IHE Patient Care Coordination (PCC) Technical Framework Supplement

Newborn Discharge Summary (NDS)

Trial Implementation

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Foreword

This is a supplement to the IHE Patient Care Coordination Technical Framework V6.0. Each supplement undergoes a process of public comment and trial implementation before being incorporated into the volumes of the Technical Frameworks.

This supplement is submitted for Trial Implementation as of August 30, 2010 and will be available for testing at subsequent IHE Connectathons. The supplement may be amended based on the results of testing. Following successful testing it will be incorporated into the Patient Care Coordination Technical Framework. Comments are invited and may be submitted on the IHE forums at http://forums.rsna.org/forumdisplay.php?f=309 or by email to pcc@ihe.net.

This supplement describes changes to the existing technical framework documents and where indicated amends text by addition (bold underline) or removal (bold strikethrough), as well as addition of large new sections introduced by editor’s instructions to “add new text” or similar, which for readability are not bolded or underlined.

“Boxed” instructions like the sample below indicate to the Volume Editor how to integrate the relevant section(s) into the relevant Technical Framework volume:

Replace Section X.X by the following:

General information about IHE can be found at: www.ihe.net

Information about IHE Patient Care Coordination can be found at:

http://www.ihe.net/Domains/index.cfm

Information about the structure of IHE Technical Frameworks and Supplements can be found at:

http://www.ihe.net/About/process.cfm and http://www.ihe.net/profiles/index.cfm

The current version of the IHE Technical Framework can be found at:

http://www.ihe.net/Technical_Framework/index.cfm
CONTENTS

INTRODUCTION ............................................................................................................................................. 3

HOW TO READ THE NEWBORN DISCHARGE SUMMARY PROFILE SUPPLEMENT .................................. 3
HOW TO ACCESS THE REFERENCE MATERIAL ....................................................................................... 4
OPEN ISSUES AND QUESTIONS .................................................................................................................... 4
CLOSED ISSUES ................................................................................................................................................ 5

VOLUME 1 – PROFILES .................................................................................................................................. 6

1.5 COPYRIGHT PERMISSIONS .................................................................................................................... 6
2.4 DEPENDENCIES OF THE PCC INTEGRATION PROFILES .................................................................. 6
2.5 HISTORY OF ANNUAL CHANGES ........................................................................................................ 6

X NEWBORN DISCHARGE SUMMARY PROFILE ........................................................................................... 7

X.1 PURPOSE AND SCOPE ............................................................................................................................ 7
X.2 PROCESS FLOW ........................................................................................................................................... 9
  X.2.1 Use Cases ........................................................................................................................................... 9
  X.2.2 Diagrams ........................................................................................................................................... 11
X.3 ACTORS/TRANSACTIONS ......................................................................................................................... 11
  X.3.1 Requirements of Actors .................................................................................................................... 11
X.4 OPTIONS .................................................................................................................................................... 11
X.5 GROUPINGS .............................................................................................................................................. 12
X.6 SECURITY CONSIDERATIONS ................................................................................................................... 12
X.7 CONTENT MODULES ............................................................................................................................... 12

GLOSSARY ...................................................................................................................................................... 14

VOLUME 2 – TRANSACTIONS AND CONTENT MODULES ............................................................................. 15

5.0 NAMESPACEs AND VOCABULARIES ...................................................................................................... 16
  5.1 IHE FORMAT CODES ............................................................................................................................. 16

6.0 PCC CONTENT MODULES ......................................................................................................................... 17
  6.3 HL7 VERSION 3.0 CONTENT MODULES ............................................................................................... 17
  6.3.1 CDA Document Content Modules .................................................................................................. 17
Introduction

This supplement is written for Trial Implementation. It is written as changes to the documents listed below. The reader should have already read and understood these documents:

1. PCC Technical Framework Volume 1, Revision 6.0
2. PCC Technical Framework Volume 2, Revision 6.0

This supplement also references other documents¹. The reader should have already read and understood these documents:

1. IT Infrastructure Technical Framework Volume 1, Revision 7.0
2. IT Infrastructure Technical Framework Volume 2, Revision 7.0
3. IT Infrastructure Technical Framework Volume 3, Revision 7.0
4. The Patient Identifier Cross-Reference (PIX) and Patient Demographic Query (PDQ) HL7 v3 Supplement to the IT Infrastructure Technical Framework.
5. HL7 and other standards documents referenced in Volume 1 and Volume 2

How to read the Newborn Discharge Summary Profile supplement

Please see the below documents that will need to referenced to fully understand the profiles in this supplement. Each document has a short description describing what is contained.

