Digital Mother-Child Health Care

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Digital child health: opportunities and obstacles. A joint statement of European Academy of Paediatrics and European Confederation of Primary Care Paediatricians Frontiers December 2023

The **EAP** and the **ECPCP** strongly support the development of **European Health Data Space** and emphasise that **health data regarding children and adolescents** must be possible to use at **every contact** with healthcare wherever this contact takes place in Europe.

Standardizing digital data using appropriate protocols of **interoperability** would make it possible to interpret the information in all computerised systems **despite the different languages in Europe.**

Brussels, March 18th 2025

To mark the adoption of the **European Health Data Space (EHDS) Regulation**—published in the Official Journal of the European Union on 5 March 2025—

the European Commission's Directorate-General for Health and Food Safety (DG SANTE) and the European Health and Digital Executive Agency (HaDEA) hosted a high-level event in Brussels, under the auspices of the Polish Presidency of the Council of the EU.

Dubrovnik, April 4-5 2025

The EAP and ECPCP adopted a statement embracing the EHDS.

However, medical doctors are not **trained in informatics**.

A short survey among paediatricians on their knowledge of digital standards revealed that the EAP spring meeting

17/20 **ICD** (international classification for disease) (**85%**),

5/20 **LOINC** (observations and measurements) (**25%**),

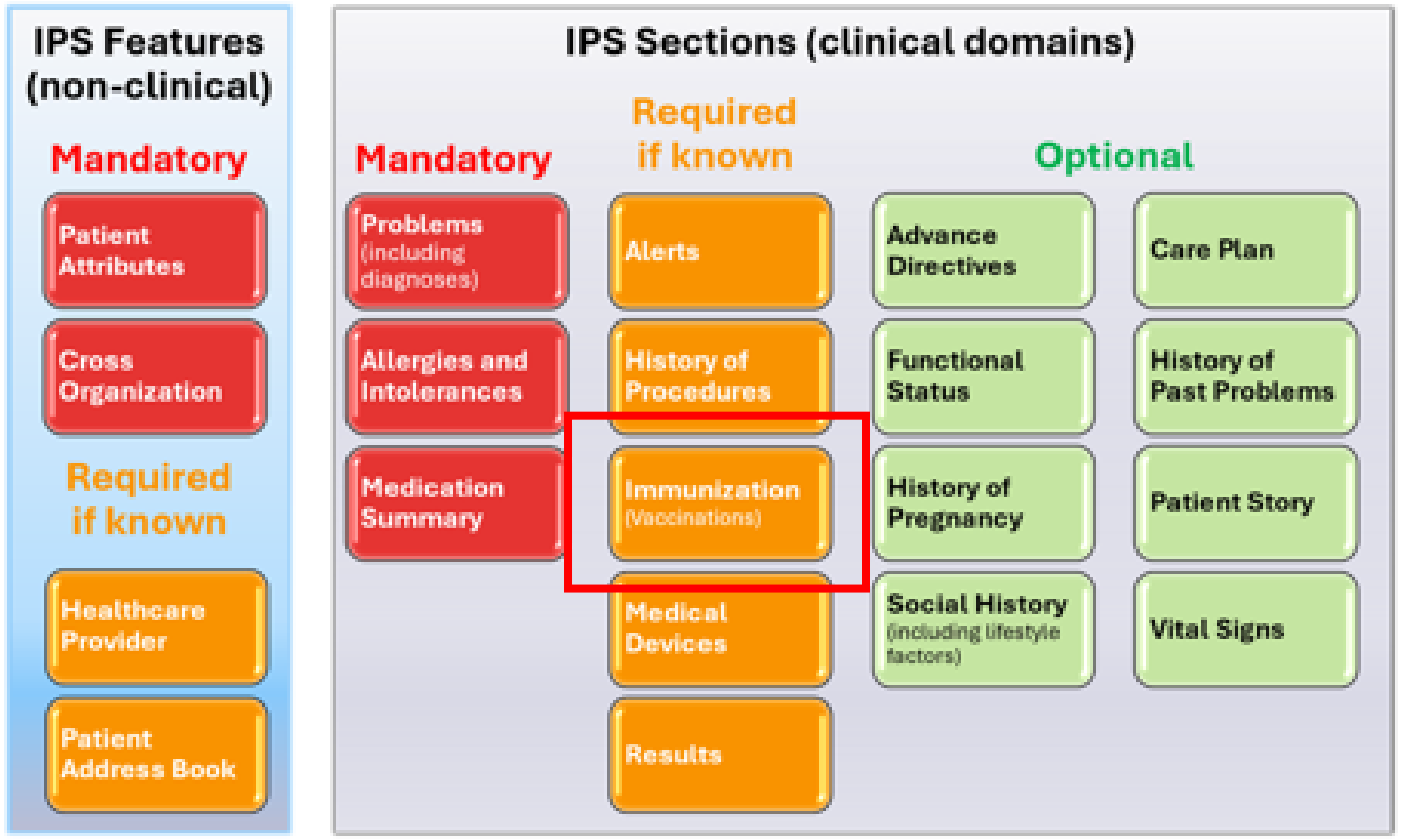
4/20 **ICF** (functioning) (**20%**),

2/20 **HL7** (**10%**).

International Patient Summary updated October 2025

https://international-patient-summary.net/iso-27269/

ISO 27269:2025 – The International Patient Summary



What is ISO?

ISO is the short name for the International Organization for Standardization.
https://www.iso.org/healthcare/electronic-health-records

It is a matter of building on the basics: turning a

simple patient chart into an electronic health record (EHR)

What is the **International Patient Summmary**

As specified in ISO 27269, the IPS dataset is a ***"minimal, non-exhaustive set of data elements required for the international patient summary"***.

A Patient Summary is defined by ISO/TR 12773-1:2009 as a *"Health record extract comprising a standardized collection of clinical and contextual information (retrospective, concurrent, prospective) that provides a* ***snapshot in time*** ***of a subject of care's health information and healthcare."***

