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Maternal and Child Health

AHIC Extension/Gap

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1.0 Preface and Introduction

1.1 Background

In April and June of 2008, the American Health Information Community (AHIC) approved a recommendation to develop documents that address extensions/gaps from the use cases published between 2006 and 2008. One of the extensions/gaps prioritized for subsequent processing in the national health agenda activities in 2009 was Maternal and Child Health.

AHIC requested that the Maternal and Child Health Extension/Gap address the ability to exchange obstetric and pediatric patient information between Electronic Health Records (EHRs), the ability to incorporate pediatric assessment tools, guidelines and assessment schedules into EHRs, the ability to exchange standardized patient assessments for antenatal care, pre-natal care, labor and delivery and post-partum care between EHRs and the ability to incorporate assessment tools, guidelines and assessment schedules into EHRs for antenatal care, pre-natal care, labor and delivery and post-partum care, as well as the ability to exchange this information with appropriate Public Health programs.

This extension/gap document is being developed by the Office of the National Coordinator (ONC) to represent the AHIC priorities and provide context for the national health agenda activities, beginning with the selection of harmonized standards by the Healthcare Information Technology Standards Panel (HITSP). Components that need to be considered during the standards identification and harmonization activities include standardized vocabulary, data elements, datasets, and technical standards that support the processes and the communication of maternal and child health information between clinicians, public health and services. This document is the Final AHIC Maternal and Child Health Extension/Gap. Feedback received on the Draft AHIC Extension/Gap has been considered and incorporated into this document where applicable.

HITSP is expected to reuse standards, where applicable, from standards previously recognized by the Secretary of Health and Human Services, to specify and constrain how standards are to be used to advance interoperability and to work with Standards Development Organizations to see that gaps in standards are filled.

1.2 Progress to Date

To date, the national health agenda, including work by AHIC, have not yet formally addressed the communication of maternal and child health information between clinicians, public health, and services.



- The 2006 EHR – Laboratory Results Use Case includes the needs for communicating Laboratory Results from an LIS to an EHR or other clinical systems;
- The 2008 Personalized Healthcare Use Case includes the needs for communicating clinician-initiated genetic/genomic laboratory test results including interpretive information from a Laboratory Information System (LIS) to an EHR;
- The 2008 Immunizations and Response Management Use Case includes the needs for communicating immunization and drug administration information between clinicians, registries, consumers, those individuals in public health roles, and the exchange of information regarding the management and inventory status of vaccines and drugs;
- The 2008 Public Health Case Reporting Use Case includes the needs for communicating reporting laboratory test results to public health when specific reporting criteria are met. This use case also describes the communication of public health case reporting criteria for incorporation into EHR systems and utilization by clinicians;
- The 2008 Consultations and Transfers of Care Use Case includes the need for communicating information to request and fulfill a consultation and support transfers of care; and
- The 2009 Newborn Screening Use Case includes the needs for communicating information for the ordering and resulting of screenings and normal, abnormal, out of range, and confirmatory results.



2.0 Overview and Scope

2.1 Document/Request Overview

This extension/gap document is focused on information needs to facilitate the electronic exchange of maternal and child health information. The 2009 Maternal and Child Health Extension/Gap Document is divided into the following sections:

- Section 1.0, Preface and Introduction, describes the progress to date, the additional priorities identified by the AHIC, the resulting extensions/gaps, and their purpose.
- Section 2.0, Overview and Scope, describes the sections of an extension/gap document, the request being made to HITSP, and the scope of that request.
- Section 3.0, Functional Needs, describes the combination of end-user needs and system behaviors that support interoperability and information exchange.
- Section 4.0, Stakeholder Communities, describes individuals and organizations that participate in activities described in this extension/gap document.
- Section 5.0, Issues and Obstacles, describes issues and obstacles that may need to be planned for, addressed, or resolved to achieve the capabilities described in the extension/gap document.
- Section 6.0, References to Use Case Scenarios, describes various scenarios and information exchanges that assist in the communication of information. Scenarios may be from previously published 2006 – 2008 Use Cases and/or new scenarios may be described.
- Section 7.0, Events and Actions provides a greater level of detail for the scenario and includes information flows. Specific events and actions for each perspective and scenario are presented and discussed. Events and actions are not intended to be prescriptive.
- Section 8.0, Information Exchange, describes information exchange capabilities needed to support the scenarios and the high-level information exchanges.
- Section 9.0, Data Set Considerations, identifies specific opportunities for identification of information and/or data relevant to this extension/gap document. These opportunities may support future identification, development, and harmonization of standards.
- Appendix A, Glossary, provides contextual descriptions of key concepts and terms introduced in this extension/gap document.

2.2 Scope

Maternal and child health can be defined as multiple programs serving various populations of consumers. For the purposes of this extension/gap document, the period of time included in maternal and child health is from the determination of pregnancy for the mother-to-be continuing throughout early childhood.

