



Information requirements for child health information systems

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Information requirements for child health information systems

Prepared by the Child Health Information Systems Transition Steering Group

Contents

Contents.....	4
1. Introduction	7
1.1 Genesis of this work.....	7
1.2 Purpose of and audience for this document.....	7
1.3 Background and policy context	8
1.4 Transition in the health and care system	9
1.5 Maternity and children's dataset	11
1.6 Information strategy and the shared child health record	13
1.7 Outcome measures for children	14
2. Definition of a child health information system	15
2.1 Introduction	15
2.2 Functionality.....	15
2.3 Historical context.....	16
2.4 System market for CHIS	17
3. Notes on how to use this document.....	18
3.1 Introduction	18
3.2 General considerations	18
3.3 Population coverage	20
3.4 Consistency in information for primary uses	20
3.5 Secondary uses of data	20
4. General requirements	22
4.1 Introduction	22
4.2 References	22
4.4 External interfaces	24
5. Registration and scope of responsibility	29
5.1 Introduction	29
5.2 Functional requirements	30
5.3 Clinical coding.....	33
5.4 External interfaces	34
5.5 Future developments	34
6. Safeguarding	35
6.1 Introduction	35
6.2 Target cohort and schedule	36
6.3 Functional requirements	36
6.4 Clinical coding.....	37
7. Newborn and infant physical examination.....	38
7.1 Introduction	38
7.2 Target cohort and schedule	39
7.3 Functional requirements	39
7.4 Clinical coding.....	39

7.5	External interfaces	39
7.6	Future developments	40
8.	Newborn blood spot screening.....	41
8.1	Introduction	41
8.2	References	42
8.3	Target cohort and schedule	42
8.4	Functional requirements	42
8.5	Clinical coding.....	45
8.6	External interfaces	46
8.7	Future developments	47
9.	Newborn Hearing Screening Programme	49
9.1	Introduction	49
9.2	References	49
9.3	Target cohort and schedule	49
9.4	Functional requirements	50
9.5	Clinical coding.....	50
9.6	External interfaces	51
10.	Handover from midwifery	53
10.1	Introduction	53
10.3	External interfaces	55
10.4	Clinical coding.....	55
11.	Health promotion	56
11.1	Introduction	56
11.2	References	56
11.3	Functional requirements	57
11.4	Other functional requirements.....	64
11.5	Clinical coding.....	66
11.6	External interfaces	66
12.	Immunisation.....	67
12.1	Introduction	67
12.2	References	68
12.3	Target schedule and cohort	69
12.4	Functional requirements	69
12.5	Clinical coding.....	73
12.6	External interfaces	73
12.7	Future developments	74
13.	National Child Measurement Programme	75
13.1	Introduction	75
13.2	References	76
13.3	Target cohort and schedule	76
13.4	Functional requirements	76
13.5	Clinical coding.....	78
13.6	External interfaces	78

13.7	Future developments	79
14.	Supporting looked after children	80
14.1	Introduction	80
14.2	References	80
14.3	Target cohort and schedule	80
14.4	Functional requirements	80
14.5	Clinical coding	83
15.	Disability, long-term care and those with special educational needs requiring health input	84
15.1	Introduction	84
15.2	References	84
15.3	Target cohort and schedule	85
15.4	Functional requirements	85
15.5	Clinical coding	86
15.6	External interface details	87
Annex A:	Proposed content for a shared record of child health and care	88
Annex B:	Abbreviations	90

1. Introduction

1.1 Genesis of this work

- 1.1.1 The initial work for this document was commissioned in 2007 by the Department of Health/Connecting for Health Child Health Programme to establish universal information requirements for child health information systems (CHIS). The detailed specifications within this document result from the repeated engagement since then of numerous clinical and informatics colleagues without whom this current document and project would not have been possible.
- 1.1.2 This has now been further revised with further clinical, informatics and policy engagement under the auspices of 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. The remit of the group is to ensure the safe transition of CHIS to the future health and care system while promoting effective improvements and reductions in variability of systems across England.

1.2 Purpose of and audience for this document

- 1.2.1 The purpose of the document is to set out the information requirements for the delivery of child health services that take account of:
- a consensus of all guidance across the professional bodies ie colleges, professional and specialist bodies for nursing, medicine and the professions allied to medicine
 - policy, standards and guidelines for child health programmes, such as immunisation, screening and the Healthy Child Programme
 - statutory requirements for delivery of child health services
 - interpretation of legislation and consent rules for information sharing in support of the Caldicott guardian responsibilities.
- 1.2.2 The intention is that this document will help to deliver consistency in functionality and efficacy of these important information systems during transition to the future health and care system. The next step in supporting this work will be to develop this information requirements document into an outline business specification, detailing the technical requirements of an information system that meets the information requirements specified within this document.

- 1.2.3 The document is directed primarily at colleagues within Connecting for Health in order to build an outline business specification to support future commissioning of CHIS. It will be of interest to people who are currently involved in the commissioning and delivery of these information systems or who now or in the future will rely on these systems to fulfil their own responsibilities. This could include, but is not limited to:
- primary care trusts (PCTs), particularly commissioners of these systems, those involved in screening and immunisation, and public health staff moving to local authorities
 - the NHS Commissioning Board
 - Clinical Commissioning Groups
 - Public Health England
 - community services staff, particularly community paediatricians and Child Health Record Department staff
 - general practitioners (GPs) and their staff
 - health visitors
 - school nurses
 - local authorities, particularly Directorates of Children's services and Public Health
 - suppliers of CHIS
 - health protection units.
- 1.2.4 The document has not been prepared to support re-commissioning of CHIS by local commissioners prior to the transition to future NHS structures due in April 2013. It should not be relied upon as a final source of information for these or other purposes due to the changing nature of many policies in this area.

1.3 Background and policy context

- 1.3.1 CHIS are patient administration systems currently operated at a local level, commissioned by PCTs, and which support a variety of child health related activities, including public health services such as immunisation and childhood screening. They are 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 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 a commissioning strategy).
- 1.3.2 The NHS Connecting for Health child health programme, which began this work in 2006, was established in order to address a number of identified concerns about child health information. These included the observation that

in 2006 within the NHS Connecting for Health cluster/local service providers there was evidence of:

- differing pace of progress in respect of child health
- 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.

1.4 Transition in the health and care system

1.4.1 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:

- *Equity and Excellence: Liberating the NHS* (July 2010) (NHS White Paper) set out that wherever possible and appropriate commissioning responsibilities would be devolved to the most local level. 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 currently exercised by PCTs. The NHS White Paper placed great emphasis on the importance of information, both for people using services, and about those people for the professionals providing those services
- *Achieving Equity and Excellence for Children* (September 2010) also stressed the importance of sharing information between appropriate professionals to enable delivery of effective care for children, especially vulnerable and at-risk young people
- *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 PCTs, 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
- *The Healthy Child Programme (HCP)* is the key 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. The Healthy Child Programme is for all children and families from pregnancy to 19 years and is offered in clinic settings,

children's centres, GP surgeries and the home. It is led and delivered by health visitors and their teams.

- 1.4.2 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.
- 1.4.3 The factsheets on the role of public health in local government (December 2011)¹ set out what public health services local authorities will be responsible for in the future health and care system. This included consideration of the following services for children:
- public health services for children and young people aged 5-19 (including Healthy Child Programme 5-19)
 - the National Child Measurement Programme (NCMP)
- 1.4.4 The following services will remain the responsibility of the NHS, via the new NHS Commissioning Board in the short term, with the aim of transferring to local authority responsibility by 2015:
- Healthy Child Programme from birth to age five
 - health visiting
 - Family Nurse Partnership.
- (NB: childhood immunisation will remain the responsibility of the NHS Commissioning Board in the long term)
- 1.4.5 The factsheets acknowledged the role of CHIS in delivery of many the services listed above, noting that:

In line with this direction of travel, we are also transferring responsibility for commissioning effective Child Health Information Systems to the NHS Commissioning Board, also to be funded by the public health budget. This decision will be reviewed in 2015 to determine longer-term plans. We will engage further on the detail of these proposals, particularly in respect of transition arrangements and the best way to begin to involve local authorities in local commissioning of these services in partnership with the NHS.

¹ <http://healthandcare.dh.gov.uk/public-health-system>

In the meantime, Public Health England will retain a close interest in the specification of Child Health Information Systems, to ensure public health requirements, such as accurate and effective collection on the delivery of childhood immunisations, are met.²

- 1.4.6 Public Health England is a new national organisation, due to come into being in April 2013, which will take on a range of public health responsibilities currently conducted by a number of other organisations, including the Health Protection Agency, the National Screening Committees and the public health observatories. Public Health England will advise the Secretary of State for Health on those public health responsibilities he chooses to devolve to the NHS Commissioning Board, including CHIS.
- 1.4.7 This document is the first in a series of work packages aimed at promoting better capture, storage, use and sharing of information on children. The overall project is a collaboration between:
- the Department of Health, including those responsible for policy on child health, and the development of Public Health England
 - NHS Connecting for Health, which currently has responsibility relating to information systems in the NHS
 - the NHS Commissioning Board, which will have responsibility from April 2013 for the commissioning of CHIS
 - the Health Protection Agency, which has responsibility for collection and analysis of information on childhood immunisation
 - the National Screening Committee, which sets policy on the delivery of childhood screening programmes
 - the Child and Maternal Health Observatory, which provides information and intelligence on child health issues
 - the NHS Information Centre, which will provide a focal point for health and care data, including children's information.

1.5 Maternity and children's dataset

- 1.5.1 Information on child health is currently collected at PCT level (on differing systems) on topics ranging from birth details, screening results and immunisation to growth measurements on school entry, breastfeeding indicators and social care information. Correspondingly, there is no current national aggregation of clinical data about child health.
- 1.5.2 The maternity and children's dataset is a new dataset specifically developed for all NHS commissioned maternity, child health, and child and adolescent

² Public Health in Local Government: commissioning responsibilities, DH, December 2011; p2

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.

- 1.5.3 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 the NHS in England and are therefore required data collections for NHS organisations.
- 1.5.4 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 plans to integrate social services or educational systems into a trust-wide 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 for the time being be recorded in NHS-based systems.
- 1.5.5 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, 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.
- 1.5.6 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. Implementation of the maternity and children's

dataset will take approximately one year. The dataset will be housed by a new data warehouse, which is an interim solution before a strategic solution linked to other secondary uses datasets is defined.

- 1.5.7 CHIS 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.

1.6 Information strategy and the shared child health record

- 1.6.1 In its response to the NHS Future Forum's second report³, the Government committed to published an information strategy for health and social care in England in spring 2012. This strategy will build on the Information Revolution consultation⁴, 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.
- 1.6.2 CHIS 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, CHIS need to be able to:
- 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.

³http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_132088.pdf

⁴http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_120598.pdf

- 1.6.3 Given the upcoming changes in commissioning responsibility for CHIS, it is thought that drawing together all the current requirements for child health information collection and sharing will be helpful. 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, and contains for each child a health protection and promotion, as well as illness biography. The common core content could form the basis of a shared record of child health and care, and what such a shared record might look like is attached at annex A. No decision has yet been taken as to whether amending contracts for existing CHIS to use such a shared record in the future will be viable, beneficial or affordable.
- 1.6.4 This document does not propose a centralised reporting repository or single IT system for the collection and storage of information on children's health. It is about securing consistency in records across the country where possible and appropriate, to promote better, safer and more effective care for children. This would involve working with future commissioners of information standards for health data to embed child health and illness information is effectively embedded within the future NHS, public health and social care structures.

1.7 Outcome measures for children

- 1.7.1 Outcome measures for children are an increasing priority area in line with the Public Health Outcomes Framework⁵ and the NHS Outcomes Framework⁶. Such measures are essential for service planning and the effective delivery of care to children. The Public Health Outcomes Framework includes a population based measure of child development at age 2 to 2.5 years. The development of this measure is currently underway and, when finalised, the required information will need to be captured on CHIS 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) is likely to produce recommendations that will also need to be incorporated into this document as part of the future requirements for CHIS.

⁵

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132358

⁶ www.dh.gov.uk/health/2011/12/nhs-outcomes-framework-renewed-focus-on-improving-patient-results

2. Definition of a child health information system

2.1 Introduction

- 2.1.1 CHIS are information technology solutions for recording defined data about and providing defined services to support individual children's health, for all children in a given local population. Increasingly this is integrated with the formation of an individual child's electronic record in the community.

