Data Sharing Protocol

Template and considerations
Introduction:
The purpose of this document is to consider specific elements that should be included in a data sharing agreement for the purposes of sharing live birth data with children’s centres. The wording and layout of this template is not prescriptive and should be adapted to the needs of individual local authorities, and their legal requirements.

1. This document should be cross-referenced against existing privacy statements and overarching corporate data privacy protocols, procedures and statements that each party to the data sharing protocol already has in place. Prior to drawing up an agreement, the partner organisations should complete (jointly or separately) a Privacy Impact Assessment (PIA) covering this exchange of information. In addition, reference should be made to local child protection plans to ensure that the arrangements in the protocol do not undermine those in the local protection plans.

2. There are at least three organisations that could be affected by this protocol. Namely the local health service, the local authority, and the children’s centres they commission (e.g. local schools or voluntary organisations for example). The provision of children’s centres is a local authority function and third parties may be contracted to provide the centre and/or the administration of the centre, in which case they should be included in the protocol.

3. The responsibility for the data, once sourced from the health trust is that of the local authority, the data controller. The exchange of data and the data flows between the Council and the third parties should be subject to any formal and legal contractual arrangements. The third parties are data processors and any third parties should be named and the data flow and protection arrangements identified in this protocol.

4. As mentioned in ‘The Right Start’ report, the protocol should include a named ‘owner’, ideally at the Director level within both the local authority and the health service, and the Caldicott Guardian in the health service.

5. Importantly the protocol should identify that exchange of live birth data with the local authority assists in meeting some key outcomes to improve the delivery of children’s centres in the local area.

6. The protocol should reference the three requirements for data sharing (also referenced in ‘The Right Start’ report: Data sharing should (a) be appropriate, (b) ensure better and more efficient outcomes for the client, and (c) be cost-effective insofar as it produces real savings to the public purse. An example statement can be found in the endnotes.

Purpose:

1. This protocol helps to facilitate efficient, valued and timely sharing of live birth data to support the universal provision and access of children’s centres. It is designed specifically to meet shared objectives:
   • To improve their performance in contacting new families, they require details from the NHS, to include details of all new births
   • Provision of appropriate care services
   • Improving the health of the population
   • Supporting people in need
   • Supporting legal and statutory requirements
   • Managing and planning services
   • Developing interagency strategies
   • Common Assessment Framework.
2. The organisations involved in providing services to the public have a legal responsibility under provisions in The Health and Social Care Act 2012, Local Government Act 2000 and Children Act 2004 when sharing personal details, the data will be properly controlled and the individual’s rights will be respected.

3. The protocol may want to reference the following legal frameworks (or note that they meet the requirements of):

   a. *The Data Protection Act 1998*
      i. Schedule 2.1
      ii. Schedule 2.6(1)
      iii. Schedule 3.1
   
   b. *The common law duty of confidentiality*

   c. The Duty of confidence

   d. Human Rights Act 1998
      i. Article 8. This protocol ensures that data sharing is proportionate within the meaning of Article 8.2.

   e. *Caldicott Principles*

   f. The Confidentiality NHS Code of Practice

   g. The NHS Care Record Guarantee for England

   h. The Social Care Record Guarantee for England
      i. The ISO/IEC 27000 series of information security standards
         i. specifically NHS-Net and GSX

   j. The Information Security NHS Code of Practice

   k. The Records Management NHS Code of Practice

   l. *Health Act 1999*
      i. Section 27

   m. *The Health and Social Care Act 2012*
      i. Section 75

   n. *The Children Act 2004*
      i. Section 10
      ii. Section 11

   o. Children Act 2004 Information Databases Regulations 2007
      i. Paragraph 7 – data retention

   p. *Local Government Act 2000*
      i. Part 1
      ii. Part 2
      iii. Section 2(1)
      iv. Section 2(5)
      v. Section 3

q. Immigration and Asylum Act 1999
   i. Section 20

Those marked with an * are mandatory references

4. Each partner to the protocol will ensure that all of their staff who are affected by it are aware of its contents, and the obligations it and any information sharing agreements (ISA) which are created place upon them.
Elements of a data sharing agreement between partner organisations

