Document Management

Revision History

<table>
<thead>
<tr>
<th>Version</th>
<th>Date</th>
<th>Summary of Changes</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.1</td>
<td>27.03.2018</td>
<td>First draft created by Nicola Quinn, Project Manager, RCP Health Informatics Unit</td>
</tr>
<tr>
<td>0.2</td>
<td>25.04.2018</td>
<td>Second draft created by Nicola Quinn, Project Manager, RCP Health Informatics Unit incorporating feedback from Karen Selby, Jan Hoogewerf, Andy Thompson, Catherine Porter, Darren Wooldridge and Geraldine Hughes</td>
</tr>
<tr>
<td>0.3</td>
<td>15.05.2018</td>
<td>Third draft created by Nicola Quinn, Project Manager, RCP Health Informatics Unit incorporating updates following expert review group meeting on 9 May 2018</td>
</tr>
<tr>
<td>0.4</td>
<td>21.05.2018</td>
<td>Fourth draft created by Nicola Quinn, Project Manager, RCP Health Informatics Unit incorporating feedback from Geraldine Hughes, Jan Hoogewerf and Andy Thompson</td>
</tr>
<tr>
<td>0.5</td>
<td>20.07.2018</td>
<td>Fifth draft created by Nicola Quinn, Project Manager, RCP Health Informatics Unit incorporating feedback from PRSB Assurance Committee</td>
</tr>
<tr>
<td>0.6</td>
<td>27.07.2018</td>
<td>Sixth draft created by Nicola Quinn, Project Manager, RCP Health Informatics Unit incorporating feedback from PRSB Assurance Committee and project board</td>
</tr>
<tr>
<td>1.0</td>
<td>05.11.2019</td>
<td>Minor update to final report cover pages, to include planned review date and route for user feedback.</td>
</tr>
</tbody>
</table>

Reviewers

This document must be reviewed by the following people:

<table>
<thead>
<tr>
<th>Reviewer name</th>
<th>Title / Responsibility</th>
<th>Date</th>
<th>Version</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helen Harger</td>
<td>NHS Digital Project Manager</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jan Hoogewerf</td>
<td>RCP, Health Informatics Unit, Programme Manager</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Karen Selby</td>
<td>Clinical Lead, Obstetrician</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neill Jones</td>
<td>Clinical Adviser, GP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Geraldine Hughes</td>
<td>Clinical Adviser, Midwife</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Andy Thompson</td>
<td>Higher Business Analyse, NHS Digital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PRSB assurance committee</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Approved by

This document must be approved by the following people:

<table>
<thead>
<tr>
<th>Name</th>
<th>Signature</th>
<th>Title</th>
<th>Date</th>
<th>Version</th>
</tr>
</thead>
<tbody>
<tr>
<td>Project board</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Glossary of Terms

<table>
<thead>
<tr>
<th>Term / Abbreviation</th>
<th>What it stands for</th>
</tr>
</thead>
<tbody>
<tr>
<td>AoMRC</td>
<td>Academy of Medical Royal Colleges</td>
</tr>
<tr>
<td>BA</td>
<td>Business Analyst</td>
</tr>
<tr>
<td>BCS</td>
<td>British Computer Society</td>
</tr>
<tr>
<td>BMA</td>
<td>British Medical Association</td>
</tr>
<tr>
<td>CCG</td>
<td>Clinical Commissioning Groups</td>
</tr>
<tr>
<td>CCIO</td>
<td>Chief Clinical Information Officer</td>
</tr>
<tr>
<td>CIO</td>
<td>Chief Information Officer</td>
</tr>
<tr>
<td>CDGRS</td>
<td>Clinical Documentation and Generic Record Standards</td>
</tr>
<tr>
<td>DHR</td>
<td>Digital Health Record</td>
</tr>
<tr>
<td>FHIR</td>
<td>Fast Healthcare Interoperability Resources</td>
</tr>
<tr>
<td>HIG</td>
<td>Health Informatics Group (of the RCGP)</td>
</tr>
<tr>
<td>HIU</td>
<td>Health Informatics Unit (of the RCP)</td>
</tr>
<tr>
<td>HL7</td>
<td>Health Level 7</td>
</tr>
<tr>
<td>HV</td>
<td>Health Visitor</td>
</tr>
<tr>
<td>LMC</td>
<td>Local Medical Committees</td>
</tr>
<tr>
<td>NIB</td>
<td>National Information Board</td>
</tr>
<tr>
<td>NHSCC</td>
<td>NHS Clinical Commissioners</td>
</tr>
<tr>
<td>PHR</td>
<td>Personal Health and Care Record</td>
</tr>
<tr>
<td>PID</td>
<td>Project Initiation Document</td>
</tr>
<tr>
<td>PRSB</td>
<td>Professional Record Standards Body for Health and Social Care</td>
</tr>
<tr>
<td>RCGP</td>
<td>Royal College of General Practitioners</td>
</tr>
<tr>
<td>RCM</td>
<td>Royal College of Midwives</td>
</tr>
<tr>
<td>RCM</td>
<td>Royal College of Midwives</td>
</tr>
<tr>
<td>RCN</td>
<td>Royal College of Nursing</td>
</tr>
<tr>
<td>RCOG</td>
<td>Royal College of Obstetricians and Gynaecologists</td>
</tr>
<tr>
<td>RCP</td>
<td>Royal College of Physicians</td>
</tr>
<tr>
<td>RCPCH</td>
<td>Royal College of Paediatrics and Child Health</td>
</tr>
<tr>
<td>RCPsych</td>
<td>Royal College of Psychiatrists</td>
</tr>
<tr>
<td>SNOMED-CT</td>
<td>Systematized Nomenclature of Medicine - Clinical Terms</td>
</tr>
</tbody>
</table>
Related Documents