2.2 Functionality

- 2.2.1 All CHIS-like systems should be able to generate lists and schedules for immunisation, surveillance, some screening programmes and health promotion services, although these may also be produced by GP practice systems (especially immunisation). It is important that such functionality is integrated with the ability to enable clinicians to record their work with children as well as health and illness data. The extent of this use varies and the systems are not necessarily considered well-adapted for specialist services, such as community paediatrics. There are local paper forms and some home-grown IT solutions for enabling additional information and data to be entered onto the local system. Some systems are already providing an electronic patient record, meeting, at least partially, the expectations set out in the Information Revolution⁷ about the collection of data at the point of care, and the storage of that data in a manner that serves both primary and secondary purposes.
- 2.2.2 The age ranges covered by each Child Health Record Department (CHRD) vary. The following list of items represents a sample of the administrative functions most CHIS provide but the picture is expected to vary significantly across the country:
- links with maternity services to receive the initial birth details and NHS number
 - providing a central data repository and fail-safe manager for the New Born Blood Spot Screening Programme
 - acting as a failsafe for and enabling liaison with the Newborn Hearing Screening Programme

⁷http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_120598.pdf

- liaising with midwives and health visitors to ensure that new born blood spot screening is completed in time
- receiving newborn blood spot results from the central screening laboratory
- reporting to GPs of immunisations undertaken in schools or other venues, eg health visitor held clinics
- inputting immunisations undertaken within GP practice
- inputting immunisation history of children moved into the primary care organisation (PCO) area and sending information when a child has moved out of an area
- providing GP practices of lists of children's outstanding immunisations
- providing immunisation coordinators with relevant information for targeted vaccination in the event of an outbreak
- posting correspondence to parents for immunisation appointments
- providing data on immunisation coverage to the PCO and the Health Protection Agency
- recording school age "screening" with data from school nurses
- recording NCMP results
- posting out the result letter from NCMP
- recording human papillomavirus (HPV) and school-based vaccinations from school nurses
- notifying other CHRDs of babies/children who have moved out of or in to the area.

2.3 Historical context

- 2.3.1 CHIS emerged in response to the requirement to automate some of the processes undertaken by administrative staff within CHRD. Most PCTs currently have a CHRD to manage the administrative element of delivering universal services to children, such as immunisation and screening. As CHIS were developed in response to demand from the NHS, and due to the evolving nature of the NHS since 1974, systems are not always coterminous with PCT boundaries: a single CHIS may cover more than one PCT, and a single PCT may have to work with more than one CHIS to ensure coverage for all the children for which it is responsible.
- 2.3.2 In 2010, PCTs split their commissioning responsibilities from their provider function under the Transforming Community Services agenda. Many community services were transferred to other organisations, including foundation trusts and mental health trusts, while others became standalone organisations, such as social enterprises. Many PCTs included CHRDs and the information systems on which they relied as part of their community services and therefore many CHRD and CHIS are now commissioned by PCTs from trusts and third sector organisations.

2.4 System market for CHIS

- 2.4.1 Since CHIS have developed in response to commissioner requirements, and have not been subject to centralised, mandatory specification, there are a range of suppliers and system types currently available in England. A survey by the Department of Health in 2011 of the informatics capability of NHS trusts revealed there are at approximately 99 CHIS covering 152 PCTs in England. These are supplied by at least 17 external suppliers (ie excluding where in-house solutions have been developed by trusts), but a limited number of suppliers dominate the market, with the top three suppliers supplying 55% of the systems in place.

3. Notes on how to use this document

3.1 Introduction

- 3.1.1 It is important to note that this document is intended to augment existing contractual requirements documentation. To that end, 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), or clinical 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.

3.2 General considerations

- 3.2.1 To reflect the transition period this document avoids the use of the term PCT instead, the term “primary care organisation” (PCO) is used to refer to the combination of commissioning and provisioning organisations involved in the delivery of care to a defined local population. This may include clinical commissioning groups, local authorities, or others. Where the term PCT has been used in this document, it is used advisedly and refers to the organisation that has statutory responsibility for the child.
- 3.2.2 This document identifies all data flows into and out of a PCO that are required to deliver each child healthcare service to a national standard, including:
- critical and intimate linkages required with maternal records as more than 95% of babies are born in hospital and hence have a hospital newborn record.
 - Transmission of Newborn Screening coverage and results data requires links between labs, maternity units, CHRDs and GPs, all of whom are served by a variety of different system suppliers and systems.
 - information flows for both the social care and education departments have been described, in order to improve integration with the local authority.
- 3.2.3 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” (including adopted and fostered children)
- children with a child protection plan (requiring safeguarding approaches to be implemented).

3.2.4 Diagram 1 shows how these “sets” of children relate to each other.

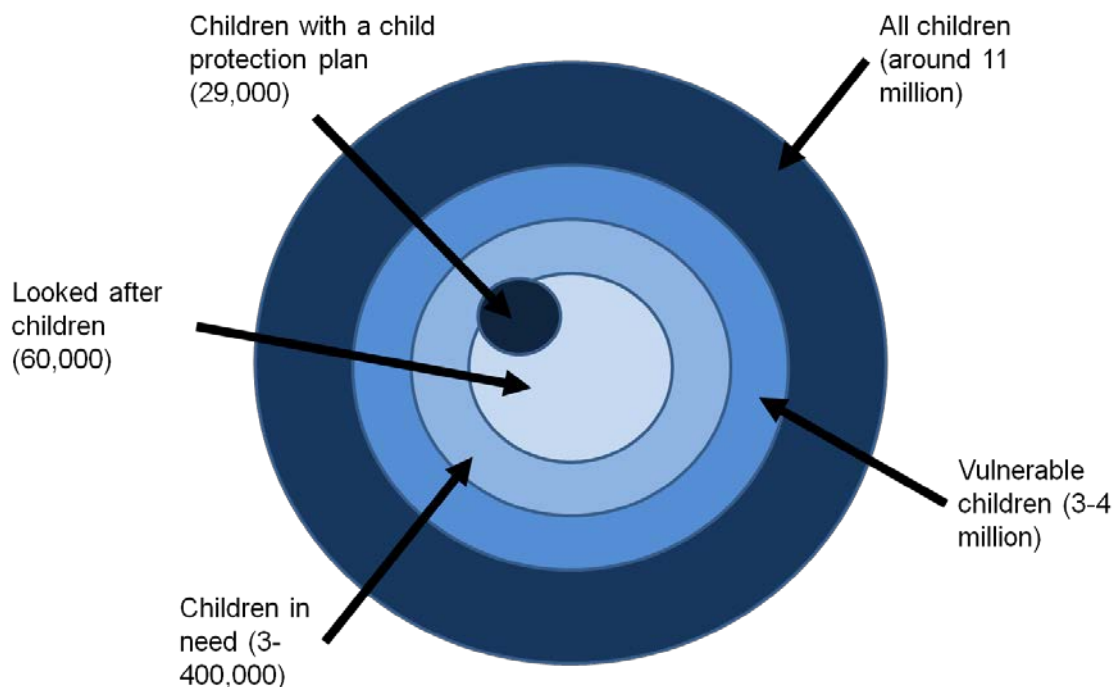


Diagram 1: Classifications of children according to relative needs

3.2.5 CHIS should support the following children’s services:

- pre-school hearing screening
- vision/amblyopia screening
- supporting children with acute or chronic disorders
- supporting children with mental health issues
- handover to adult services.

3.2.6 However, at the moment standard functional requirements have not been agreed. Information requirements for supporting children with disabilities or complex health needs are being revised and will be issued as a supplementary chapter to this document.

3.3 Population coverage

- 3.3.1 Ensuring high target population coverage is a safety issue in terms of benefiting individual children in respect of immunisation (direct protection from vaccine-preventable diseases through immunisation and indirect protection of those not vaccinated arising from herd immunity) and screening (prevention of and early detection of disorders, enabling early intervention and treatment and preventing severe disability in some conditions). IT functionality in the form of child health information or record systems in PCOs is required to support delivery of these services in a way which is equivalent to but additional to IT systems in place in general practice or in hospital-based patient administration systems and electronic patient record systems.
- 3.3.2 In the course of carrying out research for this document it has become apparent that currently there is confusion about the definition of the cohort to whom a service is to be delivered and the definition of which children a PCO is responsible for (as opposed to another PCO). This document has attempted to define this in Chapter 5 but that will need to be reviewed in the light of new organisational arrangements.

3.4 Consistency in information for primary uses

- 3.4.1 This document seeks to enable national consistency in respect of child health information with the aim of reducing inequality and inconsistency and minimise data quality deficits. The focus of the requirements therefore is on programmes where there is national consensus, protocols and standards – that is, a requirement beyond “good practice” for which there might be good reason for local variation. A national programme with agreed national definitions allows care to be continued across boundaries and enables consistent national and regional data to be available.

3.5 Secondary uses of data

- 3.5.1 For secondary uses, the requirements have been set out in the NHS Information Centre developments of the maternity and child health data sets (including the new dataset) and the NHS Information Centre has provided associated arguments and case of need. However, all the data items required need to be recorded in the first place during the course of delivery of care, mostly by the health services but for some items by social and education services and which have been recorded in the health record.

3.5.2 The aim of this document in regard to secondary uses data is to produce a checklist against which existing and future commissioners and system vendors can match their developments and existing proposals to ensure their outputs are fit for purpose. This is in order to:

- support clinical advisory groups by characterising the information needs for central national requirements to avoid error and omission
- 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 NHS Information Centre for secondary uses purposes
- flag and to focus on the critical linkages between child health delivery systems, maternity records, laboratories and GP practice systems in terms of communication records and provision of failsafe processes
- promote consistency of experience of care on the part of patients
- improve decision making at community and population level in order to address inequalities in health and wellbeing of children
- address at a national level and thereby disseminate the legal framework for consent and information and data sharing which is so vital in the provision of child health particularly for vulnerable children
- avoid introduction of systems which are not fit for purpose or are insufficiently flexible to take on emerging policies.

4. General requirements

4.1 Introduction

- 4.1.1 This section contains requirements that apply to the delivery of all or a large majority of children's services.

4.2 References

Ref: no	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 Functional requirements

Recording entries against a child's record

- 4.3.1 It must be possible to record entries against a child's record, in real time, in all settings and locations where care is provided and contact is made with the child. The privilege level of such access should be appropriately constrained for the role that the user is engaged in.
- 4.3.2 It should be possible to associate electronic documents and images (including scanned paper documents) with a child's record.
- 4.3.3 It must be possible to gain access to a child's record access in all settings and locations where care is provided. The privilege level of such access should be appropriately constrained for the role that the user is engaged in.

Visibility of child's status

- 4.3.4 Having opened a child's record it should be possible to view the child's status categories on the initial screen. Such categories should include:
- children in need of protection
 - children with special educational needs

Information requirements for child health information systems

- children with disabilities
- children in need of continuing care
- looked after children
- children being fostered or awaiting adoption
- children leaving care
- children who are excluded
- homeless, refugees, asylum seekers and travellers
- young offenders
- in transition to adult services
- children who are due/overdue various interventions (eg immunisations, screens and reviews).

Reports and reporting

- 4.3.5 In addition to those listed in the rest of the document, the following reports must be available:
- number discharged, followed up, referred on, left area or arrived newly into the area, died
 - number of children referred to each agency and/or professional group
 - number of outstanding appointments for review (including those for immunisations)
 - completeness of service provision, ie services/appliances being provided and services required but not being provided
 - children who are due/overdue various intervention, ie immunisations, screens, and reviews
 - all statutory reports and the ability to track children through various pathways, eg special educational needs, looked after children.
- 4.3.6 It should be possible for PCOs to be able to write reports that make use of any items of data stored against the child's record without recourse to the system developer or vendor for further development.

Maximise the value of an appointment

- 4.3.7 The systems must assist the PCO in trying to identify how to deliver the most services to children through the fewest number of appointments.

Evaluating a child's "pathway" and "need classification"

- 4.3.8 Each interaction with a child should be taken as an opportunity to evaluate whether to move a child onto:
- a different "pathway" or branch of a "pathway" such as a specialised pathways for targeted services, or, in more general terms, from "universal"

Information requirements for child health information systems

(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)

- a different “need classification”, eg 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”.

4.4 External interfaces

Communication about children recorded on the CHIS

4.4.1 All communications within and without the PCO relating to one or more children, whether electronic, paper or verbal, must use the NHS number as the principal identifier for the child.

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

Consent and information sharing requirements

4.4.3 PCOs must take consent and sharing requirements into account when deploying information systems, establishing interfaces with other organisations and people, and determining local information governance policy.

