

# Children's & Maternity Services Information Strategy

**Supporting the Children's, Young People  
and Maternity Services National Service  
Framework**

***Part of the agenda for "Every child matters:  
Change for children"***

# Children’s & Maternity Services Information Strategy

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# Introduction and summary

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## What is the Information Strategy and what are its purposes?

1. The Children's & Maternity Services Information Strategy has been written to coincide with the publication of the Children's & Maternity Services **National Service Framework** (NSF) and to support its Standards. It reflects the needs for information that have been expressed through Advisory Groups of interested parties, generally referred to as 'stakeholders', who include representatives of the public, parents and carers, social care, educational and clinical professionals, charitable and voluntary organisations, managers, planners, commissioners and policy makers.
2. The purposes of the Children's & Maternity Services Information Strategy are to ensure that:
  - The building blocks are in place both nationally and locally for sharing data within the NHS and with and between other agencies; for identifying children and young people and having their up-to-date records available wherever they present to the NHS; for making knowledge accessible to improve care; for identifying children with additional needs and ensuring early effective intervention to address these whether by NHS or other children's services agencies; for the development of information for children and young people, their parents and carers and for the general public; for recording, analysing and interpreting data for the direct care of children and young people and for commissioning, managing and planning services; and for ensuring that NHS staff, children, young people, parents and carers know how to use the IT facilities that are available to them
  - The implementation of the Standards in the NSF are facilitated by the availability of the relevant data and the means to record, analyse and interpret that data

## Who should read the Information Strategy and how?

3. The Information Strategy is meant for a wide audience in accordance with the purposes set out above. All 'stakeholders' will find something of interest for them, but in particular:
  - Senior staff in national organisations such as the Department for Education and Skills, the Office for Standards in Education, the Department of Health, the National Programme for Information Technology, the NHS Information Authority, the Commission for Healthcare Audit and Inspection and the Commission for Social Care Inspection whose roles include the implementation of high level actions arising from new policy initiatives

- Senior staff in local NHS organisations providing services for children and young people who can ensure that their staff know how to gain access to, use and interpret the data in their information systems and who can ensure that children, young people, parents and carers receive the information that they need, when they need it
- Commissioners, managers and planners working for Strategic Health Authorities, Local Authorities and Primary Care Trusts as well as local hospitals who wish to improve local service provision
- Professionals, children, young people, their parents and carers and the general public so that they understand what is being developed for their use nationally and locally

## **Plurality and Diversity – NHS Foundation Trusts, Independent Sector NHS Treatment Centres and other new providers**

4. Over time, an increasing amount of NHS services will be delivered by independent organisations such as NHSFTs, which are not performance managed by SHAs. This places particular importance on the role of PCTs as commissioners in securing improvements in performance and timely implementation of the National Service Frameworks. PCTs will thus need to ensure that contracts with NHSFTs and other independent providers reflect the requirements of National Service Frameworks and that progress towards improving standards of care is reviewed on a regular basis. As such this document is made available to those organisations for information only.

## **What should I do now?**

**A [Document Navigation Guide](#) is available [here](#).**

**If you have not already done so, it is recommended that you should now read and print out the brief instructions in the Guide before going any further.**

## **What are the ‘Big Questions’ for this Information Strategy?**

5. The big questions that this Information Strategy addresses are as follows:
  - How does the NHS know the identity of a child or young person it is dealing with and what their needs are wherever they are seen?
  - How do NHS professionals know that the service they offer is the right one for that child or young person and how do they communicate that information to other colleagues in the NHS and in other agencies?

- Are all the agencies aware that a child may be in touch with other agencies and that concerns about a particular child, and information about their needs, are shared and being acted on?
- How does a child, young person, parent or carer know he or she is getting the best possible treatment from the National Health Service?
- How can a person take an active role in managing his or her own health or help their children to do so?
- How can the NHS plan to provide improving services and check to see that it is succeeding?

## **Tables of National and Local Actions**

6. The Information Strategy is based around a series of tables containing National and Local Actions associated with themes that reflect the needs for information expressed by interested parties who have been consulted. The themes are 'Cross Agency Working', 'Information for Direct Care of Children, Young People, Mothers and Mothers-to-Be', 'Information for Secondary Purposes', 'Access to Knowledge' and 'Training and Development'. Each action is linked to 'Supporting Information' that explains the background to and the reasoning behind the action.
7. The National Actions have been agreed with the national organisations named in the actions and the Local Actions are intended as guidance to encourage local NHS organisations to build on the national developments.
8. The National and Local Action tables are described below.
9. If you so wish at this point you can access the tables directly as you read through the rest of this Introduction and Summary by holding down the 'Ctrl' key on your keyboard and clicking with your mouse over the arrow ► to the right of each table's name. You can then navigate back to the Introduction and Summary by using the arrow ► in the top right-hand corner of each table.

## **Recommendation:**

**We recommend in the first instance that you read through the rest of this Introduction and Summary and the Background section which follows before looking at the National and Local Action tables.**

## Table 1: Cross-Agency Working ►

10. This table contains actions for cross-agency working. The actions are designed to ensure that the NHS, Social Care, Education and other agencies are able to share information, particularly about children and young people where they may have additional needs for a variety of reasons, but also about mothers and mothers-to-be.
11. The Department for Education and Skills (DfES) will produce definitive guidance on how strategic planning agencies in children's services should cooperate to make arrangements for information sharing in pursuit of their proposed duties to cooperate to promote children's well-being (subject to the passage of the Children Bill) (National Action 1.1)
12. The DfES will lead work to scope how appropriate computer systems might facilitate sharing of information between agencies (National Action 1.2)
13. The DfES will lead cross-agency work to ensure that all practitioners in children's services have access to training on information sharing (National Action 1.3)
14. Primary Care Trusts and other agencies should consider co-operating in local arrangements to establish joint arrangements and protocols for information sharing where that is necessary to help a child or young person who has additional needs if they are to achieve the Every Child Matters outcomes of being healthy, staying safe, enjoying and achieving, making a positive contribution, and economic well-being (Local Action 1.1)
15. Although no specific action is included in the Information Strategy it is foreseen that the Children, Young People and Families Directorate of the Department for Education and Skills and the Department of Health will use the indicators of the CHILD, PERISTAT and REPROSTAT projects as indicators of outcome measures of the implementation of the Children's & Maternity Services NSF over the next 10 years and to inform the process of identifying appropriate indicators for the Planning and Priority Framework (PPF) for the NHS and for the Comprehensive Performance Assessment (CPA) for Local Authorities. Furthermore it is expected that these indicators will be used by the Healthcare Commission, the Commission for Social Care Inspection (CSCI) and the Office for Standards in Education (Ofsted) when developing the joint inspection framework for children's services and that they may use them when preparing to inspect local services for children. Details of these indicators are included for information, as at present the collection of these indicators by NHS Organisations is on a purely voluntary basis. Further details of these projects are contained in [Appendix 1](#).

## **Table 2: Information for Direct Care of Children, Young People, Mothers and Mothers-to-Be**

16. The Department for Education and Skills (DfES) will produce definitive guidance on how agencies delivering statutory children's services should share information in pursuit of their proposed duties to safeguard children and promote their welfare (subject to the passage of the Children Bill) (National Action 2.1)
17. Local Service Providers (LSP) will be instructed by Cluster Management Boards (the group of local NHS organisations overseeing the implementation of the NHS Care Records Service (NCRS) in their area) to implement any additional requirements to their contract arising from this Information Strategy (National Action 2.2). Local NHS organisations will work individually and collectively with the LSP to ensure that their electronic information systems are in place and delivering the integrated solutions that they need (Local Action 2.1).
18. The National Programme for Information Technology (NPfIT) will ensure that data items used to record and describe the care and management of children and young people and mothers and mothers-to-be will be available for use in updating the central 'Spine Record' (the electronic NHS Care Record that will contain a patient's full clinical history from the time that the record comes into existence). (National Action 2.3)
19. During the period of implementation of National Actions 2.2 and 2.3 the NHS Information Authority will advise the Clinical Records Development Board of the specific needs of children's and maternity services and monitor progress on behalf of the Department of Health (DH). (National Action 2.4)
20. Drawing on the national guidance in National Action 2.1, local NHS organisations are encouraged to examine the issues surrounding the sharing of information and to use the results to ensure that the interests of children and young people, their parents and carers and of mothers and mothers-to-be are recognised and properly safeguarded (Local Action 2.2)

## **Table 3: Information for Secondary Purposes**

21. The National Programme for IT (NPfIT) will ensure that the data held on the central 'Spine Record' (the electronic NHS Care Record that will contain a person's full clinical history from the time that the record comes into existence: see also National Action 2.3) is available for analytical (so-called 'secondary') purposes (National Action 3.1). To this end local NHS organisations are encouraged to work with their Local Service Providers (LSP) to ensure that their systems are upgraded to meet their needs for secondary purposes data (Local Action 3.1) and to understand how to access the data from the NHS Care Record (Local Action 3.2).
22. The Department of Health and the NHS Information Authority will examine the adequacy of Hospital Episode Statistics (HES) and Healthcare Resource Groups

(HRG) for children's and maternity services and make recommendations for any improvements (National Action 3.2), while Local Action 3.3 points to the need for local NHS organisations to have sufficient clinical coders trained in the coding of conditions associated with children and young people.

23. National Action 3.3 draws attention to the National Analytical Service (NAS) being developed by the NHS Information Authority to support national secondary information requirements, e.g. activity and outcome for epidemiology, clinical governance, public health and service planning. Local Action 3.4 encourages local NHS organisations to employ appropriate analytical and epidemiological skills locally where it can be justified or to call upon the services of the NAS where it cannot.
24. The Healthcare Commission will work with the Department for Education and Skills (DfES), the Department of Health (DH) and key stakeholders to develop suitable performance indicators for national and local use (National Action 3.4) as well as national comparative clinical audit plans (National Action 3.5). Local NHS organisations are encouraged to participate in national comparative audit in Local Action 3.5.
25. Local Action 3.6 points local NHS organisations in the direction of the NHS Information Authority which is developing products to assist health professionals in the delivery and monitoring of the NSF standards.

#### **Table 4: Access to Knowledge**

26. The Department of Health's Children's and Maternity NSF website will act as a central link to supporting programmes of work (National Action 4.1).
27. Under National Action 4.2 the National electronic Library for Health (NeLH) will act as the central repository for all information about children's and maternity services issues and their information resource, amongst others, will be used by NHS Direct and NHS Direct Online to develop information suitable for the needs of children, young people, parents and carers, mothers, mothers-to-be and the public.
28. NHS Direct Online will provide a web-based service giving access to recognised sources of high quality information designed primarily for use by children and young people, parents and carers, mothers, mothers-to-be and members of the public (National Action 4.3).
29. With the help of the information produced by the first three National Actions local NHS organisations are encouraged to develop information about the services that are available locally as well as information about the diagnosis, treatment and management of related conditions (Local Action 4.1).
30. Under Local Action 4.2 local NHS organisations delivering children's and maternity services are asked to consider that professional staff and families have ready

access to the knowledge base through implementation of the necessary IT infrastructure.

31. Under National Action 4.4 NHS Direct will undertake the necessary actions to enable it to continue to be a safe source of telephone information and advice for children and young people, parents and carers, mothers and mothers-to-be and for the general public.
32. Under National Action 4.5 the Department of Health will include the needs of children, young people, mothers and mothers-to-be in its review, currently underway, of patients' information needs across all the NSF areas

### **Table 5: Training and Development**

33. The NHS Health Informatics Service of the NHS Information Authority will lead on the development of informatics special interest groups (National Action 5.1). It will also develop a series of educational packages to support career development and help staff in the use of systems used in children's and maternity services (National Actions 5.2 and 5.3).
34. Locally NHS organisations delivering children's and maternity services are encouraged to offer their staff appropriate training and support in developing their skills and knowledge (Local Action 5.1) and help children, young people, parents and carers in their understanding of how to access and use the information that they receive (Local Action 5.2).

**Now please read the 'Background' section of the Information Strategy which gives information about how and where stakeholders present to the service and what their information needs are.**

**It will also lead you on to a Map of Tables which will help you to understand better how the tables and their supporting information are set out and where to find them.**

**Move now to the ['Background'](#) section of the Information Strategy**

# Background

## Making contact with the National Health Service

**Children and young people, mothers and mothers-to-be may make contact with the National Health Service in a number of different possible settings in different places**

- At antenatal clinics
- In a maternity unit or at home at the time of birth
- At a neonatal or paediatric intensive care unit at birth or later in childhood
- At home when a community nurse or GP visits
- At a GP's surgery for routine visits for minor illnesses, advice on healthy living, for screening or for immunisation
- On the telephone to NHS Direct
- At an A&E department
- On a children's ward or at a day hospital as an emergency, as a booked case for medical problems or to undergo a planned or emergency surgical procedure
- At an outpatients clinic as a new case or for routine follow-up
- At a specialist unit, for example a renal dialysis unit or a diabetes clinic
- At a child development centre or child health clinic for children, for example, with special needs
- At school for routine check-ups
- At walk-in centres
- At children's hospices or respite units
- At family planning clinics
- At Child and Adolescent Mental Health Services (CAMHS)
- In various adult settings where children and young people may routinely be seen

**Depending on their age and circumstances, children and young people, mothers and mothers-to-be may make contact with the National Health Service at different times and for different reasons:**

- On a single occasion
- Routinely or sporadically
- With or without their parents or carers
- On their own initiative
- With real or imaginary concerns

- Openly or secretly
- In an emergency or by referral from a GP or specialist
- Via social workers following reported abuse or neglect
- Via the police or prison services when in custody
- After contact with a voluntary or charitable service such as Child Line or the Samaritans

## The Big Questions:

- How does the NHS know the identity of a child or young person it is dealing with and what their needs are wherever they are seen?
- How do NHS professionals know that the service they offer is the right one for that child or young person and how do they communicate that information to other colleagues in the NHS and in other agencies?
- Are all the agencies aware that a child may be in touch with other agencies and that concerns about a particular child, and information about their needs, are shared and being acted on?
- How does a child, young person, parent or carer know he or she is getting the best possible treatment from the National Health Service?
- How can a person take an active role in managing his or her own health or help their children to do so?
- How can the NHS plan to provide improving services and check to see that it is succeeding?

