Birthdefectsreporting FHIR IG Proposal
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Birth Defect Reporting FHIR IG

Owning work group name
Public Health

Committee Approval Date:
WG approval: May 16 2019
FMG approval: May 22 2019
Clinical SD approval: June 3 2019

Publishing Lead
Craig Newman - craig.newman_at_altarum.org

Contributing or Reviewing Work Groups
None

FHIR Development Project Insight ID
Project ID 1532

Scope of coverage
This proposal covers the reporting of birth defects for human patients up to the age of 12 years in the United States. Reporting is from a provider in either a hospital or ambulatory location to a jurisdictional birth defect registry. Reporting may happen at the time of birth or any time afterwards if a birth defect is diagnosed later. Content for reporting includes demographics and vital records content for the individual, family/social context, pregnancy/delivery information and also specific clinical content related to the birth defect(s) for the patient.

Content location
TBD - is there a suggested github repository pathway?

Proposed IG realm and code
us/birthdefectreporting

Maintenance Plan
Altarum works with the state of Michigan to develop and support their birth defect registry. This association is expected to continue after the publication of the IG.

Short Description
The purpose of the Birth Defects Reporting FHIR IG is to provide guidance on reporting birth defects, either at the time of birth or afterwards, from a provider to a jurisdictional birth defects registry. The IG covers reporting requirements from both the ambulatory and hospital contexts.

Long Description
The scope of this project is to produce and ballot a Standard for Trial Use (STU) Fast Healthcare Interoperability Resources (FHIR) implementation guide (IG) for use in reporting of birth defects in the U.S. to jurisdictional birth defect registries. Automation of the reporting process adds efficiencies that dramatically improves the efficacy of collecting data related to birth defects and patient outcomes.
The clinical content being exchanged will be derived from a birth defects domain analysis model (which itself is an extension of a vital records domain analysis model). Content areas include patient demographics, related persons (mother, father), labor and delivery events and patient conditions (birth defects). Reporting is covered not only at the time of birth, but also through later stages of childhood.

Involved parties
The project is being sponsored by the state of Michigan but will include input from a variety of other jurisdictions as well as Health IT developers.

Expected implementations
The state of Michigan is expected to implement this IG in conjunction with healthcare organizations in the state.

Content sources
The Birth Defects domain analysis model will be the primary source of clinical content. The development of this DAM will consult the existing Vital Records DAM and reuse components where possible. Where requirements overlap, the US Core FHIR profiles will be used to directly or as the basis for developing unique birth defect reporting profiles.

Example Scenarios
Example scenarios include: 1) reporting of a newborn birth defect at the time of birth from a hospital context 2) reporting a birth defect identified later in life (during childhood) from an ambulatory (or hospital outpatient) context

IG Relationships
This IG may overlap in patient-centric content with the vital records death reporting IG. Where possible, the two IGs will be harmonized. The IG will also use R4 US Core profiles where possible.

Timelines
Work on the IG will begin in early 2020. The anticipated ballot target date is September 2020 (meeting the standard FHIR IG deadlines for that ballot cycle). Ballot reconciliation will happen in the fall of 2020. A publication date is expected in late 2020 or early 2021.

When IG Proposal Is Complete
When you have completed your proposal, please send an email to FMGcontact@HL7.org

FMG Notes