IPS in FHIR

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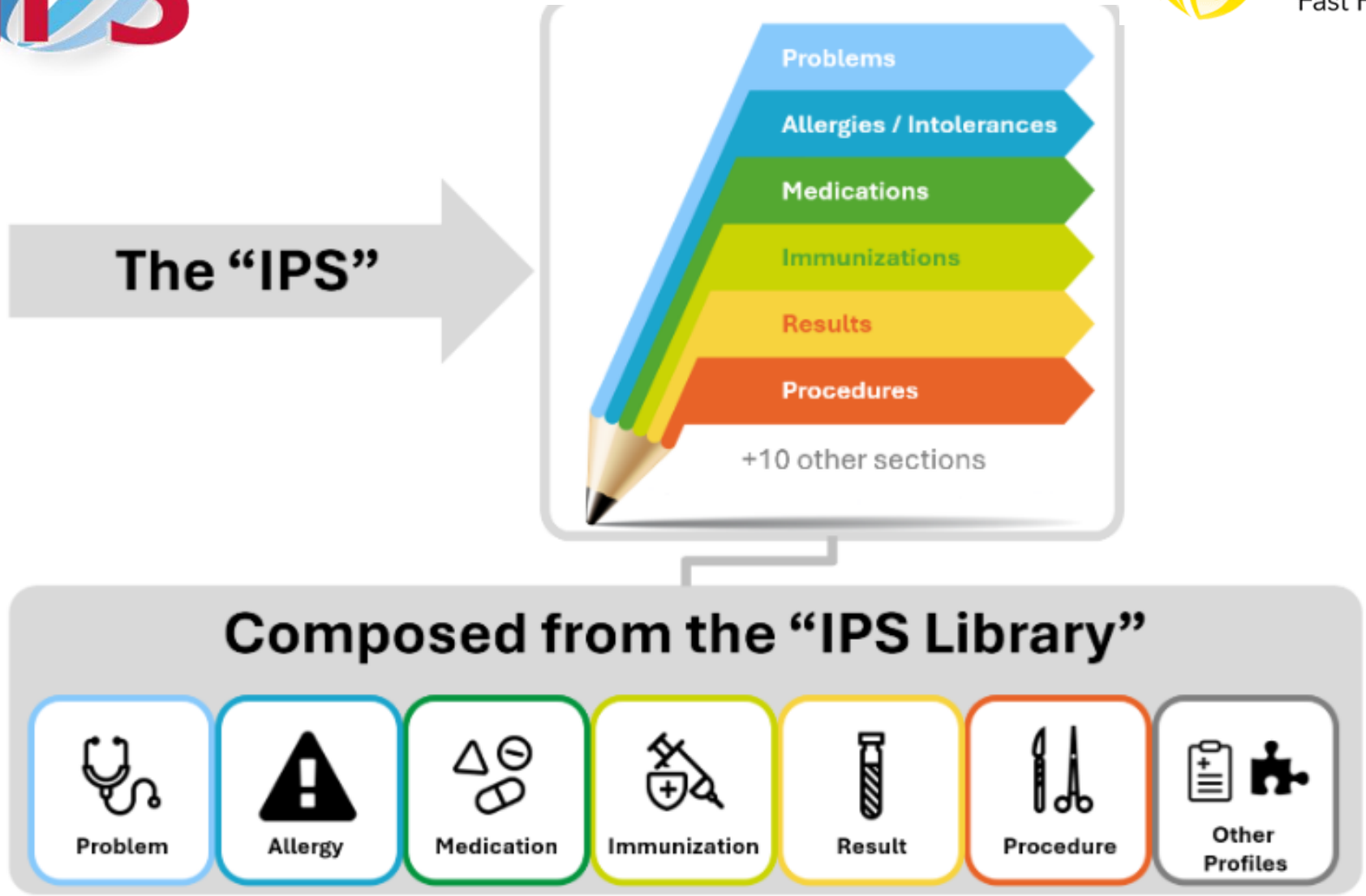
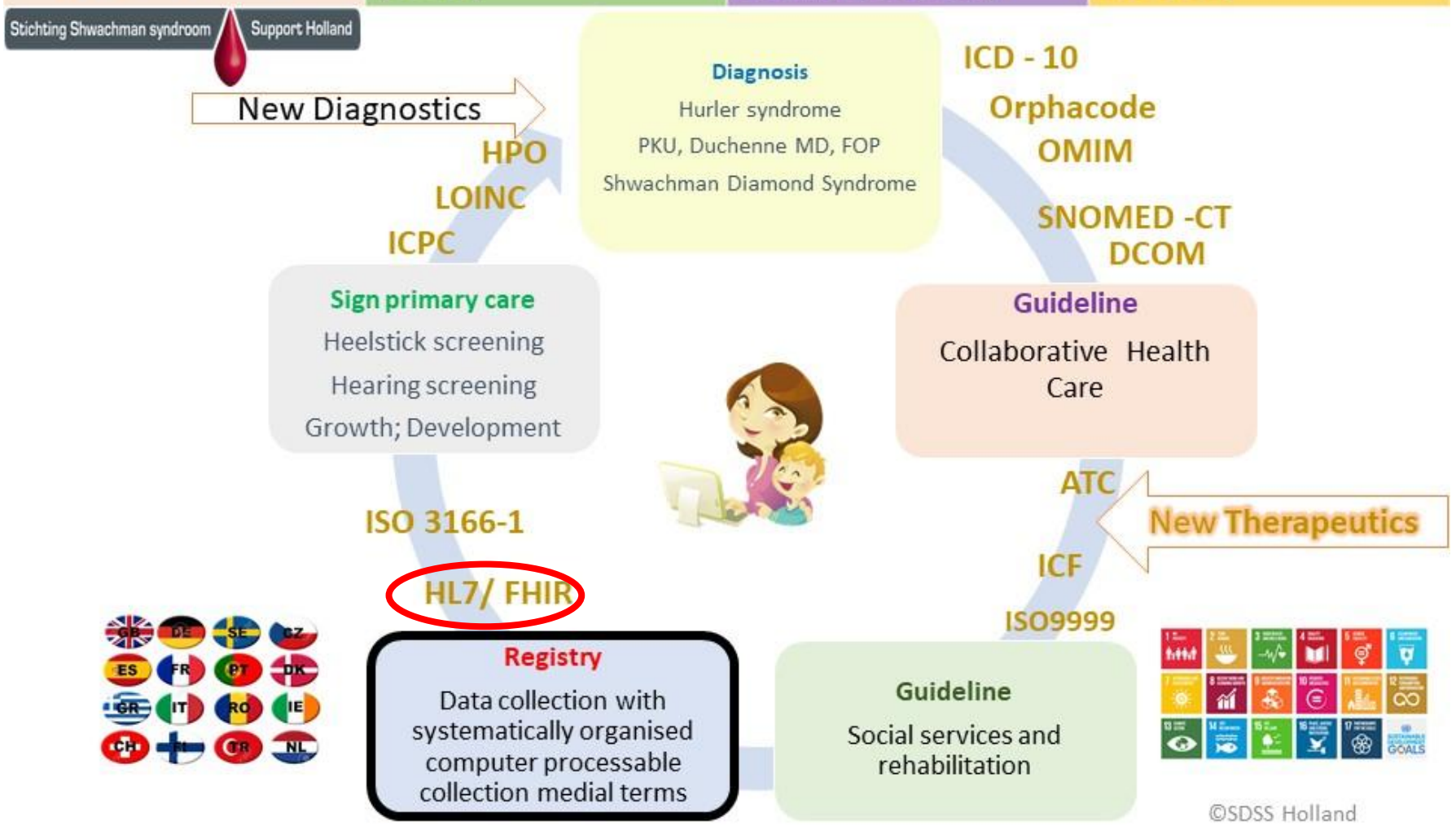


Patient Informatiom	Primary Care	Diagnosis Collaborative care	Social Services
www.shwachman.nl https://rarecare.world	Growth retardation Recurrent infections (LOINC)	Guideline SDS (Orphanetcode; SNOMED, ATC e.a.)	Recurrent illness Fatigue, Short (ICF-CY; ISO 9999)



International terminologies as a tool for interoperability in child health

Towards a Global Integrated Digital Preventive Child Health Model

One code = One meaning

ICPC: International Classification of Primary Care

HPO: Human Phenotype Ontology

LOINC Standard for identifying health measurements, observations, and documents

ICD: International Classification of Diseases

ICF: International Classification of function

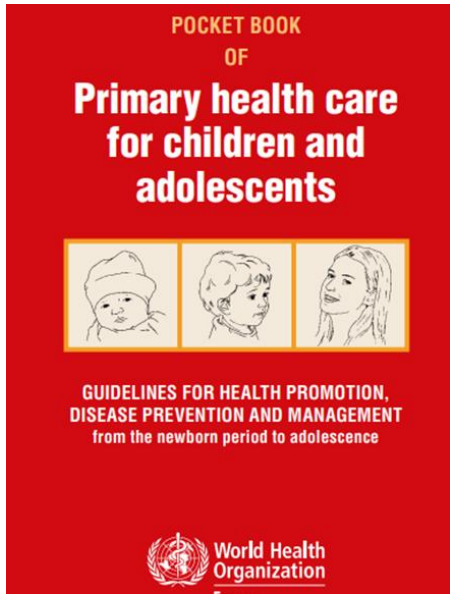
ATC: Anatomical Therapeutic Chemical Classification System

ORPHA: Classification of rare diseases

OMIM: Catalog of Human Genes and Genetic Disorders

Use of terminologies enables semantic interoperability between systems using HL7 CDA and FHIR

World Health Organization



The health information system ensures

the collection, analysis and use of data to ensure early, appropriate action to improve the care of every child

3.2 Well-child visit: birth – 72 hours

Most children will be seen in hospital for these visits; if not, they ought to be seen by the primary care provider within 24 hours of birth and again at 48–72 hours.

- Look for congenital diseases and jaundice
- Support caregivers.

History

- Problems during pregnancy, e.g. diabetes, medications, substance abuse, acute or chronic infections, mental or social stress, abnormal test results, e.g. positive group B Streptococcus, HIV, hepatitis B
- Mode of delivery and problems during or after birth
- Congenital disorders in the family, e.g. hip problems
- Hip dysplasia risk factors, e.g. twin pregnancy, breech position
- Problems passing meconium and urine

What does this mean?

