HL7® FHIR® DevDays

JUNE | 2023

Pregnancy, fetal, and child health record

Lilian Minne, Nictiz & Michael Tan, HL7

HL7 FHIR DevDays 2023 | Hybrid Edition, Amsterdam | June 6–9, 2023 | @HL7 | @FirelyTeam | #fhirdevdays | www.devdays.com

ORGANIZED BY firely | HL7 International

Who are we?

Lilian Minne

Interoperability expert, Nictiz

Involved in birth care since 2019

Michael Tan

Subject matter expert

Past product manager child health & obstetrics, Nictiz

HL7 co-chair Patient Care Work Group

Content

- Background
  - Working group, project goal & project questions
  - Methodology & related projects
- Results
  - Use cases
  - Fetus modeling, R5 extension
  - FHIR IG
- Next steps
- Q&A

Background – Working group & project goal

- CHOICE working group
  - International collaboration in obstetrics and child health projects
    - Netherlands, USA, Australia, Sri Lanka, Germany, UK
  - Active since January 2020 (HL7 WGM Sydney)

- Project goal
  - Achieve uniform method for handling of data of the unborn child
  - Provide guidance on implementation, use and handling of relevant FHIR resources and terminology

Background - Project Questions

- How do we express the subject fetus?
- How do we express the relationship between mother and her fetus(ses)?
- In which situations do we consider the fetus as a separate resource?
- Which data do we relate to the fetus (instead of the mother)?
- And which data to the pregnancy?
- What is the impact for procedures and medication if it is specifically meant for the fetus and not the mother?
- …

Background – Methodology & Related Projects

- Methodology
  - Define use cases
  - Set priorities
  - Define data
  - Define transactions
  - Define technical framework

- Related projects
  - BFDR – Vital Records Birth and Fetal Death Reporting
  - MMM - Longitudinal Maternal & Infant Health Information for Research
  - …

Results - Use cases

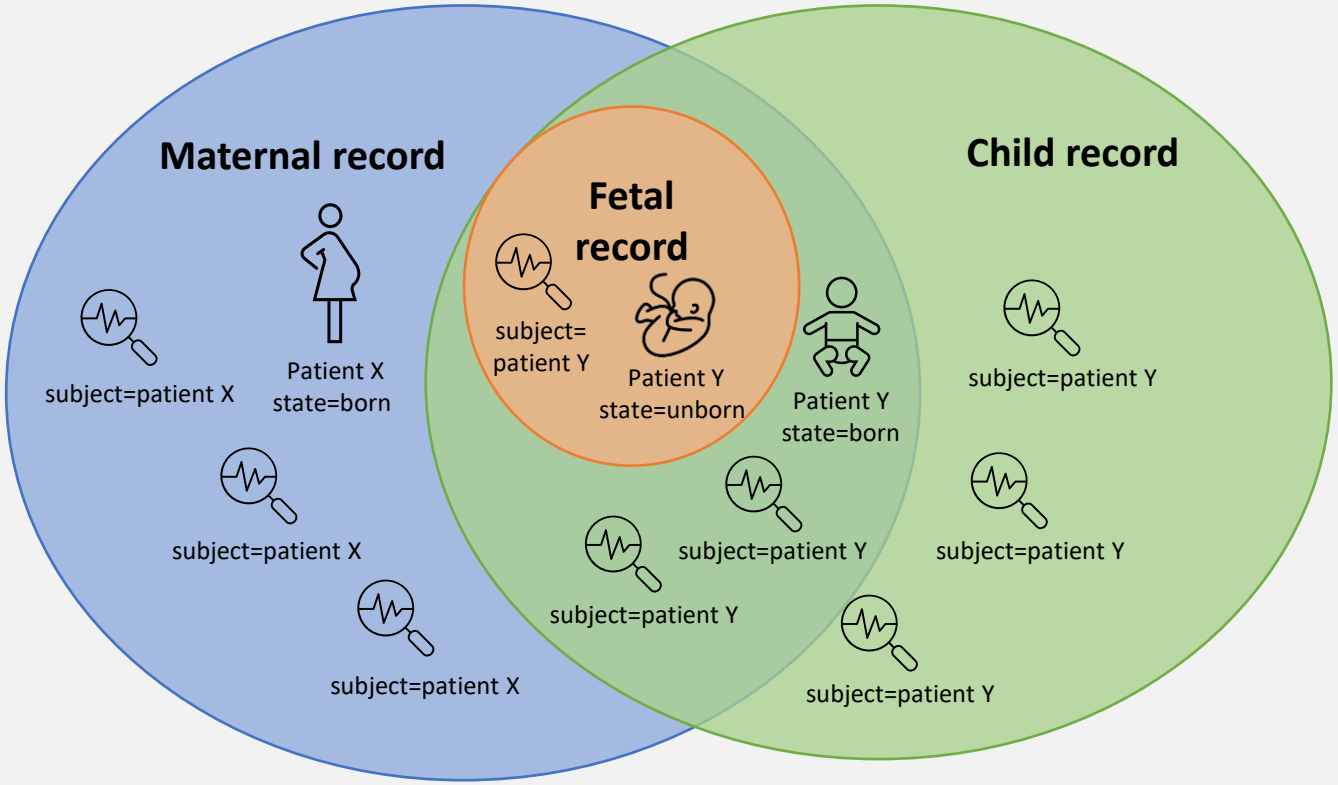
- Service request
  - Request for administering Prostoglandin E to newborn directly after birth
- Result reporting
  - Report results of ultrasound containing data of mother, fetus or both
- Data transfer
  - Transfer of fetus data (and relevant maternal data) to child care
- *Data reporting*
- *Research querying*