These documents will provide additional information.

<table>
<thead>
<tr>
<th>Ref no</th>
<th>Title</th>
</tr>
</thead>
</table>

Document Control:
The controlled copy of this document is maintained in the HSCIC corporate network. Any copies of this document held outside of that area, in whatever format (e.g. paper, email attachment), are considered to have passed out of control and should be checked for currency and validity.

Planned Review Date and Route for User Feedback

The next maintenance review of this document is planned for August 2021, subject to agreement with NHS Digital as the commissioning body.

Please direct any comments or enquiries related to the project report and implementation of the standard to support@theprsbo.org.
Contents

1 Introduction 6
  1.1 Purpose of this document 6
  1.2 Nomenclature 6
  1.3 Background
    1.3.1 Project summary 7
    1.3.2 Policy context 7
    1.3.3 Project scope 9
    1.3.4 Project governance 10

2 Record structure 10

3 Data models 10

4 Methodology 11
  4.1 Project approach 11
  4.2 Evidence gathering and review, and mapping to existing PRSB headings 11
  4.3 Consultations via workshop 1 and survey 1 12
  4.4 Consultation via specialist review group meetings 13
  4.5 Consultation via workshop 2 and survey 2 14
  4.6 Clinical informatician review 15
  4.7 Expert review group meeting 16
  4.8 Expert review group meeting 16

5 Participation in consultation processes 16
  5.1 Participation in survey 1 16
  5.2 Participation in survey 2 18
  5.3 Participation in workshop 1 held on 9 November 2017 20
  5.4 Participation in workshop 2 held on 14 December 2017 21
  5.5 Participation in alcohol and tobacco specialist meeting on 15 January 2018 21
  5.6 Participation in mental health and well-being specialist meeting on 16 January 2018 22
  5.7 Participation in safeguarding specialist meeting held on 16 January 2018 23
  5.8 Participation in expert review group meeting held on 9 May 2018 23

6 Implementation guidance 24
1 Introduction

1.1 Purpose of this document

This document is a summary report of the maternity record standard project. It presents:

➢ Evidence and consensus based standard headings and content definitions for a maternity record with supporting data models and implementation guidance.

➢ The methodology adopted to develop the standard headings, content definitions, data models and implementation guidance for a maternity record.

NHS Digital commissioned the Professional Record Standards Body (PRSB) to undertake this project. This report has been prepared by the Royal College of Physicians’ Health Informatics Unit, which was subcontracted by the Professional Record Standards Body to facilitate development of the standard, to the point where formal endorsement is sought from the Professional Record Standards Body members. The Royal College of Midwives were represented at project board level1.

Clinical leadership has been provided by an obstetrician who is a member of the Royal College of Obstetricians and a Chief Clinical Information Officer (CCIO), a midwife who is a member of the Royal College of Nursing, a GP who is a member of the Royal College of General Practitioners, and a health visitor. In addition, a paediatrician and paediatric nurse with clinical informatics expertise and who were involved in the child health record standard project provided advice on the interface of the maternity record standard with the child health record.

1.2 Nomenclature

The project team has grappled with the language to use when describing the pregnant individual. We have received mixed feedback at every stage of the project consultation. We have used ‘woman’ in this report because it was the majority position. However, we recognise that this may change as further work is done within service user representative groups, Royal colleges and other specialist societies.

---

1 The Royal College of Midwives has a membership of 46,788 midwives, 6224 student midwives and 1214 maternity support workers
Likewise, the project struggled to come up with nomenclature to describe within the record structure and data model the health care professional that is undertaking a clinical task. We have used ‘performing professional’. This term caused some debate in the first consultation workshop; however, we do not have a satisfactory alternative.

1.3 Background

1.3.1 Project summary

This project seeks to improve care experienced by pregnant women and their babies by developing standards for a digital maternity record to allow clinical information to be recorded, exchanged and accessed consistently across care settings.

The aims of this work are:

➢ to ensure that information about the health of pregnant women and their babies will be easily available on a timely basis to anyone that may need the information (parents, health and care professionals and public health professionals), whenever they need it.

➢ to enable information to be recorded in a common language and made available to women and health and care professionals.

