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Child Health Information
in the
South East Region

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This project was commissioned by the South East Public Health Observatory to review and map the sources of information available about children and the child health data that are available from routine systems the South East Region. The project had two main components:

1. A review of data collected routine about children, including both local data available from national systems and data collected in local systems.
2. A two-part questionnaire survey to ascertain what data were held locally. The first part sought to identify the people within each PCT in the South East Region who were responsible for specific aspects of children's services. The second part was to send a questionnaire to the people who were identified, to enquire about the local data they held or used.

Results

Routinely collected data

A number of routine data systems containing data about children were identified and several more were under development. In many cases data from them were not routinely published. Others published data but did not disaggregate the below regional level. The National Congenital Anomaly System publishes data for strategic health authorities, data about children with special education needs are published for local education authorities, and data about maternity care are published by NHS trust. Birth and death registration data are available as individual records and tabulations for primary care trusts for use within the NHS only, although less detailed data are available for electoral wards and local authorities.

Surveys of information held in primary care trusts

The project was planned to take place in two stages:

1. Identification of the people who were the leads for children's services in each PCT.
2. A survey of the people responsible for children's services in each PCT to ascertain what information was held.

The first stage turned out to be both time consuming and fruitless because of the way that, in many PCTs, responsibility for different aspects of services for children was split between a number of people. As a result, it proved impossible to compile a complete list of potential respondents in the way originally envisaged. The plans were therefore revised and a survey was undertaken of managers of child health computer systems in the Region.

A short questionnaire was sent in June 2004 to request information about the structure of these systems and about the information held in them. Twenty four systems, using ten different types of software were in operation to support child health services in the 49 PCTs in the Region. Eight systems covered the population of only one PCT while one system covered the population of five PCTs. Four PCTs were covered by more than one system.

In some areas, clinical staff could access the systems directly to view and update data. Most data were entered by clerical staff using paper records supplied by clinical staff. All systems contained a common core of data, maintaining a register of children currently living in the area and adding information about new births and immunisation. Most kept information about early childhood developmental screening and school health. Many included results of newborn screening.

Information about children with special needs and children on child protection registers was less commonly recorded and information about children's mental health was rarely recorded.

The extent of recording of key data items, such as ethnicity, breastfeeding and childhood obesity varied between systems both in the type of information collected and the timing for recording it. Information can be aggregated for some areas but coherent information could not be generated for the whole region.

It was not possible to list the individual data items in child health systems. For most systems, this was not available and system managers lacked documentation for the systems they managed, as software suppliers were reluctant or unwilling to make this information available to them.

By 2004, NHS numbers should have been included in all NHS records and this is crucial to developments in IT within the NHS. Records for all children born since allocation at birth began in October 2002 included an NHS number, In contrast, it was estimated that in for nearly half the PCTs, NHS numbers were present in between 70 and 90 per cent of records of older children. Only an estimated three quarters of records of all children moving into a different PCT area included an NHS number. All child health systems retained previous addresses and names for children, but with over two million children in the South East Region the scale of these shortfalls in the recording of NHS numbers is considerable.

Child health systems contain a wealth of information and there is considerable investment in the time and effort needed to collect, enter and maintain it. Considerable effort is therefore needed to benefit from this investment and ensure that more consistent information becomes available in the future.

Key messages

Data from routine national systems

A number of routine national systems contain data about child health. Data from some are not published and data from most others are not disaggregated below regional or strategic health authority level. Local data for PCTs derived from birth and death registration are mainly provided for use within the NHS and more detailed data cannot be shared with non-NHS staff.

Registers

Two congenital anomalies systems in the regions cover counties in the former Wessex and Oxford regions. There is no congenital anomalies register covering Kent, Surrey and Sussex.

The 4Child register is one of only three in England collecting data about children with cerebral palsy. Data about cerebral palsy and visual and hearing impairments are collected for children previously or currently resident in Oxfordshire, Berkshire and Buckinghamshire plus Northamptonshire, which is no longer in the South East Region.

Child health computer systems

A survey of managers of child health systems in the South East in 2004 found that there were 24 systems, using ten different types of software, covering areas of variable size. As a consequence of successive NHS reconfigurations, many systems covered more than one PCT and several PCTs held information in more than one child health system, each covering a different part of their area.

In most systems, clerks entered information manually from paper records. Clinical staff entered data directly in only a minority of systems. A new interactive system was being introduced to cover all of Kent.

All systems maintained a population register of children resident in the areas they covered and contained data from birth notification and immunisation. Information about pre-school development was collected for 90 per cent of children in the South East Region and school health information was collected for 85 per cent. In 40 per cent of the Region, systems were used for special needs, in under 30 per cent for child protection and in very few for information about children's use of mental health services.

Records for most children born since the introduction of allocation of NHS numbers at birth contained an NHS number, but recording was not complete for older children, especially those who had moved into new areas. Action is urgently needed to stop further erosion.

Recording of key data items, such as ethnicity, breastfeeding and childhood obesity was incomplete. Coverage varied between systems, both in the type and completeness of information recorded and the timing for recording it. Information could be aggregated for some areas but coherent information could not be generated for the whole Region.

Child health systems were designed as operational systems. The information in them is not used for regular reporting of aggregated data about child health in the population.

System managers did not have access to lists of individual data items, as software suppliers were reluctant or unwilling to make this information available to them. This gap in information has serious implications for the development of new child health systems in the National Programme for IT.

Child health systems contain a wealth of information and considerable efforts are made to collect, enter and maintain it. To realise this investment, action is urgently needed to ensure that more complete and consistent information is collected and that data are published regularly.

1 Introduction

1.1 Background

Children are a focus of concern for all societies. In England, highly publicised failures to protect the lives and wellbeing of individual children have resulted in public enquiries, consultations and the introduction of new legislation. The Children Act, 2004 completely changed the structures of the health, social services and education agencies responsible for children. These followed changes in the strategic and management structures within the NHS, with the establishment of strategic health authorities and primary care trusts.

Further changes are on the way, in line with the agenda for children's services set out in the National Service Framework For Children, Young People And Maternity Services.[1] This sets out eleven standards for care, with a focus on the integration of services to meet the needs of children. Its vision is of a service which is child and family focused with a central role for public health services in ensuring that the needs of mothers and children are addressed. The framework recognises that children and young people have different needs from adults and that services should be tailored to meet their specific requirements.[2]

To monitor and assess the impact of these changes, reliable and relevant data are needed, but so far data about children have not bee collected in a concerted way. Major investment is taking place in IT for individual patient care and the National Programme for IT aims to completely restructure all aspects of information about patients. Its vision is of an integrated paperless record system with information collected once only and within which provision is made to use standardised messaging systems to share information between NHS agencies. The impact of these changes on child health information should be monitored to ensure continuity and prevent loss of population-based information.

1.2 Aims

The project was commissioned by the South East Public Health Observatory to review and map the sources of information available about children and the child health data that are available from routine systems the South East Region. The project had two main components:

1. A review of routine data collected about children, including both local data available from national systems and data collected in local systems.
2. A two-part questionnaire survey. The first part sought to identify the people within each PCT in the South East Region who were responsible for specific aspects of children's services. The second focused on the use and contents of child health systems. A questionnaire was used to request information about the structure of these systems and about the information held in them.

2 Routine data sources

2.1 Overview of information collected at birth

When a baby is born, information about the event is recorded in a number of different systems. The organisation providing maternity care records information about the mother and baby or babies. This information may be recorded on paper and/or on a computer system which may or may not be linked to the relevant hospital computer system. For each birth, a record is forwarded from the hospital system to the Maternity Hospital Episode Statistics (HES) database. By law, the birth must be notified to the local director of public health. In most cases, the notification now includes the NHS number, which has been issued to the baby at birth by the NHS Numbers for Babies Service. In practice, the notifications are sent to community child health departments. These then forward a limited amount of information about the birth to local registrars of births marriages and deaths. Additional information is collected from the babies' parents when the births are registered.

Each of these procedures involves recording information which can be used in the process of monitoring child health. The way in which these systems work has changed and is likely to continue to change in response to developments and investments in information technology. This section gives an overview of their state in 2004 and the extent to which data from them can be used locally.

2.2 Birth notification

Births have been notified to the local official responsible for public health since 1907 and this has been compulsory since 1915. Since 1948, this system of notification has become embedded in the routine workings of the NHS and in particular the community child health services. Birth notification is now required under the NHS Act 1977.[3] Within 36 hours of occurrence, a registrable live or stillbirth must be notified to the 'District Medical Officer', now known as the Director of Public Health (DPH). In practice, the notification is now sent directly to the community child health system so that a new child health record can be created. The notification is the responsibility of the mother's birth attendant, usually the midwife.

Until recently, most birth notifications have been sent on paper. There has been some progress in the development of electronic linkages between maternity and child health computer systems. In some trusts, the notification is sent as an electronic message from the local maternity system to the child health system, followed by a signed paper copy. The notification is sent to the child health system in the area in which the baby is born. Notifications relating to babies resident in other areas are then forwarded to the relevant community child health department. In most areas, the child health system retains information about all births. Some, particularly those where information is still entered manually, restrict the data to notifications relating to residents of their own area.

The form of the notification can be determined locally and so the contents vary, but there is a common core of information. The National Child Health Computer System was one of the earliest computerised systems to be used widely in England and Wales. The data fields for birth notification reflect broadly the scope of information notified in the 1970s and 1980s. There was no national guidance, so the form of notification evolved in a haphazard fashion, largely reflecting the items

held in local maternity systems. The standardised 'minimum dataset' of items to be provided to HES probably contributed to the establishment of a common core of standardised information.

Table 2.1 Data fields in the National Child Health Computer System (NCHCS)

Baby	**Birth**
Date of birth	Number of babies born
Surname	Ranking for multiple births
Sex	Time of birth
Ethnicity (optional)	Place of birth
Length of gestation	Labour onset method
Live/Still birth	Method of delivery
Birthweight	Place of birth
	Geographical area of hospital at birth
	Geographical area of hospital subsequent to birth
Mother	
Date of birth	Intended place of birth
Ethnicity	Reason for change
Gestation at booking	
	Infant resuscitation after delivery (optional)
Previous live births	Date of death
Previous stillbirths	Hospital admissions after birth
Previous miscarriages / terminations	Congenital malformation observable at birth
Previous pregnancies	
Previous neonatal deaths	**Other**
Single parent family	GP at birth

The notification serves a variety of purposes. One of these is to set up the baby's record on the local child health system. This is used to administer national immunisation and pre-school developmental assessment programmes. The notification often includes the maternity discharge information recorded as a part of the handover from the midwife and obstetrician to the health visitor and general practitioner. An important function of the birth notification is the verification for civil registration purposes that a birth has occurred. Information about the birth is passed to the local register office so that the birth registration can be completed, as described below.

In England, data from birth notifications are not systematically analysed at a national level. This means that most of the data are unpublished, making it difficult to comment on their accuracy and completeness. In some areas, notification data are analysed locally and such analyses are more likely to include an indication of the quality of the data.

Ascertainment of births through the notification process is likely to be very complete because of the integration with registration. Some reconciliation between birth notification and birth registration has been attempted by ONS. The large number of systems in use, the potential for duplication especially for records relating to babies born outside their area of residence and the changes in babies' names that can occur between birth and registration makes this process difficult.

Use of the notification as a discharge summary to inform subsequent care of the mother and baby increases the accuracy of the clinical information compared with returns that are made purely for statistical purposes. Errors that are detected by subsequent contact with the mother are likely to be corrected only in the individual manual records held by health visitors and GPs and are not usually corrected on child health systems.

2.3 Live birth registration

Live births must be registered at the local register office within 42 days of occurrence. The informant, usually the baby's mother and/or father, provides the details requested by the registrar.

In the past, the details were entered on a 'draft entry' form, but this process is now computerised. This information can be given in any register office, but if it is not the office in the area where the birth took place, the information will be forwarded to this office and the entry will be made in its register. The registrar issues a birth certificate to the informants. The information about live births recorded by the registrar is shown in Table 2.2.

Table 2.2 Data items on the 'draft entry' form used for registering live births on Form 309 (Rev)

Administrative	Father (if married or joint registration)
GRO reference number	Name and Surname
District and sub-district numbers	Place of birth
Register number	Occupation
Date of registration	
Entry number	
	Confidential particulars
Birth	Father's date of birth (if named)
Date and place of birth	Mother's date of birth
Multiple birth, yes or no	*Where child born in within marriage*
Number of births this maternity	Date of marriage
Sex	Has the mother been married more than once
Name and surname	Number of mother's previous children
Address including postcode	Number born alive
	Number still-born
Mother	**Detail added from birth notification**
Name and Surname	Birthweight
Place of birth	
Occupation	**NHS number** issued prior to October 2002
Maiden surname	Since October 2002 obtained from
Surname at marriage if different from maiden name	birth notification
Usual address	
	Informant

In particular, the information recorded includes the parents' occupations and dates and places of birth. Information about the father can be recorded only if the birth is within marriage or is jointly registered by both parents. For births outside marriage registered by the mother on her own, only the mother's particulars are recorded. Before 1986, the mother's occupation was not recorded for births within marriage or for jointly registered births outside marriage.

Additional items of information about births and stillbirths are collected in confidence under the Population (Statistics) Acts of 1938, as amended in 1960.[4;5] These are added to the draft entry but do not appear in the publicly accessible final entry to the birth register. Confidential particulars include legal marital status, and details of any previous children born within the current or any previous marriage.

