Harmonisation of digital interoperable clinical standards



Abstract

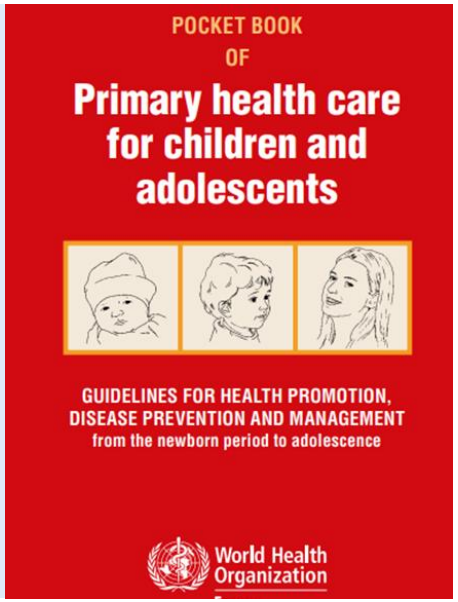
- The EHDS is designed to assure **quality digitalisation** of health care coordination and the continuity of care.
- The EHDS includes a minimum set of information defined as international standard ISO 27269:2025 – **International Patient Summary Standard (IPS).**
- The digitalisation of clinical records systems is supporting clinical care providers in hospitals, institutions, primary care clinics as well as a personal health care environment. Each recommended IPS data domain consists **of multiple interoperable standardized data elements**, while data elements may be represented by different interoperable standards. In practice the specified IPS domains are related to each other.
- WHO's pocket book of **primary health care for children and adolescents** is a guideline for health promotion, disease prevention and management from the newborn period to adolescence.
- Some clinical examples from the *Pocket Book* are presented as use-cases to illustrate data assignment to a structured clinical vocabulary to demonstrate how digital quality of data descriptions, such as with **ICD, ICF, LOINC and SNOMED**, match international real life medical practice based on **written language** medical guidelines and textbooks.

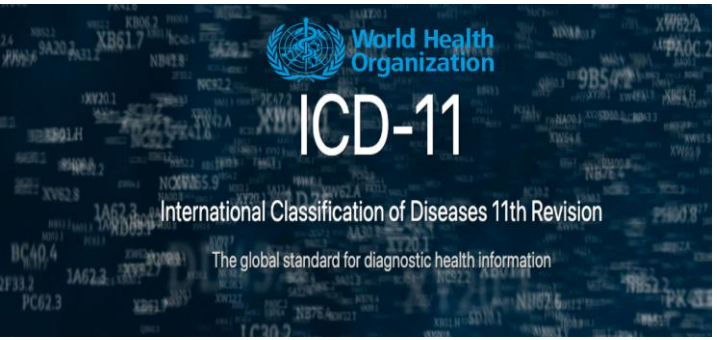
Liesbeth Siderius, the Netherlands



Global Data, Local Care: Advancing Smarter Standards

- European Health Data Space is a regulation building on existing electronic systems and standards
- Clinicans are trained and work according evidence based medical guidelines
- Standards are originally not specifically designed to support the digitalisation of medical guidelines





What is ICD-11? The International Classification of Diseases, 11th Revision (ICD-11) is the international reference classification for health-influencing conditions and factors. It is mandated by the WHO Constitution (Articles 2(s), 21(b), 22 and 64). ICD-11 came into effect on 1 January 2022. ICD-11 supports the recording,

- reporting and analysis of mortality and morbidity data across primary, secondary and tertiary care
- informs regulation, epidemiology, clinical research and health financing
- statistical classification with an embedded clinical terminology in a single integrated system

https://icd.who.int/en/

LOINC®

LOINC Knowledge Base

Our knowledge base is a compendium of documentation regarding LOINC. It is collected in several major divisions which relate to different aspects of the terminology. The LOINC Users' Guide is the primary resource outlining methodology, heuristics, and editorial guidelines.

https://loinc.org/search

SNOMED CT
The global language of healthcare

- Every **concept** represents a unique clinical meaning, which is referenced using a unique, numeric and machine readable SNOMED CT **identifier**.
- The identifier provides an unambiguous unique reference to each concept and does not have any ascribed human interpretable meaning.

https://snomedbrowser.org

Representations of an ontology are intended to designate certain combinations of classes with precisely defined meanings, and relations between them: on the quality issue of missing concepts (related to completeness) in SNOMED CT.
Hao et al. BMC Medical Informatics and Decision Making 2023, 23(Suppl 1):87 https://doi.org/10.1186/s12911-023-02183-7

The WHO Collaborating Centre for Drug Statistics Methodology : The central body responsible for the development and maintenance of the **ATC/DDD system**. This Centre is located at the Norwegian Institute of Public Health (NIPH) and the main activities of the Centre are drawn up in an agreement between the WHO Headquarters and the Government of Norway.

Structure and principles

Structure

In the ATC classification system, the active substances are classified in a hierarchy with five different levels.

https://atcddd.fhi.no/atc_ddd_index/



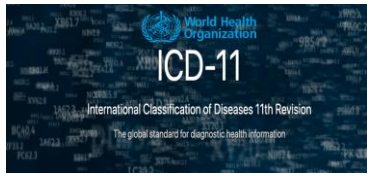
Global Data, Local Care: Advancing Smarter Standards



Well child visits- Vaccination- Disease

Care Plan

Relation between the Pocket book and codes?

