project, as the standards have to be consistent from pregnancy through to child birth and the neonatal period. It is also recommended that the following issues identified as being out of scope for the project should be considered as part of the NHS Digital maternity project:
    - Maternal drugs in pregnancy (which may affect the baby)
    - Concealed pregnancies
    - Other birth related procedures and issues (water births, induction, delayed cord clamping, still births).

6. Each documentation entry must have the date and time recorded and the identity of the person creating the documentation. This information should be recorded in an electronic record automatically, by date and time stamping each entry and associating it with the personal identification of the individual recording it. There should also be the ability to record the actual person who undertook the intervention, where required.

7. The recommendations included in this report relate to the headings and descriptions consulted on by the project team. It does not provide a fully detailed information model; this has been done by NHS Digital, based upon the recommendations. These

information models contain additional data items (such as data required for administrative purposes and secondary uses).

3.2. Newly Developed Record Headings

This section contains headings which have been newly developed for this project.

3.2.1. Birth Details

Following the consultation the project team recommend that the following headings and definitions are used to record details about the birth.

Birth details (these will be obtained from maternity records)	
Maternal problems in pregnancy	Maternal medical conditions or infectious diseases arising in pregnancy which may have an impact on the foetus, e.g. gestational diabetes, rubella etc.
Foetal problems diagnosed before birth	Problems with the foetus diagnosed with screening or ultrasound e.g. Down syndrome, congenital heart disease etc.
Length of gestation	Gestational age in weeks and days (usually equivalent to length of pregnancy).
Type of delivery	Type of delivery for the baby, e.g. vacuum extraction, breech extraction, elective caesarean section etc.
Type(s) of delivery (attempted)	The type(s) of delivery for the baby that was attempted, but was not the final delivery method.
Problems during delivery	Problems experienced by the baby during delivery e.g. cord prolapse, meconium aspiration, foetal distress etc.
Birth order	The sequence in which this baby was born (one of one, one of two etc).
Multiple birth	Where the baby is one of a multiple birth, to include the total number of offspring and to include whether the baby is identical to one of the siblings.
Birth weight	Numeric value for weight at birth.
Location of birth	The place of birth (including the address and organisation name where relevant).
Delivery place type	The type of place in which the baby was born (e.g. private health facility, domestic address, NHS hospital, midwifery led unit etc.)
Neonatal resuscitation	Details of neonatal resuscitation measures required, e.g. chest compression, oxygen mask etc.
Spontaneous respiration	The length of time between delivery of the baby and the time spontaneous respiration began.
Put to breast	Whether or not the baby was put to the breast.

APGAR score	A set of observations made on the baby following birth to check adaptation to life outside the womb.
Physical problems detected at birth	Physical problems identified with the baby at, or shortly after, birth. E.g. cleft lip/palate, extensive bruising, cephalohaematoma etc.

3.2.1.1. Babies Admitted to Neonatal Intensive Care Units

The project team recommends that NHS Digital considers additional work on an event related to baby admissions to Neonatal Intensive Care Units (NICU). Existing PRSB headings for admission and discharge could be used for this purpose.

3.2.1.2. Place, Date and Time of Birth

Some survey respondents felt that place of birth, date/time of birth should be included in the birth details section. The project team recommendation is that these items should form part of the person demographics but can be carried as part of the birth details.

3.2.1.3. Type of Delivery

Following the consultation, the project team recommends that the following values are used for type of delivery (these are aligned with the "delivery method" national codes from the Maternity Services Dataset):

- Spontaneous vertex
- Spontaneous other cephalic
- Low forceps, not breech
- Other forceps, not breech
- Ventouse, vacuum extraction
- Breech
- Breech extraction
- Elective caesarean section
- Emergency caesarean section

In line with the expert reference group consensus, the project team recommends that a heading is created for 'attempted deliveries' to capture methods attempted which did not result in the birth of the child.

3.2.1.4. Multiple Births

Following the consultation, the project team recommends that implementation guidance should explain how testing would determine whether siblings are identical or not in the case of multiple births. In most cases identical siblings will be identified before birth by ultrasound scan.

3.2.1.5. Maternal Problems in Pregnancy

Following the consultation, the project team recommends that the following values are used for maternal problems in pregnancy which may have an impact on the foetus (these are based upon the "maternity medical diagnosis type" national codes from the Maternity Services Dataset, but have been amended in line with the PRSB consultation):

- Gestational diabetes
- Diabetes

- Systemic lupus erythematosus (SLE)
- Mother taking opioids
- Thyrotoxicosis
- Hypothyroidism
- Anti - D positive
- Immune thrombocytopenia
- Vitamin D deficiency/osteoporosis
- Myotonic dystrophy
- Achondroplasia
- Rubella
- Cytomegalovirus (CMV)
- Chicken Pox
- Hepatitis B antigen/antibody
- Hepatitis C
- Toxoplasmosis
- Group B streptococcus colonisation
- HIV
- Anticonvulsant therapy
- Alcohol abuse
- Myasthenia gravis

The project team recognises that consent would be needed for this information to appear in the child's record and this needs to be considered as part of the related maternity record project.

3.2.1.6. Problems During Delivery

Following the consultation, the project team recommends that the following values are used for problems during delivery (these are based upon the "baby complication at birth diagnosis" national codes from the Maternity Services Dataset, but have been amended in line with the PRSB consultation):

- Shoulder dystocia
- Cord prolapse
- Foetal distress
- Meconium aspiration
- Acute foetal blood loss

3.2.1.7. APGAR Scores

Due to the high level of consensus the project team recommends that all three APGAR scores are included (1, 5 and 10 minutes) however implementation guidance should specify that the 10 minute score should only be recorded where the score is poor at 1 and 5 minutes.

3.2.1.8. Physical Problems Detected at Birth

Following the consultation the project team recommends that the following values are used for physical problems detected at birth:

- Cephalohaematoma
- Extensive bruising
- Talipes equina varus
- Laceration
- Erb's Palsy

- Cleft lip
- Cleft palate
- Anal atresia
- Fractured clavicle

3.2.2. Measurements

Following the consultation the project team recommend the following headings and definitions are used:

Measurements	
Weight	Numeric value for weight.
Height/ length	Numeric value for the body length.
Head circumference	Numeric value for head circumference.
BMI centile	Child BMI centile calculated using the height/weight/gender and age of the child.

The NHSD information models will contain a separate heading for the National Child Measurement Programme (NCMP) which includes additional information, such as the school where the measurement takes place. However, all measurements taken as part of the NCMP would appear in the above measurements section.

