Public Health
England

Protecting and improving the nation's health

Output and information requirements specification: for the Child Health information service and systems

About Public Health England

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Glossary of terms

Term	Acronym	Definition
Accident and Emergency	A&E	Hospital departments to assess and treat patients with serious injuries or illnesses
Automated auditory brainstem response	AARB	New-born hearing screening test undertaken in the first weeks of life
Auditory brainstem response	ABR	Test that measures parts of a child's nervous system that affects hearing
Ages and Stages Questionnaire	ASQ	Measure to help monitor a child's development across the country to observe changes in population in health year to year to track children's outcomes as they grow up
British Association for Adoption & Fostering	BAAF	A registered Voluntary Adoption Agency and Adoption Support Agency
Bacilli Calmette-Guerin	BCG	BCG vaccine protects against Tuberculosis which is a serious infection affects the lungs
Common Assessment Framework	CAF	A government paper which forms an important part of a strategy for helping children and young people to achieve priority outcomes
Children's and Adolescent Mental Health Services	CAMHS	NHS-provided services for children in the mental health arena in the UK.
Clinical Commissioning Group	CCG	NHS organisations set up by the Health and Social care Act 2012 to organise the delivery of NHS services in England
Child Health Information Service	CHIS	This service comprises of three components. The CHISs, the CHRD and the PCHR
Child Health Information Service System	CHISs	The systems while they vary generally provide some sort of cohort analysis function for children services as well as a call and recall function

Child Health Promotion Programme	CHPP	Specific targets programme of health interventions aimed at improving the health and wellbeing of children
Child Health Record Department	CHRD	The people who manage and maintain the details on the child health record system
Child Protection	CP	A set of usually government-run services designed to protect children and young people who are underage.
Child Protection Plan	CPP	A plan devised by professionals to keep children safe from harm
Children and Young People's Health Services Dataset	CYPHS	The dataset standards for children and young people. One component of the Maternity and Children's Dataset
Comma Separated Values	CSV	CSV is a common, relatively simple file format
Commissioning organisation	CO	An organisation that purchases healthcare services and/or systems to support such services
Cover of vaccination evaluated rapidly	COVER	UK quarterly data and commentary on coverage achieved by the UK childhood immunisation programme.
Department for Education	DFE	UK government department with responsibility for infant, primary and secondary education.
Deoxyribonucleic Acid	DNA	One of the three major macromolecules that are essential for all known forms of life. It contains the genetic instructions used in the development and functioning of all known living organisms
Did Not Attend	DNA	Description for a patient who did not arrive for their scheduled appointment
Further Education	FE	Schools and Further Education Colleges
File Transfer Protocol	FTP	A standard network protocol used to transfer files from one host to another host over a network

General Practitioner	GP	A General Practitioner is a medical doctor who treats acute and chronic illnesses and provides preventative care and health education to patients
Glutaric aciduria type 1	GA1	An inherited metabolic condition that from 2015 is being screened for as part of the newborn Blood Spot Screening process.
Healthy Child Programme	HCP	An effective ad high-quality preventive programme for childhood to provide the foundation of a healthy society. Understanding of how early childhood development can both be promoted and damaged
Health Level 7	HL7	An all-volunteer, non-profit organisation involved in development of international healthcare informatics interoperability standards
Human papillomavirus	HPV	Human papilloma virus (HPV) is the name for a group of viruses that affect your skin and the moist membranes lining your body, for example, in your cervix, anus, mouth and throat. HPV is a common and highly contagious infection, with over three quarters of sexually active women acquiring it at some time in their lives.
Homocystinuria	HCU	An inherited metabolic condition that from 2015 is being screened for as part of the newborn Blood Spot Screening process.
Human papillomavirus	HPV	A virus which can be transmitted to a foetus during birth
Hypertext Transfer Protocol	HTTP	A networking protocol for distributed, collaborative, hypermedia information systems

Information Governance	IG	A set of multi-disciplinary structures, policies, procedures, processes and controls implemented to manage information to support an organisation's immediate and future regulatory, legal, risk, environmental and operational requirements.
Information Technology	IT	The application of computers and telecommunications equipment to store, retrieve, transmit and manipulate data
Intra Operability Toolkit	ITK	Toolkit which enables differing IT applications to transmit and receive data
Isovaleric acidaemia	IVA	An inherited metabolic condition that from 2015 is being screened for as part of the new-born Blood Spot Screening process.
Local Authorities	LAs	A form of public administration, responsible for local services such as education, transport, planning and following the Health and Social Care Act 2012, now responsible for many public health functions.
Looked After Children	LAC	Children subject to a Care Order, looked after by the state, according to relevant national legislation, including ‘accommodated’ children on a voluntary basis
Laboratory Information Management System	LIMS	A software-based system offering a key set of features that support a modern laboratory's operations.
Maple syrup urine disease	(MSUD)	An inherited metabolic condition that from 2015 is being screened for as part of the newborn Blood Spot Screening process.

Maternity and Children's Data Set	MCDS	The MCDS is made up of three standards. These are the:- Maternity Services Data Set (MSDS) Children and Young People's Health Services (CYPHS) Data Set Child and Adolescent Mental Health Services (CAMHS) Data Set
Measles mumps and rubella	MMR	Measles mumps and rubella are common highly infectious conditions that can have serious, potentially fatal complications, including meningitis, swelling of the brain encephalitis and deafness
Medicines and Healthcare Products Regulatory Agency	MHRA	A government agency which is responsible for ensuring that medicines and medical devices work, and are acceptably safe.
Medium Chain Acyl Dehydrogenase Deficiency	MCADD	A rare inherited disorder where your body cannot metabolise (break down) fat properly
Multi-agency team	MAT	A group of professionals from health, education & social services all work together in order to meet individual needs of each child.
National Children's Measurement Programme	NCMP	A government backed work programme to increase public and professional for engaging with children and families about healthy lifestyles and weight issues
Newborn and Infant Physical Examination	NIPE	Newborn physical examination screening which covers four elements heart, eyes, hips and testes

NHS England	NHS England	NHS England is an executive non-departmental public body of the Department of Health. NHS England oversees the budget, planning, delivery and day to day operation of the commissioning side of the NHS in England as set out in the Health and Social Care Act 2012. It holds the contracts for Primary care and NHS dentists
Newborn Blood Spot Screening Programme	NHSNBS	Part of the suite of newborn screening programmes offering screening for the following genetic and metabolic disorders: Sickle cell disease, (SC) Cystic Fibrosis (CF), Congenital Hypothyroidism (CH), medium-chain acyl-CoA dehydrogenase deficiency (MCADD), phenylketonuria (PKU), Isovaleric acidaemia (IVA), Homocystinuria (HCU)), Maple syrup urine disease (MSUD), Glutaric aciduria type 1 (GA1) and Isovaleric acidaemia (IVA).
NHS Health & Social Care Information Centre	NHS HSCIC	England's central, authoritative source of health and social care information.
NHS Information Authority	NHSIA	The NHS Information Authority is fully part of the NHS and focused on the real challenge of implementing Information for Health.
National Health Service Information Standards Board	NHS ISB	The Information Standards Board (ISB) approves information standards for the NHS and adult social care in England
NHS Newborn Hearing Screening Programme	NHSP	Aims to identify moderate, severe and profound deafness and hearing impairment in newborn babies to give babies a better 'life chance' from an early age

NHS Numbers for Babies	NN4B	A previous service that provided allocation of NHS numbers to newborn babies
Newborn and Infant Physical Examination	NIPE	Part of the suite of NHS new-born screening programmes and offers providing holistic assessment of the health and wellbeing of the new-born baby. NIPE compromises 2 examinations; the first completed within 72 hrs of birth and the second one within 6 to 8 weeks.
Otoacoustic emissions	OAE	A sound which is generated from within the inner ear.
Organisation Data Service	ODS	Facilitation of providing unique identification codes for organisational entities of interest to the NHS, for example NHS Trusts or COs
Personal Child Health Record	PCHR	A health and development record given to parents/ carers at a child's birth.
Primary Care Trust	PCT	Primary Care Trusts were organisations under the old NHS system. NHS England took on full statutory responsibilities from these in April 2013
Personal Demographic Service	PDS	National electronic database of NHS patient demographic details such as name, address, date of birth and NHS Number.
Public Health England	PHE	National organisation working to protect and improve the nation’s health and wellbeing, and reduce health inequalities
Screening management and reporting tools	SMART	Tool designed to provide a robust and consistent means of capturing data from the newborn and infant examinations, supporting health professionalism improving the quality, timeliness and consistency of examinations and reduce late diagnosis

'Systematized Nomenclature of Medicine Clinical Terms	SNOMED	The standard clinical terminology for the NHS to support recording of clinical information, in a way that supports data management and analysis to support patient care, while enabling data extraction and data exchange.
Simple Object Access Protocol	SOAP	Protocol specification for exchanging structured information in the implementation of Web Services
Statutory Order	SO	An official instruction (made by a judge or magistrate) that a child should be taken into care
Secondary Uses Service	SUS	A single source of comprehensive data that provides access to anonymous patient-based data for purposes other than direct clinical care
Team Around the Child	TAC	A model of service provision in which a range of different practitioners come together to help and support an individual child or young person.
Unique reference number	URN	Patient identifier unique to the individual
Universal Description, Discovery and Integration	UDDI v3.0	Extensible Markup Language (XML)-based registry for businesses worldwide to list themselves on the Internet and a mechanism to register and locate web service applications
United Kingdom Newborn Screening Programmes	UK NSP	DH funded programmes to assure high quality screening services offered for babies and their parents. Programmes include the NHS Newborn Blood Spot Screening Programme - NBSP –delivering newborn blood spot screening services.
Technology Reference data Update Distribution	TRUD	DH Web to enable the download of reference files from the Department of Health Informatics Directorate.

Web Services Description Language	WSDL v1.1	WSDL is an XML format for describing network services as a set of endpoints operating on messages containing either document-oriented or procedure-oriented information

1. Introduction

1.1 Overview

This document is an update of the Information Requirements Specification (IRS) and the Output Based Specification (OBS) for Child Health Information Systems that was published as two documents in 2012 by the Department of Health. It is intended to support the commissioning and delivery of services to help meet requirements within the Child Health Information System - NHS Service Specification Section 28.

This edition brings together the IRS and OBS into one document to improve the consistency of information in one source and avoid duplication. The document has been updated to include developments in the screening, immunisation, health and development requirements of children and young people which are reflected in national policy or statutory requirements that have emerged since its original publication in 2012. This revision has been led by Public Health England (PHE) with content and advice from across organisations involved in child health programmes including NHS England, Health and Social Care Information Centre (HSCIC), United Kingdom National Screening Committee and experts from the national Child Health Information System (CHIS) Programme Board and working group, clinician and managers of child health services, informatics leads and professional groups representing child health services.

The initial work for the 2012 documents was compiled by the Department of Health's Child Health Information Systems Transition Steering Group, chaired by the National Clinical Director for Children, Young People and Maternity Services, Dr Sheila Shribman. This built on earlier work initiated in 2007 by the Department of Health and Connecting for Health Child Health Programme to establish universal information requirements for child health information systems (CHIS). The content detailed within this document results from the engagement of clinical and informatics colleagues without whom this current document and project would not have been possible.

This document does not set out to repeat the many non-functional or general requirements that appear in existing contractual documentation, covering themes such as information governance, Personal Demographics Service (PDS), and clinical requirements or safety. In the event of a conflict between this document and the policy documents that are referenced from each chapter, the policy documents should take precedence unless explicitly stated otherwise.

1.2 Context

To reflect the transition period this document avoids the use of specific terms to refer to organisations involved in commissioning child health services delivery eg local health provider, Local Authority, Clinical Commissioning Group etc. Instead, the term “Commissioning Organisation” (CO) is used to refer to those organisations involved in the planning and purchasing of health services for a defined local population.

In some cases, an organisation may be responsible both for commissioning the information service that underpins delivery of healthcare services (the CHIS) and for commissioning the health service (eg immunisation). However, in some cases responsibility may be split between different organisations. Clarity about roles and responsibilities for the different parts of the public health and healthcare system in relation to CHIS will be set out in an operating model developed by the NHS England. It is worth noting that, following the Transforming Community Services agenda, in some cases the current commissioning organisation for CHIS will be separate from the child health service provider. It is anticipated that this distinction between commissioning and provision will be retained in the future.

All children receive what are known as “Universal” services. In addition, the key classifications used to differentiate the services that are offered to children are:

- vulnerable children
- children In need (eg children with disability and complex care programmes including those of life limiting disorders; and/ or those with health or special educational needs in school)
- children looked after
- children with a child protection plan

1.3 Scope

This document is limited in scope to key requirements for Child Health Information and information systems in England-only. It also recognises the varying degree and maturity of IT infrastructure and systems within Child Health Record Departments.

Use of the term information system in this document does not assume a single monolithic application. An information system may comprise many separate components.

1.4 Definition of a child health information service (CHIS)

- the IT system known as the child health information service system (CHISs); while these vary considerably, they generally provide some sort of cohort analysis function as well as a call and recall function
- a child health record department (CHRD): the people who run the information service
- a parent held child health record (PCHR): the Red Book. This gives a comprehensive local record of a child's public health (screening, immunisation and other health protection or health improvement interventions) and of their community based healthcare

1.5 How to use this document

To ensure that the requirements support the development of the entire information system, it is important to consider all stakeholders in the development and who will be responsible for different components or services underpinned by the CHIS. Within this document, a priority has been placed against each requirement, which is expanded upon below:

Where **MUST** is outlined, this will indicate that the definition is an absolute requirement of the specification, and services should be able to demonstrate compliance.
Where **SHOULD** is outlined, this will indicate that there may exist valid reasons in particular circumstances to ignore a particular item, but the full implications must be understood and carefully weighed before choosing a different course.
Where **MAY** is outlined, this will indicate that the requirement is truly optional.

1.6 Document purpose

The purpose of this updated document is to set out the information requirements for the delivery of child health services that take account of:

- the Healthy Child Programme https://www.gov.uk/government/policies/giving-all-children-a-healthy-start-in-life
- outcomes of the Public Health Outcomes Framework http://www.phoutcomes.info/
- a consensus of guidance across the professional bodies ie colleges and professional bodies for nursing, medicine; and allied health policy, standards and guidelines for child health programmes, such as immunisation, screening or statutory requirements for child health services
- interpretation of legislation and consent rules for information sharing in support of the Caldicott guardian responsibilities. http://systems.hscic.gov.uk/infogov/caldicott

The Information Requirement Specification within this document details the technical requirements of an information service that is necessary to the Healthy Child Programme. The Output Based specification provides the high level requirements intended to guide software development and implementation of Child Health Service Information Systems (CHISs). This document identifies the data flows into and out from a CHISs that are required to support delivery of each element of the child health service, and to enable relevant data-sharing to a national standard, which among others include:

- critical and intimate linkages required with maternal records as more than 95% of babies are born in hospital.
- transmission of screening coverage and results data requires links between laboratories, maternity units, CHRDs and GPs, all of whom are served by a variety of different system suppliers and systems: http://www.isb.nhs.uk/documents/isb-0089/amd-8-2014/index_html
- known Information flows for health, social care and education departments have been described, in order to improve integration with the Local Authority.
- benchmarking of services at local and national level utilising the information standards of the Maternity and Children's Data Set (MCDS): http://www.hscic.gov.uk/maternityandchildren

The primary objective of CHIS is to ensure standardised and accurate data and information to support the commissioning and delivery of child health services. This means providing a service that delivers a comprehensive local record of a child's public health (screening, immunisation and other health protection or health improvement interventions) and of their community based healthcare.

IO1	Use information to improve health outcomes for children and families.
IO2	Produce uniform data and process for child health systems that will provide a basis for consistent information exchange across health and care leading to better outcomes for all children.
IO3	Proposing a clinically driven national standard for supporting local procurement and commissioning of child health information service systems.
IO4	Allowing for better information exchange across other multiple agencies leading to improved outcomes for the child.
105	To support the national and local delivery of the national Healthy Child Programme as originally mandated in the Section 7a of the NHS Mandate and subsequently for Local Authorities by further regulation.

Additionally CHIS should support:

- standardised information and data handover of care from midwifery
- children with acute or chronic disorders
- children with mental health issues

- standardised information and data handover to adult services
- looked after Children
- improve early detection of potential safeguarding issues
- disabled children and children and young people with complex health needs

1.7 Audiences

In addition to the above, this document outlines the functional and non-functional requirements to meet the needs of the Child Health service which are covered in more detail throughout this document. The OBS elements of this document are directed primarily at colleagues within NHS England in order to build an outline business case to support the future commissioning of CHISs. It will be of interest to people who are currently involved in the commissioning and delivery of these information systems and those who will have this responsibility or in the future and those who rely on these systems to fulfill their own responsibilities.

The term ‘commissioning organisations’ (COs) has been used throughout this document to refer to those responsible for contracting for the Child Health Information Service (CHIS), and/or responsible for contracting for screening, immunisation and other child health services.

This could include, but is not limited to:
- Public Health England and their staff
- Community Services staff, particularly community paediatricians and Child Health Record Departments and staff in information and performance teams
- General Practitioners (GPs) and their staff
- Health Visitors
- Newborn Hearing Screening Teams
- Newborn Screening laboratories
- School Nurses
- Schools
- NHS England and Regional Teams
- Local authorities, particularly Directorates of Children’s services and Public Health as commissioners of child health services 5 – 19 years and from 1 October 2015 the commissioners of 0 – 5 year services
- Screening and immunisation teams
- Clinical Commissioning Groups (CCGs)
- System suppliers of CHISs
- Health Protection Units
- Chief Information Officers/Leads
- midwives and midwifery units
- clinical staff including community Pediatrician’s, Health Visitors and all those involved in providing the requirements of the Healthy Child Programme

- pathology services (local and regional)

It is acknowledged that this document reflects the current child health information requirements but that these will evolve and increase over time to reflect clinical and policy changes. Therefore it is important to note a future refresh will be needed to reflect these requirements.

2. Background and policy context

2.1 Overview

CHISs are child health information service systems currently operated at a local level, they are commissioned locally and the commissioning standards are overseen by NHS England. A significant proportion of these systems are currently part of the Local Service Provider contracts originally delivered under the National Programme for IT, which expire in 2015/16 and new commissioning arrangements need to be established.

The system supports a variety of child health related activities, including public health services such as immunisation and childhood screening. They are also important as they provide information about individual children's health (which can be useful eg during an outbreak of a disease for which some children may need to be immunised), but also provide a population-perspective, enabling effective targeting of services (eg they capture non-GP-registered children enabling a whole population view to be taken about needs to inform local commissioning strategy).

In summary all CHIS systems provide a database of information on a population of children for the purposes of immunisation, screening and delivery of the Health child programme 0-5. However in some instances they have been developed to support the delivery of care to individual children and have become integrated within an electronic community child health record.

NHS England were given the responsibility for Child Health Information Service Systems in 2013 via Section 7A of the NHS mandate following the identification of a number of concerns about child health information. These included:

- differing pace of progress in respect of child health information
- differing content in proposed developments in that there was insufficient account being taken of existing national standards and guidance and emerging national standards and guidance
- child health records were often not complete particularly where a child had moved geographical areas
- CHISs often do not have the capability to interface with other applications such as GP, community and midwifery systems

2.2 Transition in the health and care system

The health and care system, within which universal and specific services for children operate, is undergoing significant change some of which is set out in the following documents:

- Department of Health: Scope of 0-5 public health services transfer https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/404655/SCOPE_of_transfer_paper.pdf
- Health Visiting Programme and 0-5 Commissioning of Public Health Services Factsheet (2014). A fact sheet providing background on the Health Visiting Programme and the transfer of commissioning to local authorities from October 2015 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/373380/Factsheet_v2.pdf
- Public Health Services for 0-5 year olds: transfer of commissioning responsibilities to local authorities; formal guidance published by Department of Health supported by Public Health England, NHS England and the Local Government Association: https://www.gov.uk/government/publications/transfer-of-0-5-childrens-public-health-commissioning-to-local-authorities

These set out the key considerations in the transfer of commissioning responsibilities for the 0-5 year old Healthy Child Programme to ensure a stable transition process which will maintain service continuity and support the continued development of the service, offering best outcomes for children and their families by ensuring clear and robust contractual arrangements are in place between commissioners and service providers through transition. The transfer of 0-5 years commissioning to local authorities will enable joined up children's Public Health commissioning and services across health, education and Social Care from 0-19 years old, improving continuity for children and their families.

The scope of the transfer of commissioning responsibilities is:

- aspects of the 0-5 years Healthy Child Programme which relate to health visiting services (universal, community and targeted services) and Family Nurse Partnership services (targeted services for teenage mothers)
- the following commissioning responsibilities which are also aspects of the 0-5 years Healthy Child Programme will remain with NHS England:
  - Child Health Information Service Systems, to be reviewed in 2020
  - in the meantime, Public Health England will retain a close interest in the specification of Child Health Information Service Systems, to ensure public health requirements, such as accurate and effective collection on the delivery of childhood immunisations, are met
  - antenatal, newborn and infant screening including the infant physical examination delivered at 6-8 weeks by GPs (also known as Child Health Surveillance)
  - Child Health Immunisations

2.3 Personalised Health and Care 2020

Personalised Health and Care 2020 highlights one of the greatest opportunities of the 21st century, which is the potential to safely harness the power of technology to transform our society, to meet the challenges of improving health and providing better, safer, sustainable care for all.

To date the health and care system has only begun to exploit the potential of using data and technology at a national or local level. The ambition is for a health and care system that enables people to make healthier choices, to be more resilient, to deal more effectively with illness and disability when it arises, and to have happier, longer lives in old age; a health and care system where technology can help tackle inequalities and improve access to services for the vulnerable.

Personalised Health and Care 2020 considers what progress the health and care system has already made and what can be learnt from other industries and the wider economy. It then sets out proposals which include:

- ‘enable individuals to make the right health and care choices’ – citizens to have full access to their care records and access to an expanding set of NHS-accredited health and care apps and digital information services
- ‘give care professionals and carers access to all the data, information and knowledge they need’ – real-time digital information on a person’s health and care by 2020 for all NHS-funded services, and comprehensive data on the outcomes and value of services to support improvement and sustainability
- ‘make the quality of care transparent’ – publish comparative information on all publicly funded health and care services, including the results of treatment and what patients and carers say
- ‘build and sustain public trust’ – ensure citizens are confident about sharing their data to improve care and health outcomes
- ‘bring forward life-saving treatments and support innovation and growth’ – make England a leading digital health economy in the world and develop new resources to support research and maximise the benefits of new medicines and treatments, particularly in light of breakthroughs in genomic science to combat long-term conditions including cancer, mental health services and tackling infectious diseases
- support care professionals to make the best use of data and technology’ – in future all members of the health, care and social care workforce must have the knowledge and skills to embrace the opportunities of information
- this framework explains the aim to deliver this change and what it will mean for patients, services users, citizens and professionals; Child Health Information Services and systems are key to achieving this ambition.

2.4 Supporting strategies and outcome measures for child health

2.4.1 Maternity and children's dataset

Maternity and Children's Dataset (MCDS) is a comprehensive data collection on maternal and child health which is collected from different systems that include maternity, Child Health Information Service Systems and CAMHS systems. Information on child health is collected on topics ranging from birth details, screening results and immunisation to growth measurements on school entry, breastfeeding indicators and social care information.

The maternity and children's dataset is a new dataset specifically developed for all commissioned maternity, child health, and child and adolescent mental health services (CAMHS) as a key driver to achieving better outcomes of care for mothers, babies and children. It comprises three separate information standards for (i) maternity services (ISB 1515), (ii) children's and young people's health services (ISB 1069), and (iii) CAMHS (up to age 19) (ISB 1072).

The maternity and children's dataset supports the Healthy Child Programme and provides comparative, mother and child-centric data that will be used to improve clinical quality and service efficiency; and to commission services in a way that improves health and reduces inequalities. The three information standards that comprise the data set have received full approval from the Information Standards Board for Health and Social Care as information standards for England and are therefore mandated data collections for organisations which provide these services.

In line with a core aim of the Healthy Child Programme being the encouragement of partnerships between agencies in service development, the data items required by the child health dataset as a necessity will relate to domains ranging from primary and secondary care to social services and education. There are no current firm plans to integrate social services or educational systems into a data collection service (although this might be the long-term ideal), and so the national maternity and children's dataset has been designed to collect information at the same standard and granularity as those systems but must currently be recorded in locally based systems.

Implementation of the dataset will, for the first time:

- allow maternal and child health data to be linked (using the NHS number) so that vital information can be used to improve services
- improve accountability, making it easier for the public to access comparative information to support them in making decisions about their care
- record outcomes to contribute to clinical risk management and governance to reduce litigation costs

- provide activity data on which to base mandatory tariffs for acute paediatrics', children's and adolescent mental health services (CAMHS) and children's palliative care
- support the development of maternity networks and changes to the maternity tariff to extend women's choices of maternity care
- underpin the improvement of local information systems to meet dataset standards

Like other clinical datasets this one is designed for secondary use purposes using patient care records, so that clinical information can directly inform the planning and commissioning of services. Without this solution, there is no efficient means of making these data available to commissioners, service providers and stakeholders. CHISs will be required to collect some of the data for the maternity and children's dataset, ensuring that data is collected only once, and used for multiple purposes. The requirements set out in this document reflect and include the requirements of the new dataset.

2.4.2 Public Health Outcomes Framework 2014/2015

Outcome measures for children are an increasing priority area in line with the Public Health Outcomes Framework and the NHS Outcomes Framework. Such measures are essential for service planning and the effective delivery of care to children. The Public Health Outcomes Framework includes an indicator 3.3[1] for population vaccination coverage this indicator will use data from CHIS and cover all vaccination programmes across the life course, as previous evidence shows that highlighting vaccination programmes encourages improvements in uptake levels. In addition, a population based measure of child development at age 2-2.5 years is currently underway and, when finalised, the required information will need to be captured on CHISs together with the accompanying information flows to other parts of the system. Similarly the Children and Young People's Outcome Strategy (announced 26 January 2012) has produced recommendations that are incorporated into this document as part of the future requirements for CHISs.

2.4.3 The Section 7A Agreement Health and Social Care Act (2012)

The Section7A agreement of the Health and Social Care Act 2012 sets out the governance, key deliverables and ambitions for public health functions which are to be commissioned by NHS England. It is agreed annually through tripartite negotiations between Public Health England, Department of Health and NHS England.

A series of service specifications underpin the Section 7A Agreement, setting out the expectations of the service that should be commissioned and the levels of performance

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[1] CHIS will need to provide data by resident populations for some of the sub-indicators included in the 3.3 indicator for population vaccination coverage.

and quality that should be achieved by providers. The Section 7A Agreement provides the mandate through which funding will pass from the Department of Health to NHS England to deliver on these specifications.

The content of each year's Section 7A Agreement is collated and proposed by the various public health programme boards, for prioritisation by the tripartite NHS Public Health Steering Group and onward consideration by the Senior Oversight Group. The resulting recommendations are given for approval by the NHS England Board and the Secretary of State.

2.4.4 National Health Visitor Programme (2011)

A national programme to deliver the Government's commitment by 2015 to:

- increase health visitors by 4,200 full time equivalents
- create a transformed, rejuvenated health visiting service providing improved outcomes for children and families
- improve health and wellbeing outcomes for under-fives
- reduce health inequalities

This programme is being delivered in partnership between the Department Health, NHS England, Public Heath England, and Health Education England. NHS England is responsible under the NHS Mandate Section 7A for commissioning the additional capacity and service transformation for children as part of the National School Nurse Development Programme.

2.4.5 Equity and Excellence: Liberating the NHS (July 2010) (NHS White Paper)

Set out plans for commissioning responsibilities to be devolved to the most local level where possible and appropriate. Subsequently it has been clarified that groups of health professionals operating within the primary care sector as clinical commissioning groups will take on many of the roles previously exercised by Primary Care Trusts. The NHS White Paper placed great emphasis on the importance of information, both for people using services and about those people and professionals providing those services.

2.4.6 Achieving Equity and Excellence for Children (September 2010)

Stressed the importance of sharing information between appropriate professionals to enable delivery of effective care for children, especially vulnerable and at-risk young people.

2.4.7 Healthy Lives, Healthy People (November 2010) (Public Health White Paper)

Set out that in the future public health system, local authorities will undertake many of the public health duties currently discharged by Primary Care Trusts, focused on improving the health of their population. It described a life course approach to protecting and promoting the public's health, which included an emphasis on starting and developing well. The Public Health White Paper emphasised the importance of information in supporting effective planning, commissioning, delivery and evaluation of services.

2.4.8 The Healthy Child Programme (HCP): Pregnancy and the first 5 years of life (2009)

This focused on providing a universal service for improving the health and wellbeing of children, through health and development reviews, health promotion, parenting support, screening and immunisation programmes. Its goals are to identify and treat problems early, help parents to care well for their children, change health behaviours and protect against preventable diseases. The programme is based on a systematic review of evidence and is expected to prevent problems in child health and development and contribute to a reduction in health inequalities.

Actions include:
- help parents develop a strong bond with children
- encourage care that keeps children healthy and safe
- protect children from serious diseases, through screening and immunisation
- reduce childhood obesity by promoting healthy eating and physical activity
- encourage mothers to breastfeed
- identify problems in children's health and development (for example learning difficulties) and safety (for example parental neglect), so that they can get help with their problems as early as possible
- make sure children are prepared for school
- identify and help children with problems that might affect their chances later in life

The Healthy Child Programme which is a prevention and early intervention public health programme offered to all families is led and delivered by health visitors and their teams. This work provides the foundation stage for the Healthy Child 5-19 Programme.

Together these changes represent a significant shift in the way in which Services are planned, commissioned and delivered for health and care, including those provided for children. England has a long tradition of providing preventive, universal care for all Children in the population, recognising the benefits of, for example, immunisation against disease, screening to enable early identification of illness or disability, and the importance of providing support to young families in protecting and promoting the health of their children.

The changes to the health and care system provide an opportunity to further the reach of these programmes by drawing together, in mutual responsibility, the work of local authorities, clinical commissioning groups and local services.
Commissioning of those elements of the 0-5 Healthy Child Programme which are led by health visitors and family nurses, will move from NHS England to local authorities on 1 October 2015.

2.4.9 Information strategy and the shared child health record

In its response to the NHS Future Forum's second report, the Government published an information strategy for health and social care in England. This strategy built on the Information Revolution consultation, which discussed a challenging idea in relation to electronic care records – that these could be used both to deliver safer, integrated care, but also progressively become the main source for all patient and professional information, including secondary uses of such data. Potential secondary uses of care data include population health, clinical improvement, research and commissioning.