Requirements for maternal and child health can be summarized as:



- The exchange of pregnancy, birth event, screening and immunization information between public or private health facilities, EHRs, and information systems supporting public health programs and/or services.
- The use of this information to aid in the integration of various public health programs and/or services in order to facilitate enrollment by consumers who would benefit from these services. While social or other services are not always appropriate, many maternal and child health public health programs serve broad catchments of at risk populations and the requisite information flows and screening. Similarly, related services and the populations they serve, benefit from broad awareness and consideration.

There are four key elements on this timeline which address important information exchanges which include:

- A. Determination of pregnancy;
- B. The birth event and incorporation of antepartum information;
- C. Referral to and coordination of health related programs and registries such as Vital Records, Newborn Screening, Immunizations and Lead, Vision, Hearing, and other Developmental Screenings. (Although Newborn Screening occurs within this time period and is an integral part of maternal and child health, the complexity and specific needs of that process led to the creation of a separate Use Case, the 2009 Newborn Screening Use Case); and
- D. Referral to and enrollment in various public health programs and/or services.

Identification, development, and harmonization of standards to support the interoperability associated with maternal and child health has been preliminarily addressed but requires additional work with standards and professional organizations, care delivery organizations, and organizations providing information technology services and products to the healthcare industry. As mentioned in Section 1.0, the needs expressed here have not been fully addressed by the national health agenda's standardization efforts. Examples of gaps in industry standards are outlined in the upcoming sections of this extension/gap document.



3.0 Functional Needs

This section describes a combination of end-user needs and system behaviors to support the users during the exchange of maternal and child health information. Support for this exchange includes the development of interoperability standards for vocabularies, data elements, datasets, and other technical components that are implicit in these functional needs. Rather than an all-inclusive list of functional requirements, key capabilities are outlined below. The descriptions in this section are not intended to prescribe policy nor propose architectures required to implement capabilities.

- A. The ability to communicate the determination of pregnancy from a clinical system (i.e. EHR) to public health agencies.
 - i. When pregnancy is determined, a laboratory test may be completed and/or an examination may be done to positively determine a pregnancy. This information might be entered into an EHR and could then be communicated via electronic messaging to public health agencies. The initial determination of pregnancy may occur in a variety of settings, including fee-for-service, private practice, hospital-based ambulatory care, and/or public health programs.
- B. The ability to communicate pregnancy screening results from the testing centers to public health and various services such as WIC and Medicaid health and wellness programs. In the context of maternal and child health, Medicaid is both a Services organization and a Healthcare Payor. Medicaid administers and provides social or other services such as case management in the Early Periodic Screening, Diagnosis and Treatment (EPSDT) Program and also reimburses clinicians for services rendered as they relate to maternal and child health follow-up and care activity.
- C. The ability to communicate antepartum information to, and between EHRs. For example, from the mother's clinician's EHR to the EHR of the birthing facility when they are different. This information may, at times, be exchanged throughout the pregnancy, just prior to or at the delivery, or during the neonatal period. In some circumstances, information may be sent to, and in some cases, accessed by the birthing facility.
 - i. This information may include instructions or advice for pregnancy management, such as recommended screening and testing, recommended schedule of examinations, nutritional information or other suggestions for management of a pregnancy.
 - ii. The information may include information tailored to specific health needs of the pregnant woman.
- D. The ability to communicate birth information to birth-related systems.
 - i. The ability to communicate the birth event and related information from an EHR to public health, registries, and programs.



- ii. The ability to electronically communicate the birth event information to the vital records department with responsibility for recording birth events for a locale.
- iii. The ability to electronically communicate the birth event along with related information to an additional number of organizations that administer screening programs.
 - a. These programs may include Newborn Screening (Described in the 2009 Newborn Screening Use Case), Immunization status databases (described in the 2008 Immunizations and Response Management Use Case) and other registries.
 - b. Screening programs mandated at the state level that may be required later in childhood may include lead, vision, and hearing screening programs, or others. Although these screening programs are mandated at the state level, it is expected that most states have similarities in the requirements for information. (See Data Set Considerations section for further details.)
- E. The ability to communicate screening results for the newborn/child from the testing centers to public health and various services.
 - i. A variety of metabolic, hearing and other screening tests are mandated at the state level. The resulting test information needs to be communicated back to public health. Depending on the results of the testing, it may trigger a wide array of referrals to available medical services, social or other services, or organizations for assistance or intervention (described in detail in the 2008 Newborn Screening Use Case).
 - ii. Likewise, as the child develops, he/she will be screened in early childhood for additional conditions such as lead poisoning, hearing, and vision as well as developmental screenings. The results of any additional screening needs to be communicated back to public health such that in cases of poisoning, the infant or child and guardians can be referred to the appropriate medical program or services for possible intervention, treatment and/or education.
- F. The ability to communicate immunization records and well visit information from the EHR to public health.
 - i. The immunization record information may be exchanged with all relevant public health agencies.
 - ii. The immunization record information may also be communicated between EHRs, school health records, or other systems.
- G. The ability to communicate information related to the previous scenarios for the purpose of transferring information that may assist social or other services in determining eligibility and potentially enrolling participants.