3.2.3. Feeding Status

Following the consultation, the project team recommend that the following headings and definitions are used:

Feeding status	
First milk feed	Whether or not the baby's first feed was breast milk.
Milk feeding status of the baby	Whether the baby is totally breast milk fed, partially breast milk fed, or not breast milk fed. To be recorded each time a baby has contact with a health professional.
Date breast milk feeding stopped	Date of last breast milk feed to the nearest month and year.
Introduction of solids	Whether the baby has been introduced to solid foods at the time seen.
Feeding method	A record of the predominant feeding method for the baby, e.g., breast fed, bottle/cup fed, gastrostomy, nasogastric feeds etc.
Feeding concerns	A record of any concerns about the baby's feeding.

In line with the consultation, the project team recommend that implementation guidance explains that duration of breastfeeding is calculated by asking mothers if they breastfed their child. If so, they should be asked when the last date of breast milk feeding was (to the nearest month and year). Implementation guidance should also make clear that 'feeding method' and 'feeding concerns' should be recorded each time the child is seen.

3.2.4. National Screening Reviews

Following the consultation the project team has recommended the following headings and definitions are used to record national screening reviews:

National screening reviews	
National screening programme	The overarching screening programme. e.g. • Newborn blood spot screening, • newborn hearing screening, • newborn and infant physical examination (72 hours), • newborn and infant physical examination (6-8 weeks).
Specific test performed	The specific screening test performed, e.g. examination of heart, phenylketonuria (PKU) screening, automated otoacoustic emission (AOAE) test etc. This may include site and laterality where applicable e.g. left ear, right eye etc.
Screening test result	The result or outcome of the specific test (this may include the status e.g. declined, deferred etc.).
Screening review outcome	The overall outcome of the screening test (this may include the status e.g. declined, deferred etc.).
Comments	Supporting text may be given regarding the screening test, outcome and actions taken.

Implementation guidance should explain that this generic information model can be used for any type of screening review. System design should allow templates with the appropriate subheadings for the various reviews to be generated by selecting the type of review from a drop-down list. The NHS Digital information models have developed specific models for each screening review, but these align with the generic model.

3.2.5. Parent / Guardian / Personal Comments

Following the consultation, the project team recommend the following headings and definitions are used to record parent / guardian/ personal comments:

Parent / guardian/ personal comments	
Parent / guardian / personal comment	Free text comment made by the parent / guardian of the child, or the child themselves.

3.2.6. Personal Contacts

Following the consultation the project team recommend the following headings and definitions are used to record personal contacts:

Personal contacts	
Name	The name of the person.
NHS number	The NHS number of the personal contact.
Relationship	The personal relationship the individual has to the child (e.g. father, grandmother, family friend etc.).
Parental responsibility	Flag to indicate whether the personal contact has parental responsibility.
Contact details	Contact details of the person (e.g. telephone number, email address etc.).

3.2.7. Professional Contacts

Following the consultation the project team recommend the following headings and definitions are used to record professional contacts:

Professional contacts	
Name / team	The name of the person or the team responsible.
Role	The professional role the individual has in relation to the child (e.g. nursery nurse, health visitor, school nurse etc.).
Speciality	The speciality of the professional responsible (e.g. health visiting, school nursing etc.).
Team	The name of the team, if the name of the person has been entered.
Organisation	The name of the organisation responsible.
Contact details	Contact details of the person (e.g. telephone number, email address etc.).
Start date	The start date of the relationship with the health professional.
End date	The end date of the relationship with the health professional.

3.2.8. Immunisations

Following the consultation the project team recommend the following headings and definitions are used to record immunisations:

Immunisations	
Name of immunisation	Which immunisation has been administered (SNOMED CT code – list of available immunisations)
Vaccine product	Vaccine product administered.
Manufacturer	The vaccine manufacturer.
Batch number	The batch number of the vaccine.
Site	Body site vaccine was administered into.
Route	How vaccine entered the body.
Dose amount	Amount of vaccine administered.
Dose sequence	Nominal position in a series of vaccines.

Outcome status	Whether the vaccine was administered or not, including the reason why.
Reported	A flag to indicate the information was reported to a healthcare professional.
Indication	The clinical indication or reason for administering the immunisation.

3.2.9. Developmental Skills

Following the consultation the project team recommend the following headings and definitions are used for recording developmental skills:

Developmental skills	
Developmental skill	The name of the developmental skill (e.g. walks independently, smiles, finger feeds etc.).
Date first achieved	The date the developmental skill was first achieved (developmental first) as reported by the parent. This is primarily for parent reporting as part of parent child health record at the time the skill is acquired.
Date of enquiry	The date the parent or carer was asked by a health professional about the developmental skill (milestone).
Result of enquiry	Whether the developmental skill was achieved, not achieved or equivocal.
Date of observation	The date a health professional observed or tested a developmental skill (milestone).
Result of observation	Whether the developmental skill was achieved, not achieved or equivocal.
Comments	Supporting text may be given regarding the developmental skill.

Implementation guidance should specify that a partial date can be entered if the parent is unsure of the exact date the developmental skill was achieved.

In the online survey for work package 2/3, respondents were asked whether the developmental skills included in the Personal Child Health Record should be changed. Although some respondents suggested changes, the response rate for this question was small. Our framework allows for other developmental skills to be added or removed as required.

The project team recommends that a list of SNOMED CT developmental skills is defined by the UKTC working with parents and the PRSB. The subset should include developmental skills for children up to the age of five years, for use by the wider child health community. This subset should also include the following developmental skills which survey respondents suggested should be recorded to indicate that the child is ready to start school:

- Listening skills
- Communication skills
- Ability to dress/undress
- Ability to follow instructions
- Toilet trained

3.2.10. Health and Wellbeing Reviews

Following the consultation the project team recommended the following headings and definitions are used for health and wellbeing reviews:

Health and wellbeing reviews	
Type of review	The type of health and wellbeing review: • Post-birth review • New baby review • 6-8 week health visitor review • 1 year review • 2-2 ½ year health and development review • School entry review • Ad-hoc health review • Other reviews
Examination findings	*(Use of existing examination findings headings)*
Problems and issues	*(Use of existing problems and issues headings)*
Feeding status	*(Use of existing feeding status headings)*
Social context	*(Use of existing social context headings)*
Developmental skills	*(Use of existing developmental skills headings)*
Measurements	*(Use of existing measurements headings)*
Safety alerts	*(Use of existing safety alerts headings)*
Assessment scales	*(Use of existing assessment scales headings)*
Information and advice given	*(Use of existing information and advice given headings)*
Other progress reports	*A summary of other progress reports e.g. early years progress reports, school progress reports etc.*
Comments	Supporting text may be given regarding the health and wellbeing review.

