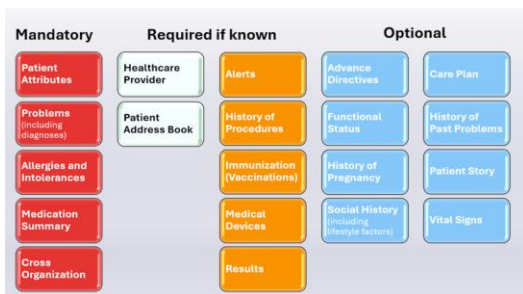
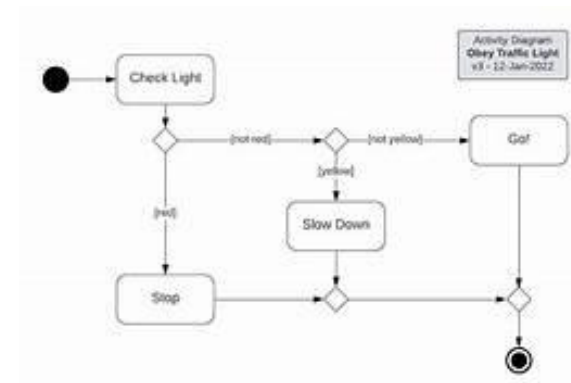


Using Unified Modeling Language (UML) to Bridge Clinical Practice and Health Data Interoperability in Paediatrics



Liesbeth Siderius^{1,2} Sahan Damsiri Perera³, Nora Karara^{4,5}

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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.



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%**).

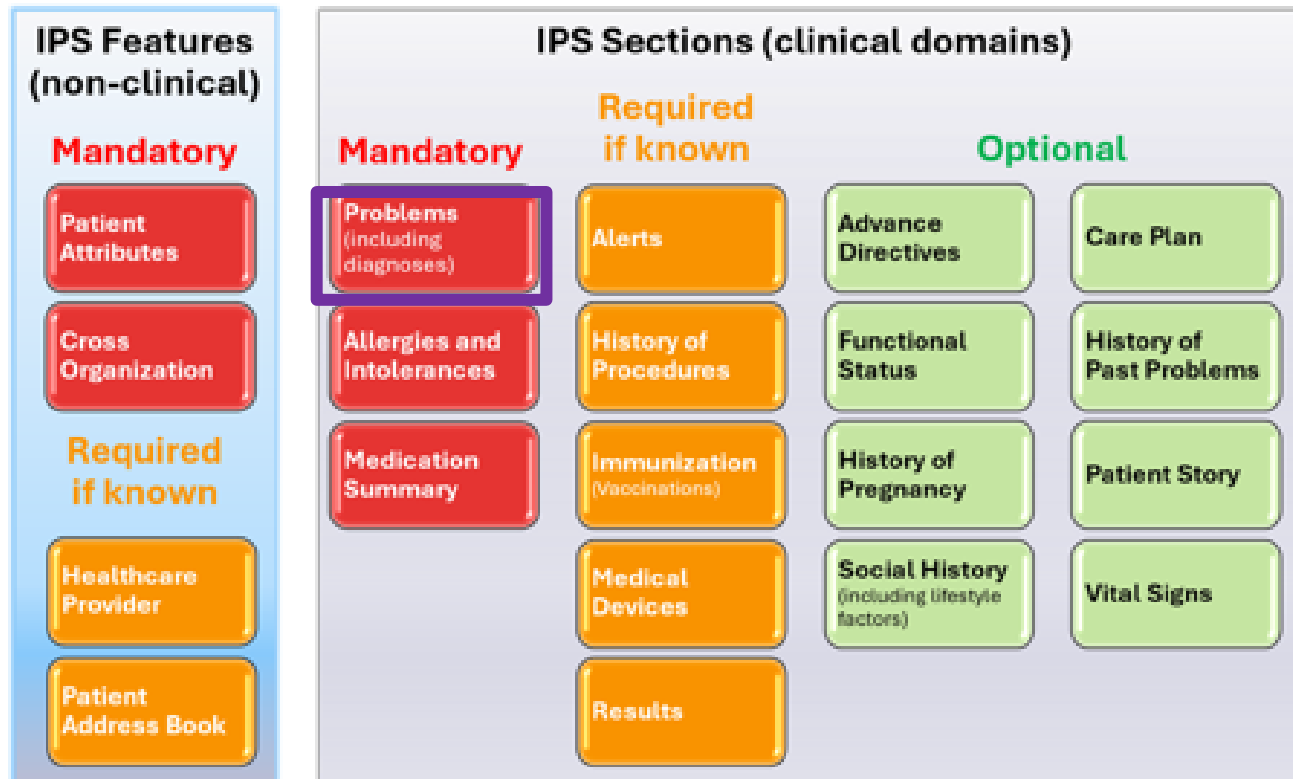


International Patient Summary updated October 2025

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



ISO 27269:2025 – The International Patient Summary



Patient Summary in Action: Putting Health Data in Patients' Hands

Patient Summary at Canada Health Infoway 26 september 2025





IPS in FHIR



FHIR
Fast Healthcare Interoperability Resources

The “IPS”



Composed from the “IPS Library”