- i. An important goal in the sharing of information between the private or public medical records and public health and services is the successful enrollment of consumers into available and important public health programs and services for which they are eligible. Enrollment efforts may be aided by accurate and timely transfer of information between and among systems.
- H. The ability for systems to receive information required in order to notify a provider that: the consumer may meet initial criteria for a referral to services or public health and what specific services or public health programs may be suitable for the consumer.
- I. The ability to comply with all state and federal privacy and confidentiality laws and regulations, including the Health Insurance Portability and Accountability Act (HIPAA) and Family Educational Rights and Privacy Act Regulations (FERPA).



4.0 Stakeholder Communities

Examples of stakeholders who may be directly or indirectly involved in the exchange of maternal and child health information have been listed below. Specific descriptions of each type of stakeholder can be found in the previous 2006 – 2008 AHIC Use Cases.

Stakeholders that may be directly involved in the exchange of maternal and child health information may include: Clinicians, Public Health, Services, Allied Health Providers, Education, and Testing Laboratories.

Stakeholders that may assist in maternal and child health communication may include: EHR System Suppliers, Public Health System Suppliers, Health Record Bank System Suppliers, Employers, Emergency Medical Systems, and Laboratory System Suppliers.

Stakeholders that may be sources or recipients of maternal and child health information may include: Patients, Consumers, Knowledge Suppliers, Public Health, Government Agencies, Services, Laboratory Organizations, and Healthcare Payors.



5.0 Issues and Obstacles

A number of issues in today's health information technology environment are obstacles to achieving the healthcare data standardization and interoperability to promote patient safety, reduce healthcare costs, and increase the value of electronic health information exchange. Some general issues were described within the 2006 – 2008 AHIC Use Cases. Examples of specific issues and obstacles related to maternal and child health are outlined below.

A. Integration of Systems

- i. At the present time, there is a lack of electronic communication of information among various public health and social service programs and systems.
 - a. Without integration of these systems consumers and patients who may be eligible for these services may not avail themselves of some vital and necessary services.
 - b. Enrollment takes place in multiple programs and multiple systems and some consumers may be overlooked or may miss the opportunity to participate in services.
- ii. Currently, electronic connection between clinical EHR systems and public health and social or other services is limited.
 - a. Without an electronic connection and subsequent communication among these three health care arenas, consumers that may be in need may not take advantage of the programs and services available to them.

B. Sharing of Information

- i. In order for consumers to benefit from the wide array of services potentially available to them, information needs to flow between EHRs, public health and social or other services.
 - a. Without the ability to electronically communicate vital information about screening and social programs from public health to EHR systems, it may be difficult for clinicians to become aware of and/or offer opportunities for additional services to consumers.
 - b. Without the ability to electronically communicate health information about pregnancy, birth events, and/or early childhood from EHRs to social or other services, appropriate delivery of services may be hampered, delayed or ineffective.
- ii. In order for programs to work effectively, there may be a need to share information between jurisdictions.
 - a. The mobility of today's population between jurisdictional boundaries exposes the need for communicating medical and social or other services information across jurisdiction boundaries.

C. Policy Issues

- i. In order for information to be communicated accurately and safely between healthcare providers and providers of social systems, a clear and unambiguous



understanding of relevant regulations and health care standards must be applied to systems communicating information.

- a. Without an understanding of privacy and confidentiality policy and rules that are in place, the information may be either over-restricted or improperly shared via communication between healthcare providers and providers of government social services.
 - b. Without commonly used standards for health care information across jurisdictions, the communication and accurate interpretation of information may be problematic when the information is exchanged between EHRs and public health entities.
- ii. There may be specialized information needs for children in foster care systems, or if the biological parent(s) do not have legal access to the child's health care record.
 - iii. In some instances there may be misunderstandings regarding the guidelines from HIPAA and FERPA, the two main policies covering the exchange of information in the maternal and child health arena.
 - a. Without proper understanding and application of HIPAA and FERPA regulations, there may be some unnecessary restrictions applied to the exchange of information particularly when information must be exchanged between healthcare facilities, schools and social or other services.

D. Infrastructure Support

- i. In order for public health to transition from largely paper based systems to interoperable electronic systems, additional funding may be required.
 - a. Without sufficient funding and formal guidance, full integration and interoperability of the maternal and child health among public health systems information may not come to fruition.