- If we communicate an **observation result**, we need to:
  - Identify the observation type: what is it that we are observing
  - Result description: readable text for anyone to understand
  - Result value: depending on the observation type, it needs to be agreed how the result value is structured, such as:
    - **Yes/No**
    - **Number with units of measurement**
    - **Code and name of organism identified in a sample**

- One of the problems is to differentiate between the observation type and the result value
  - Is the test for organisms in general, with **MRSA** as a possible result
  - Is the test for MRSA in particular, with **Yes/No** as a possible result

The IPS Section Results

H1	H2	H3	H4	Conformance	Description	Subclause containing further details
IPS section: Results Synonyms: Observations Acronyms: None				RK	Required if information about Results is known.	22.2
	Observation results			R	List	22.3
		Observation result		R	Label Concept	
			Date of observation	R	Date Time or Period	
			Observation type	R	Coded Element	22.4
			Result description	RK	Text	22.5
			Result value	C	Any	22.6
			Observation result	C	Label Concept	22.7
			Performer	O	Healthcare Provider	22.8
			Observer	RK	Healthcare Provider	22.9

Different levels of coding result values

- Clinical **measurement** for an individual patient
  - HbA1c 53 mmol/mol
    - Observation type: 59261-8 (LOINC) – “HbA1c standardized per IFCC-RMP for CDT (Bld) [Molar fraction]”
    - **Result value: 53 mmol/mol**

- Clinical **observation** for an individual patient
  - History of high blood glucose
    - Observation type: 97062-4 (LOINC) – “Hx of High blood glucose”
    - **Result value: YES**

Apgar Score LOINC and SNOMED CT

LOINC

LOINC CODE
48332-1

LONG COMMON NAME
10 minute Apgar panel

Reference Information

Type	Source	Reference
Article	NCBI PubMed	Apgar V. A proposal for a new method of evaluation of the newborn infant. Curr Res Anesth
Article	NCBI PubMed	American Academy of Pediatrics, Committee on Fetus and Newborn; American College of C Obstetric Practice. The Apgar score. Pediatrics. 2006 Apr;117(4):1444-7. Link to PubMed

Panel Hierarchy

Details for each LOINC in Panel | LHC-Forms

LOINC	Name	R/O/C	Cardinality
48332-1	10 minute Apgar panel		
32401-2	10 minute Apgar Color		1..1
32402-0	10 minute Apgar Heart rate		1..1
32404-6	10 minute Apgar Reflex irritability		1..1
32403-8	10 minute Apgar Muscle tone		1..1
32405-3	10 minute Apgar Respiratory effort		1..1
9271-8	10 minute Apgar Score		1..1

NHS Digital SNOMED CT Browser

© SNOMED International 2017 v1.36.4 - Hosted and maintained by NHS Digital

	(observable entity)
Apgar score 4 (finding)	Apgar score 4 (finding)
Apgar score 5 (finding)	Apgar score 5 (finding)
Apgar score 0 (finding)	Apgar score 0 (finding)
Apgar score 8 (finding)	Apgar score 8 (finding)
Apgar score 9 (finding)	Apgar score 9 (finding)
Apgar score 3 (finding)	Apgar score 3 (finding)
Apgar score 1 (finding)	Apgar score 1 (finding)
Apgar score 7 (finding)	Apgar score 7 (finding)
Apgar score 6 (finding)	Apgar score 6 (finding)
Apgar score 10 (finding)	Apgar score 10 (finding)
Apgar score at 5 minutes	Apgar score at 5 minutes (observable entity)
Apgar score at 20 minutes	Apgar score at 20 minutes (observable entity)
Apgar score at 10 minutes	Apgar score at 10 minutes (observable entity)
Apgar score at 15 minutes	Apgar score at 15 minutes (observable entity)

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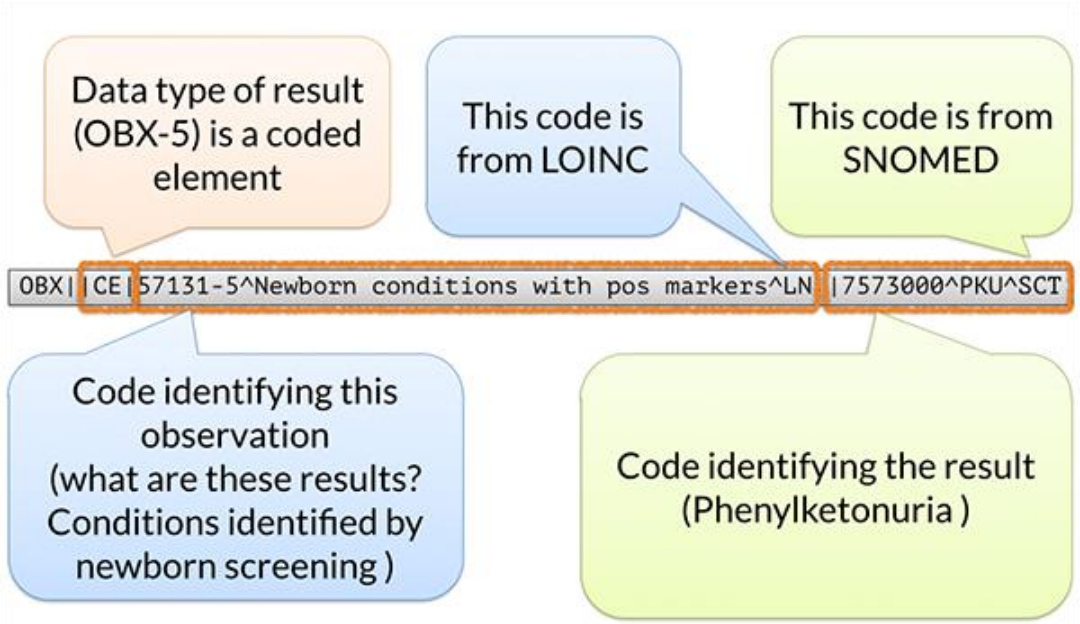
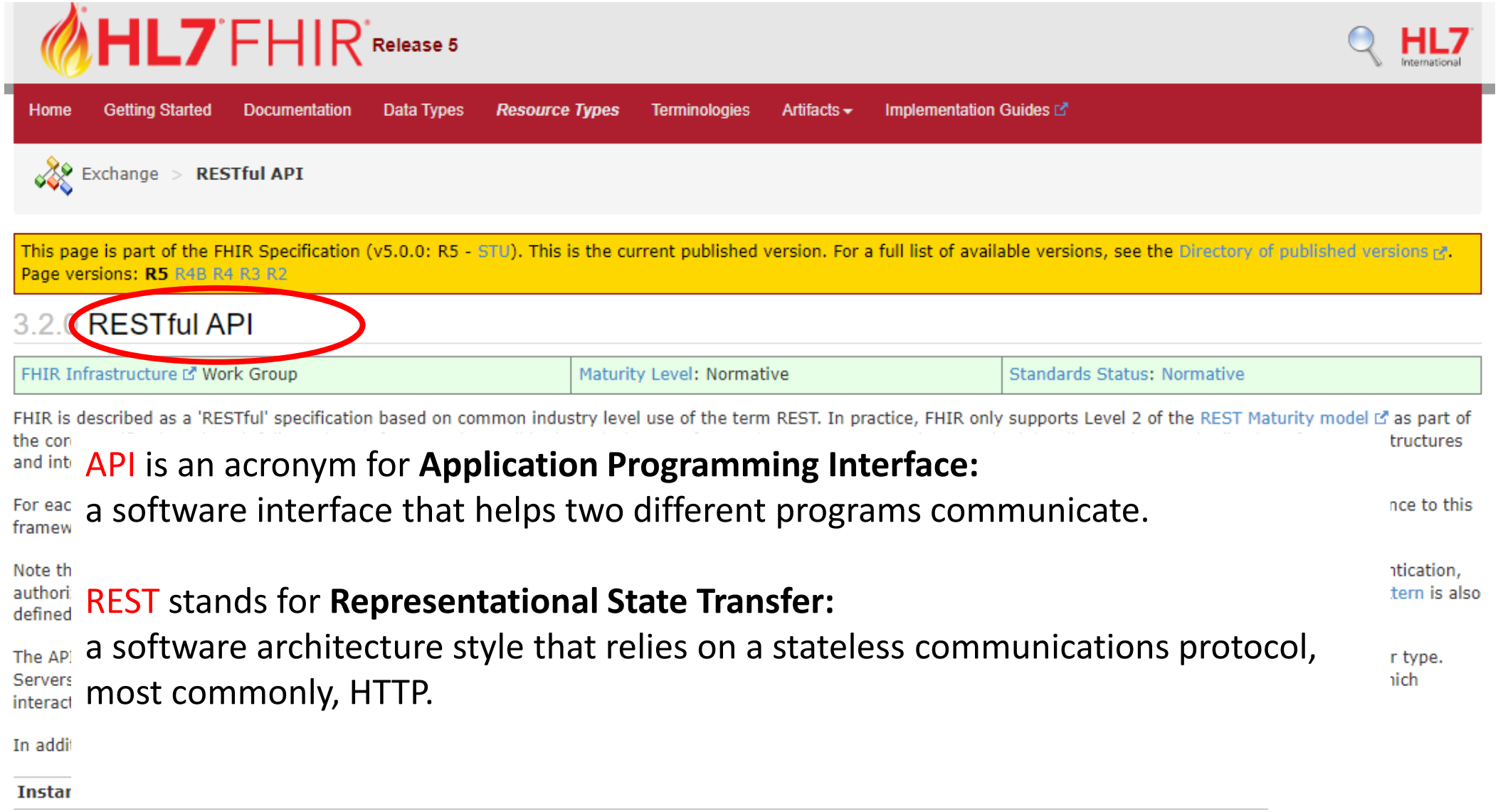
Problems, Immunizations, Medication, Results