The baby's birthweight is obtained from birth notification via the local community child health system. The name and address of the mother and baby, the date and place of birth and the birthweight are extracted from the birth notification and used as a crosscheck.

Because of the legal requirement for a birth certificate, which is issued after registration, very few births are unregistered and birth registration data are therefore largely complete. The accuracy of the information supplied is the responsibility of the informant. There are legal penalties for providing false information. The Office for National Statistics undertakes consistency checks and believes that the information it receives is by and large correct.[6]

Some data items are optional. For example, the mother is not required to give her occupation, if the father's has already been recorded. By 2001 only 73 per cent of mothers recorded a codable occupation at birth registration.[7;8] Although, in some cases, this may have been because the mother

was young and not yet in paid employment, it is generally considered that mothers' occupations are also under-recorded.

ONS produces annual vital statistics (VS) tabulations for local authority and NHS areas on CD-ROM. Tables for NHS areas are restricted to use within the NHS. These are listed in Table 2.3.

Table 2.3 Vital statistics tables for local and health authorities

	Description	Level of disaggregation
VS1	Births and infant mortality summary files	Primary care trusts and local authorities
VS2	Births by birthweight	Primary care trusts and local authorities
	Maternities and births by mother's age, place of birth and parity	
VS3	Deaths, excluding neonatal deaths, by cause and age	Primary care trusts and local authorities
VS3Sc	Deaths, excluding neonatal deaths, by cause and sex	Primary care trusts and local authorities
VS4	Live births, stillbirths and deaths by age and sex	Wards within local authorities
VS4D	Deaths, excluding neonatal deaths, for selected cause categories	Wards within local authorities
VS5	Infant and perinatal mortality by sex	Primary care trusts and local authorities

ONS also provides primary care trusts with files containing anonymised birth and death records for every birth occurring to residents of the PCT and every death of a resident. Strategic health authorities are provided with files for all of their PCTS. They can obtain data for surrounding areas by paying a small charge.

2.4 NHS numbers for babies (NN4B)

Up to 2002, local registrars of births and deaths issued NHS numbers to babies. The NHS numbers issued at birth before 1990 were derived from the number of the entry into the birth register. Subsequently, the format of NHS numbers was changed to remove any identifying features. The NHS number was sent by the registrar to the local child health department for inclusion in the child health record. It was also sent, along with other registration details, to the NHS Central Register so that it could be incorporated into general practice records when the child was registered with a general practitioner. As births can be registered up to six weeks after they occur, this led to delays in passing babies' NHS numbers on to clinical staff. Many ill babies did not leave hospital alive, and were thus never registered with a GP. Accounting for the use of services and needs of this small but potentially expensive group of babies was complicated by the fact that their NHS numbers may not have been incorporated into their hospital records. In addition the strategies set out in *Information for health* require a unique identifier in order to build up an electronic health record of each person's health care, starting from birth.[9]

The NHS Numbers For Babies Service[10] was launched at midnight on 29 October 2002. Its main purpose is to issue NHS numbers to babies as soon as possible after birth. The NHS number cannot be issued manually and can only be created using a linked computer. The Central Issue System (CIS) allocates each newborn baby with an NHS numbers and this is printed on the birth notification form that is produced by the maternity unit. In addition, the Central Issue System sends an electronic copy of the birth notification to the local child health department. The birth notifications from the CIS can be either printed and then entered into the child health system manually or read in automatically. The data items that are collected through NN4B are shown in Table 2.4.

It was originally envisaged that NN4B data would replace birth notification data entirely but because of their limited scope, local child health services were left to decide how to use the

notification. Local register offices ceased to issue NHS numbers and child health departments now send them NHS numbers along with other details of babies born.

Table 2.4 The NHS Numbers for Babies dataset

Baby	Place of birth
Name	Hospital or maternity unit
NHS number	Delivery place type code
Date of birth	
Delivery time	**Mother**
Sex	Name
Live or still birth	NHS number
Birthweight	Date of birth
Gestation length	
Number of births in this confinement	**Healthcare professionals**
Birth order	Name of person notifying birth
Suspected congenital anomaly, yes or no	GP name
Ethnic category (defined by mother)	Practice name
Patient's (baby's) usual address	Practice address
Postcode of patient's (baby's) usual address	Postcode of practice
Baby discharge address	National GP code
Postcode of baby discharge address	National practice code
	Child health organisation code

Notification and registration of births are legal requirements so the data relate to a whole geographical population and not an enrolled population using a particular service, as is the case with data held by maternity units. NN4B information is collected and held for only six months on the CIS. There are no resources in the NN4B service itself to analyse these data or publish tabulations. As was mentioned earlier, in England data from traditional birth notifications sent to child health systems are not routinely published.

2.5 Stillbirth and death registration

If a baby is born dead after 24 or more completed weeks of pregnancy, it should be registered as a stillbirth. The items recorded at live birth registration are also recorded for stillbirths, but a certificate of cause of stillbirth completed by a doctor is needed for registration and additional items shown in Table 2.5 are recorded. These are gestational age at birth, causes of death, whether death occurred before or during delivery, and whether or not a post-mortem has been performed. The medical certificate has separate spaces to record conditions in the mother and the fetus. Data about numbers of stillbirths in each local authority and NHS area are included in the annual VS tables on CD-ROM listed in Table 2.3.

Table 2.5 Additional data items on the 'draft entry' used for registering stillbirths on Form 308 (rev)

Details from Medical Certificate of Stillbirth	
Gestation at birth	Timing of stillbirth:
Fetal causes of death	Before labour / after labour / not known
Maternal causes of death	Is a post-mortem being carried out

Every death must be registered to obtain a death certificate, without which a burial or cremation cannot be carried out. The informant is required to report details of the death at the local register office. Information about the cause of death is obtained from the medical certificate of cause of death, which is issued to the informant by a medical practitioner. This is the doctor in attendance during the final illness. If the deceased person has not been attended by a doctor in the two weeks

prior to death, or if there is uncertainty about the cause of death, the case is referred to a coroner. The coroner has to reach a conclusion about the probable cause of death, and decide whether the death is lawful or not. When the coroner is satisfied about this, the medical certificate of cause of death is issued.

Special medical certificates are used for certifying causes of neonatal death. Like stillbirth certificates, these have separate spaces for conditions in the mother and the baby. For deaths of people aged 28 days or more, a standard certificate is used. This follows WHO conventions in attributing cause of death, with the first listed condition being the immediate cause of death and the second and third listed conditions being those underlying the preceding condition.

As for a birth registration, the registrar will enter details onto a 'draft entry' form, which has now been computerised. Copies of these are provided to the local public health department. In the past, these were provided on paper, but they are now provided annually as the Public Health Mortality File. Aggregated death data for local areas are circulated as the VS tables listed in Table 2.4. Data about stillbirths are included in the version of the VS tables made available for use within the NHS, but not among those shared with agencies and people outside the NHS.

Table 2.6 Data items on the 'draft entry' form used for registering deaths on Form 310 (rev)

Name of sub-district
Administrative area
Date and place of death
Name and surname of the deceased
Sex
Maiden surname, if the deceased was a woman who had married
Date and place of birth
Occupation
Name and occupation of husband, where the deceased was a married woman or widow
Usual address
Informant: name, surname, qualifications, usual address
Cause of death/doctor or coroner's name and qualifications
Signature of informant
Date of registration
Signature of registrar

Since 1975, information collected at the registration of deaths of children aged under one year have been linked to their birth registration details so that information from both sources can be used in statistical analyses. This was subsequently extended so that deaths at any age of children born from 1993 onwards are now linked to their birth registration records. This linked file is used for analyses for England and Wales as a whole but is not used routinely for producing data for local areas. Aggregated data for local areas

2.6 Confidential Enquiry into Maternal and Child Health (CEMACH)

The Confidential Enquiry into Stillbirths and Deaths in Infancy was set up in 1992 in England, Wales and Northern Ireland. Basic data for all late fetal deaths from 20 weeks of gestation, all stillbirths and all infant deaths were collected via a 'rapid report form', subsequently renamed a 'Perinatal death notification'. In 2003, the Confidential Enquiry into Maternal Deaths, which dated back to 1928 and the Confidential Enquiry into Stillbirths and Deaths and Infancy were brought together into a single organisation. From 2004, data collection about late fetal deaths at 20 and 21 weeks of gestation and was dropped. The collection of data about postneonatal deaths was

transferred to a new enquiry about deaths in childhood.   The information collected on the perinatal death notification form changes from year to year but a basic core of items, shown in Table 2.7 is maintained. CEMACH publishes national summaries by country and with some tabulations by region, but does not publish data for individual hospital trusts, except in diagrammatic form.[11]

More detailed information is collated about subsets of deaths and this is then examined by expert panels to identify sub-standard care which could have contributed to the death or stillbirth. As the judgements can be subjective, control groups have been used from 1998 onwards to improve interpretation of the findings of enquiries.[12]

Table 2.7 Data items in the CEMACH perinatal standard dataset

Mother	**Baby**
Hospital number	Case definition (Late fetal loss, stillbirth, early neonatal death, late neonatal death)
NHS number	Baby's residential address if different from mother
Postcode of mother's place of residence	Postcode
Date of birth and age	Sex
Ethnic group of mother	Birthweight
Date of delivery	Gestational age at birth
Time of delivery	Was this a legal abortion?
Place of delivery	Baby's age at death
Number of fetuses / babies this pregnancy	When did death occur?
Birth order	Place of death
Mode of delivery	Date of diagnosis of death
Was this a breech presentation?	Time of diagnosis of death
	Cause of death
	Extended Wigglesworth class
	Fetal and infant classification
	Obstetric classification (Aberdeen)
	Postmortem carried out

The new national child health enquiry programme began in early 2004. The overall aim of this enquiry is to improve the health of children older than 28 days and up to the age of 18 years. The focus of the enquiry is on children of 28 or more years of age. It aims to identify patterns of practice or service provision related to adverse outcomes, which could include death or morbidity. It is currently choosing a topic for its first special enquiry to start in 2005/6. The three short listed topics are unintentional/ accidental injury, child protection and an overview of child deaths.

2.7 Hospital Episode Statistics

The Hospital Episode Statistics (HES) started in the financial year 1987-88 and should contain a record of for every episode of in-patient or day case care in NHS hospitals in England. HES covers all medical specialities and should include private patients treated in NHS Hospitals. The HES database is a record level database of hospital admissions and is currently populated by taking an annual snapshot of a sub-set of the data about each individual completed episode of care submitted by NHS trusts to the NHS-Wide Clearing Service (NWCS). A separate database is held for each financial year, containing approximately 11 million admitted patient records from all NHS trusts in England. In the future this information will come from the National Programme for IT via the Secondary Uses Service.

Maternity HES started in 1989-90 and should include records of all episodes of care in maternity departments. If a delivery takes place during an episode, a 'maternity tail' should be appended to the admitted patient care record but this can be missing if the hospital's maternity system is not linked to its main IT system or it does not have a maternity system. This is likely to change with the implementation of the National Programme for IT, but initial problems with new maternity systems means that improvements may be slow. The coverage increased from 70 per cent of deliveries in 2001-02 to 72 per cent in 2002-03, but there was no further increase in 2003-04.[13] Coverage of home deliveries fell slightly from 15 per cent in 2002-03 to 14 per cent in 2003-04. Only 0.5 per cent of registered deliveries occurred in private hospitals and very few of these were included in Maternity HES.

Maternity HES is derived from two specialised sets of episode data that contain identifiers for the mother and each baby, delivery data and birth data. Birth data are duplicated if the pregnancy is multiple. In addition to the maternity record the mother and baby each generate a core HES episode record. These capture demographic details, details of up to three procedures and up to six diagnoses for each completed episode. Recommendations from the Körner Committee ensured that a new record was generated for each baby at the time of birth.[14] The core episode record for the mother, which includes the birth is routinely linked to the Maternity HES record, which contains data items such as ethnicity, complications and operations for the mother and complications for the baby.

The quality and completeness of data submitted to HES is variable. This is probably a reflection of the variety of definitions used locally. It is unclear whether this will improve under the National Programme for IT. Ethnic origin in particular is under-reported. Occupations are not recorded in HES.

Data are also collected about episodes of antenatal and postnatal in-patient care in maternity departments. In 2003-04 there were 77,400 admissions for suspected fetal problems. Many of the other reasons for antenatal admission, such as the 61,700 admissions with antepartum haemorrhage, could impact on the later health of the baby after birth. These episodes are not routinely linked with the Maternity HES record, nor to each other. It is therefore not possible to determine how many of these are single episodes and how many are repeated episodes in the same pregnancy, nor how these actually relate to the subsequent health of the child.

If a mother or baby is ill and transferred from a maternity unit to another unit such as an intensive therapy unit or a neonatal unit, the information about this is recorded in a separate episode in non-Maternity HES. These episodes are also not routinely linked to the Maternity HES record.

If babies and children are admitted to hospital after birth this will generate HES episode data for each admission. Each completed episode will include details of diagnoses and procedures carried out during that period of hospital stay. Since July 2004 HES, has extracted information from the NHS-Wide Clearing Service about outpatient and accident and emergency attendances. These are being backdated to include all submitted episodes from April 2003. Submission of core information to the NHS-Wide Clearing Service about outpatient attendances, is mandatory, as for inpatient episodes but submission of accident and emergency data is subject to local agreements.