4.4.4 Considerations include:

- taking account of the role of the parent(s) regarding consent and confidentiality and the issues of emerging competence (see reference 4.2)
- national Information governance policy (see reference 4.1).

4.4.5 There are two distinctly different scenarios that require separate consideration:

- sharing within the NHS; including between primary, hospital based specialist care and community child health – for both universal and specialty care
- sharing between health services and other partner agencies, especially local authority education and social care services.

Information shared within the NHS and beyond

4.4.6 There is much guidance and general professional support for the concepts of information sharing in the best interests of providing high quality and safe healthcare for children within health services; and indeed on the whole

parents expect this to take place. Much current and past practice has been on the basis of “implied consent” although processes are in place aiming to ensure that all parents and children are aware of the benefits and needs for this. New challenges for information governance will undoubtedly emerge from the current transition in the health and care system and the increasing need to share information beyond the NHS for effective service delivery. Any developments in this area will need to be taken into account in external interfaces required by CHIS in the longer term.

- 4.4.7 Within any given week and frequently even within a day children receive healthcare from healthcare professionals in differing services and in a number of different locations, eg GP surgery, within school and home, in A&E or in a number of specialist outpatient clinic or wards or child development centre and even in different hospitals within a day. This is illustrated in the table below.

	Primary care			Hospital		Community child health				Child and adolescent mental health
	General practitioner	Health visitor	Practice nurse	Paediatric surgical A&E	Child Development Centre Therapists	Paediatrician	Midwife	Health visitor	School nurse	Community paediatrician
Immunisation and vaccination	Y	Y	Y	Y	Y	Y	Y	Y	Y	
Screening	Y	Y	Y	Y ⁸	Y	Y	Y	Y	Y	
Child health promotion	Y	Y	Y		Y	Y	Y	Y	Y	
Acute and chronic	Y	Y	Y	Y	Y		Y	Y	Y	Y
Safeguarding	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Disability	Y	Y	Y	Y	Y		Y	Y	Y	Y
Education support	Y	Y		Y	Y		Y	Y	Y	Y
Looked after	Y	Y	Y	Y	Y		Y	Y	Y	Y
Asylum seekers	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Table 1: The differing healthcare locations and professionals relevant to child health

4.4.8 Access to a shared record such as suggested in Annex A for all relevant healthcare professionals then becomes an essential part of safe and good quality care.

Information shared between the NHS and other partner agencies

4.4.9 These scenarios include Common Assessment Framework reports and linkage with local authorities (see chapter 12). Such information sharing with

⁸Required by the pathology laboratory

other agencies is guided by nationally agreed consent and data sharing rules within legal frameworks and guidance⁹. Table 2 illustrates common information sharing arrangements that information systems should support.

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 2: Common information sharing arrangements that CHIS should support

4.4.10 The system must:

- provide the facility to record the date the information was released, by whom and to whom
- 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
- be able to exclude those withholding consent when producing reports to be shared
- 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.

4.4.11 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

⁹<https://www.education.gov.uk/publications/standard/publicationdetail/page1/DCSF-00807-2008> HM Government Information Sharing Guidance for Practitioners & Managers

¹⁰Some Looked After Children services are partly based in acute trusts

Personal Demographics Service synchronisation

- 4.4.12 All systems that hold clinical and demographic records should be capable of synchronising updates with PDS. Furthermore, a PDS search facility must be available in order to support the recording of information against a child's record in the event that the NHS number is either not present or not verified.

5. Registration and scope of responsibility

5.1 Introduction

5.1.1 This chapter addresses the issue of which children a PCO should hold details on and what is the status of the PCO'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 PCO. This chapter addresses this question.

5.1.2 Diagram 2 below sets the system and organisational context within which the functions described in this chapter take place.

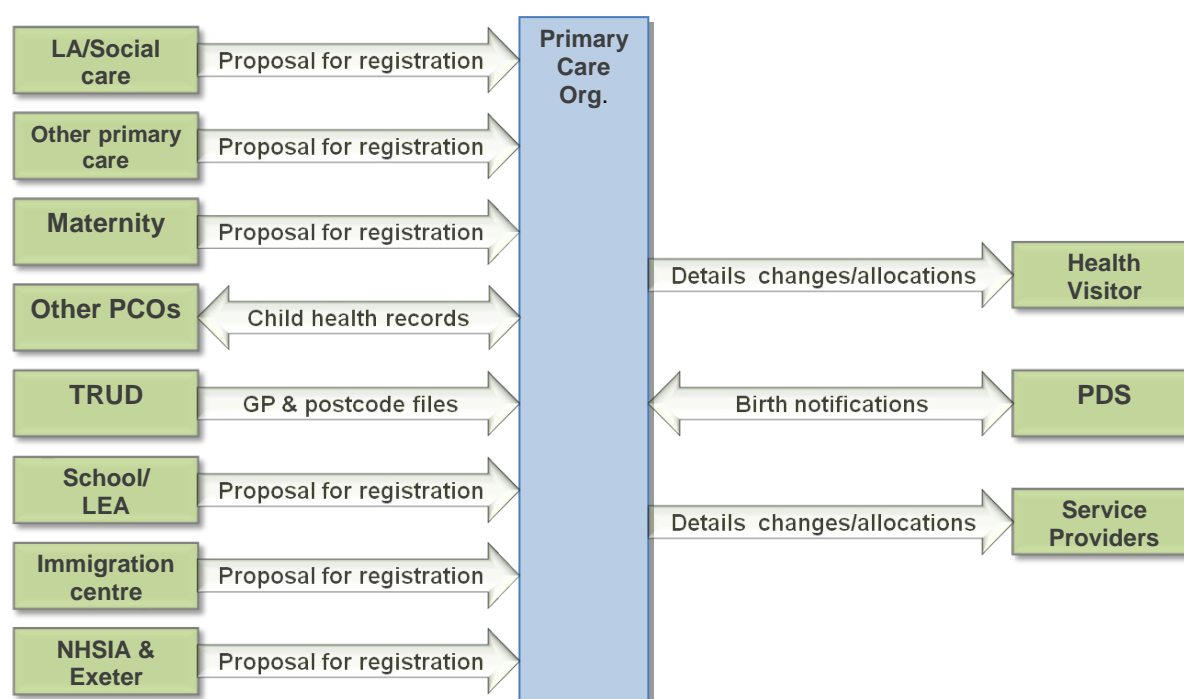


Diagram 2: External interfaces required to support child registration and deregistration

5.2 Functional requirements

Maintaining a register of statutory responsibility

- 5.2.1 The PCO should ensure that their database includes all children for whom they have a statutory responsibility. Currently the PCO responsibility is determined foremostly by whether the child has a registration at a GP practice that is associated with the PCO, or, in the event that the child is not registered with a GP, by the child's postcode of usual address placing them inside the geographic area of the PCO footprint.
- 5.2.2 The list of which GP practices and residential postcodes are associated with each PCO are maintained centrally on a national basis and published through Technology Reference Data Update Distribution Service. Further work will be required by the NHS Commissioning Board to establish the footprints of PCOs responsible for CHIS in the future system.

Status of responsibility of the PCO to the child

- 5.2.3 It is necessary to be able to identify whether the PCO has the statutory responsibility for the child. If the child is the responsibility of the PCO 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 PCO regardless of the registration or address of the individual children.
- 5.2.4 Changes in a PCO's scope of responsibility can be triggered by a number of events as outlined in the following sections. In relation to each child, the PCO must maintain a list of services that the PCO is responsible for fulfilling and, where appropriate, record the commissioning organisation.

Registration and deregistration

- 5.2.5 Information regarding children who need to be registered can come from:
- PDS
 - maternity service
 - Other community and primary care services
 - school lists
 - local education authority
 - local authority social care
 - hospital services
 - immigration centres

- Exeter Service
 - other PCOs
- 5.2.6 It should be possible to perform traces on PDS in order to obtain an NHS number and GP and synchronise the record with known demographics.
- 5.2.7 Types of registration include:
- registration upon birth: upon receipt of a PDS birth notification a child record must be created
 - move in from other PCO: A child record should be created when a child moves in from another PCO. A process should be put in place to transfer the record from the previous PCO in as complete a form as possible
 - immigration: A child record should be created when a child moves into the PCO'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.
- 5.2.8 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 PCO. The reasons for this can include:
- transfer to another PCO: the PCO must be able to alter the status to indicate that it no longer has statutory responsibility for the child and upon request the PCO must be able to send a detailed record to the new PCO. The PCO must record a forwarding address for the child, or if not known record as "address not known". It may be that the PCO still retains responsibility for delivering services under by arrangement with the new responsible PCO
 - move abroad/emigrate: The PCO 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 PCO must be able to send a detailed record to the new health service. The PCO 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.

Information requirements for child health information systems

Allocation to health visitor or school nurse

- 5.2.9 If the child does not have an allocated health visitor or school nurse, the PCO 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.

Notifiable congenital malformations

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

Storage and tracking of records

- 5.2.11 The PCO must provide storage of the records of:
- every child aged 0-19 years for which the PCO 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 PCO provides services under an arrangement with another PCO who has the statutory responsibility for the child.
- 5.2.12 The PCO 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.

Demographic updates

- 5.2.13 The child's record should be synchronised with PDS whenever a record is used or updated. The synchronisation trigger events are covered in detail in the PDS compliance documentation.

Maintain family relationship between records

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

Maintaining patient and family preferences

- 5.2.15 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, 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.

Tracking schools

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

De-duplicating, merging and correcting records

- 5.2.18 The PCO must be able, through a controlled method, to merge or link dispersed information for an individual person upon recognizing the identity of that person.
- 5.2.19 If health information has been mistakenly associated with a person, then the PCO 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.
- 5.2.20 If health information has been mistakenly associated with a patient, the PCO 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.

5.3 Clinical coding

- 5.3.1 There is a need to develop agreed standard codes for safeguarding dataset items.

5.4 External interfaces

5.4.1 This section describes any interfaces for which standards have been set.

Personal demographics service

5.4.2 PDS issues birth notification messages, details of which can be found in the current Message Implementation Manual.

Link to the antenatal record

5.4.3 There is a need to be able to record information pertaining to the unborn child and to ensure that that and information about the family relevant to the child is incorporated seamlessly into the baby's record at birth.

Personal Child Health Record (PCHR)

5.4.4 PCOs should consider printing pages for inclusion in the PCHR, incorporating data that is known about the child such as their NHS number and relevant local information such as the address of the nearest child health clinic. Such pages should conform to the current revision of the PCHR. Pages in the PCHR that are relevant to this chapter are:

- child's details
- local information.

5.5 Future developments

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

- a digitised PCHR: An electronic version of the PCHR, perhaps 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 that and information about the family relevant to the child is incorporated seamlessly into the baby's record at birth

6. Safeguarding

6.1 Introduction

6.1.1 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.”

6.1.2 The subject of safeguarding can be broken down into the following topics:

- identification and assessment
- referral to the local authority
- support and tailoring of services.

6.1.3 Safeguarding is a service that should be woven into the delivery of all child health services hence references are made in a number of chapters in this specification to safeguarding issues, including the means of identification and assessment. In addition, the topic of referral to the local authority is handled in the chapter on Formal Reviews.

6.1.4 Once a child has a protection plan in place, there are no specific, additional services that need to be delivered to the child, so support and tailoring of services is covered in the relevant chapters.

6.1.5 This chapter focuses on safeguarding-specific information systems issues, such as coding schemes and integration with national systems that contribute to safeguarding.