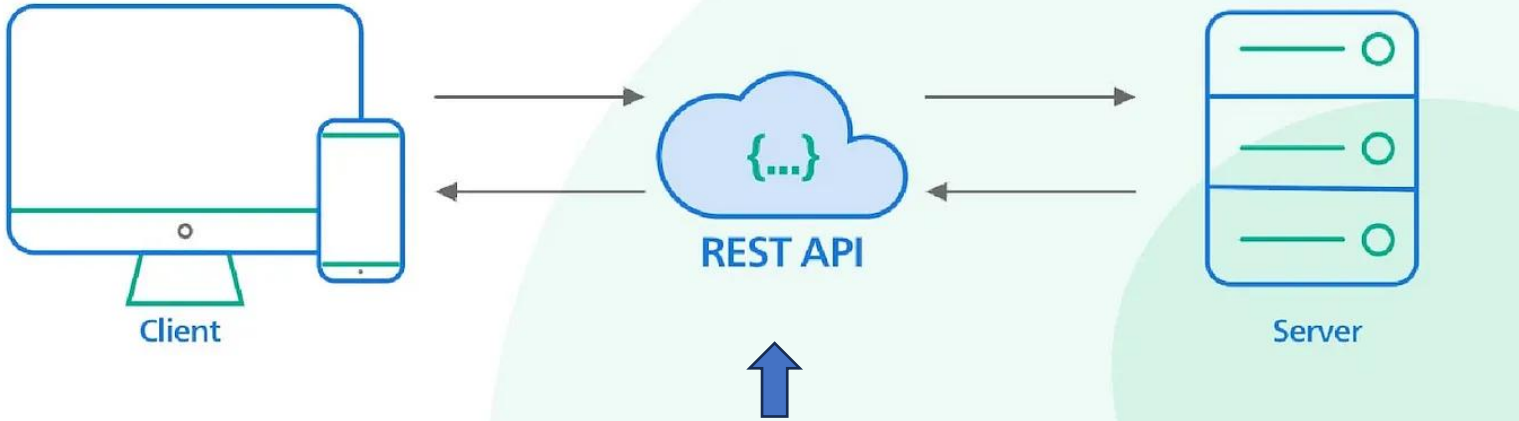


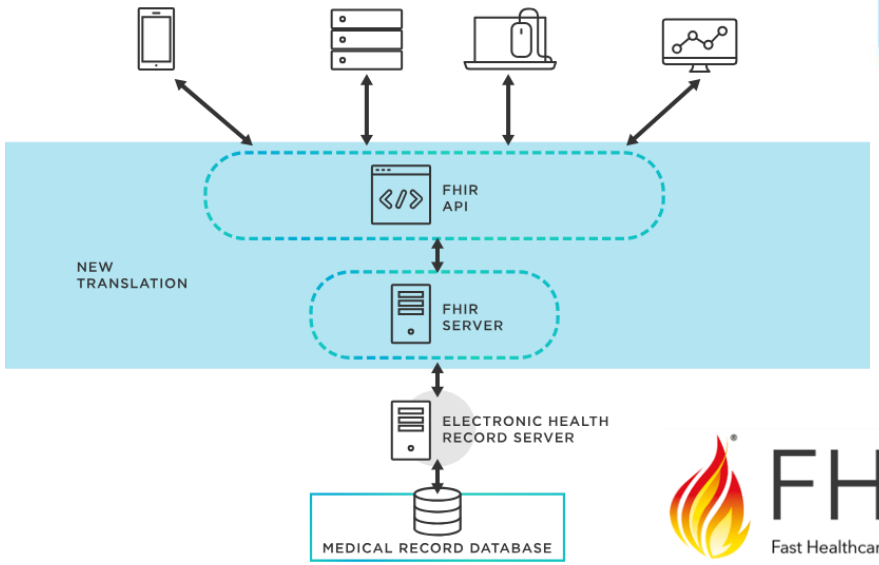
Terminologies enable semantic interoperability in health information exchange standards systems using HL7 CDA and FHIR



https://www.serphouse.com/blog/google-maps-apis-guide-to-location/

Why is RESTful API so popular





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https://blog.bytebytego.com/p/why-is-restful-api-so-popular

https://www.tibco.com/glossary/what-is-hl7-fhir

(updated: January 2025)

Table 2: Summary of WHO Position Papers - Recommended Routine Immunizations for Children

Antigen		Age of 1st Dose	Doses in Primary Series	Interval Between Doses			Booster Dose	Considerations (see footnotes for details)
				1st to 2nd	2nd to 3rd	3rd to 4th		
Recommendations for all children								
BCG [1]		As soon as possible after birth	1					Birth dose and HIV; Universal vs selective vaccination; Co-administration; Vaccination of older age groups; Pregnancy
Hepatitis B [2]	**Option 1**	As soon as possible after birth (<24h)	3	4 weeks (min) with DTPCV1	4 weeks (min) with DTPCV2			Premature and low birth weight; Co-administration and combination vaccine; High risk groups
	Option 2	As soon as possible after birth High risk groups	4	4 weeks (min) with DTPCV1	4 weeks (min) with DTPCV2			
Polio [3]	**bOPV + IPV** "Preferred schedule" (fractional Salk-IPV permitted)	bOPV 6 weeks IPV 14 weeks	5 (3 bOPV and 2 IPV)	bOPV 4 weeks (min) (e.g. with DTPCV2) IPV ≥ 4 months (min) (e.g. with MCV)	bOPV 4 weeks (min) (e.g. with DTPCV3)			bOPV birth dose; Type of vaccine; Fractional dose IPV; Transmission and importation risk; Local epidemiology, programmatic implications and feasibility for "early" option
	bOPV+IPV "Early Option" (full dose IPV only)	bOPV 6 weeks IPV 6 weeks	5 (3 bOPV and 2 IPV)	bOPV 4 weeks (min) (e.g. with DTPCV2) IPV 14 weeks (min) (e.g. with DTPCV3)	bOPV 4 weeks (min) (e.g. with DTPCV3)			
	IPV / bOPV Sequential	8 weeks (IPV 1st) bOPV (4-8 weeks after 2nd IPV)	4 (2 IPV followed by ≥ 2 bOPV)	IPV (4-8 weeks)	bOPV (4-8 weeks)	bOPV (4-8 weeks)		
	IPV-only	6-8 weeks	3	4-8 weeks	4-8 weeks		IPV booster (6 months after 3rd dose) is needed when 1st dose given at < 8 weeks	Only for countries in polio-free regions with a very low risk of importation and sustained high routine immunisation coverage (DTP3 > 90%)
	Alternative IPV-only (fractional permitted)	≥14 weeks	2	≥ 4 months (e.g. with MCV)				
DTP-containing vaccine [4]		6 weeks (min)	3	4 weeks (min) - 8 weeks	4 weeks (min) - 8 weeks		3 Boosters 12-23 months (DTP-containing vaccine); 4-7 years (Td/ DT containing vaccine), see footnotes; and 9-15 yrs (Td)	Delayed/ interrupted schedule Combination vaccine; Maternal immunization

Refer to https://www.who.int/teams/immunization-vaccines-and-biologicals/policies/position-papers for table & position paper updates.