CHIS systems are no exception to the expectation that better use should be made of data captured at the point of care and some systems in use around the country are already meeting this requirement, providing both a database of information on a population of children, and supporting the delivery of care to individual children. To achieve this status of being an electronic patient record, as well as a database of information required for secondary purposes, CHISs need to be able to:

- receive information which is relevant for the wellbeing of the child that has been captured during the pregnancy and antenatal period, and has an impact on the child, and that this is made available to the CHISs
- exchange information electronically with other systems, including GP systems and for national data returns
- enable appropriate access by multiple professionals, including those located in primary, community and secondary care settings
- produce a summary report for any individual child capturing the key health events for the purposes of professional review
- to enable care information to be recorded once, shared across boundaries safely and used for multiple purposes
- allow parents, carers and young people to access their health and care records online

This also makes it possible to identify a common core content for child health records, and to inform future commissioning that may seek to address any gaps in current provision and this core content. The child health record exists for each child additional to the GP’s record for all and hospital records for some children, and contains for each child a health protection and promotion section, as well as illness biography. The common core content would form the basis of a shared record of child health and care, and what such a shared record should contain.

3. Operational principles

3.1 Overview

CHIS are currently operated at a local level by providers and commissioned by NHS England until at least 2020 to provide opportunity for upgrading specifications in local contracts. They support a variety of local child health related activities, including immunisation, screening and health and development reviews, and provide opportunity for health promotion.
Due to the evolving nature of the NHS since 1974, systems are not always coterminous with either organisational or geographical boundaries, yet they have to provide information on a number of different population bases.
The extent of CHIS solution and use varies across the country and include local paper forms, home-grown IT solutions and those that already provide an electronic patient record. All CHIS systems should be able to generate lists and schedules for immunisation, surveillance and health promotion services, to enable clinicians to record their key activities and interventions or measurement, screening, assessment and outcomes; incorporating heath protection, health promotion and health data.
The systems are not necessarily well-adapted for specialist services, such as community paediatrics.

3.2 Architectural considerations and principles

A child-focussed public health record must be available to all healthcare professionals with the relevant permissions who have contact with a child. It should adhere to the following principles:

1. A child health record will be built from birth information through to transition to adult services and may contain elements of the maternal record.
2. Significant elements of the child health record will provide the foundation for the child's adult record.
3. Parents/Carers/Children will have access to their records within a consent framework.
4. A child's record must pass from CHIS to CHIS as a child moves from one geographical area of responsibility to another.
5. There will be multi-agency sharing with in an agreed consent framework.

The DH is adopting some of the key principles as identified in the published Information Strategy (The power of information: Putting all of us in control of the health and care information we need, May 2012) to drive interoperability, value for money and usability of the service. These include:

- re-Use: where existing national services and infrastructure exist they should be used in preference to new services or infrastructure, or a compelling business case be produced to support the duplication of location of similar
- adoption and development of existing and new standards including:
  - Maternity Services secondary uses dataset
  - Children and Young People's Health Services (CYPHS) secondary uses dataset
  - Child and Adolescent Mental Health (CAMHS) services secondary uses dataset
  - COVER ISN

All standards (including messaging and interfaces) should make use of existing NHS standards and processes, and implementations should comply with those published by the NHS Information Standards Board. Where new standards are required, they should be based on existing NHS standards and protocols, and should be developed with approval by the NHS England Standardisation Committee for Care Information (SCCI) process to make them available to the wider NHS and Government in the UK.

3.3 Overarching principles

The table below outlines the overarching principles and requirements for all the services and systems involved. The majority of these principles and requirements will be covered in greater detail later in this document. These requirements will help to shape the functionality required to meet the needs of the organisations involved and to act as an interoperable information source for all key stakeholders in the development of CHIS Services. The high level principles supporting the commissioning and procuring of CHIS should be considered the starting place for what the service will deliver.

Req Id	**Overarching principles**
CHISOP001	Access and use of the CHIS must not increase a clinician's workload nor disrupt operation of clinical practice and should be as efficient as or more so than the existing processes.
CHISOP002	The service should be available 24 hours a day, 365 days a year
CHISOP003	The CHIS requirements will support the development of future health and care systems to promote effective improvements and reductions in variability of systems across England
CHISOP004	The CHIS systems must support the use of existing clinical standards and guidance and also be flexible enough to support emerging new Programmes, national standards and guidance
CHISOP005	The system should support the universal and specific services for children, as outlined within; - Section 7 A agreements and requirements (2014/15) - 2015-16 National Health Visiting Core Service Specification (2014)

	- National Health Visitor Plan: progress to date and implementation 2013 onwards(2013) - Health and Social Care Act (April 2012) - National Health Visitor Programme (2011) - Achieving Equity and Excellence for Children (September 2010) - Healthy Lives, Healthy People (November 2010) (Public Health White Paper) http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121941 - Healthy Child Programme (2009) https://www.gov.uk/government/publications/healthy-child-programme-pregnancy-and-the-first-5-years-of-life - UK NSC Screening Programmes - The National Immunisation Programme (http://immunisation.dh.gov.uk)
CHISOP006	The CHIS systems must support improvements in health and care for children with regards to the way in which; - Services are planned - Services are commissioned - Services are delivered
CHISOP007	The CHIS systems must support public health requirements as outlined by Public Health England
CHISOP008	The CHIS systems must support, the capture, storage, use, sharing and reporting of child health information.
CHISOP009	The system should support the delivery of safe and integrated care and over time become the main source for all patient and professional information, including the secondary use of such data, eg Population Health, Clinical Improvement, Research and Commissioning
CHISOP010	The CHIS system must be capable of capturing and reporting the 5 universal elements of the HCP namely Antenatal health promotion visits New baby review 6-8 week assessment 1 year assessment 2-21/2 assessment These elements are being mandated from October 2015 as evidence shows that these are key times to ensure that parents are supported to give their child the best start in life.
CHISOP011	CHIS systems will contain all the child related data items necessary to comply with the following national datasets: - Maternity Services Secondary Uses Data Set http://www.hscic.gov.uk/maternityandchildren/maternity - Children and Young People's Health Services (CYPHS) Secondary Uses Data Set http://www.hscic.gov.uk/maternityandchildren/CYPHS

	- Child and Adolescent Mental Health Services (CAMHS) Secondary Uses Data Set http://www.hscic.gov.uk/CAMHS - COVER ISN They will also produce extracts for dataset submission.
CHISOP012	The system must be able to provide secondary uses information and aggregate reporting at national and local level in order to; - Support quality assurance and commissioning outcomes for local authorities and PHE. - Improve data quality and consistency and thus quality management for the nationally agreed programmes: ie Healthy Child Programme as well as immunisation, screening, and developmental and other progress reviews - Assist in the delivery of other requirements set by the Health and Social care Information centre (HSCIC) or HSCIC for secondary uses purposes - Flag and to focus on the critical linkages between child health delivery and screening systems, maternity records, laboratories and GP practice systems in terms of communication records and provision of failsafe processes - Improve decision making at community and population level in order to address inequalities and outcomes in health and wellbeing of children
CHISOP013	CHIS systems should support extensive system interoperability to deliver the critical linkages between child health delivery systems, maternity records, the personal child health record (PCHR), the eRed Book, national screening systems, laboratories and GP practice systems in terms of communication of records and provision of failsafe processes.
CHISOP014	CHIS systems should support patient access and the provision of information to/or interoperability with a personal child health record (eRed Book)
CHISOP015	CHIS systems should address consent at a national level and thereby disseminate the legal framework for consent and information and data sharing which is vital for the provision of care. The information sharing approaches should be consistent with GMC 0-18 requirements. http://www.gmc-uk.org/guidance/ethical_guidance/children_guidance_index.asp
CHISOP016	CHIS systems must support a summary record of child health information for export to other systems. The proposed subset of this information is contained in the Appendix B.
CHISOP017	In development of the system, consideration should be given to support the integration of information arising from social services and educational information systems, and any other commissioned alternative providers.

Subsequent sections in this document translate these principles into high-level requirements under the following headings:

- general functional requirements– functionality which is common to all child health information services and systems
- service-specific requirements – functionality specific to each component of the child health service
- non-functional requirements – which cover issues of architecture, interoperability of systems and information governance

4. Functional requirements

4.1 General functional requirements

The following high-level requirements will require further elaboration with the supplier and user base to derive detailed system functionality. Functionality described here is common to all or most of the services which are covered by a child health information system. This section must be read prior to reading the service-specific functionality which only describes the information needs of services over and above these general requirements.

Service-specific functionality is outlined in chapters 5-15 of this document and non-functional requirements are addressed in chapter 16.

Each supplier must outline how they will meet each of the following Functional Requirements.
The keywords Must, Should and May should be interpreted as described in section 1.5. Please note that we do not describe datasets and data items in detail in this document as for secondary uses the requirements have already been set out in the Health and Social Care Information Centre’s (HSCIC) Maternity and Children’s Dataset.

The Maternity and Children's Data Set incorporates the following individual information standards/datasets:

- Maternity Services Secondary Uses Data Set
  http://www.hscic.gov.uk/maternityandchildren/maternity
- Children and Young People’s Health Services (CYPHS) Secondary Uses Data Set
  http://www.hscic.gov.uk/maternityandchildren/CYPHS
- Child and Adolescent Mental Health Services (CAMHS) Secondary Uses Data Set
  http://www.hscic.gov.uk/CAMHS

Compliance with these datasets is addressed in chapter 3, Overarching principles.

4.1.1 Use of NHS Number

NHS Number		
CHISCC001	The service must use validated NHS numbers as the unique identifier for receiving, storing, reconciling, updating and sharing information.	MUST
CHISCC002	The system must use the NHS Number to link maternal	MUST

	and child health data[2].	
CHISCC003	The service must use and store a validated NHS Number for each individual. (This must be displayed in the format as outlined from the Information Standards Board for Health & Social Care. ISB 1504, in the required 3 3 4 format (*eg 943 476 2812*)	MUST

4.1.2 PDS Compliance

PDS		
CHISCC004	The system must provide the functionality to search for child patients using usual search mechanisms verified by PDS. The search capabilities should be equal to or improve on PDS simple search and advance traces. This includes the searches for and recording of aliases. Searches on any combination of these names should also be available.	MUST
CHISCC005	The system must perform synchronisation in line with the NHS Spine Service, PDS Compliance Requirements, where a record is accessed and updated.	MUST
CHISCC006	The system must enable the CO through a controlled method, to merge or link dispersed information for an individual person upon recognising the identity of that person.	MUST

4.1.3 National Coding Systems and Reference Data

National Coding Systems and Reference Data		
CHISCC007	The system must use national standards for coding where available, e.g. SNOMED	MUST
CHISCC008	The system must use Organisation Data Service codes.	MUST
CHISCC009	The system must be able and flexible enough to support the associated coding for all dataset items when these become available.	MUST

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[2] When a baby is born it does not have a registered GP until a GMS1 form is completed by a parent. The mother's GP is used as a proxy until the baby is registered in the expectation it will be with the same GP. It should be noted that the parent can register the child with a different GP.

4.1.4 Health Professional Access to Records

Health Professional Access to Records		
CHISCC0010	The system must not impact the ability of the clinician to record children's health protection, health promotion and services data, nor increase or disrupt operation of clinical practice.	MUST
CHISCC011	The system must interface with mobile and agile units to enable a user to record and store data entered at the point of care.	MUST
CHISCC012	The system must support the appropriate access by multiple professionals, including those located in primary, community and secondary care settings.	MUST
CHISCC013	Systems that are accessed by individuals involved in providing care must be updated in real time with record entries against the child’s record.	MUST
CHISCC014	The system must ensure that the privilege level of access to the system is appropriately constrained and applicable to the role of the user.	MUST
CHISCC015	Access to system and records must only to be granted to those with genuine need to access data in provision of care.	MUST
CHISCC016	The system must allow a user to access a child’s record in all settings and locations where care is provided.	MUST

4.1.5 Parent/Guardian/Carer/Young People’s Access to Records

CHISCC017	The system should allow parents, carers and young people online access to their health and care records.	SHOULD

4.1.6 Standard Data Formats

CHISCC018	The presentation of any date & times must be in a standardised format, and consistent with the user Interface standards that the Information Standards Board ratified	MUST

4.1.7 Data Retention

Data Retention		
CHISCC019	The system must be capable of storing a record with appropriate flags for each individual child, until they reach their 25 birthday (or 26th if young person was 17 at conclusion of treatment), or up to 8 years after death. https://www.gov.uk/government/publications/new-study-highlights-positive-impact-of-digital-technology-in-health-and-social-care	MUST

4.1.8 Outcomes

Outcomes		
CHISCC020	The system must be able to record outcomes and to contribute to clinical risk management.	MUST
CHISCC021	The system must be able to support the recording, storing and sharing of Children and Young People's Outcomes (as will be outlined in the Department of Health's Children and Young People's Outcome Strategy) and the Early Years Profile http://atlas.chimat.org.uk/IAS/dataviews/earlyyearsprofile and Health Visitors Dashboard http://www.england.nhs.uk/wp-content/uploads/2014/12/hv-serv-spec-dec14-fin.pdf	MUST
CHISCC022	The system must support the capture of outcome measures for children in line with the Public Health Outcomes Framework and the NHS Outcomes Framework and the Children and Young People's Outcome Framework.	MUST

4.1.9 Interface and Messaging Principles

Interfaces and Messaging Principles		
CHISCC023	Messaging systems used to transmit messages containing personal data about a patient must keep a log of message transmissions. (This log will contain the time, origin, destination of the message, the message ID but not its content).	MUST
CHISCC024	Where appropriate, systems should provide notification of receipt of a message by a recipient (read receipt) when	SHOULD

	requested to do so by the originator.	
CHISCC025	The system must interface data in real time.	MUST
CHISCC026	The system must be able to exchange information electronically with appropriate systems to support the provision of care.	MUST
CHISCC027	The system must be able to record care information once, share this safely across organisational boundaries and enable the use of this information for multiple purposes.	MUST
CHISCC028	The system must support relevant messaging specifications in line with national messaging standards eg syncing of records with PDS, receipt or birth notification messages, and support for receipt of demographic updates from NHAIS via Org Links. Further information on ITKs can be found here http://systems.hscic.gov.uk/interop/background/specs	MUST

4.1.10 Interfaces with other systems

CHIS system providers are responsible for providing electronic interfaces to allow information to be sent and received and where appropriate accessed by Educational, Local Authority and NHS Care System users for direct care purposes. Interoperability of systems is vital to ensure that professionals have up to date information about the health of children for whom they have a responsibility.

CHISCC029	The system must support the electronic exchange of information with other systems, including GP systems and for National Data Returns. Some of these information exchanges are established, but others, for example between CHIS and maternity systems are recommended to be considered for future developments.
	Consideration should be given to;
	- *which other systems/organisations the exchange of information would be undertaken with*
	- *the frequency of the sharing of the information*
	- *the number of concurrent users*
	- *- confirmation about which health events would trigger the sending of information*
	- *automated processes or manually sharing with:*
	    - *Other CHIS systems*
	    - *GP Systems*
	    - *Screening systems – e.g. newborn blood spot, newborn physical examination, newborn hearing and the collation of national UK NSC Key Performance Indicators*
	    - *Maternity*
		MUST

	- *Exeter (e.g. for HPV vaccination details relevant for cancer screening)* - *LA systems* - *Central data collections (eg ImmForm and COVER for immunisations)* - *Others* *The above list is not exhaustive*	
CHISCC030	The system must be able to share the Outcome measures with accompanying information flows to other systems (see CHISCC0018)	MUST
CHISCC031	The system must be able to receive and record school-age “screening” with data from immunisation practitioners and school nurses.	MUST
CHISCC032	The system must be able to notify other CHIS service providers of babies/children/adolescents up to 19 years of age, who have moved out of or in to the area, or from abroad.	MUST
CHISCC033	The system must interface with other systems and include Common Assessment Framework reports, for example.	MUST
CHISCC034	The system must be capable of receiving birth notification messages from PDS.	MUST
CHISCC035	The system must be able to send and receive the child’s record electronically.	MUST
CHISCC036	The system should be able to send and receive information electronically between health and education to support children with complex needs.	SHOULD
CHISCC037	The system must be able to subscribe to and receive results information from NHS Newborn Screening Programmes	MUST
CHISCC038	The system must integrate with an electronic health record (e.g. Personal Child Health Record, eRed Book and GP systems), which all parties, (including parents and adolescents) would collaborate to maintain).	MUST

Common information sharing[3]

Information sharing with other agencies is guided by nationally agreed consent and data sharing rules within legal frameworks and guidance[4].

Hospital	**GP**	**CHIS**	**Item**	**Social care**	**Education**
Y	Y	Y	Disability register	Y	Y
Y[10]	Y	Y	Looked after children health assessments/status	Y	Y
Y	Y	Y	Child protection status	Y	Y
Y	Y	Y	Child protection action processes	Y	Y
		Y	School roll		Y
Y	Y	Y	Special educational needs statement	Y	Y
Y	Y	Y	Special educational needs reviews		Y

Table 1: Common information sharing arrangements that information systems should support

4.1.11 Reporting

Common Reporting		
CHISCC039	The system must be capable of meeting and producing the following reporting requirements: - User Configurable - Predefined - Statutory - By Domain	MUST
CHISCC040	- The system must provide the following reports about an individual patient or group of patients[5] - Number Discharged - Followed Up - Referred - Left Area	MUST

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[3] Some Looked after children services are partly based in acute trusts.

[4] https://www.education.gov.uk/publications/standard/publicationdetail/page1/DCSF-00807-2008 HM Government Information Sharing Guidance for Practitioners & Managers

[5] The CHIS system population should include all children resident in an area, all children registered with a GP in the area, and all children who are in schools within the local area but are neither locally registered nor locally resident. A child's record can be held on more than one CHIS, for example where they live and where they access services, and it is important that both records are maintained with accurate up-to-date information.

	- Arrived Newly into the Area - Died	
CHISCC041	The system must provide reports on the number of Outstanding Appointments for Review (including those for immunisations).	MUST
CHISCC042	The system should be capable of generating reports that enable further data analysis e.g. CSV format.	SHOULD
CHISCC043	The system must be able to produce a summary report for any individual child, capturing the key health events for the purposes of professional review.	MUST
CHISCC044	The system must be able to report to GPs of immunisations undertaken in schools or other venues, e.g. health visitor held clinics.	MUST
CHISCC045	The system must provide reports on the Completeness of Service provision, i.e. Services/Appliances, being provided and services requirements but not being provided.	MUST
CHISCC046	The system must provider reports on children who are due/ overdue various interventions, e.g. immunisations, screens and reviews	MUST
CHISCC047	The system must provide all statutory reports and provide the ability to track children through various pathways, e.g. special educational needs, looked after children.	MUST
CHISCC048	The system must enable the CO to run a report that identifies all children for whom a school has not been recorded.	MUST
CHISCC049	The system must allow the user to write reports that make use of any items of data stored against the child's record. This includes the use of template reports, one off reports and ad-hoc reports.	MUST
CHISCC050	The system must be able to generate reports for front-end users based on any data field combinations and local population configurations.	MUST
CHISCC051	The system must be able to use locally configurable and editable letter templates.	MUST

4.1.12 Electronic Document Management

CHISCC052	It must be possible to associate electronic documents and images (including scanned paper documents) with a child's record.	MUST

4.1.13 Management of Population Cohorts

Required Id	Requirement Description	Priority
CHISCC053	The system must be able to create and maintain a record for all children for whom the CO has a statutory responsibility by including details of; - the registration at a GP practice[6], the school the child is attending and school code that is associated with the CO, or; - where there is no registered GP, the inclusion of the child's postcode of their usual address, placing them inside the geographic area of the CO footprint for school aged children.	MUST
CHISCC054	The system must be able to receive the national list of GP practices and residential postcodes from the Technological Reference Data Update Distribution Service and school codes[7].	MUST
CHISCC055	The system must be able to create and maintain the relationship of GP practices associated to each CO, utilising the nationally maintained mapping of post code to CCG.	MUST
CHISCC056	The system must enable the CO to maintain the area of residential postcodes and school codes within the local authority in a flexible enough way.	MUST
CHISCC057	The system must be able to record which organisations have been contracted to provide services for each child. This includes the arrangement for some services to be provided to school children by the CO regardless of the registration or address of a child.	MUST
CHISCC058	The system must be capable of storing a record for each individual child, where services are being given on behalf of another CO who has statutory responsibility for that child.	MUST
CHISCC059	The system must be capable of creating and maintaining the records of every child within the responsible area of the end user and those treated by the service user, who live outside of that area. This includes storage and maintenance of records of children no longer living in the area, e.g. moved-out records, transfer-out births, stillbirths	MUST

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[6] When a baby is born it does not have a registered GP until a GMS1form is completed by a parent. The mother's GP is used as a proxy until the baby is registered in the expectation they will be registered with the same GP as themselves. Although they may choose to register the child at a different GP practice.

[7] School codes is an addition to this existing requirement.

	and deceased.	
CHISCC060	The system must be capable of holding the current and previous school and children’s centre for a child. This must also include schools that are outside the care community but are attended by pupils who are resident or registered within the care community. *Consideration should be given to the use of locally defined school codes, and nationally defined codes where applicable, provided by the DfE.*	MUST
CHISCC061	The system must be capable of storing a record for children who have moved out of area.	MUST

4.1.14 Dataset Compliance

Required Id	**Requirement Description**	**Priority**
CHISCC062	The system must support the following three dataset where appropriate, including all updated releases: 1.Maternity Services Data Set (MSDS) http://www.hscic.gov.uk/maternityandchildren/maternity 2.Children and Young People's Health Services (CYPHS) data set http://www.hscic.gov.uk/maternityandchildren/CYPHS 3.Child and Adolescent Mental Health Services (CAMHS) data set http://www.hscic.gov.uk/CAMHS The three data sets above combined form the overarching Maternity and Children's Data Set (MCDS) http://www.hscic.gov.uk/maternityandchildren Please note, at time of publication development was underway to combine the current MHLDDS v1.1 and CAMHS v2.0 (which integrates CAMHS v1.0 and CYP IAPT) data sets, forming the new Mental Health Services Data Set (MHSDS). http://www.hscic.gov.uk/mhsds	MUST
CHISCC063	The system must be capable of supporting other approved data sets.	MUST

4.2 Core Child Health Record Content

As stated in the over-arching principles, child health service information systems must support the universal and specific services for children, as outlined within;

- Health and Social Care Act (April 2012) http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted
- Achieving Equity and Excellence for Children (September 2010) https://www.gov.uk/government/publications/achieving-equity-and-excellence-for-children
- Healthy Lives, Healthy People (November 2010) (Public Health White Paper) http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121941
- The National Immunisation Programme http://immunisation.dh.gov.uk which is now also a Public Health Outcomes Framework requirement
- The Healthy Child Programme (HCP) https://www.gov.uk/government/policies/giving-all-children-a-healthy-start-in-life

The requirements below describe both this core content of the child health record but also make reference to a summary child health record which needs to be readily viewable and available for exchange with other systems.

4.2.1 Core requirements

<table>
<tr><th>Required Id</th><th>Requirement Description</th><th>Priority</th></tr>
<tr><td>CHISCR001</td><td>The system must be able to collect child health information and support national aggregation of clinical data about child health, including;
- birth details
- screening results
- immunisation (including pre and post immunisation testing)
- growth measurements (height and weight)
- breast feeding indicators
- social care information
This list is not exhaustive and development of the system must be flexible enough to support additional clinical data requirements.</td><td>MUST</td></tr>
<tr><td>CHISCR002</td><td><table>
<tr><th>Item</th><th>Population</th></tr>
<tr><td>Results of screening</td><td>All</td></tr>
<tr><td>Results of immunisation</td><td>All</td></tr>
<tr><td>Feeding</td><td>All</td></tr>
<tr><td>Gestation age</td><td>All</td></tr>
</table></td><td></td></tr>
</table>

<table>
<tr><td></td><td>
<table>
<tr><td>Head circumference</td><td>All</td></tr>
<tr><td>Weights (inc birth)</td><td>All</td></tr>
<tr><td>Height</td><td>All</td></tr>
<tr><td>Progress reviews</td><td>All</td></tr>
<tr><td>Significant acute or chronic disorder</td><td>Some</td></tr>
<tr><td>Significant family history</td><td>Some</td></tr>
<tr><td>Long-term disorders and therapy</td><td>Some</td></tr>
<tr><td>Intensive Healthy Child Programme</td><td>Few</td></tr>
<tr><td>Disability and or complex conditions</td><td>Few</td></tr>
<tr><td>Special educational needs Education, Health & Care Plan (EHC)</td><td>Few</td></tr>
<tr><td>Child in need assessment</td><td>Few</td></tr>
<tr><td>Common assessment framework</td><td>Few</td></tr>
<tr><td>‘Looked after” child assessment</td><td>Few</td></tr>
<tr><td>Child protection plan</td><td>Few</td></tr>
</table>
A summary child health record will be viewable and capable of exchange consisting of:
</td><td></td></tr>
<tr><td>CHISCR003</td><td>The child health summary record must be readily accessible for every child and parent/carer and agency involved in the child’s care.</td><td>MUST</td></tr>
<tr><td>CHISCR004</td><td>The system must be able to provide the facility to record the parent/guardian’s consent or withholding of consent to release data to any department of the local authority, to schools, or any other named agency.</td><td>MUST</td></tr>
<tr><td>CHISCR005</td><td>The system must be able to exclude those withholding consent when producing reports to be shared.</td><td>MUST</td></tr>
<tr><td>CHISCR006</td><td>The system must be able to provide the facility to record why information was released if no consent given along with the date the information was released, by and to whom.</td><td>MUST</td></tr>
<tr><td>CHISCR007</td><td>When information is released without consent, the system must enable the selection of standard reasons, which could include:
· the law sets aside confidentiality, e.g. Section 251 of the NHS Act 2006
· the law overrides confidentiality, e.g. Section 47 of Children Act (to protect a vulnerable child)
· the disclosure is ordered by a Court
· the public interest served by disclosure is sufficient to override confidentiality considerations.</td><td>MUST</td></tr>
</table>

CHISCR008	The system must be able to record the mandated service points for the Healthy Child Programme: antenatal visit, new birth visit, 6-8 week review, 1 year review and 2 to 2.5 year review. To enable this, the system also needs to be able to record and store all data items in the Health Visitor dashboard	MUST
CHISCR009	The system must be able to record and store the population based measure of child development at age 2 to 2.5 years as specified by the Public Health Outcome Framework (Indicator 2.5: child development at 2–2.5 years https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/382115/PHOF_Part_2_Technical_Specifications_Autumn_2014_refresh_02.12.2014_FINAL.pdf)	MUST
CHISCR010	The system must be able to record and store the immunisation data required for the Public Health Outcomes Framework indicator 3.3: population vaccination coverage. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/382115/PHOF_Part_2_Technical_Specifications_Autumn_2014_refresh_02.12.2014_FINAL.pdf)	
CHISCR011	The system must record and support the long term management of children with acute or chronic disorders.	MUST
CHISCR012	The system must support the ability for each healthcare professional to record relevant core items for each child for the universal programme in whatever service this has taken place. If this is a review that has taken place with no significant items which justify a detailed record being made this must also be supported, ie it must be possible to record that the review has taken place even when the review has no significant outputs.	MUST
CHISCR013	The system must be capable of recording information pertaining to the unborn child and to ensure that this, and information about the family relevant to the child in question, is incorporated seamlessly into the baby's record at birth. This information will come from and need to be sent to a variety of sources, all of which must be supported, e.g. Maternity, GP, Labs, Genetics Service and Transfusion Service.	MUST
CHISCR014	The system must enable a health professional to record any special needs requirements of a child.	MUST
CHISCR015	The system must support children services handover to adult services.	MUST
CHISCR016	The system must record and support the long term management of children with mental health issues.	MUST
CHISCR017	The system must be able to schedule regular reviews of a child's health assessment.	MUST

CHISCR018	The system must be capable of recording the name and role of the healthcare professional treating or screening the child.	MUST

4.2.2 Decision Support – Indicators, Prompts, Alerts[8]

Req Id	**Requirement Description**	**Priority**
CHISCR019	The system must ensure that any healthcare professional involved in any formal reviews of, or delivery of care to a Looked After Child is made aware of the child's special status, and, in addition, of the presence of a Child Protection Plan, and any identified Special Needs. *Consideration should be given to any special status coding and where this is available, ideally this should be used.*	MUST
CHISCR020	The system must provide indicator information of the child's universal status which should be immediately available when accessing the record. - Vulnerable children - Children in need (eg children with disability and complex care programmes including those of life limiting disorders; and/or those with health or special educational needs in school) - Children "looked after" - Children with a child protection plan (requiring safeguarding approaches to be implemented). Consideration should be given to any 'Status Indicator' coding and using these where applicable. Consideration for how all this information is displayed should be given.	MUST
CHISCR021	On the initial screen the system must display the Child's protection plan status.	MUST
CHISCR022	On the initial screen the system must display the child's Child with Special Educational Needs status.	MUST

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[8] Please note, the requirement to display young offender status on the initial screen has been removed..