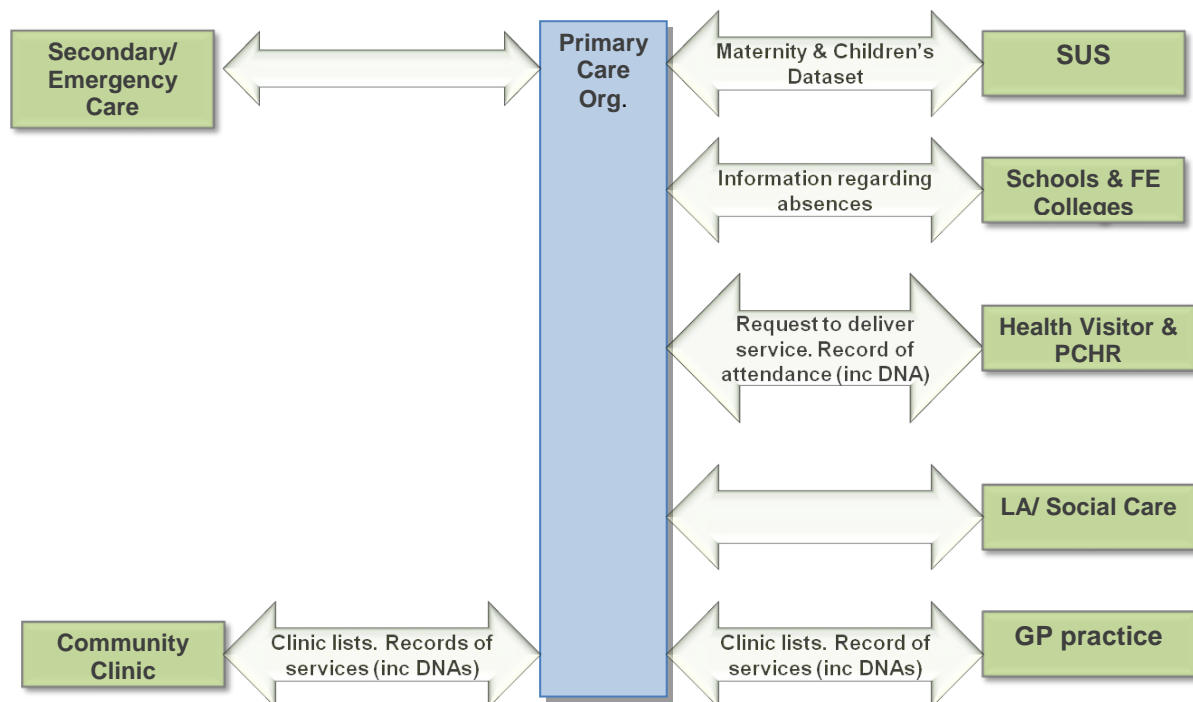


Diagram 3: External interfaces required for safeguarding

6.2 Target cohort and schedule

6.2.1 All children should be subject to checks for safeguarding issues.

6.3 Functional requirements

Maintain safeguarding dataset

6.3.1 To conduct safeguarding responsibilities, a PCO must maintain a record of relevant information from many different sources, as is demonstrated by the diagram 3. This includes visibility of a child's status such as having a child protection plan or a statutory order. There is a need for a standard safeguarding dataset to be developed as suggested in Annex B.

Share safeguarding dataset with local authority

6.3.2 PCO systems must be able to receive relevant information from the local authority such as notification of a child protection plan or statutory order. 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 Clinical coding

- 6.4.1 There is a need to develop agreed standard codes for safeguarding dataset items.

7. Newborn and infant physical examination

7.1 Introduction

- 7.1.1 The newborn and infant physical examination (NIPE) is performed for all children and should take place within the first 72 hours of birth. 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. A further examination of the child takes place when he or she is 6-8 weeks old.
- 7.1.2 Each of these screening tests has their own 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 to a paediatric specialist.
- 7.1.3 NB: This chapter describes the situation that will exist if the NIPE Screening Management And Reporting Tools (SMART) IT System is adopted. Currently, the system is being piloted by a number of trusts.

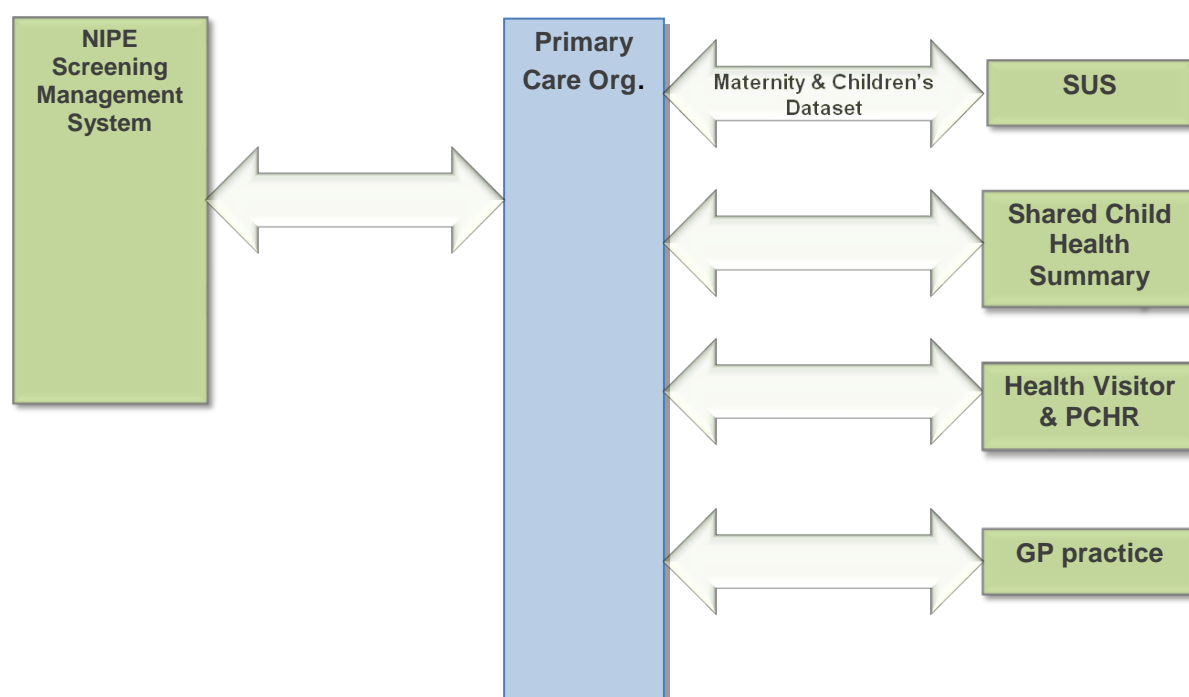


Diagram 4: External interfaces required for newborn infant physical examination

7.2 Target cohort and schedule

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

7.3 Functional requirements

Run failsafe process

- 7.3.1 The PCO 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 PCO 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 PCO
 - no notification of the 6-8 week physical examination results or dissent to all investigations are recorded.
- 7.3.2 The report should indicate the process status for each child in the list, eg “no action taken”.

7.4 Clinical coding

- 7.4.1 A set of standard process management ,clinical and outcome codes for NIPE are being devised.

7.5 External interfaces

Personal Child Health Record (PCHR)

- 7.5.1 PCOs should consider printing pages for inclusion in the PCHR, incorporating data that is known about the child such as their NHS number and relevant local information such as the address of the nearest child health clinic. Such pages should conform to the current revision of the PCHR. The pages in the PCHR that is relevant to this chapter are:
- birth details and newborn examination
 - 6-8 week review.

7.6 Future developments

Standard age criteria

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

8. Newborn blood spot screening

8.1 Introduction

8.1.1 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
- congenital hypothyroidism
- cystic fibrosis
- sickle cell disease
- medium chain acyl CoA dehydrogenase deficiency (MCADD)

8.1.2 Diagram 5 shows all of the interactions that a PCO needs to conduct with external entities (systems, organisations and people) in the course of providing the newborn blood spot screening service.

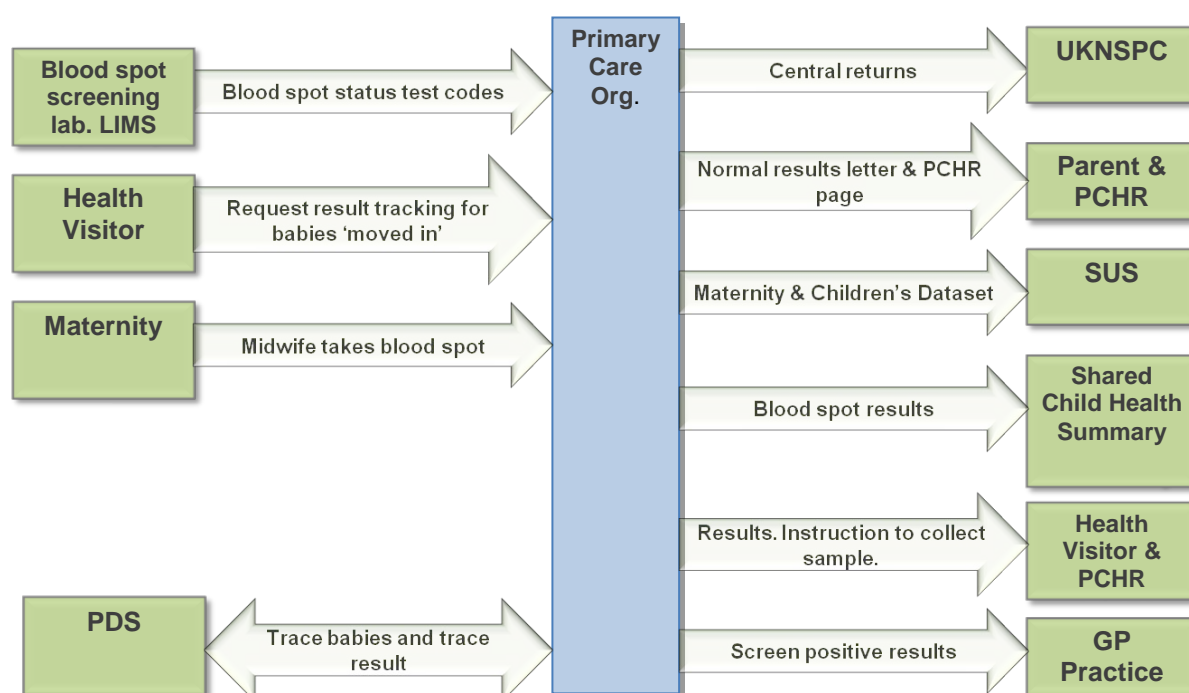


Diagram 5: External interfaces required for newborn blood spot screening

8.2 References

Ref: no	File CM Reference number or equivalent	Title	Version
8.1	NPFIT-FNT-CRD-SIPM-0025.05	Newborn Blood Spot Messaging Requirements	1.5
8.2	SSC/IP/vD02	Newborn Status Codes and Results to Parents Implementation Plan	1.0
8.3	http://www.ic.nhs.uk/services/maternity-and-childrens-data-set/maternity-services-secondary-uses-data-set	Maternity Services secondary uses Dataset and children and young people's health services secondary uses dataset	1.1
8.4	NPFIT-FNT-TO-DPM-0491	Message Implementation Manual	8.0.00 Draft B
8.5	SSC/CHG/v2.0	Child Health Status Code Specification	2.0

8.3 Target cohort and schedule

- 8.3.1 PCOs 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.

8.4 Functional requirements

- 8.4.1 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 PCO's systems that support the administration of newborn blood spot screening.

Identify children to be screened

- 8.4.2 The PCO 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 birth unit community midwifery team 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 PCOs to initiate a blood spot screen.

Information requirements for child health information systems

- 8.4.3 To ensure that all eligible children are offered the blood spot screening test the PCO must be able to schedule a daily report that lists children with the following characteristics:
- they are the responsibility of this PCO
 - 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.
- 8.4.4 The report should indicate the process status for each child in the list, eg “no action taken” or “sample requested”.

Invite subject

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

Receive status codes from laboratories

- 8.4.7 The PCO 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 PCO’s care.
- 8.4.8 PCOs must record receipt of status code 01 against the child’s record. The PCO will be sent the results of the screening test by the laboratory. The PCO 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.
- 8.4.9 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 PCO must not store such results against the child’s record. In the event that a child has an elevated immunoreactive trypsin reading, the PCO 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.

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

Repeat test

- 8.4.11 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.
- 8.4.12 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 PCO must take responsibility for organising a repeat sample to be collected.
- 8.4.13 PCOs 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 PCO staff.
- 8.4.14 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.
- 8.4.15 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, and four months after the last transfusion for sickle cell disease.
- 8.4.16 To support the above processes the PCO must be able to produce reports in accordance with reference 0.5.

Report results

- 8.4.17 The screening laboratory has the responsibility for initiating clinical follow-up in the event of adverse investigation results. However, the PCO 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 PCO 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.

- 8.4.18 The PCO should record the date on which the 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), the date recorded should be the letter's dispatch date.

Support for managing delays to the process

- 8.4.19 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 PCO must be able to identify this situation and expedite the process in a timely fashion.
- 8.4.20 In the event that a repeat sample is not required and a terminal status code (ie "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 five 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 PCO must be able to identify this situation and expedite the process in a timely fashion.
- 8.4.21 In the event that a repeat sample is required and a terminal status code (ie "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 five 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 PCO must be able to identify this situation and expedite the process in a timely fashion.
- 8.4.22 These requirements can be met by implementing daily reports as specified in reference 0.5.