This table summarizes the WHO vaccination recommendations for children.The ages/intervals cited are for the development of country specific schedules and are not for health workers.

National schedules should be based on local epidemiologic, programmatic, resource & policy considerations. While vaccines are universally recommended, some children may have contraindications to particular vaccines.

P.1 / 14

National Institute for Public Health and the Environment
Ministry of Health, Welfare and Sport

Which vaccinations will my child receive?

Injection against RSV

- **0-2 weeks** for babies born from October through March
- **0-7 months** for babies born from April through September

6-9 weeks

- Rota
- (DTaP-IPV - Hib - HBV)*

3 months

- Rota
- DTaP-IPV - Hib - HBV
- Pneu

5 months

- DTaP-IPV - Hib - HBV
- Pneu

Abbreviations and what they mean

RS	Respiratory syncytial virus (RSV)
Rota	Rotavirus
D	Diphtheria
aP	Whooping cough (pertussis)
T	Tetanus
P	Polio
Hib	*Haemophilus influenzae* type b
HBV	Hepatitis B virus
Pneu	Pneumococcal disease
M	Mumps
M	Measles
R	Rubella
MenACWY	Meningococcal disease types ACWY
HPV	Human papillomavirus

Questions? Ask at the well-baby clinic or go to rijksvaccinatieprogramma.nl/en

12 months

- DTaP-IPV - Hib - HBV
- Pneu

14 months

- MMR
- MenACWY

3 years

- MMR

5 years

- DTaP

10 years

- HPV
- 2nd vaccination 6 months later

14 years

- DT-IPV
- MenACWY

* Only if the mother was not vaccinated against whooping cough during pregnancy (maternal whooping cough vaccination). This extra vaccine dose is also given in special circumstances. The paediatrician will discuss this with you.

DTaP-IPV - Hib – HBV vaccination Dependant on mother and child data

maternal pertussis vaccination in Netherlands

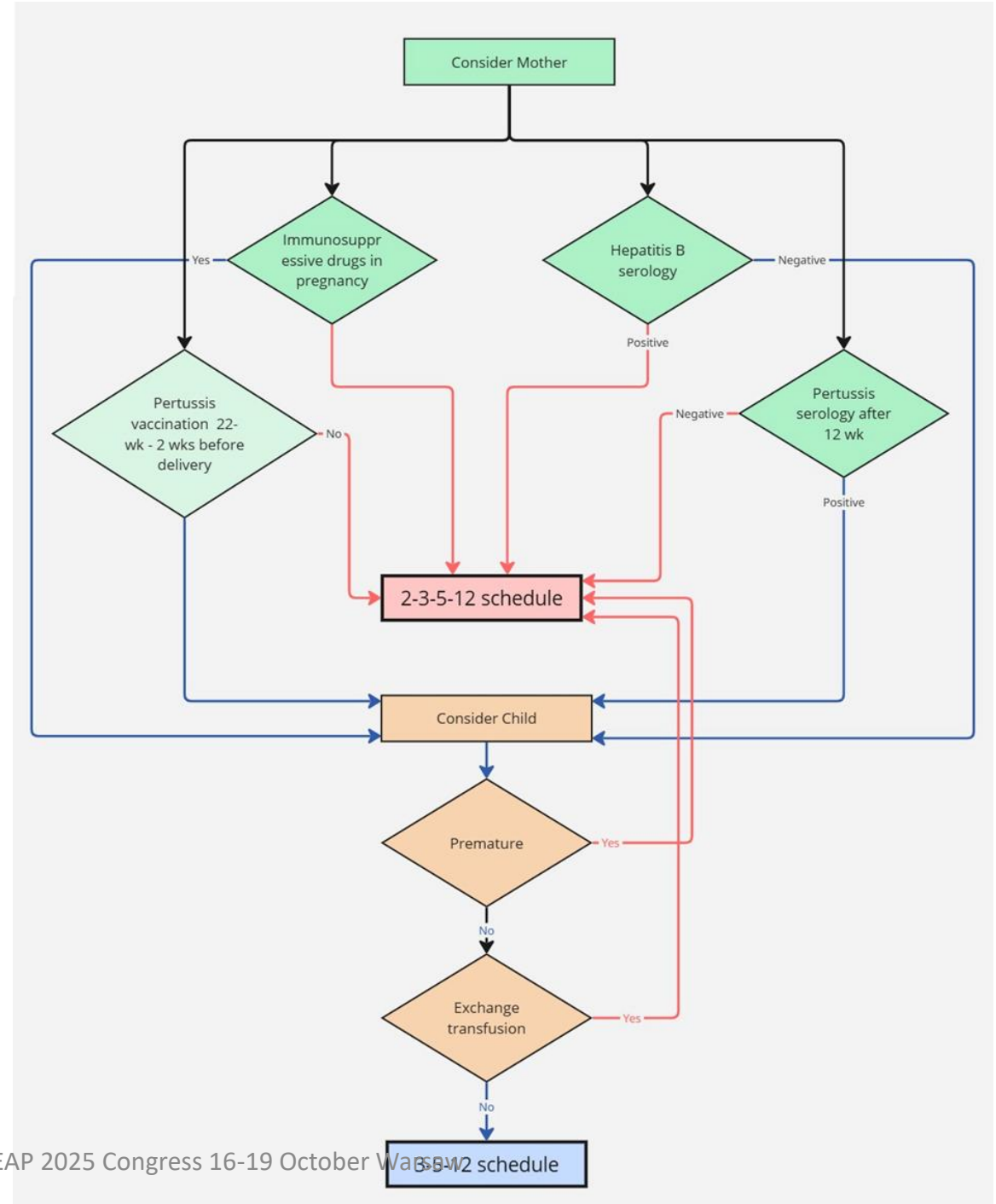
In the Netherlands children's first year pertussis vaccination scheme has two variants in months of age depending on several data of mother, pregnancy and child:
2-3-5 -12 or
3-5-12

To make data interoperable we need to select data points are illustrated as [person – data point] necessary to exchange data from one (or more) providers / institute.

Maternal/Infant condition	Child's vaccination schedule
Mother vaccinated against pertussis during pregnancy (at ≥22 weeks and ≥2 weeks before delivery)	3–5–12 months
Mother had pertussis infection (proven by serology or PCR after 12+ weeks gestation)	3–5–12 months
Mother is hepatitis B carrier	2–3–5–12 months
Mother took immunosuppressive drugs during pregnancy (e.g., Infliximab)	2–3–5–12 months
Child born premature (<37 weeks)	2–3–5–12 months
Child had an exchange blood transfusion	2–3–5–12 months