CHISCR023	On the initial screen the system must display the child's Disability status.	MUST
CHISCR024	On the initial screen the system must display the child's Continuing Care status.	MUST
CHISCR025	On the initial screen the system must display the child's Looked After Child status.	MUST
CHISCR026	On the initial screen the system must display the child's Fostered or Awaiting Adoption status.	MUST
CHISCR027	On the initial screen the system must display the child's Leaving Care status.	MUST
CHISCR028	On the initial screen the system must display the child's Excluded (from school) status.	MUST
CHISCR029	On the initial screen the system must display the child's Homeless, Refugee, Asylum Seeker or Traveller status.	MUST
CHISCR030	On the initial screen the system must display the child's Transition into Adult Services status.	MUST

CHISCR031	On the initial screen the system must display the child's Due/ Overdue to Various Interventions (eg Immunisations, Screens, Review) status.	MUST
CHISCR032	The system should support the identification of how to deliver the most services to children through the fewest number of appointments, e.g. one-stop clinics where children with complex needs see a variety of professionals, e.g. paediatrician to access developmental needs on same day as being reviewed by paediatric neurosurgeon; e.g. attending local clinic for immunisation as well as developmental review.	SHOULD
CHISCR033	The system should support the decision-making process on whether to move a child onto a different “pathway” or branch of a “pathway” such as specialised pathways for targeted services, or, in more general terms, from “universal” (provided to all children) to “progressive” (additional services for those children meeting specific criteria) or “intensive” (rigorous programmes for the most at risk or in need children/families). The pathways described must be configurable to support local requirements; this may include the incorporation of any nationally defined pathways.	SHOULD
CHISCR034	The system should support the decision-making process on whether to move a child onto; a different “need classification”, e.g. following an encounter it may be appropriate to initiate a review with other professionals with a view to identifying the child as being “in need”.	SHOULD

4.2.3 Caseload Management

CHISCR035	The system must be capable of associating a health professional/team with each individual child for a particular service, eg health visitor/school nurse.	MUST
CHISCR036	The system must enable a health professional and/or team to have read/write access to all pertinent information relating to a child for whom they have responsibility to provide care.	MUST

4.2.4 Tariffs

Req Id	Requirement Description	Priority
CHISCR037	The system must provide activity data for present mandatory tariffs and future development of tariffs for child health	MUST
CHISCR038	The system must enable the use of National tariffs including Child Health & Maternity.	MUST
CHISCR039	The system should allow localisation of tariffs.	SHOULD
CHISCR040	The system must be capable of providing automated reporting to open Exeter for payment purposes.	MUST

4.2.5 Mental Health

Req Id	Requirement Description	Priority
CHISCR041	The system must record and support the long term management of children with mental health issues.	MUST

4.2.6 Scheduling

Req Id	Requirement Description	Priority
CHISCR042	The system must be able to generate lists and schedules (for Immunisation, Surveillance and Health Promotion Services^) and enable this functionality to be integrated, enabling clinicians to record their work with children as well as heath protection, health promotion and health service data. *Consideration should be given to which systems should be able to generate lists and schedules, not just the CHIS.* ^ 5 core areas of the Healthy Child Programme will be mandated when commissioning transfers to local authorities in October 2015. They are initial antenatal visits, new baby reviews and child development assessments at 6-8 weeks, one year, and 2 to 2.5 years.	MUST
CHISCR043	Where the status is changed to 'Deceased' the system must cancel all appointments or planned activity for the child, eg immunisation schedule.	MUST

4.3 References

Ref:	Title	Ref. Number and/or URL	Version
4.1	NHS Care Record Guarantee	http://www.nigb.nhs.uk/guarantee	2011
4.2	HM Government Information Sharing Guidance for Practitioners and Managers	https://www.education.gov.uk/publications/standard /publicationdetail/page1/DCSF-00807-2008	2008
4.3	HSCIC A guide to confidentiality in health and social care	http://www.hscic.gov.uk/media/12822/Guide-to-confidentiality-in-health-and-social-care/pdf/HSCIC-guide-to-confidentiality.pdf	V1.1 2013

Service and Domain Specific Requirements

The following sections contain requirements particular to a domain, for example, ‘Registration’ or to a specific service provided by child health professionals, for example, Immunisation.

General functional requirements which are common to more than one service or domain, for example, ‘Reporting’ are not repeated in this section. Readers are strongly advised to familiarise themselves with chapter 4 prior to reading this section.

Similarly chapter 16 details the non-functional requirements for CHIS systems such as conformance to information governance, role-based access, security audit etc. Again these are common requirements across services so are not repeated here.

5. Registration and management of demographics

5.1 Introduction

This chapter addresses the issue of which children a CO should hold details on and what is the status of the CO's responsibility towards the children in its database. There is considerable uncertainty among many professionals involved in the delivery of care to children as to where ultimate responsibility lies, in particular where children live near the border with another CO. This chapter also addresses the functional requirements of maintaining a register of statutory responsibility as part of the information requirements specification, which are over and above the general functional requirements outlined in Chapter 4, which must be read prior to consideration of this chapter.

5.2 Information data flows

5.2.1 Registration Overview

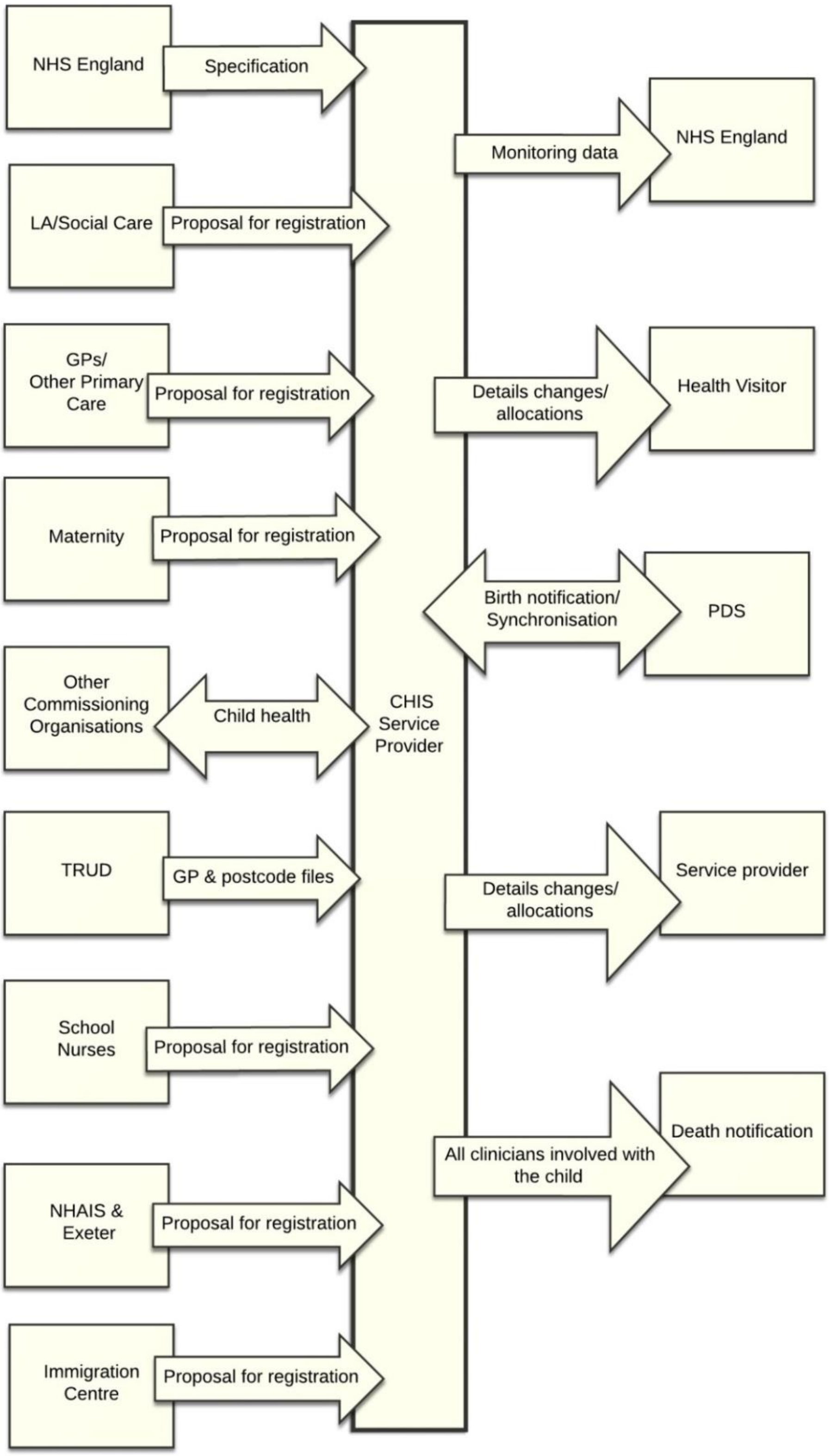

Diagram 1: Child registration and deregistration data flows and required external interfaces

5.2.2 Information data flows table

Originator	Recipient	Dataset/ Information
CHIS system[9]	Other CHIS systems	Child Health Records
CHIS system	Health Visitor	Details Changes/Allocations
CHIS system	Service Provider	Details Changes/Allocations
CHIS system	PDS	Exit Posting Information
CHIS system	All Clinicians involved with the Child	Death Notification
CHIS system	NHS England	Monitoring Data
Immigration Centre	CHIS system	Registration
Local Authority Social Care	CHIS system	Proposal for Registration
Maternity	CHIS system	Proposal for Registration
NHAIS & Exeter	CHIS system	Proposal for Registration
GP	CHIS system	Proposal for Registration
Other Primary Care	CHIS system	Proposal for Registration
Other COs	CHIS system	Child Health Records
PDS	CHIS system	Birth Notifications
TRUD	CHIS system	GP & Postcode Files
School/LA	CHIS system	Proposal for Registration
NHS England	CHIS system	Specification

5.3 Functional requirements

5.3.1 Maintaining a register of statutory responsibility

The CO should ensure that their database includes all children for whom they have a statutory responsibility. This includes the child population resident within the local area, the child population registered with GP practices in the local area, and all children who are in schools within the local area but are neither locally registered nor locally resident.

The list of which GP practices and schools and residential postcodes are associated with each CO are maintained centrally on a national basis and published through

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[9] Please note, the data flow diagram above features the term ‘CHIS service provider’, and ‘CHIS system’ is then used in the table above. CHIS system is the preferred term.

Technology Reference Data Update Distribution Service. Further work will be required by NHS England to establish the footprints of COs responsible for CHIS in the future system. Continual work will be required as commissioning arrangements evolve and the possibility of service and CHIS provision is re-commissioned. Hence CHIS systems need to be sufficiently flexible to allow such changes to be reflected in their databases.

5.3.2 Status of responsibility of the CO to the child

It is necessary to be able to identify whether the CO has the statutory responsibility for the child. If the child is the responsibility of the CO but the delivery of certain services have been contracted to multiple providers it should be possible to record which organisations have been contracted to provide which services for the child. This requirement includes the arrangement for some services to be provided to school children by the CO regardless of the registration or address of the individual children.

Changes in a CO’s scope of responsibility can be triggered by a number of events as outlined in the following sections. In relation to each child, the CO must maintain a list of services that the CO is responsible for fulfilling and, where appropriate, record the commissioning organisation for all aspects of the service.

5.3.3 Registration and deregistration

Information regarding children who need to be registered can come from:
- PDS (as birth notification or other update)
- GP Practices
- maternity service
- other community and primary care services
- school lists
- local education authority
- local authority social care
- hospital services
  immigration centres
- NHAIS (GP practice lists maintained by Primary Care Service Agencies)
- other COs

Types of registration include:
- registration upon birth: upon receipt of a PDS birth notification a child record must be created
- move in from other CO: A child record should be created when a child moves in from another CO. A process should be put in place to transfer the record from the previous CO in as complete a form as possible

- immigration: A child record should be created when a child moves into the CO's jurisdiction from another country, including another home country. A process should be put in place to, where possible, obtain as many details from the child's previous health service.

By "deregistration" all that is meant is that the child's record status is changed to indicate that they are no longer the responsibility of the CO. The reasons for this can include:

- transfer to another CO: the CO must be able to alter the status to indicate that it no longer has statutory responsibility for the child and upon request the CO must be able to send a detailed record to the new CO. The CO must record a forwarding address for the child, or if not known record as "address not known". It may be that the CO still retains responsibility for delivering services under by arrangement with the new responsible CO
- move abroad/emigrate: The CO must be able to alter the status of the child's record to indicate that it no longer has statutory responsibility for the child. This is performed on PDS (known as an "exit posting'). Upon request the CO must be able to send a detailed record to the new health service. The CO must record a forwarding address for the child, or if not known record as "address not known"
- death: Where the status is changed to deceased, a date must be entered and a date of death must cancel all appointments or planned activity for the child. A cause of death must, if known, be recorded using recognised coding. Procedures should be in place to ensure that health professionals, including the child death review panel, involved in the care of the child are made aware of the child's death. In all cases CHIS should update PDS if aware of a death and if the death status has been found on PDS while tracing, should follow the procedures for example, enter date of death, and cancel all appointments.

5.3.4 Allocation to health visitor or school nurse

If the child does not have an allocated health visitor or school nurse, the CO should allocate a health visitor (or health visiting team) or school nurse team to a child and make available all pertinent information relating to the child.

5.3.5. Notifiable congenital malformations

The CO should be able to record details of any notifiable congenital malformations of a child using standard codes.

5.3.6 Storage and tracking of records

The CO must provide storage of the records of:

- every child aged 0-19 years for which the CO has statutory responsibility (the records must be kept until the child is 25 years old)
- children no longer living in the area, eg moved-out records, transfer-out births
- every child for which the CO provides services under an arrangement with another CO who has the statutory responsibility for the child.

The CO must be able to record the tracking of records, ie record source of records and date received or details of where records have been sent and when.

5.3.7 Demographic updates

The system should be able to send and receive demographic details to enable an up to date record.

5.3.8 Maintain family relationship between records

It should be possible for a CO to maintain linkages between the child and their siblings (including half and step siblings) and parents through recording NHS numbers.

5.3.9 Maintaining patient and family preferences

It should be possible to record and maintain patient/family preferences and concerns, such as with language, religion, culture, medication choice, invasive testing, compliance with the Mental Capacity Act 2005, and advance directives. It should be possible for such information to be incorporated in relevant communications and, in addition, made available to staff who will come into contact with the child and immediate family.

5.3.10 Tracking schools

It should be possible for the CO to keep a record of the child’s current and previous school. This must also include schools that are outside the care community but are attended by pupils who are resident or registered within the care community.

It should be possible for the CO to be able to run a report that identifies all children for whom a school has not been recorded.

5.3.11 De-duplicating, merging and correcting records

The CO must be able, through a controlled method, to merge or link dispersed information for an individual person upon recognizing the identity of that person.

If health information has been mistakenly associated with a person, then the CO must provide the ability to mark the information as erroneous in the record of the person in which it was mistakenly associated and represent that information as erroneous in all outputs containing that information.

If health information has been mistakenly associated with a patient, the CO must provide the ability to associate it with the correct patient. Subject access requests

5.2.21 A printout of a whole record, conforming to the Data Protection Act, must be available to respond to any access to records requests.

5.4 Electronic interface requirements

5.4.1 Overview

This section describes any interfaces for which standards have been set. Personal demographics service (PDS) issues birth notification messages, details of which can be found in the current Message Implementation Manual. http://systems.hscic.gov.uk/demographics/births or direct to the supporting documentation (including compliance documentation) at: http://systems.hscic.gov.uk/demographics/births/supporting-documents
There is a need to be able to record information pertaining to the unborn child and to ensure that information about the family relevant to the child eg hepatitis B status is incorporated seamlessly into the baby's record at birth.

5.4.2 Electronic interface requirements

Req Id	**Requirement Description**	**Priority**
CHISRE001	The system must be able to receive and send registration and deregistration information to all relevant organisations and agencies involved.[10]	MUST
CHISRE002	The system must be capable of utilising existing interfaces and where feasible have the flexibility for	MUST

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[10] Where more recent information is held on the CHIS regarding a child than on the PDS, this will be reconciled. This process is addressed in the section 4.1.9 Interface and messaging principles within chapter 4 of this document.

	new interfaces for all sources of Registration and Deregistration of children for whom the CO has statutory responsibility. The following list is for illustrative purposes only and is not an exhaustive list; - PDS (see 5.2.13 in the Information Requirements Specification) - Maternity Service - Other Community and Primary Care Services - School Lists - Local Education Authority - Local Authority Social Care - Hospital Services - Immigration Centres - Exeter - Other CHIS service providers	
CHISRE003	The system must be able to receive notifications and updates from PDS and upon receipt a child record must be created.	MUST
CHISRE004[11]	The system must be able to send a detailed record to the new CHIS service provider.	MUST
CHISRE005	The system must be able to receive notifications from other CHIS service providers including the child's previous records.	MUST
CHISRE006	The system must be able to receive records relevant to the child's health and care, transferred from the previous system/organisation using the mandatory core data sets as a minimum.	MUST

5.4.3 Registration Core Components

Req Id	Requirement Description	Priority
CHISRE007	The system must be able to record and display the status of the COs responsibility for each child within its database.	MUST
CHISRE008	The system must be able to record the different types of registration including; - Registration upon Birth - Move in from another CO's area of responsibility - Immigration: A child record should be created when	MUST

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[11] Please note at time of publication in 2015, information standards had not been developed for CHISRE04, 05, 06, 07, 10, 11, 12 and 13.

	a child moves into the CO's jurisdiction from another country, including another home country.	
CHISRE009	The system must be capable of creating a record; - On receipt of a birth notification from PDS - On receipt of a manual birth notification - When a child moves in from another CO geographical area - For a child immigrating in to the area from another country including home countries Where receipt of information has been received the system must support this either electronically or manually and be able to update records accordingly.	MUST
CHISRE010	The system must be capable of generating a record transfer request for all children transferring into the CO's geographical area of responsibility.	MUST
CHISRE011	The system must be able to import and store child health information from other organisations. Consideration should be given to what constitutes a complete record, when this is imported from other CHIS services providers including any standards used and any datasets provided to ensure these can be supported. A complete record must include a full vaccination history.	MUST
CHISRE012	The system must be able to send a detailed record to a new CHIS provider.	MUST
CHISRE013	The system must be capable of creating a record for export where a child is registered with another CO. This should be done electronically.	MUST
CHISRE014	Where the death of a child has been identified the system must inform all health professionals involved in the care of the child, of the child's death and also the lead clinician for the child death review process, according to local processes.	MUST
CHISRE015	Child death: where the status on CHIS is changed to deceased, a date must be entered and a date of death must cancel all appointments or planned activity for the child.	MUST
CHISRE016	The system must be able track records, including the Source, the Date received, the Date Sent and the CHIS to whom it has been sent.	MUST
CHISRE017	The system must enable the creation/ maintenance/ removal of linkages between a child and their siblings, parents and carers/guardians.	MUST

CHISRE018	Where adoption of the child has taken place, the system must not maintain a family link with pre-adoption family.	MUST
CHISRE019	The system must display the data fields below, on one screen or homogenised area to allow quick access. Please refer to the NHS Data Dictionary for data standards for items such as address, post code, telephone numbers, and to PDS specifications as there are sometimes variations from the NHS Data Dictionary and need to be used where there is interaction with PDS. Data fields: - surname (previous and alias) - forenames - date of birth - address - postcode - home and mobile phone numbers - residence area - NHS Number (check digit validated when manually entered) - status (NHS Number status[12]) - GP - Health Visitor - treatment centre - exam centre - location of paper files - school attended - ethnicity of both mother & baby - ethnicity – the application has the ability to record that a request for information was declined - public health nurse team code - gender - CO of residence (ODS code)[13] - CO of registration - linked to GP practice (ODS code) - GP Practice (linked to CO code) (ODS code)	MUST
CHISRE020	The system must be capable of making available information about patient/family preferences and	MUST

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[12] NHS Data Dictonary includes the NHS number status indicator codes http://www.datadictionary.nhs.uk/data_dictionary/data_field_notes/n/nhs/nhs_number_status_indicator_code_de.asp?shownav=1

[13] http://systems.hscic.gov.uk/data/ods

	concerns, such as with language, religion, culture, medication choice, invasive testing, compliance with the Mental Capacity Act 2005, and advance directives, to staff who will come into contact with the child and immediate family where appropriate. Where patient choice about treatment is expressed, this should also be captured. E.g. it is important that administrative staff know that an individual may be deaf.	
CHISRE021	Where a child has had a still born sibling the system must record antenatal/neonatal information pertaining to the details of that still birth and unborn baby.	MUST
CHISRE022	The system may enable the CO to create, maintain and remove linkages to paternal records that may be available via maternity records, in line with local agreements, and national protocols for information governance and data protection.	MAY

5.5 Future developments

The following is for information, due to work still in development:

- exchange of information between CHIS, maternity record and PCHR:
  An electronic version of the PCHR, ideally integrated with an electronic health record, which all parties (including parents and adolescents) would collaborate to maintain
- link to the maternity/newborn record: There is a need to be able to record information pertaining to the unborn child and to ensure that information about the family relevant to the child is incorporated seamlessly into the baby's record at birth. And that relevant information contained in the maternity record is transferred electronically to the CHIS system, which could potentially be linked to the registration of the child's NHS number. Ideally this should also start the information population of the PCHR

6. Safeguarding

6.1 Introduction

The requirements in this chapter relate specifically to safeguarding aspects of the Child Health Information Service.
The Government has defined the term “safeguarding children” as:
“The process of protecting children from abuse or neglect, preventing impairment of their health and development, and ensuring they are growing up in circumstances consistent with the provision of safe and effective care that enables children to have optimum life chances and enter adulthood successfully.”

Safeguarding should be woven into the delivery of all child health services. References are made in a number of chapters within this specification to safeguarding issues, including the means of identification and assessment. Further background on safeguarding requirements can be found via https://www.gov.uk/childrens-services/safeguarding-children

This chapter focuses on safeguarding-specific information systems issues, such as coding schemes and integration with national systems that contribute to safeguarding which are over and above the general functional requirements outlined in Chapter 4, which must be read prior to consideration of this chapter.

6.2 Information data flows

6.2.1. Safeguarding overview

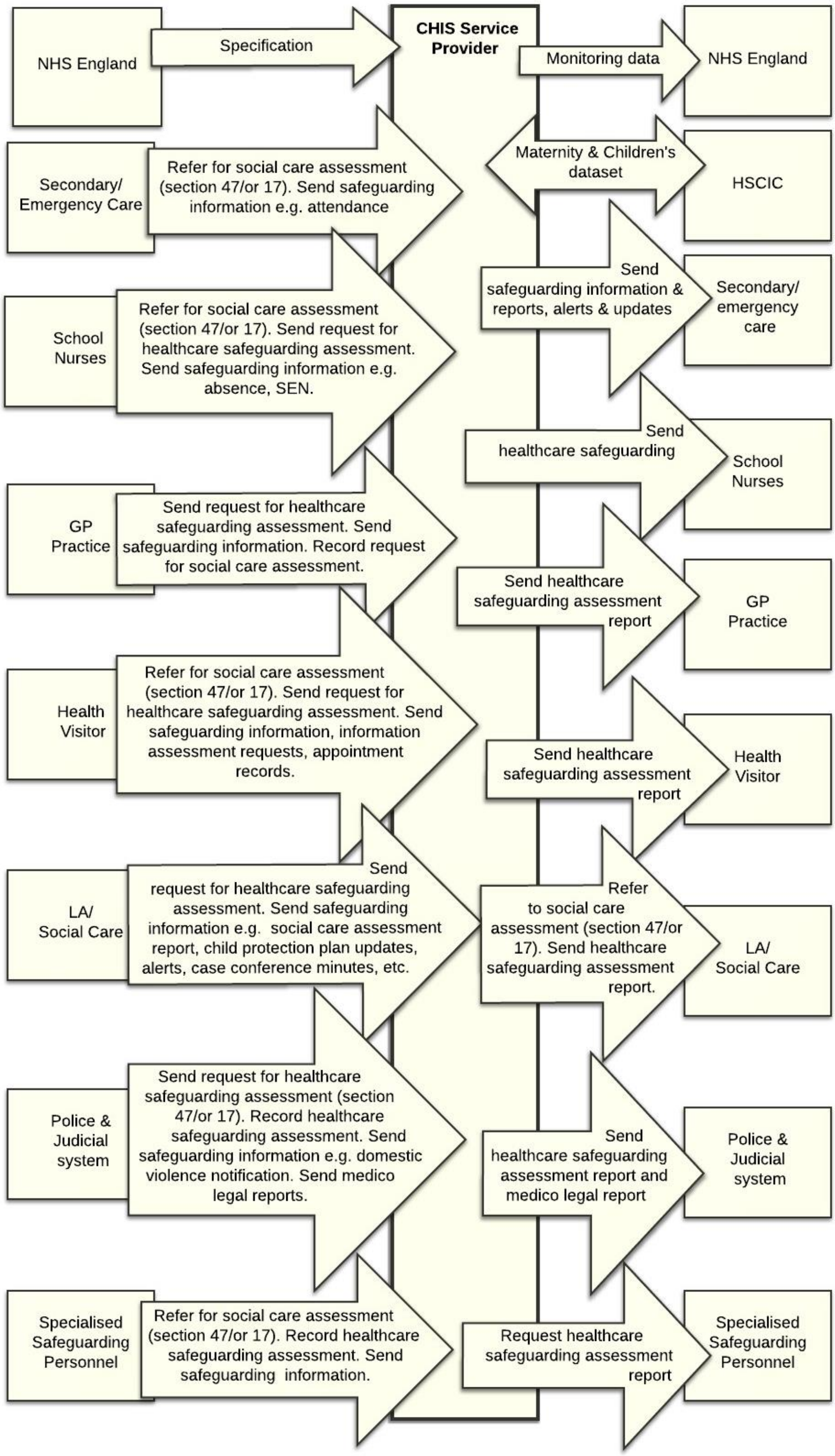

Diagram 2: Safeguarding data flows and required external interfaces

6.2.2 Information data flows table

Originator	**Recipient**	**Dataset/ Information**
CHIS system[14]	Secondary & Emergency Care	Safeguarding Information & reports, alerts and updates
CHIS system	HSCIC	Maternity & Children's Dataset
CHIS system	School Nurses	Social and Health Care safeguarding reports
CHIS system	GP	Health safeguarding assessment report, Care plan report, Letters Discharge reports
CHIS system	Health Visitor & PHCR	Healthcare safeguarding assessment report Reports and updates
CHIS system	Local Authority/ Social Care	Referral for Social care assessment (Section 47/or Section 17). Healthcare safeguarding assessment report
CHIS system	Courts/Judicial system (electronic interface not yet available)	Healthcare safeguarding assessment report and Medico legal report
CHIS system	Specialised Safeguarding Personnel	Request for Healthcare safeguarding assessment
CHIS system	NHS England	Monitoring Data
Secondary & Emergency Care	CHIS system	Refer for Social care assessment. (Section 47/or Section 17). Send Safeguarding information e .g. attendance at A+E Episode level, Care plans
School Nurses	CHIS system	Refer for Social care assessment. (Section 47/or Section 17). Send Request for Healthcare safeguarding assessment. Safeguarding information e.g. absence/SEN

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[14] Please note, the data flow diagram above features the term ‘CHIS service provider’, and ‘CHIS system’ is then used in the table above. CHIS system is the preferred term.

GP	CHIS system	Request for Healthcare safeguarding assessment. Safeguarding information. Request for social care assessment. Notification of Health issues
Health Visitor	CHIS system	Request for Health care assessment, Notification of family/housing/safety concerns Record of attendance (including did not attends). Refer for Social care assessment (Section 47/or Section 17). Request for Healthcare safeguarding assessment. Send Safeguarding information. Information assessment requests, Appointment records.
Local Authority Social Care	CHIS system	Requests for Healthcare safeguarding assessment. Send Safeguarding Information e.g. Social care assessment report, Child protection plans updates, alerts, Case Conference minutes etc.
Courts/Judicial system	CHIS system (electronic interface not yet available)	Safety concerns, notification of domestic violence. Requests for Healthcare. Safeguarding assessment [Section47/Section17]. Send Safeguarding information egeg Domestic Violence notification. Medico legal reports
Specialised Safeguarding Personnel	CHIS system	Refer for Social care assessment [Section47/Section17]. Record Healthcare Safeguarding assessment. Send Safeguarding information
HSCIC	CHIS system	Maternity & Children's Dataset
NHS England	CHIS system	Specification

6.3 Functional requirements

6.3.1 Maintain safeguarding dataset

To conduct safeguarding responsibilities, a CO must maintain a record of relevant information from many different sources, as is demonstrated by the diagram. This includes visibility of a child’s status such as having a child protection plan or being looked after. Such data may be more reliable with the introduction of the Child

Protection Information Sharing Project (CPIS).

6.3.2 Share safeguarding dataset with local authority

CO systems must be able to receive relevant information from the local authority such as notification of a child protection plan or looked after plan. Likewise health services safeguarding information should be easily shared with the local authority as the statutory agency for safeguarding children subject to local data sharing agreements.

6.4 Electronic interface requirements

Req Id	Requirement Description	Priority
CHISSR001	The system must be capable of utilising existing interfaces and, where feasible, have the flexibility for new interfaces for all safeguarding activities pertaining to children.	MUST
CHISSR002	The system must be able to receive relevant information from the local authority such as notification of a child protection plan or statutory order.	MUST
CHISSR003	Health services safeguarding information must be easily shared with the Local Authority as the statutory agency for safeguarding children, subject to local data-sharing agreements.	MUST
CHISSR004	The system must be capable of sending and receiving where appropriate child safeguarding information requirements.	MUST

6.5 Core components

6.5.1 Target cohort and schedule

All children should be subject to checks for safeguarding issues.

6.5.2 Core components requirements

Req Id	Requirement Description	Priority
CHISSR005	The system must support the capture of the following information when formal reviews of the child’s health are conducted; - Care status from social care	MUST

	- Parental responsibility - Previous and current addresses - Social worker - Birth parent - Current carer - For review health assessment update on Healthy Child Programme and other actions Access to any court reports	
CHISSR006	The system must clearly highlight if a child has a Child Protection Plan and what the status of that plan is during any review.	MUST

6.6 References

Ref: no	File CM Reference number or equivalent	Document title	Version No
6.6.1	https://www.gov.uk/childrens-services/safeguarding-children	Department for Education Safeguarding children	
6.6.2	http://systems.hscic.gov.uk/cpis	Child Protection Information Sharing Project (CPIS)	

7. Newborn and infant physical examination (NIPE)

7.1 Introduction

The requirements in this section relate specifically to Newborn and Infant Physical Examination aspects of CHIS, which are over and above the general functional requirements outlined in Chapter 4 of this document, which must be read prior to consideration of this chapter.

The newborn and infant physical examination (NIPE) is offered to all babies. The initial examination should take place within the first 72 hours of birth and again at 6-8 weeks of age. It includes screening for developmental dysplasia of the hip, congenital heart conditions, congenital cataract and undescended testes in boys; in addition a full physical examination including detection of some congenital abnormalities is undertaken. The 6-8 week examination is the responsibility of the child's GP.

Each of these conditions has a pathway of care and is distinct from the general newborn examination, which may detect other congenital abnormalities for which there is not a formal screening programme. Where a possible abnormality is detected the baby is referred for a specialist assessment.