Results - Explored fetus modeling options

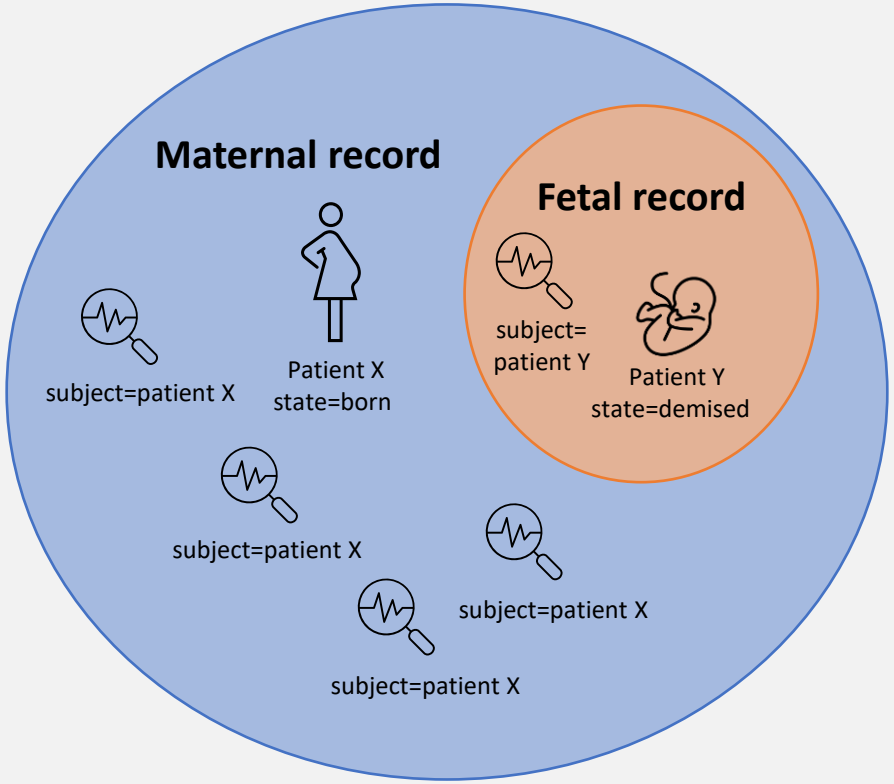
- BodyStructure
- New resource for Fetus
- Patient
  - Born status extension boolean value (true/false)
  - Born status extension coded value (born/unborn/demised/unknown)
  - Birth date unavailable with data absent reason unborn
  - Replace birthDate with birth[x] choice element (birthDate and birthBoolean)

Zulip conversation

Results - Record of the born child



Results - Record of the unborn child



Results - Born status extension in Patient (R5)

The patient resource is a FHIR resource that is maintained by the Patient Administration Work Group. The project team has discussed previously mentioned options with PCWG and PAWG. This has been recorded in Jira under FHIR_39466. The decision was taken in January 2023 during the HL7 WGM in Henderson. The Patient resource with extension with a coded value (option 3B) is viewed as the best choice.