**These are the questions which the National Service Framework and this Information Strategy address**

**The Information Strategy, through its proposals for action, puts in place the fundamental building blocks both nationally and locally for:**

- Sharing data within the NHS and with and between other agencies
- Identifying children and young people and having their up-to-date records readily available wherever they present to the service
- Making knowledge accessible to improve care and patient involvement
- Developing information suitable for children, young people, parents, carers and the general public

- Recording, analysing and interpreting data for the direct care of children and young people and for commissioning, managing and planning services

**So what information have the different interested parties said they need in order to help to bring about answers to the above questions and to help the Information Strategy to succeed in its objectives?**

**We have been told that children, young people, their parents and their carers, mothers and mothers-to-be need:**

- First and foremost, information that:
  - Is relevant to their concerns at the time
  - Is given in a way that they can understand, whether verbally or written
  - Is accurate and up-to-date and, therefore, reliable. For example, about available services
  - They can take away with them for studying later or for future reference
  - Helps them to understand where they can find out more for themselves
  - Explains about who else might be allowed to see information about them and what they can do about it
  - Explains their right to see their own health records and how to go about it
  - Is suitable, in particular, for teenagers and young people
- Then, **on health issues** themselves, they want information:
  - About any specific condition they may have and how they can help themselves
  - About how to live a healthy life (health promotion information)
  - About common conditions and how to deal with them
  - About potentially serious conditions, particularly if they or their child might be at risk of such conditions themselves
  - About specialist services
  - About dangers around the home and simple first aid including basic resuscitation

**We have been told that healthcare professionals need:**

- Accurate information to identify, in particular, a child's or young person's records and to ensure that it is complete
- Access to their patients' electronic health records and all other previous records
- Information to help them to record their findings, formulations and management plans on the electronic health record

- Information to help them communicate with other professionals providing care or services
- Access to relevant information from other agencies, especially if a child or young person is thought to be at risk of harm
- Access to information about any local and national services that parents and carers may need to think about using
- Information to support decision making about treatment and prescribing
- Access to information in appropriate formats for parents

***We have been told that commissioners, managers, planner, epidemiologists and researchers need:***

- Information about local and national populations by, for example, age, gender, Townsend score and ethnic origin (cohort definition)
- Information about the prevalence of key childhood diseases, illnesses and conditions in the local and national populations by, for example, age, sex and ethnic origin (Defined variables on denominator population)
- Information about deaths (both expected and unexpected, and injuries, both accidental and non-accidental)
- Information about the take-up and effectiveness of particular local services for children and young people, for example children's community nursing teams, hospital at home, ambulatory services, A&E
- Information about the effectiveness of particular interventions by locality, for example children's heart surgery or renal dialysis and transplantation
- Information about services to be commissioned including outcomes
- Such information should be suitably aggregated and anonymised except where specific consent has been given by the child, the young person or the responsible adult for use of data that can be identified to them

**The needs for information expressed by all the interested parties have helped to formulate the National and Local Actions that are proposed in this Information Strategy**

**Turn now to the [Map of Tables](#) to see how the tables of National and Local Actions are arranged and how to find them.**

## 1 Cross-Agency Working National Actions

### Guidance on Arrangements for Information Sharing

1.1 The Department for Education and Skills (DfES) will produce definitive guidance on how strategic planning agencies in children's services should cooperate to make arrangements for information sharing in pursuit of their proposed duties to cooperate to promote children's well-being (subject to the passage of the Children Bill) [\(Ctrl/Click here for more details....\)](#)

### Computer Systems to Support Information Sharing

1.2 The DfES will lead work to scope how appropriate computer systems might facilitate sharing of information between agencies. [\(Ctrl/Click here for more details....\)](#)

### Training **C H L N** **S A**

1.3 The DfES will lead cross-agency work to ensure that all practitioners in children's services have access to training on information sharing. [\(Ctrl/Click here for more details....\)](#)

## 1 Cross-Agency Working Local Actions

### Local Cooperation to Establish Joint Arrangements for Information Sharing

1.1 Primary Care Trusts and other agencies should consider, co-operating in local arrangements to establish joint arrangements and protocols for information sharing where that is necessary to help a child or young person who has additional needs if they are to achieve the Every Child Matters outcomes of being healthy, staying safe, enjoying and achieving, making a positive contribution, and economic well-being. [\(Ctrl/Click here for more details\)](#)

## 2 Information for Direct Care of Children, Young People, Mothers and Mothers-to-Be National Actions

### Information Sharing Guidance **P C H L N** ☀

2.1 The Department for Education and Skills (DfES) will produce definitive guidance on how agencies delivering statutory children's services should share information in pursuit of their proposed duties to safeguard children and promote their welfare (subject to the passage of the Children Bill). [\(Ctrl/Click here for more details....\)](#)

### Implementation of the Children's & Maternity Services NSF

#### Core Service **C H L N** ☀

2.2 Under the NHS Care Records Service (NCRS) programme Cluster Management Boards will instruct Local Service Providers (LSP) to implement additional requirements under the Children's & Maternity Services NSF Core Service as a result of recommendations made in these National and Local Actions. [\(Ctrl/Click here for more details....\)](#)

### Support for Children's and Maternity Data Items on the NCRS

#### Spine Record **C H N** ☀

2.3 The National Programme for IT (NPfIT) will identify the data items used to record and describe the care and management of children, young people and mothers/mothers-to-be and coordinate a programme to ensure that they are submitted to, and receive approval for use from, the NHS Information Standards Board (ISB). NPfIT will confirm that, once approval from the ISB has been received, such data items will be available for use in updating the Spine Record. [\(Ctrl/Click here for more details....\)](#)

### NHSIA NSF Implementation Strategy Programme **N**

2.4 The NHS Information Authority (NHSIA) NSF Implementation Strategy Programme has the remit to advise the National Clinical Advisory Board of the specific needs of Children's and Maternity Services (professionals, children and young people, their parents and carers as well as mothers) during the period of implementation of National Actions 1.2 and 1.3 and to monitor progress on behalf of the Department of Health. [\(Ctrl/Click here for more details....\)](#)

## 2 Information for Direct Care of Children, Young People, Mothers and Mothers-to-Be Local Actions

### Use of Electronic Information Systems **C H L** ☀

2.1 Local Service Providers (LSP) will work with NHS organisations delivering children's and maternity services through the NHS Care Records Service (NCRS) programme Cluster Management Boards to ensure that the electronic information systems (EIS) delivered under the Core Service are embedded in the management and care of children, young people and mothers. [\(Ctrl/Click here for more details....\)](#)

### Information Sharing **P C H L** ☀

2.2 NHS organisations delivering children's and maternity services are encouraged to carry out a formal examination of the issues relating to information sharing for all relevant stakeholders and to use the results to ensure that the interests of children, young people, parents, carers, third parties and mothers/mothers-to-be as well as care professionals are recognised and properly safeguarded. [\(Ctrl/Click here for more details....\)](#)

### 3 Information for Secondary Purposes National Actions

#### Access to Approved Data Items for Secondary Analysis **CHLN**

3.1 Approved data items used to record and describe the care and management of children, young people and mothers/mothers-to-be will appear on the Spine Record. The National Programme for IT (NPfIT) through the LSP will ensure that stakeholders for secondary purposes information can gain access to this data, subject to security and confidentiality considerations, either locally or through the services of national organisations established for this purpose such as the National Analytical Service. [\(Ctrl/Click here for more details....\)](#)

#### Hospital Episode Statistics (HES) and Healthcare Resource Groups (HRG) **CHLN**

3.2 The Department of Health, working with the NHS Information Authority and other key stakeholders, will examine the adequacy of coding of data for HES in relation to children's and maternity services and make recommendations for any improvements. This work will link in with work currently underway examining the adequacy of Healthcare Resource Groups in relation to children and young people, make recommendations for any improvements and plan for their introduction as soon as possible. [\(Ctrl/Click here for more details....\)](#)

#### National Analytical Services (NAS) **CHLN**

3.3 The NHS Information Authority is developing a National Analytical Service (NAS) to support national secondary information requirements, e.g. activity and outcome for epidemiology, clinical governance, public health and service planning based on the Secondary Uses Service under development by the NPfIT Spine Project. The children and maternity services community will call upon the services of the NAS as they become available. [\(Ctrl/Click here for more details....\)](#)

#### Performance Indicators **CHLN**

3.4 The Healthcare Commission will work with the Children, Young People and Families Directorate of the Department for Education and Skills, the Department of Health and other key stakeholders to develop suitable performance indicators for national and local use. [\(Ctrl/Click here for more details....\)](#)

#### Information for Audit **CHLN**

3.5 The Healthcare Commission will work with the Children, Young People and Families Directorate of the Department for Education and Skills, the Department of Health and key stakeholders to develop a national comparative clinical audit mechanism for children's and maternity services within a framework of standards for national audit as a matter of priority. [\(Ctrl/Click here for more details....\)](#)

### 3 Information for Secondary Purposes Local Actions

#### Electronic Information Systems **CHL**

3.1 NHS organisations delivering children's and maternity services are advised to collaborate with the LSP to implement the upgrades to their electronic information systems when available. [\(Ctrl/Click here for more details....\)](#)

#### Data Items for Secondary Analysis **CHL**

3.2 NHS organisations delivering children's and maternity services are advised to work with their LSP to understand the procedures for gaining access to data items on Spine Records for secondary analysis purposes. [\(Ctrl/Click here for more details....\)](#)

#### Clinical Coding Capability **CHL**

3.3 NHS organisations delivering children's and maternity services are advised to make every effort to have sufficient clinical coders who are trained in the coding of conditions associated with children and young people so as to take full advantage of the improvements arising from the recommendations that will be made by the Department of Health under National Action 3.2. [\(Ctrl/Click here for more details....\)](#)

#### Analytical Capability **CHL**

3.4 Access to the appropriate analytical and epidemiological skills is essential if data for audit and other purposes are to be handled and interpreted correctly. NHS organisations delivering children's and maternity services are advised to employ such services for data interpretation locally where it can be justified but call upon national services, such as the National Analytical Service, where it cannot. [\(Ctrl/Click here for more details....\)](#)

#### Information for Audit **CHL**

3.5 NHS organisations delivering children's and maternity services are encouraged to participate in national comparative audit of the structure, process and outcome of their work. This could include, for example, families' opinions, suggestions, transport arrangements, as well as audit of activity, outcomes, waiting lists and admissions to wards with feedback used to inform change. [\(Ctrl/Click here for more details....\)](#)

#### Delivery and Monitoring of the NSF Standards **CHLN**

3.6 NHS organisations delivering children's and maternity services could make use of the products being developed by the NHS Information Authority to assist health professionals in the delivery and monitoring of the NSF standards. [\(Ctrl/Click here for more details....\)](#)

## 4 Access to Knowledge National Actions

### National Website of Information Links **P C H L N** **S A**

4.1 The Department of Health Children's and Maternity NSF website will act as a central link to supporting programmes of work including links to the NeLH, NHS Direct Online and professional as well as charitable organisations. ([Ctrl/Click here for more details....](#))

### National electronic Library for Health (NeLH)

#### Central Repository **P C H L N**

4.2 Whilst designed primarily for the use of health professionals, the NeLH will act as the central repository for all information about children's and maternity issues whether for children, young people, parents and carers, mothers, the public or health professionals. This information resource will be used by NHS Direct and NHS Direct Online to develop information suitable for the needs of children, parents, other carers, mothers and the public. ([Ctrl/Click here for more details....](#))

### NHS Direct Online

#### General Information **P**

4.3 Drawing on information from a range of sources including the National electronic Library for Health (NeLH), NHS Direct Online will provide a web-based service giving access to recognised sources of high quality information designed primarily for use by children and young people, parents and carers, mothers and members of the public. ([Ctrl/Click here for more details....](#))

### NHS Direct

#### Provision of Information and Advice for the Public **P**

4.4 Working with all the appropriate stakeholders and sources of medical knowledge NHS Direct will undertake the necessary actions to enable it to continue to be a safe source of telephone information and advice for children and young people, their parents and carers as well as members of the general public. ([Ctrl/Click here for more details....](#))

### National Review of Patient Information Needs **P**

4.5 The Department of Health will include the needs of children, young people, mothers and mothers-to-be in its review of patients' information needs across all the NSF areas. ([Ctrl/Click here for more details....](#))

## 4 Access to Knowledge Local Actions

### Information for Children and Young People, their Parents and Carers, for Mothers/Mothers-to-Be and for the Public **P C L**

4.1 NHS organisations delivering children's and maternity services could, by using the services described in National Actions 3.1 to 3.3 and 3.5, make available a full range of information for children and young people, their parents and carers, for mothers and for the public about the diagnosis, treatment and management of related conditions and about services that are available locally. ([Ctrl/Click here for more details....](#))

### Access to the IT Infrastructure **P C L**

4.2 NHS organisations delivering children's and maternity services need to consider that professional staff and families have ready access to the knowledge base through implementation of the necessary IT infrastructure. ([Ctrl/Click here for more details....](#))

## 5 Training and Development National Actions

### Children's and Maternity Informatics Special Interest Group **P C H L**

5.1 The NHSIA in partnership with the informatics community within children's and maternity services will develop a special interest group through the Informatics Learning Network available from the NHS Health Informatics Service programme of the NHSIA. The first step will be to establish a web site and moderator. [\(Ctrl/Click here for more details....\)](#)

### Educational Packages for Use of Systems **C H L**

5.2 The NHS Health Informatics Service, in partnership with the informatics community within children's and maternity services will develop an educational package for NHS organisations embarking on electronic data collection or who have systems not yet fully utilised, to provide a practical guide on how to embed an electronic clinical information system in the delivery of direct care. [\(Ctrl/Click here for more details....\)](#)

### Educational Packages for Career Development **C H L**

5.3 The NHS Health Informatics Service, in partnership with the informatics community within children's and maternity services will develop an educational package to support NHS organisations delivering children's and maternity services in providing career development and succession planning. [\(Ctrl/Click here for more details....\)](#)

## 5 Training and Development Local Actions

### Training and Support for Staff **C H L**

5.1 NHS organisations delivering children's and maternity services are encouraged to give staff with responsibilities for data and the preparation of information the appropriate training and support in developing their skills and knowledge. [\(Ctrl/Click here for more details....\)](#)

### Support for Children and Carers **P C H L**

5.2 NHS organisations delivering children's and maternity services are encouraged that, wherever access to information is given to children, young people, parents and carers via, for example, a workstation located on their premises, help and support as well as sufficient material are readily available so that they can use the IT system appropriately and understand the information they receive. [\(Ctrl/Click here for more details....\)](#)

# Cross Agency Working

## Supporting Information for 'Guidance on Arrangements for Information Sharing'

**1.1 The Department for Education and Skills (DfES) will produce definitive guidance on how strategic planning agencies in children's services should cooperate to make arrangements for information sharing in pursuit of their proposed duties to cooperate to promote children's well-being (subject to the passage of the Children Bill). (See also [National Action 2.1](#))**

### *Background to the issues of information sharing in children's services*

Specific rules and considerations apply to the sharing of information on the clinical details of a child or young person's condition or treatment. These are set out later in this section under the heading "Background to issues of information sharing in the NHS on health issues". In the relatively small number of cases where there is reason to believe that a child is at risk of harm from abuse or neglect, there are clear procedures of which most NHS staff are aware, reflecting the guidance in the DfES booklet "What to do if you suspect a child is being abused". Information may in these circumstances be shared without seeking consent.

In the much larger number of cases where abuse or neglect is not suspected, but health staff recognise that a child has additional needs beyond medical treatment which should be met in order to develop normally and achieve good outcomes, the position on information sharing has been less clear. Often health staff and their managers have not felt able to share, or enter into arrangements to share, other information about a child which they believe is important to promote the child's welfare or the well-being of children in general. Section 27 of the Children's Act 1989 provides a basis for information sharing by health managers when requested to do so by a local authority in order to promote the reasonable health or development of children. However experience shows that not all Primary Care Trusts have felt able to enter into such arrangements, and generally such requests are treated reactively and only considered individually on a case-by-case basis.

The Government is aiming to shift the emphasis across services to children, including health, so that all practitioners see it as part of their job, if they can see that a child is not thriving, to take some action, which may include sharing information about that child; and so that health managers see it as part of their job to cooperate in local arrangements to enable information sharing where that is required to promote children's well-being.

The Government therefore intends, through the Children Bill currently before Parliament, to place new duties on Trusts to cooperate to promote well-being and to safeguard children and promote their welfare. Subject to the passage of the relevant provisions in the Bill the DfES will in February 2005 publish statutory guidance which will make it clear that appropriate arrangements to share non-clinical information with practitioners in other agencies will be one of the ways in

which Trusts can discharge these duties. In this way doubts about the view of such arrangements for Trusts should be removed. There will also be statutory guidance on how practitioners in Trusts may share such non-clinical information and the legal position on consent. The guidance will make it clear that it is good practice to seek consent for such information sharing, and that the common law duty of confidentiality will still apply.