The lack of routine linkage within HES is a consequence of its original purpose which was to enable managers to monitor activity within the NHS. Increasingly, however the need to link data about the same person is being recognised and it was decided that NHS numbers should be included on all NHS records. This has taken some time to achieve but its inclusion is a core feature of changes now being implemented by the National Programme for IT. The availability of NHS

numbers has led to an important change in HES data, namely the introduction of a new variable 'hesid' which allows records for the same person to be identified and linked without identifying them. This will allow better use of HES data for longitudinal studies, particularly those that aim to monitor the health of children.

Table 2.8 HES admitted patient care record minimum dataset with 'maternity tail'

Commissioning details	**Consultant episode details**
Organisation	Age at start of episode
Site	Episode number
Purchaser	Start of episode date
GP	End of episode date
Referrer	Duration of episode
	Consultant code
Patient details	Specialty function code
Date of birth	Specialty function code for shared care
Postcode	Patient diagnosis codes (up to 6)
NHS Number	Operative procedure codes (up to 4)
Sex, marital status	Neonatal level of care
Ethnic origin	
Record type	Data about patient discharge
Carer support indicator	Discharge date
Intended management	Discharge method
Local patient ID	Discharge destination
Spell number	
	Maternity tail – delivery details
Provider spell	Date of birth of mother
Admission method	First antenatal assessment date
Decided to admit date	Total previous pregnancies
Start date	Length of gestation
Duration elective waiting time	Delivery place type, intended
Source of admission	Delivery place type, actual
Category of patient	Delivery place type, reason for change
Patient classification	Labour/delivery onset method
	Delivery method
	Status of person conducting delivery
	Anaesthetic given in labour/delivery
	Anaesthetic given in post-labour/delivery
	Number of babies
	Date of birth of baby or babies
	Maternity tail – baby details
	Sex of baby
	Birth order
	Live or stillbirth
	Birthweight
	Method of resuscitation

Most standard tabulations of HES data are published electronically on the Health and Social Care Information Centre web site, which was established in April 2005. These are mainly data for England as a whole. Only overall numbers of in-patient episodes for all children aged 1-14 are available at primary care trust on the web site. More detailed analyses have to be requested specially from the Information Centre's commercial suppliers, Northgate Information Solutions and a charge is made for this. For Maternity HES, an annual bulletin is published on paper as well as on the internet.[13] It contains national trends, regional variations and data for individual trusts or maternity units.

2.8 British Association of Perinatal Medicine minimum dataset

Neonatal units expanded and developed during the last quarter of the twentieth century. There are now four levels of care, ranging from transitional care, which may be provided on maternity wards to neonatal intensive care, which caters for the needs of very sick and often very small babies.

Since 1997 the British Association of Perinatal Medicine has been collecting a data from neonatal units. This was driven by the need for consistent information to be able to report on the activities and monitor the emerging sub-specialty of neonatal medicine. The data collection is voluntary, and the aim of aggregating information into a national dataset has yet to be realised. The aim is to collect a standardised core of information from all units. Barriers to be overcome include issues of professional confidentiality, incentive, cost and the feasibility of collecting data from units with varying degrees of computerisation and types of hardware and software.

Table 2.9 British Association of Perinatal Medicine neonatal data items, 2004

Static data items	Daily data items
Name/code of hospital *	ET tube in situ
Mother's NHS number *	Receiving positive airways pressure
Postcode of mother's residence at the time of birth *	Surfactant given
Planned place of delivery at booking *	Receiving oxygen therapy
Place of birth *	Current weight
Baby's NHS number *	Full exchange transfusion done
Date of birth *	Partial exchange transfusion done
Time of birth *	Receiving peritoneal dialysis
Source of admission to the unit	On treatment with inotrope, pulmonary vasodilator
Date of admission	or prostaglandin
Time of admission	Receiving 1:1 nursing care
Birthweight *	Receiving peritoneal dialysis
Best estimate of gestational age at delivery *	Receiving parenteral nutrition
Sex *	On treatment for convulsions
Number of fetuses *	On treatment for neonatal abstinence syndrome
Birth order *	Recurrent apnoea requiring frequent interventions
Antenatal steroids *	Intra-arterial/central venous (incl umbilical) line in situ
Date of discharge, transfer or death *	
Time of death	**Derived items**
Discharge or transfer destination *	Days of respiratory support
Whether postmortem performed *	Days of positive airways pressure
Weight at discharge home	Date of final added oxygen
Head circumference at discharge home	Number of intensive care days
Oxygen at discharge home	Number of special care days
Surfactant therapy	Number of normal care days
Chest drain for pulmonary air leak	
Date of first retinopathy of newborn screen	
Cerebral ultrasound (as per local policy)	
Hearing screening (as per local policy)	
Shunt surgery for hydrocephalus	
Surgery for patent ductus arteriosus	
Surgery for necrotising enterocolitis	

* Items collected for all babies who die irrespective of whether they are admitted to a neonatal unit

The dataset was first defined in 1997 and a review of data items was published in 2004.[15] This suggested extending the data collected, as shown in Table 2.9. The static data items incorporate the core data items in the original dataset. Additional data collected for a review of neonatal care. This recognised the need to include some data about babies who died before admission to a neonatal unit. In addition there is a set of data items to be recorded daily about each child on the unit and used to derive further information about each child at the time of discharge. Collection of further data about the services available in the units and staffing is also recommended in the review.

A new computerised system is being introduced to neonatal units in the south and east of England, including units in London, Kent and Surrey and Sussex. Discussion is taking place about extending this to neonatal units in hospitals elsewhere, including the rest of the South East Region. The driving forces behind the development of this system extend beyond the need to audit care in individual neonatal units and demonstrate that the outcomes for babies admitted into neonatal units are improving. The frequency with which babies move between hospitals requires that the information about the baby is also transferred rapidly and accurately between units. The development of neonatal networks requires information to ensure that the care provided is consistent, matched to activity, and that transfers between units are appropriate.[16]

The system has been designed and developed specifically for neonatal intensive care. A key concept is its integration with the other hospital systems to extract data already recorded in the patient administration and maternity systems. It can also access data online for babies transferred from neonatal units in another hospital. The system is designed to keep detailed daily information about patient care, staffing levels and transfers into and out of each unit. The data are fully compliant with the British Association for Perinatal Medicine revised dataset. The dataset can be extended by recording information about transfers and long-term outcomes.

It is envisaged that these data can be used either at neonatal unit, hospital or neonatal network level, or at a population level to provide summary reports, population based analyses of outcome at different levels of area aggregation of neonatal care or to monitor progress against agreed service targets.

2.9 National neonatal audit

After the publication of a national review of neonatal care by the Department of Health in April 2003, a consultation revealed widespread support for its recommendations. Continuing audit was regarded as a key part of the quality management of the provision of care. The Healthcare Commission invited tenders for a national audit of neonatal care to be returned by August 1 2005. It was due to announce the result of the tender process in September 2005, but had not done so by October 14.

2.10 The National Congenital Anomaly System

The National Congenital Anomaly System (NCAS), was set up in 1964 following the birth of children with severe limb anomalies to mothers who had taken thalidomide.[17] NCAS receives notifications from two major sources, local health authorities and regional registers. It is a voluntary system intended to cover congenital anomalies in all live births and stillbirths. As shown in Table 2.10 below, data are collected about the specific conditions, the mother's age, parity and usual place of residence, the baby's sex and birthweight and the parents' occupations.

The system was originally set up to contain notifications of all anomalies apparent at birth or in the first seven days of life, but the criteria were subsequently widened to include anomalies diagnosed later in the baby's life. To limit the reporting of minor anomalies without major implications for the long-term health or wellbeing of children, a list of minor abnormalities to be excluded from notification was introduced in 1990. This had been compiled by the European Concerted Action on Congenital Anomalies and Twins (EUROCAT).

Abortions are not included in the notification system, unless they take place after 24 completed weeks of pregnancy and are therefore also registrable as stillbirths. Medical conditions on earlier terminations are tabulated by the Department of Health when processing abortion notifications. These terminations for fetal anomaly take place under the Abortion Act 1967 as amended by the Human Fertilisation and Embryology Act 1990. For monitoring strategies aimed at the prevention of anomalies, information is needed about fetuses in pregnancies terminated before 24 weeks. This is important for Down Syndrome and neural tube defects, which are relatively common serious malformations where most cases now are detected by antenatal screening in the second trimester of pregnancy.[18;19] When considering the health of children in the population the focus is on babies who are live born and in particular on those who survive.

Traditionally, notifications have been sent directly to the Office for National Statistics on Form SD56. The details notified are listed in Table 2.10. These are extracted from birth notifications and may be supplemented with additional information obtained after birth by hospital and community based clinicians. Supplementary information is particularly important for anomalies where there are no visible signs at birth, such as anomalies of the internal organs such as the heart and kidneys.

Table 2.10 Data items collected on Form SD56, congenital anomalies

Child	Mother/father
NHS number	Mother's address, including post code
Area in which baby was born	Area of usual residence
Place of birth	Date of birth/age
Date of birth	Date of last menstrual period
Sex	Mother's occupation
Live or stillbirth	Father's occupation
Single or multiple birth	Number and outcome of previous pregnancies
Estimated gestation	
Birthweight	**Details of the anomaly(s)**
	Detailed text description of the anomaly(s)

In areas where there were particular research and public health interests in congenital anomalies, coupled with longstanding concerns about under-ascertainment local and regional congenital anomaly registers were developed.[20] These use multiple sources of ascertainment, often actively sought out, and include known anomalies in all pregnancies, rather than being restricted to births. In the 1990s, ONS asked areas with local or regional congenital anomalies registers to share their data with the national scheme, rather than duplicating effort by returning Form SD56. Every local register, apart from that in the West Midlands, now does this. In 2003, the local registers reporting to ONS covered 45 per cent of births in England and Wales.[21] In an earlier analysis, data from local registers for the years 1991-99 were used to assess the ascertainment of congenital anomalies on the National Congenital Anomaly System. Excluding cases where the pregnancy was terminated, NCAS was notified of only 40 per cent of the babies with anomalies recorded in local registers in England.[20]

In the South East Region, there are two congenital anomaly registers. The Wessex Antenatally Diagnosed Anomalies register (WANDA) has covered the former Wessex NHS Region since 1994. The Oxford Congenital Abnormalities Register (OXCAR) covered Oxfordshire from 1991 to 2003 and was then extended to form the Congenital Anomaly Register for Oxfordshire, Berkshire and Buckinghamshire (CAROBB).

Table 2.11 Congenital anomaly registers in the South East Region

Register	Period of operation	Upper age limit for notifications	Geographical coverage
Oxford Congenital Anomaly Register (OXCAR)	1991-2003	One year	Oxfordshire
Congenital Anomaly Register for Oxfordshire, Berkshire & Buckinghamshire (CAROBB)	2004-	One year	Oxfordshire Berkshire, Buckinghamshire
Wessex Antenatally Diagnosed Congenital Anomalies Register (WANDA)	1994 -	No upper limit	Former Wessex Region (Dorset, Hampshire, Salisbury and Isle of Wight) and the Channel Isles

In areas where the introduction of the NHS Numbers for Babies birth notification has led to the discontinuation of the fuller form of birth notification, this has had a serious effect on notification of congenital anomalies. On NN4B notifications, all that is recorded is the presence or absence of congenital anomalies, rather than details of the anomalies present at birth. Child health departments do not necessarily have the resources to obtain more detailed information. This means that in some areas without registers, there will be increasing underascertainment of anomalies.

The Office for National Statistics has a system for routine surveillance to detect local increases in congenital anomaly rates. Analysis is undertaken quarterly and strategic health authorities are informed of any increases observed. An increase in the rate of any given condition may reflect changes in reporting practice rather than prevalence of the condition. Congenital anomaly statistics are published annually by ONS in *Congenital anomaly statistics, Series MB3*. Most tables relate to England and Wales as a whole, but there are some analyses by strategic health authority.

2.11 Registers of cerebral palsy and other impairments

4Child, formerly the Oxford Register of Early Childhood Ascertainment holds data about children with cerebral palsy, vision impairments or hearing impairments who were born from 1984 onwards in the four counties of Oxfordshire, Berkshire, Buckinghamshire and Northamptonshire. These were the four counties of the former Oxford NHS Region and the geographical coverage has remained essentially the same, although Northamptonshire is now in the East Midlands Region and the other three counties are in the South East Region. The register also holds information about children with these impairments who were born outside these four counties but were living in one of them at the time of notification. The register is based in the National Perinatal Epidemiology Unit. Further information about it can be found in its annual reports and other publications which can be found on the Unit web site http://www.npeu.ox.ac.uk. The annual reports include some tabulations by county.

There is no national system for collecting data about cerebral palsy, but *4Child* and four other registers have formed the UK Collaborative Network of Cerebral Palsy Databases, Registers and Surveys (UKCP). Of the four other registers, two, the Merseyside and Cheshire Cerebral Palsy Register and the North of England Collaborative Cerebral Palsy Survey, are in England. The other

two registers cover Scotland and Northern Ireland. Together with other registers in Europe, they form the Surveillance of Cerebral Palsy in Europe.(SCPE) There are no similar networks of registers monitoring visual and hearing impairments in England.

2.12 Surveys commissioned by the Department of Health and other government departments

A number of surveys commissioned by central government are either directly relevant to child health, or include data about children along with information about the population as a whole. None of these, apart for the census of population are large enough to have data about children at a local level, but most have tabulations by region. The main surveys are listed in Table 2.12. In general local tabulations of census data tend to focus more on the health of older people than that of children, as they are fewer in number and more healthy.