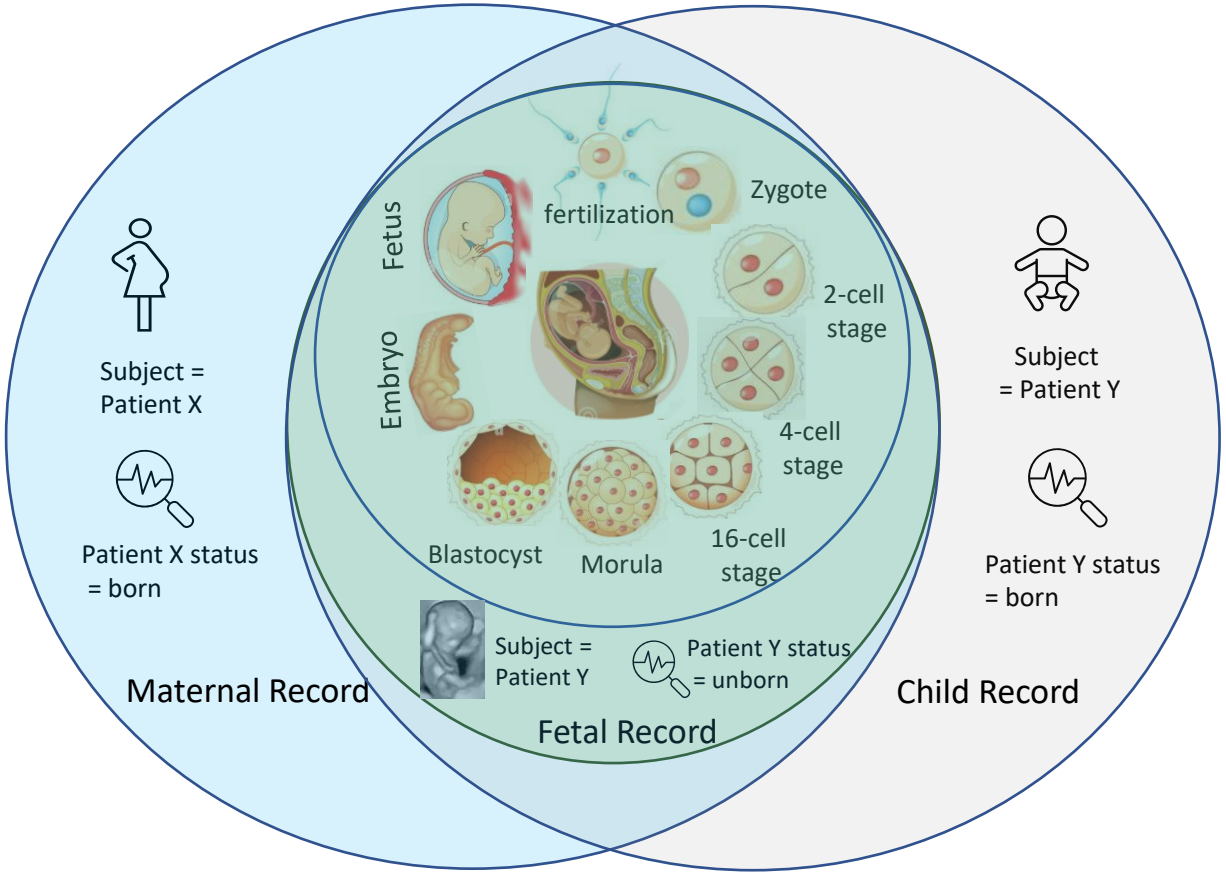
	IS MATERNAL PERTUSSIS VACCINATION PERFORMED IN YOUR COUNTRY/ REGION?	IF SO DOES THAT LEAD TO AN ADJUSTED CHILD VACCINATION SCHEME	ARE THERE SPECIFIC CONDITIONS TO BE CONSIDERED TO DECIDE ABOUT CHILD VACCINATION SCHEME?
LITHUANIA	Maternal pertussis vaccination is strongly recommended during pregnancy in Lithuania and is reimbursed by the government	Maternal vaccination status currently has no influence on infant vaccination schedule as the vaccination rates during pregnancy are low (less than 20 %).	- Individualized vaccination schedules are applied only in children with chronic or immunocompromising conditions.
HUNGARY	The mothers are informed, but it's not mandatory	first vaccine at age 2 months, next: 3 month, next: 4 month	Contraindications for vaccination: 1. Feverish illness 2. Immunological impairment: 3. Previous occurrence of serious adverse events following vaccination
FINLAND	Yes, must check the status, and if not adequately covered, booster is strongly recommended	No	Yes, a minority (immunodeficient, extremely preterm, certain risk groups etc.) gets an individualised scheme
GERMANY	Tdap Vaccine issued regularly in Pregnancy and offered/recommended nationally.	Schedule is: TdPaP+hib+hepB plus Pneumococcus at 2-4-12 months. (since 2020)	Special groups
ITALY	In Italy, maternal vaccination against pertussis is recommended and actively offered during each pregnancy, preferably between the 27th and 36th week of gestation, using the Tdap vaccine	No. Maternal vaccination does not modify or delay the standard child vaccination schedule in Italy.	Yes. While the standard vaccination schedule applies to all healthy infants, specific clinical conditions may require tailored vaccination approaches,
TURKEY	In Turkey, maternal pertussis vaccination has just started in April 2025.	Child vaccination scheme is still same	

DTaP-IPV - Hib – HBV Dependant on mother and child data



Child Health & Obstetrics International Collaboration and Exploration

Conceptual diagram: Mother-Fetus-Child concepts, 2022

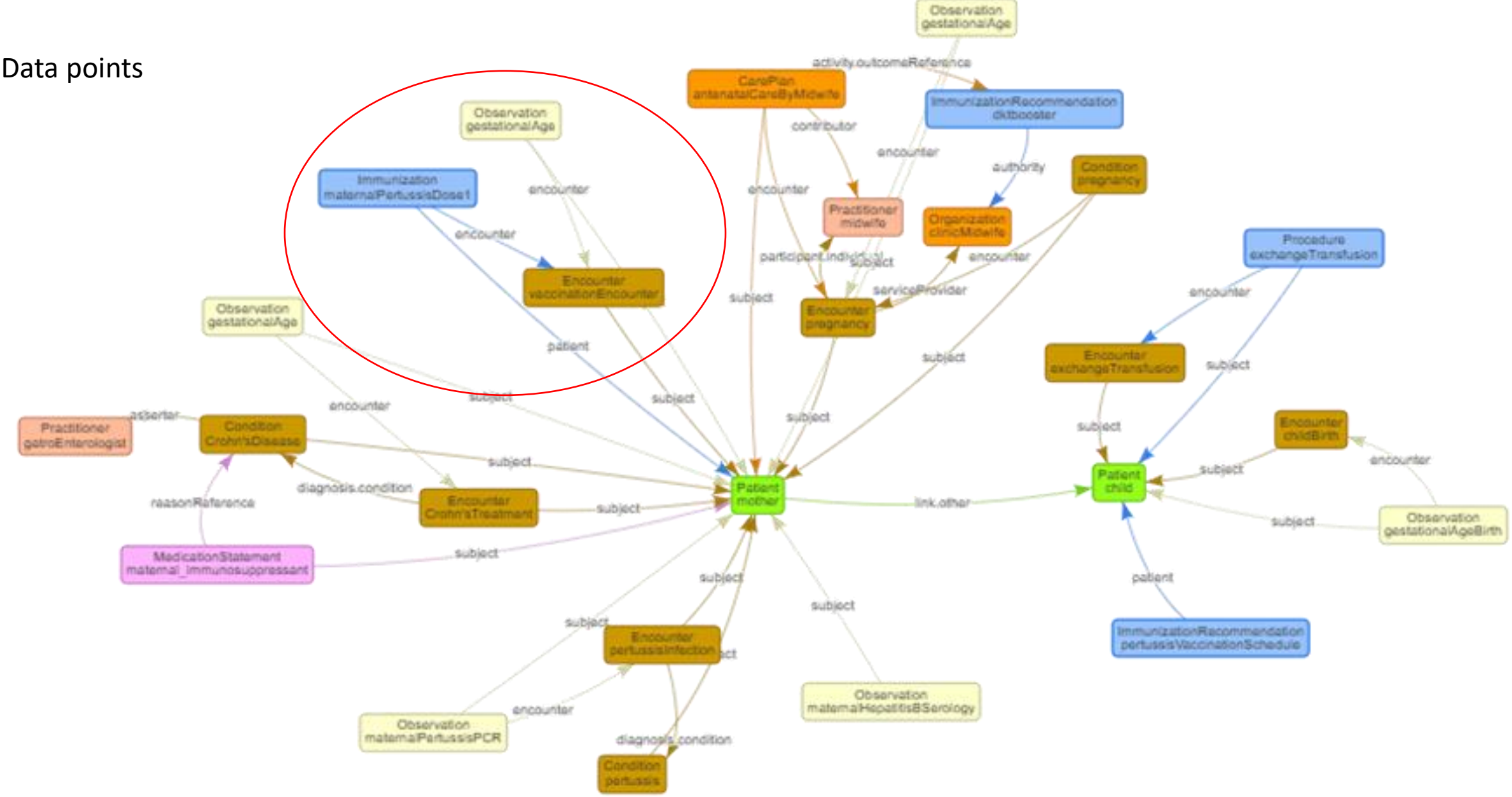


HL7 International

Key modelling question:
At what stage/when does a fetus stop being a body part of the pregnant woman and becomes an entity