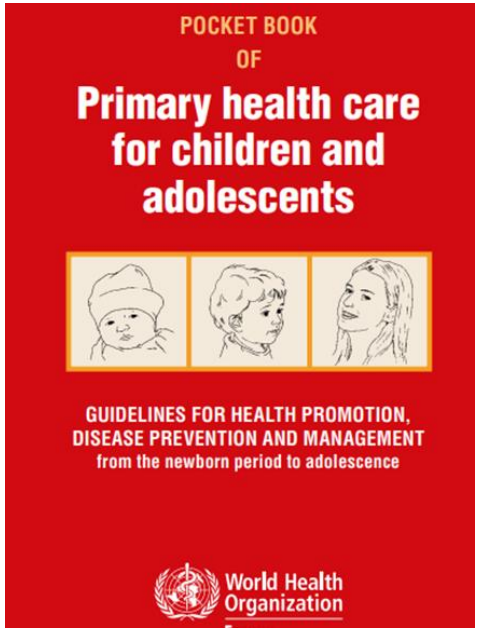


QA00.1 Routine health check for child over 28 days of age through 19 years of age.

LOINC®

39294-4
Children's preventive health services attachment Set

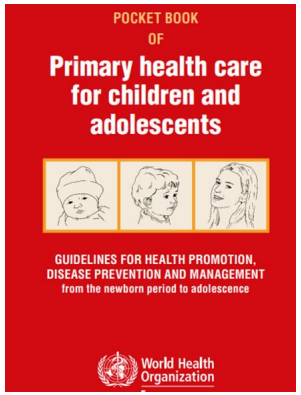
39235-7	Immunization data Set CPHS	0..*	
39236-5	Vaccine code (CPT) CPHS	1..1	
39237-3	Immunization status CPHS	1..1	
30973-2	Dose number	0..1	
30957-5	Manufacturer name [Identifier] Vaccine	0..1	
30959-1	Lot number [Identifier] Vaccine	0..1	
3141-9	Body weight Measured	1..1	[lb_av];kg
3137-7	Body height Measured	1..1	[in_us];cm;m
39156-5	Body mass index (BMI) [Ratio]	1..1	kg/m2
8480-6	Systolic blood pressure	1..1	mm[Hg]
8462-4	Diastolic blood pressure	1..1	mm[Hg]
9843-4	Head Occipital-frontal circumference	0..1	cm
8339-4	Birth weight Measured	0..1	[lb_av];kg;g