Table 2.12 Surveys of aspects of child health or including data about children commissioned by the Department of Health and other government departments

Survey	Time period or frequency	Coverage
Infant feeding	Five yearly, 1975 – 2005	United Kingdom
Children's dental health	Ten-yearly, 1973 – 2003	United Kingdom
Health Survey for England	Annually from 1991. Focus on children and young adults in 1997 and 2002	England
Census of population	Ten yearly, with questions on health in 1991 and 2002	United Kingdom
Persistence, onset, risk factors and outcomes of childhood mental disorders	1999, with sample followed up in 2002	Great Britain
Mental health of children and young people. A survey of the mental health of children and young people, aged 5-16.	2004	Great Britain
Smoking, drinking and drug use among young people	Annual	England
Children and adolescents who try to harm, hurt or kill themselves	1999	Great Britain
National diet and nutrition survey: young people aged 4-18 years	1997	Great Britain

2.13 National child health mapping project

This new exercise was commissioned from the Dr Foster organisation as part of the National Service Framework and is run by a team based at the University of Durham. After a pilot, the first round of data collection is under way using a web-based questionnaire. Service commissioners are asked to provide data about their budgets and about the structures and processes for commissioning children's and maternity services. Providers of services supply data about staffing and vacancies, location and focus of services and IT systems wanted and used. Further information can be found on the web site http://www.childhealthmapping.org.uk/.

2.14 Child health computer systems

Child health computer systems have evolved since the late 1960s when the first systems were established in East and West Sussex and in Hertfordshire. A recommendation made in 1973 by the

Table 2.13 Birth data items collected as part in the National Child Health Computing System (NCHCS) and in the Regional Interactive Child Health System (RICHS)

NCHCS	RICHS
Baby	**Baby**
Date of birth	Date of birth
Surname	Surname
Sex	Sex
Ethnicity (optional)	(See mother's ethnicity below)
Length of gestation	Gestation period
Live/Still birth	Live/Still birth
Birthweight	Birthweight
	Length at birth
	Head circumference at birth
	Onset of regular respiration
	Apgar Score
Infant resuscitation after delivery (optional)	Resuscitation (Yes or no and details)
Date of death	Died within 24 hrs
"	Died between 1 and 7 days
"	Died between 8 and 28 days
Hospital admissions after birth	Transferred to hospital within 28 days
	Special care baby unit
Congenital malformation observable at birth	Congenital abnormalities (Yes or no and details)
Mother	**Mother**
Do Date of birth	Date of birth
	PAS number
	NHS number
(See baby's ethnicity above)	Ethnicity
Previous live births	Previous live births
Previous stillbirths	
Previous miscarriages / terminations	Previous miscarriages
Previous pregnancies	Previous pregnancies
Previous neonatal deaths	
Single parent family	One parent family
	Sickle Cell Test
	HEP B Screen
	Thalassaemia Test
	Alphafetoprotein (AFP)
	Amniocentesis
Birth	**Birth**
Gestational age at booking	When booked
Number of babies born	No births this confinement
Ranking for multiple births	Rank within birth
Time of birth	Time of birth
Place of birth	Place of birth
Labour onset method (optional)	Type of labour
Method of delivery	Mode of delivery
Place of birth	Place of delivery
DHA of hospital at birth	(Can derive)
DHA of hospital subsequent to birth	
Intended place of birth (optional)	Intended place of delivery
Reason for change (optional)	Reason for change
Other	**Other**
GP at birth	GP at birth
	Health clinic at birth
	Health visitor at birth
Address at birth	Postcode at birth
Address subsequent to birth	
	Born in RICHS
	Resident in RICHS
	Transfer code?

Department of Health and Social Security led to the commissioning of the National Child Health System from the Welsh Health Technical Services Organisation. Overall responsibility for advice on the content, design and development came from the Child Health Computing Committee, consisting of representatives from all English NHS regions, relevant professional bodies and government departments.[22]

The National Child Health Computing System was designed initially for batch operation on NHS mainframe computers, a strategy adopted to enable universal access by health authorities at that time. The system consisted of a child register and three independent modules for immunisation, pre-school health and school health. Flexibility was built into the system to allow individual authorities to determine their own medical schedules. By 1987 the system was operating in 120 districts and became the model for all subsequent child health systems. These include the Regional Interactive Child Health System (RICHS), which was developed by the former North East Thames Regional Health Authority and implemented in all its districts.

As described earlier, children's records are initiated by birth notification. If a child moves to a different area in the pre-school years, a health visitor enters their details onto the system. Although most systems are not designed primarily for statistical analysis, some analyses are done locally on a routine or ad-hoc basis.

Table 2.14 Child Health Informatics Centre Core/ RCPCH updated essential core dataset, October 2002

A. Demographics i	**E. Health promotion/reviews**
ECD A1 NHS number of child	ECD E1 Neonatal examination
ECD A2 NHS number of biological mother	ECD E2 Four/six week pre-school check
ECD A3 Date of birth	ECD E3 Eight/thirteen month pre-school check
ECD A4 Gender	ECD E4 Two year pre-school review *
ECD A5 Ethnic group	ECD E5 Three/three and a half year pre-school check
B. Demographics ii (updatable)	ECD E6 Primary school entry review *
ECD B1 *Post code*	ECD E7 Secondary school entry review *
ECD B2 *GP practice code)*	ECD E8 Secondary school 16+ review *
ECD B3 Mother's educational status	**F. Health markers**
C Birth details	*ECD F1 Significant conditions* *
ECD C1 Birth order	ECD F2 Disability status at age two years *
ECD C2 Birthweight	ECD F3 Disability status at age five years *
ECD C3 Place of birth	ECD F4 Immunisation status
ECD C4 Gestational age	**G. Social/educational markers**
D. Early life/neonatal screening	*ECD G1 Child Protection Register status*
ECD D1 *Breast feeding*	*ECD G2 Care status*
ECD D2 Admitted to Neonatal Intensive Care	*ECD G3 Code of Educational Practice stage*
ECD D3 Neonatal Screening – PKU	**H. Service use**
ECD D4 Neonatal Screen – Hypothyroidism	*ECD H1 Accidents* *
ECD D5 Neonatal Screening - Sickle cell	*ECD H2 A&E Attendance* *
ECD D6 Neonatal screening – Hearing	*ECD H3 Hospital admission*
ECD D7 Neonatal screening – Cystic fibrosis	*ECD H4 Hospital outpatient attendance* *
	I. Death
	ECD I1 Date of death
	ECD I2 Cause of death

* Still under development in October 2002
Items in *italics* require regular updating.

Systems vary considerably in their structure and functionality. The software systems are provided and maintained by private sector companies but the data are managed within the NHS. The data recorded in the systems can also vary. This can cause problems if the systems record different data items. The populations covered by individual systems reflect past rather than current health service

boundaries. This can lead to complex arrangements for primary care trusts whose populations may be covered by two or more systems, and for child health systems where the child health services that provide the prospective information about children may be based in two or more primary care trusts.

Table 2.15 Child Health Informatics Centre Core Data Set: significant conditions with some indicative ICD10 codes

A. Learning Disorders
1. General (F71-F79)
Mental retardation: MLD, SLD, or untestable, so profound
2. Specific (F81) Reading, Mathematics, and /or writing disorder
3. Developmental/cognitive problem (R62.0) This diagnostic term can be used to describe pre school children with significant delay in milestones on formal testing.

B. Neurodevelopmental problems
1. Neuromuscular conditions e.g. muscular dystrophy (G71.0), spina bifida (Q05)
2. Cerebral palsy, even in mild form (to help epidemiological studies) (G80)
3. Hearing (H90.3-5; Q16)
 a) Loss greater than 40dB in better ear for more than 9 months.
 b) Loss in one ear greater than 60dB. If glue ear is found or suspected as the cause the child should be put on the register until the hearing improves.
4. Visual impairment (H54) with corrected vision worse than 6/18 in better eye.
5. Autism (F84)
 Childhood autism
 Pervasive developmental disorder/Autistic spectrum disorder NOS
 Asperger's syndrome
6. ADHD / ADD (F90)
7. Speech and language difficulties (F80)
 Communication disorder
 Expressive language disorder
 Mixed receptive-expressive language disorder
 Communication disorder NOS
8. Motor skills disorder
 Developmental co-ordination disorder (F82)

C. Congenital, inherited disorders
1. Chromosomal disorders e.g. Down (Q90), Turner's (Q96)
2. Metabolic or endocrine disorders requiring treatment
 e.g. Hypothyroidism(E03), phenylketonuria (E70), growth hormone deficiency (E23), congenital adrenal hyperplasia (E25).
3. Congenital heart disease (Q24-Q28) with symptoms or restrictions on lifestyle.
4. Chronic respiratory disorder e.g. cystic fibrosis (E84), BPD (P27)
5. Major skeletal abnormalities, (Q65-Q79) e.g. achrondroplasia or osteogenesis imperfecta
6. Haemoglobinopathies, e.g. sickle cell disease (D57), (not trait only).
7. Coagulation disorders (D66-D68) requiring regular or at least six monthly treatment.

D. Acquired conditions
1. Diabetes (E10)
2. Asthma (J45) if the condition is unusual or severe enough to require daily preventive therapy with service review/nurse support in school.
3. Immune deficiencies, including AIDS and ARC (B20-B24), (but not HIV positive only).
4. Epilepsy (G40) on anticonvulsant therapy.
5. Chronic liver (K73) or renal (N18) failure
6. Inflammatory bowel disease (K50-K52) or other bowel disease causing significant school absence or requiring specialist community children's nurse support.
7. Severe skin conditions causing restrictions e.g. epidermiolysis bullosa (Q81, L12)
8. Chronic arthritis (M08) / connective tissue disease (M30-M36) / chronic osteomyelitis (M86)
9. Acquired musculo-skeletal problem e.g. post RTA (T90-T91) or amputation (Z89).
10. Malignant disease (C00-C97) / children on cytotoxic therapy.
11. Diagnosed chronic fatigue syndrome/ME (G93.3).
12. Special nursing needs (Z97-Z99), e.g. tracheostomy, or requiring nursing assistance with toileting (Z51).
13. Severe disfiguring conditions, e.g. large visible birth mark or burn scars (L90.5, Q82.5, D22).

E. Behavioural problems e.g.:
1. Non-organic sleep disorder (F51)
2. Conduct disorder (F91)
2. Conduct disorder (F91)
4. Emotional disorder (FF93)
5. Disorder of social functioning (F94)
Grade severity as global rating of overall functioning [see 'The classification of child and adolescent mental diagnosis in primary care' DSM -PC Ed. Wolraich M, 1996 American Academy of Pediatrics]

 1. (Mild unlikely to cause serious developmental difficulties or impairments of functioning – Do not include / register)
 2. Moderate: May cause, or is causing some serious developmental difficulties or impairment. Further evaluation and intervention planning are warranted.
 3. Severe: Is causing serious difficulties with dysfunction in one or more key areas of the child's life. Mental health referral and comprehensive treatment planning are often indicated, possible on an urgent basis.

F. Psychiatric
1. Diagnosed eating disorders (F50), Anorexia, Bulimia
2. Psychiatric disorders receiving psychiatric treatment e.g.
 Severe behaviour problem (e.g. those above)
 Anxiety disorder (F41)
 Major depressive disorder (F31-F39)
 Obsessive Compulsive Disorder (F42)

G. Other, miscellaneous
1. By discussion (NOS) local agreement
2. Anaphylaxis (T78)

The Child Health Informatics Centre, formerly the Child Health Informatics Consortium, has been working with the Royal College of Paediatrics and Child Health and others to produce common datasets. Its updated recommended core dataset was published in 2002 and is shown in Table 2.14.

Its dataset for significant conditions in sick children, shown in Table 2.15, has been accepted as a part of the Children's National Service Framework.

2.15 Registers of children with special educational needs

Local education authorities hold registers of children with statements of special educational needs, which can arise from impairments such as visual and hearing impairments or cerebral palsy. The Department for Education and Skills publishes statistics about pupils with special educational needs annually by local authority and type of school attended

2.16 Child protection registers

Held by social services. Copies of the register are made available to the health service. Each PCT should have a named person with responsibility for child protection. Responsibility for national statistics about numbers of children on child protection registers has passed from the Department for Education and Skills.

2.17 Primary care systems

Most children are registered with a general practitioner. Minimal demographic details of all patients registered with a general practitioner are held in the NHS Central Register. This includes the name, address, date of birth, sex and NHS number. Individual practices hold more detailed records on paper and usually now on a computer.

Quality Management and Analysis System (QMAS)

The Quality Management and Analysis System, known as QMAS, is a new single, national IT system, set up with the aim of giving GP practices and primary care trusts objective evidence and feedback on the quality of care delivered to patients. The system compares each practice with national achievement targets detailed in the GMS (General Medical Services) contract, which sets out the way GPs work and the way they are financially rewarded. As GP practices are rewarded financially according to the quality of care they provide, the payment rules that underpin the GMS Contract are being implemented consistently across all systems and all practices in England. QMAS ensures that this is achieved. QMAS allows GP practices to analyse the data they collect about the number of services and the quality of care they deliver, such as maternity services or chronic disease management clinics. The purpose of this is to provide an incentive for GPs to treat patients in the community rather than referring them to hospital for treatment such as diagnosis or minor operations.

The Prescribing Support Unit is part of the Health and Social Care Information Centre. It has established a new service to make information from the primary care Quality and Outcomes Framework (QOF) available to a wider user base. Its new information service is based on the 146 indicators in the Quality, Prevalence and Indicator Database (QPID), which is derived from QOF data held in the national QMAS database, developed by the National Programme for IT, now part of NHS Connecting for Health. . The only data about children relate to whether maternity services and

child health surveillance services are offered. Providing each of these will win a practice six points to contribute towards a possible maximum of 1050 points. Information can be found down to PCT and practice level on the Health and Social Care Information Centre web site http://www.icservices.nhs.uk/qofdocuments/data.htm.