8.5 Clinical coding

- 8.5.1 Systematized Nomenclature of Medicine (SNOMED) codes representing all of the screening process states and clinical outcomes are defined in reference 8.1. Equivalent codes exist for other nationally maintained clinical coding schemes, with mappings being maintained by the UK Terminology Centre.

8.6 External interfaces

- 8.6.1 This section provides details of the interfaces that the PCO must put in place with external systems and organisations as shown in Diagram 5 above.

Screening laboratory

- 8.6.2 PCOs should be able to receive screening results from the screening laboratory that use the nationally agreed status codes as described in reference 8.2. The national target implementation date is March 2010. PCOs should be able to receive screening results as Spine messages as described in reference 8.1.
- 8.6.3 PCOs should plan for an extended period during which results could be received either electronically or on paper depending on which screening laboratory is involved.

Parents

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

Shared child health record

- 8.6.5 Messages are being developed to send information about newborn blood screening (among other child-related information) to the shared child health record. PCOs 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.

Maternity and child health secondary uses dataset

- 8.6.6 Newborn blood spot results are part of the NHS Information Centre's children and young people's health service, the details of which can be found in reference 8.3. At present, the standard mechanism for submitting the maternity and children's dataset to the NHS Information Centre's secondary uses service are under development.

UK Newborn Screening Programme Centre

- 8.6.7 As from March 2010 data collection will no longer be performed using the current web-based tool. Instead a Microsoft Excel spreadsheet template will be used.

Registered GP

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

Health visitor

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

Personal Child Health Record

- 8.6.10 PCOs should consider printing pages for inclusion in the PCHR, incorporating data that is known about the child such as their NHS number and relevant local information such as the address of the nearest child health clinic. Such pages should conform to the current revision of the PCHR. The pages in the PCHR that is relevant to this chapter are:
- 6-8 week review.

8.7 Future developments

- 8.7.1 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
 - HL7v3 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.
 - standard page for PCHR: An approved design for a page for blood spot results that could be printed and inserted in the PCHR.

Information requirements for child health information systems

- SUS interface: A standard, electronic mechanism for sending datasets to SUS.
- NHS Information Centre's maternity and children's secondary uses service interface: A standard, electronic mechanism for sending the maternity, children and young people's health service datasets is in development.

9. Newborn Hearing Screening Programme

9.1 Introduction

9.1.1 The Newborn Hearing Screening Programme aims to screen all newborn children in England for hearing abnormalities. In June 2000, the Government announced that it would pilot the introduction of newborn hearing screening to replace the existing programme of infant distraction tests, following advice from the UK National Screening Committee based on the health technology assessment review.

9.1.2 Since then phased implementation of the programme has proceeded across the whole of England and now every baby born in England is offered screening within the first weeks of birth.

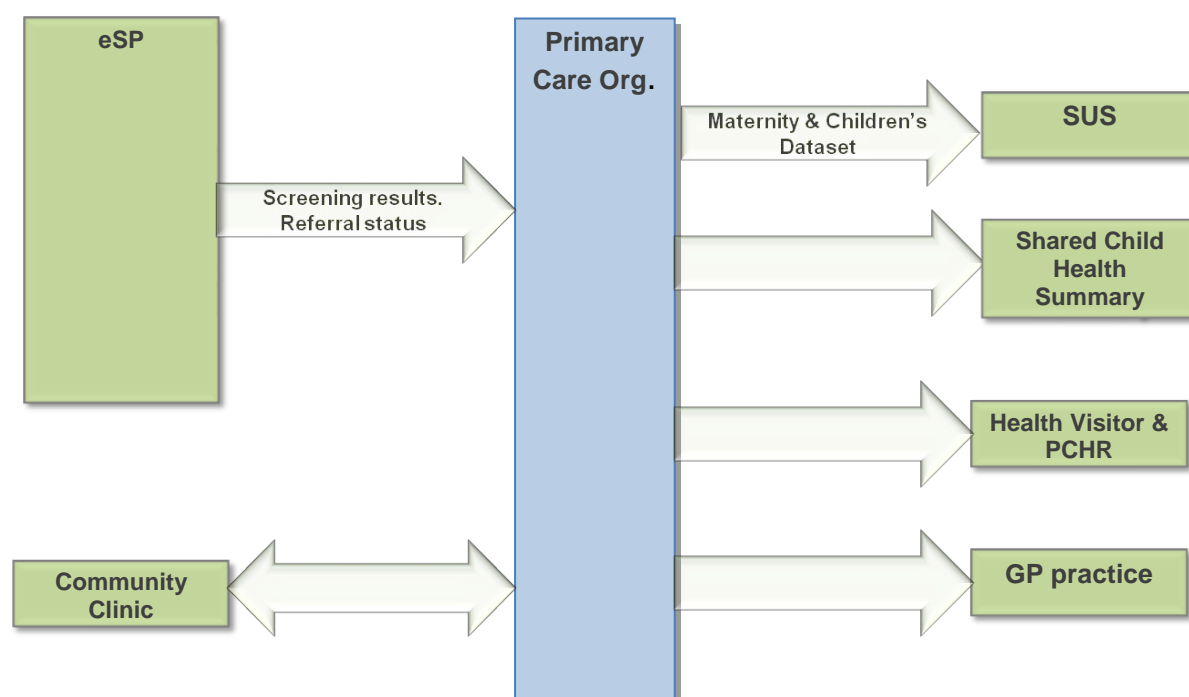


Diagram 6: External interfaces required for the newborn hearing programme

9.2 References

9.2.1 No documents have been referenced in this chapter.

9.3 Target cohort and schedule

- 9.3.1 The primary screening process is managed by the central existing system provider screening management system, but the PCO still has responsibility for ensuring coverage of all of the children for which it is responsible, and assuring the quality of the service.

9.4 Functional requirements

Run failsafe process

- 9.4.1 The PCO must ensure that all the children for whom they are responsible are offered the Newborn Hearing Screening Programme. Ideally screening should be completed before discharge from hospital but to ensure that all eligible children are offered the Newborn Hearing Screening Programme, the PCO must be able to schedule a daily report that lists children with the following characteristics:
- they are the responsibility of this PCO
 - no notification received of the results or dissent to all investigations are recorded.

Invitation to baby

- 9.4.2 If the above report indicates that the process is not completed in hospital, an outpatient or clinic appointment or home visit is required to complete the process, usually within one visit.
- 9.4.3 The aim should be to complete screening by 44 weeks gestational age (four weeks corrected age), though it should also be noted that the baby should not be screened if less than 34 weeks gestational age.
- 9.4.4 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 (OAE) 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
 - in most cases the referral will be at age 7-12 months for behavioural testing.
- 9.4.5 The report should indicate the process status for each child in the list, eg “no action taken”.

9.5 Clinical coding

- 9.5.1 Where currently available standard codes should be used and further ones developed

9.6 External interfaces

Existing systems provider

- 9.6.1 The following data is made available to child health systems through electronic interfaces with the existing systems provider or through manual data entry. In addition to the generic baby identifier and demographic details the following information needs to be held locally with the child's record and is currently entered onto the PCHR:

Data item	Comment
Place	Testing location
Tester ID	
Equipment No	Individual identifier
Consent: Test	Yes/No
Consent: Data	Yes/No
Test: 1st OAE	
Test 2nd OAE	
Date of test	
Right ear clear response:	Yes/No/Not tested/Incomplete
Test No	
Reason for not tested/incomplete	
Left ear clear response:	Yes/No/Not tested/Incomplete
Test number	
Reason for not tested/incomplete	
Further management	Discharge For further screen OAE/AABR Refer for ABR test Later follow up at eight months
Appointment for further screen on/at	Date/Time/Location
Appointment for ABR test on/at	Date/Time/Location
Reason for follow up	Text
Name of tester	

Table 3: Newborn Hearing Dataset

Personal Child Health Record

- 9.6.2 PCOs should consider printing pages for inclusion in the PCHR, incorporating data that is known about the child such as their NHS number and relevant local information such as the address of the nearest child health clinic. Such pages should conform to the current revision of the PCHR. The pages in the PCHR that is relevant to this chapter are:
- Newborn hearing screening programme.

10. Handover from midwifery

10.1 Introduction

- 10.1.1 The 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 PCO.

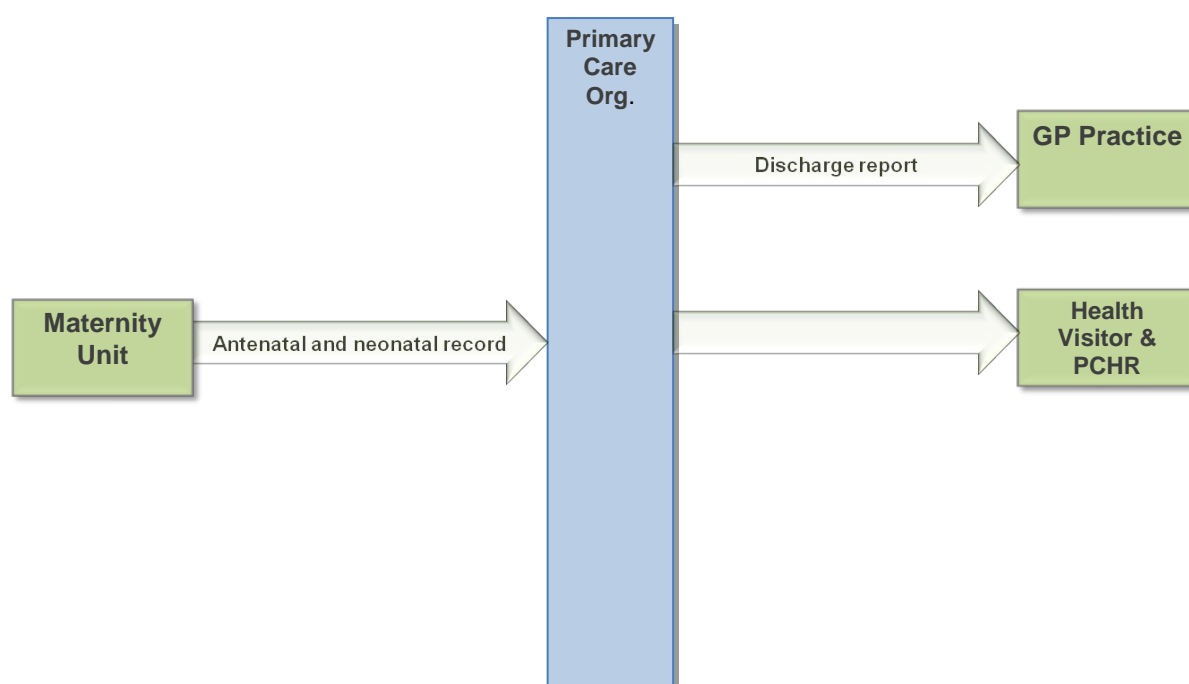


Diagram 7: External interfaces required to manage the handover from community midwifery

10.2 Functional requirements

Receive information from midwifery

- 10.2.1 The PCO 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 PCO 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.

- 10.2.2 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 eg sickle cell status, maternal hepatitis B, at risk of tuberculosis
 - time of birth
 - telephone number
 - mother's surname and forename
 - 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 eg alternative home
 - feeding status
 - the route and dosage of any vitamin K administered.
- 10.2.3 In addition, it is expected that a number of health promotion activities take place before the PCO 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
 - preparation for parenthood and birth.
- 10.2.4 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

Information requirements for child health information systems

- all results from the Antenatal Sickle Cell and Thalassaemia Screening Programme.

Distribute hospital discharge summary

- 10.2.5 The PCO 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.

10.3 External interfaces

Personal Child Health Record

- 10.3.1 PCOs should consider printing pages for inclusion in the PCHR, incorporating data that is known about the child such as their NHS number and relevant local information such as the address of the nearest child health clinic. Such pages should conform to the current revision of the PCHR. Pages in the PCHR that are relevant to this chapter are:
- birth details and newborn examination
 - important health problems
 - family history.

10.4 Clinical coding

- 10.4.1 Where currently available standard codes should be used and further ones developed.

11. Health promotion

11.1 Introduction

11.1.1 This chapter principally covers health promotion and protection activities that are scheduled for delivery to the child from 14 days onwards as these are commissioned by the PCO. Some other topics such as screening may also come under the heading of health promotion, but they are covered in other, specific chapters.