Implementation guidance should explain that this generic information model can be used for **any** type of health and wellbeing review, the examples covered by 'type of review' above are consistent with English requirements, however the model is flexible to allow other reviews which may be carried out in other countries of the UK . System design should allow templates with the appropriate subheadings for the various reviews to be generated by selecting the type of review from a drop-down list. The NHS Digital information models have developed specific models for each health and wellbeing review, but these align with the generic model.

Implementation guidance should also explain that problems which are detected with the baby prior to discharge from the post-natal ward, which may include reasons for admission to a neonatal intensive care unit (NICU), e.g. respiratory distress, neonatal fits, hypothermia, etc. should be recorded as examination findings in the post-birth review.

3.2.11. Educational History

The project team were not able to consult widely on a model for 'educational history' however the NHS Digital team suggested the following model which is aligned with the Children and Young People's Dataset. The project team recognises that the educational aspects of a child health record are much broader than educational history but support the following NHS Digital developed model:

Educational history	
Educational establishment	Name of educational establishment including the unique reference number.
Type of educational establishment	Phase/type of education establishment.
Year from	The year the child attended the school from.
Year to	The year the child left the school.
Educational assessment	The outcome of an educational assessment.
Type of special educational need	The type of special educational needs for the child.

3.3. Existing Record Headings Amended for Child Health Use Case

This section contains existing headings which have been amended for the child health use case.

3.3.1 Individual requirements

Following the consultation the project team recommended the following headings and definitions are used to record the individual requirements a child or their guardian have:

Individual requirements	
Child or parent / carer / guardian	An indicator of whether the individual requirement relates to the child or their primary carer.
Individual requirements	Individual requirements that a person has. These may be communication, cultural, cognitive or mobility needs related to themselves or their primary carer.
Accessible information - communication support	Outlines capability and support required in order to in order to provide accessibility, with regard to disability.
Accessible information - requires communication professional	Requirement for a communication professional to be present in order to provide accessibility, with regard to disability.
Accessible information - requires specific contact method	Requirement for a specific contact method in order to provide accessibility, with regard to disability.
Accessible information - requires specific information format	Requires information in a specific format in order to provide accessibility, with regard to disability.
Mobility needs	A child's or their primary carer's personal physical movement between two spaces that achieves participation and a degree of independence.
Cognition	An indicator of cognitive impairment to be considered when

	communicating related to the child or their primary carer.

3.3.2. Family History

Following the consultation the project team recommended the following headings and definitions are used to record information about family history:

Family history	
Condition or diagnosis	The condition or diagnosis in family relations deemed to be significant to the care or health of the child.
Relationship to child	The relationship of the person with the condition to the child.
Maternal or paternal relation	Record of whether the condition or diagnosis was on the mother's or father's side of the family, where needed e.g. paternal grandfather.
Comment	Any further textual comment.

The project team recommends that a SNOMED CT shortlist of preferred terms is created for common family history conditions. In line with the findings from the analysis the project team recommends the following conditions to be included in this shortlist:

- Mental health problems
- Learning disabilities
- Eczema
- Allergies
- Epilepsy
- Heart conditions
- Hip dysplasia
- Hearing deficits
- Asthma
- Diabetes

The maternity project should consider family history recorded at the maternity booking and how it can be communicated through to the child's record.

3.3.3. Social Context

Following the consultation the project team recommend the following headings and definitions are used to record details about the child's social context:

Social context	
Family and household	
Household(s) composition	Details of others living in the same household(s) and their relationship with the child.
Other significant individuals	People deemed as key by family and/or healthcare professionals in the child's life that do not live in the same home(s).
Household(s) environment	Factors in the household(s) which impact the child's health and wellbeing, to include smoking in the home, alcohol/substance use etc.
Mother's educational status	The highest educational qualification attained by the child's mother.
Accommodation status	An indication of the type of accommodation where the child lives. This should be based on the main or permanent residence.
Mother's employment status	The employment status and occupation of the mother.

Father's employment status	The employment status and occupation of the father.
Household social services support	Whether or not any household member had/has social services support.
Personal	
Lifestyle	The record of lifestyle choices made by the child which are pertinent to his or her health and well-being, e.g., the record of the physical activity level, pets, hobbies, sexual habits etc.
Smoking	Latest or current smoking status of the child.
Alcohol intake	Latest or current alcohol consumption record of the child.
Drug/substance use	Record of any drug/substance use by the child.
Social circumstances	The record of the child's social background, network and personal circumstances, e.g., housing, religious, ethnic/spiritual needs and social concerns.

Standards are currently being developed by the University of Birmingham, University Hospital Birmingham and the Royal College of Physician's Health Informatics Unit for recording the consumption of alcohol and tobacco. Once completed they could provide structured content under these headings.

3.3.4. Assessment Scales

Following the consultation, the project team recommends the following headings and definitions are used to record assessment scales:

Assessment scales	
Assessment scale name	The name of the overarching assessment scale used e.g. Bayley, Griffiths, Ages & Stages Questionnaire etc.
Global score	The total global score from the assessment.
Subscale name	The name of the subscale used (where relevant).
Subscale score	The total subscale score from the assessment.
Comment	Supporting text may be given regarding the assessment scale as a whole or a subscale.

3.3.5. Professional Summary

Following the consultation, the project team recommends that the following headings and definitions are used to record a professional summary:

Professional summary	
Professional summary	Summary of the encounter. Where possible, very brief. This may include interpretation of findings and results, opinion and specific action(s). Planned actions will be recorded under 'plan'.

Note that this heading is the same as 'clinical summary' included in current PRSB information models, the name and definition have been changed to reflect the fact that the summary might be recorded by a health care professional other than a clinician.

3.3.6. Plan and Requested Actions

Following the consultation the project team recommend the following headings and definitions are used to record a plan and requested actions:

Plan and requested actions	
Plan and requested actions	A simple free text description of the plan of action following the contact with the child. This may include actions for the parent, child, healthcare professional (e.g. health visitor) and review details.

Please note that care plans are out of scope of the project.

3.2.7. Legal Information

The project team recommend that the existing PRSB heading of legal information would be used to record the following headings:

Legal information	
Local authority	The named local authority.
Looked after child	
Looked after child start date	Start date of a 'looked after child'.
Looked after child end date	End date of a 'looked after child'.
Child protection plan	
Child protection plan start date	Start date of a child protection plan.
Child protection plan end date	End date of a child protection plan.