➢ to ensure recommendations are practical and fit for purpose by adopting an evidence-based approach and consulting widely with pregnant women and parents, health and care professionals and suppliers of maternity health information systems.

➢ to enable information to be effectively re-used for secondary purposes, such as research, audit and public health surveillance, without requiring separate data collection exercises.

➢ to support the delivery of the NHS England’s Maternity Transformation Programme and Better Births agenda.

The project built on the outputs of previous PRSB projects, including the healthy child record, the hospital discharge summary and other transfer of care standards (emergency care, mental health and ambulance to ED), and crisis care documentation.

The information models produced by this project will be used by NHS Digital to develop technical specifications which will enable interoperability between maternity records in different care settings. The implementation will be managed by NHS Digital working in collaboration with the PRSB, INTEROPen, industry and implementation sites. The ongoing maintenance of the standard will be managed through a maintenance process.

1.3.2 Policy context
‘Better births’ National maternity review (2016) and Maternity Transformation Board

The national maternity review recommended that NHS England and the National Information Board (NIB) should support the national roll out of interoperable maternity records for professional use, combined with support for a digital tool (or personal health record) for women as an urgent priority.

Four different recommendations were made, each of which relies on interoperability of health information, that is, information on an individual’s pregnancy will need to be exchanged with a range of health professionals in the network of maternity care outside of the hospital setting. These settings potentially all use different systems. The information should also be made accessible to/shared with the woman.

In the September 2016 report to the Maternity Transformation Board, NHS Digital made two recommendations in respect of a record data model and interoperability:

(1) Assume a common approach to interoperability, personal health records and use of central digital infrastructure

Child health has defined an approach to interoperability and personal health records which relies on the creation of a set of common messages (events), which will be exchangeable across systems. This approach will be tested further in the discovery period and validated within a field test. A similar model should prove viable for maternity and can be taken forward as a common requirement to be hosted on central digital infrastructure. Assuming a satisfactory discovery period, this element could be taken forward in the same programme business case for maternity: the common approach reducing overall costs and timelines for delivery.

(2) Begin work early on a maternity record specification

For interoperability of maternity information to be possible, there must be standardisation of content (data items), followed by an agreement on the technical specification for exchange. Even if a discovery phase recommends a ‘view only’ approach to professional and personal maternity records, this still requires a definition of what elements are to be viewable. Professional agreement on standard data is often difficult to achieve, so work needs to be started early given the centrality of interoperability to the digital ambitions of the Maternity Review.
The need for a standard record data model (digital maternity discovery report)

Health and care information which is to be exchanged between information systems automatically (e.g. from maternity services systems to GPs’ systems, or between different providers of maternity care using different information systems) must be in a recognisable structure and format for the receiving system to correctly present the information to a healthcare professional in an understandable manner. There is no such ‘recognisable structure and format’ agreed for maternity data, other than that required to support secondary uses of information via the Maternity Services Data Set (MSDS). This means that not only can maternity systems not talk to each other without a recognisable structure and format, (i.e. there is a lack of interoperability between maternity information systems), neither can they talk to information systems in other care settings. A standard record data model is the ‘recognisable structure and format’ needed, so that systems can ‘talk to each other’ in a common language.

1.3.3 Project scope

The project scope was set out in the project initiation document (PID). The scope included:

➢ to agree evidence and consensus based standard maternity record requirements.
➢ to agree requirements that are practical and feasible to implement and which provide stakeholders (citizens and health and care professionals) with the information that they need, noting any clinical safety and information governance considerations that arise.
➢ To achieve consensus of professional and citizen organisations to establish the maternity record as a national standard. The standard will be endorsed by appropriate professional and citizen representative bodies and the PRSB and published on the PRSB website. For a list of the main PRSB member organisations: [http://www.theprsb.org/members/](http://www.theprsb.org/members/). The final report (this document) containing the final draft record structure and data models will be published on the PRSB website after the project board has agreed the final draft.

Exclusions from the scope included:

➢ Records that are used in the provision of maternity and perinatal care in one healthcare service/setting only and which do not need to be shared outside that service/setting.
➢ Administrative headings and content definitions which do not have clinical content or use.
The header information, which will be the same for all messages, for example 'identifying type', 'originating organisation', 'IT system' etc.

What and how information pertinent to the baby contained in the maternal record including post-natal care is transferred to the child health record, HV & primary care

What & how maternal postnatal information is transferred to HV & GP records

Technical specifications (eg Fast Healthcare Interoperability Resources [FHIR] profiles), which will be developed by NHS Digital based on the requirements produced by this project.

Authoring of any new SNOMED CT terms that are required. NHS Digital will provide a terminologist to work closely with the project and to provide relevant Systematized Nomenclature of Medicine - Clinical Terms (SNOMED CT).

1.3.4 Project governance

Oversight of the project was provided by a project board. End user representation at project board level was provided by:

- An obstetrician
- A user of maternity services
- NHS Digital
- A health visitor
- A midwife
- A GP with specialist interest in perinatal mental health
- A paediatrician

Clinical leadership and advice at project team level was provided by an obstetrician, a midwife, a GP and a health visitor.