The Government is also proposing through the Bill powers to enable it to prescribe standards for a national network of databases containing basic identifying details about each child, contact details for practitioners involved with the child, and a facility for these practitioners to indicate whether they have a cause for concern about the child which means that other practitioners should contact them as a priority. Implementation is subject to the will of Parliament and no commitment has yet been made to a timetable. The Bill proposes that specified information may be supplied to such a database notwithstanding the common law duty of confidentiality. The provisions of the Data Protection Act will still apply to such data processing. For more details see National Action 1.2

#### Background to the issues of information sharing in the NHS on health issues

Children today are recognised as having special needs and rights comparable to other groups in society. However, in the NHS services for children have often been fitted into services designed for the treatment of adults, sometimes with an adverse effect on children.

In addition, there have been several adverse events, such as at the Bristol Royal Infirmary and the death of Victoria Climbié with their subsequent inquiries conducted by, respectively, Professor Ian Kennedy and Lord Laming, which have highlighted sub optimal services for children, their special health care needs and their vulnerability. In particular, poor information systems and/or poor information sharing have been identified as contributing factors.

Very young children are not able to understand medical issues and their parents or guardians need to receive information on their behalf and give consent to procedures, treatments and the sharing of information. In order to do this carers and children when it is appropriate, need ready access to information that is easy to understand.

Although most parents would agree to allow information on their own child to be shared with interested parties or used for statistical or research purposes there is a small minority who may refuse to allow information to be shared for a variety of reasons. In particular, parents who may have abused their child are often concerned to limit information sharing in case it reveals additional evidence of injury or abuse. Minority groups who feel threatened or insecure may be more likely to refuse to share information while their children may, as a result, be at increased risk of poor health.

Conversely, occasionally there are situations where parents have misused information about their children to gain benefits or manipulated information to improve access to services or education. While these are the exception, it is important to be aware of how information about children can occasionally be abused for personal gain.

The state of health or mind of the carer is often one of the biggest determinants of a child's welfare. The disclosure or non-disclosure of information about carers to other care professionals could, therefore, make the difference between either protecting the child or exposing him or her to serious risk. Care professionals will need to understand how far they can go in making this type of information available.

The modern NHS is being developed around a range of ambitious electronic information systems, most notably the NHS Care Record. In theory, information sharing will become easier but there will need to be safeguards to ensure that data are safe and confidential and that shared information does not disadvantage children, their carers or third parties. This has particular relevance to children who invariably have carers and parents and who will grow up and wish to access their own records in due course.

Information about third parties or given by third parties needs to be given special consideration. It may be necessary to keep such information separate from the main part of the notes because of the need to protect people who report abuse or to ensure that children are adequately prepared for unexpected information such as paternity issues or adoption.

Why is information necessary?

Information enables professionals to improve the care that they give to children, both directly by way of the treatment and management of disease and illness and indirectly by securing better and more appropriate services for children by monitoring activity and outcomes on a larger scale. The best care can only be provided if all the relevant information is readily available and used appropriately to inform decisions.

What are the consequences if information is not available or shared?

Children at risk

Where information about children who may be at risk is not shared between the appropriate agencies at the right time the professionals in those agencies may not recognise the existence of risk or be unable to take action to help such children or even to identify that they exist.

Child health promotion

If, for any reason, children's details are not registered with the local Primary Care Trust, children may not be offered immunisations at the correct time or recalled if they fail to attend. This puts these children at increased risk of avoidable natural

diseases. This failure is not necessarily related to conscientious objection to immunisation but may be due to unusual life style such as travellers or refugees. Similarly, if personal information is withheld children may miss screening for a range of treatable conditions normally detected at birth or soon after. This puts them at increased risk of brain damage and other serious or catastrophic long term conditions. These conditions are usually recessively inherited and some of these groups are at increased risk because of a culture of cousin marriages or other inbreeding patterns.

#### Development of services for children

Figures collected for analysis of activity and outcome will be incomplete if data are missing. The people who refuse to allow data to be used for secondary purposes are likely to be different to people who consent and thus their omission will result in skewed data. Certain postcodes and minority groups are associated with high levels of educational, social and economic deprivation. This reflects on health status and ability to use the existing services effectively. An opt-in system will therefore doubly disadvantage children from minority and deprived groups.

#### Issues around informed consent

##### Treatment

Parents, carers and guardians are authorised to consent to treatment and or information sharing on behalf of the children in their care. This is usually done willingly. Sometimes parents object to the treatment recommended for cultural reasons (Jehovah's Witnesses and blood transfusion) or because they are not convinced by the medical arguments on risk and benefit (MMR vaccination).

##### Consent by a minor

Children who are deemed to be competent may consent to treatment against their parents' wishes. Lord Fraser in the case of *Gillick v West Norfolk and Wisbech Area Health Authority* (1985) laid down a number of criteria which a professional should consider in order to be satisfied about a child's competence. In the case of a girl under 16 who elects to take oral contraceptives the GP has an obligation not only to care for the child by providing reasonable treatment but also a duty of confidence to keep this information from others, particularly parents who may wish to know whether or not their daughter is taking these precautions.

##### Refusal of treatment

The law is less clear about the right of a competent child to refuse reasonable treatment. In practice it is usually, but not always possible to persuade a competent child to accept the recommended treatment. Small children are often reluctant to have treatment (such as injections or operations) but are overruled. There is a fine judgement about when it is appropriate to force an unwilling child to have treatment they are refusing, when physical force is appropriate and when it could be interpreted as an assault.

#### Information sharing

### Special issues for children

In complying with the Data Protection Act 1998 and the common law duty of confidence the NHS has gradually been moving away from a system where notes were owned by health authorities and trusts and patients were not allowed to view their own notes, to an acceptance that all citizens have rights of access to their own notes and a right to be involved in their own care. This also applies to parents and children but there are special issues related to the competence of the child to understand, the needs of the child for protection from harm by dangerous people, the protection of third party information and occasionally conflicting interests of the various parties.

### Copy to parents

A recent government initiative, copying letters to patients, demands a culture change among health professionals. It has been proposed that by early 2004 all correspondence should be copied to the patient (or in the case of children, the parents or carers). Patients will be able to keep their own files or medical records and encouraged to understand the correspondence and use it to support their care. This is particularly useful for both acute and chronic conditions. Special consideration will be required where there are concerns about child protection.

### Copy to child

Children, once competent, are also entitled to copy correspondence although the precise time of competence has not been defined and will vary from child to child, as will the particular information that is to be shared. Competent children may not necessarily wish to take the responsibility for copied correspondence or wish to be exposed to the burden of knowledge that this implies. There is a difference between understanding, emotional readiness for factual information and the desire to be independent of parents.

### Parental consent

Parents may fear the sharing of information and therefore withhold consent to share information against the best interest of the child either because they may have something to hide with respect to the child (previous child protection issues) or because of real or unfounded fears that their personal information may be used in a way that is not in their own interest (concerns about mental health and insurance) even if it might be in the best interest of the child (professionals need to know if the carer has a mental health problem). Parents may also wish to protect a child with chronic illness from the full lifetime implications and prognosis of their condition.

### Interested parties

On occasions there will be a conflict of interest between the needs of the child and the wishes of the parents in respect of information sharing. This is most acutely represented by the needs of a child who may have been abused. On the other hand, sometimes the conflict is reversed: for example, the parent who uses information about the child's condition to gain increased benefits or better access to education or other services. The information sharing systems in place must recognise these potential conflicts and include measures to address this.

### Needs of the courts

The legal system often requires specific information in the form of reports and access to other records for a variety of reasons including child protection. The court may require that otherwise confidential information is exposed. The paediatrician has a duty of care to the child that is 'paramount'. This may conflict with the interests of third parties or parents who have given information in good faith on a confidential basis.

### Information that may be withheld

There are sources of information that are confidential either because the child or parent/carer/guardian has given information on a strictly confidential basis (for example a family member with HIV/AIDS). This must be recognised, and in the electronic era, such information must be stored separately and more securely (perhaps in a 'sealed envelope') so that it cannot be accessed with the remainder of the notes. However, there may be exceptional circumstances when authorised personnel may be allowed to access this information urgently leaving an audit trail so that abuse of the 'sealed envelope' can be detected by appointed information 'guardians'. Such information disclosure should be subject to tracing and audit.

### Third parties

Apart from the obvious information sharing issues and conflicts described above, special consideration should be given to the needs and protection of third parties when information in clinical notes is made available to the patient. For example, if an allegation of suspected child abuse has been made, the person making the allegation must be protected. Another example is the use of tissue typing for identification of potential live organ donors. A small but significant number of putative fathers are not the genetic fathers of their children. Presumably the mother, but usually not the father or child, is aware of this possibility. It is essential that parents understand the implications of tissue typing and that results are discussed discretely and appropriately in a timely and sensitive way to protect the child and unsuspecting third party. Under the Data Protection Act 1998, where there is a duty of confidence to the third party, the third party must give their consent to any disclosure of data unless there is a robust public interest issue.

### No surprises

There should be no surprises for children, parents or third parties. Health professionals must be aware of the power and sensitivity of stored information and consider the right time and method for sharing it with the owner of the notes if so entitled (e.g. paternity). If there is no entitlement (report of child abuse by a third party) the information should be protected. When contentious or confidential information is gathered it should be put into a safe store so that it can be shared systematically and appropriately when the time is right (e.g. adoption, familial disease).

### Transition to adulthood

As children mature and grow into adults they have adult rights to see and understand their own notes and records. They need to be prepared for this knowledge. For example, if they have a life limiting condition they need to have been informed about it before they read it in their notes. Similarly, other personal

information such as adoption or IVF needs to be revealed in a sensitive and appropriate way. Such situations are covered by the Data Protection Act 1998.

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## Cross Agency Working

### Supporting Information for ‘Computer Systems to Support Information Sharing’

#### 1.2 The DfES will lead work to scope how appropriate computer systems might facilitate sharing of information between agencies.

The “Every Child Matters” Green Paper identified five outcomes which matter most to children and young people – being healthy; staying safe; enjoying and achieving; making a positive contribution; and economic well-being. It highlighted better information sharing as key to successful early intervention to help children who require additional support to achieve those outcomes. It suggested that better information sharing could be enabled by databases containing basic information on all children.

This note sets out the DfES’s intentions in terms of:

- The objectives
- What information would be kept?
- Which children and young people would be covered?
- Which services would have practitioners who will have access to the databases?
- How databases fit with other Every Child Matters proposals
- Next steps towards implementation

These matters will be debated in the House of Commons in the autumn as it scrutinises the relevant clause in the Children Bill. The proposals are subject to Parliamentary approval of the relevant provisions, both in the Bill itself, and subsequently in regulations.

#### **Objectives**

The objectives of information sharing databases would be:

- to help practitioners identify quickly a child they have contact with, and whether that child is getting the universal services (education, primary health care) to which he or she is entitled; and

- to enable earlier identification of needs and earlier and more effective action to address them by providing a tool for practitioners to identify who else is involved with or has a concern about a child

Information sharing databases would also be an important tool to encourage better communication and closer working between different professionals and practitioners.

Information sharing databases are not intended to provide an integrated case management system, replace case record systems already under development in health (NHS Care Records) or social care (Integrated Children's System), or record statements of a child's needs or observations about a child.

### **What information would be kept?**

Databases can be best conceived of as indexes which would contain the following information:

(i) Basic details to identify a child and whether they are receiving universal services. These are name, address, date of birth, gender, a unique identifying number, name and contact details of a person with parental responsibility or care of the child, name and contact details for school or other educational setting, and names and contact details of GP practice and of any health visitor or equivalent

(ii) Name and contact details for other practitioners involved with a child, so professionals can see who to contact if they wish to discuss a child's additional needs with another practitioner

(iii) An indicator of whether a practitioner has a cause for concern about a child, so professionals can see who to contact as a matter of priority to discuss a child's additional needs

The Government will consult in autumn 2004 on how best to approach the recording of practitioner details when the service the practitioner is delivering is a sensitive one, and on how indicators of a cause for concern should operate in practice.

### **Which children and young people would be covered?**

Databases or indexes would support the Every Child Matters policy objective of identifying early, particularly through universal services such as education and health, children with additional needs which should be addressed if they are to achieve the Every Child Matters outcomes, and then addressing those needs early. This group of children has previously been described as "vulnerable children" and it is estimated that at any one time 3-4 million children have such needs.

Each area should have the basic data recorded for each child up to their 18<sup>th</sup> birthday. This is because:

(i) It is not possible to predict in advance which children will have needs for additional services

(ii) Any child or young person could require the support of those services at any time in their childhood

(iii) All children have the right to the universal services (education, primary health care) that the basic data will show whether or not they are receiving, and will then as necessary trigger local action to ensure they do receive them

To help ensure that the transition from youth to adult services is managed smoothly, it may also be desirable to make provision to retain information on the databases for young adults with multiple needs, for example care leavers and young people with disabilities, for a period after their 18th birthday, with their consent.

Which services would have practitioners who will have access to the databases? Access would be granted according to the professional role of the practitioner. All practitioners with access will have to have had relevant training and to have undergone appropriate checks. It is envisaged that the following statutory services will have practitioners who will have access to the child index: education, early years and childcare services, Connexions, health, social care, Youth Offending Teams, police, probation, prisons, Young Offender Institutions and secure training centres. Local authority housing services and non-statutory voluntary services might also have practitioners with access, where appropriate. In many of these services, access will be through one or more central users. For example in a secondary school, staff with distinct pastoral responsibilities, such as Heads of Year, would have access rather than every teacher.

How databases fit with other Every Child Matters proposals

Databases or indexes would be taken forward as a distinct but related part of a wider series of proposals to improve information sharing and assessment so as to identify earlier children with additional needs and to meet their needs sooner and more effectively. These other proposals include:

(i) New duties on public bodies to cooperate to promote children's well-being, and on a range of bodies delivering services to children to safeguard them and promote their welfare. These duties are set out in Clauses 7 and 8 of the Children Bill. Statutory guidance, due to be published in draft in October and in its final version in February, will make it clear that effective arrangements and procedures to share information about children and young people with additional needs is part of how bodies will discharge their new duties. It will offer guidance on the circumstances in which information should be shared, on when and how consent should be sought, and on when information may be shared without consent. This guidance will be backed up by OFSTED inspection and the CPA

(ii) A Common Assessment Framework to improve the quality of diagnosis of a child's needs before referrals are made; to improve the transferability between professionals of basic assessments of a child's needs; and to reduce the number and intensity of separate assessments that a child with additional needs has to undergo

(iii) A vision for how universal, targeted and specialist services should work together through multi-agency working to identify children with additional needs and address those needs, including the role of a lead professional for such children

(iv) Training on information sharing to be available across the children's services workforce through a common core of training, embedded in initial training, continuous professional updating, and local change programmes across children's services

(v) The development of children's services directories which enable practitioners, and parents, young people and children, to see what services are available locally, their eligibility criteria, and which facilitate referrals including self-referrals

### **Next steps towards implementation**

On the basis of independent technical advice the Government has concluded that a database or index programme is technically and operationally feasible, incorporating robust levels of security, using proven existing technology. The current stage of the programme includes work to:

- model business processes, particularly for the option of 150 local indexes based on top-tier local authority boundaries with a national monitoring facility to oversee the network
- identify the source for a unique identifying number
- produce a recommended option for procuring the necessary technology
- produce a business case covering costs and benefits
- develop an implementation plan

Decisions on whether and over what timescale to proceed to implement such a network will be made in late 2004. Any decision to proceed will be dependent on the passage of the relevant provisions in the Children Bill and therefore subject to the will of Parliament. It will also be dependent on the availability of resources for set up and maintenance of such a network, in the light of more detailed work on costs and benefits.