Implementation guidance should explain that the legal information section covers 'looked after children' and children protection plans; both should include the relevant local authority, start and end dates (where end dates are not entered, the plans should be considered still in place). Once end dates have been entered the information should remain on health and care systems for 364 days.

3.4. Previously Developed Record Headings

This section contains headings which have been developed as part of the standards for the structure and content of acute medical records or previous Professional Record Standards Body projects. We propose that these headings be included as part of the child health project standard, however should be amended with child centered examples where appropriate.

3.4.1. Patient Demographics

Patient demographics

Patient name	The full name of the patient.
Patient preferred name	The name by which a patient wishes to be addressed.
Date of birth	The date of birth of the patient (may include time of birth for a child).
Place of birth	The town and country of birth of the patient.
Sex	The person's phenotypic sex. Determines how the person will be treated clinically.
Gender	As the patient wishes to portray themselves.
Ethnicity	The ethnicity of the patient.
Religion	The religious affiliation as specified by the person.
NHS number	The unique identifier for a patient within the NHS in England and Wales.
Other identifier	Country specific or local identifier, e.g., Community Health Index (CHI) in Scotland.
Patient address	Patient's usual place of residence.
Patient email address	Email address of the patient.
Patient telephone number	Telephone contact details of the patient. To include, e.g., mobile, work and home number if available.
Communication preferences	Preferred contact method, e.g., sign language, letter, phone, etc. Also preferred written communication format, e.g., large print, braille.

NHS Digital have also created a subset of personal demographics to provide a historical record of demographics. This demographics history aligns with the above model.

3.4.2. GP Practice

GP practice	
GP name	Where the patient or patient's representative offers the name of a GP as their usual GP.
GP practice details	Name and address of the patient's registered GP practice.
GP practice identifier	The identifier of the registered GP practice.

3.4.3. Problems and Issues

Problems and issues	
Problems and issues	Summary of problems that require investigation or treatment. This would include significant examination findings which are likely to have relevance, yet are not a diagnosis.
Comment	Any further textual comment to clarify, such as statement that information is partial or incomplete.

Implementation guidance should recommend that coded items (including functional codes) are included in the values for problem and issues.

3.4.4. Examination Findings

Examination findings	
Examination	The examination performed, e.g. general appearance, vital signs, mental state, head and neck examination, oral examination, cardiovascular system, respiratory system, abdomen, genitourinary, nervous system, musculoskeletal system, skin. This could include site and must include laterality where applicable.
Examination findings	The record of findings from the examinations performed.

3.4.5. Diagnoses

Diagnoses	
Diagnosis/symptom	The diagnosis or symptom identified.
Stage of disease	The stage of the disease where relevant.
Comment	Supporting text may be given covering diagnosis confirmation, active diagnosis being treated.

Implementation guidance should reference the Royal College of Paediatrics and Child Health SNOMED CT terms for childhood disabilities (http://www.rcpch.ac.uk/system/files/protected/page/BACDDTSandExplanatoryGlossaryGovernanceFen2016.pdf)

3.4.6. Medications and Medical Devices (this model would be used to record vitamin K administration)

Medications and medical devices	
New medications	
Medication name	May be generic name or brand name (as appropriate).
Form	Form of the medicinal substance e.g. capsules, tablets, liquid.
Route	Medication administration description (oral, IM, IV, etc.): may include method of administration, (e.g., by infusion, via nebuliser, via NG tube) and/or site of use, (e.g., 'to wound', 'to left eye', etc.).
Dose directions description	A single plain text phrase describing the entire medication dosage and administration directions, including dose quantity and medication frequency
Dose direction duration	How long to continue dose including do not discontinue. Coded text.
Additional instruction	Allows for: * requirements for adherence support, e.g., compliance aids, prompts and packaging requirements * additional information about specific medicines, e.g., where specific brand required * person requirements, e.g., unable to swallow tablets.
Indication	Reason for medication being prescribed, where known.

Course status	The status of this prescription in an ambulatory (outpatient/GP/community) context.
Start date/time	The date and/or time that the medication course should begin.
End date/time	The date and/or time that the medication course should finish.
Comment /recommendation	Suggestions about duration and/or review, on-going monitoring requirements, advice on starting, discontinuing or changing medication.
Medical devices	The record of dietary supplements, dressings and equipment that the patient is currently taking or using.

3.4.7. Allergies and Adverse Reactions

Allergies and adverse reactions	
Causative agent	The agent such as food, drug or substances that has caused or may cause an allergy, intolerance or adverse reaction in this patient.
Description of reaction	A description of the manifestation of the allergic or adverse reaction experienced by the patient. For example, skin rash, swelling at injection site etc.
Type of reaction	The type of reaction experienced by the patient (allergic, adverse, intolerance).
Severity	A description of the severity of the reaction.
Certainty	A description of the certainty that the stated causative agent caused the allergic or adverse reaction.
Evidence	Results of investigations that confirmed the certainty of the diagnosis. Examples might include results of skin prick allergy tests.
Probability of recurrence	Probability of the reaction (allergic, adverse, intolerant) occurring.
Date first experienced	When the reaction was first experienced. May be a date or partial date (e.g. year) or text (e.g. during childhood).

3.4.8. Safety Alerts

Safety alerts	
Risks to self	Risks the patient poses to themselves, e.g., suicide, overdose, self-harm, self-neglect.
Risks to others	Risks to care professionals or others.
Risk from others	Details of where a child is at risk from an identified person e.g. family member etc.

Implementation guidance should explain that these headings should be used to record any safeguarding issues which have been identified. These issues must be acted upon by reporting these to the appropriate authority and any significant related actions should be included in the ‘plan and requested actions’ section.

It is important to note that arrangements for communicating safeguarding information are currently under review and hence these requirements may be subject to change.

3.4.9. Clinical Risk Factors

Clinical risk factors	
Relevant clinical risk factor	Factors that have been shown to be associated with the development of a medical condition being considered as a diagnosis. E.g. being overweight, smoker, no use of sun screen, enzyme deficiency.
Clinical risk assessment	Specific risk assessments required/undertaken.
Risk mitigation	Action taken to reduce the clinical risk and date actioned.

3.4.10. Information and Advice Given

Information and advice given	
Information and advice given	This includes – what information (including health promotional messages) – to whom it was given. The oral or written information or advice given to the patient, carer, other authorised representative, care professional or other third party. May include advice about actions related to medicines or other ongoing care activities on an 'information prescription'. State here if there are concerns about the extent to which the patient and/or carer understands the information provided about diagnosis, prognosis and treatment.