6.0 References to Use Case Scenarios

The Maternal and Child Health Extension/Gap Draft Document focuses on the exchange of a core set of information between clinicians, public health, and services. Specific events and information exchanges have been selected from previous use cases for contextual purposes. These information exchanges are briefly described below and are identified by labeling information exchange arrows with reference labels and/or using icons which represent specific use cases which have been previously published.

- The 2006 Electronic Health Records Use Case which includes laboratory results reporting.
- The 2008 Personalized Healthcare Use Case contains a scenario that includes the communication of clinician initiated orders.
- The 2008 Consultations and Transfers of Care Use Case includes the need for communicating information to request and fulfill a consultation and support transfers of care from one provider or system to another.
- The 2009 Newborn Screening Use Case includes the ordering and resulting of metabolic, auditory and other screenings post birth.
- The 2008 Immunizations and Response Management Use Case which includes vaccine and drug administration and reporting.
- The 2008 Public Health Case Reporting Use Case contains a scenario that includes the communication of requirements by various sources and the incorporation of these requirements into EHRs, etc.

There are several events and information flows which have not been addressed in previous Use Cases. These events and information flows are labeled as Focus Flows 1, 2, 3, and 4.



Figure 6-1 Maternal and Child Health Scenario

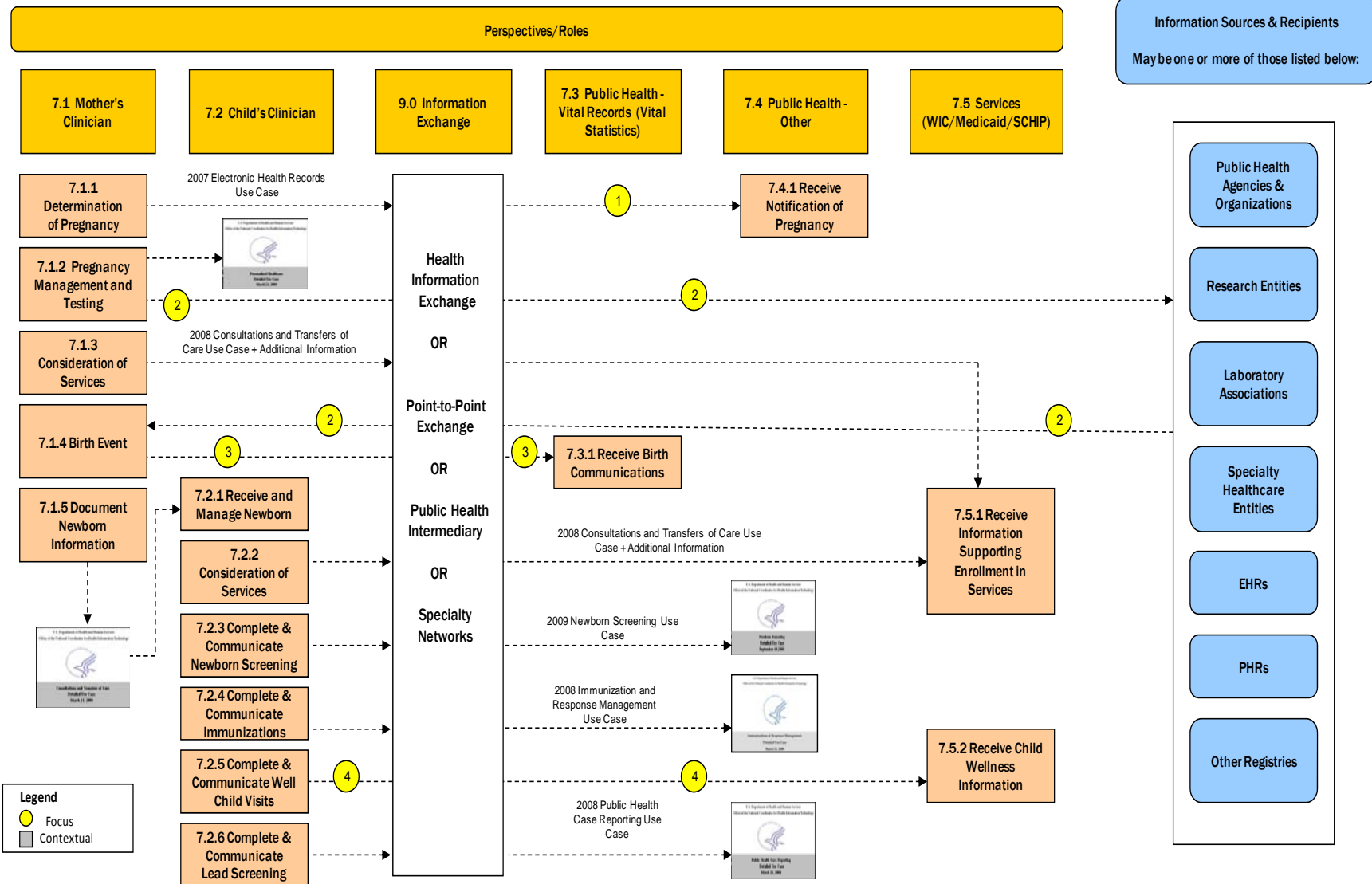






Figure 6-2 Information Flows

- 1 Through health information exchange activities the determination of pregnancy is communicated from the mother's clinician to public health.
- 2 Antepartum information is communicated from an ambulatory setting to the birthing facility.
- 3 Through health information exchange activities the birth is communicated from the mother's clinician to public health.
- 4 As well child visits are completed, information regarding these visits/assessments may be communicated through health information exchange activities to services including Medicaid and educational facilities.

Legend

-  Focus: Information exchange that is a primary focus of this use case.
-  Contextual: Information exchange that is not the primary focus of the use case, but is provided for contextual understanding.



7.0 Events and Actions Maternal and Child Health

Figure 7-1 Mother's Clinician Perspective

Code	Description	Comments
7.1.1	Event: Determination of Pregnancy	Focus Flow 1
7.1.1.1	Action: Clinician determines pregnancy.	The mother's clinician will perform laboratory tests, ultrasonographic and/or physical examinations to determine if a pregnancy is present. If it is appropriate, this information could be sent via information exchange to public health in order to a) ensure that the pregnant mother is present in the system and b) to make preliminary assessments regarding potential for utilization of social services offered by public health.
7.1.2	Event: Pregnancy Management and Testing	Focus Flow 2
7.1.2.1	Action: Mother's clinician manages the pregnancy.	Throughout the pregnancy the mother may undergo routine obstetrical visits and undergo various kinds of prenatal testing on both mother and fetus, such as, physical exams, laboratory tests for gestational diabetes, pre-eclampsia, and blood pressure monitoring on the pregnant patient, or genetic or other testing on the fetus. This information in aggregate may be referred to as the antepartum information.