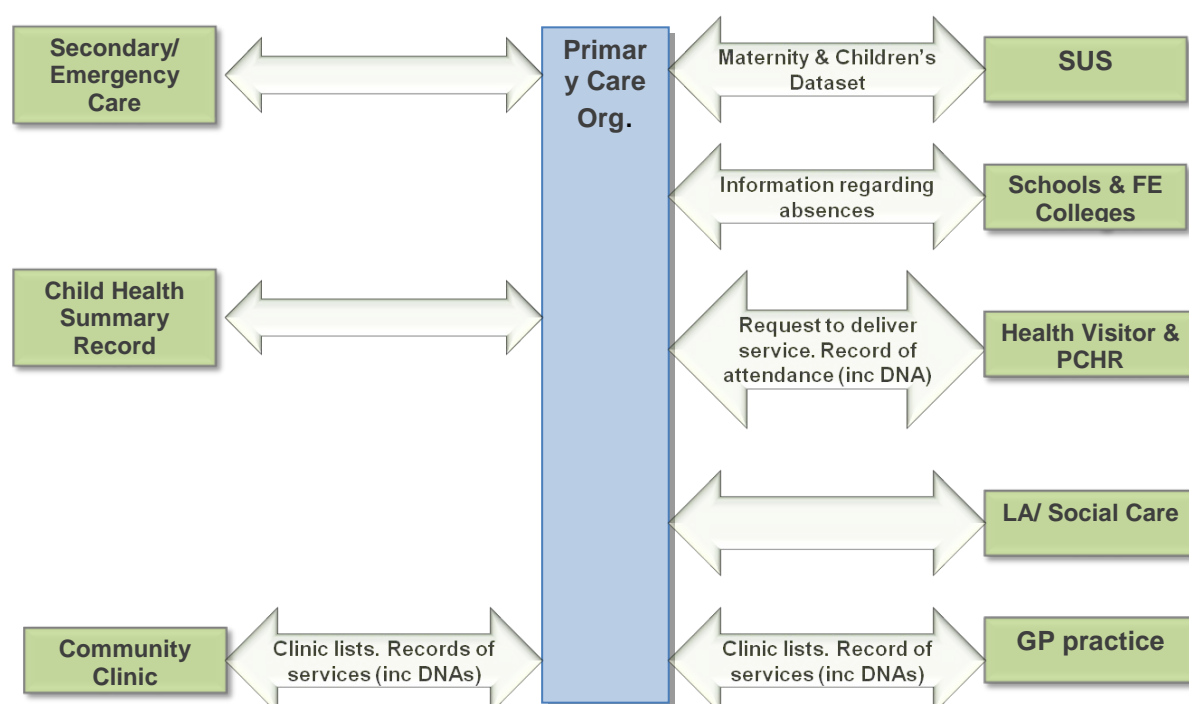


Diagram 8: External interfaces required for health promotion

11.2 References

Ref: no	File CM Reference number or equivalent	Title
11.1	DH Gateway reference 9211	The Child Health Promotion Programme - Pregnancy and the first five years of life
11.2	DH Gateway reference 12287	Healthy Child Programme - From 5-19 years old
11.3	ISBN 0113224257	Framework for the assessment of children in need and their families

11.3 Functional requirements

Universal services for the first five years of life

- 11.3.1 Reference 11.1 provides PCOs 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, ie all services to all children, and a progressive basis, ie some services to some children that have been identified with particular needs.
- 11.3.2 This chapter describes how information systems should be used to support the deliver 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.
- 11.3.3 The schedule for delivering universal services is shown in table 4.

Information requirements for child health information systems

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		Y	Y	Y	Y		Y	Y	Y	Y	Y
Identifying need for extra management		Y	Y	Y	Y		Y	Y	Y	Y	Y
Breast feeding support		Y	Y	Y	Y						
Infant feeding advice		Y	Y	Y	Y						
Focus on involvement of father		Y	Y						Y		
Life style	Y										
Parental Information	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	
New baby review at age 14 days		Y									
Assess maternal mental health		Y	Y				Y				
Home safety advice and assessment		Y					Y				
Baby physical examination			Y								
Measure and plot and assess weight and head circumference			Y								
Measure and plot and assess weight				Y	Y		Y	Y			
Measure and plot and assess weight and height											Y
Record breast feeding status		Y	Y	Y	Y						
Immunisation schedule ¹¹			Y	Y	Y		Y	Y		Y	

¹¹ The immunisation schedule is subject to unscheduled changes and current guidance (the Green Book) should be consulted

Information requirements for child health information systems

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 test behavioural test if not screened in neonatal						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
Hearing test											Y
Preschool vision screen											Y
Inform children, parent, school on specific health issues											Y
Handover to school nurse											Y

Table 4: Universal services delivery schedule for 0-5 year olds

¹² The immunisation schedule is subject to unscheduled changes and current guidance (the Green Book) should be consulted

Universal services from five to 11 years old

11.3.4 Reference 11.2 provides PCOs 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, ie all services to all children, and a progressive basis, ie some services to some children that have been identified with particular needs.

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

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 ¹³	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 5: Universal services delivery schedule for 5-11 year olds

¹³ the immunisation schedule is subject to unscheduled changes and current guidance (the Green Book) should be consulted

Universal services from 11 to 16 years old

11.3.7 Reference 11.2 provides PCOs 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.

11.3.8 This chapter 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.

11.3.9 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 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 6: Universal services delivery schedule for 11-16 year olds

Universal services from 16 to 19 years old

11.3.10 Reference 11.2 provides PCOs 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

¹⁴the immunisation schedule is subject to unscheduled changes and current guidance (the Green Book) should be consulted

basis, ie all services to all children, and a progressive basis, ie some services to some children that have been identified with particular needs.

11.3.11 This chapter 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.

11.3.12 The schedule for delivering universal services is shown in table 7.

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 7: Universal services delivery schedule for 16-19 year olds

Reviews and progressive services

11.3.13 The schedule of health promotion reviews is:

- 6-8 weeks, all children, led by health visitor, face to face
- 12 months, some children, led by health visitor
- two to 2.5 years, all children, led by health visitor, face to face
- school entry, led by school nurse.

11.3.14 Not all children and families will have face-to-face contact with the health visitor-led health promotion team at age 12 months. Only those who are judged to need this will be seen at this point although a face-to-face review will take place for all at age 2.5

¹⁵the immunisation schedule is subject to unscheduled changes and current guidance (the Green Book) should be consulted

years. Thus the system must provide the health visitor who reviews the records of each child with the information collated in a format which permits identification of those who may need a HCP face-to-face review or intervention so that the lead health visitor can schedule and review the results of that review.

11.3.15 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.

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

Progressive services

11.3.17 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 as shown in diagram 9.

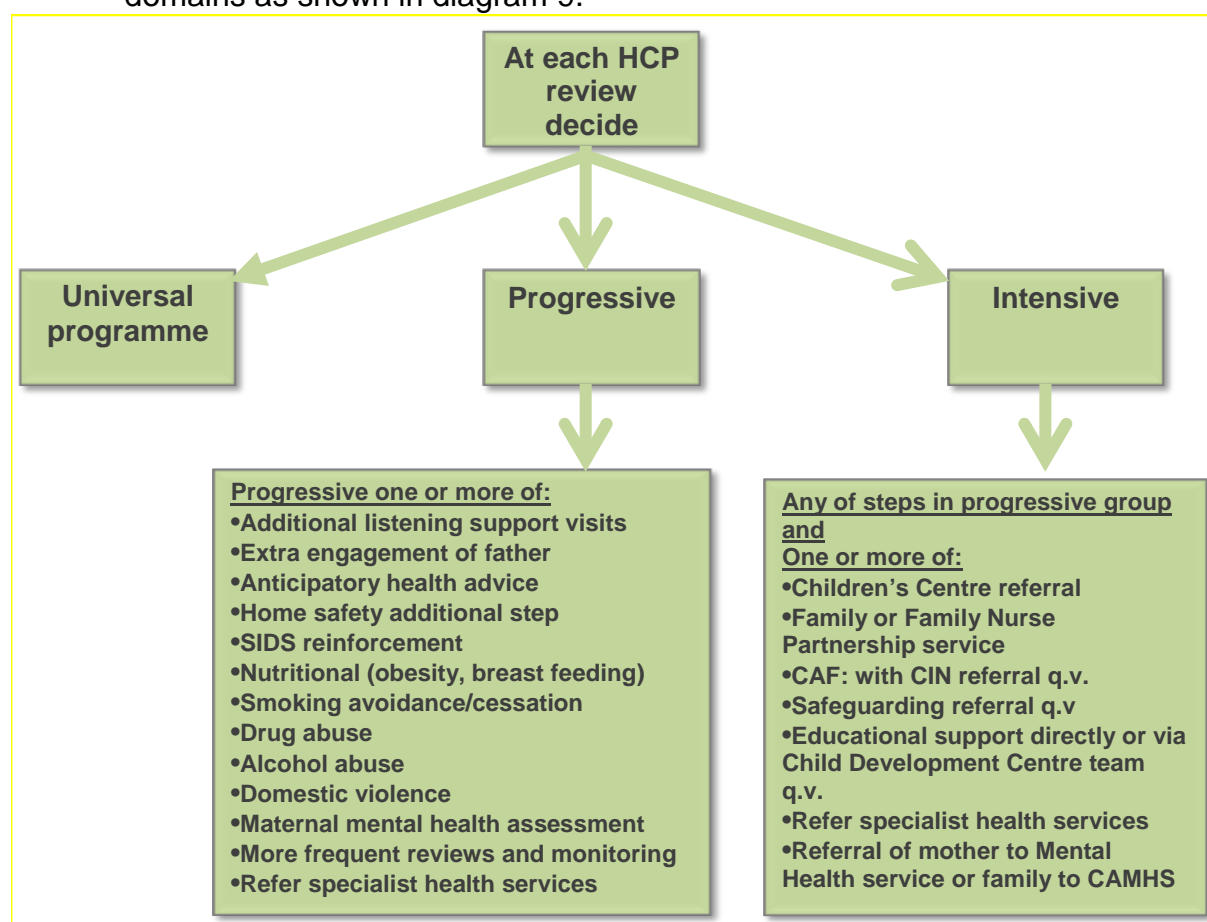


Diagram 9: Common assessment framework

11.4 Other functional requirements

Recording information

- 11.4.1 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 PCO 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.
- 11.4.2 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 PCO 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.

Record access

- 11.4.3 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.

Reporting

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

Common assessment framework

11.4.5 For a few children an assessment will be performed under the CAF (see reference 11.3). Typically this will be led by a health visitor. CAF information is collecting against a number of “domains” as detailed in table 8.

Domains	Information to gather
Antenatal	<ul style="list-style-type: none"> • General health of mother • Screening – as recommended by the National Screening Committee • Emotional health • Assessment risk and protective factors
The child	<ul style="list-style-type: none"> • General health • Emotional and social development • Physical development • Speech and language development • Self-care skills and independence
Parenting	<ul style="list-style-type: none"> • Emotional warmth /stimulation • Care giving • Father's contribution • Ensuring safety and protection • Guidance, boundaries and stimulation
Family	<ul style="list-style-type: none"> • 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 8: Common assessment framework

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

- not known/not assessed
- no problem
- mild/suspected
- moderate
- severe
- profound.

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

11.4.8 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.

11.4.9 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.

11.5 Clinical coding

11.5.1 There is a need to develop agreed standard codes for safeguarding dataset items.

11.6 External interfaces

Local authority

11.6.1 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. 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
- statement issued (at stage 5)
- statement revoked.

Personal Child Health Record

11.6.2 PCOs should consider printing pages for inclusion in the PCHR, incorporating data that is known about the child such as their NHS number and relevant local information such as the address of the nearest child health clinic. Such pages should conform to the current revision of the PCHR. Pages in the PCHR that are relevant to this chapter are:

- 6-8 week review
- health reviews.

12. Immunisation

12.1 Introduction

12.1.1 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
- measles, mumps and rubella.

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

- human papillomavirus (HPV)
- hepatitis B
- tuberculosis
- influenza
- varicella.

12.1.3 It also offers immunoglobulins for passive immunity and ad hoc vaccinations eg for travel.

12.1.4 Diagram 10 shows all of the interactions that a PCO needs to conduct with external entities (systems, organisations and people) in the course of providing the immunisation programme.