Problem



Allergy



Medication



Immunization



Result



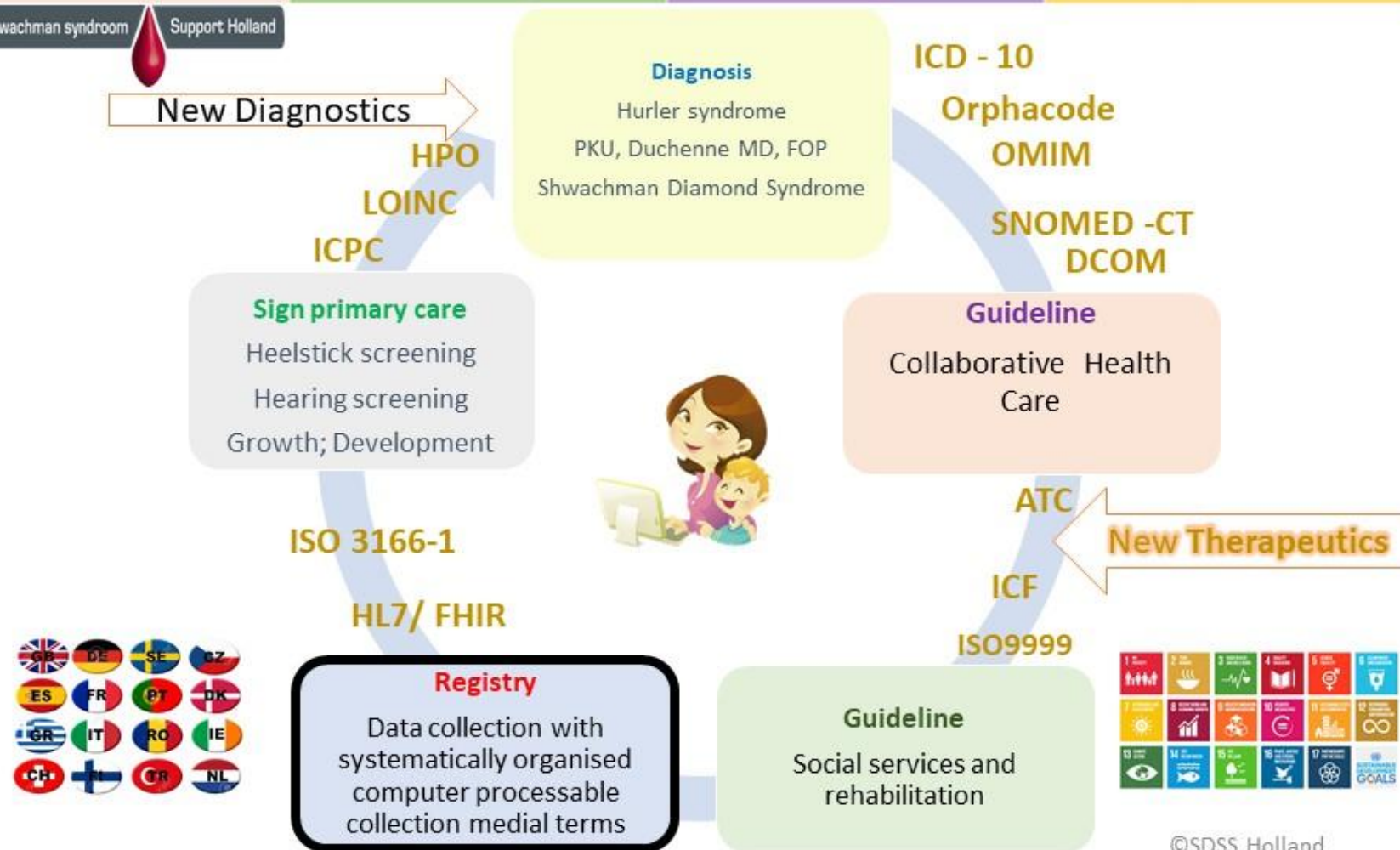
Procedure



Other
Profiles

Patient Information	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)