7.1.2.2	Action: Assessment of risks.	Early in the pregnancy the mother's clinician may assess the patient for risk factors that may impact the pregnant woman's health, and/or the health of the fetus. These risk factors may include but are not limited to medical, familial, or occupational.



Code	Description	Comments
7.1.2.3	Action: Documentation of antepartum information.	During the course of the pregnancy the mother's clinician documents information relating to the previous two actions. An example of a format for documenting this information is the Antepartum Record suggested by the American College of Obstetrics and Gynecology (ACOG). This Antepartum Record includes informational details about the office visits including any physical examinations, menstrual history, prior pregnancy history, general medical history, genetic/teratology testing, infection history (if any), and all examinations, testing, or findings involving the fetus such as ultrasonographic exams. An antepartum record may be part of the clinician's EHR or patient's PHR and could be used as the basis for an electronic message to convey antepartum information to the birthing facility just prior to, during, or just after the birth event.
7.1.2.4	Action: Antepartum information shared with birthing facility.	At various points during the pregnancy, antepartum information may be communicated to or accessed by the birthing facility. Ideally, the information would be available prior to the birth, but it may be advantageous for the birthing facility to be able to request the data from the mother's clinician's EHR or from the patient's PHR if available. This information can assist the mother's clinician, the child's clinician and the birthing facility in assuring a smooth transition from ambulatory care to care received at the birthing facility during delivery, during the neonatal period, and beyond.
7.1.3	Event: Consideration of Services	
7.1.3.1	Action: Mother's clinician makes recommendations for social or other services, if appropriate.	During the course of pregnancy, the mother's clinician may make recommendations, if appropriate, for referral to public health and/or services such as WIC, Medicaid, or SCHIP programs. This general process has been included in the 2008 Consultations and Transfers of Care Use Case. The 2008 Consultations and Transfers of Care Use Case also includes information needs which are expanded in the 2009 Newborn Screening Use Case.
7.1.4	Event: Birth Event	Focus Flow 2 and Focus Flow 3



Code	Description	Comments
7.1.4.1	Action: Birth information is communicated to Vital Records/Vital Statistics.	At the time of the birth, information could be communicated via an electronic message from the birthing institution to the public health department of vital records or vital statistics. Information would include standard patient demographic information listed in the Dataset Considerations section of this document. This information would include any outcome of the pregnancy, including elective or spontaneous termination, still births and other outcomes other than a normal delivery.
7.1.5	Event: Document Newborn Information	
7.1.5.1	Action: Mother's clinician documents birth and newborn information.	At the time of birth, the mother's clinician documents information regarding the birth and the health status of the newborn. At this point in the process, the care of the newborn is turned over to the pediatric clinician and a new EHR is initiated for the infant. All health records from this point forward are kept in separate EHRs for the mother and the infant. The infant's health information is generally communicated from the mother's clinician to the child's clinician within the birthing facility, or may be shared via information exchange activities between the mother's clinician's EHR and the EHR of the birthing facility.