2 Record structure

Please refer to the data model and NHS Digital's implementation guidance when reading this document. These can be found on the PRSB website at www.theprsb.org/standards/maternityrecord/ in supporting documentation.

3 Data models

Please refer to the record structure document above and NHS Digital’s implementation guidance when reading this document. These can be found on the PRSB website at www.theprsb.org/standards/maternityrecord/ in support documentation.
4 Methodology

4.1 Project approach

The project was conducted according to the editorial principles for the development of record standards, developed by the RCP and adopted by the PRSB. The focus was on:

➢ Identifying what information pregnant women and their healthcare professionals require in a maternity record and what information it would be preferable to have in a coded form.

➢ Identifying what structured (and coded) information it is feasible to include in a maternity record and how this may change with the implementation of more integrated digital patient record systems. This will help to inform phasing of implementation in trusts.

➢ Engaging with pregnant women, parents, specialists and relevant professional bodies to ensure that the standard meets their needs, they are engaged and support implementation of a maternity record, based on the standard.

4.2 Evidence gathering and review, and mapping to existing PRSB headings

This section outlines the evidence gathering and review processes undertaken to develop the first draft of the standard.

Purpose:

➢ To develop a first draft of the record headings, content definitions and data models that are evidence based.

Following the national maternity review and recommendations (Better Births https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf) NHS Digital commenced the discovery process in February 2017 to establish an understanding of the variation and the issues related to record structure and data collection within maternity services country wide. The first expert reference group for midwives was held in February 2017 during which there was an introduction to the record review and participants were asked to share their local hand held notes.

Following this an extensive review of both the hand held notes and several leading maternity digital record systems in England was undertaken and general themes identified. This content was:

---

Data sources consulted in development of initial draft
➢ reviewed to identify the purpose for which the information was collected and how it would be used;
➢ mapped against PRSB endorsed standards to identify where existing headings could be used as they are, what existing headings needed to be amended for the maternity use case and what new headings needed to be developed for the maternity use case. The content was mapped to the PRSB Healthy Child Record standard, the 2013 Academy of Medical Royal College’s (AoMRC) clinical record standards and subsequent PRSB standards, including transfer of care standards and crisis care documentation standards.

Findings from the mapping exercise were used to create draft 1 of the maternity record structure.

4.3 Consultations via workshop 1 and survey 1
This section outlines the consultations that happened at workshop 1 and via survey 1.

Purposes:
➢ To develop a second draft of the record headings, content definitions in relation to antenatal care, and evidence based implementation guidance. The views of key stakeholders on the draft were captured and considered at this early stage.
➢ To ensure that the project products are consensus-based.

Consultation workshop
Draft 1 of the headings and content definitions were discussed at a consultation workshop held on 9 November 2017. There were 57 attendees (see Section 5.3), comprising parents, voluntary sector, health/care professionals, industry and other stakeholders.

Areas consulted on in the workshop were:
• Review of the overall maternity record structure headings and definitions, to identify gaps and overlaps
• Detailed discussion on 'medical history'
• Detailed discussion on 'clinical risk factors'.

Perinatal institute notes: http://www.preg.info/PerinatalNotes/Default.aspx
Maternity Services Dataset - http://content.digital.nhs.uk/maternityandchildren/maternity
NHS Data Dictionary - http://www.datadictionary.nhs.uk/
Public Health England Screening Programmes
Several Maternity Department Record notes in England
Several Clinical System Supplier records in England
PDS requirements for patient demographic details
Post consultation review

Following the workshop, the consultation findings were discussed with the project clinical lead and clinical advisors in a telephone call. This informed the second draft of standard headings and content definitions, data models and the first draft implementation guidance.

The project team used the findings from the workshop to identify:

➢ areas to be discussed in three specialist review meetings, held in January 2018;
➢ items to be put to wider consultation via survey.

Survey 1
The survey was open from 8 December 2017 to 22 January 2018.

Areas covered in the survey were:
1. What types of 'investigation results' would be expected to be included in a maternity record?
2. How should ‘family history’ be recorded?
3. How should ‘clinical risk factors’ be recorded?
4. What types of information should be recorded under ‘past obstetric history’?
5. Should a pregnancy that ends before 24 weeks be referred to as ‘fetal loss' or ‘fetal demise’?

There were 815 responses to the survey. Findings from the survey can be found at www.theprsb.org/standards/maternityrecord/ in supporting documentation. A breakdown of respondents can be found in section 5.1 of this report.

The project team reviewed the findings from the survey and recommended changes to the draft record headings, definitions and implementation guidance. The following criteria were used by the project team when reviewing the findings

a) a significant majority of respondents demonstrate a preference for a position;
b) a stronger rationale for an alternative minority position is demonstrated, e.g. patient safety;
c) a suggestion is not assessed as practical to implement at this time.