[Child Health & Obstetrics International Collaboration and Exploration - Patient Care - Confluence (hl7.org)]

Data points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encounter
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encounter
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Organization clinicMidwife
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Encounter vaccinationEncounter
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patient
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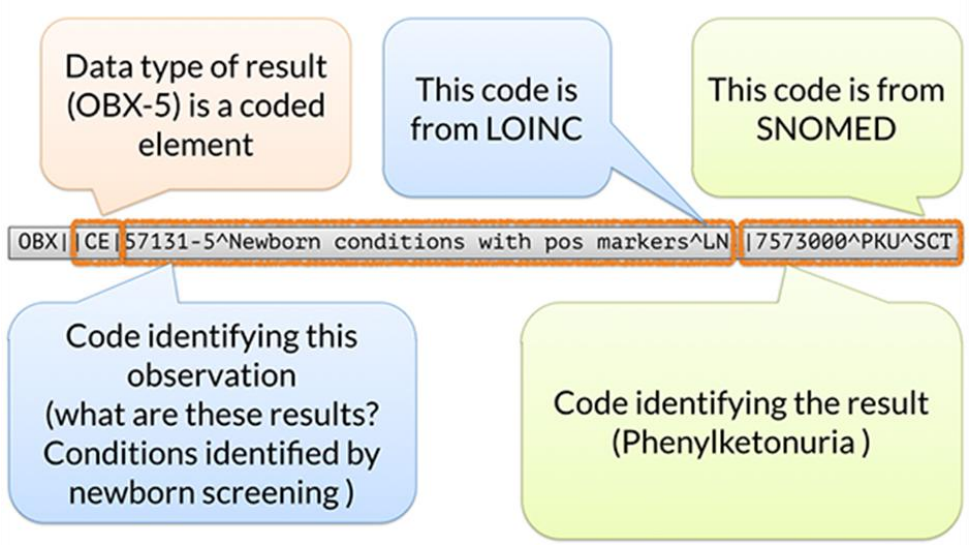


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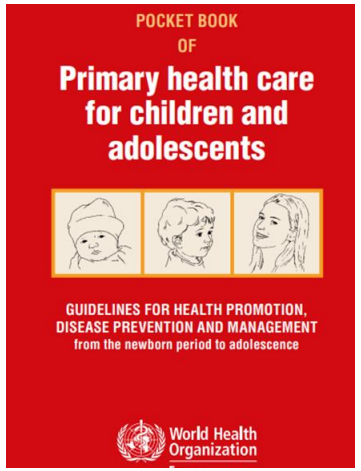
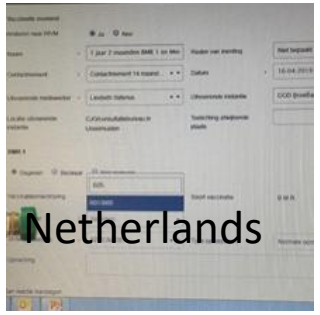
Digital Modelling of Primary Child Health

World Health Organization

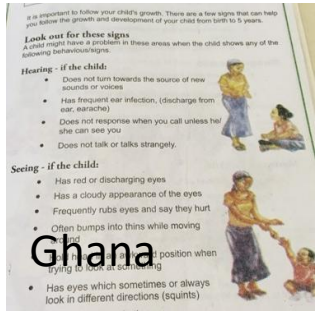


https://www.who.int/europe/publications/i/item/9789289057622

Preventive Child Health Records

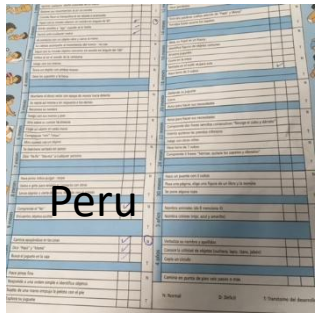


Netherlands



Ghana

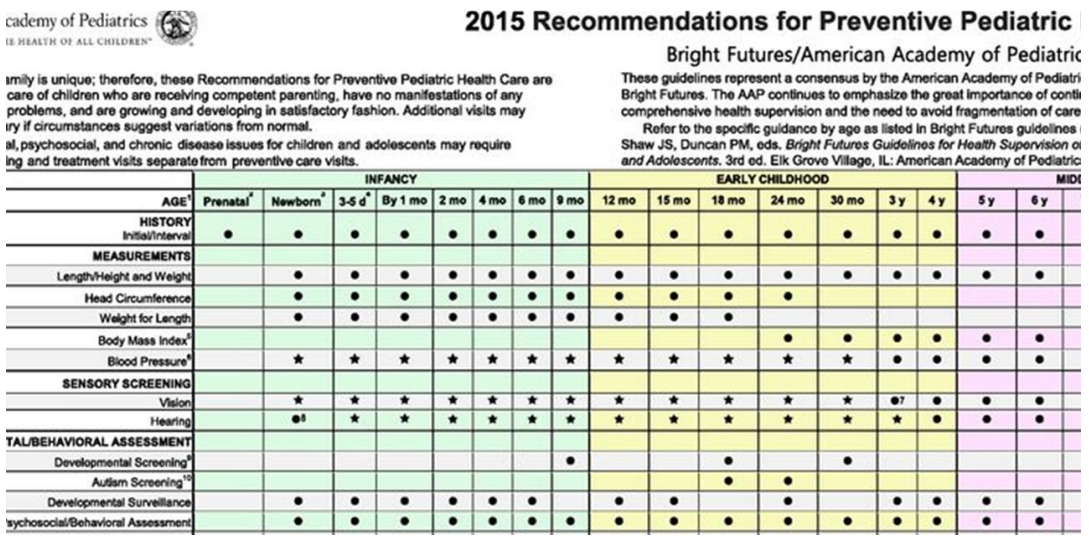
Spain



Peru

Sri Lanka

Poland



cademy of Pediatrics
IE HEALTH OF ALL CHILDREN®

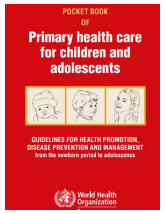
2015 Recommendations for Preventive Pediatric

Bright Futures/American Academy of Pediatric

amily is unique; therefore, these Recommendations for Preventive Pediatric Health Care are care of children who are receiving competent parenting, have no manifestations of any problems, and are growing and developing in satisfactory fashion. Additional visits may ry if circumstances suggest variations from normal.
al, psychosocial, and chronic disease issues for children and adolescents may require ng and treatment visits separate from preventive care visits.

These guidelines represent a consensus by the American Academy of Pediatri Bright Futures. The AAP continues to emphasize the great importance of conti comprehensive health supervision and the need to avoid fragmentation of care
Refer to the specific guidance by age as listed in Bright Futures guidelines
Shaw JS, Duncan PM, eds. *Bright Futures Guidelines for Health Supervision o and Adolescents*. 3rd ed. Elk Grove Village, IL: American Academy of Pediatric

	INFANCY								EARLY CHILDHOOD								MID
AGE[1]	Prenatal[2]	Newborn[3]	3-5 d[4]	By 1 mo	2 mo	4 mo	6 mo	9 mo	12 mo	15 mo	18 mo	24 mo	30 mo	3 y	4 y	5 y	6 y
HISTORY Initial/Interval	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
MEASUREMENTS																	
Length/Height and Weight		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
Head Circumference		●	●	●	●	●	●	●	●	●	●	●					
Weight for Length		●	●	●	●	●	●	●	●	●	●						
Body Mass Index[5]												●	●	●	●	●	●
Blood Pressure[6]		★	★	★	★	★	★	★	★	★	★	★	★	●	●	●	●
SENSORY SCREENING																	
Vision		★	★	★	★	★	★	★	★	★	★	★	★	●[7]	●	●	●
Hearing		●[8]	★	★	★	★	★	★	★	★	★	★	★	★	●	●	●
TAL/BEHAVIORAL ASSESSMENT																	
Developmental Screening[9]								●			●		●				
Autism Screening[10]											●	●					
Developmental Surveillance		●	●	●	●	●	●		●	●		●		●	●	●	●
sychosocial/Behavioral Assessment		●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●



Beta Thalassemia

A four Month Old Child at PHC Visit In Sri Lanka

7.14 Thalassaemia

Thalassaemias are a group of autosomal-recessive hereditary blood disorders, which are characterized by defective haemoglobin chains. Based on the defective globin chain, they are classified as either α- or β-thalassaemia. They are more common in Mediterranean countries but immigration has led to wider distribution.