The extension has been included in FHIR R5. Description of the extension: HL7.FHIR.UV.EXTENSIONS\Patient Born Status - FHIR v5.0.0

Terminology binding for BornStatus: HL7.FHIR.UV.EXTENSIONS\born status - FHIR v5.0.0

Link to FHIR documentation about how to relate a mother and a child in FHIR: https://www.hl7.org/fhir/patient.html#maternity .

Results - FHIR IG

Home Background Guidance Artifacts Downloads

Table of Contents > Home

InternationalBirthAndChildModel - Local Development build (v0.1.0). See the Directory of published versions

1 Home

Official URL: **https://fhir.org/fhir/ImplementationGuide/international-birth-and-child-model/ImplementationGuide/international-birth-and-child-model**	*Version*: **0.1.0**
Draft as of 2023-05-12	*Computable Name*: InternationalBirthAndChildModel

1.1 Background

- Background
- How to read this Guide

1.1.1 Introduction

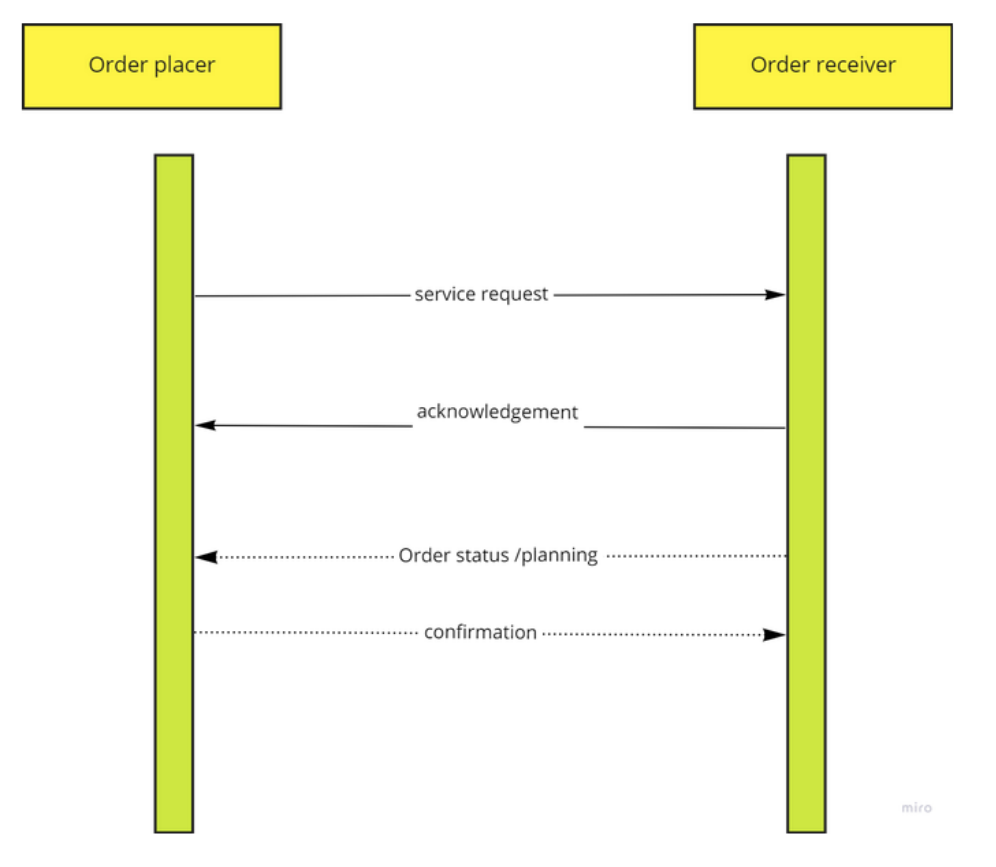
This implementation guide aims to provide guidelines and support on the handling of fetus data in FHIR.

No one disputes that when a child is born, that the child can be a patient with it's own unique identifier. The mother herself is also a recognizable patient, but there are no rules for the unborn child in the period when it is conceived as an embryo until its birth. Some systems record the data of the foetus as if it is a body tissue of the mother. Other systems do have some form of resource that resembles a patient.

There is obviously a need to relate the data to the foetus, because the data is not a characteristic of the mother, but rather to this specific foetus, for example the femur length. This is even more the case for twins or triplets, where each foetus have their own characteristics that need to be distinguished from each other.