The General Practice Research Database (formerly VAMP)

The General Practice Research Database (GPRD) is a computerised database of anonymised longitudinal medical records from almost 400 primary care practices throughout the UK. It is the largest and most comprehensive source of data of its kind and is used worldwide for research by the pharmaceutical industry, clinical research organisations, regulators, government departments and academic institutions. In 2005, data were being collected on over 3 million active patients. It is maintained by the Medicines and Healthcare products Regulatory Agency. Its GPRD Division provides data and services to support medical and public health research in a variety of areas including clinical research planning, drug utilisation, studies of treatment patterns, clinical epidemiology, drug safety, health outcomes, pharmacoeconomics, and health service planning. Its greatest strength is is pharmaceutical research. It is expensive to access and data from it are not published routinely. Because it is anonymised, data from resarch studies are not usually published for local areas.

2.18 Summary

Table 2.16 Summary of availability of data about child health from routine systems and registers

Data system	Level of disaggregation at which data are routinely available
Birth notification	None published routinely. Birth data published in conjunction with ONS' birth registration data.
Registration of live births	Tabulations for local authorities and totals for wards available for general use. Summaries for PCTs and individual records available for use within the NHS.
NHS numbers for babies	Data are not analysed. They are held for six months, then deleted.
Stillbirths	Data available at PCT level for use within the NHS only.
Registration of deaths	Tabulations for local authorities and totals for wards available for general use. Summaries for PCTs and individual records available for use within the NHS.
Confidential enquiry into maternal and child health	Stillbirths and neonatal deaths for maternity units published in anonymised diagrammatic form.
Hospital Episode Statistics	Data about births and maternity care published by NHS trust
British Association of Perinatal Medicine	No data published currently but a new system is being developed.
National Neonatal Audit	Data collection has not yet begun.
National Congenital Anomaly System	Data published for strategic health authorities
Local congenital anomaly registers	Cover Hampshire and the Isle of Wight, Oxfordshire, Berkshire and Buckinghamshire in the South East Region plus Dorset and the Channel Isles
4Child register of cerebral palsy, visual and hearing impairments	Covers Oxfordshire, Buckinghamshire and Berkshire in the South East region plus Northhamptonshire
Nationally commissioned surveys	Regional tabulations
Child health mapping	Data about services for trusts and PCTs. Still under development
Child health computer systems	No data routinely published.
Children with special educational needs	Tabulations by local education authority.
Children on child protection registers	Tabulations by social services authority.
Quality Management and Analysis System (QMAS)	Data produced for general practices but not about child health.

This review shows that there is wide variation in the extent to which aggregated data from routine systems are available locally in the South East Region. In general, the data available below regional level are limited. This is summarised in Table 2.16 below.

3.   Survey of Child Health Information in the South East Region

Aims

The project aimed to document the information relating to children and their health held in the geographical area covered by the South East Public Health Observatory. In order to do this a comprehensive survey was undertaken to identify the people responsible for health services for children and young people so that a questionnaire could be sent to ask about the information they held. At the time the survey was undertaken in 2004, the administrative unit for the management of primary care and community services was the primary care trust (PCT). Governance and guardianship of NHS community based data was arranged at this level.

Methods

It was planned that the project would take place in two stages:

1. Identification of the people who were the leads for children's services in each PCT.
2. A survey of the people responsible for children's services in each PCT, to ascertain what information was held. As it was found to be impossible to identify all the people concerned, a survey of child health systems managers was undertaken instead.

3.1 Identification of children's leads in primary care trusts

At the time of the survey, the NHS Information Authority (NHSIA) was responsible for the NHS Organisation Codes Service which holds information about addresses of NHS and other health care organisations for the NHS and the Department of Health. A copy of the November 2003 edition of the NHS Organisation Codes was searched for details of each of the 49 PCTs within the four strategic health authorities which make up the South East Government Office Region. We called each PCT and asked to be put through to the person responsible for children's services, or their PA or secretary.

An email contact was requested in order to send the first questionnaire, shown in Appendix 2. This questionnaire requested the names and contact details of the staff taking a lead for the various child and adolescent health services, and other agencies.

Many PCTs appeared to have difficulty in responding, and some commented that it was not easy to obtain all the information requested.   The responses are summarised in Table 3.1. Thirty-six of the 49 PCTs responded. In most cases an email address and telephone number was provided in addition to the name, title and address of each person named.   The gaps in Table 3.1, particularly those for PCTs in Kent, reflect different levels of contacting the respondents. There were several instances where the organisation of services for children spanned more than one PCT. In Kent, four PCTs shared the responsibility for services, with each taking a lead for a different area.   Wycombe responded on its own behalf and on behalf of Chiltern and South Bucks PCT. Slough PCT reported that Windsor, Ascot and Maidenhead PCT managed services for children in Slough as well as in its own area.

Table 3.1 Summary of responses from each PCT

Key: N - Name   E - E-mail

SHA and PCT area	Overall responsibility (N E)	Primary care services for children	Vaccination and immunisation	Health visiting	School health	Special needs	Mental health services for children	Child protection	Sexual health and advice	Public health as it relates to children	Child health system manager	Primary care computing	Information management	Named contact in social services	Named contact in education authority	Sure start	Other organisations in the area
Thames Valley																	
Milton Keynes	ö ö	√√	√√	√√	√√	√√	√√	√√	√√			√√	√√	√√	√√	√√ √√	√
Newbury and Community	ö ö	√√	√√	√√	√√	√√	√√	√√	√√	√√		√√			√√	√√ √√	
Reading	ö ö	√√	√√	√√	√√	√√	√√	√√	√√	√√			√√	√√	√		
Wokingham	ö	√	√	√	√	√	√	√	√	√		√√			√		
Vale of Aylesbury	ö ö	√√	√√	√√	√√	√	√√	√	√√			√√	√	√		√	√
North East Oxfordshire	ö ö	√√	√√	√	√√	√√	√√		√√			√√	√	√			
Cherwell Vale											√√						
Oxford City		√√	√√														
South East Oxfordshire	ö ö	√√	√√	√√	√√	√√	√√	√√	√√			√√	√√	√√	√√		
South West Oxfordshire				√√			√√		√√		√√						
Bracknell Forest				√√			√√		√√		√√	√√					
Windsor, Ascot and Maidenhead																	
Slough	ö		√		√	√	√	√			√	√			√		
Chiltern and South Bucks	ö	√	√	√	√	√	√	√	√	√		√	√	√	√	√	√
Wycombe	ö	√	√	√	√	√	√	√	√	√		√	√	√	√	√	√
Hampshire and Isle of Wight																	
Isle of Wight	ö ö	√√	√√	√√	√√	√√	√√	√√	√√	√√		√√	√√	√√	√√	√√ √√	
Mid-Hampshire	ö ö	√√	√√	√√	√√			√√	√√		√√	√√	√√	√√	√√	√√ √√	√√
Eastleigh and Test Valley South	ö ö	√√					√√				√√					√√ √√	√√
New Forest	ö ö	√√	√√		√	√√	√√					√	√√	√√			
Southampton City	ö ö	√√	√√	√√	√√	√√	√√	√√	√√	√√		√√	√√	√√	√√	√√ √√	
East Hampshire	ö ö	√√	√√		√√	√√	√√	√√	√√	√√		√√	√√	√√	√√		
Portsmouth City Teaching	ö ö	√√	√√	√√	√√	√√	√√	√√	√√	√√		√√	√√	√√			
Fareham and Gosport	ö ö	√√	√√		√√	√√	√√	√√	√√	√√		√√	√√	√√	√√	√√ √√	
North Hampshire	ö ö	√√	√√	√	√√	√√	√	√√	√			√√		√	√√	√ √	
Blackwater Valley and Hart																	
Kent																	
Dartford, Gravesham and Swanley																	
South West Kent																	
Maidstone Weald																	
Medway																	
Swale																	
Ashford	ö	√	√	√	√		√		√	√	√	√	√		√		
Canterbury and Coastal	ö	√	√	√	√		√		√	√	√	√	√		√		
East Kent Coastal	ö	√	√	√	√		√		√	√	√	√	√		√		
Shepway	ö	√	√	√	√		√		√	√	√	√	√		√		
Surrey and Sussex																	
Guildford and Waverley	ö ö	√√	√√	√√	√√	√	√	√	√√	√√		√		√√	√√	√ √	√
Surrey Heath and Woking	ö ö	√√	√√	√√	√√	√	√√	√√	√√	√√		√	√√	√√	√√	√ √	
North Surrey	ö ö	√√	√√	√√	√√	√√	√√	√	√√	√√		√	√√	√√		√ √	√
Bexhill and Rother	ö ö	√√	√√	√√	√√	√√	√√	√√	√√	√√		√√	√√	√√	√√	√√ √√	
Hastings and St Leonards		√√			√√							√√					
East Elmbridge and Mid Surrey	ö	√√	√√	√√	√		√		√√	√√		√√	√√	√√			
East Surrey																	
Crawley	ö ö	√√	√√	√√	√√	√√	√√	√√	√√	√√		√√	√√	√√		√√	
Horsham and Chanctonbury	ö ö	√√	√		√			√√	√√			√√	√		√		
Adur, Arun and Worthing																	
Mid-Sussex		√	√		√	√	√			√		√√	√√		√		
Western Sussex																	
Brighton and Hove City	ö ö	√√	√√	√√	√√	√√	√√	√√	√√	√√		√√	√√	√√	√√		
Eastbourne Downs	ö ö	√√	√√	√	√√	√√	√√	√√	√√	√√		√	√√	√√	√√	√√	
Sussex Downs and Weald	ö ö	√√	√√	√√	√√	√√	√√	√√	√√	√√		√√	√√	√√	√√		

1 - Primary care services for children
2 - Health visiting
3 - Vaccination and immunisation
4 - School health
5 - Special needs
6 - Sexual health and advice
7 - Child protection
8 - Mental health services for children

10 - Public health as it relates to children
11 - Overall responsibility for children and children's services
12 - Manager of child health system that covers children in the area
13 - Person with overall responsibility for primary care computing
14 - Person responsible for information management in the PCT area
15 - Named contact in local social services department
16 - Named contact in local education authority
17 - Other statutory/voluntary organisations in the area

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Table 3.2 shows the percentage of responding PCTs which could identify a person responsible for various aspects of services for children. Only 82 per cent identified a the person with overall responsibility for the core services relating to children and adolescents. This may reflect differences in management structures. It is possible that there is a less hierarchical structure for the management of children's services in some areas.

In many PCTs one person was responsible for several areas of child health services. Eighty seven per cent of PCTs were able to identify leads for primary care services for children and 85 per cent were able to do so for health visiting. It is disappointing that only 74 per cent could identify a lead for child protection. Less than half of the PCT respondents were able to provide named contacts in social services, education or other organisations working locally with children. Only two thirds of responding PCTs were able to name the manager of the child health system or the people responsible for information management. Cross-boundary provision of some services, the fact that PCTs were relatively new at the time and the reorganisation of staff responsibilities may have contributed to this situation.

Table 3.2 Respondents' ability to identify people with responsibility for aspects of services for children.

Area of responsibility	Percentage of all replies
Overall responsibility for children and children's services	82
Core health services for children and adolescents	
Primary care services for children	87
Health visiting	85
Vaccination and immunisation	74
School health	82
Special needs	64
Child protection	74
Mental health services for children and adolescents	77
Sexual health and advice for adolescents	87
Information services	
Manager of child health system that covers the area	67
Overall responsibility for primary care computing	62
Responsible for information management in the PCT area	62
Public health as it relates to children	85
Other agencies with responsibilities for children	
10- Sure start	79
15 - Named contact in local social services department	46
16 - Named contact in the local education authority	36
17 - Other statutory/voluntary organisations	15

It became apparent that responses to the first stage were very slow, difficult to interpret and would not readily form a basis for the second part of the project. The objectives were therefore revised. It was decided to focus on information in child health systems, which are a key source of information about children and to direct questionnaires to managers of these systems.

3.2 Survey of child health system managers in the South East Region

Child health systems, the ways in which they are used and the information they contain are known to vary widely. In order to document the use of systems in the South East Region an email questionnaire, shown in Appendix 3, was emailed to named managers of the child health systems. If the manager had not been identified in the questionnaire to PCTs described above, a contact name was obtained from the Child Heath Informatics Consortium (CHIC). In most instances contact was made with the system manager before sending the questionnaire as email addresses were not usually included with the information returned from the PCTs and had not been collected by CHIC.

The questionnaire was sent in the form of a Word table. In order to standardise replies a series of options was presented for most questions, with instructions to delete those which were not relevant. Each of the responses was copied into a column in an Excel spreadsheet, and weighted according to the number of PCT areas covered by the system. Data were transferred to SAS to generate a series of weighted frequencies.

Responses

A response was obtained from all of the 24 child health system managers. There was some delay and confusion as our questionnaire coincided with an apparently similar questionnaire from the Department of Health and also data collection by ONS for the National Evaluation of Sure Start. Despite this, the managers were in general exceptionally helpful and willing to co-operate. The majority returned the questionnaire by email. Two were returned by post. Three gave responses verbally over the telephone and a copy of the completed questionnaire was sent for confirmation.