Stichting Shwachman syndroom Support Holland



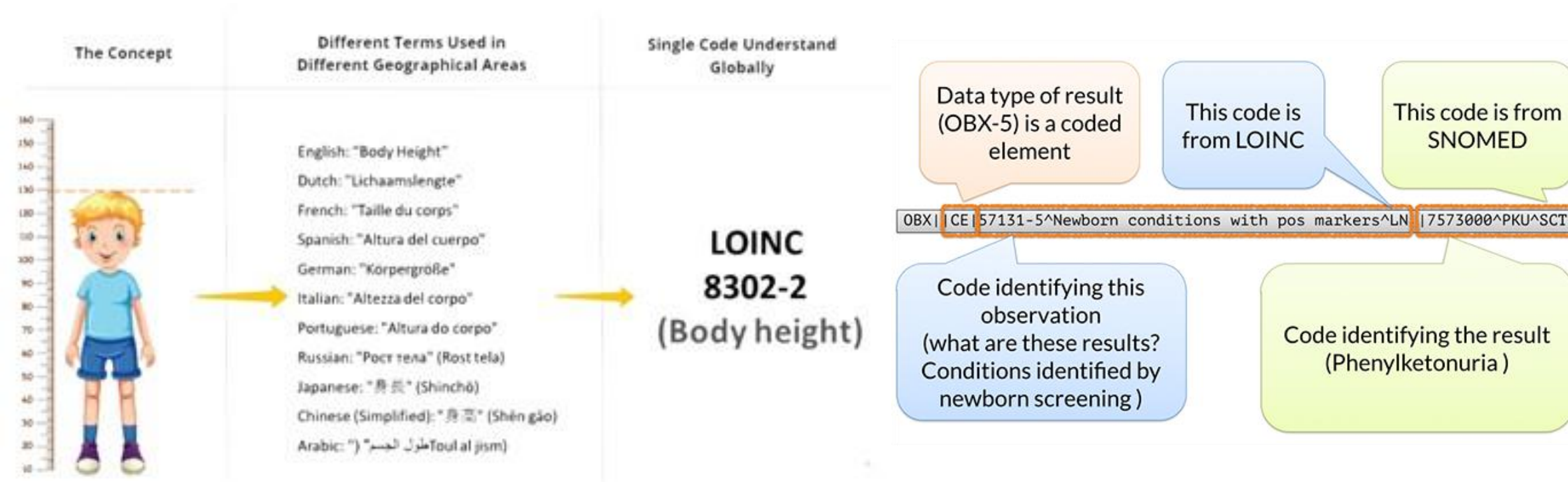
©SDSS Holland



FHIR

Fast Healthcare Interoperability Resources

Problems, Immunizations, Medication, Results



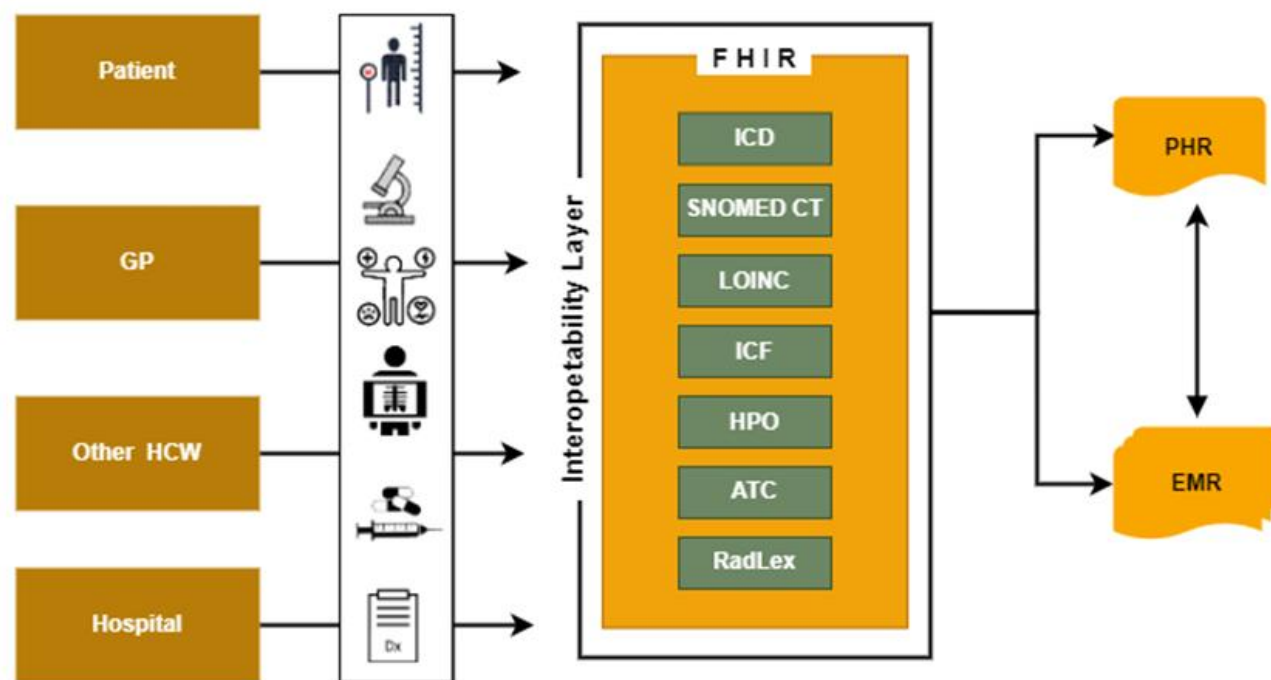
The IPS Section Results

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



Title “Digital child health: opportunities and obstacles”, by Liesbeth Siderius*, Sahan Damsiri Perera, Lars Gelander, Lina Jankauskaite, Manuel Katz, Arunas Valiulis, Adamos A. Hadjipanayis, Laura Realí and Zachi Grossman, published in “Frontiers in Pediatrics-Children and Health”.

Front. Pediatr., 22 December 2023
Sec. Children and Health
Volume 11 - 2023 | <https://doi.org/10.3389/fped.2023.1264829>



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

Management of Neonatal Hypoglycaemia immediate Post Partum

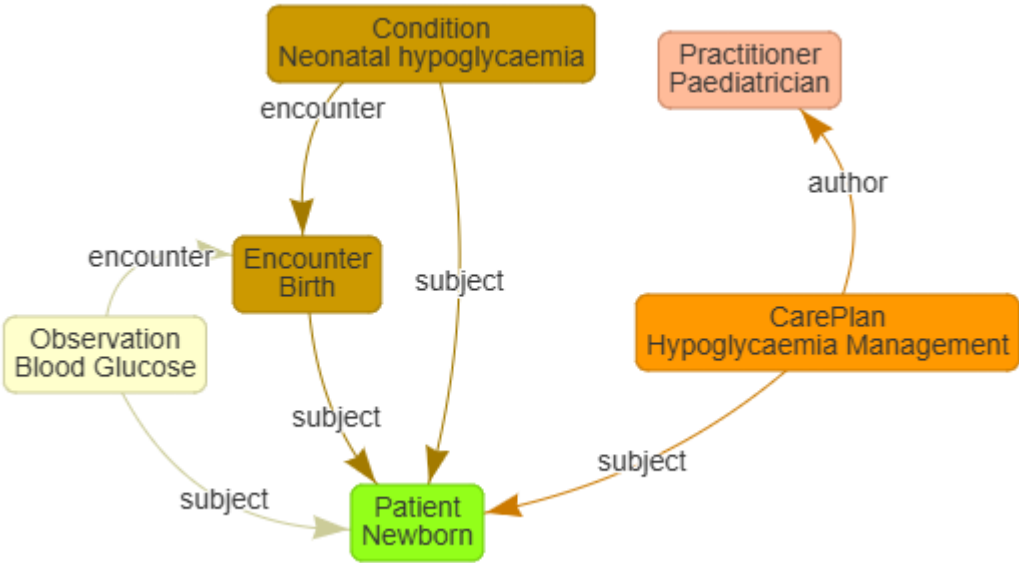
Case : The child had a birthweight of 3,6 kg in LOINC. One hour after birth the newborn had a blood glucose of 1,4 mmol LOINC. The child was given 2,0 ml Glucose gel ATC V06DC01. 2 hours after birth the glucose was 2,1 LOINC

	1-2 uur na geboorte	2-24 uur na geboorte	24-48 uur na geboorte
Streefwaarde	≥2.0 mmol/l	≥2.6 mmol/l	≥2.6 mmol/l
Interventiegrens	≤1.5 mmol/l	≤1.9 mmol/l	<2.6 mmol/l
		<2.6 mmol/l bij: *recidiverende waarden tussen 2.0 en 2.5 mmol/l *onvoldoende stijging op voorgaande interventies	

Tabel 1: Streefwaarde en interventiegrens bij verschillende uren postpartum bij pasgeborenen

***Dosering glucogel (uit protocol NWZ Alkmaar):**
Glucogel® 40%: 200mg/kg lichaamsgewicht = 0,5 ml/kg lichaamsgewicht

Geboortegewicht	Glucogel® 40% in ml	Glucose in gram
> 2.0 – 2.5 kg	1.25 ml	0.5 gram
> 2.5 – 3.0 kg	1.50 ml	0.6 gram
> 3.0 – 3.5 kg	1.75 ml	0.7 gram
> 3.5 – 4.0 kg	2.00 ml	0.8 gram
> 4.0 – 4.5 kg	2.25 ml	0.9 gram
> 4.5 – 5.0 kg	2.50 ml	1.0 gram



Birth weight	LOINC	8339-4 - Birth weight Measured
Blood glucose	LOINC	14749-6 Glucose [Moles/volume] in Serum or Plasma
2,0 ml Glucose gel	ATC	V06DC01