Figure 7-2 Child's Clinician Perspective

Code	Description	Comments
7.2.1	Event: Receive and Manage Newborn	
7.2.1.1	Action: Child's clinician begins to handle medical management of infant.	Immediately after birth, the child's clinician takes over the medical management of the infant. This includes all examinations and screenings after the birth. The transfer of care process, including several information flows is generally described in detail in the 2008 Consultations and Transfers of Care Use Case.
7.2.2	Event: Consideration of Services	
7.2.2.1	Action: Child's clinician makes additional recommendations for social or other services, if appropriate.	After the birth, the child's clinician may make recommendations for referral to various appropriate services. These services include WIC and other pertinent referrals. This general process has been described in the 2008 Consultations and Transfers of Care Use Case. The 2008 Consultations and Transfers of Care Use Case also describes information needs which are expanded in the 2009 Newborn Screening Use Case.
7.2.3	Event: Complete & Communicate Newborn Screening.	
7.2.3.1	Action: The child's clinician manages newborn screening and the results are communicated.	The child's clinician handles the management of the newborn screening process including both the Newborn Blood Spot metabolic testing and the Early Hearing Detection and Intervention screening. This process is described in detail in the 2009 Newborn Screening Use Case.
7.2.4	Event: Complete & Communicate Immunizations	



7.2.4.1	Action: The child's clinician manages the immunization process.	The child's clinician manages the immunization process throughout childhood and the results are communicated to public health. This process is described in detail in the 2008 Immunizations and Response Management Use Case.
7.2.5	Event: Complete & Communicate Well Child Visits	Focus Flow 4
7.2.5.1	Action: Child's clinician manages well visits through childhood.	The child's clinician is responsible for managing well visits and communicating this information. If the child is covered under Medicaid or related services, then this information is handled via the Early Periodic Screening, Diagnosis and Treatment (EPSDT) Program; the child health component of Medicaid. This is required in every state and represents a huge volume of information flowing from providers to public health. Some of the data to be included in this information flow is listed in the Dataset Considerations section of this document. In addition, the child's clinician may provide information regarding children with special health needs. This information may be relevant to the child's Individualized Educational Program (IEP), Individual Family Service Plan and other programs intended to foster early intervention in accordance with Part C of the Individuals with Disabilities Education Act (IDEA).
7.2.6	Event: Complete & Communicate Lead Screening	
7.2.6.1	Action: Child's clinician carries out blood lead screening during early childhood.	During early childhood, the child's clinician carries out and manages blood lead screening. This information is usually reported to public health in the form of a case report, although a non-positive result may be sent to public health but not in the form of a case report. This process including several information flows is described in detail in the 2008 Public Health Case Reporting Use Case.



Figure 7-3 Public Health Perspective – Vital Records (Vital Statistics)

Code	Description	Comments
7.3.1	Event: Receive Birth Communications	Focus Flow 3
7.3.1.1	Action: Vital Records receives information about the birth.	At the time of birth, the mother's clinician or the birthing institution is responsible for the reporting of the birth and a standard set of information to Vital Records. Vital Records receives this information and integrates it into the public health. This information could be sent via electronic message through an information exchange to facilitate timely integration of this information and used to track other population related public health information. Some states have fully integrated systems which exchange information regarding the pregnancy, the birth, and short and long-term follow-up

Figure 7-4 Public Health Perspective-Other

Code	Description	Comments
7.4.1	Event: Receive Notification of Pregnancy	Focus Flow 1
7.4.1.1	Action: Pregnancy information is sent to public health.	The mother's clinician makes the determination of pregnancy and sends relevant information via information exchange activities to public health. Public health integrates this information into the appropriate databases and registries including birth defect registries. Some of the relevant data is listed in the Dataset Considerations section of this document.



Figure 7-5 Services Perspective (WIC/Medicaid/SCHIP)

Code	Description	Comments
7.5.1	Event: Receive Information Supporting Enrollment in Services	
7.5.1.1	Action: Services receive information regarding enrollment into services.	The mother's clinician prior to birth and the child's clinician after birth and during childhood sends information to help support enrollment into services for mother and child if they are needed. The information exchanges needed to support this activity have been described in detail in the 2008 Consultations and Transfers of Care Use Case. The programs include WIC, various Medicaid programs such as the EPSDT program and other important programs such as SCHIP.
7.5.2	Event: Receive Child Wellness Information	Focus Flow 4
7.5.2.1	Action: Services receive wellness information via EPSDT.	The EPSDT is the child health component of Medicaid. The child's clinician communicates information obtained at well visits to public health which receives this information and integrates it into their databases and registries. This model is gradually being adopted by private payors as well. Examples of some of the data that is received by public health in this important step are listed in the Dataset Considerations section of this document.