1. **Perinatal Workflow (PW):** makes use of the antepartum, labor and delivery, postpartum, and newborn delivery profiles (some are in this supplement and many are in other supplements).

2. **Content Modules Supplement:** This document contains all PCC Section Templates, Entry Templates and Value Sets that are NOT in Final Text (that is, they are not in the Technical Framework Volume 2).

3. **PCC Technical Framework Volume 2, Revision 6.0 (published August 2010):** This contains all PCC Section Templates, Entry Templates and Value Sets (among other things) that ARE in Final Text.

¹ The first four documents can be located on the IHE Website at http://www.ihe.net/Technical_Framework/index.cfm#IT. The remaining documents can be obtained from their respective publishers.
How to Access the Reference Material

To access Perinatal Workflow and Content Modules supplements as well as PCC Technical Framework Volume 2 Revision 6.0 refer to the same web page from which you accessed this supplement.

Open Issues and Questions

1) Several sections are pulled over from other related profiles (and sometimes added to) and we need to address how to resolve this. It is likely something in the Groupings section, but could also go in an appendix as this same need applies to Antepartum and Labor and Delivery profiles.

2) A Process Flow Diagram is still needed to represent the flow of this data between systems.

3) The Vital Records Birth Registration does not yet exist as a Content Profile but is one of the context areas that will interact with the NDS. Use of a placeholder may be appropriate.

4) Newborn screening lab results are sent to the hospital using HL7 v2.5.1 messages and public health labs will not generate V3 XD-Lab reports but having such document reports will be useful. There is no profile for newborn screening labs but one is not necessary because it builds on existing lab message profiles constrained by special vocabularies and sample messages developed and maintained at NLM. It is not clear whether a profile is needed for newborn screening labs (NBSL) or if the NDS can be a content consumer for NBSL and integrate the data into the NDS eliminating the need for a separate XD-Lab document or a newborn screening lab document conforming to XD-lab could be produced and included in a folder with the NDS. It also would be possible to create a separate content profile for newborn screening, but it may be more appropriate to keep newborn screening results as part of the laboratory result section of a newborn discharge medical summary. The key issue determining how newborn screening lab results should be handled is the problem that they are typically sent to the hospital after the newborn has left the hospital.

5) Newborn Hearing Screening is being developed as its own profile in 2010 and until it is complete and it is clear what it includes, it must be a placeholder for NDS. The EHDI profile calls for sending the results as an Early Hearing Care Plan (EHCP) which is a separate document from the NDS and includes both the hearing screening results and decision support recommendations. Some hospitals enter the hearing screening results directly on the NDS and some attach it as a separate document such as the EHCP.

6) The NDS includes data on both the mother and the newborn that are stored in the newborn’s record. It will be necessary to carefully develop methods for correctly
identifying the patient on which the data elements were collected. Separate sections have been included for maternal, fetal, and newborn labs based on other perinatal profiles.

7) A special problem occurs in the problem list where problems identified in the mother are relevant for the newborn and should either be entered as part of the family history using the codes and terms relevant to the mother, or in the newborn’s problem list under a different code and term such as exposure to HIV for the newborn whose mother has HIV. Qualifiers such as “Family History of …” do not work correctly for the newborn’s problem list and can misidentify newborns as having problems which they do not have but may only be at risk for.

8) This year, the QRPH profiles are limited to EHDI and Newborn Metabolic Screening by dried blood spot (NBS) was not included. In future years, there may be a need to coordinate with a QRPH NBS profile and other bedside newborn screening devices (in addition to hearing testing) such as oxygen saturation for congenital heart disease or transcutaneous bilirubin measurement may generate screening results that need to be added to the NDS.