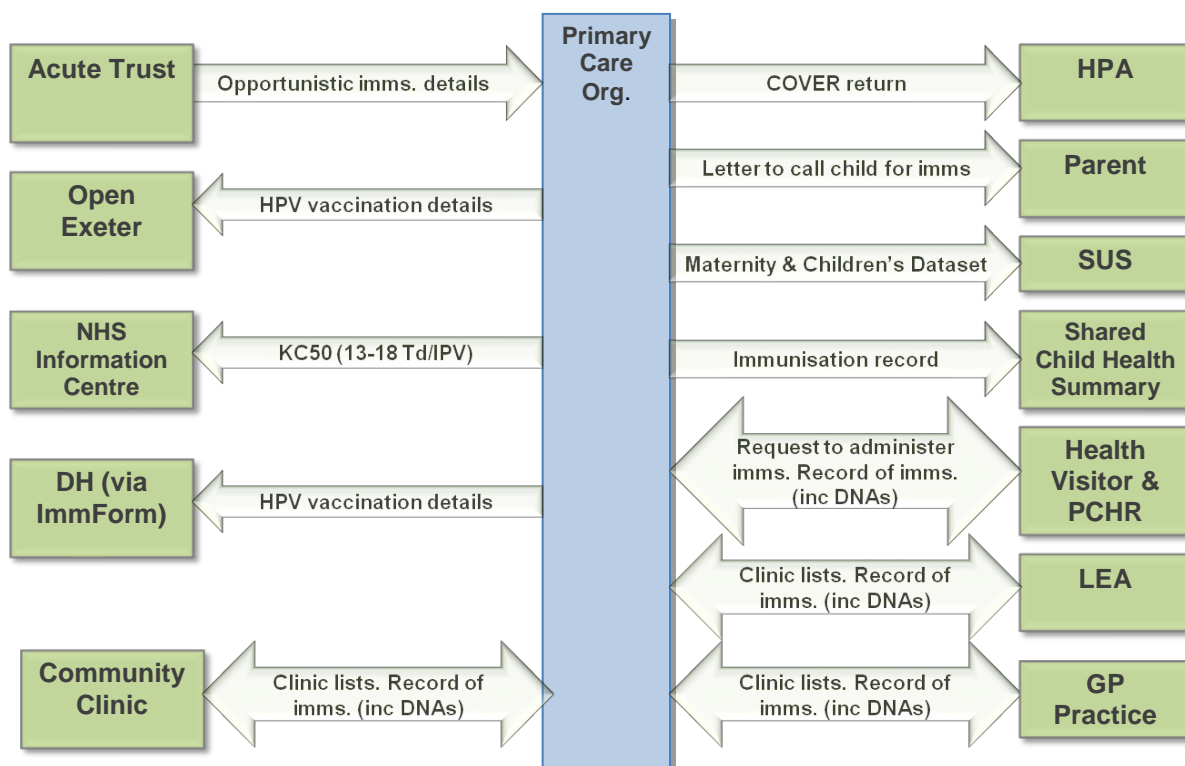


Diagram 10: External interfaces required for immunisation programme

12.2 References

- 12.2.1 Guidance for immunisation and vaccination in England is produced by the Department of Health and informed by advice and recommendations of the Joint Committee on Vaccination and Immunisation and set out in the Green Book (reference 12.1).
- 12.2.2 The following documents have been referenced in this chapter and will provide additional information.

Ref: no	File CM Ref. Number or equiv.	Title	Version
12.1	http://www.dh.gov.uk/en/Publichealth/Healthprotection/Immunisation/Greenbook/DH_4097254	Department of Health Green Book	October 2007
12.2	http://www.hpa.org.uk/HPA/Topics/InfectiousDiseases/InfectionsAZ/1204031507699/	COVER data	
12.3	http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1194947406156	Vaccination of Individuals with Uncertain or Incomplete Immunisation Status	April 2010
12.4	http://www.dh.gov.uk/en/Publichealth/Immunisation/DH_119387	Department of Health website about ImmForm	October 2010
12.5	http://www.dh.gov.uk/en/Publichealth/Immunisation/Keyvaccineinformation/DH_125275	Department of Health Key vaccination information: Hepatitis B	June 2011

12.2.4 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 (reference 12.1). It is therefore, important that the design of CHIS allows sufficient flexibility so that changes to the schedule of existing immunisations or the addition of new immunisations for children of any age can be made in a straightforward and timely manner.

12.3 Target schedule and cohort

12.3.1 PCOs have a requirement to ensure that all of the children that it is responsible for, up to the age of 19, have had or are offered immunisations in accordance with the Department of Health Green Book (reference 12.1).

12.4 Functional requirements

Identify children to be immunised

12.4.1 The PCO must be able to identify which children need to receive which immunisations, based on the guidance in the Green Book (reference 12.1). In addition, the PCO 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, see reference 12.5).

Provide support for the routine immunisation programme

- 12.4.2 The PCO should follow the schedule of ideal ages for the routine immunisation of children in accordance with the Department of Health Green Book (reference 12.1).
- 12.4.3 The PCO must be able to update the personal child health record on the shared child health record as described in the “External interfaces” section below.

Support variant scheduling for an individual

- 12.4.4 The system should be capable of supporting a variation to the schedule. Such a variation may be imposed because the immunisation record is uncertain or immunisations are given late or missed. Alternatively, variant schedules may be chosen because of risk factors, eg a child who is at risk of measles (eg due to exposure) might be given an earlier immunisation.
- 12.4.5 In the event that a child’s vaccinations or immunisations are missed, late or unknown the PCO must take action to regularise the situation as described by the Health Protection Agency in reference 12.3.

Flexibility of immunisation scheduling for a cohort population

- 12.4.6 Vaccines schedules change very frequently and new vaccines become available in this country either on or off a schedule. New vaccines are introduced into the national programme and catch-up programmes are often run. It is essential that all computer solutions used are sufficiently adaptable to easily and speedily accommodate these changes.
- 12.4.7 The system must be flexible enough to allow an internal schedule to be set according to local needs. For example, calling 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.

Invite children for immunisation

- 12.4.8 The system should be capable of inviting children for immunisations, and also able to allocate appointments in the PCO 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.
- 12.4.9 The immunisation could be administered by any one of:
- health visitors

- practice nurses
- GPs
- school nurses
- other.

Record details of immunisations

12.4.10 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 (eg address and type of location, eg GP surgery, school, community clinic)
- site of administration (eg left arm)
- diseases protected against
- antigen
- batch number.

12.4.11 It must be able to record:

- product name
- manufacturer.

12.4.12 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, eg documentary evidence exists, or unvalidated statement by parent.

Record refusals

12.4.13 The PCO 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.

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

12.4.15 The PCO 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.”

Record “did not attends”

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

Recording contraindications and adverse reactions

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

12.4.18 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).

12.4.19 The system must allow the user to record the subsequent action to be taken.

Record additional immunisations given

12.4.19 Children may receive doses of vaccines that are not scheduled. These may be extra doses of scheduled vaccines eg 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.

12.4.20 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.

Reporting and central returns

12.4.21 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.

12.4.22 The PCO must be able to submit central returns for the immunisation programme as described in the “External interfaces” section below.

Tracking payments owed to GPs

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

12.5 Clinical coding

12.5.1 Where currently available standard codes should be used and further ones developed.

12.6 External interfaces

12.6.1 The system must be able to receive and send information to external interfaces such as:

- provider units: PCOs should be informed about opportunistic immunisations by return of an unscheduled immunisation form from such units as A&E, acute units and walk in centres
- personal child health record: PCOs should consider printing pages for inclusion in the PCHR, incorporating data that is known about the child such as their NHS number and relevant local information such as the address of the nearest child health clinic. Such pages should conform to the current revision of the PCHR. Pages in the PCHR that are relevant to this chapter are – immunisation
- Open Exeter: GPs or PCO staff can perform direct entry into the Open Exeter system of information regarding those who have been offered and given the HPV vaccines. Open Exeter provides the facility for users to load large volumes of HPV data from CSV files. This facility is able to handle up to 5,000 records per file. The specification of the CSV file layout is available on the Open Exeter on-screen help
- the NHS Information Centre’s maternity and child health secondary uses service: The PCO must be able to submit data to the maternity and child health Secondary Uses Service, part of the NHS Information Centre’s Children and Young People Health Services Dataset
- Health Protection Agency: On a quarterly basis, the PCO must send Cover of Vaccination Evaluated Rapidly (COVER) (see reference 12.2) data to the Health Protection Agency
- the NHS Information Centre: The COVER programme does not monitor school leaver immunisation or BCG testing and vaccination; these activities need to be

reported on a standard form (known as “KC50”) annually to the NHS Information Centre

- Immform: The PCO must be able to submit data to the Department of Health Immform site www.immform.dh.gov.uk.

12.7 Future developments

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 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 eg in defined clinical risk groups.

12.7.1 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 CHIS 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.

Recording manufacturer source

12.7.4 In the near future a number of vaccines against the same diseases will be available from different manufacturers. It would be highly desirable if the product name and manufacturer source for immunisations delivered are added to the minimum requirement.

Transition in the public health system

12.7.5 In the future the role of the COVER team will transfer from the Health Protection Agency to the new public health organisation Public Health England. The same requirements for immunisation data, though, are likely to remain in the future system with submission to Public Health England.

13. National Child Measurement Programme

13.1 Introduction

13.1.1 The NCMP is an important public health programme to monitor and tackle childhood obesity. Every year public health staff visit schools to weigh and measure children in Reception Year and Year 6 as part of this programme.

13.1.2 Local areas use NCMP data to set local goals to tackle child obesity and direct services for children to those most in need. Individual children's results are shared with their parents along with information about locally available leisure and weight management services for children, providing families with the information they need to make lifestyle changes if they choose to.

13.1.3 Until their dissolution in 2013, PCTs will remain responsible for the local delivery of the NCMP. However, delivery of the programme varies across England, because PCTs can commission a provider to deliver the programme on their behalf.

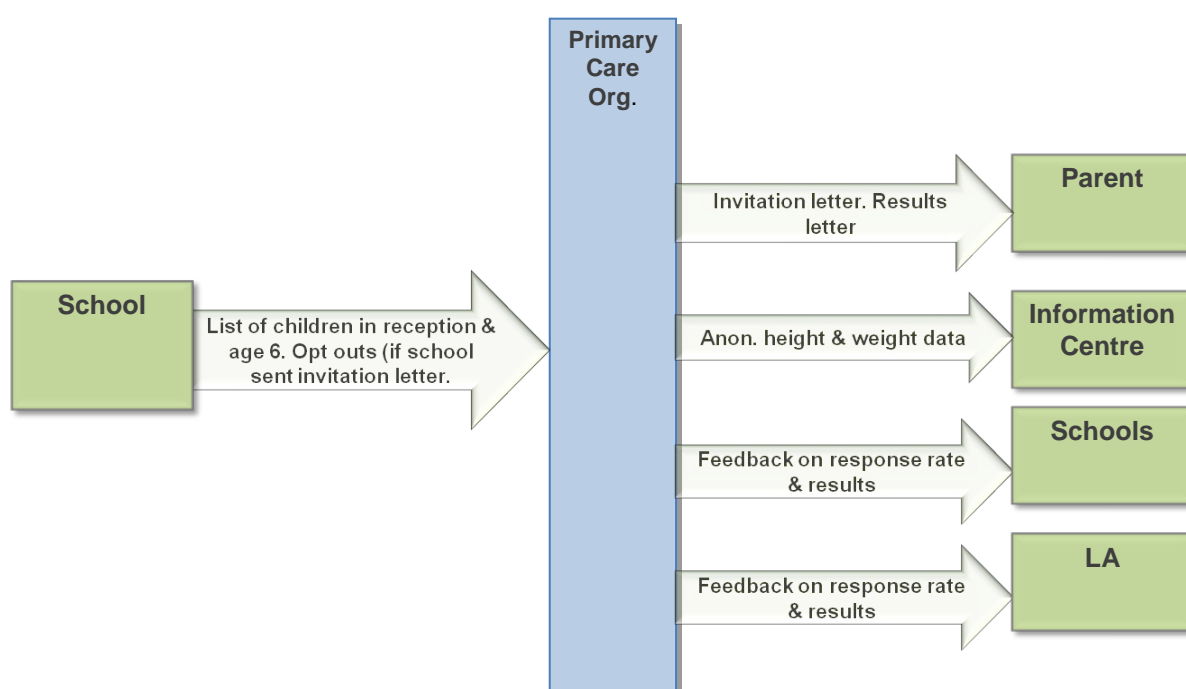


Diagram 11: External interfaces required for the National Child Measurement Programme

13.2 References

13.2.1 These documents have been referenced in this chapter and will provide additional information.

Ref: no	File CM Reference number or equivalent	Title	Version
13.1	DH Gateway ref: 13682 http://www.dh.gov.uk/en/PublicHealth/Obesity/DH_073787	National Child Measurement Programme Guidance for Primary Care Trusts	2010/11
13.2	https://ncmp.ic.nhs.uk/	The NHS Information Centre NCMP upload and parental feedback tools.	N/A
13.3	www.noo.org.uk/noo_pub/ncmp	The National Obesity Observatory NCMP analysis guidance for PCTs and public health observatories	2009/10
13.4	http://www.ic.nhs.uk/ncmp/validation	The NHS Information Centre's updated validation guidance contains details of child health system ethnic codes	May 2011

13.3 Target cohort and schedule

- 13.3.1 NCMP requires the measurement of all children in Reception Year and Year 6 who are pupils within the eligible schools in a local area unless their parent or guardian opt them out , or they are absent on the day of measurement.
- 13.3.2 Every maintained primary and middle school within the PCT boundary should be included. A list of maintained schools within each PCT boundary is provided in the Parental Feedback and Upload Tools that are available to PCTs and local authorities to download from the NHS Information Centre website (reference 13.2). Schools can be added or removed from the list in these tools according to which schools the local public health team routinely works with and whether any schools have closed or new schools opened. When submitting the data, it will be necessary to confirm that every school is under the responsibility of only one local area.
- 13.3.3 Measurements can be undertaken at any time during the school year, and the PCT is responsible for submitting data for schools within the PCT boundary to the NHS Information Centre at the end of each school year. The deadline for upload will be published in Department of Health guidance each year.