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# Cross Agency Working

## Supporting Information for 'Training'

**1.3 The DfES will lead cross-agency work to ensure that all practitioners in children's services have access to training on information sharing.**

The development, subject to the will of Parliament, of statutory guidance on information sharing under the proposed duties for Trusts and other agencies under the Children Bill should be supported by appropriate training programmes for staff. This will need to include initial training for health and other practitioners; legislative change training and continuous professional updating for more experienced professionals, and management and leadership programmes for people with responsibility for leading and managing change locally.

The DfES will develop a strategy for information sharing training which it will integrate with the plans of health agencies for training their staff, education and training establishments for training the future health workforce, the DfES's own plans for a common core of training for workers across in children's services integrated with occupational standards, and wider programmes of local change training for children's services incorporating training for multi-agency working, the introduction of a Common Assessment Framework, and the role of a lead professional for children with multiple needs. While much of this training will need to be agency or profession-specific for practical reasons, the DfES will seek to maximise the commonality of approaches and the opportunities for local joint training across services and professional disciplines in order to help break down barriers.

The DfES will, subject to the passage of the relevant provisions in the Children Bill and a decision by Ministers to proceed, ensure that any roll-out of a national network of information sharing databases is accompanied by appropriate training for practitioners on their use including the legislative framework and on good practice.

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# Information for Direct Care of Children, Young People, Mothers and Mothers-to-Be

## Supporting Information for 'Information Sharing Guidance'

**2.1 The Department for Education and Skills (DfES) will produce definitive guidance on how agencies delivering statutory children's services should share information in pursuit of their proposed duties to safeguard children and promote their welfare (subject to the passage of the Children Bill).**

Refer to the Supporting Information for [National Action 1.1 'Information Sharing Guidance'](#).

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## Information for Direct Care of Children, Young People, Mothers and Mothers-to-Be

### **Supporting Information for 'Implementation of the Children's & Maternity Services NSF Core Service'**

**2.2 Under the NHS Care Records Service (NCRS) programme Cluster Management Boards will instruct Local Service Providers (LSP) to implement additional requirements under the Children's & Maternity Services NSF Core Service as a result of recommendations made in these National and Local Actions.**

Children and young people may come into contact with the NHS via a number of different channels at different times. The current system of paper or disparate local electronic records means that each of these contacts may result in a separate record being kept for them. This makes it impossible for anyone involved in their care to have a comprehensive and sensible overview.

The introduction of the NHS Care Records Service (NCRS), initiated by the National Programme for Information Technology (NPfIT), will provide patients, including children and young people, in England with a single set of electronic medical and care notes. It will hold a summary of contacts with all care providers and become the master source of an individual's medical history.

The NCRS will also mean that the key records relating to the health of a child or young person will be accessible to any healthcare professional that needs access. The patient records will also follow a consistent format, ensuring that the care pathways taken can be clearly understood by all care professionals.

The NCRS will help the NHS to move towards providing patient-centred care, by ensuring that information about a patient, including children and young people, follows the patient so it is available wherever and whenever it is needed.

The NCRS will improve the quality and convenience of care available to children and young people, by ensuring that the right information is available to the right people at the right time.

The NCRS implements its programme across the country in regions known as 'clusters'. Each cluster is overseen by a 'Cluster Management Board' whose role,

amongst other things, is to ensure that the implementation runs to time and to budget and to ensure that all required resources are made available.

Cluster Management Boards instruct local suppliers of the service, known as Local Service Providers (LSP), to implement services that have been specified in the Output Based Specification Contract (OBSC). Sections 160 to 168 were developed to enable LSP and National Application Service Providers (NASP) to understand the requirements for the published National Service Framework Information Strategies and to quote for and carry out the work of developing the necessary systems. The OBS included the requirements for the published Information Strategies as well as outline information for those under development. In the case of Children's & Maternity Services (Section 166) these requirements will be upgraded and introduced to the LSP as contract changes under a change control procedure.

As children, young people and mothers do not represent one single condition that can be treated, the functional specification for information systems can best concentrate on identifying the data items and functions that will be most applicable to the healthcare and treatment of children, young people and mothers and which would not be available in an otherwise generic system.

Generic requirements of information systems that are particularly relevant to children's and maternity services include:

- The ability for professionals to share information in an accurate and timely way when children, young people and mothers are seen in primary, secondary or tertiary care settings or when they transfer from one setting to another, for example when young people with chronic illness transfer from a children's unit to an adult unit or when a child changes GP
- The need to ensure that data is recorded once only in order to minimise the frustration often experienced by, especially, parents of repeating details of, for example, family history to different care professionals at different times
- Functionality to enable children, young people, their parents and carers as well as mothers to access their records through the NHS Direct Online web site with the proviso that there should be appropriate protection for third party information such as reported abuse, paternity issues etc
- Provision of a facility for children, young people and their parents to view their records and participate in the management of their own condition where this is appropriate
- The ability to share information about children and young people safely and in a confidential way with their parents and carers and, when appropriate, with third parties and with adequate preparation and support for the all concerned. For further information visit the data protection website at <http://www.dataprotection.gov.uk/>
- Generation of the data required for secondary purposes

The Child Health Informatics Consortium (CHIC) has developed a service specification for Primary Care Trusts and Child Health Teams to use when procuring child health systems. However, it has been estimated that there are anything up to seventeen different child health systems in use, mainly in primary care, with as many suppliers. These systems were originally developed to support immunisation and screening and play a valuable role in the day-to-day management of these matters. However, such systems often do not integrate with the main GP systems or even with screening laboratories.

On the other hand, the management of information about children and young people in secondary care is generally a function of the main hospital information system which may not recognise specific children's issues.

There are three main systems in use to support maternity services. These are Serconia, Euroking and Protos. These systems have varying degrees of connectivity with other NHS systems and in many cases are stand-alone.

With the advent of the NPfIT it is time for the LSP to review these systems and to further develop them to meet the needs of the latest requirements for the care and management of all children, young people and mothers/mothers-to-be throughout the NHS regardless of setting.

For this purpose the specific requirements to support the direct care and management of children and young people, mothers and mothers-to-be should, therefore, include, but not be limited to, the following:

- Ability to support serial online biochemical and other tests, X-rays and biopsies with electronic links to laboratories. This should include alerts for abnormal results after adjusting for age
- Ability to track physiological measurements such as head circumference, height and weight and to express them as centiles with alerts for significant changes
- Ability to carry out data transformation such as BMI (Body Mass Index)
- Functionality to track, call and recall children and young people for immunisation and screening as one-off exercises
- Functionality to support the National Screening Programme, already set out in LSP contracts, but with reference particularly to its mission to create an antenatal and newborn screening programme which integrates all of the individual tests and programmes with a common information system holding the child's health record and taking into account the Numbers for Babies programme with the need to link the child's record longitudinally with that of its mother. It is envisaged that screening results would be included on the national Spine Record. The National Screening Programme will require individual LSP to cooperate with each other to develop national solutions to the functionality needs of the various programmes

- Ability to provide decision support systems based on national guidelines or protocols, e.g. NICE, particularly with regard to medicines and prescribing
- Information to monitor the standards of the relevant professional bodies
- Information to monitor the standards outlined in the Children's & Maternity National Service Framework and other NSFs such as Diabetes, CHD, Renal Services and Long Term Conditions
- Functionality to support prescribing for children and young people
- Functionality to access data from the Spine Record for secondary analysis purposes
- Functionality to access the Spine Record for mothers/mothers-to-be wherever they present
- Functionality to link the mother's and the child's records
- Ability to generate data suitable for inclusion in the Personal Child Health Record
- Ability to generate a contemporaneous woman-held antenatal record

Furthermore, in the light of the Green Paper 'Every Child Matters', the Children's Bill and the forthcoming Children's Act, the NCRS will need to introduce the following additional functionality into the Core Service:

- Functionality that will require users of clinical information systems to identify children and young people by a universally agreed identifier, once this has been established
- Functionality to ensure that certain information contained within the NHS Care Records of children and young people can be shared with other agencies, with particular emphasis on child protection issues
- Functionality to enable care professionals to access and use the common assessment framework for children and young people so that, once updated, it can be accessed and viewed by all care professionals subject to security and confidentiality criteria written into the software

In essence, therefore, the Core Service requirement for Children's & Maternity Services will be amended to reflect the following steps for implementation by each LSP:

- Working with existing suppliers, to maintain, upgrade and integrate, as required, electronic information systems (EIS) hardware and software, or appropriate modules of such systems, in use in primary, secondary and tertiary care for the diagnosis, treatment and management of children and young people and of mothers, drawing on the experience in the current child health systems and maternity systems in use around the country
- To deploy such systems where they are required but where they are not present

- To develop functionality within these EIS which mandates the use of a unique identifier for each child or young person
- To develop functionality within these EIS to enable the sharing of appropriate data with other agencies
- To develop functionality within these EIS to enable healthcare professionals to access and use the common assessment framework for children and young people so that, once updated, it can be accessed and viewed by care professionals from other agencies, subject to security and confidentiality criteria written into the software
- To deploy a set of messages based on the agreed data items to populate the national Spine Record (see National Action 1.3)
- To develop functionality to enable access to data items from the Spine Record for secondary analysis purposes

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## Information for Direct Care of Children, Young People, Mothers and Mothers-to-Be

### Supporting Information for ‘Support for Children’s and Maternity Data Items on the NCRS Spine Record’

**2.3 The National Programme for IT (NPfIT) will identify the data items used to record and describe the care and management of children, young people and mothers/mothers-to-be and coordinate a programme to ensure that they are submitted to, and receive approval for use from, the NHS Information Standards Board (ISB). NPfIT will confirm that, once approval from the ISB has been received, such data items will be available for use in updating the Spine Record.**

At the centre of the NHS Care Record Service is the ‘Spine Record’ which will bring together data and information for each child or young person in a single record. The Spine Record is to be designed and implemented at national level by the selected National Application Service Provider (NASP) and the work is to be overseen by the Spine Project of the National Programme for Information Technology (NPfIT).

In order for the Spine Record to be maintained for specific data relating to children, young people and mothers/mothers-to-be every data item used for this purpose will need to have been approved for use by the NHS Information Standards Board (ISB). The project within the National Programme for Information Technology (NPfIT), known as the Spine Project, has agreed that the Spine Record will be capable of being updated by these data items once they have been approved by

the ISB and provision has been made for their use in local electronic clinical information systems.

The data items, therefore, will need to be identified and submitted for approval, where they are not already approved. Possible sources of such data items are, for example, the CHILd project (see National Action 2.4), the Child Health Informatics Consortium's (CHIC) 'Essential Core Dataset', the CAMHS dataset developed by the CAMHS Academic Unit in Bedfordshire, the Birth Notification Data Set, and the Maternity Data Dictionary and Maternity Dataset developed by the NHS Information Authority. Consideration will need to be given to the requirements of the various national screening programmes whose needs are not currently completely satisfied by the above datasets. In particular, for example, the CHIC dataset is not correct in relation to the bloodspot programme.

It may be of interest to note that one study found that "information on the health of local children is considered by service planners and providers to be incomplete, inaccessible and of little utility". (Report dated March 2004 of *the Child Health Information Project* funded by Tyne & Wear Health Action Zone). To ensure, therefore, that complete coverage of data items is achieved there will need to be considerable consultation with stakeholders.

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## Information for Direct Care of Children, Young People, Mothers and Mothers-to-Be

### Supporting Information for 'NHSIA NSF Implementation Strategy Programme'

**2.4 The NHS Information Authority (NHSIA) NSF Implementation Strategy Programme has the remit to advise the National Clinical Advisory Board of the specific needs of Children's and Maternity Services (professionals, children and young people, their parents and carers as well as mothers) during the period of implementation of National Actions 1.2 and 1.3 and to monitor progress on behalf of the Department of Health.**

The work of the Cluster Management Boards and the Spine Project in fulfilling their roles as set out in National Actions 1.2 and 1.3 will be informed by the knowledge and expertise of the NHS Information Authority (NHSIA) NSF Implementation Programme via the National Clinical Advisory Board. The Programme is resourced by clinical and information specialists across the whole spectrum of NSF Information Strategies and is able to take the broader view of information needs within the NHS as well as being able to reflect the needs of particular conditions and client groups.

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# Information for Secondary Purposes

## Supporting Information for 'Access to Approved Data Items for Secondary Analysis'

**3.1 Approved data items used to record and describe the care and management of children, young people and mothers/mothers-to-be will appear on the Spine Record. The National Programme for IT (NPfIT) through the LSP will ensure that stakeholders for secondary purposes information can gain access to this data, subject to security and confidentiality considerations, either locally or through the services of national organisations established for this purpose such as the National Analytical Service.**

There are at present many datasets in use throughout the field of children's and maternity services. Few, if any, of these datasets are approved by the NHS Information Standards Board (ISB) and there is little coordination.

National Action 1.3 envisages a programme, under the auspices of the NPfIT, which will identify the data items that are needed to record and describe the care and management of children, young people and mothers/mothers-to-be and arrange for them to be approved by the ISB and therefore to appear on the Spine Record as they are used.

This will make such items available also for secondary analysis purposes through extraction and analysis from the Spine Record. Such extraction and analysis could be performed locally or through the services of national organisations established for this purpose such as the National Analytical Service. See National Action 2.3.

There are many stakeholders for secondary purposes information and the National Programme for IT (NPfIT) will need to ensure, through working with the appropriate partners, that the necessary hardware, software and procedures are in place to enable such organisations to extract the data they require.

One example that it may be useful for the NPfIT and the LSP to refer to as part of the implementation of this action is that of the MANNERS (Maternal and Neonatal Electronic Recording System) project of the Perinatal Institute. The MANNERS software uses a core dataset based largely on data that has already been defined. Fine-tuning is done through an iterative process of multidisciplinary consultation and field-testing in maternal and neonatal units. The Perinatal Institute's IT unit programs the software and updates and amends the data fields as required. As the software runs on the Institute's central server, all units use the most up to date version. The project is paid for by the West Midlands Specialist Services Agency, which recognises the need for data for events / outcomes as well as for denominators, i.e. all pregnancies and all babies/children.

A full list of the current functionality of MANNERS to date is listed below:

#### MATERNITY

- Customised Growth Charts
- Calculated EDD by scan
- Maternal label with NHS No. barcode
- A/N Screening Report
- Calculated time of ROM to birth
- Calculated gestation at delivery
- LW summary
- Birth Congenital Anomaly Notification
- Delivery report & graphs
- BMI
- Calculated gestation at each A/N scan
- A/N Congenital Anomaly Notification
- Calculated length of 1st, 2nd & 3<sup>rd</sup> stage of labour
- Calculated birth centile minutes
- Maternal transfer summary
- Baby transfer summary
- Neonatal label with NHS No. barcode
- Admissions report & graphs

#### NEONATAL

- Calculated Apgars @ 1, 5 & 10 minutes
- Death notification
- Neonatal Congenital Anomaly Notification
- Discharge report & graphs
- Discharge notification
- Neonatal summary
- Admission report & graphs

The following is a list of possible stakeholders for secondary purposes information relating to Children's and Maternity Services of the National Health Service:

BirthChoiceUK

British Association of Community Child Health (BACCH)

British Association of Perinatal Medicine (BAPM)

British Maternal & Fetal Medicine Society

Children, Young People and Families Directorate of the Department for Education and Skills (various agencies including Sure Start, Quality Protects and the Children's Fund)

Community Practitioners' and Health Visitors' Association (CPHVA)

Department of Health

Healthcare Commission (formerly known as CHAI)

Maternal and Child Health Statistics Exchange Group

National Analysis Service

National Patient Record Analysis Service (NPRAS)

National Screening Programme (See National Action 4.2)

NHS Primary Care Trusts

Office of National Statistics

Perinatal Institute

Public Health Observatories

Royal College of Midwives

Royal College of Nursing

Royal College of Paediatrics and Child Health

Royal College of Psychiatrists

Royal College of Physicians (Faculty of Public Health Physicians)

Royal College of Surgeons

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## Information for Secondary Purposes

### **Supporting Information for ‘Hospital Episode Statistics (HES) and Healthcare Resource Groups (HRG)’**

**3.2 The Department of Health, working with the NHS Information Authority and other key stakeholders, will examine the adequacy of coding of data for HES in relation to children’s and maternity services and make recommendations for any improvements. This work will link in with work currently underway examining the adequacy of Healthcare Resource Groups in relation to children and young people, make recommendations for any improvements and plan for their introduction as soon as possible.**

The reporting of Hospital Episode Statistics is achieved through the use of OPCS-4 (surgical procedure) and IDS-10 (disease) codes. In turn these codes contribute towards Healthcare Resource Groups (HRG).