4. Next Steps

This report contains the final recommendations made by the PRSB to NHS Digital following the parent and health and care professional consultation process. This report has been signed off by the PRSB assurance committee and the project board subject to being updated in line with their comments.

The recommendations in this report are currently being used by NHS Digital to update their information models and related implementation guidance on which they will base technical specifications to enable information to be communicated electronically between existing NHS IT systems via a central national hub.

This report will be published in draft alongside the NHS Digital developed healthy child record specification, healthy child events specification and preliminary implementation guidance.

The final draft deliverables will then be sent to relevant professional bodies to seek their endorsement before being released as a PRSB endorsed standard.

5. Appendix A – Stakeholders

This appendix describes the stakeholders who participated in the workshops, the online surveys and the expert reference group.

Work package 1: Workshop attendees (05 April 2017)

Organisation	Name
Association of Directors of Children's Services	Karen Graham
Bliss	Mehali Patel
British Academy of Childhood Disability	Indrani Banerjee
British and Irish Orthoptic Society	Michelle Wood
British Dietetic Association	Jessica Williams
Cerner	Tim James
Cerner	Lorraine Edwards
Chartered Society of Physiotherapy	Elizabeth Gray
Clevermed	Peter Badger
Royal College of Occupational Therapists	Beverley Hicks
Community Practitioners and Health Visitors Association	Obi Amadi
Community Practitioners and Health Visitors Association	Marina Copping
EMIS	Andy Williams
eRedbook Advisory Board	Catherine Powell
Great Ormond Street Hospital for Children NHS Foundation Trust	David Elliman
Guys & St Thomas' NHS Foundation Trust	Taiwo Wright
In Practice Systems (INPS)	Jonathan Behr
Livewell Southwest	Denise Edgecombe
National Childbirth Trust	Elizabeth Duff
National Children's Bureau	Andrew Fellowes
National Children's Bureau	Amanda Allard
NHS Digital	Geraldine Hughes
NHS Digital	Chris Dickson
NHS Digital	Julia Gudgeon
NHS Digital	Wendy Mawdsley
NHS England	Michael Curtis
Parent Representative	Pippa Hammett
Parent Representative	Amoy Sinaswee
Parent Representative	Jo Morgan
Parent Representative	Nadine Taylor
Parent Representative	Sabin Qureshi
Public Health England	Adam Gregory
Public Health England	Jill Walker
Public Health England	Coleen Milligan
Public Health England	Jane Hibbert

Royal College of Midwives	Mervi Jokinen
Royal College of Nursing	Lynn Sayer
Royal College of Nursing	Zabeda Ali-Fogarty
Royal College of Obstetrics and Gynaecology	Karen Selby
Royal College of Paediatrics and Child Health	Helen Bedford
Royal College of Speech and Language Therapists	Himali de Silva
Royal College of Speech and Language Therapists	Gillian Kennedy
Royal Pharmaceutical Society	Stephen Tomlin
Servelec	Vicky Mudd
Shrewsbury & Telford Hospital NHS Trust	Adam Gornal
SiteKit	Corinna Dymond
SiteKit	Rob Walker
TPP	John Parry
Western Health and Social Care Trust	Ray Nethercott

Work package 1: Survey respondents (by role)

Role	Number	%
Health visitor	247	26.08%
Parent / carer	158	16.68%
Paediatrician	100	10.56%
Nurse	89	9.40%
Midwife	58	6.12%
Allied health professional	48	5.07%
General practitioner	39	4.12%
Other doctor	27	2.85%
Informatician	25	2.64%
IT system supplier	9	0.95%
Pharmacist	7	0.74%
Social care worker	6	0.63%
Psychiatrist	4	0.42%
Other	130	13.73%
Total	**947**	

Work package 2: Workshop attendees (05 June 2017)

Organisation	Name
British Association for Community Child Health	Gabriel Whitlingum
Cerner	Tim James
Council for Disabled Children	Andrew Fellowes
EMIS	Andy Williams
EMIS	Karen King
eRedbook Advisory Board	Catherine Powell
eRedbook Advisory Board	Sarah Neil
eRedbook Advisory Board	Susan Norman
General and Adolescent Paediatric Research	Alastair Sutcliffe

Collaborative UK and Ireland	
Great Ormond Street Hospital for Children NHS Foundation Trust	David Elliman
Guys and St Thomas' NHS Foundation Trust	Taiwo Wright
Institute of Health Visiting	Elaine McInnes
Institute of Health Visiting	Hannah Richard
Islington Early Years Transformation and Healthy Child Programme	Lucy Naden
Kent Community Health Foundation Trust	Tracy Body
NHS Digital	Caron Swinscoe
NHS Digital	Chris Dickson
NHS Digital	David Low
NHS Digital	Nicholas Richman
NHS South, Central and West Commissioning Support Unit	Iona Rees
North East London Foundation Trust	Georgina Inniss
North East London NHS Foundation Trust	Abike Akinpelu
Parent Representative	Bhavini Patel
Parent Representative	Iza Gill
Parent Representative	Nadine Taylor
Parent Representative	Sabin Qureshi
Public Health England	Coleen Milligan
Public Health England	Michael Edelstein
Royal College of General Practitioners	Libby Morris
Royal College of General Practitioners	Phil Koczan
Royal College of Occupational Therapists	Caroline Leverett
Royal College of Paediatrics and Child Health	Helen Bedford
School and Public Health Nurses Association	Jill Beswick
Servelec	Vicky Mudd
SiteKit	Corinna Dymond
South Warwickshire NHS Foundation Trust	Diane Aldersley
Whittington Health NHS Trust	Geraldine Butler
Whittington Health NHS Trust	Gita Patel

Work package 3: Workshop attendees (03 July 2017)

Organisation	Name
BLISS	Josie Anderson
British Academy of Childhood Disability	Indrani Banerjee
British Association for Community Child Health	Gabriel Whitlingum
British Dietetic Association	Jessica Williams
British Medical Association General Practitioners Committee	Farah Jameel
Cerner	Tim James
Chartered Society of Physiotherapy	Natalie Drane
Community Practitioners and Health Visitors Association	Marina Copping
Council for Disabled Children	Andrew Fellowes
EMIS	Andy Williams