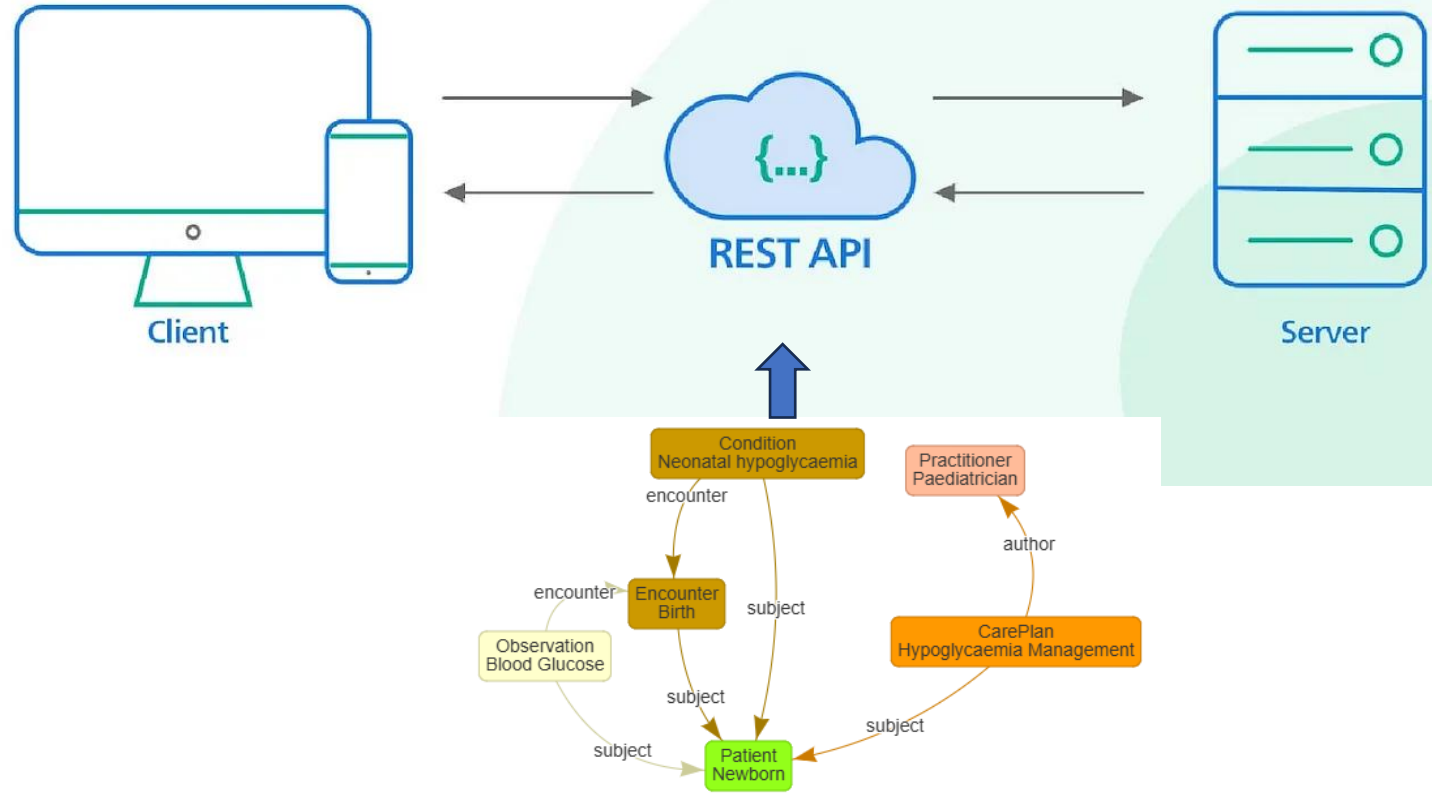


Mastering Google
Maps APIs: Your Guide
to Location Intelligence



<https://www.serpouse.com/blog/google-maps-apis-guide-to-location/>



Why is RESTful API so popular



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

EAP 2025 Congress 16-19 October Warsaw

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



HomeGetting StartedDocumentationData TypesResource TypesTerminologiesArtifactsImplementation Guides

Exchange > RESTful API

This page is part of the FHIR Specification (v5.0.0: R5 - STU). This is the current published version. For a full list of available versions, see the [Directory of published versions](#).
Page versions: [R5](#) [R4B](#) [R4](#) [R3](#) [R2](#)

3.2.1 RESTful API

FHIR Infrastructure Work Group	Maturity Level: Normative	Standards Status: Normative
--	---------------------------	-----------------------------

FHIR is described as a 'RESTful' specification based on common industry level use of the term REST. In practice, FHIR only supports Level 2 of the [REST Maturity model](#) as part of the core FHIR structures and interfaces.

For each FHIR framework, there is a corresponding RESTful API.

Note that the RESTful API is defined by the FHIR specification.

The API is defined by the FHIR specification.

In addition, the FHIR specification defines the RESTful API.

Insta

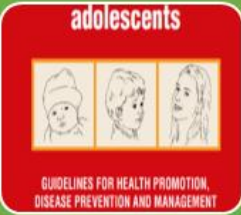
API is an acronym for **Application Programming Interface**:

a software interface that helps two different programs communicate.

REST stands for **Representational State Transfer**:

a software architecture style that relies on a stateless communications protocol, most commonly, HTTP.