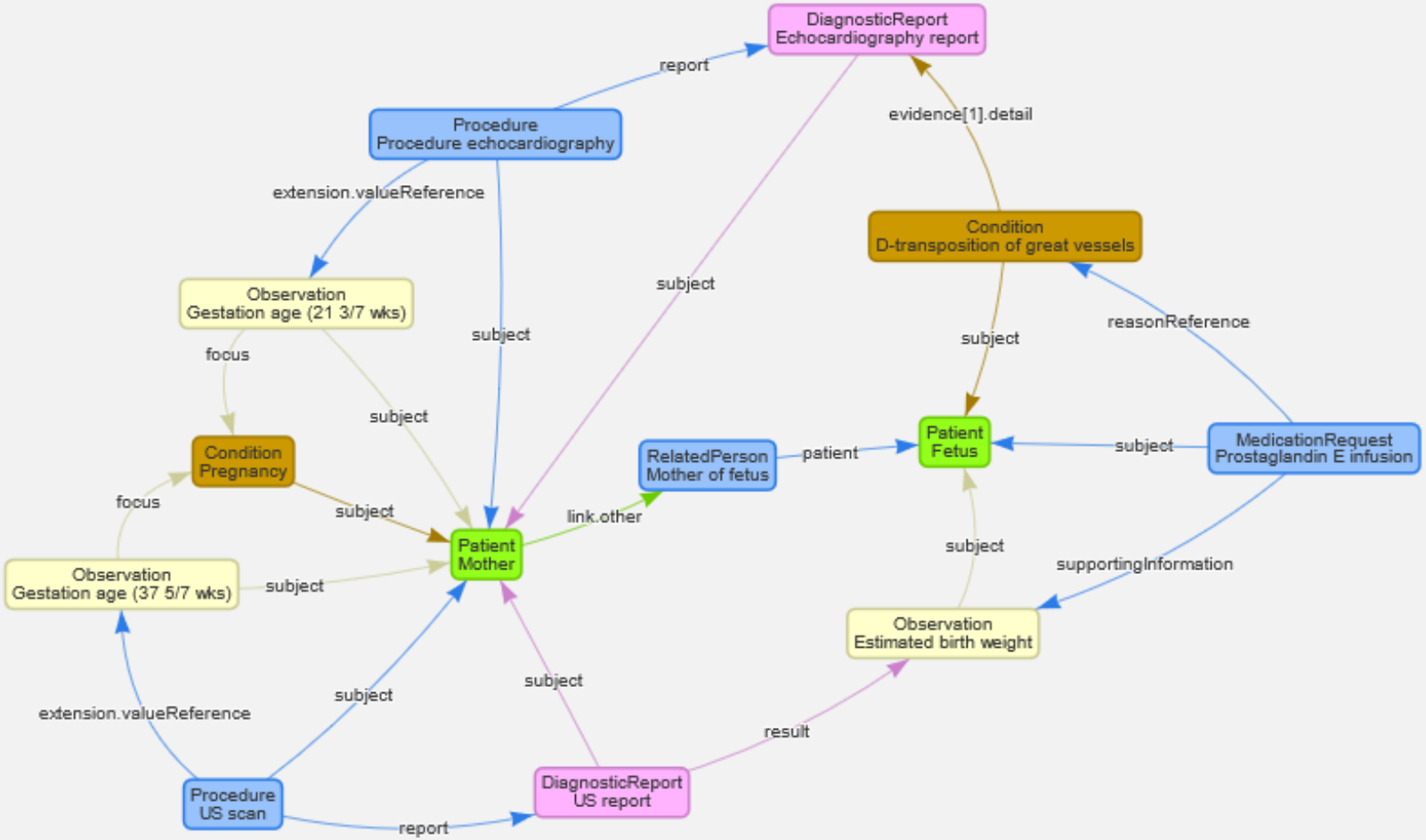
But if it is a resource with an identifier, how do you deal with this identifier? On the other hand certain resources, like a procedure, expect a reference to a subject. Are there restrictions to these subjects? Or is it able to be filled with new type of resource? These are some of the questions we dive into in this project. Additional questions are summed up in the paragraph about project questions.