Great Ormond Street Hospital for Children NHS Foundation Trust	David Elliman
Harlow Printing	Vince Hume
ICAN	Amanda Baxter
Institute of Health Visiting	Elaine McInnes
NHS Digital	Chris Dickson
NHS Digital	David Low
Northgate Public Services	Richard Hewitt
Parent Representative	Ruth Caudwell
Parent Representative	Iza Gill
Parent Representative	Amoy Sinaswee
Parent Representative	Nadine Taylor
Public Health England	Coleen Milligan
Royal College of General Practitioners	Phil Koczan
Royal College of General Practitioners	Libby Morris
Royal College of Nursing	Joanna Grant
Royal College of Occupational Therapists	Caroline Leverett
Royal College of Occupational Therapists	Lesley Smith
Royal College of Paediatrics and Child Health	Helen Bedford
Royal College of Speech and Language Therapists	Sophie Scott
Royal College of Speech and Language Therapists	Himali de Silva
School and Public Health Nurses Association	Jill Beswick
Servelec	Vicky Mudd
Whittington Health NHS Trust	Gita Patel

Work package 2/3: Survey respondents (by role)

Role	Number	%
Parent / carer	379	31.53%
Health visitor	157	13.06%
Allied health professional	88	7.32%
Paediatrician	67	5.57%
Other nurse	62	5.16%
School nurse	61	5.07%
Public health professional	50	4.16%
Midwife	43	3.58%
General practitioner	42	3.49%
Early years practitioner	35	2.91%
Informatician	31	2.58%
Psychologist	27	2.25%
Other doctor	18	1.50%
IT system supplier	14	1.16%
Teacher	13	1.08%
Social care worker	4	0.33%
Psychiatrist	2	0.17%
Pharmacist	2	0.17%
Other	107	8.90%
Total	**1202**	

Expert reference group attendees (05 October 2017)

Organisation	Name
British Association for Community Child Health	Gabriel Whitlingum
Cerner	Lorraine Edwards
EMIS	Steve Roberts
Great Ormond Street Hospital for Children NHS Foundation Trust	David Elliman
NHS Digital	Chris Dickson
NHS Digital	Geraldine Hughes
NHS Digital	David Low
Public Health England	Helen Duncan
Royal College of General Practitioners	Phil Koczan
Royal College of Paediatrics and Child Health	Helen Bedford
Servelec	Vicky Mudd

6. Appendix B – Survey Results and Analysis

This appendix provides a summary of the quantitative and qualitative analysis of the online survey results.

7.1. Work package 1

7.1.1. Birth Details

Respondents were provided with the draft birth details headings and asked if they felt there were any essential pieces of information missing. A thematic analysis of the qualitative responses identified the following common themes and the project team's recommended response:

Additional birth detail information	Recommended Response
Baby admitted to neonatal intensive care unit	Add a new heading called 'problems detected prior to discharge' this heading may include reasons for admission to a NICU, including respiratory distress, neonatal fits, hypothermia, feeding difficulties etc. Consider including admission to NICU as a new event.
Baby's blood group	This needs to be considered by PRSB as there is not an obvious place in the record to record this.
Place of birth of the child	This would be recorded under the 'person demographics' section but may be carried as part of the birth details.
Maternal drugs in pregnancy	This should be considered by the NHS Digital maternity events project.
Parental mental health	This should be considered by the NHS Digital maternity events project.
Oral health of the child	This would be included as part of the health and wellbeing reviews.

7.1.2. Type of Delivery

Respondents were provided with the following options for type of delivery and asked if there were other types of delivery they would like to see included:

- Spontaneous Vertex
- Spontaneous Other Cephalic
- Low forceps, not breech
- Other Forceps, not breech
- Ventouse, Vacuum extraction
- Breech
- Breech Extraction
- Elective caesarean section
- Emergency caesarean section
- Other

A thematic analysis of the qualitative responses identified the following common themes and the project team's recommended response:

Other types of delivery	Recommended Response
Include Born Before Arrival (BBA)	Recommend including a new heading to record 'location of birth'
Include concealed pregnancy	This should be considered by the NHS Digital maternity events project
Water birth	This should be considered by the NHS Digital maternity events project
Category of caesarean section	This should be considered by the NHS Digital maternity events project
Shoulder dystocia	This should be considered by the NHS Digital maternity events project
Still birth	This should be considered by the NHS Digital maternity events project
Induction	This should be considered by the NHS Digital maternity events project
Delayed cord clamping	This should be considered by the NHS Digital maternity events project

Respondents were also asked if it was appropriate to record more than one option for 'type of delivery'. The responses were as follows:

Response	Number	%
Yes	267	43%
No	134	22%
Not Sure	214	35%

N: 615

In line with the survey findings, the project team recommends that it is appropriate for more than one option to be selected, for example forceps or ventouse proceeding to a caesarean section.

7.1.3. Maternal Problems in Pregnancy

Respondents were provided with the following options for maternal problems in pregnancy and asked if there were other types of delivery they would like to see included:

- Diabetes
- Gestational diabetes
- Systemic Lupus Erythematosus (SLE)
- Mother taking opioids
- Thyrotoxicosis
- Anti - D positive
- Idiopathic Thrombocytopenic Purpura
- Vitamin D deficiency/osteoporosis
- Myotonic dystrophy
- Achondroplasia
- Rubella
- Cytomegalovirus (CMV)
- Hepatitis B antigen/antibody
- Toxoplasmosis

- Group B streptococcus colonization
- HIV
- Anticonvulsant therapy
- Alcohol abuse
- Myasthenia Gravis

A thematic analysis of the qualitative responses identified the following common themes and the project team's recommended response:

Other maternal problems in pregnancy	Recommended Response
Hypothyroidism	Recommend including this as an additional option
Chicken Pox	Recommend including this as an additional option
Hepatitis C	Recommend including this as an additional option
Maternal mental health problem	This is too general and not appropriate to include a range of specific mental health disorders

7.1.4. Problems During Delivery

Respondents were provided with the following options for problems during delivery and asked if the list was appropriate:

- Shoulder dystocia
- Foetal heart deceleration
- Cord prolapse
- Acute foetal compromise
- Foetal acidaemia
- Meconium Aspiration Syndrome
- Acute foetal blood loss

A thematic analysis of the qualitative responses identified the following common themes and the project team's recommended response

Problems during delivery	Recommended Response
Foetal heart deceleration is common and can be a normal part of labour	Remove these options and replace with 'Foetal distress'
Acute foetal compromise was felt to be vague	
Foetal acidaemia is not an isolated finding and is usually because of one of the other problems during delivery	
Meconium Aspiration Syndrome is diagnosed after the birth however Meconium Aspiration may be present at birth	Change to 'Meconium Aspiration'

7.1.5. Neonatal Resuscitation

Respondents were asked if 'neonatal resuscitation' was an appropriate term. 73% of respondents felt that it was, 7% did not think it was appropriate and 20% were not sure. Due to the high level of consensus the project team recommends that this term is retained.