Open Access FHIR RESTfull API Library



Mother and Child Health

- Growth & Development
- Conditions



Computable clinical guidelines

- Thalassemia
- Shwachman Diamond Syndrome



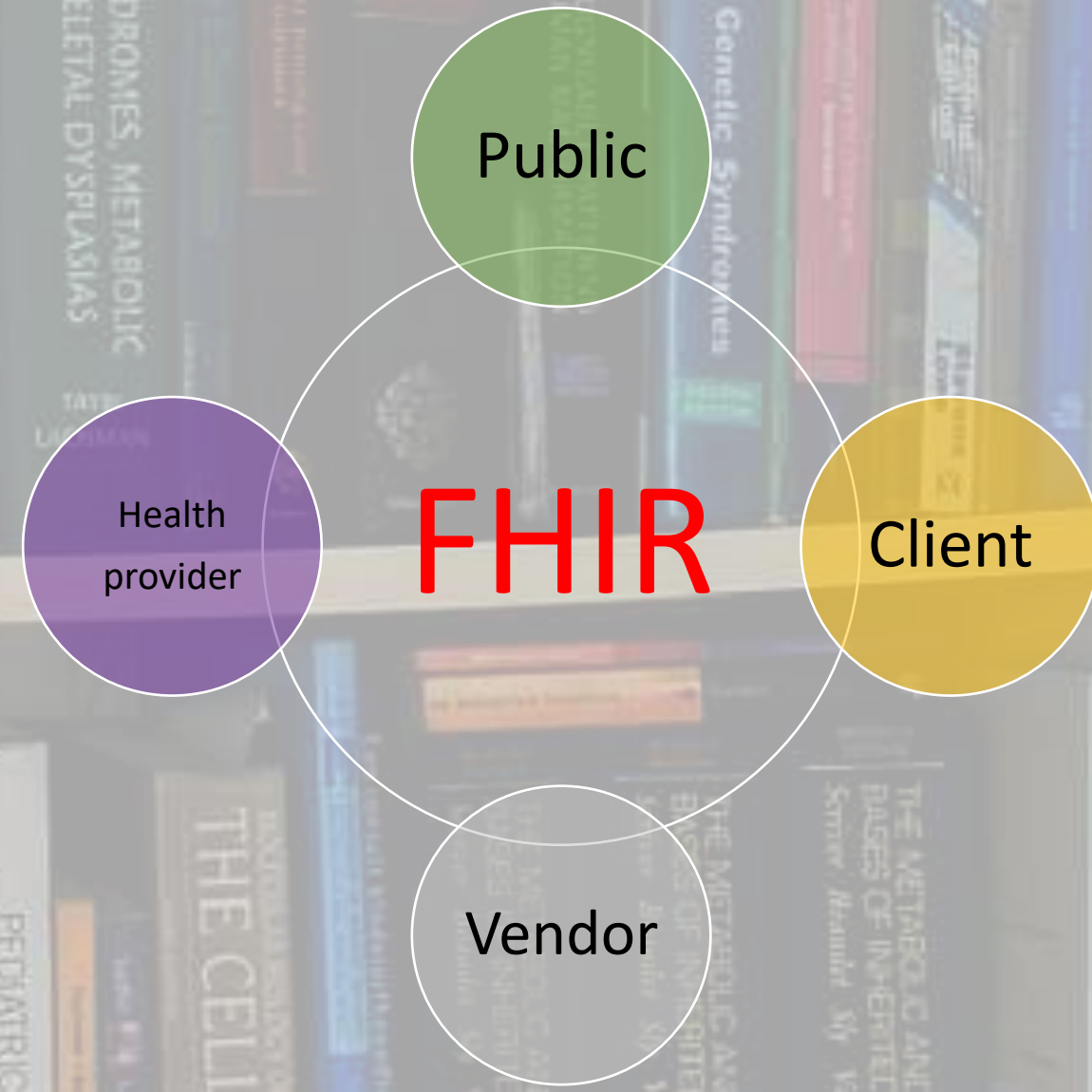
Immunizations

- Vaccination schemes



Social Support

- ICF
- ISO 9999



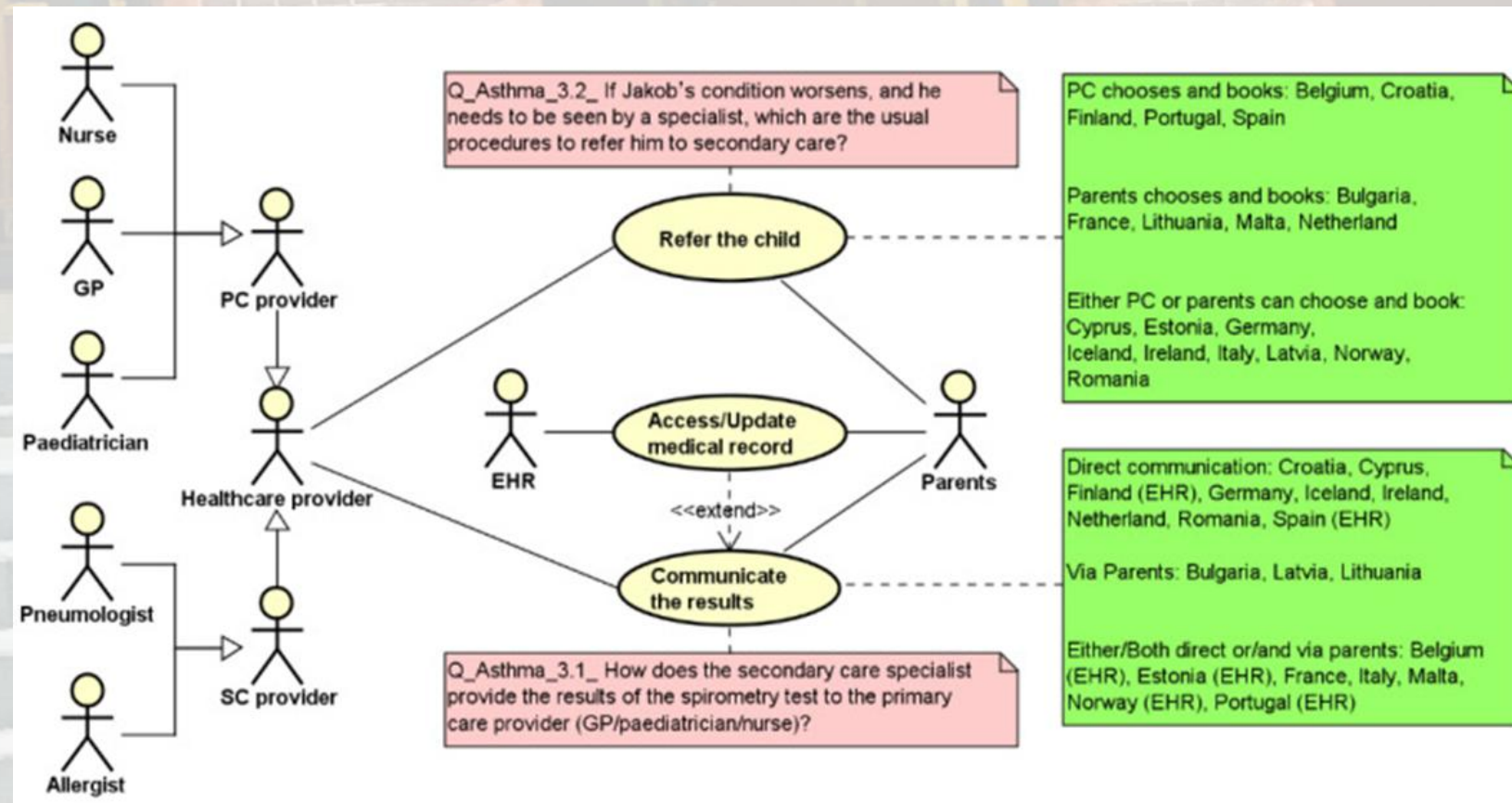


The Haque, November 15-16 2018

The management and provision of primary care services for children differ considerably from country to country: **MOCHA project**

UML (Unified Modeling Language) can **support cross-country comparison** with a special focus :

Pecoraro F, Luzi D. Using Unified Modeling Language to Analyze Business Processes in the Delivery of Child Health Services. Int J Environ Res Public Health. 2022 Oct 18;19(20):13456. doi: 10.3390/ijerph192013456. PMID: 36294033; PMCID: PMC9602458.