If systems covered areas in more than one PCT, managers were given the option of providing separate answers for each PCT area separately. Only the manager of the system based in Southampton City took up this option. This system covers three PCT areas so 26 sets of responses were received from 24 system managers covering 49 PCTs in the South East Region, as shown in Table 3.3

Geographical coverage

An important feature of child health systems is that they provide population-based information about children in defined geographical areas. It is important that child health systems do not duplicate coverage and that all areas are covered. The PCT areas covered by each system are shown in Figure 3.1.

Child health systems predate the current configuration of NHS administrative boundaries, which have changed several times since most of the child health systems were established. As described above, child health systems are complex and needed for various national and local programmes. A range of software is used, making it difficult to merge and divide systems when NHS boundaries change. It is therefore not surprising that child health systems tend to have retained their original boundaries. Over half the systems serviced more than one PCT. For the most part when a system covered more than one PCT all the PCTs concerned were in the same Strategic Health Authority. The one exception was the system based in Blackwater Valley and Hart PCT in the Hampshire and

Isle of Wight SHA area. It also covered three PCTs in the Surrey and Sussex Strategic Health Authority area.

The system based in Western Sussex PCT maintains child health information for that and three other PCTs and also collects information for hearing and vision screening programmes for children in a further two PCT areas. This is indicated in Figure 3.1 by paler shading.

A third of the child health systems in use covered a single PCT and a third covered three or more PCTs, as Table 3.3 shows. Six systems covered parts of PCT areas. It was beyond the scope of this project to determine the exact proportions, but as no PCT was covered by more than two systems, it was assumed that the each covered half the PCT. Using this assumption each system response was assigned a weight related to the number of PCT areas covered, as shown in Table 3.3. The aim of this weighting was to relate the system managers' responses to the 49 units, which correspond to the 49 PCTs in the South East Region.

Table 3.3 Numbers of PCTs covered by child health systems in the South East Region

Number of PCTs covered by system	Systems		System responses	Weighted responses
	Number	**Percentage**	**Number**	
0.5			1	0.5 **
1.0	8	33.3	10	10.0 **
1.5	4	16.7	4	6.0
2.0	4	16.7	4	8.0
2.5 **	2	8.3	1	2.5 **
3.0	3	12.5	3	9.0
4.0	2	8.3	2	8.0
5.0	1	4.2	1	5.0
Total	**24**	**100.0**	**26**	**49.0**

** One system manager provided individual responses for each of the three (two whole and one part) PCT areas covered.

Software used

At the time of the survey, ten different types of software were being used for child health systems in the South East Region. Two systems predominated, SWIFT and the National Child Health System, both provided by McKesson HBOC Inc. Between them they covered the equivalent of 35 or 71 per cent of the 49 PCT areas.

All the PCTs in the Kent Strategic Health Authority used the same system but were in the process of migrating from the National Child Health System to Care Plus, which was to be situated on a single platform. Use of the new system will enable community and primary care services to access information about a child anywhere in Kent. Previously such a facility existed for look only purposes, but with Care Plus records can be updated wherever the child is seen. The decision about the range and use of the System will be made within each PCT. Where changes were indicated an increase the range of child health information was planned once the move to the Care Plus system had taken place.

Figure 3.1 Child health systems in the South East Region, showing the populations covered.

Primary care trust	Child health system	§ PCT in which the system is based

Milton Keynes — § McKesson HBO, SWIFT
Newbury and Community
Reading
Wokingham — § Torrex, PEAK
Vale of Aylesbury — § McKesson HBO, SWIFT
North East Oxfordshire
Cherwell Vale
Oxford City — § McKesson HBO, SWIFT
South East Oxfordshire
South West Oxfordshire
Bracknell Forest
Windsor, Ascot and Maidenhead — § McKesson HBO, SW Systems
Slough
Chiltern and South Bucks
Wycombe — § McKesson HBO, Smart Term

Isle of Wight — § McKesson HBO, SWIFT
Mid-Hampshire — § McKesson HBO, SWIFT
Eastleigh and Test Valley South
New Forest
Southampton City — § McKesson HBO, SWIFT
East Hampshire
Portsmouth City Teaching — § McKesson HBO, SWIFT
Fareham and Gosport
North Hampshire — § Health Soloution Wales, CH2000
Blackwater Valley and Hart — § Torrex Continuum

Guildford and Waverley
Surrey Heath and Woking — § CSE,Interhealth
North Surrey
Bexhill and Rother
Hastings and St Leonards — § McKesson HBO, NCHS
East Elmbridge and Mid Surrey — Interhealth, CSE Servelec §
East Surrey — § In4tek, Comwise
Crawley
Horsham and Chanctonbury
Adur, Arun and Worthing
Mid-Sussex
Western Sussex — Health solutions Wales, CH2000 §
Brighton and Hove City — McKesson HBO, NCHS §
Eastbourne Downs — Health Soloutions Wales §
Sussex Downs and Weald

Dartford, Gravesham and Swanley — McKesson HBO, NCHS changing to Careplus §
South West Kent — McKesson HBO, NCHS changing to Careplus §
Maidstone Weald — McKesson HBO, NCHS changing to Careplus §
Medway — McKesson HBO, NCHS changing to Careplus §
Swale
Ashford
Canterbury and Coastal
East Kent Coastal — McKesson HBO, NCHS changing to Careplus §
Shepway

The paler grey shading denotes that some information is collected about children in this area, but the system does not hold demographic information for these children.

Uses of child health systems

System managers were asked about the use of their child heath system for various activities related to the community child health services. All used the systems to hold information to identify children and their demographic characteristics, along with birth notification details and information about vaccination and immunisation. Although not asked specifically, many of the system managers commented that the system was also being used for neonatal screening for PKU and hypothyroidism and, in some areas, for vision and hearing screening programmes. One system, based in North Hampshire PCT, was piloting the inclusion of information about attendances at

accident and emergency departments. Pre-school developmental screening information was held in 44 of the 49 PCT areas, and school health information was held in 41.5 PCTs, as Table 3.4 shows. Fewer providers of services to children with special needs and child protection teams used child health systems. Children seen by these services may just be flagged or limited information may be held about their conditions. Only one system held information for Child and Adolescent Mental Health teams but this was limited to flagging children who were being seen by the service in the three PCTs covered by this system.

Table 3.4 Uses of child health systems

Area of child health services	Whether information is recorded in systems											
	Yes	No	Partial	Other	Missing	Total	Yes	No	Partial	Other	Missing	Total
	Weighted number of responses						*Percentage of weighted responses*					
Identification and demographic	49.0	-	-	-	-	49.0	100	-	-	-	-	100
Birth notification	49.0	-	-	-	-	49.0	100	-	-	-	-	100
Pre-school development	44.0	5.0	-	-	-	49.0	90	10	-	-	-	100
Vaccination and immunisation	49.0	-	-	-	-	49.0	100	-	-	-	-	100
School health	41.5	2.5	5.0	-	-	49.0	85	5	10	-	-	100
Special needs	20.0	20.5	7.5	1.0	-	49.0	41	42	15	2	-	100
Child protection	13.5	32.0	-	3.5	-	49.0	28	65	-	7	-	100
Child and adolescent mental health	-	43.5	-	3.0	2.5	49.0	-	89	-	6	5	100

Data held in the systems

System managers were asked to append a list of the data items in their systems on the assumption that this should be a straightforward matter. It was not appreciated at the outset of the survey how difficult it would be to obtain this information. It appeared, however, that the original documentation for the systems had not been retained, or that the companies providing the support for the child health systems had not made this information available to system managers.

One system manager suggested that, as it is a requirement to provide for any individual who makes a proper request all the information that is held about them, it would be possible to derive a list of data items by running a series of such requests and then removing the actual data. Another suggested copying the input screens and making a list of the data items and coding options. As this would have involved a substantial amount of work for individual system managers, it was not pursued.

The Child Health Informatics Consortium provided a list of child health system manager contacts who liaise with software providers. The system managers liaising with the SWIFT system and National Child Health System were contacted but were unable to help. Direct approaches to McKesson were met with polite but unhelpful responses. It is extremely surprising that such information is not publicly available and that it should be treated as a commercial secret. The company expressed the view that a great deal of effort had gone into developing the software, including the data definitions, so making the list public could help competitors. This raises important questions about who was actually driving the collection of information and whether it was the software providers who decided on the data items and definitions rather than their customers who used the systems..

In the future, the information currently held in child health systems will be held by the National Care Records Service, along with all other NHS data. For this reason, it was assumed that someone would have details of the data items being held and their formats. An approach was therefore made to Martin Machray, who was responsible for the Information Strategy for the Children's and

Maternity NSF.[23] He, in turn, recommended approaching a colleague in the NHS Information Authority, whose suggestion was to contact the Child Health Informatics Consortium.

This is because the Consortium had compiled a minimum dataset and therefore contacted the software suppliers to ascertain whether their systems would support the recommended items. Contact was made with the person who worked on this project and had managed, with considerable difficulty, to obtain information about most of the systems.[24] The full report of the project was never published. Unfortunately, the information about data items was not retained.

Who accesses the systems?

It would appear that few people are able to access child health systems directly. Health visitors accessed the systems directly in only 8 of the 49 PCTs and in 23 PCTs health visitors never accessed the system. School nurses had slightly greater access. In 17.5 PCTs, they had direct access but in a further 19.5, they had no access. Child health doctors had similar patterns of access, while GPs were less likely\to have access. In most PCTs, child and adolescent mental health services staff did not access child health systems. Some system managers commented that rather than accessing the systems directly, clinicians would obtain information by telephoning child health system staff.

Table 3.5 Extent to which staff had access to the child health system

Category of staff	Access to child health system										
	Regularly	Occasionally	Never	Not applicable	Missing	Total	Regularly	Occasionally	Never	Not applicable	Total
	Weighted number of responses						*Percentage of weighted replies*				
Health visitors	8.0	14.0	23.0	0.0	4.0	49.0	18	31	51	0	100
School nurses	17.5	12.0	19.5	0.0	0.0	49.0	36	24	40	0	100
Special needs staff	12.0	22.0	15.0	0.0	0.0	49.0	24	45	31	0	100
Child protection staff	3.0	2.5	35.5	0.0	8.0	49.0	7	6	87	0	100
Child health doctors	17.0	2.0	19.5	5.0	5.5	49.0	39	5	45	11	100
General practitioners	12.0	8.0	23.5	0.0	5.5	49.0	28	18	54	0	100
Child and adolescent mental health staff	2.5	3.5	39.0	0.0	4.0	49.0	6	8	87	0	100

Lack of access to a computer or terminal is likely to have been a major factor restricting access to child health systems. The extent of computer networking in the community will also affect accessibility by staff in remote centres. Child health services have been traditionally provided in community clinics, although organisational changes have led some to move to primary care sites. In most cases staff have office space in the clinics where they most often work. In the future, Windows-based systems with enhanced security and audit trails to identify and track users of the systems will provide greater flexibility. Many of the older systems still in use are less sophisticated and require direct wiring or cumbersome dial-up connections.

System managers were asked to assess the extent to which staff had access to computers and their replies are shown in Table 3.6. Many system managers were unable to assess the extent to which community staff involved with children had access to computers or the extent to which available computers could access child health systems, so there were a number of missing replies. Despite the uncertainty in the replies, it appeared doctors and school nurses were more likely than health visitors to have access to computers.

Table 3.6 Estimated percentages of staff who had access to computers

Category of staff	Estimated percentage with access to computers						Estimated percentage with access to computers				
	All	Over 75 per cent	75 per cent and under	None	Not known or no	Total	All	Over 75 per cent	75 per cent and under	None	Total
	Weighted number of responses						*Percentage of weighted replies*				
Health visitors	13.5	1.5	9.0	3.0	22.0	49.0	50	6	33	11	100
School nurses	23.5	4.5	2.0	3.0	16.0	49.0	71	14	6	9	100
Special needs staff	14.5	0.0	5.0	3.0	26.5	49.0	64	0	22	13	100
Child protection staff	17.0	2.0	3.0	3.0	24.0	49.0	68	8	12	12	100
Child health doctors	27.5	1.5	0.0	3.0	17.0	49.0	86	5	0	9	100
General practitioners	23.5	0.0	0.0	4.5	21.0	49.0	84	0	0	16	100
Child and adolescent mental health	11.0	1.0	0.0	4.5	32.5	49.0	67	6	0	27	100

Updating information

Given the poor access to computers, it is not surprising that the most usual way of updating records was by supplying a paper record, as Table 3.7 shows. In a few instances information was supplied by telephone to clerical staff in the child health departments.

Table 3.7 Staff who updated records in child health systems

Subject	Records updated by						Records updated by				
	Clerical staff	Clinical staff	Other staff	Clerical, clinical or other staff	No reply	Total	Clerical staff	Clinical staff	Other staff	Clerical, clinical or other staff	Total known
	Weighted number of responses						*Percentage of weighted replies*				
Demographic details	39.5	-	-	8.0	1.5	49.0	83	-	-	17	100
Records of children who move in	42.5	-	6.5	-	-	49.0	87	-	13	-	100
Vaccination and immunisation	49.0	-	-	-	-	49.0	100	-	-	-	100
School health	41.0	1.0		1.5	5.5	49.0	94	2	-	3	100
Special needs	26.5	-	3.0	-	19.5	49.0	90	-	10	-	100
Child and adolescent mental	-	-	3.0	-	46.0	49.0	-	-	100	-	100

Initiation of child health records at birth

Children's records on child health systems are initiated by a notification of birth from a midwife or other birth attendant to the local Director of Public Health. In recent decades, most notifications have usually come from maternity units. In addition, since October 2002, notifications of birth have been passed to all child health departments by the Central Issuing System of the NHS Numbers for Babies Programme. Most maternity units have continued to send the much fuller information in their birth notification in parallel with this.