8.0 Information Exchange

The information exchange requirements for the effective selection and communication of maternal and child health information may comprise:

- The ability to exchange pediatric patient assessment information between EHRs;
- The ability to exchange standardized patient assessments for antenatal care, pre-natal care, labor and delivery and post-partum care between EHRs; and
- The ability to incorporate assessment tools, guidelines and assessment schedules into EHRs for antenatal care, pre-natal care, labor and delivery and post-partum care.

Examples of information exchange capabilities described above and in Section 2.0 may include: Data Delivery, Routing, Data Retrieval, and Subject Data Matching. Descriptions of each of these are in the previous 2006 – 2008 AHIC Use Cases.

The functional capabilities may be provided fully or partially by a variety of organizations including: health information exchange organizations, integrated care delivery networks, provider organizations, health record banks, public health networks, specialty networks, and others.

While not described in this section, Health Information Exchange (HIE) and Point-to-Point exchanges assist in the completion of the processes described in this extension/gap document. Examples of HIEs and Point-to-Point exchanges can be found in the previous 2006 – 2008 AHIC Use Cases.



9.0 Maternal and Child Health Dataset Considerations

The following non-exhaustive information categories and limited examples illustrate some of the information needs from this extension/gap document.

A. Determination of Pregnancy

- i. Pregnancy testing
- ii. Hormonal assays
- iii. Transabdominal or transvaginal ultrasound

B. Antepartum Information

- i. Maternal age
- ii. Maternal occupation
- iii. Medical history
- iv. Menstrual history
- v. Past pregnancy history
- vi. Genetic screenings
- vii. Risk factors

C. Communication of Birth Event

- i. Birth certificate
 - a. Child's name, to include first, middle, and last
 - b. Date of birth
 - c. Sex
 - d. City of birth
 - e. County of birth
 - f. Parent name, mother's name, in some cases, unmarried and married
 - g. Parent name, father's name
 - h. Race

D. Additional Information Needed for Enrollment

- i. Nutritional risk requirement
- ii. Verification of pregnancy
- iii. Housing authentication
- iv. Proof of income
- v. Proof of citizenship/residency status



E. Reporting Well Child Information

- i. Well care exams
 - a. Nutritional screening
 - b. Developmental screening
 - c. Dental screening
 - d. Physical exam
 - (A) Weight, height, head circumference measurements
 - i. Percentile
 - (B) Immunizations provided
- ii. Laboratory test ordered
- iii. Screening results
 - a. Tuberculin test
 - b. Blood/lead test referral
 - c. Hgb/Hct (HRisk/WIC)
- iv. Referrals
 - a. WIC
 - b. Behavioral/developmental
 - c. Dental
 - d. Nutritional
 - e. Speech
 - f. Early education
 - g. Specialist



Appendix A: Glossary

The 2006 – 2008 AHIC Use Cases contained general terms and their contextual descriptions. Listed below are the new terms that are specific to this extension/gap document.

Allied Health Providers: Healthcare providers with patient care responsibilities focusing on fields which affecting the mother or child such as occupational therapy, physical therapy, nutrition, speech therapy, and audiology.

American College of Obstetrics and Gynecology (ACOG): ACOG is a private, voluntary, nonprofit membership organization of individuals providing health care for women. The areas of focus include advocacy for quality health care for women, maintaining high standards of clinical practice, promoting patient education, and increasing awareness among its members and the public of issues facing women's health care. ACOG has developed a comprehensive example of an Antepartum Record which has been referenced in this document.

Antepartum Information: This may include routine obstetrical visits, prenatal testing on the mother and fetus, physical exams, laboratory tests on the pregnant patient, or genetic or other testing on the fetus.

Clinicians: Healthcare providers with patient care responsibilities, including physicians, advanced practice nurses, physician assistants, nurses, pharmacists, dentist, oral surgeons and other licensed and credentialed personnel involved in treating patients.

Child's Clinician: Healthcare providers with patient care responsibilities focusing on the child, including pediatricians, other physicians, advanced practice nurses, physician assistants, neonatologists, nurses, pharmacists, and other licensed and credentialed personnel involved in treating patients.

Consumers: Members of the public that include patients as well as caregivers, patient advocates, surrogates, family members, and other parties who may be acting for, or in support of, a patient receiving or potentially receiving healthcare services.

Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program: The child health component of Medicaid that is required in every state and designed to meet the special physical, emotional, and developmental needs of low-income children. Federal law requires that Medicaid cover a very comprehensive set of benefits and services for children, different from adult benefits.

Emergency Medical Systems: The organized arrangement of field and hospital clinicians, response and transport vehicles, protocols and procedures responsible for patient care and transport from time of injury/illness through the delivery of emergency care.