4.4 Consultation via specialist review group meetings

The project team identified early in the project that some areas of the record needed dedicated time with clinical and subject specialists to work through the maternity use cases. In response three specialist review meetings were convened.

Purposes:
➢ To gain expert input into areas of the maternity record identified as requiring specialist exploration, before being consulted on more widely.

➢ To ensure that the draft models developed are evidence and consensus based.

There were three specialist meetings in January 2018. The themes were mental health and well-being, safeguarding and tobacco and alcohol intake.

The outputs from the specialist meetings informed:

➢ the second and third drafts of the headings, definitions and data models
➢ content for the implementation guidance
➢ items to be put to wider consultation via survey 2.

A list of those who attended the specialist review group meetings can be found in sections 5.5 – 5.7 of this report.

4.5 Consultation via workshop 2 and survey 2

Please find below the consultation processes employed in workshop 2 and survey 2.

Purposes:

➢ To develop a third draft of the record headings, content definitions in relation to intrapartum and postnatal, and evidence based implementation guidance. Please note that extensive consultation on the components of a postnatal baby record took place during the Healthy Child project (2017). It was decided by the project team that a repeat of that consultation was not necessary; therefore resources went into consulting on areas of the record not previously consulted on.

➢ To ensure that the project products are consensus-based.

Consultation workshop

Draft 2 of the headings and content definitions were discussed at a consultation workshop held on 14 December 2018. There were 67 attendees, comprising of parents, voluntary sector, health/care professionals, industry and other stakeholders.

Areas consulted on in the workshop were:

• Pregnancy assessment and intrapartum assessment
• Birth record
• Birth and management plan

Post consultation review
Following the workshop, the outcomes were discussed with the project clinical lead and clinical advisors in a telephone call. This informed the third draft of standard headings and content definitions, data models and the first draft implementation guidance.

The project team used the findings from the workshop to identify items to be put to wider consultation via survey 2.

Survey 2
The survey was open from 1 March 2018 to 19 March 2018.

Areas covered in the survey were:

1. Smoking of tobacco and alcohol intake
2. Mental health and well-being
3. Safeguarding and social risk factors
4. Delivery and birth record
5. Immunisations

There were 761 responses. Findings from the survey can be found at www.theprsb.org/standards/maternityrecord/ in supporting documentation. A breakdown of survey respondents can be found in section 5.2 of this report.

The project team reviewed the findings from the survey and recommended changes to the draft record headings, definitions and implementation guidance. The following criteria were used by the project team when reviewing the findings:

a) A significant majority of respondents demonstrate a preference for a position;
b) A stronger rationale for an alternative minority position is demonstrated, e.g. patient safety;
c) A suggestion is not assessed as practical to implement at this time.

4.6 Clinical informatician review
Draft 3 headings, definitions and data models were shared with clinical informaticians and other experts. The whole record structure and data models were circulated to thirty-four system suppliers, clinical informaticians and terminology/technical specialists for their review. An additional fifty-two clinicians and specialists were invited to feedback on subsections of the record related to their specialities/area of expertise. The clinicians and specialists had attended earlier consultations, e.g. workshop or specialist review group meeting.

One hundred and thirty-seven comments were received from seventeen respondents. The comments were collated and reviewed in an all-day project team meeting on 11 April 2018. The record standard and data model was updated.
4.7 Expert review group meeting

Draft 4 of the headings, definitions and data models were reviewed at an expert review group meeting held from 10am-4pm on 9 May 2018. The purpose of this meeting was to discuss any issues not resolved through the previous consultation processes. The project team took examination findings, social context and relevant past, medical, surgical and mental health history to the meetings. Attendees brought the use of SNOMED CT and medications and medical devices. A list of attendees can be found in section 5.8 of this report.

4.8 Expert review group meeting

The PRSB Assurance Committee were asked to review an earlier draft of this document for quality and adherence to the PRSB standard development process. They were content that the PRSB process had been followed but raised concerns about whether the content of two standard headings, ‘relevant past medical, surgical and mental health history’ and ‘examination findings’, would support interoperability outside maternity settings, a key benefit of having a standard and a driver behind the project. The project team devised revised structures for these headings being mindful of the findings from extensive consultations on this area with healthcare professionals and women during the project. The revisions were discussed with the assurance committee and a draft agreed. The draft was circulated to expert review group meeting attendees and others identified by project board members for comment. The project team reviewed the feedback, which was positive, and confirmed the final draft included in this document.