Respondents were also asked if they would like to see 1, 5 and 10 minute APGAR scores in the child health record. The results are provided in the following table:

APGAR score	Number	%
1 minute APGAR	366	65%
5 minute APGAR	356	63%
10 minute APGAR	320	57%
None of the above	13	2%
Unsure	147	26%

N: 562

Thematic analysis of the qualitative comments identified a common theme that the 10 minute score should only be recorded if the score is poor at 1 and 5 minutes.

Due to the high level of consensus the project team recommends that all 3 APGAR scores are included however implementation guidance should specify that the 10 minute score should only be recorded where the score is poor at 1 and 5 minutes.

7.1.6. Abnormalities Detected at Birth

Respondents were asked which of the terms were preferable to describe physical problems with the baby identified at, or shortly after, birth:

1. Physical abnormalities detected at birth
2. Physical problems detected at birth

Preferred term	Number	%
Physical abnormalities detected at birth	188	34%
Physical problems detected at birth	245	45%
Neither	59	11%
Unsure	57	10%

N: 549

In line with the survey findings, the project team recommends that physical problems detected at birth should be included as a heading.

Respondents were provided with the following options for physical problems detected at birth and asked if the list was appropriate:

- Cephalohaematoma
- Caput succedaneum
- Extensive bruising
- Erythematous skin rash
- Vesicular skin rash
- Talipes equina varus
- Plagiocephaly
- Laceration
- Erb's Palsy
- Cleft lip

- Cleft palate
- Anal atresia
- Absent finger
- Absent toe
- Fractured clavicle
- Other (SNOMED CT)

A thematic analysis of the qualitative responses identified the following common themes and the project team's recommended response.

Physical problems detected at birth	Recommended Response
Caput succedaneum is a common result of the labour process and has no ongoing significance	Remove this option from the list
Erythematous and vesicular skin rashes are very common and should not be in the same list as physical problems	Remove this option from the list
Plagiocephaly often occurs following vaginal delivery but rarely persists.	Remove this option from the list
Absent finger/ toe is uncommon	Remove this option from the list

7.1.7. Multiple Births

Respondents were asked in cases of multiple births is it important to record if the baby is identical to one of the siblings. The results are provided in the following table:

Record whether babies are identical	Number	%
Yes	419	76%
No	63	11%
Unsure	67	12%

Respondents were also asked who this information was important to. 82% felt it would be important to parents/carers, 95% felt it would be important to health and care professionals and 44% felt it was important to public health professionals.

In line with the survey findings the project team recommends that the 'multiple births' heading definition states to record whether the baby is identical to one of the siblings.

7.1.8. Screening Reviews

Respondents were provided with the draft screening review headings and asked if they were appropriate. A thematic analysis of the qualitative responses identified the following common themes and the project team's recommended response:

Additional birth detail information	Recommended response
Protocol was felt to be confusing and not useful	Remove this heading from the section
Screening test status should include a deferred option	Recommend including deferred as an option

7.1.9. Feeding Status

Respondents were provided with the draft feeding status headings and asked if they were appropriate. The results are provided in the following table:

Feeding status headings appropriate?	Number	%
Yes	345	65%
No	145	28%
Unsure	37	7%

N: 527

Thematic analysis of the qualitative responses identified one common theme; that it is important to know the method by which the baby is fed. The recommendation is that the 'alternative feeding methods' heading is amended to 'feeding method' to include whether the baby is breast fed, bottle/cup fed in addition to the alternative feeding methods (gastrostomy, nasogastric feeds etc.).

Respondents were provided with the following options for feeding status and asked if the list was appropriate:

- Totally breast milk fed
- Partially breast milk fed
- Not breast fed

Thematic analysis of the qualitative responses identified a theme which was to reference formula milk feeding. The project team recommendation is to change the 'feeding status of the baby' to 'milk feeding status of the baby'. Public health professionals requested the following options were included:

- Totally breast milk fed
- Partially breast milk fed
- Not breast milk fed

7.1.10. Babies Put to Breast

Respondents were asked if it is important to record whether or not the baby is put to the breast following delivery. 62% felt it was appropriate, 16% felt it was not appropriate and 22% were unsure. The project team recommends that this is recorded in the birth details section and considered as part of the maternity project.

7.1.11. Introduction to Solids

Respondents were asked if it is important to record when the baby is introduced to solid food. 75% felt it was appropriate, 7% felt it was not appropriate and 18% were unsure. The project team recommends that this should be recorded under the 'introduction of solids' heading.

7.2. Work package 2 / 3

7.2.1. Developmental Firsts / Milestones

Respondents were asked which of the following terms they preferred to describe important things which children do for the first time:

- Milestones

- Developmental firsts

Of the 763 people who responded to the question, the preference was for the term ‘milestones’ (65%), as opposed to ‘developmental firsts (28%). A further 7% of respondents provided alternative terms.

The following table shows the results, broken down by respondent group:

	Developmental firsts	Milestones	Other term	Total (N)
Parent / carer	35%	63%	2%	234
Health visitor	25%	66%	9%	121
Allied health professional	17%	78%	5%	59
Paediatrician	15%	76%	9%	54
Other nurse	36%	57%	7%	42
School nurse	28%	70%	3%	40
General practitioner	23%	65%	13%	31
Midwife	35%	62%	4%	26
Public health professional	21%	54%	25%	24
Early years practitioner	38%	52%	10%	21
Psychologist	21%	64%	14%	14
Informatician	36%	36%	29%	14
Other doctor	8%	67%	25%	12
IT system supplier	40%	60%	0%	5
Teacher	60%	20%	20%	5
Social care worker	0%	100%	0%	4
Psychiatrist	0%	100%	0%	1
Other	21%	71%	7%	56
Total (N)	**211**	**498**	**54**	**763**

Respondents were asked whether the milestones included in the Personal Child Health Record should be changed. Although some respondents suggested changes to the milestones, the response rate for this question was small. Our framework allows for other milestones to be added or removed as required. The project team recommends that a SNOMED CT list of milestones is defined by the UKTC working with parents and the PRSB.

Respondents were asked if they felt it was appropriate for age appropriate developmental firsts / milestones to be recorded for children older than two years. Of the 735 people who responded to this question:

- 63% felt they should be recorded for children two - five years
- 12% felt they should be recorded for children older than five years
- 12% felt they should not be recorded for children older than two years
- 21% were not sure.