This chapter describes the situation that will exist when the NIPE Screening Management and Reporting Tools (SMART) IT System is fully adopted. The SMART IT system is currently being rolled out across England. Further information can be found via http://newbornphysical.screening.nhs.uk/it

7.2 Information data flows

7.2.1 NIPE overview

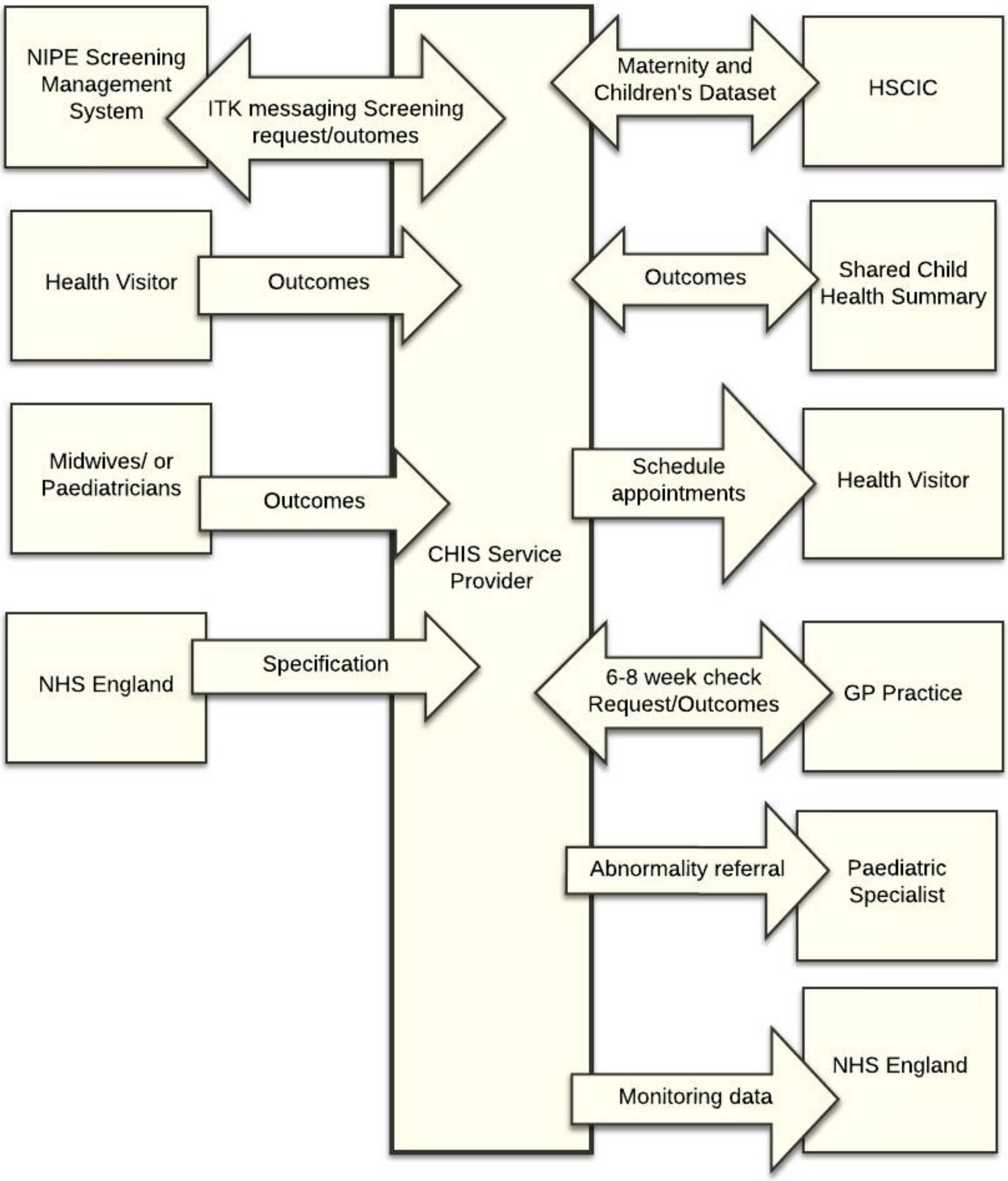

Diagram 3: Newborn infant physical examination data flows and required external interfaces

7.2.2 Information data flows table

Originator	Recipient	Dataset/ Information
CHIS system[15]	HSCIC	Maternity & Children's Dataset
CHIS system	Child Health Summary Record	Outcomes
CHIS system	Health Visitor & PCHR	Schedule appointments
CHIS system	GP	6-8 week check request/outcome
CHIS system	Paediatric Specialist	Abnormality Referral
CHIS system	NHS England	Monitoring Data
GP	CHIS system	Outcomes of the 6-8 week check
Health Visitor & PCHR	CHIS system	Outcomes
NIPE Screening Management System	CHIS system	Outcomes of screening
Child Health Summary Record	CHIS system	Outcomes
HSCIC	CHIS system	Maternity & Children's Dataset
NHS England	CHIS system	Specification

7.3 Functional requirements

7.3.1 Run failsafe process

The CO must ensure that all the children for whom they are responsible are offered the NIPE. To ensure that all eligible children are offered the 6-8 week physical examination the CO must be able to schedule a daily report that lists children with the following characteristics:

- they are aged between 6-8 weeks
- they are the responsibility of this CO
- no notification of the 6-8 week physical examination results or dissent to all investigations are recorded

The report should indicate the process status for each child in the list, eg “no action taken.

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[15] Please note, the data flow diagram above features the term ‘CHIS service provider’, and ‘CHIS system’ is then used in the table above. CHIS system is the preferred term.

7.4 Electronic interface requirements

Req Id	Requirement Description	Priority
CHISPE001	The system must be capable of receiving and sending outcomes from maternity services, GPs and Health Visitors as outlined above in data flows section above.	MUST
CHISPE002	The system must be capable of interfacing with screening management systems to receive screening outcomes via the national standard ITK CDA subscription and newborn results message	MUST
CHISPE003	The system must be capable of creating a referral for specialist assessment & treatment when a possible abnormality is detected.	MUST
CHISPE004	The system must be capable of notifying the NIPE screening management system of a referral for specialist assessment & treatment when a possible abnormality is detected.	MUST

7.5 Core compontents

7.5.1 Target cohort and schedule

The primary screening process will be managed by the central NIPE screening management system when fully implemented, but the CO has responsibility for ensuring coverage of all of the children for which it is responsible, and for assuring the quality of the service.

7.5.2 Core components requirements

Req Id	Requirement Description	Priority
CHISPE005	The system must be capable of supporting the NIPE process for all the children for whom the CO is responsible.	MUST
CHISPE006	The system must be capable of providing an overdue alert for NIPEs, where there have been no outcomes have been received from the NIPE screening service.	MUST
CHISPE007	The system must capture the NIPE screening status for each child e.g. screened/not screened.	MUST
CHISPE008	The system must be capable of placing requests for follow up NIPEs for the 6-8 week review.	MUST
CHISPE009	The system must be capable of recording initial results	MUST

	and follow up results usually after 6-8 weeks.	
CHISPE010	The system must be able to support the different pathways required for each screening test.as in CHISPE011	MUST
CHISPE011	The system must be capable of recording the results of the Newborn and Infant Physical Examination (NIPE) including; - screening for dysplasia of the hip - screening for congenital heart conditions - screening for congenital cataract - screening for un-descended testes in boys - a full physical examination including detection of some congenital abnormalities	MUST
CHISPE012	The system must be able to produce, print and export electronically a daily list/report for all children as follows: - they are the responsibility of the relevant CO - notification of the 6-8 week physical examination results or dissent to all investigations is recorded (outstanding NIPEs). - children for which it has not received screening outcomes for the 72 hours screening check - and children requiring an initial examination between 6-8 weeks that are due to have examinations required as per NIPE guidelines. - These lists should be embedded within the system as part of the process management/ workloads, and should; - include reminders of appointments required - when an examination has taken place - if a follow up to an examination is required - alert local process to action if relevant examinations have not taken place (children should be examined at the earliest opportunity in line with NIPE programme guidance).	MUST
CHISPE013	The system must be able to record a NIPE process status code for each child eg ‘No action taken’ in line with the agreed process status codes.	MUST

CHISPE014	The system must support the CO to make appointments of NIPE for an individual child, including printing of letters	MUST
CHISPE015	The system should be able to remind the user that an appointment needs to be made for a NIPE examination.	SHOULD
CHISPE016	The system must enable the user to record that an examination has taken place. It must contain details of the individuals undertaking the examination including when and where the examination took place.	MUST
CHISPE017	The system must be able to identify that a follow up appointment is required and flag accordingly.	MUST
CHISPE018	The system should be flexible enough to support changes made to NIPE.	SHOULD

7.5.3 NIPE printing

Req Id	**Requirement Description**	**Priority**
CHISPE019	The system must be capable of printing a letter inviting the child for their 6-8 week physical examination with a GP.	MUST
CHISPE020	The system must be able to print the national returns.	MUST

7.6 References

ITK messaging specification for newborn screening: messaging newborn hearing, NIPE and Bloodspot screening results to the CHIS.
http://systems.hscic.gov.uk/pathology/projects/newborn

7.7 Future developments

7.7.1 Standard age criteria

Standard criteria for the optimum age for conducting NIPE has been set – initial examination within 72 hours and second examination between six and eight weeks . Daily reporting will reflect these standards.

7.7.2 Missed appointments

Newborn NIPE screening system must be able to inform the CHIS of missed appointments and schedule for Infants up to and including three months of age who miss either optimal newborn examination within 72 hours or infant examination by 8 weeks of age. They should have the examination undertaken as soon as is possible.

8. Newborn Blood spot screening

8.1 Introduction

This section does not attempt to describe the end-to-end process, or even all of the processes that take place within primary care. Rather, it identifies functional requirements placed on the CHIS that support the administration of newborn blood spot screening which are over and above the general functional requirements outlined in Chapter 4 of this document, which must be read prior to consideration of this chapter.

Together the UK Newborn Screening Programme Centre and the NHS Sickle Cell and Thalassaemia Screening Programme work in partnership to establish standards in screening for the following disorders:

- Phenylketonuria (PKU)
- Congenital hypothyroidism (CH)
- Cystic fibrosis (CF)
- Sickle cell disease (SCD)
- Medium chain acyl CoA dehydrogenase deficiency (MCADD)
- Isovaleric acidaemia (IVA)
- Homocystinuria (HCU))
- Maple syrup urine disease (MSUD)
- Glutaric aciduria type 1 (GA1)
- Isovaleric acidaemia (IVA)

8.2 Information data flows

8.2.1 Newborn blood spot overview

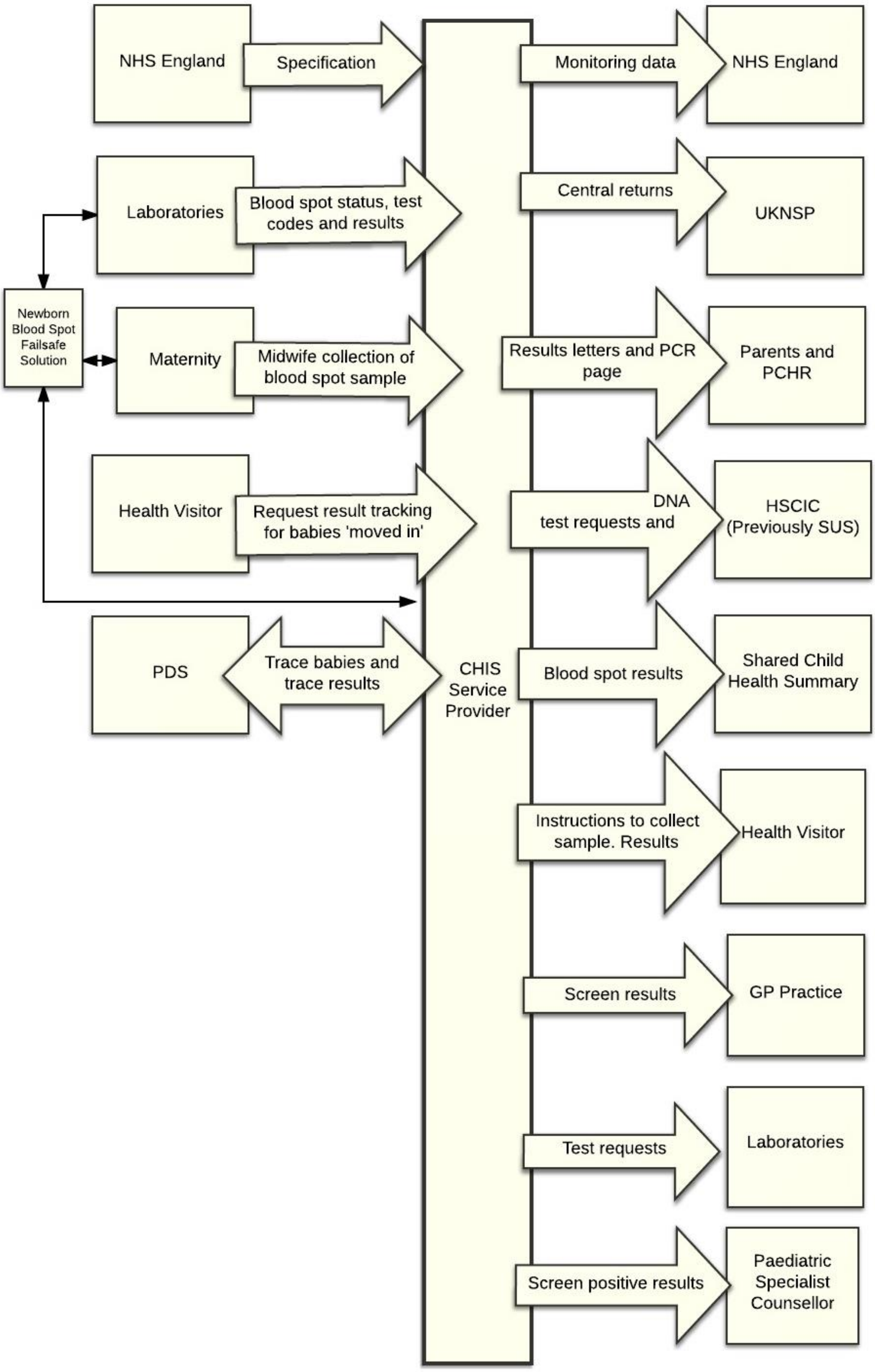

Diagram 4: Newborn blood spot screening data flows and required external interfaces

8.2.2 Information data flows table

Originator	Recipient	Dataset/Information
CHIS system[16]	NBSP	Central Returns
CHIS system	National Screening Committee	KPI Data Returns
CHIS system	Parent & PCHR	Normal Results Letter & PCHR Page
CHIS system	HSCIC	Maternity & Children's Dataset
CHIS system	Child Health Summary Record	Blood Spot Results
CHIS system	Health Visitor & PCHR	Results, Instructions to Collect Sample
CHIS system	GP	Screening Results
CHIS system	Blood Spot Screening/ DNA Laboratories	DNA test requests[17]
CHIS system	Paediatric Specialist / Counsellor	Positive screen test results
CHIS system	NHS England	Monitoring Data
PDS	CHIS system	Trace Result
Blood Spot Screening /DNA Lab. LIMS	CHIS system	Blood Spot Status Test Codes
Health Visitor	CHIS system	Request Result Tracking for Babies 'Moved In'
Maternity	CHIS system	PDS
HSCIC	CHIS system	Maternity & Children's Dataset
NHS England	CHIS system	Specification
Blood Spot Screening	Maternity Services	Newborn Blood Spot Failsafe Solution

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[16] Please note, the data flow diagram above features the term ‘CHIS service provider’, and ‘CHIS system’ is used in the table above. CHIS system is the preferred term.

[17] This can be a Blood Spot requirement if the baby has had a blood transfusion.

/DNA Lab.	Information System	

8.3 Functional requirements

8.3.1 Overview

This section does not attempt to describe the end-to-end process, or even all of the processes that take place within primary care. Rather, it identifies functional requirements placed on the Child Health Information Service that support the administration of newborn blood spot screening.

8.3.2. Identify children to be screened

The CO must ensure that all the children for whom they are responsible are offered the blood spot screening test up to the age of one year. For children
who are born in the UK, in the great majority of cases the midwifery teams will follow-up births by visiting the baby and taking the blood spot sample. However, for a variety of reasons (such as immigrant children) it may be necessary for COs to initiate a blood spot screen.

To ensure that all eligible children are offered the blood spot screening test the CO must be able to schedule a daily report that lists children with the following characteristics:

- they are the responsibility of this CO
- they are between the age of 17 days and one year
- no notification of specimen received at the laboratory or no blood spot results or all investigations have been declined.

The report should indicate the process status for each child in the list, eg “no action taken” or “sample requested”.

8.3.3 Invite subject

In the event that a CO needs to instigate blood spot screening the CHISs must support the production of an instruction to a healthcare professional (usually a health visitor) to take the sample. The CHISs must update the blood spot screening status to indicate “sample requested”.

The CO must indicate on a child’s record whether it has been offered a blood spot test. In addition, if the parents decline a test for any or all of the conditions, this must also be recorded.

8.3.4 Receive status codes from laboratories

The CO will be sent a status code 01 by screening laboratories that have implemented the national standard for electronic reporting. This status code indicates that the labs have received a blood spot card for a child in the CO's care.

COs must record receipt of status code 01 against the child's record. The CO will be sent the results of the screening test by the laboratory. The CO must be able to record the results against the child's record using the nationally agreed status codes as described in the "External interfaces" section below.

It must be noted that the results of a test for cystic fibrosis conducted on a sample taken from a child older than eight weeks are not valid. The CO must not store such results against the child's record. In the event that a child has an elevated immunoreactive trypsin reading, the CO will be sent a mutation result from a DNA laboratory. The mutation result must be stored against the child's record and be available to support quality assurance of the screening programme.

Any screening may be pre-empted because of family history or clinical need, e.g. meconium ileus. This information needs to be retained on the child's record by the CO.

8.3.5 Repeat test

All results and other status codes received for repeat tests should be stored in addition to previously received results and other status information. Thus a full chronology of activity and outcome should be maintained and be accessible.

Often, when tests need to be repeated, the baby is still in the care of the community midwifery team, and they will take responsibility for taking the repeat sample. However, if responsibility has been transferred to the health visitor, then the CO must take responsibility for organising a repeat sample to be collected.

COs must record the date and reason that a repeat sample has been requested regardless of whether the repeat sample was requested by the screening laboratory or by CO staff.

In the event that results are received for babies born at less than 32 weeks gestation (less than or equal to 31+6 days) a repeat test for CHT should be offered at 28 days or age or discharge home whichever is sooner.

If blood spot results arrive with an indication that the baby has had a blood transfusion then a repeat test must be scheduled 72 hours after the last transfusion for phenylketonuria, congenital hypothyroidism, cystic fibrosis and MCADD, HCU, MSUD, GA1 and IVA. DNA testing for SCD at 72 hours, replaces the need for 4 months repeat test after last transfusion (status codes 10 added for screen positive infants identified by DNA).

To support the above processes the CO must be able to produce reports in accordance with Maternity Commissioning Contract.

8.3.6 Report results

The screening laboratory has the responsibility for initiating clinical follow-up in the event of adverse investigation results. However, the CO has the responsibility for informing parents in the event of normal investigation results and for forwarding all results to the child's allocated health visitor. Therefore the CO must be able to report normal results to parents as described in the "External interfaces" section below and be able to send results to the child's allocated health visitor, GP, and in the future PCHR

The CO should record the date on which the parents are sent the test results, whether normal or abnormal. If notification is performed by letter (as is usually the case when all results are normal), the date recorded should be the letter's dispatch date.

8.3.7 Support for managing delays to the process

In the event that the "sample received" notification has not been received by 17 days from the child's date of birth (acceptable standard), or 14 days from the child's date of birth (achievable standard), the CO must be able to identify this situation and expedite the process in a timely fashion.

In the event that a repeat sample is not required and a terminal status code (i.e. "Declined", "Not suspected", "Carrier", "Carrier of other haemoglobin", "Not suspected other disorders follow up", "Suspected", "Not screened/screening incomplete") has not been received for all of the nine conditions by 17 days and up to 1 year from the child's date of birth (acceptable standard), or 14 days and up to 1 year from the child's date of birth (achievable standard), the CO must be able to identify this situation and expedite the process in a timely fashion.

In the event that a repeat sample is required and a terminal status code (i.e. "Declined", "Not suspected", "Carrier", "Carrier of other haemoglobin", "Not suspected other disorders follow up", "Suspected", "Not screened/screening incomplete") has not been received for all of the nine conditions by 17 days and up to 1 year from the child's date of birth (acceptable standard), or 14 days and up to 1 year from the child's date of birth (achievable standard) unless specified by the screening laboratory according to condition specific protocols, the CO must be able to identify this situation and expedite the process in a timely fashion.

These requirements can be met by implementing daily reports as specified in Maternity Commissioning Contract.

8.4 Electronic interface requirements

8.4.1 Overview

This section provides details of the interfaces that the CO must put in place with external systems and organisations as shown in Diagram 4 above.

8.4.2 Screening laboratory

COs should be able to receive screening results from the screening laboratory that use the nationally agreed status codes as described in reference 8.3. Suppliers must conform to the latest version of status codes, COs should be able to receive screening results as Spine messages as described in reference 8.1.

COs should plan for an extended period during which results could be received either electronically or on paper depending on which screening laboratory is involved.

8.4.3 Parents

COs should use the nationally agreed template for the letter to parents for normal test results. This is described in reference 8.2. COs should comply with the normal test results letter production criteria, which is listed in the appendix of reference 8.2.

8.4.4 Shared child health record

PHE has developed an ITK Newborn Screening Messaging containing Blood Spot, Hearing and NIPE outcome results to CHIS to send information about newborn blood screening to CHIS and encourages commissioners and providers to include this in contracts and to adopt this into processes. COs must use the messages defined in reference 8.4 to store blood spot screening results against a child's record on the shared child health record, and to send all subsequent updates.

8.4.5 Maternity and children‘s dataset

Newborn blood spot results need to be submitted to the NHS Information Centre’s Maternity and Children’s dataset [MCDS], the details of which can be found in reference 8.1.

8.4.6 NHS Newborn Blood Spot Screening Programme

Blood spot data is collected quarterly by the National Screening Committee and annually by the Newborn Blood Spot Screening Programme in the form of Excel spreadsheets. The CHIS should be able to report all data items as outlined in the Blood Spot Data Specification as referenced in section 8.2 above.

8.4.7 Registered GP

In the event of a screen positive result, the child’s registered GP practice should be informed of the results.

8.4.8 Health visitor

For the purposes of this document the health visitor is considered to be external to the CO as they often use systems that are not under the direct control of the CO and this dictates the means of communicating with them. The CO must forward all results to the child’s allocated health visitor.

8.4.9 Electronic interface requirements table

Req Id	**Requirement Description**	**Priority**
CHISBS001	The system must support the HL7v3 withdrawing and amending results process.	MUST
CHISBS002	The system must be capable of recording the progress of the blood spot screening process using combination of the results status code, the diary appointments made, and the date sample taken and date results recorded.	MUST
CHISBS003	The system must be capable of accommodating results received either electronically or manually. The system using use the National ITK Messaging standard for blood spot screening must be able to receive blood spot screening results from the screening laboratories including via national standards for electronic reporting.	MUST

CHISBS004	The system must support the standard, electronic mechanism for sending datasets to SUS.	MUST
CHISBS005	The system must inform the child's registered GP practice of all screening results.	MUST
CHISBS006	The system must support the electronic transmission and forwarding of all results to inform the child’s allocated health visitor.	MUST
CHISBS007	The system must be able to receive screening results as defined in the latest version of the NHS Spine Services Message Implementation Manual and must use the latest version of the nationally agreed status codes within the system and supplementary information.	MUST

8.5 Core components

8.5.1 Target cohort and schedule

COs have a statutory requirement to ensure that all of the children that it is responsible for, up to their first birthday, have had or are offered a newborn blood spot screen. This includes movers in from other parts of England, the other home countries, and from other countries.

8.5.2 Core components table

Req Id	**Requirement Description**	**Priority**
CHISBS008	The system must enable the CO to fulfil its statutory requirement of offering new born blood spot screening to all children that it has responsibility for up to the child’s first birthday.	MUST
CHISBS009	The system must enable the CO to fulfil its statutory requirement of offering new born blood spot screening to all children transferred in to the CO's area of responsibility, who have not yet reached their first birthday.	MUST
CHISBS010	The system must act as a local failsafe for enabling liaison with the Newborn Blood Spot Screening Programme, reflecting national standards where applicable.	MUST
CHISBS011	The system must be able to record all status codes of a child's blood spot screening test. These are from 01 to 10 inclusive	MUST
CHISBS012	The system must be able to record results of Phenylketonuria screening.	MUST
CHISBS013	The system must be able to record results of congenital	MUST

	hypothyroidism screening.	
CHISBS014	The system must be able to record results of cystic fibrosis screening.	MUST
CHISBS015	The system must be able to record results of sickle cell disease screening which also includes notification of status code 10 – indicated baby had received a blood transfusion prior to screening and was tested using DNA techniques	MUST
CHISBS016	The system must be able to record results of medium chain acyl CoA dehydrogenase deficiency (MCADD) screening.	MUST
CHISBS017	The system must be able to record results of Homocystinuria (HCU) Screening	MUST
CHISBS018	The system must be able to record results of Maple syrup urine disease (MSUD) screening	MUST
CHISBS019	The system must be able to record results of Glutaric aciduria type 1 (GA1) screening	MUST
CHISBS020	The system must be able to record results Isovaleric acidaemia (IVA) screening	MUST
CHISBS021	The system must be able to record that the child has been offered a blood spot test.	MUST
CHISBS022	The system must be able to record against the child's record where parents have declined tests for any or all of the conditions.	MUST
CHISBS023	The system must be able to retain any pre-empted screening requirements due to family history or clinical need, e.g. Meconium ileus, against the child's record.	MUST
CHISBS024	The system must be able to store multiple results in chronological order to allow for repeat testing.	MUST
CHISBS025	The system must be able to record the reason for retest, date request made and requestor.	MUST
CHISBS026	The system must support a process such that in the event results are received for babies born at less than 32 weeks gestation (less than or equal to 31+6 days) a repeat test for CHT can be offered at 28 days of age or discharge home whichever is sooner.	MUST
CHISBS027	The system must be able to identify and support arrangements in respect of follow-up care activities as a consequence of test results with its appropriate care pathway.	MUST
CHISBS028	In the event that the “sample received” notification has not	MUST

	been received by 17 days from the child’s date of birth (acceptable standard), or 14 days from the child’s date of birth (achievable standard), the system must notify these events to the CO to allow them to expedite the process in a timely fashion.	
CHISBS029	In the event that a repeat sample is **NOT** required and a terminal status code (i.e. “Declined”, “Not suspected”, “Carrier”, “Carrier of other haemoglobin”, “Not suspected other disorders follow up”, “Suspected“, “Not screened/ Screening incomplete”) has not been received for all of the nine conditions by 17 days and up to 1 year from the child’s date of birth (acceptable standard), or 14 days and up to 1 year from the child’s date of birth (achievable standard), the system must notify these events to the CO to allow them to expedite the process in a timely fashion.	MUST
CHISBS030	In the event that a repeat sample **IS** required and a terminal status code (“Declined”, “Not suspected”, “Carrier”, “Carrier of other haemoglobin”, “Not suspected other disorders follow up”, “Suspected“, “Not screened/ Screening incomplete”) has not been received for all of the nine conditions by 17 days and up to 1 year from the child’s date of birth (acceptable standard), or 14 days and up to 1 year from the child’s date of birth (achievable standard), the system must notify these events to the CO to allow them to expedite the process in a timely fashion.	MUST
CHISBS031	The system must have the flexibility to include additional future screening procedures.	MUST
CHISBS032	The system should record the date on which parents are given the test results, whether normal or abnormal. If notification is performed by letter (as is usually the case when all results are normal), then the date recorded, should be the letter's dispatch date.	SHOULD

8.5.3 Scheduling

Req Id	Requirement Description	Priority
CHISBS033	The system must be able to schedule a blood spot screening appointment for children that have not been screened who are up to 1 year of age and are not deceased.	MUST
CHISBS034	The system must be able to schedule a diary appointment for the healthcare professional to take the blood spot sample (usually health visitor).	MUST
CHISBS035	The system must be able to schedule repeat test appointments and requests, as and when required.	MUST
CHISBS036	Where a blood transfusion has taken place the system must schedule a repeat test 72 hours after the last transfusion for phenylketonuria, congenital hypothyroidism, cystic fibrosis and MCADD, and four months after the last transfusion for sickle cell disease. (The four month exception will not apply if the child’s record holds a result obtained via a DNA test for sickle).	MUST

8.6 Reporting

8.6.1 Reporting requirements

Req Id	Requirement Description	Priority
CHISBS037	The system must be able to schedule a daily report for blood spot screening for all children that a CO is responsible for, which lists children that are between the age of 17 days and one year with an incomplete screening result recorded.	MUST
CHISBS038	The system must be able to schedule a daily report for all children that a CO is responsible for, where no notification of specimen has been received at the laboratory.	MUST
CHISBS039	The system must be able to schedule a daily report for all children that a CO is responsible for, where there have been no blood spot results.	MUST
CHISBS040	The system must be able to schedule a daily report for all children that a CO is responsible for, where any investigation(s) have been declined.	MUST
CHISBS041	The system must be able to produce a report that indicates the process status for the Blood Spot Screening examination, for each child in the list, eg "no action taken",	MUST

	or "sample requested".	
CHISBS042	The system must enable the CO to report normal screening results to parents.	MUST
CHISBS043	The system must enable the CO to report all screening results to the child's allocated health visitor and GP.	MUST

8.6.2 Printing

Req Id	Requirement Description	Priority
CHISBS044	The system must be capable of printing the reports as defined in the blood spot screening reports section of these requirements.	MUST
CHISBS045	The system must be able to print daily diary appointments for blood spot screening, with the relevant demographics of the child to be screened for each health visitor.	MUST

8.7 References

Ref: no	File CM Reference number or equivalent	Title	Version
8.1	http://www.hscic.gov.uk/maternityandchildren	Maternity and Children's dataset Ref ISN 1513	1.1
8.2	http://newbornbloodspot.screening.nhs.uk/statuscodes#fileid12761	Child Health Blood Spot Data Specification	Published Jan 2015
8.3	http://newbornbloodspot.screening.nhs.uk/getdata.php?id=12760	Child Health Status Codes v4.2 Suppliers should check that they are using the latest version of Blood Spot Status Codes	
8.4	http://systems.hscic.gov.uk/pathology/projects/newborn	ITK messaging specification for newborn screening: messaging newborn hearing, NIPE and Bloodspot screening results to the CHIS.	