5 Participation in consultation processes

5.1 Participation in survey 1

Eight hundred and fifteen people participated in the survey. A breakdown by respondent role is presented below:

<table>
<thead>
<tr>
<th>Role</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pregnant woman or parent</td>
<td>115</td>
<td>13.81%</td>
</tr>
<tr>
<td>Allied health professional</td>
<td>9</td>
<td>1.08%</td>
</tr>
<tr>
<td>General practitioner</td>
<td>15</td>
<td>1.80%</td>
</tr>
<tr>
<td>Health visitor</td>
<td>11</td>
<td>1.32%</td>
</tr>
<tr>
<td>Health/care system vendor or developer</td>
<td>6</td>
<td>0.72%</td>
</tr>
<tr>
<td>Informatician</td>
<td>9</td>
<td>1.08%</td>
</tr>
<tr>
<td>Midwife</td>
<td>552</td>
<td>66.27%</td>
</tr>
<tr>
<td>NHS administration/ management</td>
<td>32</td>
<td>3.84%</td>
</tr>
<tr>
<td>Role</td>
<td>Count</td>
<td>Percentage</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>-------</td>
<td>------------</td>
</tr>
<tr>
<td>Nurse</td>
<td>19</td>
<td>2.28%</td>
</tr>
<tr>
<td>Obstetrician</td>
<td>52</td>
<td>6.24%</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>2</td>
<td>0.24%</td>
</tr>
<tr>
<td>Secondary care doctor (not obstetrician)</td>
<td>11</td>
<td>1.32%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>*<em>833</em></td>
<td><strong>100.00%</strong></td>
</tr>
</tbody>
</table>

* some respondents chose to enter two roles, eg informatician and clinician

Respondents were asked to provide their speciality or discipline, healthcare professional respondents had experience of at least one of the following specialties or service areas:

- Ambulatory care
- Anaesthesia
- Antenatal care
- Clinical practice facilitator
- General practice
- Gynaecology
- Home birth specialist
- Infectious diseases
- Information systems
- Maternity
- Nursing
- Obstetrics
- Paediatrics
- Patient safety
- Perinatal mental health
- Pharmacy
- Pregnant persons and parent representation
- Provision to pregnant migrants
- Psychiatry
- Public health
- Research
- Risk and governance
- Safeguarding
- Screening
5.2 **Participation in survey 2**

**Participation** Seven hundred and sixty-one people participated in the survey. A breakdown by respondent role is presented below.

<table>
<thead>
<tr>
<th>Role</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pregnant woman or parent</td>
<td>250</td>
<td>29.4</td>
</tr>
<tr>
<td>Allied health professional</td>
<td>20</td>
<td>2.4</td>
</tr>
<tr>
<td>General practitioner</td>
<td>10</td>
<td>1.2</td>
</tr>
<tr>
<td>Health visitor</td>
<td>25</td>
<td>2.9</td>
</tr>
<tr>
<td>Health/care system vendor or developer</td>
<td>10</td>
<td>1.2</td>
</tr>
<tr>
<td>Informatician</td>
<td>25</td>
<td>2.9</td>
</tr>
<tr>
<td>Midwife</td>
<td>336</td>
<td>39.6</td>
</tr>
<tr>
<td>NHS administration/ management</td>
<td>46</td>
<td>5.4</td>
</tr>
<tr>
<td>Nurse</td>
<td>35</td>
<td>4.1</td>
</tr>
<tr>
<td>Obstetrician</td>
<td>38</td>
<td>4.5</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Secondary care doctor (not obstetrician)</td>
<td>42</td>
<td>4.9</td>
</tr>
<tr>
<td>Other</td>
<td>12</td>
<td>1.4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>849*</td>
<td>100</td>
</tr>
</tbody>
</table>

* some respondents chose to enter two roles, eg informatician and clinician

Respondents were asked to provide their speciality or discipline, healthcare professional respondents had experience of at least one of the following specialties or service areas:
Acute medicine
Anaesthesia
Obstetric anaesthetist
Antenatal care
General practice
Dietetics
Domestic abuse
Gynaecology
Home birth specialist
Infectious diseases
Information systems
Midwifery
Neonatal medicine
Nursing
Obstetrics
Occupational therapy
Oncology
Paediatrics
Paramedic
Patient safety
Perinatal mental health
Physiotherapy
Pregnant persons and parent representation
Provision to pregnant migrants
Psychiatry
Psychology/therapy
Public health and policy
Radiographer
Research
Risk and governance
Social work
Safeguarding
Screening
5.3 Participation in workshop 1 held on 9 November 2017
Fifty-seven people attended representing:

- Pregnant women and parents
- Allied health professionals
- Analysts
- Chief Clinical Information Officers (CCIOs)
- Child health information systems support staff
- General practice
- Health visiting
- Informatics
- IT
- Midwifery
- Obstetrics
- Public health
- Policy makers
- System developers
5.4 Participation in workshop 2 held on 14 December 2017

Sixty-seven people attended representing:

Pregnant women and parents
CCIOs
Child Information systems support staff
General practice
Health visiting
Informatics
IT
Midwifery
Neonatology
Obstetrics
Paediatrics
Perinatal psychiatry
Public health
Policy makers
System developers

5.5 Participation in alcohol and tobacco specialist meeting on 15 January 2018

Amanda Farley  Lecturer in Public Health and Epidemiology Institute of Applied Health Research, University of Birmingham (*joined via WebEx*)

Andy Thompson  Business Analyst, NHS Digital

Darren Wooldridge  Project Manager, Health Informatics Unit, Royal College of Physicians