13.4 Functional requirements

Send pre-measurement letter to parents

- 13.4.1 An initial letter to parents informing them about the NCMP and giving them the opportunity to withdraw their child from the programme should be sent suitably far in advance of the measurement taking place. The letters can be sent in the post or via the school in pupil post. A template letter is provided by the Department of Health in reference 13.1.

Send results letter to parents

- 13.4.2 Within six weeks of the measurements being done, children's individual measurement results should be to their parents or guardians, using the editable template letter and tool available from the NHS Information Centre website. The letters should be sent via post directly to parents.

Prepare data entry sheets

- 13.4.3 The data gathered from the measurement should be recorded into Excel spreadsheets, rather than paper. Ideally, the data-entry aid provided by the NHS Information Centre alongside the parental feedback tool should be used.
- 13.4.4 The lists of children should be provided by the schools and include the following details:
- NHS number (where available)
 - name of child (first name/surname)
 - date of birth
 - sex
 - parent/carer's home address and postcode
 - ethnicity.

Upload data to the NHS Information Centre

- 13.4.5 The measurement data must be submitted to the NHS Information Centre using the Upload Tool provided. This information will include the following data:
- school unique reference number (URN)
 - date of birth
 - sex
 - date of measurement
 - height
 - weight
 - child postcode
 - ethnic code.

- 13.4.6 There is also provision for first name, surname and NHS number, which can be populated to assist the PCT with their records, but these are not mandatory and even if they are provided, they are not transmitted to the NHS Information Centre. Similarly, child postcodes are not received by the NHS Information Centre; they are translated into lower super output area.
- 13.4.7 The NHS Information Centre will validate the data and publish anonymised data at PCT and local authority level as part of an annual report.

Provide feedback to schools and the local authority

- 13.4.8 The PCO should be able to provide the schools and the local authority with feedback on aggregated NCMP results according to guidance provided by the National Obesity Observatory (reference 13.3). The following information should be provided:
- the response rate by age-group (Reception year and year 6)
 - the prevalence of overweight and obesity for the PCO for each age group
 - how the school's obesity and overweight prevalence compares with the PCO or local authority, regional or national averages.

13.5 Clinical coding

- 13.5.1 Where currently available standard codes should be used and further ones developed.

13.6 External interfaces

Parents

- 13.6.1 All areas should send a letter to parents informing them about the programme and giving them the opportunity to withdraw their child if they do not want them to be measured.
- 13.6.2 After the measurement, the results of every measured child should be sent to their parents. The NHS Information Centre provides a Parental Feedback Tool to use alongside a Department of Health template letter to facilitate this activity (both available at reference 13.2).

Schools

- 13.6.3 There is a template letter that can be sent to head teachers to initiate the measurement programme within the school.

- 13.6.4 Weight and height measurements should be collected directly into an Excel spreadsheet to facilitate easy copying into the Parental Feedback Tool and the Upload Tool.

NHS Information Centre

- 13.6.5 Submission of the data to the NHS Information Centre is done using the Upload Tool, which they provide on the submission website (reference 13.2). In addition, the Upload Tool also performs the following functions:
- pre-upload data checking
 - anonymisation (through the creation of the .CSV files used for the upload) prior to transmission, which generates a local ID field and strips out the personally identifiable fields referred to in 13.4.5/6.
- 13.6.6 In addition to the Upload Tool, public health staff will need to use the NHS Information Centre's NCMP website to view a post-upload data checking report and work through any anomalies identified before confirming that the submission is final. For further details about the data collection and the Parental Feedback and Upload Tools see reference 13.2.

13.7 Future developments

- 13.7.1 When PCTs are dissolved in 2013, local authorities will assume responsibility for commissioning the National Child Measurement Programme. They will retain the ability to commission a local provider, meaning there will remain variation in local delivery of the programme, though it will be delivered according to minimum national standards.

14. Supporting looked after children

14.1 Introduction

- 14.1.1 The processes outlined below in summary are based on the services that children who are of “looked after” status need, including health assessments on entry and then regular reviews.
- 14.1.2 Looked after children are recognised to have greater health needs than the general population and also these needs are more difficult to meet in view of mobility and 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 care for them and also with the child themselves.
- 14.1.3 Thus they:
- 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.
- 14.1.4 Although the primary responsibility lies with the social care service for reviews of status, the health needs should be met and monitored by health services. This applies also to children placed for adoption where there are issues to do with long-term health needs and background family history to be taken in to 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.

14.2 References

- 14.2.1 No documents have been referenced in this chapter

14.3 Target cohort and schedule

- 14.3.1 These services are delivered to all children that the PCO has responsibility for and who are formally registered as “children looked after”.

14.4 Functional requirements

Highlighting the child's status to healthcare professionals

- 14.4.1 The system should 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.

Maintain records

- 14.4.2 The PCO'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.

Support for formal reviews

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

Health service information:

- report on health of birth parent (one for each parent) (use British Association for Adoption and Fostering (BAAF) "Public Health (PH)" 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
 - 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.

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
- 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.

Reporting on “looked after” children

- 14.4.4 The PCO 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
 - registration with a dentist.
- 14.4.5 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.
- 14.4.6 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.

14.5 Clinical coding

14.5.1 Where currently available standard codes should be used and further ones developed.

15. Disability, long-term care and those with special educational needs requiring health input

15.1 Introduction

15.1.1 This section also covers the topic of educational support.

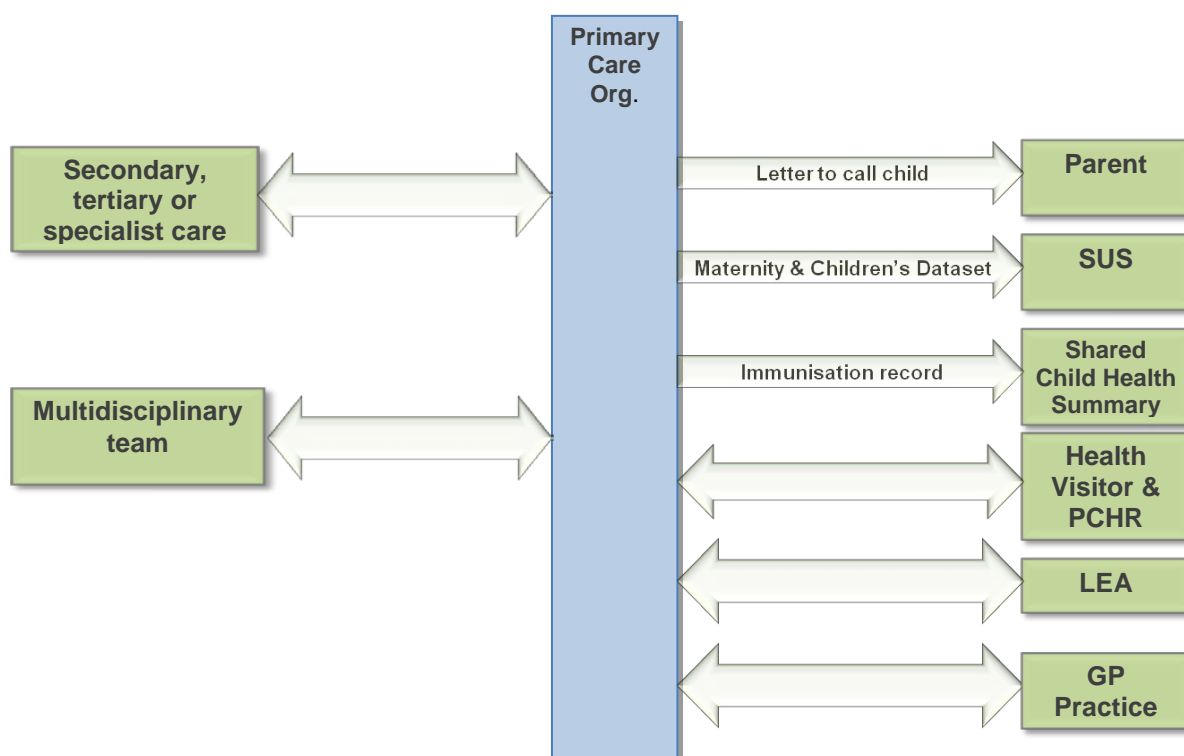


Diagram 12: External interfaces required to support children with disabilities or complex health needs

15.2 References

15.2.1 The following documents have been referenced in this chapter and will provide additional information.

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 Education & Skills	May 2003
15.3	Aiming high for disabled children: better support for families, HM Treasury and Department for Education and Skills	2007
15.4	The dignity of risk. A practical handbook for professionals working with disabled children and their families, Council for Disabled Children	
15.5	"Including me" – Managing complex health needs in schools and early years settings, Council for Disabled Children and DfES	2005

15.3 Target cohort and schedule

- 15.3.1 All children that the PCO is responsible for and who are either registered as disabled or have complex healthcare needs.

15.4 Functional requirements

Support for customised service packages

- 15.4.1 The PCO's information systems must support the planning and delivery of services, over and above those designed for the population as a whole, to children and young people who have disabilities or complex healthcare needs.

Maintain records

- 15.4.2 The PCO'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
Requires assessment of educational needs	
Trigger (1st) letter to parents – used when parents did not make request directly to local education authority	
Parental permission	
Referred for assessment of educational needs	Date
Letter received from local education 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 statement received	Date
Statement refused	
Tribunal	
Record when an assessment is overdue, from whom and the reason	

Table 9: Fields required for special educational needs procedures

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

Reports

- 15.4.4 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 children with disabilities
 - analysis of children on disability register by age and category.

15.5 Clinical coding

15.5.1 Information regarding standard sets of clinical codes is being collated and will be made available in the future.

15.6 External interface details

Local authority

- 15.6.1 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 following data sharing protocols.
- 15.6.2 The system must have fields for the recording of the categories under which the child is registered.

Annex A: Proposed content for a shared record of child health and care

The content of the shared child health record is recommended in this report 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
Special educational needs statement	Few
Child in need assessment	Few
Common assessment framework	Few
'Looked after' child assessment	Few
Child protection plan	Few

Information Requirements for Child Health Information Systems

If it is felt that further development of the content of a shared record for child health and care would be beneficial to those developing, using and providing CHIS, the CHIS Transition Steering Group will consider investing time in bringing up to date the work done to date.

Annex B: Abbreviations

Abbreviation	Detail
A&E	Accident & emergency
AABR	Automated auditory brainstem response
ABR	Auditory brainstem response
BAAF	British Association for Adoption and Fostering
BCG	Bacilli Calmette-Guerin
CAF	Common Assessment Framework
CAMHS	Child and adolescent mental health services
CHIS	Child health information systems
CHPP	Child Health Promotion Programme
CHRD	Child Health Record Department
CSV	Comma-separated values
GP	General practitioner
HCP	Health Child Programme
HPV	Human papillomavirus
IT	Information technology
MCADD	Medium chain acyl CoA dehydrogenase deficiency
MMR	Measles, mumps and rubella
NCMP	National Child Measurement Programme
NIPE	Newborn and infant physical examination
OAE	Otoacoustic emissions
PCHR	Personal child health record
PCO	Primary care organisation
PCT	Primary care trust
PDS	Personal Demographics Service
SMART	Screening management and reporting tools
URN	Unique reference number