8.8 Future developments

The following is for information only as the status of these items has not been determined:

- copy results to the registered GP and health visitor: A stated possible extension to the blood spot results messaging specification is the copying of results by the laboratory to the registered GP. Consideration will also be given to sending the results by the same means to the nominated health visitor and PCHR
- ITK messaging support for withdrawing and amending results: The initial implementation of messaging for blood spot results does not include the ability to withdraw or amend results. This facility is being considered for a later phase. Such a feature would obviate the need for the manual processes that are currently involved in carrying out these activities.
- HSCIC's maternity and children's secondary uses service interface: A standard, electronic mechanism for sending Newborn Blood spot screening results to the Maternity and Children's dataset. [XML Schema]

9. Newborn hearing screening

9.1 Introduction

The requirements in this section relate specifically to Newborn Hearing screening aspects of the Child Health Information Service which are over and above the general functional requirements outlined in Chapter 4 of this document, which must be read prior to consideration of this chapter.
The Newborn Hearing Screening Programme aims to screen all newborn babies in England up to 3 months of age to identify moderate, severe and profound hearing impairment.

Screening is carried out by the NHSP team using the NHSP screening management IT system to manage the screen, carry out failsafe checks and record screening results and outcomes. Currently there is no automatic messaging of outcomes from the NHSP Information System to CHIS. In some areas hearing screening results are manually added to CHIS but in others this is not. At publication of this document, PHE had developed a Newborn Screening ITK Message which includes a minimum data set from the NHSP Information System to CHIS and would encourage commissioners and providers to include this within contracts and in their relevant processes.

9.2 Information data flows

9.2.1 Overview Newborn hearing screening programme

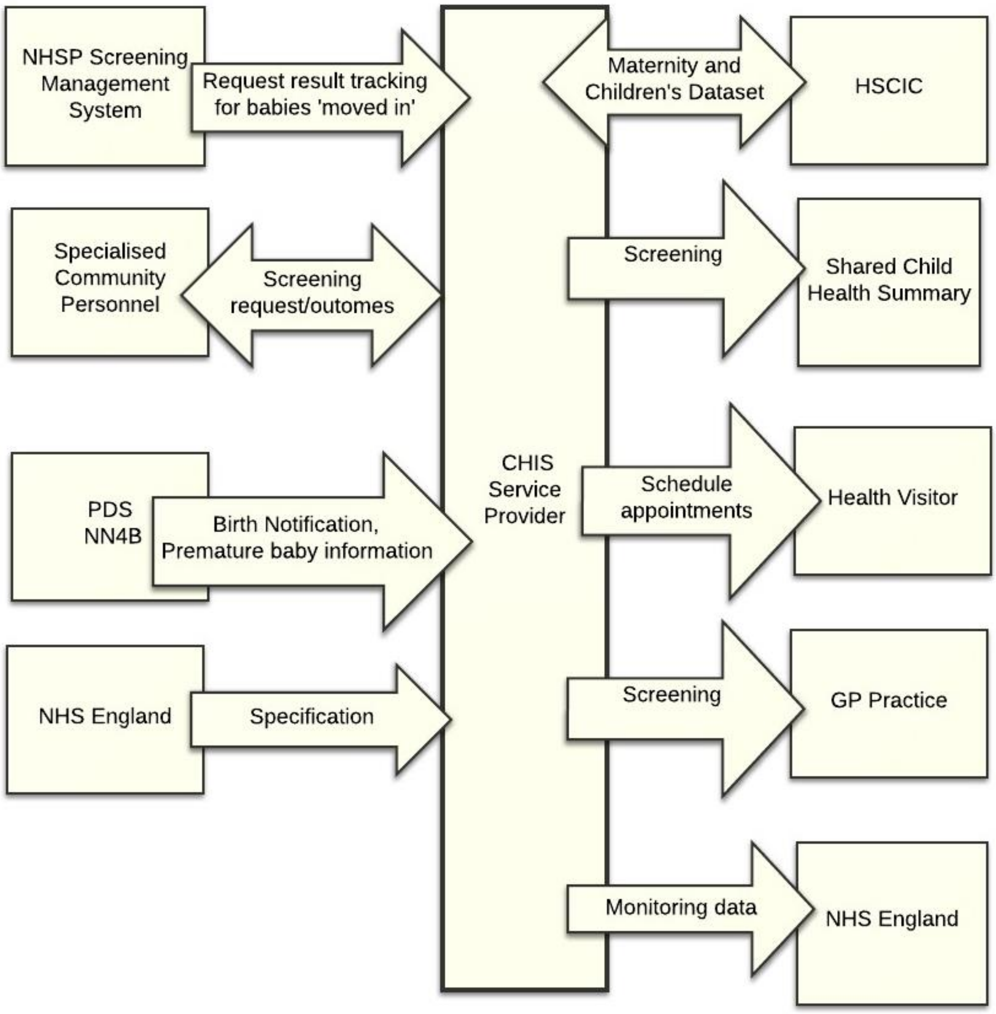

Diagram 5: Newborn hearing screening programme data flows and required external interfaces

9.2.2 Information data flows table

Originator	Recipient	Dataset/Information
CHIS system[18]	Community Clinic	Screening request
CHIS system	Child Health Summary Record	Screening outcomes
CHIS system	Health Visitor & PCHR	Scheduled appointments
CHIS system	GP	Screening outcomes
CHIS system	HSCIC	Maternity & Children's Dataset
Community Clinic	CHIS system	Screening outcomes
CHIS system	NHS England	Monitoring Data
NHSP IT system	CHIS system	Request Result Tracking for Babies 'Moved In'
PDS	CHIS system	Premature Baby Information
HSCIC	CHIS system	Maternity & Children's Dataset
NHS England	CHIS system	Specification

9.3 Functional requirements

9.3.1 Links to the failsafe process

The CO must ensure that all the children for whom they are responsible are offered the Newborn Hearing Screening Programme. Screening should ideally be completed by 4-5 weeks of age in most cases and by 3 months in all cases (with age corrected for prematurity). To ensure that all eligible children are offered the Newborn Hearing Screening Programme, the CO must be able to schedule a daily report that lists children with the following characteristics:

- they are the responsibility of this CO
- no notification received of the results or dissent to all investigations are recorded.

9.3.2 Invitation to baby

If the failsafe report indicates that the process has not been completed arrangements must be in place to complete the process.

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[18] Please note, the data flow diagram above features the term ‘CHIS service provider’, and ‘CHIS system’ is used in the table above. CHIS system is the preferred term.

The aim is to complete screening by 4-5 weeks of age in most cases and by 3 months in all cases (with an exception for babies that have not reached 44 weeks gestational age).

The policy for missed and incomplete screens is that:

- babies under age three months (corrected age) should be offered an appointment to complete the screen from whichever stage (automated otoacoustic emissions (AOAE) or automated auditory brainstem response (AABR)) had been previously reached
- babies over age three months should be considered for referral to audiology at an appropriate age
- NHSP Screening Manager is responsible for identifying child who has moved into the country after the age of 3 months and alerting Health Visitor or GP
- These babies are not eligible for newborn screening but the health visitor should discuss with the parents as soon as feasible and offer referral for age-appropriate testing.
- Health visitor is responsible for arranging audiology referral Health visitors and GPs must be informed of babies that have not completed screening. Screening teams will need to ensure that parents are provided with information about how to seek assessment in the event of future concern. The health visitor or GP should discuss with parents the implications of not having, or of not completing the screen. Parents and health visitors or GPs should be made aware that they can request an audiological assessment at any time.

The report should indicate the process status for each child in the list, eg “no action taken”.

9.4 Electronic interface requirements

9.4.1 Existing information systems provider

The following data is currently made available to child health information systems through electronic interfaces with the existing systems provider or through manual data entry. PHE has developed a Newborn Screening ITK Message which includes a minimum data set from the NHSP Information System to CHISs and would encourage commissioners and providers to include this within contracts and in their relevant processes.

However, interoperability between the two systems needs to be part of local development plans. In addition to the generic baby identifier and demographic details the information needs to be held locally with the child’s record and is currently entered onto the PCHR.

9.4.2 Newborn Hearing Dataset (Newborn ITK Messaging project)

Data Item Name	Data Item Description	Format	National Code	National Code Definition
Newborn Hearing Screening Follow up: To carry the details of how concerns following newborn hearing screening are followed up **One occurrence of this Group is required if concerns are identified** This group may need to be compiled from Care Activity and Diagnosis sections				
SCREENING OUTCOME NEWBORN HEARING SCREENING - SNOMED	Outcome of NEWBORN HEARING SCREENING - SCT Id - Synonymous Term	an15	276781000000109	Clear response no follow up required
			276791000000106	Clear response targeted follow-up required
			276811000000107	No clear response bilateral referral
			276801000000105	No clear response unilateral referral
			279591000000106	Incomplete screening contraindicated
			276851000000106	Incomplete deceased
			279611000000103	Incomplete baby unsettled
			276821000000101	Incomplete declined screen
			276831000000104	Incomplete appointment missed
			279601000000100	Incomplete lack of service capacity
			276841000000108	Incomplete lost contact
			276861000000109	Incomplete out of screening coverage
			276881000000100	Incomplete late entry
			276891000000103	Incomplete equipment malfunction
			276901000000102	Incomplete equipment not available
			276871000000102	Incomplete withdrew consent
REFERRAL DATE (NEWBORN HEARING AUDIOLOGY REFERRAL)	The date on which a referral for audiology testing was made	YYYY-MM-DDThh:mm:ss		
NEWBORN HEARING AUDIOLOGY PCHI STATUS	Audiology PCHI (Permanent Childhood Hearing Impairment) Status.	an2	01	No
			02	Yes - Confirmed PCHI bilateral
			03	Yes - Confirmed PCHI unilateral
NEWBORN HEARING AUDIOLOGY DIAGNOSTIC DATE	The date on which a audiology outcome was diagnosed. Required for calculating NSC KPI NH2 for hearing	YYYY-MM-DDThh:mm:ss		

9.4.3 External interface requirements table

Req Id	Requirement Description	Priority
CHISHS001	The system must be capable of interfacing electronically with existing systems providers or through manual data entry.	MUST
CHISHS002	The system must support interactions with the Hearing Screening services.	MUST
CHISHS003	The system must be capable of receiving hearing screening test outcomes.	MUST
CHISHS004	In order to identify premature babies, the system must be able to record the gestational age in weeks and days from the Birth Notification message from PDS	MUST
CHISHS005	In addition to those items indicated in the Newborn Hearing dataset the system must be capable of sending, storing and receiving the following: - generic baby identifier (NHS Number) - demographic details	MUST

9.5 Core components

9.5.1 Target cohort and schedule

All children should have had or been offered a newborn hearing screen by 3 months of age (corrected for prematurity). This includes movers in from the other home countries, and from other countries.

The primary screening process is managed by the NHSP IT system, but the CO still has responsibility for ensuring coverage of all of the children for which it is responsible, and assuring the quality of the service.

9.5.2 Core components requirements table

Req Id[19]	Requirement Description	Priority
CHISHS006	The system must be capable of recording and storing outcomes from hearing screening.	MUST
CHISHS007	The system must be capable of enabling the CO to offer	MUST

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[19] CHIS010, 11, 12, 13, 15 and 16, please note there is a newborn screening message to ITK standards, and antenatal ITK message is in development.

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	an appointment for hearing screening tests to a child.	
CHISHS008	The system must enable liaison with the Newborn Hearing Screening Programme.	MUST
CHISHS009	The system must notify the CO of all children, for which it is responsible.	MUST
CHISHS010	The system must be able to identify and provide a list of which children have been offered the Newborn Hearing Screening Programme, in line with requirements outlined above	MUST
CHISHS011	The system must be able to identify and provide a list of all eligible children for the Newborn Hearing Screening Programme, which are due to be, and/or have been, discharged from hospital.	MUST
CHISHS012	The system must be able to identify and provide a list of all children where: - No notification has been received of the outcome, or - Dissent to all investigations has been provided	MUST
CHISHS013	The system must enable the CO to arrange an appointment to perform outstanding hearing screening tests, where appropriate e.g. where the Health Visitor is responsible for carrying out the tests.	MUST
CHISHS014	The system must store the generic baby identifier; demographics; the newborn hearing screening dataset against each child's record. This may be manually entered or passed electronically from another system.	MUST
CHISHS015	The system must be capable of recording and storing results from hearing screening tests.	MUST
CHISHS016	The system should be capable of providing a referral for audiology testing. Consideration should be given to enable the system to co-ordinate the management of referrals for those babies; - Under 3 months of age offered screening - Greater than 3 months of age referred to audiology	SHOULD
CHISHS017	The system must be able to indicate the process status for the Hearing Screening examination, for each child in the list, e.g. "no action taken", or "sample requested".	MUST
CHISHS018	The system must be able to use gestational ages of babies to identify which children should be screened.	MUST

9.5.3 Scheduling

Req Id	Requirement Description	Priority
CHISHS019	The system must be capable of scheduling an appointment for hearing screening tests to a child.	MUST

9.6 Reporting

9.6.1 Reporting requirements

Req Id	Requirement Description	Priority
CHISHS020	The system must provide a report of those children that do not have results of a hearing screening test recorded against their record.	MUST
CHISHS021	The system must be capable reporting outcomes from hearing screening tests.	MUST

9.6.2 Printing

Req Id	Requirement Description	Priority
CHISHS022	The system must be able to print a list of children offered Newborn Hearing Screening.	MUST
CHISHS023	The system must be able to print a list of all eligible children for the Hearing screening programme, which are due to be, and/or have been discharged from hospital.	MUST
CHISHS024	The system must be able to print a list of all children where; - No notification has been received of the outcomes, or - Dissent to all investigations has been provided	MUST
CHISHS025	The system must be capable printing outcomes from hearing screening tests.	MUST

9.7 References

ITK messaging specification for newborn screening: messaging newborn hearing, NIPE and Bloodspot screening results to the CHIS.
http://systems.hscic.gov.uk/pathology/projects/newborn

10. Handover from midwifery

10.1 Introduction

The quality and extent of handover of care from one health professional or organisation to another is a common source of adverse safety issues. This chapter describes the process for an orderly transfer of responsibility for a baby's care from the community midwifery team to the CO and Health Visitor team. The Child Health Information Service system should be able to receive information collected during a woman's maternity care from the discharge and handover process that is relevant to the child's health and wellbeing, including the universal antenatal contact by health visitors. This will help facilitate care for the mother and the child within the community. This chapter outlines requirements which are over and above the general functional requirements for a CHISs detailed in Chapter 4, which must be read prior to consideration of this chapter.

It is recognised that at the time of publication of this document, that no national dataset for this handover had been agreed, and that the exchange of information between maternity information systems and Child Health Information Service systems is varied, incomplete and dependant on local arrangements. However it is recommended that the development of these requirements takes place in the future [see CHISMW001].

10.2 Information data flows

10.2.1 Handover from community midwifery overview

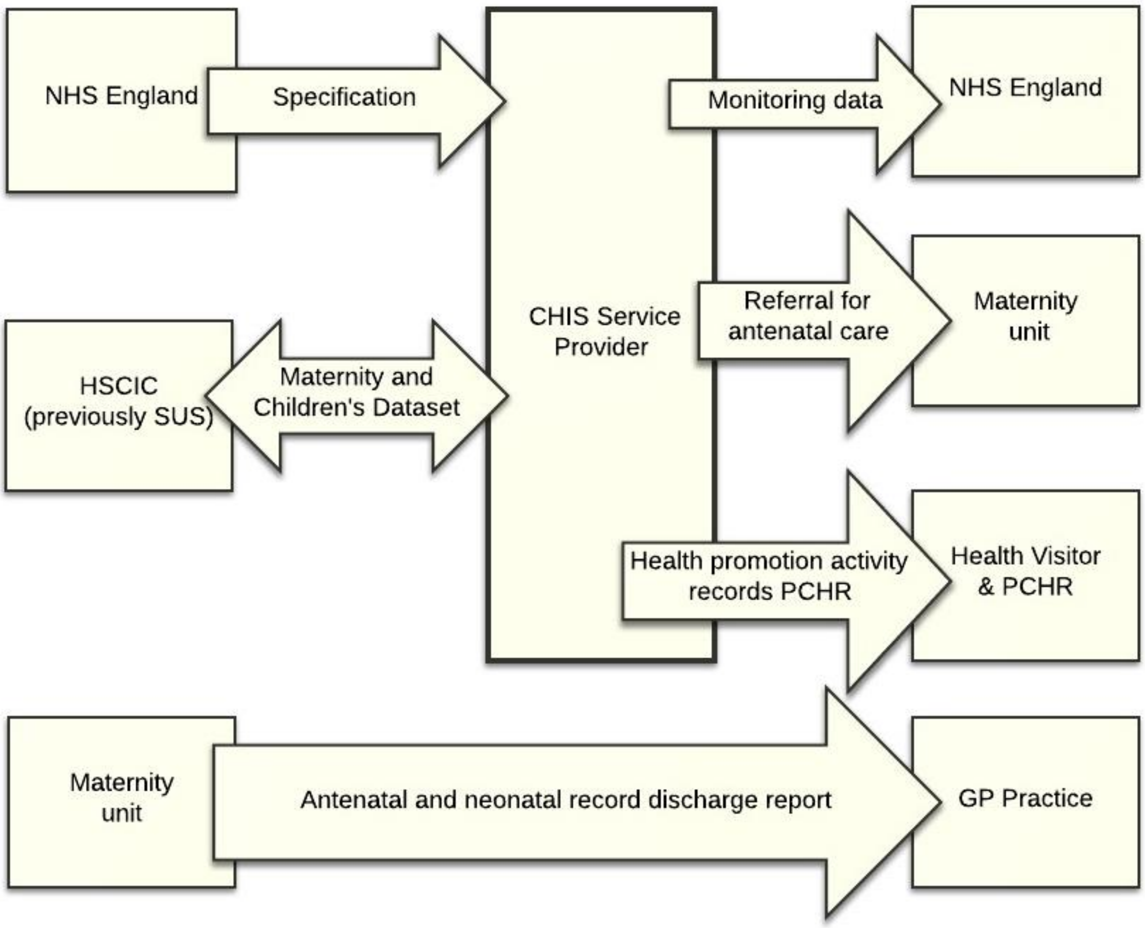

Diagram 6: Handover from community midwifery data flows and required external interfaces

10.2.2 Information data flows table

Originator	Recipient	Dataset/Information
CHIS system[20]	NHS England	Monitoring Data
GP	Maternity Unit/Provider	Referral for antenatal care
CHIS system	Health Visitor/LA	Health Promotion Activity Records PCHR
Maternity Unit/Provider	HSCIC	FGM Dataset
Maternity Unit/Provider	GP	Discharge report[21]
CHIS system	HSCIC	Maternity & Children's Dataset
NHS England	CHIS system	Specification
Maternity Unit/Provider	CHIS system	Maternity and Baby Discharge information
HSCIC	CHIS system	Maternity & Children's Dataset

10.3 Functional requirements

10.3.1 Receive information from midwifery

The CO must receive and store antenatal and neonatal information from the maternity unit. This is largely screening data, but includes infections, and some immunisations and health promotion and social support interventions. In some cases, the CO must then be able to act on the information it has received. For example, hepatitis B and tuberculosis immunisations need to be scheduled based on the antenatal and neonatal information that is shared, and the schedule should enable this to be tracked where required, e.g. for serology testing at one year for hepatitis B.

10.3.2 Data items

Every birth record must carry the nationally agreed birth registration/maternity services secondary uses dataset items and accommodate all additional local requirements, including:
- birth order if multiple birth
- birth weight
- key at risk factors e.g. sickle cell status, maternal hepatitis B, at risk of tuberculosis
- time of birth

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[20] Please note, the data flow diagram above features the term ‘CHIS service provider’, and ‘CHIS system’ is used in the table above. CHIS system is the preferred term.
[21] This usually includes a field for recording hepatitis or other infectious diseases in pregnancy.

- telephone number
- mother's surname and forename
- mother's maternal language
- mother's ethnicity
- mother's date of birth or NHS number
- mother's hospital number
- single unsupported family indicator
- maternal smoking status
- gestation in weeks and days
- birth
- live birth
- stillbirth
- date of death
- type of delivery
- Apgar score – one minute and five minutes
- head circumference
- full address
- other addresses e.g. alternative home
- feeding status
- the route and dosage of any vitamin K administered.
- details of the first dose of hepatitis B vaccination given and or immunoglobulin given if indicated (infant born to hepatitis B positive mother);
- neonatal BCG given
- special care admission
- safeguarding issues; drug/alcohol use

10.3.3 Transfer of recorded activities

In addition, it is expected that a number of health promotion activities take place before the CO assumes responsibility for the child. A record of these activities having taken place should also be transferred. Such activities include:

- promoting health and wellbeing
- identifying need for extra management
- breastfeeding: skin to skin contact; breastfeeding; infant feeding
- infant feeding advice
- life style
- parental Information
- preparation for parenthood and birth
- information for example parental substance misuse, smoking cessation advice, maternal mental health support, responsive parenting, infant mental health advice or domestic violence support.

- Immunisation schedule and advice, including noting whether next vaccine is due at 1 month (hepatitis B) or starting from routine schedule at 2 months.

The screening information to be handed over includes:
- all results relating to the Down’s and Fetal Anomaly Screening Programme
- all results from the Infectious Diseases in Pregnancy Screening Programme and post natal blood tests, including hepatitis B and neonatal BCG vaccination.
- all results from the Antenatal Sickle Cell and Thalassaemia Screening Programme.

10.3.4 Distribute hospital discharge summary

The CO should ensure that the hospital discharge summary is sent to the GP and health visitor. This information should include the outcomes of the screening programmes listed above, and that it includes the mother’s hepatitis B status.

10.4 Electronic Interface Requirements

Req Id	Requirement Description	Priority
CHISMW001	The system must be capable of receiving maternity and birth information and discharge information from the maternity unit/provider. At time of publication of this update in 2015, there is not a published data set or information standard for this information exchange, but it is recommended that future development is undertaken to enable information relevant for the health and care of the child to be enabled to transfer from maternity systems into the CHIS.	MUST
CHISMW002	The system should be capable of receiving health promotion activity records. Example activity includes the breast feeding status as per the classifications stated in the PCHR for each child.	MUST
CHISMW003	The system must be capable of receiving newborn screening results from midwifery systems (Neonatal Intensive Care, Paediatric Intensive Care Unit, Special Care Baby Unit and generic Maternity). In addition to this, the system should be able to receive additional results from midwifery systems, e.g. results from antenatal screening programmes: Down’s and Fetal Anomaly Screening Programme, Infectious Diseases in Pregnancy Screening Programme, the Antenatal Sickle Cell and Thalassaemia Screening Programme, antenatal and post natal blood tests, including for Hepatitis B and Neonatal BCG vaccination. It is expected that a number of health promotion activities	MUST

	take place before the CO assumes responsibility for the child. All notes relating to these activities should also be transferred. Such activities include: - promoting health and wellbeing - identifying need for extra management - breastfeeding support - infant feeding advice - life style - parental Information - immunisation advice, including noting whether next vaccine is due at 1 month (hepatitis B) or starting from routine schedule at 2 months. - preparation for parenthood and birth, e.g. smoking cessation advice - safeguarding information, for example parental substance misuse, maternal mental health support, responsive parenting, infant mental health advice or domestic violence support	

10.5 Core Components

Req Id	**Requirement Description**	**Priority**
CHISMW004	The system must support the nationally agreed birth registration/ maternity services secondary uses dataset items. and accommodate all additional local requirements, including; - Birth order if multiple birth - Birth weight - Key at risk factors e.g. sickle cell status, maternal hepatitis B, at risk of tuberculosis - Time of birth - Telephone number - Mother's surname and forename - Mother's maternal language - Mother's date of birth or NHS number - Mother's hospital number - Single unsupported family indicator - Gestation in weeks and days - Birth - Live birth - Stillbirth - Date of death - Type of delivery - Apgar score – one minute and five minutes - Head circumference - Full address - Other addresses, e.g. alternative home - Feeding status (skin to skin, breastfeeding, infant feeding)	MUST

	- The route and dosage of any vitamin K administered - Details of the first dose of Hepatitis B vaccination and or immunoglobulin given; and any neonatal BCG given. - Special care admission - Safeguarding issues: maternal smoking status; drug/alcohol use including alcohol during pregnancy (due to the risk of FASD (Fetal Alcohol Spectrum Disorders)	

10.6 Reporting

Req Id	Requirement Description	Priority
CHISMW005	The system must be capable of receiving a discharge summary to the GP and Health Visitor, including the outcomes of the screening programmes (Down's & Fetal Anomaly, Infectious Diseases in Pregnancy, including the mother’s Hepatitis B status, Antenatal Sickle Cell and Thalassemia).	MUST

10.7 Future developments

At the time of this documents publication, a female genital mutilation (FGM) prevalence dataset is currently being collected from Trusts, and will run until March 2015. This covers FGM that has already taken place. At the moment this is not part of CHISs but may be a future requirement and a data item recorded in the future safeguarding dataset. Further details can be found via http://www.hscic.gov.uk/catalogue/PUB15711 and http://www.isb.nhs.uk/documents/isb-1610/. From April 2015 an enhanced FGM dataset collection is due to be launched. This will also cover FGM that has already taken place.
In the future, it is intended that the FGM dataset will be extended to also cover potential risk of FGM, and FGM that is yet to happen.

11. Health promotion

11.1 Introduction

This requirements in this chapter relate principally to the health promotion and protection activities that are scheduled for delivery to the child from 14 days onwards as currently commissioned by the CO. These aspects of the Child Health Information Service are over and above the general functional requirements outlined in Chapter 4, which must also be read prior to consideration of this chapter. This commissioning responsibility will be transferring to local authority commissioners from the October 2015. Health visitors are key to the delivery of the Healthy Child Programme, in conjunction with parents, and the ‘Red Book’ also known as the personal child health record (PCHR). Some other topics such as screening may also come under the heading of health promotion, but they are covered in other specific chapters.
For Universal Services for the various age groups between 0– 9 years of age the progressive categories of children and families identified through the programme will have additional health promotion services led by a number of different professional contact groups including health visitor and school nurses to address particular needs and risks. In addition, the face–to-face contacts within the immunisation programme offer the opportunity for reviews to take place so that all children will have reviews at these points.

All reviews are universally offered but may lead to a common assessment framework (CAF) being conducted, where information gathered is based on CAF domains. From October 2015 five core stages of the Healthy Child Programme will be mandated for local authority commissioners these are the initial antenatal visit nd new baby reviews, and the subsequent child development assessments which take place at at 6-8 weeks, at one year and then at 2 to 2.5 years of age.

11.2 Information data flows

11.2.1 Health promotion overview

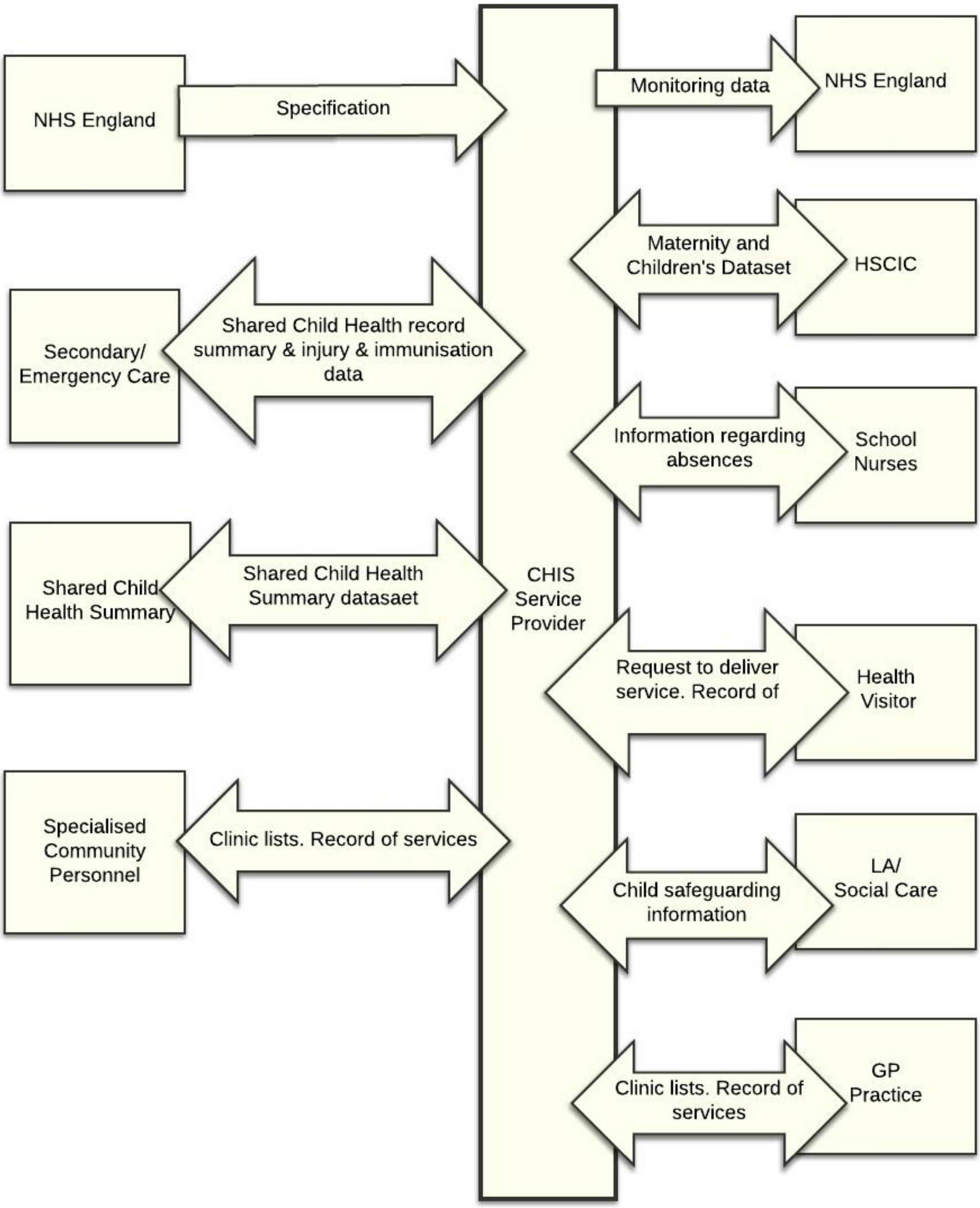

Diagram 7: Health promotion data flows and required external interfaces

11.2.2 Information data flows table

Originator	Recipient	Dataset/Information
CHIS system[22]	NHS England until October 2015, then Local authorities	Monitoring Data
CHIS system	Child Health Summary Record	Child Health Summary Record dataset request
CHIS system	Community Clinic	Clinic Lists
CHIS system	HSCIC	Maternity & Children's Dataset
CHIS system	Schools & FE Colleges	Information Regarding Absences
CHIS system	Health Visitor & PCHR	Request to deliver service
CHIS system	Local Authority Social Care	Child Safeguarding Information
CHIS system	GP	Clinic Lists
CHIS system	Secondary Emergency Care	Child Health Summary Record
NHS England	CHIS system	Specification
Community Clinic	CHIS system	Records of Services (including did not attends)
GP	CHIS system	Records of Services (including record of immunisations and did not attends)
Health Visitor & PCHR	CHIS system	Record of attendance (including did not attends)
Local Authority Social Care	CHIS system	Child Safeguarding Information
Schools & FE Colleges	CHIS system	Information Regarding Absences
Secondary & Emergency Care	CHIS system	Injury Immunisation Data Shared Child Summary
Child Health Summary Record	CHIS system	Child Health Summary Record dataset response
HSCIC	CHIS system	Maternity & Children's Dataset

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[22] Please note, the data flow diagram above features the term ‘CHIS service provider’, and ‘CHIS system’ is used in the table above. CHIS system is the preferred term.