History

Assess for risk factors:

- Family history of α- or β-thalassaemia
- History of recurrent need for transfusions in patient or family member
- Prenatal diagnosis declined by the pregnant woman or couple at risk of thalassaemia carrier status
- Ethnic background from sub-Saharan Africa, Mediterranean and Arabian peninsula, Southeast Asia, Indian subcontinent.

Symptoms

Symptoms and timing of clinical manifestation depend on the type of thalassaemia. Severity of symptoms ranges from asymptomatic minor forms or silent carrier status to death in utero in severe forms (alpha-thalassaemia major).

Symptoms include:

- Pallor
- Abdominal distension
- Failure to thrive, poor feeding, decreased activity, lethargy
- Enlarged liver and spleen
- Jaundice
- Symptoms of gallstones: sudden intense pain in upper right abdomen
- Skeletal deformities: large head with frontal and parietal bossing, "chipmunk" facies, misaligned teeth.

Investigations

- Full blood count: microcytic hypochromic anaemia
- Ferritin
- Further investigations: peripheral smear, DNA analysis, X-ray for skeletal deformities.

PCH

Vaccination: DTP

Physical exam: **Pale | Large spleen and liver**

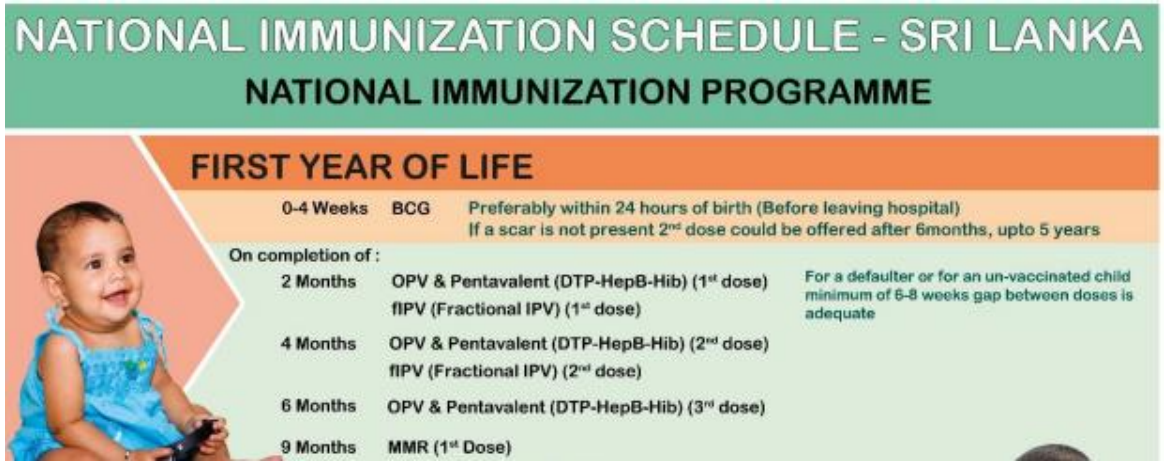
Laboratory test : Hemoglobine | Microcosis red blood cells

Referal to Thalassemia clinic

Parents are advised about routine vaccinations

Cascade Screening of Family

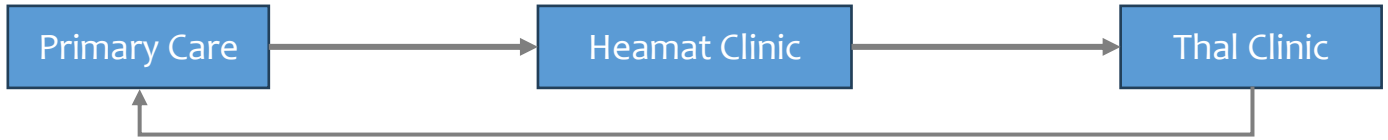
Diagnosis : Beta Thalassemia



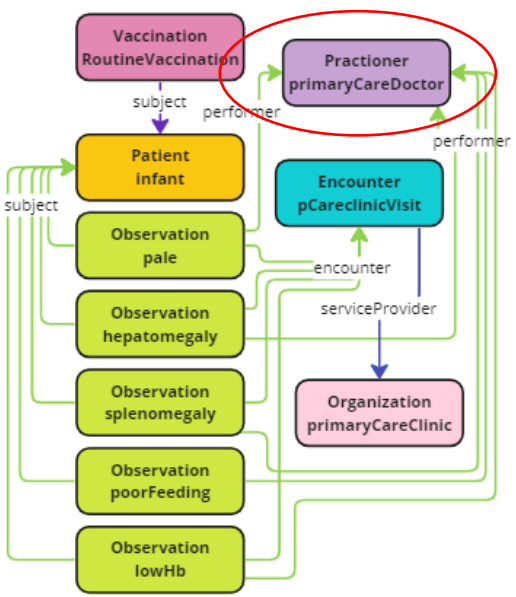
Beta Thalassemia

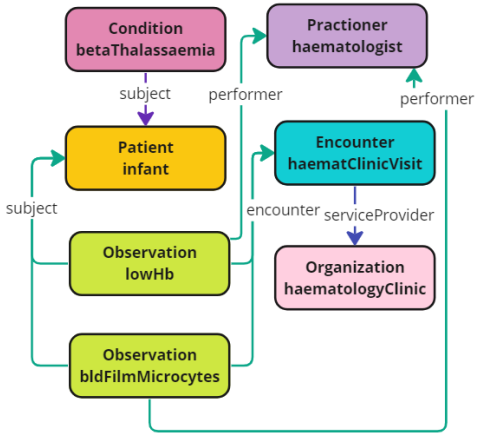
Integration in electronic health records

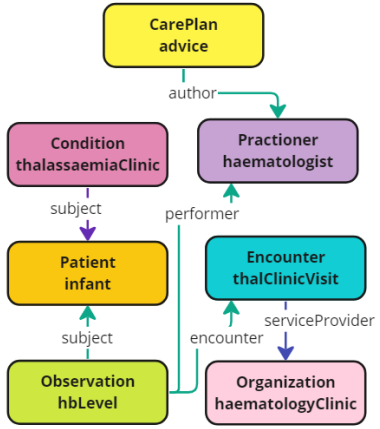
Date Flow HL7



FHIR







Terminologies

diphtheria-poliomyelitis-tetanus	ATC	J07CA01
Pallor	SNOMED CT	1237486008
Hepatomegaly	SNOMED CT	80515008
Splenomegaly	SNOMED CT	16294009
Haemoglobin concentration in blood	LOINC	718-7
Microcytes in blood film	LOINC	741-9
Feeding disorder of infancy and childhood	IDC 10	F98.2
Beta Thalassaemia	ICD 10	D56.1

Digital Language JSON

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Conclusion & Recommendation

- Childhood vaccination scheme's in Europe are similar
- Vacinations are a recommeded part of the IPS
- Harmonisation of digital vaccination registration modulated in FHIR
- Childhood vaccinations are often part of primary child health visits
- These visits include weight and height measurements

Child Health providers should get involved in digital health

YES, YOU CAN !

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Thank you

- European Pediatric Rare Disease Network

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Velibor Tasic, N- Macedonia
David Neubauer, Slovenia
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- Consensus in Pediatrics and Child Health

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- Forum Rare Diseases, Sri Lankan Pediatric Society
- EAP IT network

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Martin Postma, IT Expert, Netherlands
Rob Stegwee, IT Expert, the Netherlands

- People with a rare condition and their families

Paulo Gonçalves, Portugal

Siderius, L., Neubauer, D., Bhattacharya, A., Altorjai, P., Margvelashvili, L., Lamabadusuriya, S, Wierzba, J., Mazur, A., Albrecht, P., and Tasic, V. (2021). Universal Health Coverage “Leave No Child Behind”. Pediatria Polska - Polish Journal of Paediatrics, 96(1), pp.1-6. https://doi.org/10.5114/polp.2021.104822

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