In the South East Region, ten child health systems relied exclusively on notifications from the Central Issuing System to initiate children's records. A further four used them in combination with the notification information from the maternity unit, as Table 3.8 shows. In those where only the Central Issuing System was used, the maternity notification was still used in some circumstances, for example for some births outside maternity units and when the Central Issuing System was delayed. Half the systems used the maternity notification to initiate the child health record. A number of managers commented that the Central Issuing System notifications were checked. Two thirds were still entering data manually, including five systems which were using data from the NHS Numbers for babies Central Issuing System.

Table 3.8 Initiation of child health system records

Source of information used	Number of systems	Weighted responses	
		Number	**Percentage**
NHS Numbers for babies Central Issuing System			
Electronic entry	7	13.5	28
Manual entry	3	7.5	15
Birth notification sent directly from maternity unit			
Electronic entry	0	0.0	0
Manual entry	10	21.5	44
Both			
Electronic entry CIS, manual entry of maternity notificati	2	3.5	7
Manual entry CIS, manual entry of maternity notification	2	3.0	6
Total	**24**	**49.0**	**100**

The system based in Windsor, Ascot and Maidenhead PCT officially initiated its child health records with a maternity notification at the time of birth but used the child health system to create temporary records of anticipated birth from maternity records. This is to enable health visitors to improve the scheduling of the new birth visit and make contact with expecting mothers antenatally to discuss infant feeding.

System managers were asked separately if information from birth notification was used to supplement the information received from the Central Issuing System. All the systems which used the notification from the Central Issuing System to set up records added further information derived from the maternity notification.   This underlines the continuing value placed on the more detailed notifications supplied by maternity units. Some managers indicated that birth details were revised when the maternity discharge summary arrived. This includes further information about the baby, in particular details of neonatal assessments after birth, breastfeeding and any subsequent admission to special or intensive care.

Completeness of recording of NHS numbers

The NHS number is the key to the collation of information from records in different parts of the National Health Service and is a crucial component of the National Care Records Service being developed by the National Programme for Information Technology. The most important innovation of NHS Numbers for Babies has been the allocation of NHS numbers at birth and its availability in notifications from maternity units as well as those from the Central Issuing System. For a very small number of births, in particular home births and those occurring when the Central Issuing System is not operating, NHS numbers are missing. In these cases, child health system staff initiate the request for an NHS number for a new baby. This means that child health systems should have an NHS number for all babies born since October 2002.

The recording of NHS numbers is not necessarily as complete for older children, as Table 3.9 shows. System managers were asked to estimate the proportion of records of children aged over two years in April 2004 which had an NHS number. Under the old system of issuing NHS numbers, these children should have had their NHS number added once the birth had been registered, up to six weeks after birth.

Only two systems, covering four PCTs, considered that the recording of NHS numbers was complete for older children. One system manager explained that the missing NHS numbers were ascertained annually via batch tracing through the National Strategic Tracing Service. Most expected that over 70 per cent of records for children over two years of age would include NHS numbers. The consequences of having missing NHS numbers when the NHS moves to the National Care Record Service is that it will be difficult to link in any information from these child health records. As there are over two million children in the South East Region, having NHS numbers missing from even 10 per cent of their records would lead to a considerable loss of information.

Table 3.9 Completeness of recording of children's NHS numbers

Estimated percentage of records with a valid NHS number	Children aged over two years		Children moving in after birth	
	Weighted number of systems	Weighted percentage	Weighted number of systems	Weighted percentage
All	4.0	8.2	6.0	12.2
Over 90 per cent	20.0	40.8	4.5	9.2
Between 70 and 90 per cent	21.5	43.9	20.5	41.8
Between 50 and 70 per cent	0.0	0.0	4.5	9.2
Under 50 per cent	0.0	0.0	4.0	8.2
Don't know	2.5	5.1	9.5	19.4
Missing	1.0	2.0	0.0	0.0
Total	**49.0**	**100.0**	**49.0**	**100.0**

Even if recording of NHS numbers is complete at birth this can be eroded as children move from one area to another. Their NHS numbers should be transferred to their new PCT with their records. Child health system managers were asked to estimate the proportion of records for children moving into their areas that included the child's NHS number. Eight systems covering 20.5 PCTs estimated that the percentage of records for with complete NHS numbers for children who had moved in was only between 70 per cent and 90 per cent.

The system manager for Milton Keynes included the actual percentages in her response, as she was interested to extract the information for her own purposes. Having estimated that 70-90 per cent of children aged over two and children moving in would have a valid NHS number, she found that the actual percentages were 89 per cent and 72 per cent respectively.

Maintaining alias information

Where NHS numbers are missing it is important to have other means of identifying an individual. For example, the ability to track children, particularly those who are vulnerable, is recognised as an important function of services involved with child protection. In the absence of a single unique and universally used identifier for each child, it is necessary to use their name, address and date of birth as a means of identification...

Although changes of address are usually recorded, less attention is paid to changes of name, even though these are not uncommon. Babies may not be named in the first weeks of life. To comply with the requirements of their patient administration systems, hospitals may assign 'Baby' or 'Twin1' and 'Twin2' and the same family name as the mother. Most babies will have a name by the

time of birth registration. Names can be changed again later, especially if parents marry or separate and children take on the mother's name, or the name of the mother's new husband if she remarries. Only one child health system did not retain children's previous names in their records. This allows verification if there is a need to use identifiers other than the NHS number to link information from previous time periods.

Identification of people with parental responsibility

Examinations and vaccinations of children cannot be given without parents' consent. If parents are married it is usual for both of them to have parental responsibility for their children. If parents are not married, the mother usually has sole parental responsibility. Divorce, remarriage, legal challenges from the father, fostering and adoption can change this. It is possible for separated parents to continue to have joint parental responsibility. It is notable that only seven systems, covering 30 per cent of PCTs keep information about this, as Table 3.10 shows.

The two systems indicating that it is possible, but not actually being recorded at the present time have been included with the 'No' responses in the weighted analysis. One System manager did not elaborate, but the other suggested that this could be achieved by using a text field to record the information. Another system manager suggested that, as a proxy, the mother's name could be extracted from the birth notification.

Table 3.10 Number of child health systems and the estimated number and percentage of PCT areas where people with parental responsibility can be identified.

Whether person with parental responsibility can be identified	Number of systems	Weighted responses	
		Number	**Percentage**
Yes	7	15.0	30.6
No	14	32.5	66.3
Possibly	2	0.0	0.0
Missing	1	1.5	3.1
Total	**24**	**49.0**	**100.0**

Identification of children in care

Children in care may be in residential homes or placed with foster families. The reasons for removal from parents are complex and varied. As a group they are often referred to as 'looked after children'. The responsibility for these children often rests with Social Services. Children in care are a particularly vulnerable group and many have special health needs. Adopted children may also have special health needs. System managers were asked whether these children were identified. Fourteen child health systems, covering 50 per cent of the PCT areas had or were instituting a flag for 'looked after children'. Four systems, covering 17 per cent of the PCTs also identified adopted children as well.

Table 3.11 Identification of children who are looked after or adopted.

Identification of children in care	Number of systems	Weighted responses	
		Number	**Percentage**
Flag for looked after and adopted children	4	8.5	17.3
Flag for looked after children	9	14.5	29.6
Looked after' flag being implemented	1	1.5	3.1
No flagging	9	21.5	43.9
Missing	1	3.0	6.1
Total	**24**	**49.0**	**100.0**

Housing

System managers were asked if information about type of housing was collected and all replied that it was not. The Southampton City system manager reported that information had been generated for reports of the health status of children in tower blocks by using postcodes to identify the relevant children.

Children's ethnicity

Ethnic differences are associated with major inequalities in health so health agencies are required to have systems to monitor ethnic groups in terms of their health needs, and the provision and uptake of services. Ethnicity is a self-defined characteristic. It is not easy to measure and responses often depend on the choice of categories offered. The Census classification designed for the 2001 Census should now be used in the NHS. Although ethnicity should be self-defined, in the case of children, especially babies and pre-school age children, ethnicity is defined by the adults caring for them.

System managers were asked whether children's ethnicity was recorded. As ethnicity is a mandatory field on the NN4B birth notification, it was assumed that it would be recorded for all children, at least in the area in which they were born. In fact, it was recorded in only sixteen of the twenty-four systems, as Table 3.12 shows.

System managers were also asked how the information was collected. All 16 of those collecting it reported doing so at birth, with 11 specifying that the information was obtained from the birth notification. One system manager indicated that ethnicity of the baby was obtained at the health visitor's first visit. Four system managers indicated that ethnicity was recorded at birth but did not specify whether this was recorded by the maternity unit or by the health visitor when visiting the new baby. Thus if the parents come from different ethnic groups, the ethnicity recorded may be that of the mother rather than of the baby.

In all but one system, the information about the ethnicity of the child was obtained from the birth notification. It is not clear what is actually being recorded in the ethnicity of the child at birth field in the NN4B birth notification. Maternity units record the ethnicity of the mother at the time of antenatal booking. Given that the birth notification is usually sent within hours of the birth, it is

likely that in many instances the ethnicity reported is actually that of the mother, and not that of the child.

Table 3.12 Recording of information about children's ethnicity

Whether ethnicity was recorded	Number of systems	Weighted responses	
		Number	**Percentage**
Yes	16	33	67.3
No	7	8	16.3
Missing	1	8	16.3
All	**24**	**49**	**100.0**

In the one system where ethnicity of the child was collected from another source, this was described as the child's ethnicity recorded at the first health visitor contact. It was not stated how the ethnicity of the child was established but the process is more likely to reflect racial rather than lifestyle factors.

Of the seven system managers who reported that the ethnicity of the child was not recorded, one noted that provision was made for recording it, but the relevant field was not completed. A manager from Kent said that it would be a mandatory field after the move to the Care Plus system.

Breastfeeding

In addition to the five-yearly national surveys, more frequent local data collection is needed to assess the effectiveness of programmes to promote breastfeeding. Information about initiation of infant feeding is often included in the birth notification. It is usually included in the discharge information from maternity units. The method of feeding is also recorded in the details sent to the laboratories with the blood spot sample taken to test for Phenylketonuria (PKU).

Table 3.13 Recording of information about breastfeeding

Whether breastfeeding information was recorded	Number of systems	Weighted responses		Complete weighted responses	
		Number	**Percentage**	**Number**	**Percentage**
Recorded					
Birth notification only		6.0	12.2	6.0	18.5
Birth/PKU results and preschool visits		9.5	19.4	9.5	29.2
Preschool visits		13.0	26.5	13.0	40.0
Not specified		4.0	8.2	4.0	12.3
All	**16**	**32.5**	**66.3**	**32.5**	**100.0**
Not recorded	6	11.5	23.5		
Missing	2	5.0	10.2		
All	**24**	**49.0**	**100.0**		

Sixteen child health systems, covering two thirds of the PCTs, recorded some information about breastfeeding but six systems covering 11.5 of the 49 PCTs in the South East recorded none. For two systems, responses to this question were missing. Of the systems which included breastfeeding information, only two, covering six of the 49 PCTs, included only information from the birth notification. The other 14 systems collected information for longer periods. The length of these varied, mainly in relation to local decisions about scheduling of visits.

Weight and height measurements

Measures of height and weight are fundamental to the calculation of the body mass index, which is used to assess obesity, a major national cause for concern. System managers were asked whether height and weight were recorded in the child health systems. If so, they were asked about the stage at which this was collected, notably whether this information formed part of the pre-school or school health assessments.

In 16 systems, representing 65 per cent of the PCTs overall and 76 per cent of PCTs with non-missing responses, anthropometric measures were included in the information recorded at both the pre-school and the school health assessments. In a further two systems, measures of weight and height were included in records of school health assessments only. In total, weight and height were recorded for children in over 80 per cent of the PCT areas. One manager of a system which had facilities for recording heights and weights questioned the completeness of the data. Both managers of systems in which weight and height are not currently recorded said that the possibility of adding these items in the future was being discussed.

Table 3.14 Recording of height and weight

Recording of height and weight	Number of systems	Weighted responses		
		Number	**Percentage**	**Percentage of stated**
Preschool and school weight and height	16	32.0	65.3	76.2
Preschool weight only	1	4.0	8.2	9.5
School weight and height	2	3.5	7.1	8.3
Neither	2	2.5	5.1	6.0
All stated	**21**	**42.0**	**85.7**	**100.0**
Missing	3	7.0	14.3	
All	**24**	**49.0**	**100.0**	

Conclusions

Child health systems were some of the earliest computer systems to be introduced in the health service. Considerable investments made in the 1980s revolutionised the infrastructure for organising population-based services for child health but most systems were not subsequently updated. As a result, they are now amongst the most antiquated systems still in operation. For the most part they still rely on manual data entry and in many instances they are not directly accessible by clinical staff.

Child health data present a special challenge in the implementation the new National Care Record Service. Child health is not scheduled for inclusion until the later phases of the project. The new care records will start as soon as the system is operational, with relevant past information being added as historical detail. This strategy limits the need for the expensive and difficult process of migrating individual patient records from one system to another. This process is not appropriate to child health, where the records form the basis of ongoing population based immunisation and screening programmes. These rely on knowledge about which children have and have not been seen and the timing of this.