11.3 Functional requirements

11.3.1 Universal services for the first five years of life

Reference 11.1 provides COs with a standard description of the full range of health promotion services that should be offered to pre-school children. A distinction is made in the referenced documents to services provided on a universal basis, i.e. all services to all children, and a progressive basis, i.e. some services to some children that have been identified with particular needs.

This section describes how information systems should be used to support the delivery of the universal set of services. For the progressive categories of children and families identified through the programme there will be additional health promotion services led by health visitor contacts to address particular needs and risks.

11.3.2 Schedule for delivery of services from 0-5 years old

The schedule for delivering universal services and healthy child programme deliverables from 0-5 years is shown in table 3. The ASQ Ages and Stages questionnaire tool can be used for developmental and social-emotional screening for children from one month to 5 ½ years.
In addition to these universal contacts, there needs to be functionality in the CHIS system to capture health promotion activity from all health and care contacts, including for example details of any dental care delivered, and any optometry screening conducted prior to school entry.

Table 3: Universal services and healthy child delivery schedule for 0-5 year olds

Intervention	0-1 week	1-6 weeks	6 to 8 weeks	3 months	4 months	6m up to 12m	12m review	13m	2 to 2.5 yr	3-5 yr	4-5 yr
Promoting health and well-being, including raising awareness of dental health		Y	Y	Y	Y		Y	Y	Y	Y	Y
Identifying need for extra management	Y	Y	Y	Y	Y		Y	Y	Y	Y	Y
Breast feeding support/status	Y	Y	Y	Y	Y						
Infant feeding advice		Y	Y	Y	Y	Y	Y		Y		
Focus on involvement of father		Y	Y	Y	Y	Y	Y		Y		
Life style	Y	Y	Y	Y	Y	Y	Y				
Parental Information	Y	Y	Y	Y	Y	Y	Y				
Preparation for parenthood and birth	Y										
A/N interview CHPP team	Y										
PCHR given to parent/carer		Y									
Birth to Five book	Y										
Neonatal screening information (leaflet)	Y										
Sudden infant death syndrome advice		Y	Y								
Promoting sensitive parenting		Y	Y	Y	Y	Y	Y	Y	Y	Y	
New baby review at age 14 days		Y									
Assess maternal mental health	Y	Y	Y				Y				
Home safety advice and assessment		Y	Y	Y	Y	Y	Y				
Baby physical examination (NIPE)	Y		Y								
Measure, plot and assess weight and head circumference			Y								
Measure and plot and assess weight		Y	Y	Y	Y		Y	Y			
Measure, plot and assess weight & height											Y
Record breast feeding status	Y	Y	Y	Y	Y						
Immunisation schedule			Y	Y	Y		Y	Y		Y	

Intervention	0-1 week	1-6 weeks	6 to 8 weeks	3 months	4 months	6m up to 12m	12m review	13m	2 to 2.5 yr	3-5 yr	4-5 yr
Review hearing if not screened in neonatal and consider need for referral if concern.						Y	Y				
Child's physical, emotional, social needs			Y				Y		Y		
Language development									Y		
Motor skills									Y		
Illness history			Y				Y		Y		
Parenting consultation			Y				Y		Y		
Dental health							Y		Y		
Injury prevention		Y	Y				Y		Y		
Diet etc.			Y				Y		Y		
Developmental and behavioural advice							Y		Y		
Review immunisation status and administer scheduled and missed immunisations[12]			Y	Y	Y		Y	Y	Y		Y
Access to primary and dental care							Y		Y		Y
Preschool hearing test											Y
Preschool vision screen											Y
Inform children, parent, school on specific health issues											Y
Handover to school nurse											Y

11.3.3 Universal services from five to 11 years old

References in section 11.2 above provide COs with a standard description of the full range of health promotion services that should be offered to children who have started at school. A distinction is made in the referenced documents to services provided on a universal basis, i.e. all services to all children, and a progressive basis, ie some services to some children that have been identified with particular needs.

This section describes how information systems should be used to support the delivery of the universal set of services. For the progressive categories of children and families identified through the programme there will be additional health promotion services led by school nurse contacts to address particular needs and risks.

11.3.4 Schedule for delivery of services from 5-11 years old

The schedule for delivering universal services is shown in table 4.

Intervention	**At school entry**	**Throughout**
Sharing information about pre-school background	Y	
School entry questionnaire	Y	
Review immunisation status and administer scheduled and missed immunisations[23]	Y	Y
Review access to primary care	Y	
Review access to dental care	Y	
Review physical, emotional or developmental problems	Y	
Provide parents, children and school staff with information on specific health issues	Y	Y
Assess safeguarding risk factors	Y	Y

Table 4: Universal services delivery schedule for 5-11 year olds

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[23] The immunisation schedule is subject to unscheduled changes and current guidance (the Green Book) should be consulted

11.3.5 Universal services from 11 to 16 years old

Reference 11.2 provides COs with a standard description of the full range of health promotion services that should be offered to young people aged between 11 and 16. A distinction is made in the referenced documents to services provided on a universal basis, ie all services to all children, and a progressive basis, ie some services to some children that have been identified with particular needs.

This section describes how information systems should be used to support the delivery of the universal set of services. For the progressive categories of children and families identified through the programme there will be additional health promotion services led by school nurse contacts to address particular needs and risks.

11.3.6 Schedule for delivery of services from 11 to 16 years old

The schedule for delivering universal services is shown in table 5.

Intervention	**At school transition**	**16 yr**	**Throughout**
Young person questionnaire	Y		
Parental questionnaire	Y		
Review immunisation status, administer scheduled and missed immunisations and provide information on future vaccinations[14]	Y	Y	Y
Confirm handover of health information from previous school	Y		
Identify incipient mental health problems	Y		
Direct engagement with primary care		Y	
Provide parents, children and school staff with information on specific health issues	Y	Y	Y
Assess safeguarding risk factors	Y	Y	Y

Table 5: Universal services delivery schedule for 11-16 year olds

11.3.7 Universal services from 16 to 19 years old

Reference 11.2 provides COs with a standard description of the full range of health promotion services that should be offered to young people aged between 16 and 19. A distinction is made in the referenced documents to services provided on a universal basis, ie all services to all children, and a progressive basis, i.e. some services to some children that have been identified with particular needs.

This section describes how information systems should be used to support the delivery of the universal set of services. For the progressive categories of children and families identified through the programme there will be additional health promotion services led by school nurse contacts to address particular needs and risks.

11.3.8 Schedule for delivery of services from 16 to19 years old

The schedule for delivering universal services is shown in table 6.

Intervention	**At school transition**	**16 yr**	**Throughout**
Young person questionnaire	Y		
Parental questionnaire	Y		
Review immunisation status, administer scheduled and missed immunisations and provide information on future vaccinations[15]	Y	Y	Y
Confirm handover of health information from previous school	Y		
Identify incipient mental health problems	Y		
Direct engagement with primary care		Y	
Provide parents, children and school staff with information on specific health issues	Y	Y	Y
Assess safeguarding risk factors	Y	Y	Y

Table 6: Universal services delivery schedule for 16-19 year olds

11.3.9 Reviews

From October 2015 five core stages of the Healthy Child Programme will be mandated for local authority commissioners, these include the initial antenatal visit plus the new baby review as well as health promotion opportunities outlined below.

The schedule of health promotion reviews (also known as child development checks) is:

- 6-8 weeks, all children, led by GP, for infant physical examination, face to face and led by health visitor for other aspects
- 12 months, all children, led by health visitor
- 2 to 2.5 years, all children, led by health visitor, face to face
- school entry, led by school nurse.

In addition, the face to face contacts within the immunisation programme offer the opportunity for reviews to take place.

At each review the CO must have the facility for records to be made.

11.3.10 Progressive services

All above reviews are universally offered but may lead to a common assessment framework (CAF) being conducted so that information gathered is based on CAF domains.

11.3.11 Recording information

All contacts information about breastfeeding status should be recorded until age six months. At each contact weight and at 6-8 weeks head circumference measurements should be made and plotted on centile charts. The CO needs to be able to record that an intervention has taken place, and record items which will be permanent health biographical records for each child.

Each healthcare professional requires the facility to record relevant core items for each child for the universal programme in whatever service this has taken place and even if this is merely a review that has taken place with no significant items which justify a detailed record being made. The CO must provide the ability to record notes in GP surgeries and community child health clinics, health centres and during hospital interventions, screening, immunisations and vaccinations encounters, and also for ad hoc interventions that may take place at home or in nursery or children’s centres.

11.3.12 Record access

The system must:

- provide the health visitor leading the health promotion programme with access to the records arising from each relevant contact with each child
- provide access from GP and community child health clinics, health centres, hospital interventions, screening and immunisation and vaccination data also for ad hoc interventions that may take place at home or in nursery or children's centres.

11.3.13 Common assessment framework

For a few children an assessment will be performed under the CAF (see reference 11.8). Typically this will be led by a health visitor. CAF information is collecting against a number of "domains" as detailed in table 7 below.

Domains	Information to gather
Antenatal	- General health of mother - Screening – as recommended by the National Screening Committee - Emotional health
The child	- General health - Emotional and social development - Physical development - Speech and language development - Self-care skills and independence
Parenting	- Emotional warmth/stimulation - Care giving - Father's contribution - Ensuring safety and protection - Guidance, boundaries and stimulation
Family	- Family history and functioning - Family and social relationships - Family's health and wellbeing status - Wider family - Housing, employment and financial considerations - Social and community elements and resources, including education

Table 7: Common assessment framework domains

Each category of functioning must be recorded at each assessment as:

- not known/not assessed
- no problem

- mild/suspected
- moderate
- severe
- profound.

The hearing category may also require fields to record audiological measurements for each ear.

The system must be capable of generating the documentation for the particular assessment or review that is due, and relevant records must be available. This must include the results of previous assessments and any diagnoses held on the child's record.

It should also be possible to record:

- that a CAF assessment exists
- the date of CAF assessment
- if the CAF was completed by a health professional, then the name of the person and service/team.

11.4 Electronic interface requirements

11.4.1 Local authority interface requirements

The system must provide facilities to record and report the process within health and social care to meet statutory responsibilities in providing information to the local authority detailed in the Education Act 1996. These must be defined by the user but examples of what might be recorded are as follows:

- no special educational needs ascertained
- at stage 1
- at stage 2
- at stage 3
- referred for assessment of special educational needs (at stage 4)
- assessment already requested
- letter in lieu
- transition review
- Education Health and Care (EHC) plan issued (at stage 5)
- EHC plan rejected.

11.4.2 Electronic interface requirements table

Req Id	Requirement Description	Priority
CHISHP001	The system must be capable of sending, receiving and storing health promotion activity records for each child, including dental care and any optometry screening conducted prior to school entry.	MUST
CHISHP002	The system must be able to send, receive and store the breast feeding status as per the classifications stated in the PHCR for each child.	MUST
CHISHP003	The system must be capable of interfacing electronically with existing systems providers and users.	MUST
CHISHP004	The system must provide access to vaccination data from GP and community child health clinics, schools, health centres, hospital interventions, screening and immunisation and in addition from ad hoc interventions that may take place at home or in nursery or children's centres.	MUST
CHISHP005	The system must enable the CO to monitor the quality and coverage of the Healthy Child Programme delivery at the CO level, incorporating local and nationally defined quality measures where applicable.	MUST
CHISHP006	The system must be able to support the capturing of CAF results as outlined in Table 8 of the Information Requirements for Child Health Information Systems (Common Assessment Framework).	MUST
CHISHP007	The system must provide when required access to the records arising from each relevant contact with each child.	MUST
CHISHP008	The system must enable the CO to provide information needed for secondary uses purposes including key outcome measures for children in line with the Public Health Outcomes Framework and the NHS Outcomes Framework and the children and young people's outcome framework.	MUST
CHISHP009	The system must enable access to health promotion information via mobile access.	MUST

11.5 Core components

11.5.1. Core components requirements table

Req Id	Requirement Description	Priority
CHISHP010	The system must enable the CO to offer the full range of health promotion services to all children for which the CO is responsible, as outlined in the following documents: - DH Gateway reference 12793, Healthy Child Programme: Pregnancy and the first five years of life. 2009. Healthy Child Programme: From 5-19 years old. 2009. - Framework for the assessment of children in need and their families. (At the time of publication this reference is undergoing revision; reference table 11.3)	MUST
CHISHP011	The system must be able to support the capturing of results for the health promotion of children outlined above (Universal Services Delivery Schedule for 0-5 year olds). This includes the schedule for mandated universal interventions as part of the Healthy Child Programme which covers the initial antenatal visit, the new baby review, and the child development assessments which should take place at 6-8 weeks, at 1 year, and at 2 to 2.5 years.	MUST
CHISHP012	The system must be able to support the capturing of results for the health promotion of children outlined within above (Universal Services delivery schedule for 5-11 year olds).	MUST
CHISHP013	The system must be able to support the capturing of results for the health promotion of children outlined above (Universal Services delivery schedule for 11-16 year olds).	MUST
CHISHP014	The system must be able to support the capturing of results for the health promotion of children outlined within above (Universal Services delivery schedule for 16-19 year olds).	MUST
CHISHP015	The system must be capable of allowing appropriate healthcare professionals to review records for each child.	MUST
CHISHP016	The system must be capable of producing reports/list of those children that need follow-up with a healthcare professional.	MUST
CHISHP017	The system must be capable of producing a list of those children that need an appointment scheduling.	MUST

CHISHP018	At each review the system must be able to create new records and update existing records.	MUST
CHISHP019	The system must be able to record the breastfeeding status as per the classifications stated in the PHCR for each child; - totally - partially - not at all	MUST
CHISHP020	At each contact, the system must be able to record the weight of the child, and at 6-8 weeks, the head circumferences measurements which should be made and plotted on centile charts.	MUST
CHISHP021	The system must be able to record that an intervention has taken place and record items which will be permanent health biographical records for each child.	MUST
CHISHP022	The system must enable healthcare professionals to record relevant core items for each child in their care and under the responsibility of the CO.	MUST
CHISHP023	The system must provide ability to input notes in the appropriate area of record.	MUST
CHISHP024	The system must enable the recording of each category within the CAF assessment as: - not known - not assessed - no problem - mild/suspected - moderate - severe - profound	MUST
CHISHP025	The system must provide facilities to record monitor and audit the process within health to meet statutory responsibilities in providing information to the local authority detailed in the Education Act 1996. http://www.legislation.gov.uk/ukpga/1996/56/contents This may include, but is not exclusive to; - no Special Educational Needs ascertained (at Stage, 1, 2, 3) - initiated assessment of additional needs (Education, Health and Care plan) - trigger (1st) letter to parents; used when parents did not make request directly to local authority - parental permission - referred for assessment of educational needs	MUST

	- letter received from local authority requesting information gathering - report required from the following staff - reports completed by the following staff - record when an assessment date has been offered, with whom and where - health appendix of assessment of educational need completed - health appendix of assessment forwarded to local education authority - final EHC plan received - EHC plan rejected - tribunal Record when an assessment is overdue, from whom and the reason	
CHISHP026	The system should be able to record and store CAF Assessment information against the child's record including but not exclusive to: - the date and time of the assessment - the healthcare professional/ team performing the assessment - the healthcare professional completing and approving the report	SHOULD
CHISHP027	The system should enable the recording and storing of audiological measurements.	SHOULD

11.5.2 Scheduling requirements

Req Id	Requirement Description	Priority
CHISHP028	The system must be capable scheduling activities to enable the CO to provide care to the child under its responsibilities.	MUST
CHISHP029	The system must be capable of scheduling health promotion reviews for the following scenarios: - antenatal visit for all pregnant women led by health visitor - new birth visit all children led by HV face to face - 6-8 weeks, infant physical examination all children, led by GP, face to face - 6-8 weeks assessment, led by health visitor, face to face - 12 months assessment, all children, led by health	MUST

	visitor, face to face - 2-2.5 years assessment, all children, led by health visitor, face to face - school entry, led by school nurse.	
CHISHP030	The system should enable the scheduling of audiological measurements.	SHOULD

11.6 Reporting

11.6.1 Reporting requirements overview

The system needs to provide the ability to monitor the quality and coverage of the Healthy Child Programme delivery at CO level and to provide some information needed for secondary uses purposes including whatever key outcome measures are selected.

11.6.2 Reporting requirements table

Req Id	Requirement Description	Priority
CHISHP031	The system must be able to provide the ability to monitor the quality, coverage and outcomes from the Healthy Child Programme delivery at CO level and to provide information needed for secondary uses purposes including whatever key outcome measures are selected. This includes aggregate reporting by:- - Local Authority of residence - GP practice of registration and - school attended	MUST

11.6.3 Printing requirements table

Req Id	Requirement Description	Priority
CHISHP032	The system must be capable of generating the documentation for the particular assessment or review that is due, and all relevant records must be available. This must include the results of previous assessments and any diagnoses held on the child's record including those records previously held in paper form so scanned documents must be supported also.	MUST

11.7 References

Ref: no	File CM Reference number or equivalent	Title
11.1	DH Gateway reference 9211 https://www.gov.uk/government/policies/giving-all-children-a-healthy-start-in-life	The Child Health Promotion Programme - Pregnancy and the first five years of life
11.2	http://www.thelancastermodel.co.uk/programs/Healthy%20Child%20Programme%202009.pdf	Healthy Child Programme - From 5-19 years old
11.3	http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4003256	Department of Health (2000) Framework for the assessment of children in need and their families
11.4	http://www.england.nhs.uk/ourwork/qual-clin-lead/hlth-vistg-prog	NHS England Health Visiting Programme website
11.5	http://www.england.nhs.uk/ourwork/qual-clin-lead/hlth-vistg-prog/info/docs-res/	NHS England (2014) 2015 – 16 National Heath Visiting Core Service Specification
11.6	https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216464/dh_133352.pdf	Department of Health (2012) Getting it Right for Children and Families; Maximising the contribution of the school nursing team: Vision and Call to Action
11.7	http://agesandstages.com/	ASQ Ages and Stages questionnaire tool
11.8	http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_134463.pdf p.65	CAF Assessment information
11.9	http://www.legislation.gov.uk/ukpga/1996/56/contents	Education Act 1996
11.10	https://www.gov.uk/government/publications/healthy-child-programme-rapid-review-to-update-evidence	Public Health England (2015) Healthy child programme: rapid review to update evidence

12. Immunisation

12.1 Introduction

The requirements in this chapter relate specifically to the Immunisation Programme aspects of the Child Health Information Service, to enable data sharing to a national standard and the transmission of vaccine coverage data information to PHE in accordance with the COVER information standards notice (http://www.isb.nhs.uk/docu,ments/isb-0089/amb-8-2014/index_html). This chapter details requirements which are over and above the general functional requirements outlined in Chapter 4 of this document, which must be read prior to consideration of this chapter.

The current UK immunisation programme offers all children routine immunisation against the following infections:

- diphtheria
- tetanus
- pertussis (whooping cough)
- polio
- Haemophilus influenzae type b
- meningococcal serogroup C
- pneumococcal disease
- Rotavirus
- measles, mumps and rubella
- childhood influenza immunisation programme[24].

It also offers immunisation to selective cohorts at risk of the following conditions:

- human papillomavirus (HPV)
- hepatitis B
- tuberculosis
- influenza
- Pertussis for pregnant women[25] (running from 2014-2019)
- varicella.

It also offers immunoglobulins for passive immunity and ad hoc vaccinations eg for travel. Guidance for immunisation and vaccination in England is produced by Public Health England and informed by advice and recommendations of the Joint Committee

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[24] Chlldhood influenza immunisation is now routinely offered to children aged 2-4 years, with the aim that the programme extends in future years.

[25] Pertussis vaccination offered to all women from 2014 (programme currently running until 2019), includes any pregnant woman under 19 years of age. This programme will continue to be reviewed by JCVI and may extend beyond 2019.

on Vaccination and Immunisation and set out in the Immunisation & Screening National Delivery Framework & Local Operating Model: http://www.england.nhs.uk/wp-content/uploads/2013/05/del-frame-local-op-model-130524.pdf

Further information on routine and selective cohort immunisation programmes can be found via https://www.gov.uk/government/collections/immunisation-against-infectious-disease-the-green-book

The current complete immunisation schedule can be found here: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323504/8807_PHE_Complete_Immunisation_Schedule_A4_2014_11.pdf

12.2 Information data flows

12.2.1 Immunisation programme overview [26]

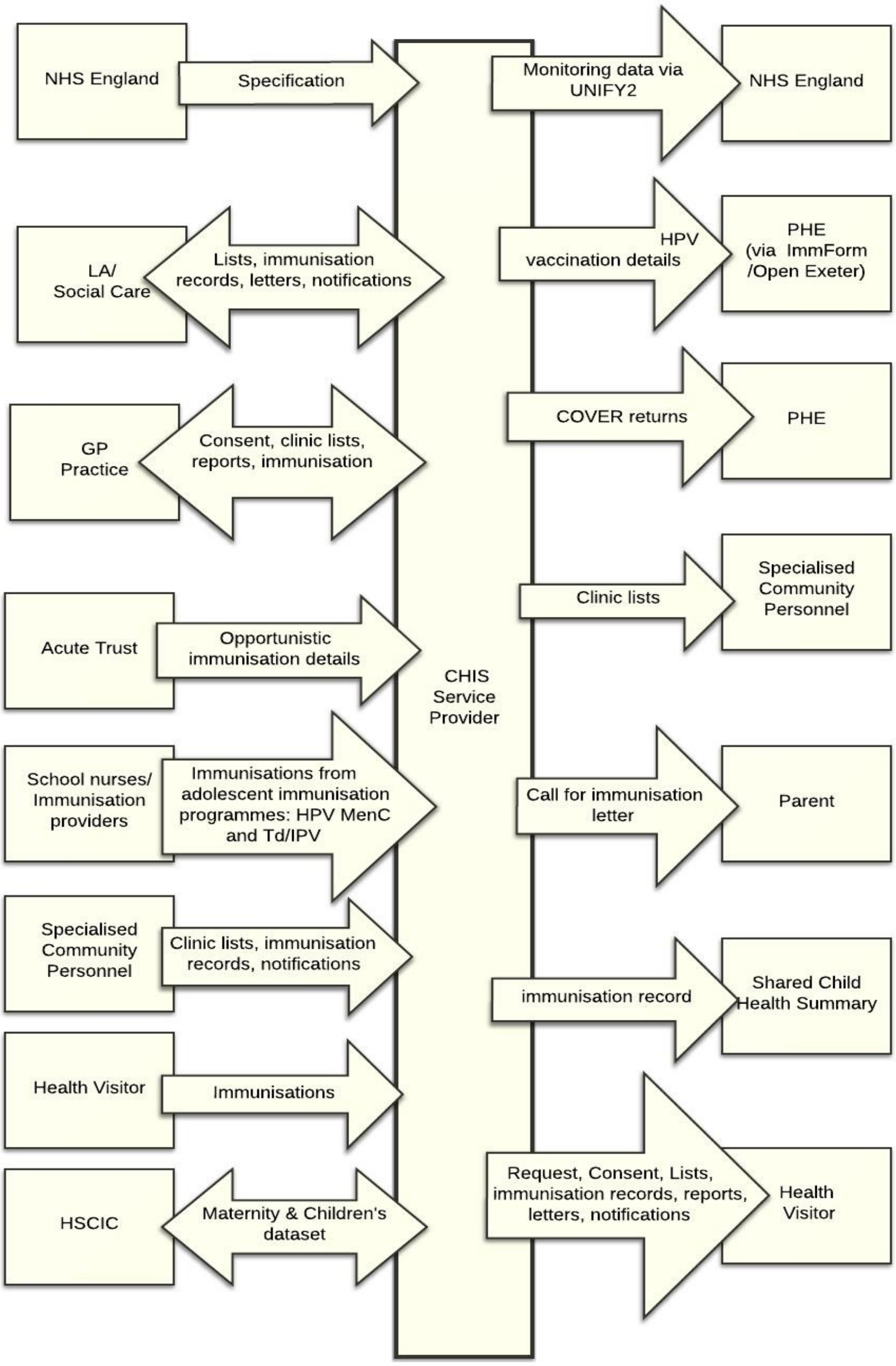

Diagram 8: Immunisation programme data flows and required external interfaces

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[26] From November 2014, a new COVER (Collection of Vaccination Evaluated Rapidly) collection information standards notice (ISN) was published for CHIS suppliers relating to recent changes to the routine childhood immunisation schedule: for the need to (a) collect coverage data via COVER for the selective neonatal BCG programme now the HSCIC KC50 is suspended, (b) refine the definition of completed courses of age-dependent vaccines, and (c) collect coverage data by local authority resident population. Further details can be found via: http://www.isb.nhs.uk/documents/isb-0089/amd-8-2014/index_html
A new annual adolescent immunisation data collection was also being considered at the time of publication of this document.

12.2.2 Information data flows table

Originator	Recipient	Dataset/Information
CHIS system[27]	NHS England (via UNIFY2)	GP level Monitoring Data (vaccine coverage)
CHIS system	Public Health England (via ImmForm)	HPV Vaccine Coverage Data
CHIS system	Community Clinic	Clinic Lists
CHIS system	Public Health England (via COVER return)	Cover of Vaccination[28] Evaluation Rapidly (COVER) Return (compliant with ISN)
CHIS system	Parent	Letter to Call Child for Immunisation (and re-call)
CHIS system	HSCIC	Maternity & Children's Dataset
CHIS system	Child Health Summary Record (CHSR)	Immunisation Record
CHIS system	Health Visitor & Personal Child Health Record (PCHR)	Request to Administer Immunisation Consent, Lists, Immunisation records, Reports, Attendance and non- attendance notifications (DNA)
CHIS system	Local authority (LA)	Clinic Lists, Immunisation records, Attendance and non-attendance notifications (DNA)
CHIS system	GP	Consent, Clinic Lists, Immunisation records, Reports, letters, Attendance and non-attendance notifications (DNA)
CHIS system	CHIS system	Electronic transfer of mandated immunisation information between CHIS systems for children transferring in/out of an area. And for immunisations given out of 'area'

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[27] Please note, the data flow diagram above features the term 'CHIS service provider', and 'CHIS system' is used in the table above. CHIS system is the preferred term.

[28] It should be noted that COVER includes registered and unregistered children, and so differs from the Unify2 return as it will be more complete.

Immunisation specification NHS England	CHIS system	Data definitions and specifications Specification
Acute Trust	CHIS system	Opportunistic Immunisation details
Community Clinic (eg opportunistic immunisations, satellite baby clinics)	CHIS system	Clinic Lists, Immunisation Records, non-attendance notifications (DNA)
GP	CHIS system	Consent, Clinic Lists, Immunisation records (including overdue vaccinations) Reports, letters Attendance and non-attendance notifications (DNA)
Health Visitor & PCHR	CHIS system	Record of Immunisations administered (including did not attends (DNA))
Local Authority	CHIS system	Record of Immunisations administered, failed, rejected, (including did not attends)[29]
HSCIC	CHIS system	Maternity & Children's Dataset
School nurses	CHIS system	Adolescent immunisation programmes: HPV MenC and Td/IPV

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[29] Enbles detailing of school based immunisation programmes, plus an understanding of the immunisation status of the school based population.

12.3 Functional requirements

12.3.1 Identify children to be immunised

The CO must be able to identify which children need to receive which immunisations, based on the guidance in the Public Health England Green Book (reference 12.1). In addition, the CO must be able to identify children who need to receive specific immunisations because their immunisation status is either unknown or incomplete, or their requirements are distinct and additional from the rest of the population (eg hepatitis B, or a child with asthma see reference 12.5). This information will be available in the child's clinical record.

12.3.2 Provide support for the routine immunisation programme

The CO should follow the schedule of ideal ages for the routine immunisation of children in accordance with the Public Health England Green Book (reference 12.1).

The CO must be able to update the personal child health record on the shared child health record as described in the "External interfaces" section below.

12.3.3 Support variant scheduling for an individual

The system should be capable of supporting a variation to the immunisation schedules to reflect clinical need and risk factors. Such a variation may be via national guidance due to public health priorities Alternatively, variant schedules may be chosen because of risk factors, eg a child who is at risk of measles (e.g. due to exposure) might be given an earlier immunisation. The Child Health Information Service system CHISs needs functionality to schedule and run catch-up programmes, including for example, where children are not available for the initial vaccination date at school.

In the event that a child's vaccinations or immunisations are missed, late or unknown the CO must take action to regularise the situation as described by Public Health England in reference 12.5.

12.3.4 Flexibility of immunisation scheduling for a cohort population

It is essential that CHISs systems are able to accommodate changes to the national vaccine programme as new vaccines and clinical evidence becomes available. This may include the introduction of new vaccines, or changes to the schedules for existing vaccinations. Changes are announced via Tripartite letters with the detail of the clinical guidelines outlined in the Green Book. Activity details of the data collection are published in an Information Standard Notice (ISN) and suppliers are required to be compliant with the requirements of these, including scheduling requirements. The response to this requirement needs to be achieved in a timely manner.

It is important that the design of CHISs allows sufficient flexibility so that changes to the schedule of existing immunisations (see COVER ISN 2014) or the addition of new immunisations for children of any age can be made in a straightforward and timely manner.