Closed Issues

1) The content creator of an NDS also functions as a content consumer for other profiles. Proper representations of these roles will be important. This is out of scope of this profile other than brief mention in the Process Flow section. Details of workflow will be handled in future work (Pediatric Workflow).
Volume 1 – Profiles

Add the following to section 1.5

1.5 Copyright Permissions

Add the following to section 2.4

2.4 Dependencies of the PCC Integration Profiles

Add the following to section 2.5

2.5 History of Annual Changes

Add Section X
X Newborn Discharge Summary Profile

The Newborn Discharge Summary represents a summary of the most critical information to a newborn care provider after discharge from the birthing facility. For 2010, the scope will be constrained to newborn discharges cared for in a normal newborn nursery and will not include newborns with complex problems cared for in a NICU. The NDS draws heavily on other content profiles and can also be used to display the results of newborn screening tests when they are available. As newborn screening results may not be available until after the newborn goes home, updating the NDS can be an effective strategy for transferring these results to future medical home (because the medical home is not always identified before the newborn leaves the hospital but the family can always identify the birthing facility where the birth occurred.)

Newborn hospital discharge represents the first transfer of care for the over 4 million newborns born in the United States each year. The NDS can play a critical role in creating a new ambulatory EHR for the newborn at the time of their first office visit which is usually 2 or 3 days after they leave the birthing facility. Information recorded on the NDS can accurately be filed in the newborn’s lifetime record. The NDS also can play a critical role in assuring that all care requirements identified during newborn hospitalization are met after discharge and can provide the basis for quality measurement reporting and provide data required for clinical decision support.

X.1 Purpose and Scope

The newborn discharge is produced when a newborn leaves the hospital and can play a critical role in creating a new ambulatory EHR at the time of the first visit following discharge. Many of the data elements that are recorded on the NDS should become a part of the lifetime record but often are not available in a newborn’s record if data is not transferred from the hospital. Ideally this data, such as the birth weight, time of birth, discharge weight, and hepatitis B immunization, should be discretely imported into the ambulatory record, but it is useful to import that data as an intact document. The same NDS can also be used to start a personal health record for the newborn.

For 2010, the NDS will be constrained in scope to the care of a newborn who did not require special care in a Neonatal Intensive Care Unit (NICU) and did not have any complex problems requiring extended stay or more complex treatment. In future years, the scope of the NDS can be expanded to include the more complex events that occur during NICU admissions.

The NDS is an example of a short stay hospital record (as sanctioned by The Joint Commission) where a single document serves several functions. A short stay hospital record includes the admission history and physical, a discharge note, and all significant progress notes so that it contains all necessary elements of a hospital discharge summary and a separate dictated discharge summary is not required. A short stay hospital record produces the discharge summary as an on-going process during the hospital stay rather than as a separate process.
Much of the data required to complete a NDS is available in other documents found other places such as the Antepartum Record and in the Labor and Delivery Record. An important purpose of the NDS is to provide accurate capture and re-use of data that was originally collected on the mother but that is of significance to the newborn.

A key purpose of the NDS is to coordinate care that is incomplete at the time of discharge and that will need to be completed in the ambulatory setting, such as repeat hearing screening or consults, or imaging studies that were ordered but not completed during the hospital or birthing facility stay.

Clinical decision support can be used to determine care requirements for newborns after discharge, and a key purpose of the NDS is to provide necessary data elements to drive CDS in the ambulatory setting.

Quality of care measures are being developed by the National Committee on Quality Assurance (NCQA) to track completion of all mandated newborn screening activities. The NDS is expected to provide key data elements necessary to measure quality which will involve integration of data from the hospital or birthing center with data from ambulatory care.

Family history is an important component of a newborn’s medical record and newborn discharge is a good time to collect an initial family history. The NDS will include sections in the medical summary designed to contain the family history. Tools are available to collect family history that could be utilized to transfer data to the NDS.

During the newborn hospital or birthing facility stay, the newborn is identified as “BabyBoy” or “BabyGirl”, and special pediatric demographics are used to handle multiple births. Before the newborn leaves the hospital a birth certificate registration is usually completed and filed with vital records. The birth certificate also contains data about the parents, such as mother’s education level, in addition to the newborn’s name. It will be useful to extract data such as birth weight from the NDS for use in completing the birth certificate registration, and data from the national standard electronic birth certificate (plus individual state additions) will be useful for updating the NDS with complete and accurate demographics.