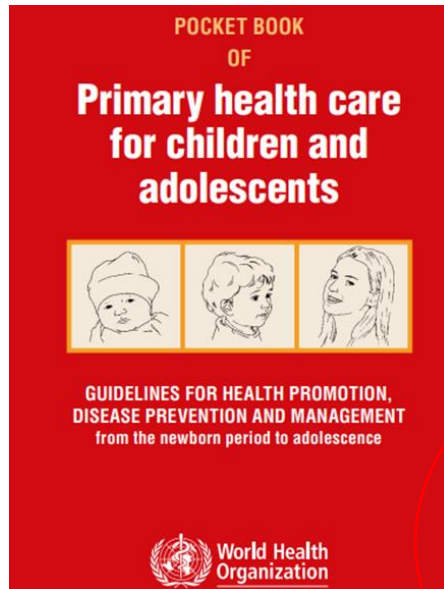


UML Case Neonatal Hypoglycemia





World Health Organization



Universal Health Coverage, leave no child behind

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.

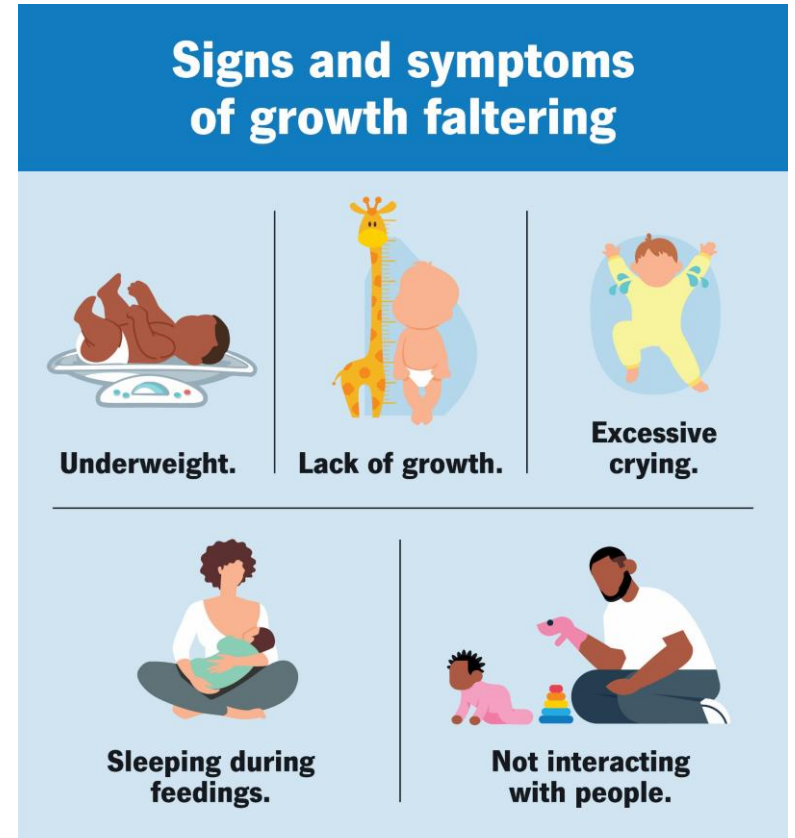
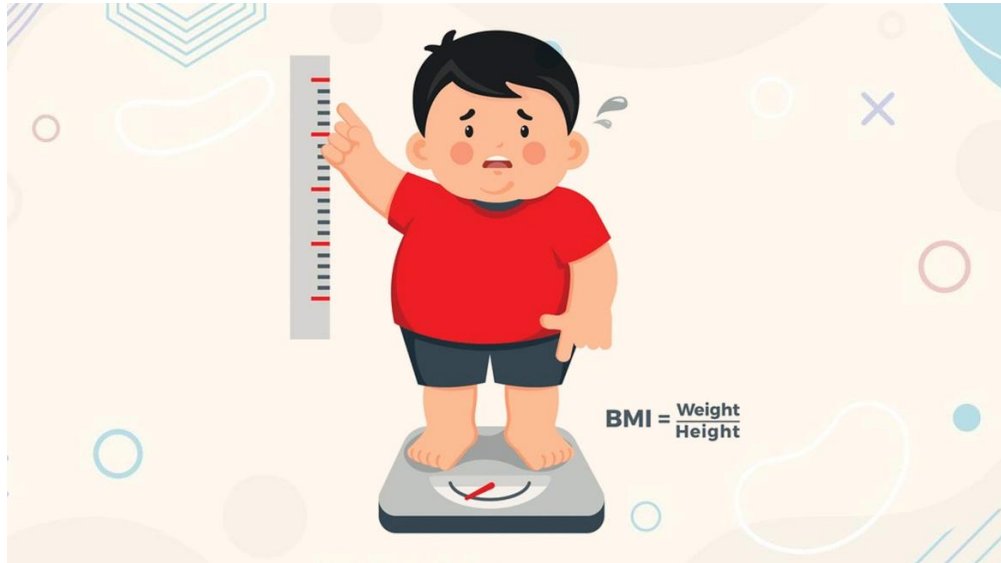
- Look for congenital diseases and jaundice
- Support caregivers.