Don Lavoie  Alcohol Programme Manager, Public Health England

Geraldine Hughes  SME Midwife (Clinical Informatics), NHS Digital (Child Health – Maternity) and clinical adviser to the maternity record standard project

Hazel Cheeseman  ASH Action on Smoking and Health, Director of Policy

Helen Harger  Senior Clinical Product Manager, NHS Digital and clinical adviser to and NHS Digital project Manager (interim) for the maternity record standard project

Janet Duckworth  Community Midwife, Morecambe Bay NHS Trust

Jill Demilew  Consultant Midwife Public Health, King’s College Hospital NHSFT

Jo Locker  Tobacco in pregnancy lead, Public Health England

Karen Selby  Consultant, Obstetrics, Gynaecology and Neonatology, Sheffield Teaching Hospitals NHS Foundation Trust, CCIO and clinical lead to the maternity record standard project

Michael Lumb  Obstetrician and CCIO North West Anglia NHS Foundation Trust

Michael Ussher  Professor of Behavioural Medicine, St George’s, University of London
Michelle Littlejohn  Health and Wellbeing Midwife, University Hospitals of Morecambe Bay, NHS Foundation Trust *(joined via WebEx)*

Neill Jones  Senior Clinical advisor to NHS Digital working on GP Systems of Choice (GPSSoC) and clinical adviser to the maternity record standard project

Nick Sheron  Faculty of Medicine, CES Academic Unit, University of Southampton

Nicola Quinn  Project Manager, Health Informatics Unit, Royal College of Physicians

Yvonne Herman  Smoking in Pregnancy Consultant and Pregnancy Lead for NCSCT, Office of Public Health, Dudley

Shamil Haroon  Academic Clinical Lecturer, Institute of Applied Health Research, University of Birmingham *(joined via WebEx)*

5.6  **Participation in mental health and well-being specialist meeting on 16 January 2018**

Adrian Burke  Consultant Adult Psychiatrist, Cheshire and Wirral NHS Trust

Andy Thompson  Business Analyst, NHS Digital

Geraldine Hughes  SME Midwife (Clinical Informatics), NHS Digital (Child Health – Maternity) and clinical adviser to the maternity record standard project

Helen Harger  Senior Clinical Product Manager, NHS Digital and clinical adviser to and NHS Digital project Manager (interim) for the maternity record standard project

Jill Demilew  Consultant Midwife Public Health, King’s College Hospital NHSFT

Juli Broder  Advanced Nurse Practitioner for Perinatal Mental Health, Peterborough and Borders Adult Locality

Julie Fallows  Community Midwife – Specialist in Mental Health, Royal Lancaster Infirmary/Westmorland General Hospital

Lesley Edwards  Advanced Midwife Practitioner for Mental Health and Learning Disabilities, Peterborough

Karen Selby  Consultant, Obstetrics, Gynaecology and Neonatology, Sheffield Teaching Hospitals NHS Foundation Trust, CCIO and clinical lead to the maternity record standard project

Livia Martucci  Consultant Perinatal Psychiatrist

Maurina Baron  Senior Lecturer in Midwifery, Middlesex University

Michael Lumb  Obstetrician and CCIO North West Anglia NHS Foundation Trust

Nazmin Begum  Specialist Midwife for Perinatal Mental Health, Bart’s Health NHS Trust

Neill Jones  Senior Clinical advisor to NHS Digital working on GP Systems of Choice (GPSSoC) and clinical adviser to the maternity record standard project

Nicola Quinn  Project Manager, Health Informatics Unit, Royal College of Physicians
5.7 Participation in safeguarding specialist meeting held on 16 January 2018

Aileen Masson  Screening, Public Health England
Andy Thompson  Business Analyst, NHS Digital
Anna Davies  Named Midwife for Safeguarding, Bart’s Health NHS Trust
Catherine Randall  Deputy Head of Safeguarding, Nursing and Midwifery Team, NHS England *(joined via WebEx)*
Chris Dickson  Principal Clinical Informatics Specialist, NHS Digital
Claire Mathews  Deputy Head of Maternity, NHS England *(joined via WebEx)*
David Low  NHS Digital and Paediatrician
Geraldine Hughes  SME Midwife (Clinical Informatics), NHS Digital (Child Health – Maternity) and clinical adviser to the maternity record standard project
Helen Harger  Senior Clinical Product Manager, NHS Digital and clinical adviser to and NHS Digital project Manager (interim) for the maternity record standard project
Jan Hoogewerf  Programme Manager, RCP Health Informatics Unit
Jane Heath  Midwife Specialist in Safeguarding
Jasvir Jutle  Specialist Midwife for Safeguarding, Bart’s Health NHS Trust
Jill Demilew  Consultant Midwife Public Health, King’s College Hospital NHSFT
Karen Selby  Consultant, Obstetrics, Gynaecology and Neonatology, Sheffield Teaching Hospitals NHS Foundation Trust, CCIO and clinical lead to the maternity record standard project
Livia Martucci  Perinatal Psychiatrist
Michael Lumb  Obstetrician and CCIO North West Anglia NHS Foundation Trust
Neill Jones  Senior Clinical advisor to NHS Digital working on GP Systems of Choice (GPSoC) and clinical adviser to the maternity record standard project
Nicola Quinn  Project Manager, RCP Health Informatics Unit
Sarah Green  Clinical Quality and Safety Manager (Safeguarding Portfolio), NHS England (London Region)
Yetunde Akinnuoye  Lecturer in Midwifery and Safeguarding Lead, Middlesex University