During the Newborn hospital admission, screening tests are performed for hearing (Early Hearing Detection and Intervention EHDI) and metabolic conditions including Phenylketonuria PKU and Congenital Hypothyroidism CH (Newborn Dried Blood Spot). The newborn discharge summary should include the dates when these tests were performed but the results are typically reported in separate documents. The hearing screening is reported as an Early Hearing Care Plan EHCP that is describe by a separate IHE EHDI profile that could be linked to the NBS. The results of the newborn dried blood sport are usually reported after newborn discharge and are typically pending laboratory tests at the time of discharge so they are usually not included in the NDS and will be reported in a separate document similar to the hearing care plan.

Because normal newborn hospitalizations are extremely brief, the results of many screening tests are not available when the newborn leaves the hospital or birthing facility. These results will be returned to the hospital where the tests were ordered but most newborns are not cared for by the same provider during the newborn hospital admission and afterwards in the medical home. It will
be extremely useful to update the NDS with the results of newborn screening tests and to make these updates available to future providers, since the future primary care provider and medical home are often not known at the time of discharge, but the hospital of birth is almost always known to future providers who can query for this data at the hospital of birth. A provider seeing the newborn for the first time in an ambulatory setting could register with the hospital to receive notice of document availability when results of newborn screening are sent to the hospital.

The hospital is usually responsible for completing newborn hearing screening if this was not done during the admission, and this is often done at a hospital run ambulatory hearing testing facility. The results of the hearing test (or re-test) can also be added to the NDS post discharge (completing an order placed during the admission) and this new information made available through a notice of document availability.

The range of problems, data observations, procedures, and medication that are relevant to care provided in the normal newborn nursery is quite limited, and this content profile will include tables of commonly used codes including mapping of ICD9, ICD10, and SNOMED codes for describing common newborn conditions and targets of newborn screening. These coding vocabulary subsets should be used to improve the quality of ambulatory problem lists in future records built from the NDS.

X.2 Process Flow

X.2.1 Use Cases

X.2.1.1 A normal newborn with no special problems

A normal newborn discharge illustrates all of the features of the profile:

1. The initial observations on the newborn are recorded in the newborn section of the labor and delivery record including the birth weight, apgar scores, and other measurements.

2. When the newborn is admitted to the normal newborn nursery, a newborn discharge summary is created as the electronic medical record for the newborn.

3. Selected data from the Mother’s antepartum history and physical is transferred to the NDS or entered manually.
X.2.1.2 A Newborn who fails to pass newborn hearing screening

A normal newborn who fails to pass the most recent hearing screening before discharge from the hospital will require additional testing after hospital discharge. The NDS contains only the results of the most recent hearing test performed prior to discharge.

X.2.1.3 A Newborn with hyperbilirubinemia

Some newborns will develop jaundice due to elevation of serum bilirubin that will require diagnostic studies and possible therapy during the newborn hospitalization and potentially after discharge. Severe elevations of bilirubin are rare, but can cause brain damage. A key role of the newborn discharge summary is to provide data for clinical decision support to determine the need for therapy and to coordinate care provided in the hospital with care required after discharge. Some newborns will have transcutaneous bilirubin measurements performed at the bedside. Some newborns will have blood drawn (usually by heel stick) for laboratory measurement of bilirubin and the results will usually be returned as HL7 v2.x lab results messages. All newborns will have the mother’s blood type measured as part of the antepartum labs.

X.2.1.4 A Newborn born to an HIV positive mother

When a mother is known to be infected with HIV, treatment is started during pregnancy and delivery to prevent transfer of the virus to the newborn. The newborn will discharged on medication that must be continued until the results of multiple PCR testing for HIV in the newborn confirms that transmission of the virus did not occur. The NDS will need to include the discharge medication and the plan for PCR testing and results of any PCR testing performed in the hospital.

X.2.1.5 A Newborn born to a mother who is positive for Hepatitis B antigen

An newborn born to a mother who is known to be Hepatitis B antigen positive requires special treatment because they must receive both the Hepatitis B vaccine (which might be optional or deferred in other newborns) and the Hepatitis B Hyperimmune Globulin (which provides passive immunity). It will be important to use the NDS to communicate the Hepatitis B lab results from the mother, the immunizations given to the newborn, and the plan of care that documents the need for future testing and careful observation of the newborn to assure that maternal newborn transmission of hepatitis has not occurred.