History

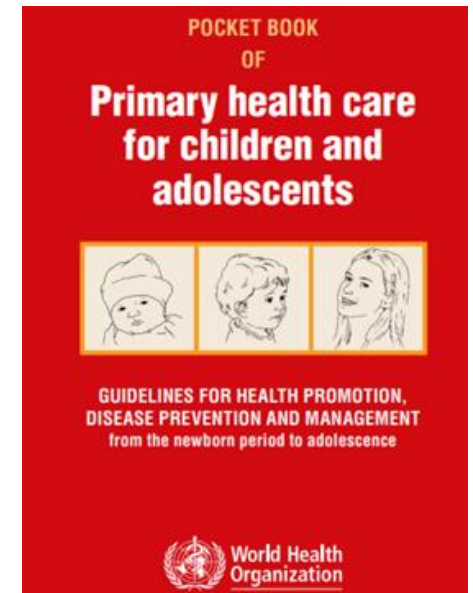
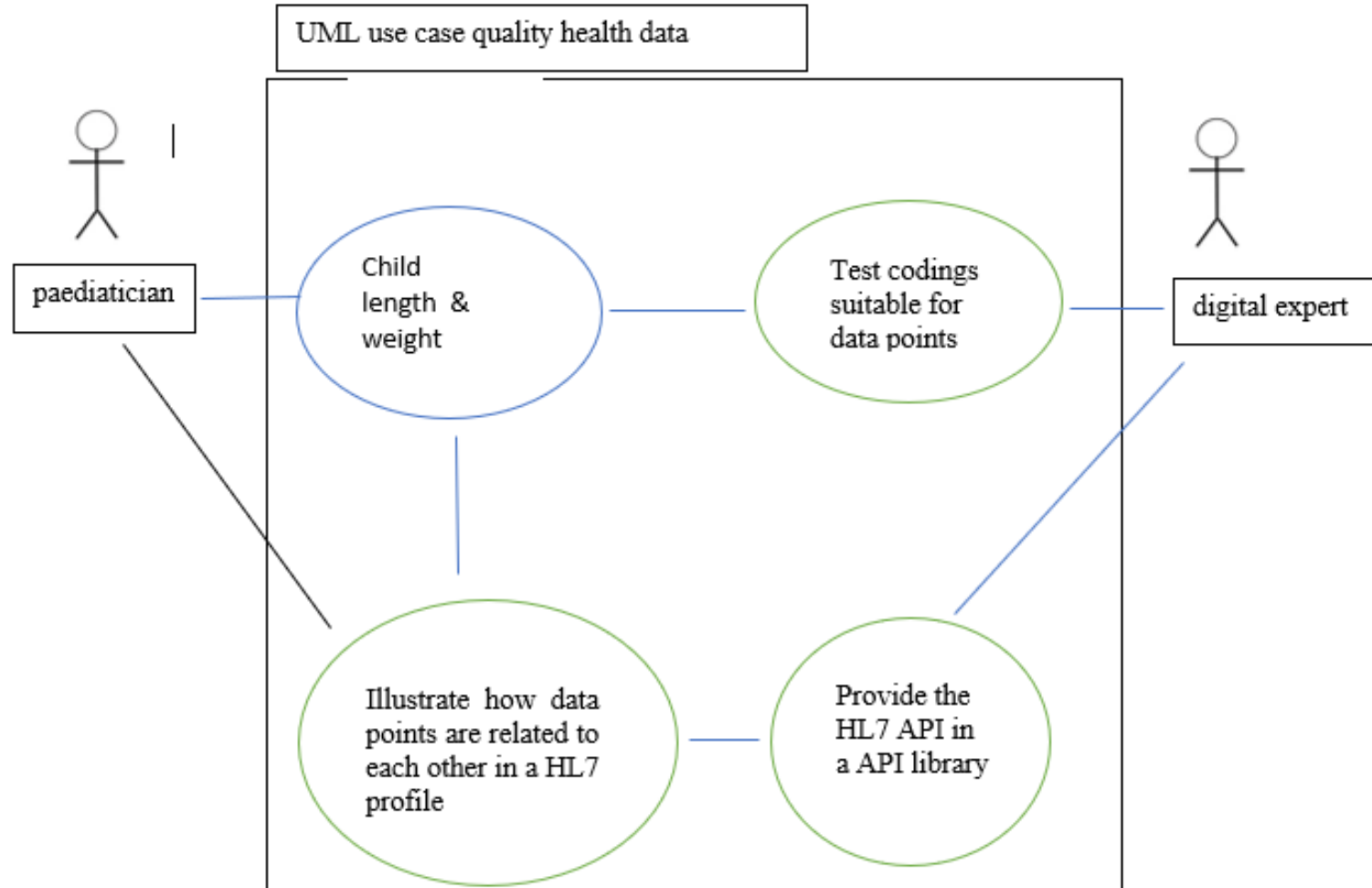
- Problems during pregnancy, e.g. diabetes, medications, substance abuse, acute or chronic infections, mental or social stress, abnormal test results, e.g. positive group B Streptococcus, HIV, hepatitis B
- Mode of delivery and problems during or after birth
- Congenital disorders in the family, e.g.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

Length, weight and BMI

Obesity versus Failure to Thrive



Lenght and weight in child health



From Feature to Medical Guideline

Feature

- Fatty Stool
- Growth Retardation
- Common infections

Shwachman

Diamond

Syndrome-

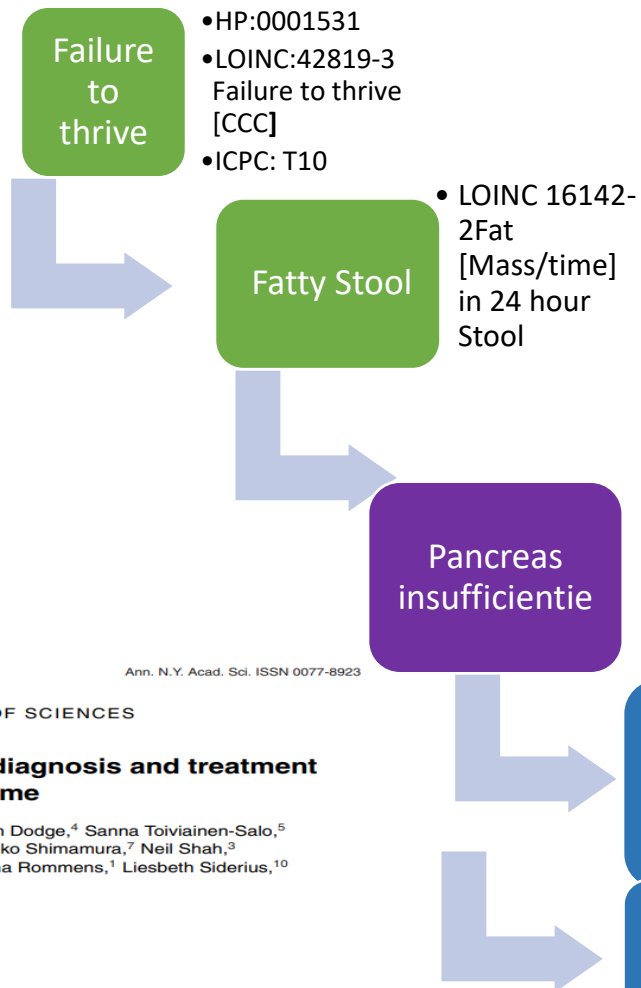
Management

- Pancreas insufficiency
- Neutropenia
- Skeletal Dysplasia
- Autisme like

ANNALS OF THE NEW YORK ACADEMY OF SCIENCES
Issue: Annals Meeting Reports

Draft consensus guidelines for diagnosis and treatment of Shwachman-Diamond syndrome