Results - Service Request

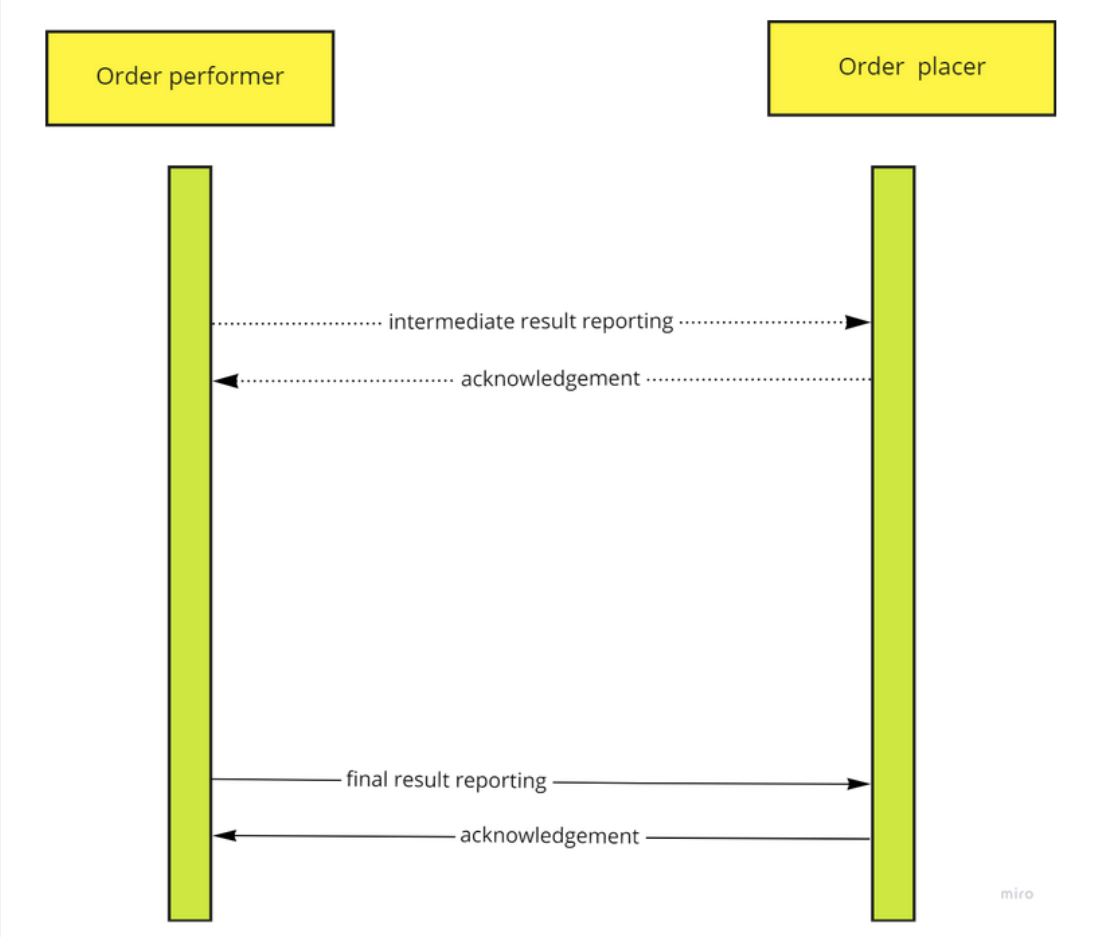


A 32 yo Gravida 3 Para 2002 Mother with a history of hypertension on labetolol during this pregnancy was diagnosed with female fetus with d-transpositon of the great arteries (SCTID: 399216004) on fetal echocardiography at 21 3/7 weeks gestation. Most recent U/S at 37 5/7 weeks revealed an estimated fetal weight of 2.960 kg.
Prostoglandin E infusion 0.01 mg/kg/min was ordered based on a dosing weight of 3kg to be initiated just after birth following umbilical line placement.