There is some concern that OPCS-4 and IDS-10 do not adequately capture procedures and diseases specific to children and young people so that the central returns do not differentiate between data for them and data for adults. Specialty classifications for children and young people are also inadequate as is coding for children and young people outside of hospitals, for example in community paediatrics and cross agency working. This leads to inadequate combinations of procedure and disease identification for Healthcare Resource Groups (HRG) for children and young people. With HRG planned to form the common currency for financial flows within the health service children’s and maternity services could fail to be properly evaluated if coding is not improved.

There is no systematic mechanism for recording chronic illness, except possibly via primary care. Even when a child or young person is admitted to hospital or seen in outpatients this is not systematically recorded, thus prevalence of long term conditions cannot be determined and it is difficult to derive information such as workload, need for services and complications.

There is also a problem relating to children or young people with chronic illness who are admitted with other conditions e.g. a child with a kidney transplant admitted with acute appendicitis. This might require much more complex management than a routine case and referral to a hospital outside the local area. Also, children and young people with complex problems may have several procedures during one admission but they do not all get captured by HES.

As far as maternity data are concerned there is now a well established data trail in HES. However, the coverage is reportedly not complete with the lack of joined-up systems in hospitals contributing to the shortfall of maternity data, i.e. maternity systems are not linking with the rest of the hospital and thus not easily being added to the commissioning datasets (CMDS). This lack of joined-up systems should be addressed by the LSP under implementation of the Children's & Maternity Services Core Service under National Action 1.2

This examination, therefore, must decide on:

- The adequacy of OPCS-4 and IDS-10 codes and the coding process in relation to children, young people and mothers-to-be
- The ability of the service, with the support of developments from the LSP, to report HES
- The adequacy of Healthcare Resource Groups for children, young people and mothers-to-be and how and when improvements could be introduced

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## Information for Secondary Purposes

### **Supporting Information for 'National Analytical Services (NAS)'**

**3.3 The NHS Information Authority is developing a National Analytical Service (NAS) to support national secondary information requirements, e.g. activity and outcome for epidemiology, clinical governance, public health and service planning based on the Secondary Uses Service under development by the NPfIT Spine Project. The children and maternity services community will call upon the services of the NAS as they become available.**

**For further information about this developing programme of work please refer to the NHS Information Authority website at**

<http://www.nhsia.nhs.uk/def/home.asp>

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# Information for Secondary Purposes

## Supporting Information for 'Performance Indicators'

**3.4 The Healthcare Commission will work with the Children, Young People and Families Directorate of the Department for Education and Skills, the Department of Health and other key stakeholders to develop suitable performance indicators for national and local use.**

As part of the NHS performance rating assessment of all NHS organisations in England the Healthcare Commission will monitor key indicators that are capable of collection as a by-product of the direct care given to patients and should be available from the electronic information systems to be developed under the NHS Care Records Service.

The Child Health Indicators of Life and Development (CHILD) project of the European Union Community Health Monitoring Programme has set out a number of indicators of children's and young people's health and welfare in its report to the European Commission in September 2002. At the same time, two other projects in the same programme, the PERISTAT and the REPROSTAT projects have identified indicators relevant to perinatal health and care and to reproduction. These indicators are available for use by the Children, Young People and Families Directorate of the Department for Education and Skills and the Department of Health to monitor the implementation of the Children's & Maternity NSF and the Healthcare Commission may well wish to adopt a similar approach as part of its NHS performance rating assessment programme.

The Healthcare Commission will also include comparative information about children's and maternity services in its development programme of indicators for the NHS to use as appropriate locally. These will be based on the NSF standards and markers of good practice, professional standards, on NICE guidelines and appraisals, and will also cover other aspects of service quality such as equality of access, patient choice and resource utilisation.

In the meantime, a Government consultation began in February 2004 on health care standards for services under the NHS under the title of 'Standards for Better Health'. The consultation proposes a set of 'core' and a set of 'developmental' standards with the overall aim of establishing key standards for the quality of care delivered across the NHS in England. The 'core' standards are expected to come into effect towards the end of 2004 with the 'developmental' standards being introduced over time as increased resources permit. The agreed standards will eventually form the framework for more closely related performance rating and inspection programmes to be undertaken by the Healthcare Commission, provisionally timetabled for introduction in 2005/6.

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# Information for Secondary Purposes

## Supporting Information for 'Information for Audit'

3.5 The Healthcare Commission will work with the Children, Young People and Families Directorate of the Department for Education and Skills, the Department of Health and key stakeholders to develop national comparative clinical audit mechanism for children's and maternity services within a framework of standards for national audit as a matter of priority.

This action is designed to ensure that work is carried out to deliver a mechanism for local clinical audit and national service mapping and review exercises that will proceed within a framework of agreed standards relating to the data items that should be collected and analysed for the purposes of measuring outcomes and for benchmarking the results against comparative local and national findings.

Because of the importance of local and national audit it is essential that all Trusts delivering children's and maternity services are adequately served by electronic data management systems capable of making data available both locally and nationally. This need has been foreseen in National Action 1.2 regarding implementation of the Children's and Maternity Services NSF Core Service by Local Service Providers under the NHS Care Records Service.

The following are examples of national service reviews already completed:

'MCH 06-07: Risk adjusted outcomes in relation to patient volume and staffing in a random stratified sample of all UK neonatal intensive care units'. To find this article, visit [dh.gov.uk](http://dh.gov.uk) and search (using Advanced Search, 'with the exact phrase') for 'Risk adjusted outcomes in relation to patient volume and staffing'.

'Neonatal intensive care services – report of the Department of Health Expert Working Group'. To find this report, visit [dh.gov.uk](http://dh.gov.uk) and search (using Advanced Search, 'with the exact phrase') for 'Neonatal intensive care services'.

'HSC 2000/017: Modernising critical care services'. Visit [dh.gov.uk/letters](http://dh.gov.uk/letters) and search (using Advanced Search, 'with the exact phrase') for 'Modernising critical care services'.

'Paediatric intensive care a framework for the future report from the National Coordinating Group on Paediatric Intensive Care to the Chief Executive of the NHS Executive'. To find this report, visit [dh.gov.uk](http://dh.gov.uk) and search (using Advanced Search, 'with the exact phrase') for 'Paediatric intensive care a framework for the future report from the National Coordinating Group'.

'Paediatric intensive care: Report of the Chief Executive of the NHS Executive to the Secretary of State Department of Health' can be found by visiting [dh.gov.uk](http://dh.gov.uk) and searching (using Advanced Search, 'with the exact phrase') for 'Paediatric intensive care: Report of the Chief Executive of the NHS Executive'.

The work that has been done to map CAMH services, now entering its second year, is showing that access for parents and children to these services has improved. The Department of Health is currently looking to extend this mapping exercise to other children's and young people's services in the NHS. This will compliment the work being undertaken by the National Workforce Information for Planning Programme Board. Details of the annual Child and Adult Mental Health Service (CAMHS) Mapping exercise can be found at:

<http://www.dur.ac.uk/camhs.mapping/>

A National Child Health Service Mapping Study, which will develop a tool to map child health services across England, has also begun development. Its aim is to produce a national profile of child health service provision that can be used locally to plan and commission services, and nationally to monitor changes over time as key policy is implemented. The exercise is to take place annually, beginning November 2005, using the Internet to collect data. The first year is expected to establish a baseline position and the annual exercise thereafter will describe the changing profile of services over time. The map will describe services in terms of workload, workforce and finance as a minimum in the context of SHA, PCT and LA boundaries.

In the meantime, a Government consultation began in February 2004 on health care standards for services under the NHS under the title of 'Standards for Better Health'. The consultation proposes a set of 'core' and a set of 'developmental' standards with the overall aim of establishing key standards for the quality of care delivered across the NHS in England. The 'core' standards are expected to come into effect towards the end of 2004 with the 'developmental' standards being introduced over time as increased resources permit. The agreed standards will eventually form the framework for more closely related performance rating and inspection programmes to be undertaken by the Healthcare Commission, provisionally timetabled for introduction in 2005/6.

Local Action 2.5 describes the requirement for local participation in comparative clinical audit.

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## Access to Knowledge

### **Supporting Information for ‘National Website of Information Links’**

**4.1 The Department of Health Children’s and Maternity NSF website will act as a central link to supporting programmes of work including links to the NeLH, NHS Direct Online and professional as well as charitable organisations.**

The Department of Health is currently considering how to broaden the access to on-line resources. Examples of such resources that are acknowledged to be of help to children, young people and parents are:

- Directory Patient Experiences (DIPEX) website for young people with conditions such as cancer, which the Department part-funds, is a well-used and well-validated website which provides advice in the form of video clips and written information on what it is like for the patient to suffer from a particular condition and to receive treatment. This has until now been primarily targeted at adults but is about to be rolled out to young people to cover certain long term conditions.
- The Expert Patient Programme which has focussed on adult care in the first few years. It is hoped to extend this to young people and to parents for the training of parents and carers and young people to deliver courses, funding for local co-ordinators in pilot sites and evaluation.
- StartHere, a self-help information service which connects people, simply and effectively, to the specialist organisations and services – statutory and voluntary, nationally and locally – that can help them most, recognising that parents may need information across a range of subjects from education, problems at school, medical conditions, benefits, housing and employment and that each of these issues may impact the others. StartHere is available on kiosks, Digital TV, bedside TVs and the internet, making it accessible across the population.

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## Access to Knowledge

### **Supporting Information for ‘National electronic Library for Health (NeLH) Central Repository’**

**4.2 Whilst designed primarily for the use of health professionals, the NeLH will act as the central repository for all information about children’s and maternity issues whether for children, young people, parents and carers, mothers, the public or health professionals. This information resource will be**

**used by NHS Direct and NHS Direct Online to develop information suitable for the needs of children, parents, other carers, mothers and the public.**

The National electronic Library for Health at <http://www.nelh.nhs.uk/> was established to provide a single source of health information primarily for health professionals but also to be accessible by families and the general public. It provides links to national agencies, access to a wide range of expert knowledge and a wealth of information in its specialist libraries. NHS Direct and NHS Direct Online draw from the NeLH when they develop their services that, however, are designed specifically for the use of patients and the general public.

The National Knowledge Service is shortly to report on the results of a scoping study into the provision of information for children and young people and their parents and carers. The NeLH, NHS Direct and NHS Direct Online will take the results of this study into account in developing their programmes.

Currently, the NeLH is embarking on a project to create a common knowledge core of information about child care and development for the school health service, teachers, social care staff, including residential care staff, and those specialists who support these front line workers. The project aims to pull together a common core of knowledge expressed in terms that all professionals can understand. By the end of the first year the common core of knowledge will have been agreed and presented on the NeLH website. In this way the NeLH will be able to demonstrate a rapid response to the changing policy context for child care and support, and in addition it will provide an important example of a knowledge service that runs across health care, social care and education.

This approach will extend the concept of a library, in this case the Child Health Specialist Library, to become a knowledge service because it will seek not only to develop a common knowledge core but to mobilise it through educational and social care settings so that professionals can have access to it whenever and wherever they need it.

The Child Health Specialist Library can now be viewed on the NeLH website at <http://rms.nelh.nhs.uk/childhealth/>

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## Access to Knowledge

### Supporting Information for 'NHS Direct Online General Information'

**4.3 Drawing on information from a range of sources including the National electronic Library for Health (NeLH), NHS Direct Online will provide a web-based service giving access to recognised sources of high quality**

**information designed primarily for use by children and young people, parents and carers, mothers and members of the public.**

NHS Direct Online has a responsibility to give information and advice that is safe, reliable and appropriate to the circumstances of the website user. It ensures this through appropriate Editorial Board, clinical governance and public involvement strategies.

As the main source of knowledge for the general public, NHS Direct Online is expected ultimately to offer a full range of information for children and young people, their parents and carers as well as for mothers in formats suitable for all ages, educational backgrounds, physical disabilities, cultural backgrounds and mother tongues. This will be achieved through creation of in-house editorial content as well as partnerships with recognised, accredited resources from professional organisations, NHS bodies and patient organisations.

NHS Direct Online is currently aimed at the adult population, with particular emphasis on the 18-30 age group. Although there is already a good deal of information relevant to parents there is currently very little in the website that is designed specifically to be attractive and interesting to children or young people.

NHS Direct Online currently manages the Informed Patient Workstream of the Department of Health's 'Improving Patient Experience' programme. This will enable the commissioning or accreditation of high quality information for parents and children which can then be disseminated through NHS Direct channels including the NHS Direct Online website, touch-screen kiosks and digital TV. The first year's activities centre on cancer and elective surgery as priorities with some cover of children's issues, such as cancer and ENT surgery in children, but there will be greater emphasis on children's issues in the second year.

NHS Direct Online launched its new HealthSpace portal in December 2003 as a 'personal organiser' module providing users with the opportunity to keep their own personal health information and request personal information feeds such as reminders. For the time being this facility is limited to those over 18 years of age because of legal issues around information sharing and confidentiality. The portal aims by December 2004 to link with the NHS Care Records Service Spine Record to allow the public enhanced facilities.

The Information Partners Programme, run by NHS Direct Online provides an accreditation mechanism whereby the organisation's processes for creating information can be accredited and their information then released onto a range of resources including the NHS Direct Online website as a direct link from the Encyclopaedia and Self Help Guide. This accreditation process will also ensure links into the new NHS Digital TV channel as well as NHS Direct Kiosk information resources and can, if the organisation wishes, allow use of an NHS endorsement mark as an Information Partner.

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# Access to Knowledge

## Supporting Information for 'NHS Direct Provision of Information and Advice for the Public'

**4.4 Working with all the appropriate stakeholders and sources of medical knowledge NHS Direct will undertake the necessary actions to enable it to continue to be a safe source of telephone information and advice for children and young people, their parents and carers as well as members of the general public.**

From April 2004 a new Special Health Authority was established to manage NHS Direct, as well as its parallel service NHS Direct Online, and at the same time Primary Care Trusts (PCTs) became responsible for commissioning their services.

The Department of Health publication dated February 2004 entitled '*NHS Direct Commissioning Framework April 2004-05 – Guidance for Primary Care Trusts on commissioning NHS Direct Services from 1 April 2004*' (available by visiting the publications library at [dh.gov.uk/publications](http://dh.gov.uk/publications)) sets out how the new arrangements will help NHS Direct to contribute to health economies meeting the needs of their local population:

NHS Direct services divide into three categories, **Nationally Directed Services** consisting of national core 0845 4647 services including NHS Direct Online and NHS Direct digital TV when it becomes available, **Nationally Enhanced Services** consisting of nationally agreed developments, such as out-of-hours and emergency care, and **Locally Enhanced Services** consisting of local service developments.