Yigal Dror,¹ Jean Donadieu,² Jutta Kogelmeier,³ John Dodge,⁴ Sanna Toiviainen-Salo,⁵ Outi Makitie,⁵ Elizabeth Kerr,¹ Cornelia Zeidler,⁶ Akiko Shimamura,⁷ Neil Shah,³ Marco Cipolli,⁸ Taco Kuipers,⁹ Peter Durie,¹ Johanna Rommens,¹ Liesbeth Siderius,¹⁰ and Johnson M. Liu¹¹



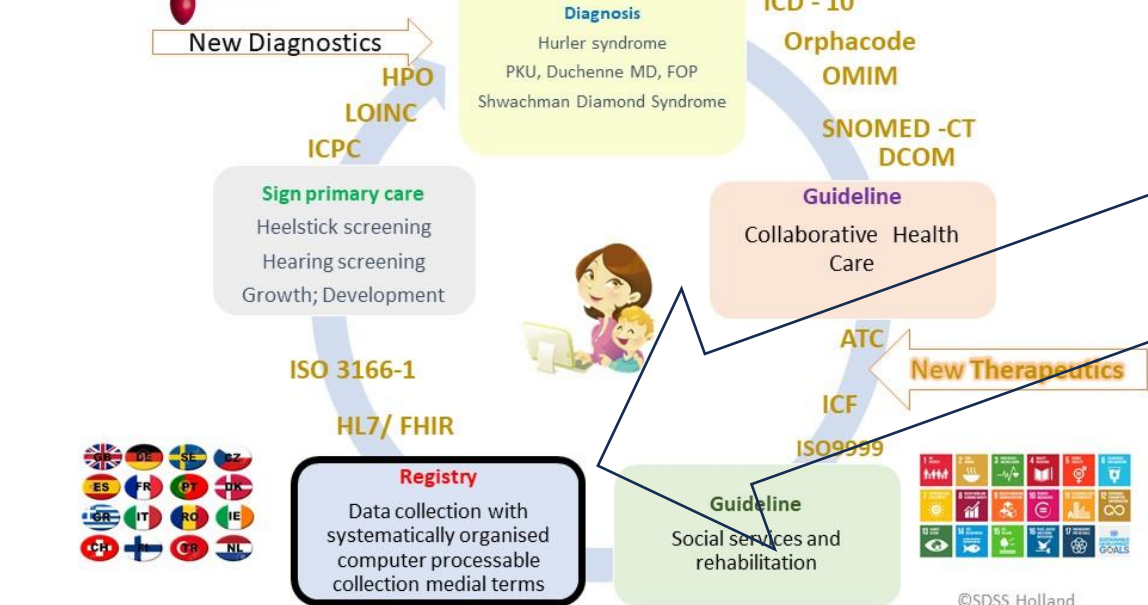
2022



Set of common data elements for rare diseases registration= Secondary Use EHDS

Patient Information	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)

Stichting Shwachman syndrome Support Holland



EUROPEAN COMMISSION
JOINT RESEARCH CENTRE
Directorate F – Health and Food
Unit F.1 – Disease Prevention

EUROPEAN PLATFORM ON RARE DISEASE REGISTRATION (EU RD Platform)
SET OF COMMON DATA ELEMENTS FOR RARE DISEASES REGISTRATION

GROUP	ELEMENT N°	E
1. Pseudonym	1.1.	Pi
2. Personal information	2.1.	D
	2.2.	Si
3. Patient Status	3.1.	Pi
	3.2.	D
4. Care pathway	4.1.	Fi
		Si

5. Disease history	5.1.	Age at onset	Age at which symptoms/signs first appeared	• Ant • At b • Dat • Und
	5.2.	Age at diagnosis	Age at which diagnosis was made	• Ant • At b • Dat • Undetermined

ORPHA
ICD 9
ICD10

6. Diagnosis	6.1.	Diagnosis of the rare disease		
	6.2.	Genetic diagnosis		
	6.3.	Undiagnosed case		

HGVS Human Genome Variety
HPO
HGNC Human Genome Nomenclature
OMIM

7. Research	7.2.	Consent to the reuse of data	Patient's consent exists for his/her data to be reused for other research purposes	<ul style="list-style-type: none">• YES• NO	
	7.3.	Biological sample	Patient's biological sample available for research	<ul style="list-style-type: none">• YES• NO	If YES answer question 7.4
	7.4.	Link to a biobank	Biological sample stored in a biobank	<ul style="list-style-type: none">• YES• NO	https://directory.bbmri-eric.eu
8. Disability	8.1.	Classification of functioning/disability	Patient's disability profile according to International Classification of Functioning and Disability (ICF)	<ul style="list-style-type: none">• Dis	https://www.who.int/classifications/whodasii/en/

ICF



Conclusion

- The **European Health Data Space** is adopted
- The **International Patient Summary**, an ISO standard, requires minimal, non-exhaustive set of data elements
- Problems or disease guidelines can be transformed to readable text for anyone to understand, **using terminologies**
- There is a **large variety** in the use of terminology per data point
- The variety may **hinder interoperability**

Recommendations

- European Paediatricians should collaborate to establish quality datapoints
- UML (Unified Modeling Language) can support cross-country comparison of terminologies

YES, YOU CAN !

please join EAP digital health group
e.siderius@kpnplanet.nl



Thank you

- European Pediatric Rare Disease Network

John Dodge, U.K.

Lali Margvelashvili, Georgia

Velibor Tasic, N- Macedonia

David Neubauer, Slovenia

Arunas Valiulis, Lithuania

Lina Jankauskaite, Lithuania

Jola Wierzba, Poland

Jernej Zavrsnik, Slovenia

- Consensus in Pediatrics and Child Health

Manuel Katz, Israel

- Forum Rare Diseases, Sri Lankan Pediatric Society

- EAP IT network

Laura Reali, Italy

Iren Kantor, Hungary

Nora Karara, Germany

- HL7 Child+Health+Obstetrics+International+Collaboration+and+Exploration

Anjan Bhattacharya, ICF expert India

Sahan Damsiri Perera, IT Expert, Sri Lanka/ Australia

Marc de Graauw, IT Expert, Netherlands

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". *Pediatrica Polska - Polish Journal of Paediatrics*, 96(1), pp.1-6.

<https://doi.org/10.5114/polp.2021.104822>

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