Results - Service Request

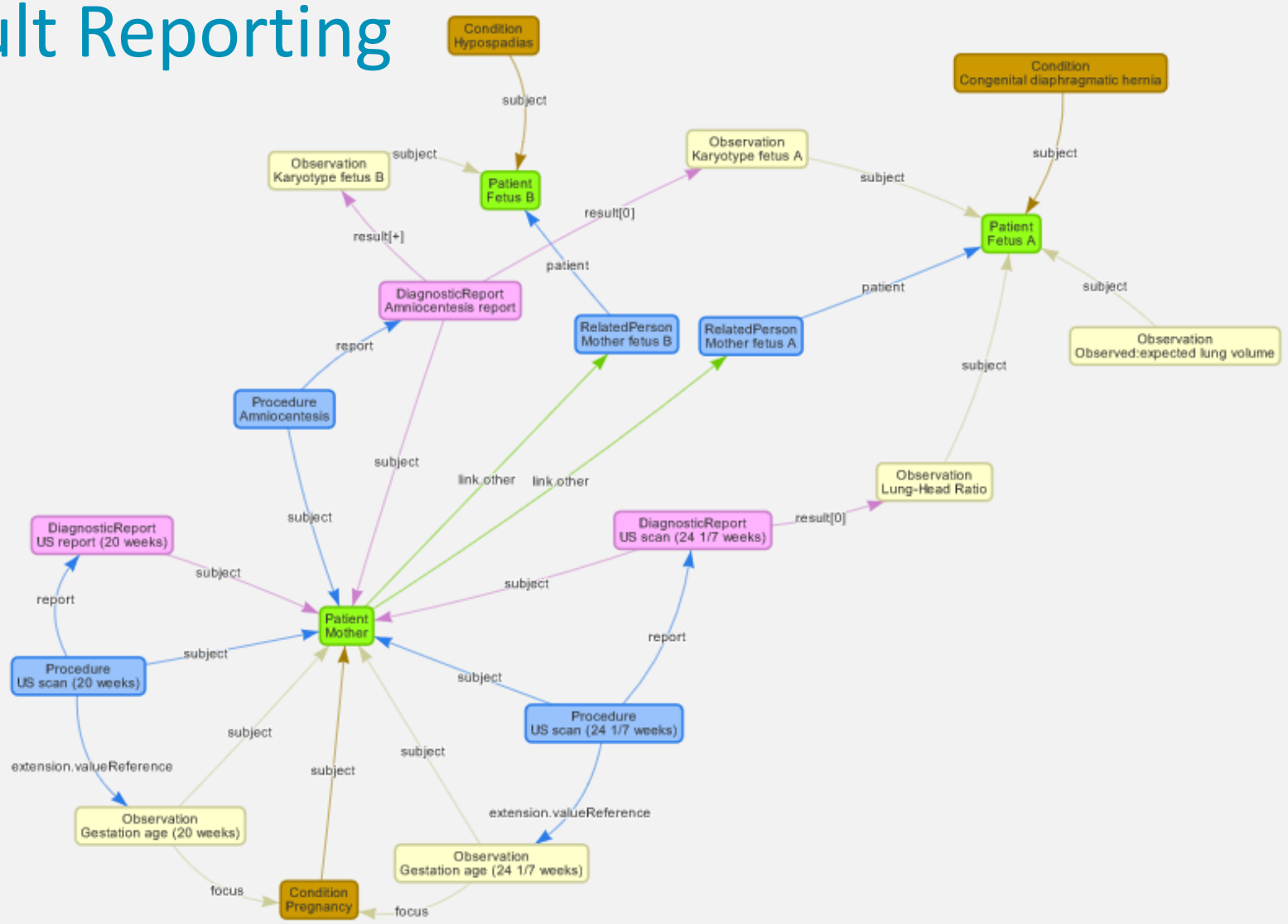


Results - Result Reporting



28 yo Gravida 1 Para 0 Mother with a dichorionic/diamniotic twin pregnancy, foetus A antenatally diagnosed with left congenital diaphragmatic hernia (CDH) containing small bowel, spleen and stomach in the left hemithorax on level 2 ultrasound at 20 weeks. Evaluation at 24 1/7 weeks revealed Lung-Head Ratio (LHR) of 0.67 via ultrasound and an observed:expected lung volume 0.21 via MRI. Normal karyotype - 46 XY on amniocentesis for both foetuses. Foetus B noted to have hypospadias on antenatal ultrasound.

Results - Result Reporting



Next steps

- Finish IG
  - Profiles
  - Terminology
- Ballot : Intention to ballot in HL7 WGM September 2023

Contact

- During DevDays, you can find / reach us here:
  - Via Whova App – Speaker's Gallery (Lilian)
  - Email Lilian: minne@nictiz.nl
  - Email Michael: mihata44@outlook.com

Q&A

ORGANIZED BY