### **Nationally Directed Services**

It is the cornerstone of the service that anyone, including parents and carers, children and young people who contact the NHS Direct service should receive consistent, high quality, locally relevant care and advice wherever they are in England.

NHS Direct is responsible for ensuring that anyone calling on 0845 4647 or accessing the website or any other medium, receive a consistent, safe and appropriate service, no matter where they are. This includes access to a 24-hour interpreting support for those whose first language is not English and to a textphone service for the hearing-impaired.

NHS Direct needs accurate, current detailed information about local services, especially primary care.

Without this, children and young people may be referred inappropriately, creating at best, frustration for both families and service providers and at worst, a serious adverse situation.

PCTs, therefore, will also ensure that accurate local information required for families enquiring about local services or needing referral onto local services is available to NHS Direct.

The staff at NHS Direct use the nhs.uk website at <http://www.nhs.uk/> to find information about GPs, dentists, pharmacies and opticians. Other community and secondary care services data is collected directly by NHS Direct staff.

NHS Direct and nhs.uk have also developed datasets, which include location of service, opening hours, contact details, etc.

PCTs, therefore, will ensure that NHS service information is available to NHS Direct by seeing to it that information on nhs.uk is regularly maintained according to agreed quality standards and by working co-operatively with NHS Direct in the collection of other local data.

The services of NHS Direct will be more widely advertised to the public in a number of different ways. For example:

- Advising callers to A&E departments of the NHS Direct number, as an alternative source of health advice. This should free up resources in A&E and reduce unnecessary trips for some families thus helping to meet four-hour A&E waiting targets.
- By December 2004 callers dialling 0845 4647, requiring out-of-hours care will usually be offered direct data transfer to an out-of-hours medical service under the Department of Health Technical Links Programme (see below)
- Advertising the 0845 4647 number, the website and NHS Direct's access to a 24-hour interpreting service.
- The use of the NHS Direct number as the second number on the GPs out-of-hours answer phone (where out-of-hours services are not already integrated with NHS Direct)

NHS Direct also has a central role in responding to national health scares, major incidents and local emergency alerts. NHS Direct can support partners in local emergency situations where the local population need to be given immediate access to telephone support.

## **Nationally Enhanced Services**

### *Out-of-Hours Integration*

The NHS Direct strategy in April 2003 identified integration with GP out-of-hours services as a key development priority. This reflects:

- The commitment in the NHS Plan to single call access to out-of-hours care
- The principles of consistency of access and quality wherever families are calling from

- The synergies between NHS Direct core business and out-of-hours clinical integration
- NHS Direct's national economies of scale and clinical governance structure
- The existence of an infrastructure for responding to the needs of families whose first language is not English
- The potential benefit which NHS Direct can offer in reducing GP workload during out-of-hours
- The role that this could play in helping to facilitate the introduction of the new GP contract

Currently, NHS Direct, as part of the Exemplar Programme to develop and test models of out-of-hours services, is integrated with 34 out-of-hours providers covering 10 million people.

#### *The Technical Links Programme*

Technical and operational links are currently being put in place to ensure calls to 0845 4647 can have patient data seamlessly transferred to the relevant out-of-hours provider by December 2004.

The Department of Health's Technical Links Programme in England allows patients who have called NHS Direct in the out-of-hours period, and who have been assessed as requiring the additional response of an out-of-hours provider, to have their clinical and demographic details electronically transferred to their out-of-hours providers. This will provide the platform on which further clinical integration can be built.

#### *Partnerships*

NHS Direct is one of many partners in out-of-hours care, including GPs, community nursing, mental health, social services, ambulance services, walk-in centres, A&E, pharmacy, dentistry and others. In the short-term the scale of NHS Direct's involvement in this partnership will vary. At its simplest, from the end of 2004 callers to 0845 4647 could have their clinical and demographic details electronically transferred to their out-of-hours provider, if needed. However at the other end of the scale, in some areas NHS Direct will act as the gateway to out-of-hours care, providing call handling, nurse assessment and transferring callers to out-of-hours providers as required.

#### *Future Integration*

In partnership with PCTs, SHAs and out-of-hours providers, the NHS Direct service will work to support full clinical integration for 100% of the population by December 2006.

There are a number of possible future service models which PCTs, out-of-hours providers, NHS Direct and other out-of-hours and unscheduled care partners may like to adopt locally for NHS Direct, for example:

- *Full clinical integration* – calls are diverted from GP surgeries during out-of-hours to NHS Direct – providing single call access – where callers are assessed, given advice or information by NHS Direct and/or referred on as appropriate.
- *Call handling only* – calls are diverted from GP surgeries out-of-hours to NHS Direct – still providing single call access. Life threatening emergencies are passed onto 999 and all other calls passed onto the out-of-hours provider. This may be particularly useful as an interim service until full clinical integration is achieved.
- *Full clinical integration where staff are co-located with out-of-hours providers* – this model is based on the full clinical integration model outlined above with the addition of nurses being co-located with out-of-hours providers. This is likely to be more expensive although PCTs may be prepared to pay a premium to support this level of close working. In this model nurses could be employed to carry out a dual role, providing telephone triage and face-to-face care.
- *Nurse assessment only* – In this model calls would be handled, and in the future possibly streamed by an out-of-hours provider and only those calls that could benefit from nurse assessment would be passed onto NHS Direct. The out-of-hours provider would need to use the NHS Direct software to support call transfer, audit and support seamless single call access. This service model is at the very early stages of piloting and will be fully evaluated over the coming months.

#### Booking Management Services

NHS Direct is positioned to support the NHS in delivering the Electronic Booking programme by extending its network of contact centres to handle telephone-booking requests. This includes interpreting, translation and textphone support. NHS Direct should also bring the expertise it has developed in delivering online services as part of a multi-channel delivery strategy.

In handling bookings, NHS Direct could also provide families and children with advice and support in exercising choice, subject to the functionality of the system.

#### Supporting Emergency Care Reform

Following the publication of Reforming Emergency Care in 2001, NHS Direct has been working with a number of partner Ambulance Services to consider how NHS Direct could best support emergency care by taking low priority ambulance calls.

There are six Category C pilots currently in place that will be evaluated over the next year. The results of the evaluation will be widely available by the end of 2004. The pilots cover three different models of NHS Direct taking Category C calls: nurses based in an ambulance control centre taking live calls; live calls transferred to NHS Direct to speak to a nurse; calls transferred to NHS Direct and placed in a queue and picked up by a nurse within 10 minutes. These models may need to be adapted during the year dependent on results identifying the most effective models.

The NHS Direct strategy identifies that NHS Direct will be able to support this agenda to some extent from 2005/06. The feedback from the pilots will provide valuable information for local partnerships on the needs of low priority ambulance calls and help identify how best local partnerships can take this forward, if they choose to do so.

As Department of Health policies relating to out-of-hours, emergency care and the new GMS contract begin to align, NHS Direct will have an increasingly important role around emergency/unscheduled care. NHS Direct will work flexibly with PCTs and other partners to provide a service that best fits the local environment.

#### Interpreting and Translation Services

In April 2004 NHS Direct will be launching a new national contract for telephone interpreting and translation services, including the provision of British Sign Language (BSL) interpretation.

#### **Locally Enhanced Services**

NHS Direct will work with PCTs and commissioning consortia to provide locally enhanced services wherever possible. The timing and implementation of these developments will be sensitive to their impact on the delivery of the nationally directed and out-of-hours services, which will be seen as the priority. There are a variety of options for locally enhanced services:

##### Use of the NHS Direct infrastructure and information or training resources

For example:

- Training of PALS staff
- Provision of local demographic information

##### Call handling service

For example:

- Out-of-hours answering service for other NHS or social care organisations (using geographic specific telephone numbers). These services may, over time become part of wider integrated out-of-hours arrangements and as such become part of the Nationally Enhanced Services.

##### Health Information Service

For example:

- Rapid response helplines for local NHS Trusts (using geographic specific telephone numbers)
- Updating and maintenance of primary care data on nhs.uk health information databases on behalf of other NHS organisations – i.e. acting as the organisations' web editor.

##### Telephone assessment services

For example:

- Outbound calling on behalf of other NHS services or organisations
- Hearing Direct, currently being piloted. NHS Direct is working with the Royal National Institute for the Deaf and some audiology services, to assess families over the phone and identify those who would benefit from a face-to-face consultation. Results of the pilot will be shared when available.
- Dental out-of-hours integration and/or support (using geographic specific telephone numbers). This service may be of interest to PCTs in light of the Dentistry Options for Change Programme, where it is felt that NHS Direct involvement could add value.

### NHS Direct and Children's and Maternity Services

The mode of operation envisaged above for NHS Direct must include consideration of the specific needs of children and young people, their families and carers as reflected in the Children's and Maternity Services National Service Framework (NSF). In particular:

Individual children, young people, as well as their families and carers should experience the service received from NHS Direct as confidential, respectful, empowering, equitable and inclusive

NHS Direct should only offer services to children and young people through staff who are specifically qualified to do so and who have the right skills for assessment and diagnosis

The NHS Direct service must continue to develop age-related algorithms and utilise the most appropriate evidence in relation to their advice to children and young people or their families and carers

Children and young people and their parents should have information, advice and support to enable them to manage minor illnesses themselves, and to access appropriate services when necessary

NHS Direct must ensure that it directs children, young people, their families and carers to the most appropriate place to receive care based on local knowledge of the available services, such as out-of-hours services, the nearest receiving unit for sick children or those who may need surgical or orthopaedic expertise.

NHS Direct should be able to advise on the best means of transport to local services given its assessment of the degree of urgency involved

NHS Direct should provide children, young people, parents and carers with information about their illness, treatment options, and relevant local support networks

The NHS Direct service must offer choice to children, young people and their families and they should help them to participate in decisions about the care and the services that they are offered

NHS Direct should ensure prompt and secure electronic communication between themselves and referral services through the NHS Care Record Service

NHS Direct should take part in the process of developing computer systems to enable sharing of information across agencies to ensure that, amongst other things, they do not allow vulnerable children to fall through the net where, for example, they are referred to A&E by NHS Direct but they fail to attend.

In partnership with GPs and paediatricians, NHS Direct should develop systems to identify and flag children and young people with certain urgent conditions (such as a tendency to sudden catastrophic asthma, anaphylaxis, or repeated seizures) to enable them to respond quickly and appropriately when such children or their parents call NHS Direct.

NHS Direct should be able to give children, young people and their parents and carers consistent, up to date, comprehensive, timely information on the safe and effective use of medicines should they be asked for it.

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## Access to Knowledge

### Supporting Information for 'National Review of Patient Information Needs'

**4.5 The Department of Health will include the needs of children, young people, mothers and mothers-to-be in its review of patients' information needs across all the NSF areas.**

A project is currently underway in the Department of Health to review the information needs of patients across all the areas addressed by previous National Service Frameworks and how they can best be met. It will now include the information needs of children, young people, mothers and mothers-to-be in the review.

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## Training and Development

### Supporting Information for 'Children's and Maternity Informatics Special Interest Group'

5.1 The NHSIA in partnership with the informatics community within children's and maternity services will develop a special interest group through the Informatics Learning Network available from the NHS Health Informatics Service programme of the NHSIA. The first step will be to establish a web site and moderator.

For further information about this developing programme of work please refer to the NHS Information Authority website at

<http://www.nhsia.nhs.uk/nhid/pages/default.asp>

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## Training and Development

### Supporting Information for 'Educational Packages for Use of Systems'

5.2 The NHS Health Informatics Service, in partnership with the informatics community within children's and maternity services will develop an educational package for NHS organisations embarking on electronic data collection or who have systems not yet fully utilised, to provide a practical guide on how to embed an electronic clinical information system in the delivery of direct care.

For further information about this developing programme of work please refer to the NHS Information Authority website at

<http://www.nhsia.nhs.uk/nhid/pages/default.asp>

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## Training and Development

### Supporting Information for 'Educational Packages for Career Development'

5.3 The NHS Health Informatics Service, in partnership with the informatics community within children's and maternity services will develop an educational package to support NHS organisations delivering children's and

**maternity services in providing career development and succession planning.**

**For further information about this developing programme of work please refer to the NHS Information Authority website at <http://www.nhsia.nhs.uk/nhid/pages/default.asp>**

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# Cross Agency Working

## **Supporting Information for ‘Local Cooperation to Establish Joint Arrangements for Information Sharing’**

**1.1 Primary Care Trusts and other agencies should consider co-operating in local arrangements to establish joint arrangements and protocols for information sharing where that is necessary to help a child or young person who has additional needs if they are to achieve the Every Child Matters outcomes of being healthy, staying safe, enjoying and achieving, making a positive contribution, and economic well-being.**

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# Information for Direct Care of Children, Young People, Mothers and Mothers-to-Be

## **Supporting Information for ‘Use of Electronic Information Systems’**

**2.1 Local Service Providers (LSP) will work with NHS organisations delivering children’s and maternity services through the NHS Care Records Service (NCRS) programme Cluster Management Boards to ensure that the electronic information systems (EIS) delivered under the Core Service are embedded in the management and care of children, young people and mothers.**

The National Programme for Information Technology (NPfIT) has responsibility for delivering the NHS Care Records Service through partnerships with national and local suppliers, known respectively as ‘National Application Service Providers’ (NASP) and Local Service Providers’ (LSP).

The LSP will work within specified geographical areas known as ‘clusters’. Cluster Management Boards will ensure that the implementation within the cluster runs to time and to budget and that all required resources are made available. They will instruct the LSP to proceed with the implementation of the services that have been specified in the documents known as Core Services.

The LSP will need to work with NHS organisations delivering children’s and maternity services to ensure that information systems are specified, designed, developed and implemented to meet the needs of families and staff as specified within the Children’s & Maternity Services NSF Core Service and later amendments referred to under National Action 2.2.

At its most fundamental the NCRS will deliver the mechanisms to enable professionals to have access to the views they need to support integrated care at the time and place required and to inform accurate diagnosis and optimum treatment. It will also support the goal of enabling children, young people and mothers to have access to and to be able to update their own records so as to assist them in becoming fully involved with their care through joint decision-making in a multi-skilled team environment.

As the National Programme moves forward with the NHS Care Records Service, NHS organisations delivering children's and maternity services will need to come together to work in partnership with the designated LSP to ensure that the systems developed for use within their cluster meet both their generic requirements for running the service and also those specific requirements that are essential to support children, young people and mothers and mothers-to-be and the health professionals caring for them.

Care should be taken by those NHS organisations delivering children's and maternity services in working with the LSP so that the functions of existing successful systems, for example child health systems based on the Child Health Informatics Consortium (CHIC) service specification, are not lost in this process, that new systems are flexible and capable of evolving over time and that provision is made for them to be supported by well trained staff familiar with the special requirements of children's and maternity services. This applies to those who input data as well as those who will operate systems. It is essential that every NHS organisation delivering children's and maternity services, whether in primary, secondary or tertiary settings should have systems which are integrated with that organisation's main system.

Finally, the National Actions in section 4 Training and Development and the corresponding Local Actions are designed to ensure that staff with the responsibility for data receive adequate and ongoing training and support. See in particular National Actions 4.2 and 4.3 and Local Action 4.1.

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## **Information for Direct Care of Children, Young People, Mothers and Mothers-to-Be**

### **Supporting Information for 'Information Sharing'**

**2.2 NHS organisations delivering children's and maternity services are encouraged to carry out a formal examination of the issues relating to information sharing for all relevant stakeholders and to use the results to ensure that the interests of children, young people, parents, carers, third parties and mothers/mothers-to-be as well as care professionals are recognised and properly safeguarded.**

National Action 1.1 envisages that the Department for Education and Skills will produce authoritative, clear and definitive guidance to all NHS professionals caring for children and young people about what information can and should be shared between them, (that is, within the NHS and with other agencies), with children and young people in their care and/or their parents and carers, and with interested or involved third parties, under what circumstances and with what safeguards of consent and confidentiality. This guidance will give local organisations the basis to proceed to investigate the issues that are relevant to their situations and to implement local solutions.

