Patient Care Work Group Updates

2020 February – Sydney WGM
Child Health Record Projects
Friday, February 7, Q3

Stephen Chu
Mike Padula
Michael Tan
Child Health in the Netherlands

- Michael Tan

February 5th 2020
Child Health programs in Netherlands

- Netherlands 17 million inhabitants
- 170,000 births per year
- Child Health starts from -7 months until 19 years old
- Child Health is active in 2 programs in the Netherlands
  - Perinatology: Obstetrics, Neonatology
  - Youth Health Program (Jeugd Gezondheids Zorg, JGZ)
Nictiz Interoperability Model

- Organizational Policy
- (Data)Workflow
- Information
- Application
- IT Infrastructure
• Prenatal screening of pregnant women and foetus
  ▪ Using Ultra sound screening (Non invasive prenatal testing NIPT)
    ✓ Down syndrome, spina bifida.....
• Uniform registration of birth data, including premature birth
  ▪ Standardized dataset, including valuesets
  ▪ Maintained in ART-DECOR
  ▪ Data used for National registries
  ▪ Monitoring premature birth in incubators
  ▪ Follow up of child after 2 years and 5 years
• Transactions using HL7v3 messages
## Geboortezorg - Datasets

### Concepten Dataset Perinatologie 2.3

<table>
<thead>
<tr>
<th>Concept</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vrouw</td>
<td>Obstetric anamnesis grouped per previous pregnancy</td>
</tr>
<tr>
<td>Zwangerschap</td>
<td>Counseling prenatal screening and prenatal diagnosis</td>
</tr>
<tr>
<td>Bevalling</td>
<td>Birth outcome (per child)</td>
</tr>
<tr>
<td>Medisch onderzoek</td>
<td>Medical investigation</td>
</tr>
<tr>
<td>Onderzoek identificatie</td>
<td>Investigation identification</td>
</tr>
<tr>
<td>Datum onderzoek</td>
<td>Date of investigation</td>
</tr>
<tr>
<td>Naam uitvoerder onderzoek</td>
<td>Name of investigator</td>
</tr>
<tr>
<td>Zorgverleningstype</td>
<td>Type of care</td>
</tr>
<tr>
<td>Zwangerschapsduur op datum onderzoek</td>
<td>Pregnancy duration on date of investigation</td>
</tr>
<tr>
<td>Onderzoektype 'Vroege zwangerschap'</td>
<td>Investigation type 'Early pregnancy'</td>
</tr>
<tr>
<td>Onderzoektype 'NT-meting'</td>
<td>Investigation type 'NT-measurement'</td>
</tr>
<tr>
<td>Onderzoektype 'SE0'</td>
<td>Investigation type 'SE0'</td>
</tr>
<tr>
<td>Onderzoektype 'GVO'</td>
<td>Investigation type 'GVO'</td>
</tr>
<tr>
<td>Onderzoektype 'Kansbeperking combinatietest'</td>
<td>Investigation type 'Risk limitation combined test'</td>
</tr>
</tbody>
</table>

### SEO-type

<table>
<thead>
<tr>
<th>Code</th>
<th>Weergavenaam</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;1&quot;</td>
<td>primair onderzoek</td>
</tr>
<tr>
<td>&quot;2&quot;</td>
<td>herhalingsonderzoek</td>
</tr>
<tr>
<td>&quot;3&quot;</td>
<td>vervolgonderzoek</td>
</tr>
</tbody>
</table>

## SEO-type

### Geërfd van: spirit1c-dataelement-51010 d.d. 2011-01-28

### Omschrijving

Aanduiding van het soort structureel echemopisch onderzoek.

### Terminglogiekoppeling

<table>
<thead>
<tr>
<th>Code</th>
<th>Weergavenaam</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;SEOType&quot;</td>
<td>SEO-type</td>
</tr>
</tbody>
</table>

### Waarde

#### Soort

<table>
<thead>
<tr>
<th>Code</th>
<th>Weergavenaam</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;ExamObjectiveType (Dynamisch)&quot;</td>
<td>ExamObjectiveType (Dynamisch)</td>
</tr>
</tbody>
</table>

### Concepten

<table>
<thead>
<tr>
<th>Concept</th>
<th>Code</th>
<th>Weergavenaam</th>
</tr>
</thead>
<tbody>
<tr>
<td>primair onderzoek</td>
<td>1</td>
<td>primair onderzoek</td>
</tr>
<tr>
<td>herhalingsonderzoek</td>
<td>2</td>
<td>herhalingsonderzoek</td>
</tr>
<tr>
<td>vervolgonderzoek</td>
<td>3</td>
<td>vervolgonderzoek</td>
</tr>
</tbody>
</table>

### Gebruik (3)
Youth Health Program

- Public Health Program for children 0-19 years old
- Focus on prevention:
  - Heel Prik: blood spot test on 23 congenital disorders
  - Tracking of development of child:
    - Eyesight, hearing, growth, dyslexia, obesity
- Healthcare is performed by municipal organizations
- Medical records are digitalized
- Dataset > 700 data elements
- Maintained in ART-DECOR
- Transactions using HL7v3 messages
Vaccination program

- Vaccination is an important part of the program
- RIVM (Rijks Instituut voor Volksgezondheid en Milieu) is responsible for the vaccination program
- Operational work is done by consultation office (for 0-4 years) and JGZ (youth health program) 5-19 years
- Currently 8 HL7v3 transactions
Challenges and issue

- Use case
- Priority
- GDPR & Legislations
- Parent/Child relations
- Infrastructure: National body for the Netherlands
- RIVM does not use G-standard nor IDMP nor SNOMED nor GTIN
- Funding of the project.
Contact: tan@nictiz.nl
Patient Care Workgroup

Care Plan topics

- **Essential Information for Children with Special Healthcare Needs**
  - For communicating patient preferences/plans in settings including urgent or emergent care
  - Initially envisioned as a possible distinct CDA template
  - Transitioned to rendering of use-cases among FHIR resources including the Care Plan resource
  - Have created multiple use-cases for complex patients with unique features, such as
    - 1 month-old with metabolic disorder (OTC deficiency) presenting to emergency department
    - 18 year-old with cystic fibrosis transitioning care providers
    - 7 year-old with autism and seizure disorder on a ketogenic diet
    - More details available: [https://confluence.hl7.org/display/PC/Essential+Information+for+Children+with+Special+Health+Care+Needs](https://confluence.hl7.org/display/PC/Essential+Information+for+Children+with+Special+Health+Care+Needs)
  - Also rendering these scenarios via resources in Clinicians of FHIR (CoF) tracks/meetings
  - May be relevant for the Multiple Chronic Condition (MCC) eCare Plan, as well
Child health record projects

US Realm

- HL7 EHRSF-M Release 2 Functional Profile: Child Health Functional Profile Release 1; Developmental Screening and Reporting Services Derived Profile, Release 1 - US Realm
  - Identifies the critical EHR capabilities for Pediatric Developmental Screening and Reporting services
  - Provides a documentation standard for the development of pediatric developmental screening and follow-up functions in EHR systems that align with existing regulatory and clinical care standards
  - Facilitates documentation and information exchange for clinical decision making
  - Facilitates aggregate reporting to relevant entities including public health agencies