The system must be flexible enough to allow an internal schedule to be set according to local priorities and locally defined populations. For example, the requirement to call children for a measles, mumps and rubella (MMR) catch-up by setting up a schedule which calls the youngest children with no MMR first and older children with only one MMR later.

12.3.5 Invite children for immunisation

The system should be capable of inviting children for immunisations, and also able to allocate appointments in the CO clinics and schools or on behalf of practices. It must be able to produce locally adaptable editable letters for transmission in mailer or short message service form and flexible clinic scheduling.

The immunisation could be administered by any one of the following health professionals:

- health visitors
- practice nurses
- GPs
- school nurses
- other (for example, community pharmacy practitioners)

12.3.6 Record details of immunisations

Vaccine information should be recorded in a consistent manner to ensure continuity of information and safe governance across systems, for example, whether it is the name or the product that is recorded. This will help ensure continuity across the country as children move between areas and different services record immunisations onto the child’s record.

The system must record vaccines in line with nationally agreed naming and utilisation conventions.

The national data dictionary codes for vaccines should be used when recording on CHIS[30]. These codes are nationally agreed, and are compliant with COVER and the Maternal and Children's Dataset ISNs.

The system must be able to record as discrete data elements data associated with any immunisation administered (including travel vaccinations) the following as a minimum:

- date administered
- administering clinician
- location (e.g. address and type of location, e.g. GP surgery, school, community clinic)
- site of administration (e.g. left arm)
- diseases protected against
- antigen
- batch number.

It must be able to record:

- product name
- manufacturer.

It must also be possible to retrospectively record immunisations given, including those given abroad. It must be possible to record as much or as little information that is available about immunisations given elsewhere, including an indicator of how certain the information is, e.g. documentary evidence exists, or unvalidated statement by parent.

12.3.7 Record refusals

The CO must record any refusal by a parent/guardian or young person to be immunised, including the reason given. This may include the entire programme or an individual antigen under which circumstances it may be appropriate to suspend routine scheduling but allow for subsequent follow-up. The system should allow a deferral; for example holiday, for which rescheduling at later date is required.

The CO must be able to identify all children whose immunisation(s) have been refused.

The CO must be able to issue recalls for an immunisation for which a previous refusal has been recorded, though it must be possible to use different wording in the invitation, eg "we know that previously you indicated that you didn't want to receive the x vaccination, but following the recent publicity we wondered if you might want to change your mind."

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[30] ttp://www.datadictionary.nhs.uk/data_dictionary/data_field_notes/i/immunisation_doses_given_total_(cover)_de.asp?shownav=

12.3.8 Record “did not attends”

The system must record did-not-attends and generate associated actions including appropriate prioritisation according to local rules.

12.3.9 Recording contraindications and adverse reactions

The CO must maintain records of vaccine issues regarding quality, potential vaccine failures, and adverse reactions. In order to fulfil this requirement, COs must record the antigen, batch number and vaccinator for every immunisation dose administered.

The system should permit the user to record the contraindication resulting in the immunisation not being given as scheduled/planned. This may include the following contraindications:

- immunosuppression
- anaphylaxis to a previous dose of the vaccine
- anaphylaxis to a constituent of the vaccine
- previous BCG (for BCG vaccine)
- positive skin test (for BCG vaccine)
- previous disease (for a few vaccines only)
- acute febrile illness (postponement only)
- evolving neurological disorder (postponement only).

The system must allow the user to record the subsequent action to be taken.
Record additional immunisations given

Children may receive doses of vaccines that are not scheduled. These may be extra doses of scheduled vaccines e.g. an “extra dose” of a tetanus containing vaccine given in A&E. Alternatively the child may be given one or more doses of other vaccines which are currently available in the UK but not included in the routine immunisation schedule, or which are available and given elsewhere in the world but not available in the UK. Any vaccines given should be recorded in the same format as the scheduled vaccines so that it is possible to work out age specific vaccination status.

Certain children require additional vaccines or doses according to identified risk factors. The system must allow the recording of specific indicators of need and the flexibility to produce a resultant individual schedule, for example neonatal hepatitis B post exposure prophylaxis, pneumococcal and influenza immunisations. It is essential that all these additional doses are clearly recorded as that may change future scheduling.

12.3.10 Tracking payments owed to GPs

The CO must maintain records of immunisations and vaccinations carried out by GP practices so that claims from GP practices can be confirmed.

12.3.11 Reporting and central returns

The system must be flexible to be able to generate reports for front end users based on any data field combinations and local population configurations.

The data must be submitted to the CO to enable them to set their commissioning priorities

The CO must be able to submit central returns for the immunisation programme as described in the “External interfaces” section, in line with current ISNs.

12.4 Electronic interface requirements

12.4.1 Electronic interface requirements overview

The system must be able to receive and send information to external interfaces such as:
- provider units: COs should be informed about opportunistic immunisations including those given as part of an outbreak (for example, when a child is given MMR early following a case of measles at a nursery) by return of an unscheduled immunisation form from such units as A&E, acute units and walk in centres
- personal child health record PCHR: COs should ensure that the CHIS immunisation configuration should mirror the current immunisation pages of the PCHR so that relevant information can be exchanged.
- Open Exeter: GPs or CO staff can directly access the Open Exeter system of information for data regarding those offered and given the HPV vaccines. The CHIS must reflect the specification of the CSV file layout which is available on the Open Exeter on-screen help page.
- maternity and data set MCDS: Health and Social Care Information Centre’s (HSCIC):. The CHISs system must comply with information data standards to enable the submission of immunisation data to the MCDS [HSCIC].
- Public Health England PHE: the CHISs system must have the capability to provide reports in the required format to other statutory organisations outside HSCIC conforming to published information data standards, e.g. PHE requirements, Cover of Vaccination Evaluated Rapidly (COVER) data quarterly and annually or data for other vaccine coverage collections such as Influenza and HPV immunisations via Immform www.immform.dh.gov.uk

12.4.2 External interface requirements table

Req Id	Requirement Description	Priority
CHISIM001	The system must be capable of interfacing with and submitting vaccine coverage data to the PHE, DH and NHS England via the "ImmForm" website (hosted by Infomax) https://www.immform.dh.gov.uk.	MUST
CHISIM002	The system must enable the CO to submit central returns for the national immunisation programme as specified in relevant ISNs published and communicated by HSCIC. http://www.isb.nhs.uk/documents/isb-0089/amd-8-2014/index_html	MUST
CHISIM003	The system must enable the CO to send vaccine coverage data for the Cover of Vaccination Evaluated Rapidly (COVER) programme to Public Health England on a quarterly and annual basis, as specified in the ISN.	MUST
CHISIM004	The system must enable the CO to receive information ideally in electronic format about opportunistic immunisations by return of an immunisation form from for example A&E, walk in centres, schools, immunisation teams working in outbreak response.	MUST
CHISIM005[31]	The system must be able to update the relevant GP system with the information flow. This should include; • Immunisation given • Consent declined • Did Not attend	MUST
CHISIM006	The system must enable the CO to view the Open Exeter system and to extract CSV files regarding those who have been offered and given vaccines	MUST
CHISIM007	The system must be capable of automated connectivity to Open Exeter.	MUST
CHISIM008	The system must be capable of receiving vaccination recall notifications from MHRA.	MUST
CHISIM009	The system must be able to report to GPs on immunisations undertaken within schools, and those in other community venues, e.g. health visitor held clinics.	MUST
CHISIM010	The system must be able to provide healthcare professionals (including GPs Health Visitors and School Health Teams) with electronic lists regarding children's immunisations. The electronic immunisation lists would include children	MUST

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[31] Please note that at time of publication of this update, no messaging standard exists for CHISIM005, 009 and 010 data flows.

	that are overdue, suspended or awaiting vaccination.	
CHISIM011	The system must be able to provide the CO (or appropriate person) with relevant information for targeted vaccination in the event of an outbreak or catch up programme For catch-up programmes and outbreak responses, the system would need to produce a comprehensive list of all children with immunisations status for each appropriate vaccine that includes batch numbers, dates of vaccination, GP, school etc.	MUST

12.5 Core components

12.5.1 Target cohort and schedule

Commissioning organisations should ensure local NHS contracts for children's services identify within the information specification or the data items required to be collected and reported. The provider of the CHISs is responsible for ensuring all those data items are recorded and complete. For example, to ensure that all of the children, up to the age of 19, have had or are offered immunisations in accordance with the Public Health England Green Book (reference 12.1).

12.5.2 Core components table

Req Id	Requirement Description	Priority
CHISIM012	The system must allow the addition, recording[32], storage and auditing of any licensed immunisation as identified in the National Immunisation Programme Green Book (ref 12.1). Read codes for use in primary care are in place for all immunisation programmes.	MUST
CHISIM013	The system must allow the recording, storing and auditing of immunoglobulin for passive immunity and ad hoc vaccinations.	MUST
CHISIM014	The system must allow updates of available immunisations for administration and reporting as indicated in the Green Book (ref 12.1 Appendix A) Tri-partite letters and ISNs. (http://www.dh.gov.uk/en/Publichealth/Healthprotection/Immunisation/Greenbook/DH_4097254)	MUST
CHISIM015	The system must enable the CO to ensure that all of the children for whom it has responsibility, up to the age of 19, have had, or are offered, immunisations	MUST
CHISIM016	The system must be able to identify children who need to	MUST

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[32] The new COVER ISN coding can be found at http://www.isb.nhs.uk/documents/isb-0089/amd-8-2014/008982014ddcr.pdf

	receive specific immunisations because their immunisation status is either unknown or incomplete, or their requirements are distinct and additional from the rest of the population (as noted in GP or other clinical records, for example, hepatitis B status, or asthma).	
CHISIM017	The system must be able to update the CHIS child health summary record with immunisation information as described in this chapter.	MUST
CHISIM018	The system must be able to identify and notify those children affected by changes to the national immunisation programme and invite them for the vaccinations they are eligible for.	MUST
CHISIM019	The system must be able to record, store and audit discrete data about any immunisation (including travel) administered in line with nationally agreed naming and utilisation conventions. A link is provided here to the national data dictionary codes for vaccines that should be used when recording on CHIS. These codes are nationally agreed, and are compliant with COVER and the Maternal and Children's Dataset • date administered • administering health professional • location (e.g. address and type of location, e.g. GP surgery, school, community clinic) • site of administration (e.g. left arm) • diseases protected against • antigen • batch number. • product name • manufacturer.	MUST
CHISIM020	The system must allow the CO to identify different population groups based on postcode for vaccine coverage estimates (resident populations, responsible populations e.g. school cohorts and GP registrations)	MUST
CHISIM021	The system must be able to identify all children whose immunisation(s) have been refused.	MUST
CHISIM022	The system must be able to issue recalls for an immunisation that has a refusal/suspension recorded.	MUST
CHISIM023	The system must record did-not-attend and generate associated actions including appropriate prioritisation according to local rules.	MUST
CHISIM024	The system must be capable of providing lists of outstanding immunisations required by individual children.	MUST

	The list should include details of the child's registered GP practice, Health Visitor cluster, School Health Team and Community Paediatric service where available.	
CHISIM025	The system must be capable of alerting and providing data to the CO or appropriate person with the relevant information including manufacturer, brand name, batch number, name of healthcare lead administering the vaccination, date administered and description of the vaccination site, should there be an issue with a particular batch of vaccination, such as a product recall.	MUST
CHISIM026	The system must enable the CO to maintain records of vaccine issues regarding quality, potential vaccine incidents, failures, and adverse reactions.	MUST
CHISIM027	The system must have the facility to record outcome measures including untoward events following or as a result of vaccination.	MUST
CHISIM028	The system must permit the user to record the contraindication (at any time) resulting in the immunisation not being given as scheduled/ planned. This may include the following contraindications: - Immuno suppression - Anaphylaxis to a previous dose of the vaccine - Previous BCG (for BCG vaccine) - Positive skin test (for BCG vaccine) - Previous disease (for a few vaccines only) - Acute febrile illness (postponement only) - Evolving neurological disorder (postponement only)	MUST
CHISIM029	The system must record the administration of the Mantoux/Heaf test and its outcome.	MUST
CHISIM030	The system must allow the user to record the follow-up action to be taken as a result of contraindications from the immunisation not being given as scheduled/ planned.	MUST
CHISIM031	The system must be capable of recording all doses including additional vaccines to those outlined in the Green Book.	MUST
CHISIM032	The system must be capable of identifying which vaccines were given as a scheduled vaccine.	MUST

CHISIM033	The system must be capable of recording doses and additional doses of vaccines that may not be available in the UK.[33]	MUST
CHISIM034	The system must enable the CO to maintain records of immunisations and vaccinations carried out by GP practices so that claims from GP practices can be confirmed.	MUST
CHISIM035	The system must be able to record vaccine brands, types and single antigens, including new codes for vaccine brands/ types where these become available.	MUST
CHISIM036	The system must be able to record multiple instances of vaccinations given and record them in date order against the relevant vaccine. The system must be able to record reasons for duplicate vaccination.	MUST
CHISIM037	The system must be able to set up a profile for each vaccine or immunoglobulin with the appropriate scheduling and alerts and should enable the profile to be associated with an individual record as appropriate.	MUST
CHISIM038	The system must be able to amend the profile described above and deactivate it in line with the Green Book and tripartite letters, PHE advice, or as advised by the CO.	MUST
CHISIM039	The system should be capable of recording, storing and auditing risk factors that influence the need for immunisation.	SHOULD
CHISIM040	The system must be able to suspend routine scheduling and enable an associated reason to be recorded.	MUST
CHISIM041	The system must be capable of recording serology testing and its outcome for Hep B at 12 months.	MUST
CHISIM042	The system must record children who receive additional vaccinations due to being identified at clinical risk, eg children with asthma who are offered a flu vaccination.	MUST

12.5.3 Scheduling requirements table

Req Id	**Requirement Description**	**Priority**
CHISIM043	The system must be able to schedule and reschedule immunisations.	MUST
CHISIM044	The system must have sufficient flexibility so that changes to the schedule of existing immunisations or the addition of	MUST

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[33] The system should be able to record and identify completed courses of vaccines/antigens as per the UK schedule even if different vaccines to those used in the UK have been given abroad (depending on age vaccine given and current age of child). See COVER Change Request http://www.isb.nhs.uk/documents/isb-0089/amd-8-2014/008982014cr.pdf

	new immunisations for children of any age can be made in a straightforward and timely manner once the ISN has been published by the HSCIC.	
CHISIM045	The system must be flexible enough to allow an internal schedule to be set according to local needs.	MUST
CHISIM046	The system must allow the recording of specific indicators of need and the flexibility to produce a resultant individual schedule.	MUST
CHISIM047	The system must be able to record the reason and date for the vaccination administered and provide the required relevant future schedule for that product.	MUST
CHISIM048	The system should be able to support any individual or once-only nationally agreed immunisation schedules that require recording, e.g. swine flu.	SHOULD
CHISIM049	The system should be able to record, store and audit the reason for the variation in the immunisation schedule.	SHOULD
CHISIM050	The system should be able to support a variation to the schedule. Variations not exclusively, should include: • Incomplete immunisation record • Early immunisations • Late immunisations • Missed immunisations • Individuals at risk of disease due to exposure • Duplicate immunisations given in error	SHOULD

12.6 Reporting

12.6.1 Reporting requirements table

Req Id	Requirement Description	Priority
CHISIM051	The system must be able to produce outputs of immunisation data as detailed in the PHE user guide to reporting to the COVER programme, which is referenced in the new ISN COVER standard http://www.isb.nhs.uk/documents/isb-0089/amd-8-2014/index_html	MUST
CHISIM052	The system must be able to automatically report immunisations to Open Exeter for payment purposes.	MUST

12.6.2 Printing requirements: Immunisation letter production

Req Id	Requirement Description	Priority
CHISIM053	The system must be capable of inviting children for immunisations, and also able to allocate appointments in relevant clinics at schools or on behalf of GP practices. The system must be able to produce locally adaptable editable letters for transmission in mailer or short message service form and flexible enough to incorporate clinic scheduling.	MUST

12.7 References

12.7.1 Overview

Guidance for immunisation and vaccination in England is produced by Public Health England and informed by advice and recommendations of the Joint Committee on Vaccination and Immunisation and set out in the Green Book (reference 12.1).

While the list of immunisations is correct at the point of publication, immunisations are added on an unscheduled basis, and so the ultimate reference must be the Green Book. The latest COVER ISN should also be referred to, to provide details for the data collections required.

12.7.2 References table

Ref: no	File CM Ref. or link	Title	Version
12.1	https://www.gov.uk/government/collections/immunisation-against-infectious-disease-the-green-book	Public Health England, Immunisation against infectious disease (The Green Book) informed by advice and recommendations of the Joint Committee on Vaccination and Immunisation	September 2014
12.2	http://www.england.nhs.uk/wp-content/uploads/2013/05/del-frame-local-op-model-130524.pdf	Immunisation & Screening National Delivery Framework & Local Operating Model	May 2013
12.3	https://www.gov.uk/government/collections/vaccine-uptake#cover-of-vaccination-evaluated-rapidly-programme	COVER data and parameters guidance for local health authorities	Updated quarterly

12.4	http://www.isb.nhs.uk/documents/isb-0089/amd-8-2014/index_html	COVER data information standard ISN	Nov 2014
12.5	https://www.gov.uk/government/publications/vaccination-of-individuals-with-uncertain-or-incomplete-immunisation-status	Vaccination of Individuals with Uncertain or Incomplete Immunisation Status	August 2014
12.6	https://www.gov.uk/government/collections/immform	Public Health England website about ImmForm	November 2013
12.7	https://www.gov.uk/government/publications/hepatitis-b-antenatal-screening-and-newborn-immunisation-programme-best-practice-guidance	Public Health England Key vaccination information and policy about Hepatitis B	July 2014
12.8	http://www.cancerscreening.nhs.uk/cervical/openexeter/index.html	Guide to uploading HPV data to Open Exeter	

12.8 Future developments

12.8.1 Revised clinical coding for antigens

While there are already codes for vaccine brands and types, codes should also exist for single antigens (as these are available in other countries), and should be able to distinguish between subtly different vaccination names.
In addition it will be helpful if the notion of different codes for 1st, 2nd, 3rd, “additional’, “booster” and “reinforcing” doses etc. could be dropped. The vaccinations given should simply be recorded and the system should be intelligent enough to add up the number of doses against each disease that a child has had, know what it should have had by a certain age and appoint or prompt if too few or too many, have or may be being offered taking into account possible additional immunisations required for some individuals e.g. in defined clinical risk groups. It should be noted that some conjugate vaccines are age dependent and so the number of doses required will vary with age. This information is given in tripartite letters introducing new vaccines and/or revised schedules for existing vaccines and is in the Green Book.

Immunisations are added on an unscheduled basis, and so the ultimate reference must be the Green Book (reference 12.1). It is therefore important that the design of CHISs allows sufficient flexibility so that changes to the schedule of existing immunisations or the addition of new immunisations can be made in a straightforward and timely manner in line with current ISNs.

12.8.2 Recording manufacturer source

A number of vaccines providing protection for the same diseases are available from different manufacturers. It would be beneficial if the CHIS had the facility to record the product name, batch number and expiry date and manufacturer source for immunisations delivered.

12.8.3 ePCHR

ePCHR is under development, and the CHISs system needs to be able to interface with this as and when detailed specifications are available

13. National child measurement programme

13.1 Introduction

This chapter details aspects of the Child Health Information Service which relate to delivery of The National Child Measurement Programme (NCMP), and are over and above the general functional requirements outlined in Chapter 4 of this document, which must be read prior to consideration of this chapter. The NCMP is a mandatory public heath function of all local authorities in England. The programme involves measuring the height and weight of Reception and Year 6 children at state-maintained schools. The programme has two key purposes:

- to provide robust public health surveillance data on child weight status: to understand and monitor obesity prevalence and trends at national and local levels, inform obesity planning and commissioning, and underpin the Public Health Outcomes Framework indicators on excess weight in 4-5 and 10-11 year olds
- to provide parents with feedback on their child’s weight status: to help them understand their child’s health status, support and encourage behaviour change, and provide a mechanism for direct engagement with families who have overweight and obese children.
- All local authorities must validate and submit their NCMP dataset to the Health and Social Care Information Centre, on an annual basis, using the HSCIC’s NCMP IT system http://www.hscic.gov.uk/ncmpsystem

This chapter details requirements which are over and above the general functional requirements outlined in Chapter 4 of this document, which must be read prior to consideration of this chapter.

https://www.gov.uk/government/publications/national-child-measurement-programme-operational-guidance

13.2 Information data flows

Originator	**Recipient**	**Dataset/ Information**
NCMP provider[34]	CHIS system	NCMP system
CHIS system	HSCIC	Height, Weight, NHS number and date of measurement

13.3 Electronic interface requirements

Req Id	**Requirement Description**	**Priority**
CHISCM001	The system must be capable of sending, storing and receiving the NCMP data of child's height, weight and date of measurement taken These are key elements of the children and young people dataset which will flow into the HSCIC.	MUST
CHISCM002	The system must enable the CO to create and submit a data file in line with Health & Social Care Information centre data requirements.	MUST
CHISCM003	Where data files for the HSCIC have to be produced, the system should be capable of running this as an automated and manual process. The system should have the flexibility to enable the CO to define an automated run with a manual override to create the data file.	SHOULD
CHISCM004	The system must validate the data at the point of entry.	MUST

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[34] The originator for this data flow is from the NCMP IT system.

13.4 References

Ref: no	File CM Reference number or equivalent	Title	Version
13.1	https://www.gov.uk/government/publications/national-child-measurement-programme-operational-guidance	National Child Measurement Programme Operational guidance	2014
13.2	http://www.hscic.gov.uk/ncmpsystem	HSCIC's NCMP IT system; for submitting data, and generating personalised result letters for parents using	N/A
13.3	http://www.noo.org.uk/NCMP/analytical_guidance www.noo.org.uk/noo_pub/ncmp	NCMP guidance for data sharing and analysis	2012/13
13.4	http://www.ic.nhs.uk/ncmp/valida tion http://www.hscic.gov.uk/media/12768/Pupil-Data-Management/pdf/Pupil_Data_Management_2014_15.pdf	The NHS Information Centre's updated validation guidance contains details of child health system ethnic codes	May 2011
13.5	http://www.hscic.gov.uk/media/15321/Reference-data/xls/NCMP_reference_data.xlsx	NCMP reference data, ethnicity codes. An outline of ethnicity codes that are accepted by the NCMP IT system.	October 2014

14. Supporting looked after children

14.1 Introduction

The requirements in this chapter relate specifically to the information and data exchange between health and care professionals and the Child Health Information Service to support effective delivery of health care for Looked after Children. These are over and above the general functional requirements outlined in Chapter 4 of this document, which must be read prior to consideration of this chapter

The information processes outlined below are based upon the services that children who are of 'looked after' status need, including health assessments on entry to statutory care, and then regular reviews.

Looked after children are recognised to have greater health needs than the general population[35] and that these needs may also be more difficult to meet, in view of the mobility of some young people and a change of carers. Their health biography can be more difficult to trace and thus needs to be carefully recorded and shared with those who have responsibility for them and also with the child themselves.

Looked after children:

- have initial health assessments on becoming 'looked after', which should be comprehensive; these often lead to identification of needs for which an action plan can be put in place in a healthcare plan
- require regular review health assessments to check again on their health status and whether they have had or benefitted from actions recorded in the healthcare plan and whether there are any unmet needs.

Although the primary responsibility lies with the social care service for reviews of status, the health needs of the child should be met and monitored by health services. This applies also to any children placed for adoption where there are long-term health needs or background family history to be taken into account. After placement for adoption healthcare plans are in place in the same way as for other children looked after until the final adoption order is made.

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[35] NICE (2010) Looked after children and young people. Public Health Guidance 28. http://www.nice.org.uk/guidance/ph28/chapter/2-context.
Department for Children and Families (2009) Statutory Guidance on Promoting the Health and Well-being of Looked After Children

14.2 Information data flows

14.2.1 Looked after children overview

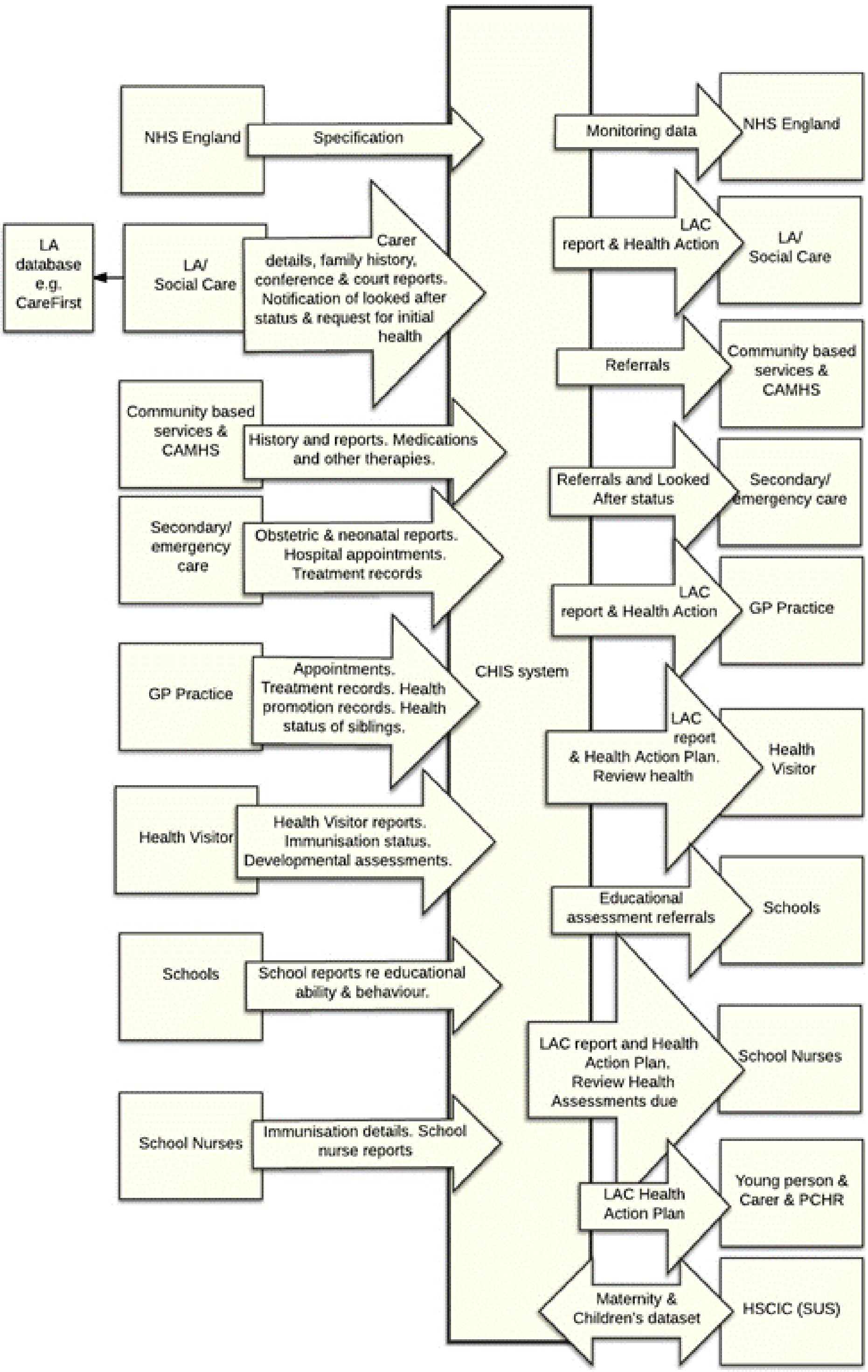

Diagram 9: Looked after children data flows and required external interfaces

14.3 Functional requirements

14.3.1 Highlighting the child's status to healthcare professionals

The system should ensure that any healthcare professional involved in any formal reviews of or delivery of care to a looked after child has visibility of such status as well as of the presence of a Child Protection Plan, and any identified special needs. Such data may be more reliable with the introduction of the Child Protection Information Sharing Project (CPIS).

14.3.2 Maintain records

The CO's systems must be able to:

- provide, when needed, summaries of the health history of a child or young person who is looked after, including their family history where relevant and appropriate, and ensure that this information is passed promptly to health professionals undertaking health assessments, subject to appropriate consents
- maintain a record of the health assessment and contribute to any necessary action within the health plan
- support regular reviews of the clinical records of looked after children and young people who are registered with them – in particular they should gather relevant information and make it available for each statutory review of the health plan.

14.3.3 Support for formal reviews

The CO's systems must support the capture of the following information when formal reviews of the child's health are conducted:

From health care:

- report on health of birth parent (one for each parent) - use British Association for Adoption and Fostering (BAAF)[36] public health forms
- obstetric report on mother and baby forms
- neonatal report on child
- health visitor records
- school nurse records
- hospital notes or summaries thereof
- child health promotion (surveillance) reports:
- growth charts
- feeding
- routine developmental assessments

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[36] British Association for Adopting and Fostering.

- hearing and vision results
- screening results including height and weight on school entry
- PCHR
- immunisation history in detail
- dental history
- health status of siblings
- medications and other therapies
- outstanding hospital or other clinic appointments
- CAMHS or other service engagement
- school reports
- GP summary records.

From social care:
- care status from social care
- parental responsibility
- consent for assessment and examination (BAAF consent form)
- previous and current addresses
- social worker
- birth parent
- siblings
- current carer
- for review health assessment update on Healthy Child Programme and other actions
- access to any court reports
- profile of behavioural and emotional well being (BAAF Carer's report)

From those with parental responsibility and when relevant child/young person:
- consent to share summary and HCP information
- agreement about how much to share with carer.

14.3.4 Reporting on 'looked after' children

The CO must be able to perform the statutory additional reporting required for looked after children. In addition to the data requirements highlighted in this chapter, the system must be able to monitor the requirements of:
- regulations of the Adoption and Children Act 2002
- Children Act (Miscellaneous Amendments) (England) Regulations 2002
- the guidance contained in "Promoting the Health of Looked After Children" on statutory and review health assessments and the Healthy Care Standard https://www.gov.uk/government/publications/promoting-the-health-and-wellbeing-of-looked-after-children
- registration with a dentist.

It must also be possible to report whether the child or young person is up to date with immunisations, particularly under national requirements relating to children continuously in local authority care between specified dates.

A suggested set of reports are:

- number and percentage of looked after children registered with GP/dentist near to address of placement
- number and percentage of looked after children with outstanding immunisations identified
- number and percentage of looked after children failing routine screening for vision/hearing
- number and percentage of looked after children referred to specialist services following assessment
- broad diagnostic breakdown of referrals made
- percentage of looked after children referrals actioned and completed within three months, by diagnostic category
- percentage of looked after children who had healthcare plans agreed by the first review.