1. The organisations party to this agreement are:
   - Name of local authority
   - Name of the local health service(s)
   - Children’s centres
   - Other ________________________________

2. Data will be transferred between the partner systems via secure encrypted transfer:
   - NHS-Net
   - GSX
   - GSE
   - Other ________________________________

3. Data is limited to:
   - Name
   - Address
   - Date of Birth
   - Mother’s Name
   - Father’s Name
   - Guardian Name
   - Other ________________________________

4. The use of data is to ensure that appropriate services are offered to the child and their parents. It is not to be used for general marketing or to promote services that do not relate to the care and health of the child or engage the parents in surveys not directly related to the improvement of services supplied by the partners to the protocol that relate to the wellbeing of the child.

5. Data will not be transferred if the parent with care or the child’s guardian has explicitly requested for it not to be shared.

6. A regular joint audit of procedures will be conducted to ensure that:
   - Informed consent is being appropriately considered by the Child’s parent or guardian.
   - Data security and data flows are being properly observed
   - Identify any new risks to the use, confidentiality and security of the shared data

7. Where appropriate the partners agree to share wider data than has been explicitly identified in the protocol for the purposes of statistical, strategic and operational management. In this case any data that should be shared will be in the form of anonymised aggregated data.

8. The protocol prohibits the use of any child data for any other purpose beyond those stated in the protocol, including commercial or business use. The Protocol will be further extended to include other public sector, private and voluntary organisations working in Partnership who deliver services.

9. This template is not proscriptive but is designed to assist in the production of a local protocol.
Each organisation should have some form of corporate overarching data sharing agreement and/or protocols at the least in the form of a framework or policy. These will typically have been prepared with some legal support and they ought to make reference to the Data Protection Act 1998.

Each organisation should have a privacy statement that describes some or all of the methods and circumstances about how the organisation collects, uses, discloses and manages personal data. This must include sensitive live birth data that can be used to identify an individual, including; name, address, date of birth, marital status. While the level of data will be limited and no medical or financial information will be exchanged the fact that a mother is expecting a baby or a baby has just been born may arguably be deduced by the action of any data exchange. Example of Sheffield Council’s privacy statement can be found at http://bit.ly/1kmFTsZ note particularly the page relating to the sharing of child data at http://bit.ly/1sfukDq

Example: Bart Health Trust core policy confidentiality code of practice http://bit.ly/1umC4Vy

The NHS and the local authority should conduct a Privacy Impact Assessment in order to evaluate potential risks in transferring data to children’s centre providers, this should be referenced in the information sharing agreement. Further information can be found in this guide produced by the Information Commissioner’s Office “Conducting Privacy Impact Assessments: Code of Practice” available here: http://ico.org.uk/for_organisations/data_protection/topic_guides/~media/documents/library/Data_Protection/Practical_application/pia-code-of-practice-final-draft.pdf

What is a child protection plan? http://bit.ly/1pCgOtl

An example outcomes statement may say that ‘The effective sharing of live birth data would (a) improve the efficiency of outreach by children’s centres, (b) the takeup of services by parents and deliver improved outcomes while minimizing the time required of them by promoting Universal Services as the first step in engaging parents, building trust and identifying needs and (c) deliver savings for tax payers through greater efficiencies and improved outcomes, while also improving the efficiency of local administration (e.g. the evaluation of interventions, minimising the amount of personal (and sensitive personal) information that is necessary to be shared), balanced against minimizing the resource implications upon partners and the privacy impact on parents to achieve the purposes outlined above.

It should be noted that the Children Act 2004 Information Databases Regulations 2007, paragraph 7 makes provision for the retention of information no longer than six years unless in cases where it may be required for section 47 of the Children Act 1989 (duty to investigate) or functions of the LSCB relating to serious case reviews or child deaths.)

Explicit consent -- Explicit consent is unmistakable. It can be given in writing or verbally, or conveyed through another form of communication such as signing or ticking or unticking of a box. Explicit consent is required when sharing data may be required for a use other than that for which the information was originally collected, or when sharing is not related to an individual’s direct health and social care.