X.2.1.6 A Newborn with a heart murmur

A heart murmur is a common finding in newborns and most are not associated with congenital heart disease. Some significant congenital heart disease is not detected by examining the newborn and it has been proposed that all newborns be screened by measuring pulse oxygenation (a vital sign on the medical summary.) This practice is undergoing evidence based review.
X.2.1.7 A Newborn with a congenital malformation such as equinovarus (club foot)

Many congenital malformations are not life threatening and do not require immediate therapy. A key role for the NDS is to document which diagnostic studies and consultations were completed during the hospitalization and which ones have been scheduled.

X.2.2 Diagrams

X.3 Actors/Transactions

There are two actors in this profile, the Content Creator and the Content Consumer. Content is created by a Content Creator and is to be consumed by a Content Consumer. The sharing or transmission of content from one actor to the other is addressed by the appropriate use of IHE profiles described below, and is out of scope of this profile. A Document Source or a Portable Media Creator may embody the Content Creator Actor. A Document Consumer, a Document Recipient, or a Portable Media Importer may embody the Content Consumer Actor. The sharing or transmission of content or updates from one actor to the other is addressed by the use of appropriate IHE profiles described in the section on Content Bindings with XDS, XDM and XDR in PCC TF-2:4.1.

X.3.1 Requirements of Actors

X.4 Options

Table X.4-1 Newborn Discharge Summary - Actors and Options

<table>
<thead>
<tr>
<th>Actor</th>
<th>Option</th>
<th>Section</th>
</tr>
</thead>
<tbody>
<tr>
<td>Content Consumer</td>
<td>View Option (See Note 1)</td>
<td>PCC TF-2: 3.1.1</td>
</tr>
<tr>
<td></td>
<td>Document Import Option (See Note 1)</td>
<td>PCC TF-2: 3.1.2</td>
</tr>
<tr>
<td></td>
<td>Section Import Option (See Note 1)</td>
<td>PCC TF-2: 3.1.3</td>
</tr>
</tbody>
</table>
X.5 Groupings

X.6 Security Considerations

X.7 Content Modules

Table X.7-1 maps data elements to existing PCC section templates. Existing section template mappings are displayed in the format of:

\[ \text{[Profile]}:\text{[Section]}:\text{[Subsection]} \]

When data elements are mapped to existing sections all existing data shall be incorporated into the section within this profile. Additional data may be added if appropriate.
<table>
<thead>
<tr>
<th>Datum</th>
<th>PCC Template Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fetal Labs</td>
<td>LDS: Coded Results</td>
</tr>
<tr>
<td>Newborn Labs</td>
<td>Coded Results</td>
</tr>
<tr>
<td>Plans at admission</td>
<td>LDHP: Care Plan</td>
</tr>
<tr>
<td>Hearing Screening</td>
<td>Coded Results</td>
</tr>
<tr>
<td>Discharge Exam</td>
<td>Discharge Physical Exam</td>
</tr>
<tr>
<td>Discharge Impression</td>
<td>Discharge Diagnosis</td>
</tr>
<tr>
<td>Plan at Discharge</td>
<td>Care Plan</td>
</tr>
<tr>
<td>Discharge Feeding Plan</td>
<td>Discharge Diet</td>
</tr>
<tr>
<td>Feeding and Output</td>
<td>Intake and Output (new section)</td>
</tr>
<tr>
<td>Medications Administered</td>
<td>Medications Administered</td>
</tr>
<tr>
<td>Immunization admin (e.g. HepB Vaccinem Hep B IG)</td>
<td>Immunizations</td>
</tr>
<tr>
<td>Newborn Complications/Anomalies</td>
<td>Problems</td>
</tr>
<tr>
<td>Pediatric Care Provider’s Name</td>
<td>Care Plan</td>
</tr>
<tr>
<td>Referrals</td>
<td>Reason for Referral</td>
</tr>
</tbody>
</table>
Glossary

Add the following terms to the Glossary:

355

Club foot
Congenital deformity of the foot in which the foot appears twisted out of position or shape.

Congenital
Existing at or dating from birth.

Equinovarus
Common form of clubfoot in which the heel is elevated and the foot turned inward.

365

Hyperbilirubinemia
The presence of excess bilirubin in the blood causing a yellowing of the skin and whites of the eyes.

Jaundice
A yellowing of the skin and whites of the eyes caused by excess bilirubin.

The Joint Commission
The independent, not-for-profit organization that accredits and certifies health care organizations and programs in the United States.