14.4 Electronic Interface Requirements

Req Id	Requirement Description	Priority
CHISLA001	The system must support the CO in being able to receive and send the following information electronically; • care status from social care • parental responsibility • consent for assessment and examination (BAAF consent form) • previous and current addresses • social worker • birth parent • current carer • for review health assessment update on Healthy Child Programme and other actions • access to any court reports • profile of behavioural and emotional well being from the Consultant Community Paediatrician (BAAF Carer's report)	MUST

14.5 Core Components

Req Id	Requirement Description	Priority
CHISLA002	The system must be able to identify children with a 'looked after' status.	MUST
CHISLA003	The system must enable the provision of aggregated data for the CO, to support the devising of local health programmes for 'Looked After' children.	MUST
CHISLA004	The system must be able to record needs assessments for 'Looked After' children.	MUST
CHISLA005	The system must enable the provision of aggregated data for the CO to support the devising of local action plans to address the health needs of 'Looked After' children.	MUST
CHISLA006	The system must enable the provision of outcome data for the CO from any local action plans to address health needs.	MUST
CHISLA007	The system must be able to provide the core data required to create a healthcare plan for a child being placed for adoption.	MUST
CHISLA008	The system must be able to mark a child's record with a 'placed for adoption status'.	MUST
CHISLA009	The system should be able to remove a 'placed for adoption' status when a child's final adoption order has been made.	MUST
CHISLA010	The system must be able to archive a child's health care plan when a final adoption order has made.	MUST
CHISLA011	The system must clearly highlight a child with a 'Looked After' status to a health professional during any formal review.	MUST
CHISLA012	The system must clearly highlight where a child with a 'Looked After' status has a Child Protection Plan to a health professional during any review.	MUST
CHISLA013	The system must clearly highlight where a child with a 'Looked After' status has any identified special needs.	MUST
CHISLA014	The system must enable a health professional to record any special needs when attending to a child with a 'Looked After' status.	MUST
CHISLA015	The system must be able to produce a summary screen of the health history of a child/ young person who has a status of 'Looked After' subject to the appropriate consent. This must include the child's family history where relevant and appropriate.	MUST

CHISLA016	The system must enable the CO to maintain a record of the health assessment and contribute to any necessary action within the health plan child/ young person who has a status of 'looked after' subject to the appropriate consent.	MUST
CHISLA017	The system must enable the CO to prepare for regular reviews of 'Looked After' children and young people who are registered with them and records that the formal review has taken place and any outcomes or referrals as a result of the review.	MUST
CHISLA018	The system must support the CO's duty to capture the formal reviews of a 'Looked After' child's health when conducted in a health setting.	MUST
CHISLA019	The system must support the CO's duty to capture the following information from health systems when formal reviews of a 'Looked After' child's health. - Obstetric report on mother and baby forms - Neonatal report on child - Health visitor records - School nurse records - Hospital notes or Summaries there of - Child health promotion (surveillance) reports - Growth charts - Feeding - Routine development assessments - Hearing and vision results - Screening results including height, weight on school entry - PCHR - Immunisation history in detail - Dental history - Health status of siblings - Medications and other therapies - Outstanding hospital or other clinic appointments - CAMHS or other service engagement - School reports - GP Summary records	MUST
CHISLA020	The system must be able to capture the following information when formal reviews of a looked after child's health from social care for formal reviews of a looked after child's health - Care status from social care - Parental responsibility - Consent for assessment and examination Consent for	MUST

	Stat IHA/RHA for child - Previous and current addresses - Social worker - Birth parent - Siblings [37] - Current carer - For review health assessment update on Healthy Child Programme and other actions - Access to any court reports - Report on health of birth parent (one for each parent) - use British Association for Adoption and Fostering (BAAF) public health forms - Profile of behavioural and emotional well being (BAAF Carer's report)	
CHISLA021	The system must be able to record consent, and the extent of consent, to share summary and healthcare professional information from those with parental responsibility for the child/ young person who has a 'Looked After' status.	MUST
CHISLA022	The system must be able to record that the child is registered with a dentist.	MUST
CHISLA023	The system must be able to record agreement about how much information to share with a carer.	MUST

14.6 Reporting

14.6.1 Reporting requirements

Req Id	Requirement Description	Priority
CHISLA024	The system must enable the CO to perform the statutory additional reporting required for looked after children.	MUST
CHISLA025	The system must enable the CO to monitor the requirements of regulations of the Adoption and Children Act 2002 www.legislation.gov.uk/ukpga/2002/38/contents	MUST
CHISLA026	The system must enable the CO to monitor the requirements of the Children Act (Miscellaneous Amendments) (England) Regulations 2002 www.dh.gov.uk/en/Publicationsandstatistics/.../DH_4004865	MUST
CHISLA027	The system must enable the CO to monitor the	MUST

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[37] It is recommended to record if a child has siblings. But the child's record should not be linked to the records of any siblings.

	requirements of the guidance contained in "Promoting the Health of Looked After Children" on statutory and review health assessments and the Healthy Care Standard https://www.gov.uk/government/publications/promoting-the-health-and-wellbeing-of-looked-after-children	
CHISLA028	The system must enable CO to report that the child/ young person is up to date with immunisations, particularly for those children residing in local authority care between specific dates.	MUST
CHISLA029	The system must be able to produce a report of the number and percentage of looked after children registered with a GP/dentist near to address of placement.	MUST
CHISLA030	The system must be able to produce a report detailing the number and percentage of looked after children with outstanding immunisations identified.	MUST
CHISLA031	The system must be able to produce a report detailing the number and percentage of looked after children called or failing routine screening for vision/ hearing.	MUST
CHISLA032	The system must be able to produce a report detailing the number and percentage of looked after children referred to specialist services following assessment.	MUST
CHISLA033	The system must be able to produce a report detailing a broad diagnostic breakdown of referrals made.	MUST
CHISLA034	The system must be able to produce a report detailing percentage of looked after children referrals actioned and completed within three months, by diagnostic category.	MUST
CHISLA035	The system must be able to produce a report detailing the percentage of looked after children who had healthcare plans agreed by the first review.	MUST

14.6.2 Printing

Req Id	Requirement Description	Priority
CHISLA036	The system must be able to print the agreement about how much information to share with a carer.	MUST

14.7 References

	Document location	**Title**	**Edition**
14.7.1	https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/276500/promoting_health_of_looked_after_children.pdf	Department for Children and Families (2009) Statutory Guidance on Promoting the Health and Well-being of Looked After Children	
14.7.2	http://www.nice.org.uk/guidance/ph28/chapter/2-context	[1] NICE (2010) Looked after children and young people. Public Health Guidance 28.	
14.7.3	http://systems.hscic.gov.uk/cpis	Child Protection Information Sharing Project (CPIS)	
14.7.4	www.legislation.gov.uk/ukpga/2002/38/contents	The Adoption and Children Act 2002	
14.7.5	http://www.legislation.gov.uk/uksi/2002/546/made	The Children Act (Miscellaneous Amendments) (England) Regulations 2002	
14.7.6	http://www.baaf.org.uk/	British Association for Adoption and Fostering	

15. Health care for disabled children, long-term care needs, and special educational needs

15.1 Introduction

The requirements in this chapter relate specifically to the information and data exchange between health and care professionals and the Child Health Information Service to support effective delivery of health care for disabled children and young people and children with long-term care needs. This chapter also details the CHIS service related interactions for children with special educational needs requiring support.

These requirements are over and above the general functional requirements outlined in Chapter 4 of this document, which must be read prior to consideration of this chapter

15.2 Information data flows

15.2.1 Disabled children, long-term care needs, and special educational needs overview

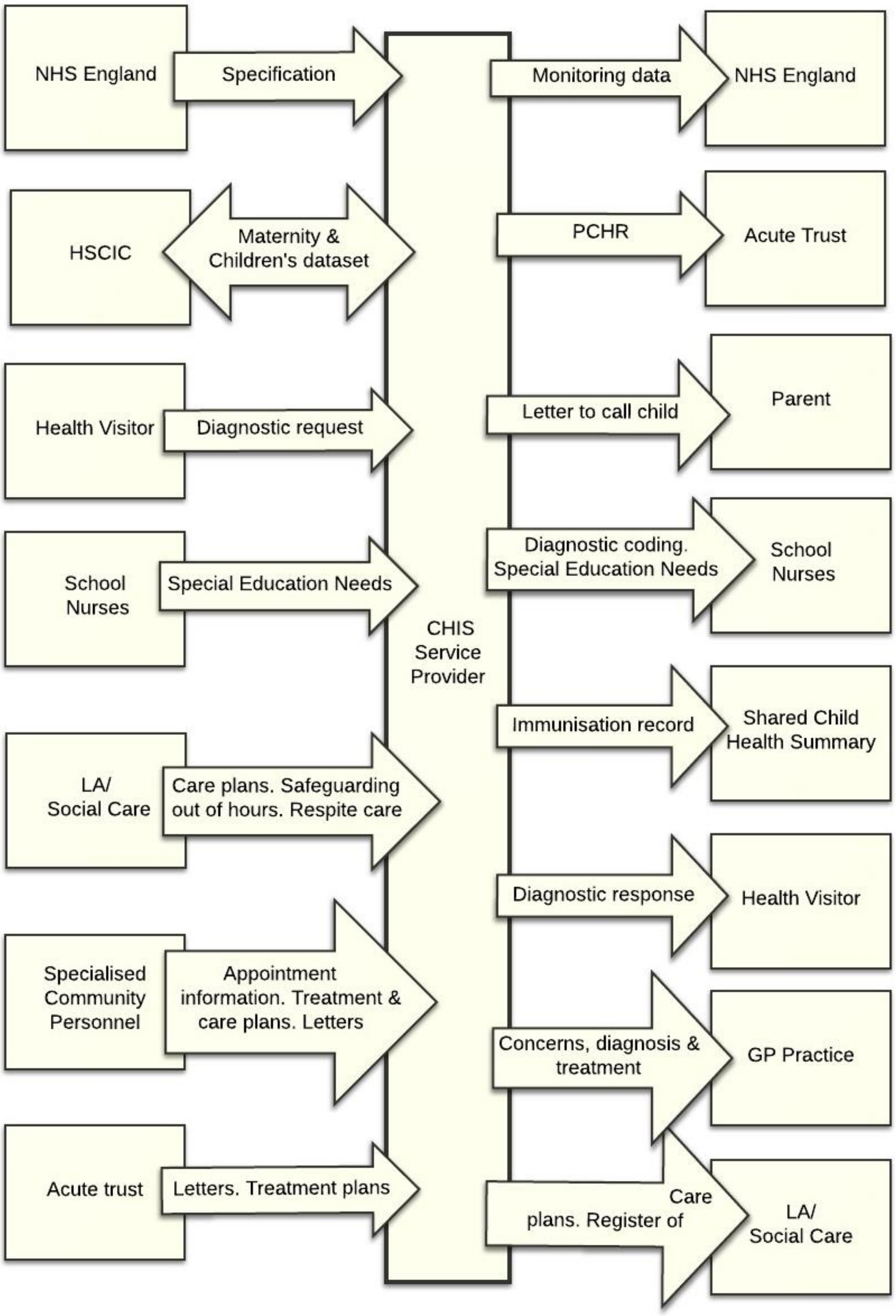

Diagram 10: Overview of data flows and required external interfaces

15.2.2 Information data flows table

Originator	Recipient	Dataset/Information
CHIS system[38]	NHS England	Monitoring Data
CHIS system	Acute Trust, Neonates, Neurodisability and Community Paediatric Teams	PCHR
CHIS system	Parent	Letter to Call Child
CHIS system	HSCIC	Maternity & Children's Dataset
CHIS system	Child Health Summary Record	Immunisation Record
CHIS system	Health Visitor & PCHR	Diagnosis response
CHIS system	LA & Schools	Diagnostic coding Special Educational Needs
CHIS system	GP	Concerns eg diagnostic, and treatment given.
CHIS system	Local Authority (eg Social care)	Health Care Plans Register of Children with Disabilities as per Schedule 2 of the Children Act 1989
NHS England	CHIS system	Specification
Health Visitor & PCHR	CHIS system	Diagnosis request
LA & Schools	CHIS system	Special Educational Needs
Social care	CHIS system	Care plans, safeguarding out of hours breaks and respite care
Acute Trust, Neonates, Neurodisability and Community Paediatric Teams	CHIS system	Neonate/Paediatric, discharge, IP/op letters. Appointments information to GP, HC and school nurse. Discharge and outpatient letters treatment and health care plans Routine health promotion

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[38] Please note, the data flow diagram above features the term 'CHIS service provider', and 'CHIS system' is used in the table above. CHIS system is the preferred term.

15.3 Functional requirements

15.3.1 Support for customised service packages

The CO's information systems must support the planning and delivery of services, over and above those designed for the population as a whole, to disabled children and young people and or those with complex healthcare needs or special educational needs and require an Education Health and Care Plan [EHC] .

15.3.2 Maintain records

The CO's information systems must maintain a full record of the assessment, care plan, treatment or interventions and outcomes. They must enable the user to comprehensively monitor a child's progress through the assessment of special educational needs procedures. The fields to be made available are as follows:

Data item	**Supporting information**
Initiated assessment of additional needs (Education, Health and Care plan)	
Trigger (1st) letter to parents – used when parents did not make request directly to local education authority	Date
Parental permission	
Referred for assessment of educational needs	Date
Letter received from local authority requesting information gathering	Date
Report required from the following staff	Name, service and date
Reports completed by the following staff	Name, service and date
Record when an assessment date has been offered, with whom and where	
Health Appendix of assessment of educational need completed	Date
Health Appendix of assessment forwarded to local education authority	Date
Final EHC plan received	Date
EHC plan rejected	
Tribunal	
Record when an assessment is overdue, from whom and the reason	

Table 8: Fields required for special educational needs procedures

15.3.3 Audit

The system must offer the facility to audit the process and timescale against assessment of educational needs and standards.

15.3.4 Reports

The following reports must be available as a minimum:
- numbers of children falling into any given disability or need category or severity category
- lists of disabled children
- analysis of children on disability register by age and category.

15.4 Electronic interface requirements

15.4.1 Electronic interface requirements table

Req Id	**Requirement Description**	**Priority**
CHISDC001	The system must be capable of providing data for the Local Authority Register of Children with Disabilities as per Schedule 2 of the Children Act 1989 (http://www.legislation.gov.uk/ukpga/1989/41/contents) following data sharing protocols.	MUST
CHISDC002	The system must have fields for the recording of the categories under which the child is registered.	MUST

15.5 Core components

15.5.1 Target cohort and schedule

All children that the CO is responsible for and who are either registered as disabled or have complex healthcare needs or who have special educational needs.

15.5.2 Core components table

Req Id	**Requirement Description**	**Priority**
CHISDC003	The system must be able to record which children the CO is responsible for and whether a child is registered as disabled or has complex healthcare needs.	MUST
CHISDC004	The system must be able to provide the CO with aggregated data on details of disabled children to customise local planning and delivery of services to children and young people who have disabilities or complex healthcare needs.	MUST
CHISDC005	The system must be able to maintain a full record of the assessment, care plan, treatment or interventions and outcomes for each child.	MUST
CHISDC006	The systems must enable the CO to comprehensively monitor a child's progress through the assessment of special educational needs procedures as outlined in the special educational needs code of practice https://www.gov.uk/government/publications/send-code-of-practice-0-to-25 The fields required are detailed in table 8 above	MUST
CHISDC007	The system must provide functionality to audit the process and timescale against assessment of educational needs.	MUST
CHISDC008	The system must have fields for the recording of the categories under which the child is registered.	MUST
CHISDC009	The system should support disabled children and those with complex health needs (when these information requirements become available).	SHOULD
CHISDC010	The system must clearly highlight where a child has any identified special needs.	MUST
CHISDC011	The system must enable a health professional to record any special needs.	MUST

15.6 Reporting

Req Id	**Requirement Description**	**Priority**
CHISDC012	The system must be able to produce reports for: - the number of children with any given disability - the need category	MUST

	- the severity category	
CHISDC013	The system must be able to produce a report of children with disabilities for whom the CO has a responsibility.	MUST
CHISDC014	The system must be able to produce reports for children on a disability register by age and category.	MUST

15.7 References

Ref: no	**Title**	**Version**
15.1	Framework for assessment of children in need, DH	2000
15.2	Together from the Start- Practical guidance for professionals working with disabled children (birth to third birthday) and their families, Department of	May 2003
15.3	Aiming high for disabled children: better support for families, HM Treasury and	2007
15.4	The dignity of risk. A practical handbook for professionals working with disabled children and their families, Council	
15.5	“Including me” – Managing complex health needs in schools and early years settings, Council for Disabled Children and DfES	2005
15.6	Special educational needs and disability code of practice: 0 to 25 years	2014
15.7	Statutory guidance on supporting pupils at school with medical conditions https://www.gov.uk/government/uploads/system/uploads/attachmen	
15.8	Early Support Programme, via National Children's Bureau ttp://www.councilfordisabledchildren.org.uk/what-we-do/networks-campaigning/early-support	Ongoing

16. Non-functional requirements

16.1 Architecture and technical requirements

Ref	Requirement	Required Response
Overview		
CPTS01	The service will contain personal sensitive information. The CHIS system (CHISs) supplier must ensure that all transactions with the service are therefore secure, and that information will be stored in a secure manner. Where encryption is used, it shall conform to HSCIC Government standards for encryption.	*Each supplier must describe its overall approach to support security and encryption requirements.*
CPTS02	The service shall comply with Technical Standards issued by HM Government. These can be found at; http://interim.cabinetoffice.gov.uk These should include the two Clinical Safety standards (formerly ISB and now published by SCCI). The purpose of the use of standards is to drive interoperability between clinical applications and NHS and Local Authority administration systems.	*Each supplier must describe how it will achieve this*
General		
CPTS03	The architecture for all system components must conform to the principles and outline design described in this module. *Each supplier must describe:* - *the overall design of the system components and the architecture that they propose, including a description, at each layer of the architecture, of the proposed technologies and their purposes* - *any commercial off-the-shelf or bespoke solutions proposed* - *the rationale for their proposal and any key benefits* - *how interfaces with the Service will be achieved* - *How performance, integrity, scalability and resilience will be preserved.* -	
Meeting the Requirements		
CPTS04	*In describing the overall architecture, particular attention should be given to the following topics:* - *how error handling will be managed, including contractual arrangements to cover instances of transaction failure and remedies for that instance* - *how data integrity and validation be applied, including the resolution of any*	

	conflicts in the information supplied by different source systems (eg differing addresses) - *how the security requirements are supported* - *how the messaging requirements are supported* - *how the data requirements are supported* - *any limitations or constraints imposed by the Service*
Flexibility and Scalability	
CPTS05	*A key driver behind the architecture is the need for interoperability with NHS systems. Each supplier must therefore describe:* - *how additional services and data would be added* - *how existing components (or systems)can be reused both in the initial deployment and in response to future change* - *the method by which scalability and performance will be achieved*
Approach	
CPTS06	*Each supplier must provide an overview of their approach to undertaking similar work, including a description of:* - *their approach to design and deployment* - *issues encountered* - *relevant lessons learned* - *Any issues that should be considered by the NHS to ensure a successful implementation.*
Benefits and Outcomes	
CPTS07	*Each supplier must describe how their architecture acts in support of the benefits and outcomes described above*
Conformity with the Delivery	
CPTS08	*Each supplier must describe how they will meet the minimum requirements for, in particular:* - *which components of the proposed architecture will be delivered at this stage* - *how phased implementation plans will be supported any additional functions it would be able to deliver*
CPTS09	*Each supplier must describe how its proposed architecture supports the primary objects outlined in section 1.6 which contributes towards child public health services.* *Each supplier must provide an outline implementation plan, including any dependencies, showing high level resource requirements, both from the IT supplier and the provider of public health services.* *Each supplier must describe any proposals for initial data take on (including data cleansing) for the service.*

16.2 Information governance

Ref	Requirement	Required Response
Overview		
CPIG001	It must be possible for user administrators to disable access for a user account. In this case, the user shall no longer be able to access the system and contact details for that user shall no longer be available to other users.	*Each supplier must describe how it will ensure that this functionality is possible*
CPIG002	Only authorised end-points must be permitted to connect to the service. The mechanism for doing so may vary between systems that consume web-services to those that submit data.	*Each supplier must describe how it will ensure end point authorisation.*
CPIG003	The system must use validated security and smart card models.	
CPIG004	Access to the Child Health Information service system [CHISs] and data will be determined at the local level with regards to who can access the information. The CHISs supplier must ensure that the relevant and validated role-based access mechanisms are in place to support this. Role-based access could be, for example, clinician-only access, administrative staff, eg receptionists, or a combination of both.	*Each supplier must describe how it will enable this*
Operating		
CPIG005	The system must allow for the correction of information that may be required. This will include the creation, updating, correcting and deleting of information.	
CPIG006	The system must be configurable to meet the requirements for continued compliance with most recent National requirements as identified on the following links: http://systems.hscic.gov.uk/rasmartcards/strategy/nhscrg [new link] https://www.education.gov.uk/publications/standard/publicationdetail/page1/DCSF-00807-2008	
CPIG007	The system must be capable of providing subject access request in line with the Data Protection Act 1998. (http://www.legislation.gov.uk/ukpga/1998/29/contents) as a	

	hard copy. This information must be available to be printed and must support the provision of all or part of the record specified.	
CPIG008	The system must support the IG and consent requirements when sharing information about a child within the NHS (including between primary, hospital-based specialist care and community child health); and between the NHS and other partner agencies, especially local authority, education and social care services.	
CPIG009	The systems must be capable of enabling any information to be marked (eg health, other, preferences) as erroneous in the record of the person in which it was mistakenly associated and represent that information as erroneous in all outputs containing that information.	
CPIG010	Where the health information has been mistakenly associated with the incorrect patient the system must enable association of the health information with the correct patient.	
CPIG011	The system must maintain a record of Consent to share parental information with the individual relating to the CHIS record. This record must record details of that consent, reasons, date, individual providing consent and to whom etc.	
CPIG012	All Child Health Information Service records must have an assigned senior clinician or Caldicott Guardian recorded against it.	
CPIG013	The system must provide the facility to record the date the information was released, by whom and to whom.	
CPIG014	The system must be able to exclude those withholding consent when producing reports to be shared.	
CPIG015	The system must be able to provide the facility to record why information was released if no consent given along with the date the information was released, by and to whom.	
CPIG016	When information is released without consent, the system must record the reasons. These could include reasons: - Under section 115 of the Crime Disorder Act 1998. Source: http://www.legislation.gov.uk/ukpga/1998/37/contents - under Section 47 of Children Act 1989 (to protect a vulnerable child) Source: http://www.legislation.gov.uk/ukpga/1989/41/section/47 - under a court order. - Where there is an overriding public interest.	

CPIG017	The system must be capable of providing subject access request in line with the Data Protection Act as a hard copy. (http://www.legislation.gov.uk/ukpga/1998/29/contents) This information must be available to be printed and must support the provision of all or part of the record specified.	
Secure Communication		
CPIG018	The confidentiality of Personal Data about a patient transmitted over the remote access links must be protected.	*If cryptographic protection is not to be provided over all links, suppliers should say how they will distinguish those links that do not require it from those that do.*
CPIG019	Messaging systems used to transmit messages containing personal data about a patient must keep a log of message transmissions. (This log will contain the time, origin and destination of the message, not its content.)	
CPIG020	Where appropriate, systems must provide notification of receipt of a message by a recipient (read receipt) when requested to do so by the originator.	
CPIG021	The network must provide acknowledgement of message submission.	
Storage		
CPIG022	Personal data about a patient must be stored within databases and/or files that are protected by an access control system.	
CPIG023	All personal data about a patient must be physically protected against theft, and either: - stored in an encrypted format - stored in an environment that is physically secure against other forms of access	*Each supplier must indicate which of these options they intend to pursue. If the option is encryption, then they should describe how the*

		cryptographic keys will be managed
CPIG024	All personal data about a patient must be backed up; - in an encrypted format - stored in a physically secure environment (In this statement, backup refers to copies of data made for short-term disaster recovery purposes, as distinguished from copies made for long term archiving purposes.)	*Each supplier must describe how they will manage the cryptographic keys.*

16.3 Business continuity/disaster recovery

Ref	**Requirement**	**Required Response**
Business Continuity		
CPBC001	A business continuity strategy is required to meet any determined service levels	*Each supplier must describe its business continuity strategy.*
Disaster Recovery		
CPBC002	A disaster recovery strategy and solution is required to meet any determined the Service levels	*Each supplier must describe its disaster recovery strategy and the scope of the proposed solution, identifying all potential disaster scenarios which recovery will be taken in order to maintain business continuity.* *Each supplier must describe the recovery plan, including:* - *documented processes and procedures* - *Roles and responsibilities.*

16.4 Standards

Ref	**Requirement**	**Required Response**
Web Services		
CPST001	*SOAP* Where Web-based services are required, they shall be developed and delivered in accordance with the latest SOAP standards. *WSDL* Where Web-based services are required, they shall be developed and delivered in accordance with the latest WSDL standards. *UDDI v3.0* Where Web-based services are required to be published to a service directory, they shall be developed and delivered in accordance with the latest UDDI standards. FHIR[39] Where appropriate FHIR should be considered for clinical communication.	
HTTP		
CPST002	Where HTTP is required, it shall adhere to the latest HTTP standards.	
FTP		
CPST003	Where FTP[40] is required, it shall support restart and recovery and adhere to the latest FTP standards, and should be only secure FTP-SFTP.	
HL7		
CPST004	Where HL7 Messages are required, they shall adhere to the latest specification. All Messages need to seek the approval of HL7-UK and NHS	

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[39] Fast Healthcare Interoperability Resources is a next generation standards framework created by HL7.

[40] File transfer protocol.

	ISB. HL7 is strategically aligned with the ISB HL7 strategic direction.	

16.5 Audit

Ref	Requirement	Required Response
Overview		
CPAU001	All actions performed within the service must be date; time and user stamped and be auditable.	*Each supplier must describe how this requirement will be met*
CPAU002	The service shall retain audit information and ensure that it is tamper-proof by all service users.	*Each supplier must describe how this requirement will be met*
CPAU003	The service must be able to provide audit reports enabling authorised personnel, including managers and system administrators, to identify patterns of service usage.	*Each supplier must describe how this requirement will be met*
CPAU004	The system must permit authorised users to easily identify - which users have viewed or amended which records, and from which organisation - when the service was accessed - which child's details were accessed This shall be via a report within the service.	*Each supplier must describe how this requirement will be met*
CPAU005	It must be possible to determine whether an individual record was present on the system at any time in the past, and whether any record present was viewed.	*Each supplier must describe how this requirement will be met*
CPAU006	The system must be able to audit all information flows to and from systems with which it interfaces with capturing and storing the transmission status information for each message received and sent.	

CPAU007	An audit of all communications with either the child and/or the parents must be maintained within the system.	

16.6 Interoperability

Ref	**Requirement**	**Required Response**
Overview		
CPIN001	The process of adoption requires an open publication and use within the NHS. Deployments based on the draft standards will be used to refine those standards and achieve successful implementations.	*Each supplier must describe how it will meet this requirement*
CPIN002	Final assurance and approval of standards will be via the NHS England SCCI Board	*Each supplier must describe how it will meet this requirement*
CPIN003	The service shall expose appropriate systems and interfaces through open standards, for redistribution, adaptation and amendment, to promote interoperability and support the NHS in further integrating its systems and services.	*Each supplier must describe how it will meet this requirement*
CPIN004	All technical standards should follow recognised professional approaches to the publication and record-keeping of the standard.	*Each supplier must describe how it will meet this requirement*

16.7 Data quality and data quality management

Ref	**Requirement**	**Required Response**
Overview		
CPDQ001	All data within the Child Health Information Service System (CHISs) must have an identified author and custodian.	*Each supplier must describe a data ownership model to be adopted, and describe how this will be used within CHIS.*
CPDQ002	The identity of a patient in relation to their unique NHS Number must be authenticated to enable information to be recorded against the correct patient	*Each supplier must describe how information available to the CPIS will be available for use in the authentication of a patient.* *Authentication processes must maintain the confidentiality requirements of other patients.* *Access control measures must be implemented to maintain the confidentiality of the patient being authenticated.* *Each supplier must describe the use of any innovative methods to ensure access control measures will maintain the confidentiality of the patient being authenticated.*
CPDQ003	Procedures concerning the usage of data quality systems must be documented.	*Each supplier will develop documented procedures for the use of its systems.* *This will be assessed and developed further if required.*
Managing Inconsistencies in Demographic Data		
CPDQ004	Where an inconsistency within personal demographic data about a patient exists this must be detected.	*Each supplier must describe how it will identify and categorise inconsistencies within personal demographic data about a patient.*
CPDQ005	Inconsistencies within personal demographic data about a patient must be resolved.	*Each supplier must describe:* - *how inconsistencies will be resolved* - *the methods by which demographic data will be manipulated* - □*where in systems containing personal demographic data about a patient the inconsistency will be resolved* - □*when the inconsistency will be resolved*

		- □*factors controlling the resolution of inconsistencies* - *How the resolution will be propagated to systems containing Personal Data about a patient so that data integrity is maintained.*

Appendix

Appendix A: Acknowledgements

We would like to thank the following contributors and reviewers for their contributions to the development of this resource

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Appendix B: Proposed content for a shared record of child health and care

The content of the shared child health record is recommended and serves two main purposes:

- for the individual child, health and illness biography which they need for the remainder of their lives
- all the multiple secondary uses of child health data for example monitoring the health of the nation's children and forming a part of any Information Centre required data sets.

Much of the information in the shared child health record will also appear in the PCHR.

Greater detail about the child's healthcare would be available in local systems for those health professionals who require it and this is defined for each screening programme in the relevant section of the report.

In summary, the proposed shared child health record will contain the following sections:

Item	**Population**
Results of screening	All
Results of immunisation	All
Feeding	All
Gestation age	All
Head circumference	All
Weights (inc birth)	All
Height	All
Progress reviews	All
Significant acute or chronic disorder	Some
Significant family history	Some
Long-term disorders and therapy	Some
Intensive Healthy Child Programme	Few
Disability	Few
Education statement/Education, health, care plan Statement of educational need/Education, Health and Care plan	Few
Child in need assessment	Few
Common assessment framework	Few
'Looked after" child assessment	Few