Implied consent --Implied consent is applicable only within the context of direct care of individuals. It refers to instances where the consent of the individual patient can be implied without having to make any positive action, such as giving their verbal agreement for a specific aspect of sharing information to proceed.

Patients can change their consent at any time. Consent is not open-ended.

Public interest applies when the holder of the information believes that the public good that would be served by sharing the information outweighs both the obligation of confidentiality owed to the individual and the public good of protecting trust in a confidential service. Sets that the sharing of limited information should proportionate to the desired outcomes.

Examples of identifiable data are:
- Name
- Address
- Postcode
- Date of Birth
- NHS Number

A duty of confidence arises when one person discloses information to another in circumstances where it is reasonable to expect that the information will be held in confidence. It is accepted that information provided by data subjects is provided in confidence and must be treated as such so long as it remains capable of identifying the individual it relates to.

Article 8 of the European Convention on Human Rights was incorporated into UK law by the Human Rights Act 1998 and recognises a right to respect for private and family life:
- Article 8.1: Everyone has the right to respect for his private and family life, his home and his correspondence.
- Article 8.2: There shall be no interference by a public authority with exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic wellbeing of the country, for the prevention of disorder or crime, protection of health and morals or for the protection of rights and freedoms of others.
Any proposal for setting aside obligations of confidentiality through HRA must:

a. pursue a legitimate aim;

b. be considered necessary in a democratic society; and

c. be proportionate to the need.

xi The Caldicott Report (December 1997) and Executive Letter (January 1999) set in motion a process of continuous improvement in medical confidentiality within the National Health Service, including the organisations now comprising the Health Protection Agency (HPA). In accordance with guidance laid out in the report, the HPA has appointed a Caldicott Guardian and Security of Information Officers (SIO), whose functions are to ensure that data handling is in accordance with the recommendations of the Caldicott Committee, subsequent guidance and requirements of the Data Protection Act. These requirements especially affect data with Personal Identifiable Information (PII). See http://bit.ly/1y83ChK

x Section 27 says that NHS bodies and local authorities shall cooperate with one another (this allows for the parties of the protocol to share information) in order to secure the health and welfare of people.

xi Section 75 is the controversial section of the act that gives provision to allowing contracting out of health functions.

Part 9 deals with health and social care information, specifically the setting up of the new information centre, dissemination of information and code of confidentiality.

xii Section 10 of the Act places a duty on children’s services authorities to have arrangements in place to promote co-operation between the authority and appropriate partner agencies to improve the well-being of children and young adults from pre-birth to 19 years (25 in case of those with disabilities) in their area in relation to five key outcomes:

• Being Healthy – physical, mental, and emotional well-being

• Staying Safe - protection from harm and neglect

• Enjoying and achieving - education, training and recreation

• Making a positive contribution

• Achieving economic well-being

xiii Local Government Act 2000 part 1 gives local authorities the power to take any steps that they consider would promote the well-being of their area and their citizens. Section 2 specifically gives local authorities “a power to do anything which they consider is likely to achieve any one or more of the following objectives”:

1 the promotion or improvement of the economic wellbeing of their area;

2 the promotion or improvement of the social wellbeing of their area;

3 the promotion or improvement of the environmental wellbeing of their area.

Section 2 (5) clearly states that a local authority may do anything for the benefit of a person or an area outside their area, if the local authority considers that it is likely to achieve one of the objectives of Section 2(1).

Section 3 prevents the local authorities from doing anything (including sharing information) for the purposes of the wellbeing (including children and young adults) if they are restricted or prevented from doing so by other relevant legislation, for example, the Human Rights Act, Data Protection Act or by the common law duty of confidentiality. It is a question of proportionality.

xiv Section 20 provides for a range of information sharing for the purposes of the Secretary of State one of which is for the purpose to undertake the provision of support for asylum seekers and their dependents.

xv Consent may be obtained through the use of a check box, example wording is included in p16 of the Right Start report

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