Transcutaneous
Passing, entering or penetration through the skin.
Volume 2 – Transactions and Content Modules
5.0 Namespaces and Vocabularies

<table>
<thead>
<tr>
<th>codeSystem</th>
<th>codeSystemName</th>
<th>Description</th>
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</table>

5.1 IHE Format Codes

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<th>Format Code</th>
<th>Media Type</th>
<th>Template ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newborn Discharge Summary</td>
<td>urn:ihe:pcc:nds:2010</td>
<td>text/xml</td>
<td>1.3.6.1.4.1.19376.1.5.3.1.1.22.1.1</td>
</tr>
</tbody>
</table>
6.0 PCC Content Modules

6.3 HL7 Version 3.0 Content Modules

6.3.1 CDA Document Content Modules

Add section 6.3.1.A

6.3.1.A Newborn Discharge Summary 1.3.6.1.4.1.19376.1.5.3.1.1.22.1.1

The Newborn Discharge Summary represents a summary of the most critical information to a newborn care provider after discharge from the birthing facility. This document content module is a Medical Summary and inherits all header constraints from Medical Summary (1.3.6.1.4.1.19376.1.5.3.1.1.2).

6.3.1. A.1 Format Code

The XDSDocumentEntry format code for this content is urn:ihe:pcc:nds:2010

6.3.1. A.2 LOINC Code

The LOINC code for this document is XX-NewbornDischargeSummary

6.3.1.A.3 Standards

<table>
<thead>
<tr>
<th>CCD</th>
<th>ASTM/HL7 Continuity of Care Document</th>
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<tbody>
<tr>
<td>CDAR2</td>
<td>HL7 CDA Release 2.0</td>
</tr>
<tr>
<td>CDTHP</td>
<td>CDA for Common Document Types History and Physical Notes (DSTU)</td>
</tr>
</tbody>
</table>

6.3.1.A.4 Specification

This section references content modules using Template Id as the key identifier. Definitions of the modules are found in either:

- IHE Patient Care Coordination Volume 2: Final Text
- IHE PCC Content Modules 2010 Supplement

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<th>Opt</th>
<th>Section Template Id / Location</th>
<th>Value Set Template Id</th>
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</thead>
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<td>Pregnancy History</td>
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<td>IHE PCC 2:6.3.3.2.18</td>
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Table 6.3.1.A.4-1 Newborn Discharge Summary Specification
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<th>Section Template Id / Location</th>
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</thead>
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<tr>
<td>prenatal care, Birth plurality,</td>
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<td></td>
</tr>
<tr>
<td>Maternal medical complications during pregnancy,</td>
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<td></td>
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</tr>
<tr>
<td>maternal surgical complications during pregnancy,</td>
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</tr>
<tr>
<td>medications used by the mother during pregnancy,</td>
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<tr>
<td>antenatal steroids, maternal allergies,</td>
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<tr>
<td>gestational age by LMP, gestational age by US,</td>
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<tr>
<td>prenatal screening chromosomal analysis,</td>
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</tr>
<tr>
<td>fetal anomalies detected by US, and intrauterine</td>
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</tr>
<tr>
<td>therapy.</td>
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<td></td>
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<td>Vol 2: 6.3.3.2.36</td>
</tr>
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<td>**Labor and Delivery Summary: Labor and Delivery</td>
<td>R</td>
<td>1.3.6.1.4.1.19376.1.5.3.1.1.21.2.3</td>
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</tr>
<tr>
<td>Events</td>
<td></td>
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<td>PCC TF Supplement CDA</td>
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<td>Content Modules</td>
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<tr>
<td></td>
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<td>(TI)</td>
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<td>PCC TF Supplement CDA</td>
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### Newborn Discharge Summary (NDS)

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410 **6.3.1.A.5 Conformance**

CDA Release 2.0 documents that conform to the requirements of this content module shall indicate their conformance by the inclusion of the appropriate `<templateId>` elements in the header of the document. This is shown in the sample document below. A CDA Document may conform to more than one template. This content module inherits from the Medical Summary content module, and so must conform to the requirements of that template as well, thus all `<templateId>` elements shown in the example below shall be included.
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  <languageCode code='en-US'/>
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      <!-- Required if known Coded Social History Section content -->
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      <!-- Required Labor and Delivery Events Section content -->
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</ClinicalDocument>
Figure 6.3.1.A.5-1 Sample Newborn Discharge Summary Document