'Information sharing' is about communicating promptly, accurately and effectively with the individual and others involved in their care within the legal framework of the Data Protection Act 1998, the Human Rights Act 1998 and the common law of confidence for the individual's benefit. The general public need to know what personal information about them is or may be shared by the professional caring for them with another care professional or indeed with another third party, knowing why that information is shared and giving or withholding consent for it to happen. For people who may wish to view their own records there should be no surprises. For care professionals it is about ensuring that individuals are prepared for and supported in viewing their own records and knowing what personal information about them they can or cannot share with others and with whom they can or cannot share it.

It is the intention that, by understanding these issues in a practical way and in ways that reflect local practice and by developing procedures that are clear to follow the interests of all parties are recognised and properly safeguarded.

The local Caldicott Guardian must be involved to ensure that information is shared within the permitted limits of security and confidentiality. Reference can also be made to ongoing work within the National Programme for Information Technology (NPfIT) on the subject of Security and Confidentiality.

Because of the particularly complex needs of children and young people, they often come under the care of a number of different care professionals who will not always be on one site. Procedures, therefore, will need to address the geographical and the multi-agency issues and, whilst such issues may be best solved by sharing information electronically, the fundamental decisions about giving families and care professionals the understanding about what may or may not be shared must be addressed whatever the method of sharing, be it on paper or electronically. Strategic Health Authorities might wish to take the lead in this respect with Primary Care Trusts working with the other agencies to bring together those organisations delivering children's and maternity services where clear procedures for sharing information would be of benefit to all concerned.

Sharing information with children, young people, parents and carers will need to be recognised as a challenging process, and great care will need to be taken over the delivery mechanisms taking into account age and language differences and differences of cultural background. Personal communication with face-to-face

delivery is advised to be the primary method for sharing information with families, backed up by written information.

Providing people with access to their own results and records, including sending them copy letters, helps to empower them and support them in becoming expert in managing their own care. However it is essential that people have been adequately prepared for any bad or unexpected information that may be included. The primary stakeholder is the child or young person and it is only logical that they, together with their parents and carers as appropriate, should be able to view their own records. This enables them to ensure completeness and accuracy of the content. Care is a partnership and sharing records is part of that process.

Special consideration should be given to information sharing when children and young people move from one care setting to another, for example where young people transfer from a children's unit to an adult unit.

Of particular value to parents is the now well-established National Standard Personal Child Health Record (PCHR), sometimes referred to as the Parent-held Child Health Record. The PCHR is ideally given to parents in the antenatal period, or as soon as possible after the birth of their child, with an explanation of its use. At the local level, the PCHR can be supplemented with materials to meet local needs, for example local service information, with any additional health promotion materials clearly evidence-based and not affecting the agreed core format.

*Health for All Children (4<sup>th</sup> Edition)* recommended that Primary Care Trusts should adopt the core format for the PCHR. In the longer term, with the development of the NHS Care Record Service, data for the core format could be obtained from information held in the child's NHS Care Record. Information and guidance on the PCHR may be obtained from <http://www.healthforallchildren.co.uk/pchr.html>

This action, therefore, seeks to encourage Trusts, PCTs and SHAs and all other organisations providing services to children and young people to help families and professionals to understand what information may or may not be shared and thereby to lead on to further benefits of enabling them to see their results and records and to participate actively in their care.

The NHS Information Authority, as part of its work to support the implementation of the Mental Health Information Strategy, has collated examples of information sharing protocols that have been developed around the country and links to those examples as well as to available guidance on the development of information sharing protocols can be found at [NHSIA : Mental Health Information Strategy](#).

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## Information for Secondary Purposes

### Supporting Information for 'Electronic Information Systems'

**3.1 NHS organisations delivering children’s and maternity services are advised to collaborate with the LSP to implement the upgrades to their electronic information systems when available.**

The Children’s & Maternity Services NSF Core Service requirement referred to in National Action 1.2 will specify that the LSP, working with existing suppliers, will maintain, upgrade and integrate, as required, electronic information systems (EIS) hardware and software, or appropriate modules of such systems, in use in primary, secondary and tertiary care for the diagnosis, treatment and management of children and young people and of mothers and mothers-to-be, drawing on the experience in the current child health systems and maternity systems in use around the country. They will also deploy such systems where they are required but where they are not present.

NHS organisations delivering children’s and maternity services should collaborate in this process as it develops.

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## Information for Secondary Purposes

**Supporting Information for ‘Data Items for Secondary Analysis’**

**3.2 NHS organisations delivering children’s and maternity services are advised to work with their LSP to understand the procedures for gaining access to data items on Spine Records for secondary analysis purposes.**

National Action 2.1 states that the National Programme for IT (NPfIT) through the LSP will ensure that stakeholders for secondary purposes information can gain access to data from the Spine Record, subject to security and confidentiality considerations, either locally or through the services of national organisations established for this purpose such as the National Analytical Service.

NHS organisations delivering children’s and maternity services should collaborate with their LSP to understand how to do this and whether to attempt to undertake local analysis or to approach the National Analytical Service.

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## Information for Secondary Purposes

**Supporting Information for ‘Clinical Coding Capability’**

**3.3 NHS organisations delivering children’s and maternity services are advised to make every effort to have sufficient clinical coders who are trained in the coding of conditions associated with children and young people so as to take full advantage of the improvements arising from the recommendations that will be made by the Department of Health under National Action 3.2.**

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## Information for Secondary Purposes

### Supporting Information for ‘Analytical Capability’

**3.4 Access to the appropriate analytical and epidemiological skills is essential if data for audit and other purposes are to be handled and interpreted correctly. NHS organisations delivering children’s and maternity services should consider employing such services for data interpretation locally where it can be justified but call upon national services, such as the National Analytical Service, where it cannot.**

Outcome data once collected should be collated and adjusted for a variety of confounding factors, for example age, diabetes and ethnic mix, if data are to be meaningful and interpreted correctly. Inappropriate data management can lead to serious problems for planners and providers. Similarly, when interpreting audit data, the appropriate methods should be used to obtain a meaningful outcome.

This means that NHS organisations delivering children’s and maternity services need access to the statistical and epidemiological skills required to handle and interpret the data required for audit and other purposes so that local data are interpreted appropriately to inform management, planning and quality improvement.

It is acknowledged, however, that not only may such skills be in short supply but also there may not be enough patients in any one area to justify an individual organisation appointing such resources. It may, therefore, be prudent and more practical to use the resources of organisations such as the National Analytical Service (NAS) who may be able to provide them with the feedback that they need. Alternatively, Strategic Health Authorities may consider a central pool of such resources to act on behalf of organisations within their area.

In order to address this issue in a comprehensive way Strategic Health Authorities might wish to establish a review of the required and available analytical capacity in their area and work with commissioners of children’s and maternity services to decide how such resources may be put to best use for the benefit of individual organisations.

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## Information for Secondary Purposes

### Supporting Information for 'Information for Audit'

**3.5 NHS organisations delivering children's and maternity services are encouraged to participate in national comparative audit of the structure, process and outcome of their work. This could include, for example, families' opinions, suggestions, transport arrangements, as well as audit of activity, outcomes, waiting lists and admissions to wards with feedback used to inform change.**

This approach will provide a more child and young person focussed service more able to meet the needs of individuals. The information would also be valuable for commissioners in performance management. Furthermore, the Healthcare Commission expects participation in national audit as an integral part of clinical governance.

An efficient unit should have processes and systems in place in order that care is continuously improved. For example, the availability of patient information and organisation of patient education could form part of a structured process. A named person could be responsible for acquiring relevant information, organising and updating it and ensuring systematic delivery to each child or young person and their parents or carers in an appropriate format. There should be a clear mechanism for children, young people, parents and carers to make constructive suggestions or voice complaints, backed up by a system for responding.

In the absence of such systems, problems that occur may not be addressed or not even recognised. Use of processes available for audit improves the organisation's efficiency and enables it to respond to problems and improve the service to children, young people, parents and carers systematically.

See [National Action 2.5](#) for details of the action on the Healthcare Commission to develop national comparative clinical audit plans for children's and maternity services within a framework of standards for national audit.

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## Information for Secondary Purposes

### Supporting Information for 'Delivery and Monitoring of the NSF Standards'

### **3.6 NHS organisations delivering children's and maternity services could make use of the products being developed by the NHS Information Authority to assist health professionals in the delivery and monitoring of the NSF standards.**

The NHS Information Authority is currently undertaking a project to explore the feasibility of developing a range of products to assist health professionals in the delivery and monitoring of the NSF standards. The project is considering the following products:

- A computerised knowledge-based monitoring system consisting of an interactive electronic questionnaire with data entry fields which would enable an organisation to record its achievements and progress against key areas of each NSF
- An information guide & checklist (IGC) similar to the existing clinical governance IGC. This will highlight generic NSF related information requirements and where to source it
- A web-based knowledge resource consisting of a series of interactive web pages designed to provide the user with a centralised resource of useful NSF related information
- An easy to use, web-based interactive 'Starters Guide' consisting of web pages providing relevant up-to-date NSF information, web links and addresses

Products are expected to be available by the beginning of April 2004.

For progress on the development of these products visit the NHS Information Authority website at <http://www.nhsia.nhs.uk/nsf/pages/toolkit/default.asp?om=m1>

Local NHS organisations planning children's and maternity services should refer to the Children's and Maternity Services National Service Framework's standards and markers of good practice which offer guidance about the matters that will need to be addressed to plan local services. The following topic areas might be considered, for example:

- Information to support the planning and commissioning of local multi-agency services to meet the needs profile of the local population.
- Information to address inequalities experienced by the local population.
- Information about the prevalence of different conditions in the local population, such as the numbers of children and young people with mental health problems, learning or physical disabilities, behavioural difficulties, drug or alcohol dependence, chronic illness etc.
- Information to support the multi-agency planning and provision of transition services for young people into adult services

- Information to support services for adults caring for children and young people in special circumstances, for instance in residential homes, foster care, secure units and youth offender institutions.
- Information to ensure the availability of the appropriate skills for the assessment, diagnosis, treatment and ongoing care for children and young people.
- Information to enable commissioning of sufficient in-patient psychiatric beds in order that all children and young people requiring admission have access to appropriate care in an environment suited to their age and development.
- Information to support commissioning of maternity services within the context of a managed care network covering all aspects of antenatal, birth and post birth care and local choice.

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## Access to Knowledge

### Supporting Information for ‘Information for Children and Young People, their Parents and Carers, for Mothers/Mothers-to-Be and for the Public’

**4.1 NHS organisations delivering children’s and maternity services could, by using the services described in National Actions 3.1 to 3.3 and 3.5, make available a full range of information for children and young people, their parents and carers, for mothers and for the public about the diagnosis, treatment and management of related conditions and about services that are available locally.**

NHS organisations delivering children’s and maternity services are advised to make available a named individual responsible for the development and availability of information for patients. Such organisations that may be linked through networks should move towards consistency of information across the network. Commissioning groups may take a view on this.

Personal, face-to-face communication should be regarded as the principal method of communication, especially with children and young people and their parents and carers. Written and other media should be available to back up and reinforce points made during discussions.

The information should be suitable for all children, young people, parents and carers as well as members of the public. It should take into account the needs of different age groups, ethnic minorities, those with literacy problems or learning difficulties and those with sensory deficits. Depending on local circumstances NHS

organisations delivering children's and maternity services may wish to concentrate their efforts, and their budgets, on one or more target groups and prepare the material in a way that meets the needs of the particular group or groups. For example, the delivery of information in a particular language may be more urgent in one area or material prepared for children or young people in a way that captures their attention might be more important in another.

Many people who do not speak English are not able to read leaflets in their own language. In those cases it may be more useful and cost effective to have an interpreter present at a consultation using a good quality English leaflet as the basis for the discussion. This approach may be preferable to having large quantities of translated material that may only rarely be used and may quickly become obsolete. Questions can be asked and answered through the interpreter who can make notes that he/she can understand.

Some people may wish to go into more detail than others. The information available must cover the needs of these individuals without compromising the needs of those who want only limited information.

Not all families have or wish to have access to the Internet. Those who do not may or may not wish to find out information for themselves. If they do they should be supported in doing so by having access to a computer terminal on site and offered help in using the equipment to find the information they require. Alternatively, people who prefer written information could be offered material that meets their needs either prepared locally or downloaded from a reliable web-based source such as NHS Direct Online.

Initially the needs of parents and carers often centre on information about their child's illness and treatment and about the services that are available to them both locally and nationally. However, they and their children also need information about the things that will have a positive impact on their lives and not just about the things that they should not be doing. With the proposed approach local NHS organisations delivering children's and maternity services should be in a position to provide access to information that gives positive information about lifestyle decisions including diet, exercise, travel, holidays and work.

There is strong evidence for the value of the 'Personal Child Health Record' (PCHR) in hard copy format which includes not only information of a medical nature specific to a baby/child but also information about healthy living and local services which parents could take advantage of. The use of these and other such records for parents and their babies/children is well established. NHS organisations delivering children's and maternity services that may be linked through networks may wish to consider introducing such records where they have not yet done so with the aim of bringing about consistency of presentation and use within their area. Organisations may also wish to consider developing and introducing a 'Young Person's Held Record'.

The Department of Health website has electronic versions of *The Pregnancy Book* and the *Birth to Five* guide, both of which are available in hard copy from the

Department of Health at PO Box 777, London SE1 6XH or by visiting [dh.gov.uk/publications](http://dh.gov.uk/publications) and searching for them in the publications library.

Information and guidance on the PCHR may be obtained from <http://www.healthforallchildren.co.uk/pchr.html>

Local NHS organisation preparing information for children, young people, their parents and carers and for mothers and mothers-to-be should refer to the Children's and Maternity Services National Service Framework's standards, interventions and markers of good practice which offer guidance about the sort of information that will make a difference. The following topic areas for information might be considered, for example:

- Information to promote healthy life choices, including information about breastfeeding, healthy diet and exercise, social and emotional wellbeing, keeping children and young people safe, avoiding smoking and minimising alcohol intake, safer sex and reducing the chances of teenagers becoming pregnant
- Information specifically targeted at parents and carers. The information could address issues that arise for children and young people during normal development, the needs of parents of children and young people with additional needs such as those who have suffered bereavement, who have mental health or behavioural difficulties, those with disabilities or a chronic illness or special educational needs. Parents and carers should have information about the local or national services that are available to them, including statutory and voluntary services, information about services providing practical and emotional support and how to get in touch with those services.
- Information to promote a better understanding in children, young people, their parents and carers and mothers and mothers-to-be of the particular illness or condition which relates to them and thereby to support them in making choices, in partnership with the health professionals, about their treatment, the management of their care and about their life style.
- Information about the services available for children and young people, not only in NHS settings but also from other agencies.
- Information about how children, young people and families might become more involved in planning, commissioning and evaluating multi-agency services.
- Information for mothers and mothers-to-be about local hospital and community maternity services and the professionals who are able to attend during childbirth.

As a quality check, NHS organisations delivering children's and maternity services who develop such material may wish to use the Centre for Health Information Quality (CHIQ – see [www.hfht.org/chig/](http://www.hfht.org/chig/) ) and DISCERN (see [www.discern.org.uk/](http://www.discern.org.uk/) for a brief online questionnaire which provides users with a valid and reliable way of

assessing the quality of written information on treatment choices for a health problem) to assess the information products that they make available locally in this way to their children, families and public.