Electronic Health Record: The electronic health record is a longitudinal electronic record of patient health information generated in one or more encounters in any care delivery setting. This information may include patient demographics, progress notes, problems,



medications, vital signs, past medical history, immunizations, laboratory information, and radiology reports.

Electronic Health Records (EHR) Systems Suppliers: Organizations which provide specific EHR solutions to clinicians and patients such as software applications and software services. These suppliers may include developers, providers, resellers, operators, and others who may provide these or similar capabilities.

Emergency Medical Systems: The organized arrangement of field and hospital clinicians, response and transport vehicles, protocols and procedures responsible for patient care and transport from time of injury/illness through the delivery of emergency care.

Employers: Organizations that employ consumers and their dependents. They may provide insurance coverage or act as a provider of PHR services.

FERPA: The Family Educational Rights and Privacy Act (FERPA) (20 U.S.C. § 1232g; 34 CFR Part 99) is a Federal law that protects the privacy of student education records. The law applies to all schools that receive funds under an applicable program of the U.S. Department of Education.

Government Agencies: Federal, state, local, territorial, or tribal departments within the United States government responsible for the oversight and administration of a specific function; government agencies may include: Department of Health and Human Services (DHHS), Food & Drug Administration (FDA), Centers for Disease Control and Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), Department of Defense (DoD), Department of Veterans Affairs (VA), Indian Health Services (IHS), and Department of Homeland Security (DHS).

Health Record Bank System Suppliers: Suppliers of entities/mechanisms for holding an individual's lifetime health records. This information may be personally controlled and may reside in various settings such as hospitals, doctor's offices, clinics, etc.

Healthcare Payors: Insurers, including health plans, self-insured employer plans, and third party administrators, providing healthcare benefits to enrolled members and reimbursing provider organizations.

HIPAA: Enacted by Congress in 1996, the Health Insurance Portability and Accountability Act (HIPAA, Title II) required the Department of Health and Human Services (HHS) to establish national standards for electronic health care transactions and national identifiers for providers, health plans, and employers. It also addressed the security and privacy of health data. As the industry adopts these standards for the efficiency and effectiveness of the nation's health care system will improve the use of electronic data interchange.

Knowledge Suppliers: Entities that use data, vocabulary, technology and/or industry standards to provide information and tools to entities delivering health care.



Laboratories: A laboratory (often abbreviated lab) is a setting where specimens are sent for testing and analysis, are resulted, and then results are communicated back to the requestor. The types of laboratories may include clinical/medical, environmental, veterinarian and may be both private and/or public.

Laboratory Organizations: Advocacy/professional organizations or societies such as the College of American Pathologists (CAP) or the National Committee for Clinical Laboratory Standards (NCCLS) which are concerned with the appropriate use of laboratory technology and interpretation of laboratory information in clinical medicine.

Laboratory Information Systems (LIS) Suppliers: Organizations that provide specific LIS solutions to clinicians and laboratories such as software applications and software services. These suppliers may include developers, providers, operators, and others who may provide these similar services.

Mother's Clinician: Healthcare providers with patient care responsibilities focusing on the mother, including OB/GYN, other physicians, midwives, advanced practice nurses, physician assistants, nurses, pharmacists, and other licensed and credentialed personnel involved in treating patients.

Patients: Members of the public who receive healthcare services.

Public Health: Federal, state, local, territorial, and tribal government organizations and clinical care personnel that exist to help protect and improve the health of their respective constituents.

Public Health System Suppliers: Suppliers of IT systems used by the various public health entities at the various levels of government (local, state, and federal). These systems are mostly used to perform the functions of bio-surveillance and health trend monitoring.

Registries: Organized systems for the collection, storage, retrieval, analysis, and dissemination of information to support health needs. This also includes government agencies and professional associations which define, develop, and support registries.

Services: Social or other programs/services assisting the maternal and child health population including but not limited to wellness and prevention services, Women, Infants, and Children (WIC), Medicaid, and the State Children's Health Insurance Program (SCHIP).

Testing Laboratories: Medical testing laboratories, either within a hospital, ambulatory, or clinician office environment and/or operating as a free-standing entity, which meet regulatory standards for clinical laboratories and analyze specimens as ordered by providers to assess the health status of patients.

Vital Records: Records of life kept under government authority, examples include birth certificates, death certificated and marriage licenses. These are compiled and stored at the State level.



Vital Statistics: Records of life events kept under government authority, examples include birth certificates, death certificates, and marriages licenses. These are compiled and stored at the Federal level.

Women, Infants, and Children (WIC): WIC is a Federal grant program for which Congress authorizes a specific amount of funds each year for the program. It is administered at the Federal level by the USDA Food and Nutrition Service. Services provided at the local level include access to supplemental nutritious foods, nutrition education and counseling at WIC clinics, and screening and referrals to other health and social services.