The systems used in the South East Region vary considerably in the information they contain. The inability of almost all of the system managers to provide details of the data items held is a sad reflection of their lack of control of the systems they manage. There is no need for secrecy about the way in which data are collected in individual systems. The failure to obtain this information from the companies which provide the systems is a worrying reminder of the dangers of commercialisation of health information.

It also creates additional problems when dealing with the ever-changing boundaries of the health services. In many areas, the difficulties involved in integrating information from different child health systems have resulted in a complicated set of cross-boundary arrangements.

A high level of completeness of recording of children's NHS numbers is necessary to ensure that information can be transferred easily between systems. It is also essential for assessment of the extent of duplication of child records within and between systems. In nearly half of the South East Region, NHS numbers were missing in over 10 per cent of records of children born before the allocation of the NHS number at birth. NHS numbers were missing in nearly half the records for younger children moving within the South East Region and who should have had a NHS number. If this erosion has continued, there will be major problems in the future when child health information is integrated with other records in the National Care Record Service devised by NPfIT.

Child health systems contain a common core of information, most important of which is a whole population record of children resident in the areas they cover. All systems maintain immunisation records. Ninety-five per cent of systems are used to record some information about health of school children. This underlines the importance of these systems as a means of maintaining a record of the shifting demographics of children.

There has been universal inclusion of information from the original birth notification, although some systems are now using the NHS numbers for babies' notification to initiate a child health record. Although, in many areas, good information is supplied at birth, this does not appear to be supplemented or updated. All systems contained a common core of data, maintaining a register of children currently living in the area and adding information about new births and immunisation. Most kept information about early childhood developmental screening and school health. Many included results of newborn screening. Information about children with special needs and children on child protection registers were less commonly recorded and information about children's mental health was rarely recorded. The extent of recording of key data items, such as ethnicity, breastfeeding and childhood obesity varied between systems both in the type of information collected and the timing for recording it. Information can be aggregated for some areas but coherent information could not be generated for the whole region.

Child health records contain a wealth of information but this would be much more valuable if there was agreement both within the South East Region and more widely about the timing and methods of recording information.

Appendix 1 The brief

Specification
Review and mapping of the sources of information and intelligence relating to children and the child health data that is available from routine data sources this should focus on health, though information about social care systems would be very useful. While much of this work will be generic to the English NHS with particular reference to the 4 Strategic Health Authorities comprising the South East Region.

Description and review of the data sources and content of the data including review of data quality, data collection processes and systems and review of the availability of the data and access processes, possibilities for data sharing between relevant agencies. A critique of the data.

Proposed start date: 1st March 2004

Proposed method
1.   Contact: via email with semi-structured telephone follow-up
Co-ordinator for children's services in each SHA and each PCT
Plus: others identified as relevant

Deliverables
1.1   Directory with contact details of co-ordinators for children's services in the SE
1.2   Survey of child relevant
            1.2.1 Health intelligence sources
            1.2.2 Data source
                Stratified by SHA PCT

Delivery date   30th April 2004

2.   Defining information regarding data sources
For each identified data source ascertain and update/create register of
        Type of system / supplier
        System manager contact details
Contact the managers and system suppliers will be by email and telephone follow-up with structured questionnaire. System suppliers will be asked about the current structure of the database and proposed modifications. System managers of individual databases will be asked a series of questions to elicit information in Appendix 1.

Deliverables:
1.   Directory with contact details of system managers of databases containing data relevant to
        children or children's services in the SE
2.   Report describing the content and scope of each data source

Delivery date: 30th May 2004

3. Mapping child health information
        A synthesis of the reports from individual data sources considering the commonality and consistency of data items, shared data items, opportunities for validation, confidentiality and consent for data use.
Deliverable
Report of data quality and potential for use
Delivery date   30th June 2004

Revision of the project brief and timescales 21st July 2004
Alison Hill, Director of PH, SEPHO
Yvonne Arthurs, Children's Lead, South East GO

It was acknowledged that the original proposal was over-ambitious and could not be met within the time. It was agreed that the project would aim to get a complete set of responses from child health system managers and write up. A telephone conference was set up for the 3rd of August to discuss the results so far.

Appendix 2 First questionnaire to primary care trusts

CITY University London

Perinatal Health and Research
24 Chiswell St,
London EC1Y 4TY

Compiling a *Directory of Sources of Child Health Intelligence*

I am commissioned by the South East Public Health Observatory to review and map sources of information and intelligence relating to children and the child health data that is available from routine data sources with particular reference to the four Strategic Health Authorities: Thames Valley ; Hampshire and Isle of Wight; Kent and Maidstone; and Surrey and Sussex.

I am compiling details of the range and scope of data available for monitoring child health, managing children's services or investigating the health of children. You have been identified as a person within your PCT with a responsibility for child health or as having a special interest in child health.   I realise there may be others. There will be three rounds of enquiries:

➢ Defining personnel with a responsibility for children, children's services and information about children

➢ Questions to persons in each service area about the scope and structure of information about children that is collected locally and retained.

➢ Questions to each person responsible for data management about how the data has been used in the past 2 years.

For the purpose of this work children are defined as persons up to the age of 16 years.

I would be grateful if you could take a few minutes to answer the questions below and return a copy of the document by reply email to l.hilder@city.ac.uk

Dr Lisa Hilder
Clinical Research Fellow

Please complete the information in the boxes below. The final box has some additional questions. If there is any other information which you feel is pertinent please use the last box for free text, e.g. if responsibility is shared across PCTs.

Note: The full information will be made available to the Public Health Observatory. The Observatory intends to e-publish a directory, but this will contain titles and addresses only. The names and email contacts requested here are to enable more directed questions to the relevant persons for this enquiry.

Part 1: Persons within each PCT with a responsibility for children and children's services.

Services areas	Lead person for each service	Comments
Primary Care Services for Children	Name: Job Title: Address: Telephone number: Email address:	
Health Visiting	Name: Job Title: Address: Telephone number: Email address:	
Vaccination and Immunisation	Name: Job Title: Address: Telephone number: Email address:	
School Health	Name: Job Title: Address: Telephone number: Email address:	
Special Needs	Name: Job Title: Address: Telephone number: Email address:	
Sexual Health and Advice	Name: Job Title: Address: Telephone number: Email address:	

Child Protection	Name: Job Title: Address: Telephone number: Email address:	
Mental Health Services for children	Name: Job Title: Address: Telephone number: Email address:	
Sure Start	Name: Job Title: Address: Telephone number: Email address:	
Public Health as it relates to children	Name: Job Title: Address: Telephone number: Email address:	
*		

*if there are other services provided by the PCT or operating within the PCT area that are not included on the list, please include them here

Who is the person with overall responsibility for children and children's services within the PCT?	Name: Job Title: Address: Telephone number: Email address:	

Part 2: Computer systems and IT

IT services	Contact details	Notes
Who manages the Child health system that covers children in the PCT area?	Name: Job Title: Address: Telephone number:	

	Email address:	
Who is the person with overall responsibility for primary care computing?	Name: Job Title: Address: Telephone number: Email address:	
Who is responsible for information management in the PCT?	Name: Job Title: Address: Telephone number: Email address	
*		

*Other relevant persons with a particular remit for IT or responsibility for data relevant to children – please insert further rows into the table if required.

Part 3: Others collecting information about children in your area.

	Contact details	Notes
Is there a named contact in the local Social Services?	Name: Job Title: Address: Telephone number: Email address:	
Is there a named contact in the local Education Authority(s)?	Name: Job Title: Address: Telephone number: Email address:	
Other statutory or voluntary organisations working with children in your area who may be collecting data	Name: Job Title: Address: Telephone number: Email address	
*		

Appendix 3 Questionnaire to system managers

Perinatal Health and Research

City University
London

Compiling a *Directory of Sources of Child Health Intelligence*

To all Child health system Managers
in Thames Valley, Hampshire and Isle of Wight, Surrey and Sussex

We are commissioned by the South East Public Health Observatory to review and map sources of information and intelligence relating to children and the child health data that is available from routine data sources with particular reference to the four Strategic Health Authorities: Thames Valley ; Hampshire and Isle of Wight; Kent and Medway; and Surrey and Sussex. We are compiling details of the range and scope of data available for monitoring child health, managing children's services or investigating the health of children. For the purpose of this work children are defined as persons up to the age of 16 years.

A report of this work will be posted on the Observatory website.

I would be grateful if you could answer the questions below and return a copy of the document by reply email to l.hilder@city.ac.uk

Shamoly Ahmed   Dr Lisa Hilder
Research Fellow   Clinical Research Fellow

What child health system is currently being used?

Who is the system provider?

When is the current contact due for renewal?

Is there a definite plan to change the system being used?
        What is the new system?
        Who is the new provider
        When will the change-over take place?
        Please indicate which components of child health are **currently** being entered into your
system. Are these in use for all the PCTs – if not please copy a table for each PCT

PCT:

	Being used	Comments
Identification and demographic details	Yes / No	
Birth notification – rosemary	Yes / No	
Pre-school development	Yes / No	
Vaccination and Immunisation	Yes / No	
School Health	Yes / No	
Special needs	Yes / No	
Child protection	Yes / No	
Child &Adolescent mental health (CAMH)	Yes / No	
Sure Start		
*	Yes/No	

* if there are any other components not listed, please add a line and enter them here

 In order to compare the scope of the data between systems across the five SHAs and to what extent data items can be mapped for the whole area.

DO YOU HAVE A LIST OF THE DATA ITEMS INCLUDED IN THE SYSTEM TOGETHER WITH THE CATEGORIES OR DEFINITIONS APPLIED.

Which PCT areas are covered by the current child health system?

PCT Areas covered	Comments

- add more lines if needed

Which statements would describe the situation in the PCT(s) covered by your system. Delete those statement which do not apply – in some instances more than one statement may apply.

        – if arrangements differ by PCT please copy a table for each and indicate the PCT at
           the top

PCT:

Who has access to a computer?	Delete as appropriate
What proportion of Health Visitors have access to a computer?	All / over 75 per cent / 25-75 per cent / less than 25 per cent / none/ don't know
What proportion of School Nurses have access to a computer?	All / over 75 per cent / 25-75 per cent / less than 25 per cent / none / don't know
What proportion of Child Health Doctors have access to a computer?	All / over 75 per cent / 25-75 per cent / less than 25 per cent / none / don't know
What proportion of GPs have access to a computer?	All / over 75 per cent / 25-75 per cent / less than 25 per cent / none / don't know
What proportion of Special Needs Staff have access to a computer?	All / over 75 per cent / 25-75 per cent / less than 25 per cent / none / don't know
What proportion of Child & Adolescent Mental Health have access to a computer?	All / over 75 per cent / 25-75 per cent / less than 25 per cent / none / don't know
What proportion of Child Protection staff have access to a computer?	All / over 75 per cent / 25-75 per cent / less than 25 per cent / none / don't know
Who accesses the child health system?	
Health Visitors	Regularly / occasionally/ never
School Nurses	Regularly / occasionally/ never
Special needs staff	Regularly / occasionally/ never
Child Protection staff	Regularly / occasionally/ never
Child Health Doctors	Regularly / occasionally/ never
GPs	Regularly / occasionally/ never
Child & Adolescent Mental Health Staff	Regularly / occasionally/ never
Initiating a child health record	
How is the record initiated by a birth?	Manual entry of CIS notification/ Electronic entry of CIS notification/ Manual entry of maternity notification / Electronic entry of maternity notification
If the record is initiated by CIS notification are additional details from maternity notifications entered?	Record initiated by maternity notification/ Maternity details added / Maternity details not added / Notification not sent from local maternity unit
Completeness of the NHS number	
Approximately what proportion of records for children born before April 2002 (now 2 years or older) have an NHS number?	All / over 90 per cent / 70-90 per cent / 50-70 per cent / less than 50 per cent / don't know
Approximately what proportion of records for children who transfer into the area include the NHS number?	All / over 90 per cent / 70-90 / 50-70 per cent / less than 50 per cent / don't know
Social and demographic details	
Does the system include previous names?	No / one previous name / more than one
Does the system include addresses?	No / one previous address / more than one
Does the system identify the person(s) with parental responsibility?	Yes / No
Does the system flag children who are fostered or adopted?	No flagging / Fostered children flagged / Adopted children flagged?
Is information about ethnicity of the child collected	Not collected/ collected at first HV contact / collected at any contact if missing

(if collected please append local codes)	
Does the system include information about the type of housing?	Yes / No
How details are entered for children who move into the area after birth?	All manual / electronic from NCHS / electronic from other systems
How are deaths ascertained?	Copy of the entry sent by the Registrar of Deaths are checked / Child Health Staff are notified by the hospital or GP / other (specify)
How are patient demographics updated?	by clerk from manual record / by clinical staff directly/ other (specify)
Breastfeeding	
Are breastfeeding details being collected?	No / Yes (specify how this is collected)
Updating records	
How are Vac & Imms data entered or updated?	by clerk from manual record / by clinical staff directly/ other (specify)
How are special needs data entered or updated?	by clerk from manual record / by clinical staff directly/ other (specify) / not applicable
How are school health data entered or updated?	by clerk from manual record / by clinical staff directly/ other (specify) / not applicable
How are CAMHs data entered or updated?	by clerk from manual record / by clinical staff directly/ other (specify) / not applicable
Add lines for other services	

What reports are run regularly from the system? Who are they sent to? How often are these queries run?

Can staff other than the child health computing staff download records from the system? If yes, who?

Have there been any other reports or extractions of data from the system in the past year? Who have they been prepared for.

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