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## Access to Knowledge

### **Supporting Information for ‘Access to the IT Infrastructure’**

**4.2 NHS organisations delivering children’s and maternity services need to consider that professional staff and families have ready access to the knowledge base through implementation of the necessary IT infrastructure.**

Information for children and young people, parents, carers and care professionals must be easily accessible otherwise there is a real danger that it will not be used and will fall into disrepute. Most information today, if it is to be up-to-date, consistent and readily available needs to be held in electronic format. For children and young people, parents, carers and care professionals to be able to see that information they must have access to it via a reliable IT infrastructure with hardware and software that is easy to use.

It would be good practice for Chief Information Officers, or their equivalents, in NHS organisations delivering children’s and maternity services to examine the extent of the coverage of their IT networks for patients and staff and to consider extending it, where necessary and appropriate, in the light of the information needs proposed in these Local Actions.

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## Training and Development

### **Supporting Information for ‘Training and Support for Staff’**

**5.1 NHS organisations delivering children’s and maternity services are encouraged to give staff with responsibilities for data and the preparation of information the appropriate training and support in developing their skills and knowledge.**

The information needs of health professionals in NHS organisations delivering children’s and maternity services will be satisfied only if they have staff trained in the use of information systems, in data entry and data interpretation and whose skills and knowledge are kept up-to-date.

Chief Information Officers, or their equivalents, in NHS organisations delivering children's and maternity services, therefore, may wish to review this element of their activities with a view to deciding how best to train as well as to support their staff and develop their careers and thereby to make the most of their investment in clinical information systems hardware and software. Support for this is also available from the NHS Health Informatics Service programme of the NHSIA under National Actions 5.1, 5.2 and 5.3.

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## Training and Development

**Supporting Information for 'Support for Children and Carers'**  
**5.2 NHS organisations delivering children's and maternity services are encouraged that, wherever access to information is given to children, young people, parents and carers via, for example, a workstation located on their premises, help and support as well as sufficient material are readily available so that they can use the IT system appropriately and understand the information they receive.**

In the same way that the information needs of health professionals in Trusts and managed networks across the local community in both primary, secondary and tertiary care will be satisfied only if they have properly trained staff, so too the information needs of children, young people, parents and carers will not be met if they do not have the knowledge of how to use the facilities that may be offered to them, such as a workstation located within, for example, a GP practice or a children's ward. Help should be available either in written form or ideally from an informed member of staff who can be on hand to support families when they are looking for information.

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## Appendix 1 - Indicators

### The CHILD Project

The Child Health Indicators of Life and Development (CHILD) project of the European Union Community Health Monitoring Programme reported to the European Commission in September 2002 detailing a number of indicators of children's health and welfare reflected in four different categories, namely:

1. Demography and Socio-economic Situation
2. Health Status
3. Determinants of Health
4. Health Systems

Within each of these categories the project identified subjects for which it believed indicators were important, but where further work was identified as being needed to define the indicator and its data sources. Additionally it identified subjects where it felt indicators would be needed but which either fell outside the scope of this project or which were already being developed by other Health Monitoring Programme (HMP) Projects.

The full September 2002 report of the CHILD project can be found at:  
[http://europa.eu.int/comm/health/ph\\_projects/2000/monitoring/fp\\_monitoring\\_2000\\_frep\\_08\\_en.pdf](http://europa.eu.int/comm/health/ph_projects/2000/monitoring/fp_monitoring_2000_frep_08_en.pdf)

### The PERISTAT Project

PERISTAT, like the CHILD project, is also a project of the European Union Community Health Monitoring Programme. Its aim was to develop indicators of perinatal health and perinatal care for health professionals, policy makers, researchers and health service user groups. The indicators provide insight into differences in health outcomes and health services during pregnancy, delivery and the post-partum period (up to the end of the first week of life).

The project identified ten core indicators, defined as those essential to monitoring perinatal health, and twenty-three recommended indicators which are those considered desirable for a more complete picture of perinatal health across the European member states. Included among the twenty-three recommended indicators are twelve that have been identified for further development. These indicators represent important aspects of perinatal health, but further work is required before they can be defined and collected.

The indicators are split into four different categories, namely:

1. Neonatal health
2. Maternal health
3. Population characteristics or risk factors

#### 4. Health care services

The working list of indicators developed by the PERISTAT project can be found at: <http://europeristat.aphp.fr/en/>

#### **The REPROSTAT Project**

REPROSTAT - Reproductive Health Indicators in the European Union - , like the CHILD and PERISTAT projects, is also a project of the European Union Community Health Monitoring Programme.

The aim of the REPROSTAT project is to develop indicators for monitoring and evaluating reproductive health in the European Union. Reproductive health indicators measure male and female sexual and reproductive health from pre-conception to delivery. These indicators also include measures of the demographic, medical, social and health system factors that influence reproductive health.

Currently, several reproductive health indicators in the EU countries cannot be compared because of differences in definitions and data collection procedures, heterogeneity in registration and variation in medical practices. Key indicators for evaluating reproductive health and the quality of health services are not available in all countries. The specific objectives of REPROSTAT, therefore, are to:

- Define indicators of reproductive health and the determinants of reproductive health for a European Union health information system
- Specify methods for the construction and publication of comparable indicators
- Assess the ability of existing data collection systems to construct these indicators

**The list of indicators developed by the REPROSTAT project and the latest news about the project can be found at: <http://www.reprostat.com/>**

While the indicators that are being developed by these projects are vital for the purpose of monitoring the health and welfare of mothers and babies and children it is accepted that they are not all being collected nor are they currently capable of being collected by present systems.

The Office for National Statistics (ONS) is, therefore, undertaking an exercise to determine the way forward in respect of all the indicators recommended for collection by the CHILD project and it would be expected that the results of its findings would feed into the work of the proposed steering committee. The ONS should consider extending the exercise to cover the indicators in the PERISTAT and REPROSTAT projects.

In support of this work the proposed steering committee would ensure that the appropriate bodies responsible for the development of data definitions and classifications, computer systems and application software for the different

agencies, for example the National Programme for Information Technology (NPfIT) for the NHS, put in place programmes of work to enable the recommended indicators to be recorded and collected as the underlying information becomes available within the services and the civil registration system.

Many of the recommended indicators represent material that might be derived from information contained in several source record systems, as for example patient records, birth and death registration records or social care records. Where relevant, there will be a need to develop and agree the clinical terminology content that will be used within each of these record systems.

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and Summary ►](#)

<b>Glossary of Terms</b>	
<b>Term</b>	<b>Description</b>
Caldicott Guardian	A senior health or social care professional with responsibility for promoting information governance within the organisation
Care Professional	Any professional, whether for example, from health, social care or education, providing care to a child.
The Healthcare Commission	Formerly known as CHAI (Commission for Healthcare Audit & Inspection) the Healthcare Commission came into operation in April 2004 when it became responsible for monitoring standards of healthcare in the NHS and private healthcare organisations across England and Wales. It will take over from the CHI, the National Care Standards Commission for inspecting private healthcare providers, the Mental Health Act Commission, and the Audit Commission's value for money studies in health.
Electronic Information System (EIS)	A comprehensive computerised system operating within a healthcare environment recording data from healthcare professionals about patients' interaction with the service from appointment to discharge.
Local Service Provider (LSP)	Suppliers of local systems and/or services appointed by the National Programme to support the NHS Care Records Service.
National Application Service Provider (NASP)	Suppliers of national systems and/or services appointed by the National Programme to support the NHS Care Records Service.
NHS Care Records Service (NCRS)	One of the four key programmes for delivery by the National Programme, the NCRS concentrates on delivery of electronic patient records and integrated systems for the NHS.
National electronic Library for Health (NeLH)	The National electronic Library for Health provides a single source of health information primarily for health professionals but also accessible by patients and the general public. It provides links to national agencies, access to a wide range of expert knowledge and a wealth of information in its specialist libraries.
National Institute for Clinical Excellence (NICE)	NICE was set up as a Special Health Authority for England and Wales on 1 April 1999. It is part of the NHS, and its role is to provide patients, health professionals and the public with authoritative, robust and reliable guidance on current "best practice". The guidance covers both individual health technologies (including medicines, medical devices, diagnostic techniques, and procedures) and the clinical management of specific conditions. NICE offers the NHS and its patients a new service, which it is intended, shall earn, and retain, the confidence and respect of the community as a whole.

## Glossary of Terms

Term	Description
National Programme for Information Technology (NPfIT)	The National Programme for IT in the NHS focuses on the key developments that will make a significant difference to improving the patient experience and the delivery of care and services. There are four key deliverables: electronic appointment booking, an electronic care records service, electronic prescribing and an underpinning IT infrastructure with sufficient connectivity and broadband capacity to support the critical national applications and local systems. To ensure delivery of the National IT Programme there are also several supporting workstreams around streamlining procurement, managing implementation in the NHS and improving the partnership and capacity with IT suppliers.
NHS Direct	NHS Direct operates a 24-hour nurse advice and health information service, providing confidential information on what to do if people are feeling ill, particular health conditions, local healthcare services, such as doctors, dentists or late night opening pharmacies and self help and support organisations.
NHS Direct Online	NHS Direct Online is a website providing high quality health information and advice for the people of England. It is unique in being supported by a 24 hour nurse advice and information helpline. If users of NHS Direct Online are in any doubt about information they read or about what action to take, they can call NHS Direct on 0845 4647
NHS Information Authority	Special Health Authority established in April 1999 to replace the previous NHS Information Management Group (IMG) and the FHS Computer Unit.
NHS Information Standards Board (ISB)	The ISB is the governing board responsible for approving data standards and other changes for adoption by the NHS.
NHS organisations delivering children's and maternity services	In the context of the Children's & Maternity Services Information Strategy National and Local Actions any organisation within the NHS that delivers care to children, young people or mother and mothers-to-be. This could be, for example, a hospital or group of hospitals or a GP surgery.

# Document Navigation Guide


This document has been prepared primarily for use electronically on the Internet. So it contains 'hyperlinks' within it which enable you to move around the document at convenient places and to go to and return to particular points. You can do this by holding down the 'Ctrl' key on your keyboard and clicking with your mouse on the underlined link provided.

## How to find your way through the Information Strategy











- You may have arrived at this Guide either from the link in the [Contents](#) page or after having read the first three points in the [Introduction and Summary](#).
  - Whichever it is, read through the rest of these instructions now.
  - When you have finished, go to the Introduction and Summary (use the link below) and carry on reading it from Point 4, or read the first three points if you have not already done so.
  - Once you have read through the Introduction and Summary select the link at the end to the '[Background](#)' section of the Information Strategy.
  - At the end of the 'Background' section select the link to the [Map of Tables](#). This explains how the tables for the National and Local Actions are set out and lets you go to each one separately.
  - (Alternatively you can, and if you are comfortable doing so, you can select the table you want to look at directly from the Introduction and Summary and then navigate back to it from the table.)
  - Read the [National and Local Actions](#) in the table of your choice. Check the [Symbols](#) against each action which indicate which of them may be of interest to you in your particular role. Print out the [Symbols Key](#) to help you.
  - At the end of each action there is a link that leads you to the section of the document that gives [Supporting Information](#) for the action. You can move backwards and forwards between the actions and the supporting information.
  - When you have finished with one table you can return to the Map of Tables and select the next table you want to look at and so on until you have read all the tables and all the supporting information. You can also access a [Glossary of Terms](#) directly from the Contents page.
- 
- [Print this Guide \(use a colour printer if possible\)](#)
  - [Go to the Introduction and Summary](#)
  - [Follow these instructions to find your way around](#)

# Map of Tables

The **National and Local Actions** are set out in a series of five **tables** which address particular themes reflecting the needs of stakeholders for information.

Press Ctrl and click on the arrow  in the top right-hand corner of the areas below to go to each set of tables for the **National Actions** and the **Local Actions**. Within each table the 'Supporting Information' can be found by clicking on the 'more details' link at the end of each action. Make sure you have a print-out of the symbols from the [Symbols Key](#).

Which are the actions that are most relevant to you? Check out the analysis of [National Actions](#) and [Local Actions](#) by stakeholder interest.

 <b>1 Cross-Agency Working</b> <b>National Actions</b>	 <b>1 Cross-Agency Working</b> <b>Local Actions</b>
 <b>2 Information for Direct Care of Children, Young People, Mothers and Mothers-to-Be</b> <b>National Actions</b>	 <b>2 Information for Direct Care of Children, Young People, Mothers and Mothers-to-Be</b> <b>Local Actions</b>
 <b>3 Information for Secondary Purposes</b> <b>National Actions</b>	 <b>Purposes</b> <b>Local Actions</b>
 <b>4 Access to Knowledge</b> <b>National Actions</b>	 <b>Local Actions</b>
 <b>5 Training and Development</b> <b>National Actions</b>	 <b>5 Training and Development</b> <b>Local Actions</b>

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[Return to the Background section](#) 

# SYMBOLS KEY

Which Actions will be of interest to me?

Look for the following **symbols** against each of the National and Local Actions in the tables which will help you to identify whether the action is likely to be relevant to you or to someone else:

I am.....	Symbol
A patient, carer or member of the public	P
A clinician or other healthcare professional	C
Health informatics staff in local NHS organisation	H
Other member of senior staff in local NHS organisation	L
Member of senior staff in national NHS organisation	N
A commissioner, manager or planner of local services	
A social care or other non-health worker	S
A member of senior staff in a non-health agency	A

## Now

- Print this page (use a colour printer if possible)
- Refer to the symbols in the Action tables

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# Who will be interested in which National Actions?

I am.....

A child, young person, carer or member of the public

A clinician or other healthcare professional

Health informatics staff in local NHS organisation

Other member of senior staff in local NHS organisation

Member of senior staff in national NHS organisation

A commissioner, manager or planner of local services

A social care or other non-health worker

A member of senior staff in a non-health agency

Symbol

P

C

H

L

N

☀

S

A

National Actions	P	C	H	L	N	☀	S	A
1.1						X		
1.2		X	X	X	X	X	X	X
1.3		X	X	X	X	X	X	X
2.1	X	X	X	X	X	X		
2.2		X	X	X	X	X		
2.3		X	X		X	X		
2.4					X			
3.1		X	X	X	X	X		
3.2		X	X	X	X	X		
3.3		X	X	X	X	X		
3.4		X	X	X	X	X		
3.5		X	X	X	X	X		
4.1	X	X	X	X	X		X	X
4.2	X	X	X	X	X			
4.3	X							
4.4	X							
4.5	X							
5.1	X	X	X	X				
5.2		X	X	X				
5.3		X	X	X				

Print this page for ease of reference when looking at the Actions  
(use a colour printer if possible)

[Return to the Map of Tables ►](#)

# Who will be interested in which Local Actions?

I am.....

A child, young person, carer or member of the public

A clinician or other healthcare professional

Health informatics staff in local NHS organisation

Other member of senior staff in local NHS organisation

Member of senior staff in national NHS organisation

A commissioner, manager or planner of local services

A social care or other non-health worker

A member of senior staff in a non-health agency

Symbol

P

C

H

L

N

☀

S

A

Local Actions	P	C	H	L	N	☀	S	A
1.1						X		
2.1		X	X	X		X		
2.2	X	X	X	X		X		
3.1		X	X	X		X		
3.2		X	X	X		X		
3.3		X	X	X		X		
3.4		X	X	X		X		
3.5		X	X	X		X		
3.6		X	X	X	X	X		
4.1	X	X		X		X		
4.2	X	X		X		X		
5.1		X	X	X				
5.2	X	X	X	X				

Print this page for ease of reference when looking at the Actions  
(use a colour printer if possible)

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