5.8 Participation in expert review group meeting held on 9 May 2018

- Peter Badger, MD, Clevermed Ltd
- Dave Barnet, NHS Digital
- Jonathan Behr, GP and Chief Medical Officer, Vision (In Practice Systems Ltd)
- Andrea Blotkamp, Clinical Fellow (Midwifery), National Maternity and Perinatal Audit, Lindsay Stewart Centre for Audit and Clinical Informatics, Royal College of Obstetricians and Gynaecologists
- Lia Brigante, Quality and Standards Advisor, Royal College of Midwives
- Colin Brown, GP and informatician
- Silas Collinge, Business Analysis Manager, NHS Digital
- Rhona Dalziel, Product Owner - Maternity, Healthcare and Life Sciences DXC technology (Lorenzo)
6 Implementation guidance

The maternity record standard implementation guidance is being developed by NHS Digital in collaboration with the project team responsible for this work. Please find below items for inclusion in the NHS Digital implementation guidance document identified during the consultation processes outlined above.

General points
• Only send information recorded at a point in time, not what was recorded previously as this information will already be available in the record.
• Where no information has been recorded, a blank record should not be sent, except for mandatory items where a ‘null’ record should be sent, with explanatory coded text eg ‘no information recorded’.

**Time stamps**
Time stamps in the record should be GMT.

**Movement between services**
Any transfer of care or movement between services, eg during labour, can be recorded using existing headings. Some systems may decide to create a template for transfers of care using the headings.

**Performing professional, date and location**
All records of clinical activity MUST include the following information: the professional performing the activity, date and location. The professional undertaking clinical work may be a separate person to the person entering the data on the system. In this instance both should be recorded.

**Social context**
It is not necessary to include the ‘performing professional’ and ‘location’ for social context information. This is because social context does not record a clinical intervention. The date that the information is entered into the system and who enters it should be recorded. It is important that the recipient knows the date that the information is recorded so that changes can be tracked over time, if needed.

**Social context – smoking**
Whether a woman attended a smoking cessation referral appointment can be recorded under the ‘smoking’ ‘comment’ section of the record.

**Social context - Alcohol**
Current alcohol consumption, alcohol consumption prior to pregnancy and alcohol consumption during the first few weeks of pregnancy should all be recorded. Where frequency of alcohol consumption and frequency of binge drinking are greater than one a week the actual number of days should be recorded.

**Professional summary/comment**
This is the place to record day-to-day/ case notes.

**Relevant past, medical, surgical and mental health history**
This section is used to record inactive conditions. Some systems may decide to add start and end dates to relevant past history.

**Fertility treatment**
Assisted conception can be recorded under gynecology history (relevant past medical, surgical and mental health history). Information on assisted conception of the current pregnancy can be linked to the relevant dataset by NHS number if the treatment took place in England.
 Obstetric history  
Length of labour: length of labour should be stored in minutes, but displayed in hours and minutes.

 Examination findings  
A number of fields are marked as required but will be mandatory at some appointments. It is up to local settings to decide when a required element is upgraded to mandatory.

**Crown-rump length** must be measurable to one decimal place.

**Fetal heart rate** indication and method for measuring should be completed.

 Birth details  
Gestation at birth should be stored in days, but displayed in weeks and days.

 Medication and medical devices  
The purpose of the record is to record medication taken prior to and at conception and current medication (these will be snapshots as and when recorded). The relevant transfer of care information models can be used for referral, discharge, and outpatient medication.

 Screening – sickle cell and thalassemia  
The outcome of the ‘venous sample performed to screen for sickle cell and thalassemia’ will be recorded from the blood test result. This will be entered by the midwife until systems are integrated.

 Screening – diabetic eye screening  
The screening review may be repeated during the pregnancy, ie there may be more than one diabetic screening record. Professional name: this should record the name of the person who graded the image. The name will be entered by the midwife from the screening report until the systems are integrated.

 Family history  
‘Family’ in this context refers to blood relations only. It is important to identify where the woman is not the biological mother.

 Outcome of pregnancy  
Where a pregnancy outcome is not a live birth, it is recommended that a local flag is displayed in the record so that it can easily be seen, and so prevent situations where a woman who has had a miscarriage presents to a service whose records show that she is still pregnant. There needs to be local agreement on information sharing and integration between early pregnancy assessment/ pregnancy related gynae and maternity services to allow for information transfer/sharing.