The following table shows the results, broken down by respondent group:

	No	Yes (for children 2 - 5 years)	Yes (for children older than 5 years)	Not sure	Total (N)
Parent / carer	16%	56%	9%	26%	241
Health visitor	16%	64%	8%	17%	124
Allied health professional	5%	72%	14%	19%	63
Paediatrician	15%	74%	11%	9%	58
School nurse	3%	64%	44%	15%	49
Other nurse	7%	63%	9%	30%	47
General practitioner	20%	70%	7%	7%	31
Midwife	12%	56%	12%	28%	27
Early years practitioner	19%	76%	10%	5%	23
Public health professional	10%	60%	20%	20%	22
Psychologist	0%	62%	23%	31%	15
Other doctor	8%	62%	0%	31%	13
Informatician	0%	77%	8%	15%	13
Teacher	20%	80%	40%	0%	7
Social care worker	50%	0%	0%	50%	4
IT system supplier	0%	100%	0%	0%	2
Psychiatrist	0%	100%	0%	0%	1
Other	0%	66%	13%	28%	53
Total (N)	**90**	**464**	**88**	**155**	**735**

7.2.2. Social Skills for Starting School

Respondents were asked if they thought it was important to record whether children have the necessary social skills to start school. Of the 749 people who responded to the question, 76% felt it was important, 10% did not think it was important and 14% were not sure.

The following table shows the results, broken down by respondent group:

	Yes	No	Not sure	Total (N)
Parent / carer	67%	16%	17%	229
Health visitor	86%	4%	10%	119
Allied health professional	78%	5%	17%	58
Paediatrician	76%	11%	13%	54
Other nurse	79%	7%	14%	43
School nurse	90%	5%	5%	40
General practitioner	53%	27%	20%	30
Midwife	76%	12%	12%	25
Public health professional	86%	0%	14%	22
Early years practitioner	90%	0%	10%	21
Psychologist	100%	0%	0%	14
Informatician	50%	21%	29%	14
Other doctor	46%	15%	38%	13
Teacher	100%	0%	0%	5
Social care worker	100%	0%	0%	4
IT system supplier	67%	33%	0%	3
Psychiatrist	100%	0%	0%	1
Other	80%	4%	17%	54
Total (N)	**567**	**74**	**108**	**749**

The respondents who answered yes to this question were asked to record which skills they felt were particularly important. Thematic analysis of the qualitative responses identified the following commonly reported skills:

- Listening skills
- Communication skills
- Ability to dress/undress
- Ability to follow instructions
- Toilet trained

7.2.3. Family History

Respondents were asked if there were any conditions in the child's parents or family which are routinely asked about. Thematic analysis of the qualitative responses identified the following common conditions:

- Mental health problems
- Learning disabilities
- Eczema
- Allergies
- Epilepsy
- Heart conditions
- Hip dysplasia
- Hearing deficits
- Asthma
- Diabetes

7.2.4. Pertinent information currently rarely shared

Respondents were asked what information they generally do not receive from other health or care professionals that could benefit them if it was shared. Thematic analysis of the qualitative responses identified the following common themes:

- Outcomes of health and care assessments
- Details of attendances/contacts with other health and care professionals
- Relevant family history
- General GP information
- Details of immunisations
- Mental health information
- Neonatal information
- Safeguarding information
- Social care information

Implementation of the recommendations made in this report should result in improvements in the recording and sharing of the above information, resulting in improved patient care.

7. Appendix C – Expert Reference Group Meeting Outputs

This appendix provides a summary of the outputs from the expert reference group meeting of 05 October 2017.

8.1. Spontaneous Respiration

NHS Digital recommended an additional heading of 'spontaneous respiration' to be added to the 'birth details' section. The expert reference group stated that it needed to be clear that this refers to respiration rather than circulation. For the PCHR, a more parent-friendly term would be 'breathing'. It is important that this heading is in the same format as recorded in maternity systems. The significance of the data is that if spontaneous respiration is delayed it can cause long-term health problems for the child. The data would also be useful for research purposes. The expert reference group agreed that spontaneous respiration and APGAR scores are distinct from one another and should be separate headings in the record. The consensus of the expert reference group was for the 'spontaneous respiration' heading to be added to the 'birth details' section.

8.2. Multiple Births

The expert reference group were asked how to address the recording of identical siblings in the case of multiple births. It can be difficult to identify identical siblings at the time of birth. It was suggested that in many cases the membranes would be checked or genetic testing would be carried out. The expert reference group agreed that it is something parents would want to know, the data is useful for research and there are also important clinical implications. Parents could also publish the information via the PCHR. The consensus was for this heading to be added to the 'birth details' section and implementation guidance should explain about how testing would determine whether siblings are identical or not.

8.3. First Milk Feed

The expert reference group were asked whether the 'first milk feed' heading should be part of the 'birth details' or 'feeding status' sections. The consensus was that it should be part of the 'feeding status' section as not all babies feed at the time of birth.

8.4. Duration of Breast Milk Feeding

The duration of breast milk feeding should be possible to be calculated from the 'feeding status' records. Currently this data is not flowing so mothers are asked retrospectively about the duration of breast milk feeding. The expert reference group suggested that mothers who are breastfeeding should be asked when they stopped breastfeeding to the nearest month in order to determine the duration. Implementation guidance should clarify how this data should be collected and recorded.

8.5. Failed Methods of Delivery

The expert reference group were asked whether the 'type of delivery' heading should include methods which were attempted but did not result in the birth of the child. Currently multiple types of delivery can be recorded but cannot be tagged as 'failed'. The consensus was that this information is important and a heading of 'attempted deliveries' is added to the birth

details section. The related maternity project should explore how this information can be extracted into the child's record.

8.6. Social Context

NHS Digital suggested the following three additional headings from the maternity dataset were added to the 'social context' section:

- Mother's employment status
- Father's employment status
- Household social services support

The expert reference group agreed these headings are useful for understanding the socio-economic context for the child. The expert reference group also recommended that the job titles of the parents should be included in addition to the employment status.

8.7. Disability

The expert reference group were asked whether the 'individual requirements' section should include information about disability and impact. Consensus was not reached at the meeting. Following the expert reference group the project clinical leads recommended that this area requires further consideration by the PRSB.

8.8. Educational History

NHS Digital identified two headings which were not consulted on in previous stages of the consultation; educational assessments and special education need. The expert reference group agreed this was important and should be included in a separate 'educational history' section, which would also include details of the educational establishment that the child attended.