Care Plan

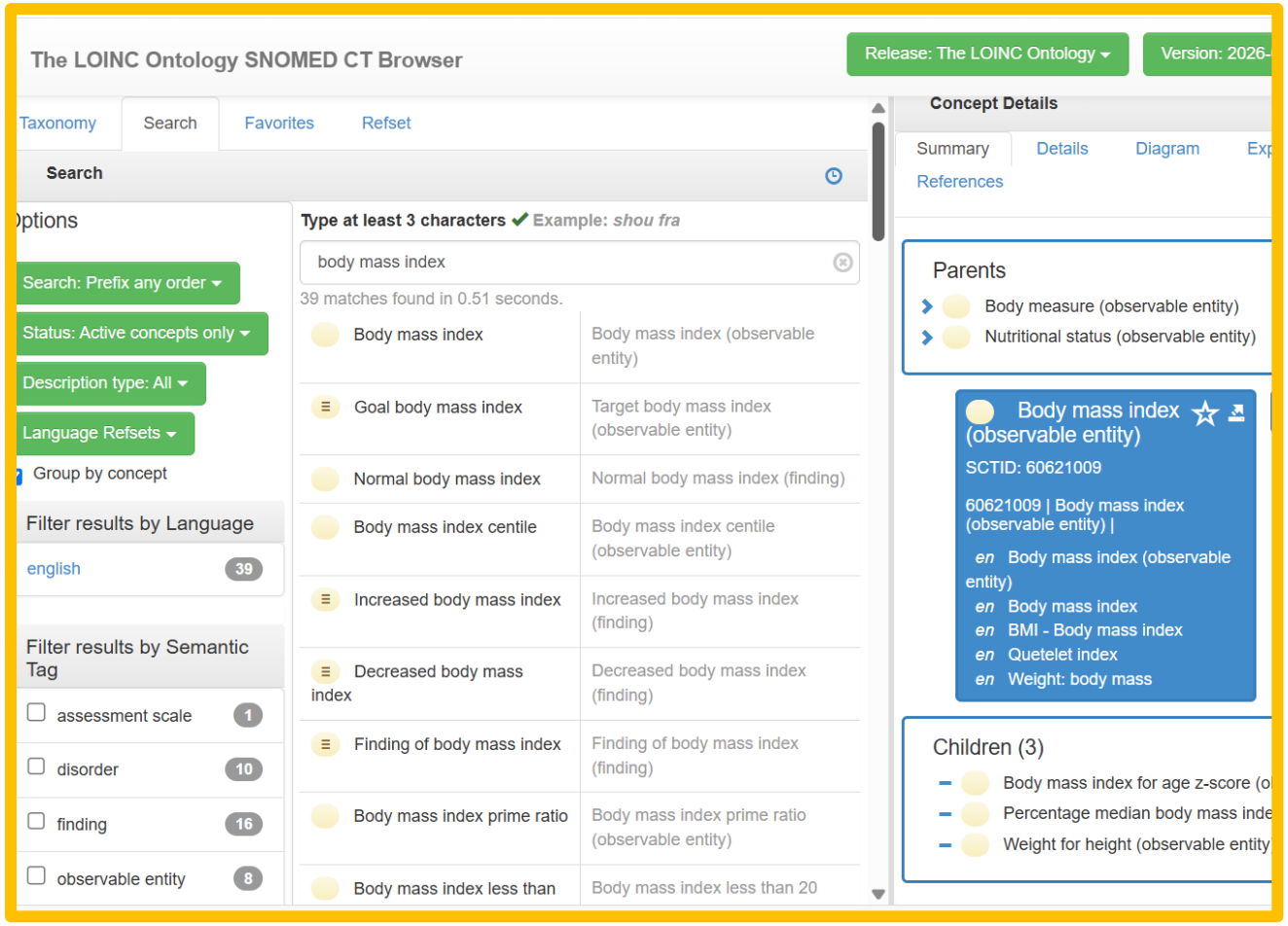
Well child visits

Nutritional status: signs of stunting, wasting, underweight, or overweight/obesity



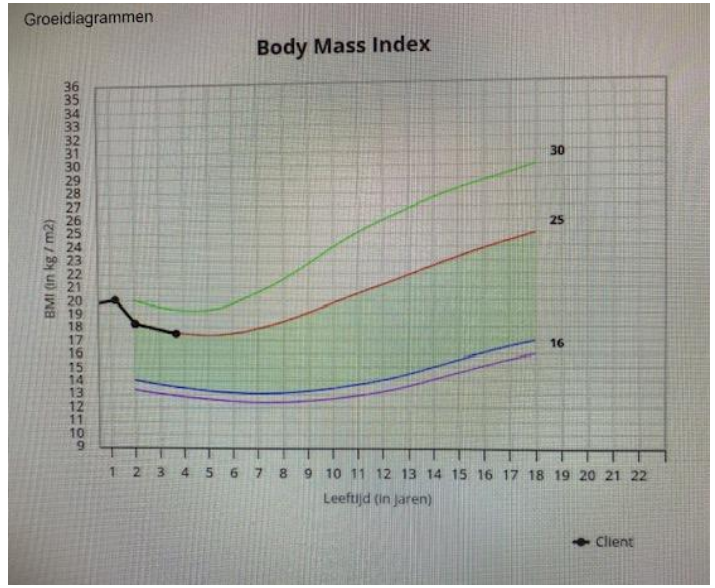
3141-9	Body weight Measured	1..1	[lb_av];kg
3137-7	Body height Measured	1..1	[in_us];cm;m
39156-5	Body mass index (BMI) [Ratio]	1..1	kg/m2

LOINC®



SNOMED CT
The global language of healthcare

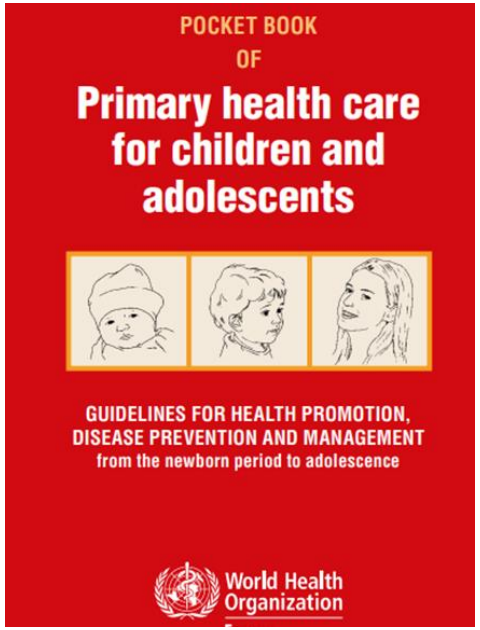
Results



Results



- **Vision red reflex**



SNOMED CT
The global language of healthcare

LOINC

LOINC CODE	LONG COMMON NAME
106763-6	Red reflex test

LOINC Names

Fully-Specified Name	Red reflex test:Find:Pt:^Patient:Ord:
Long Common Name	Red reflex test
Short Name	Red reflex test

Reflex (observable entity)
Red reflex (observable entity)
SCTID: 783819001

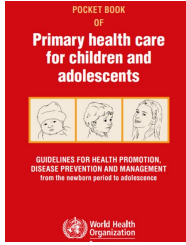
783819001 | Red reflex (observable entity)

Example Answer List: LL7005-3

Answer	Code	Score	Answer ID
Yes © *http://snomed.info/sct ID:373066001 Yes (qualifier value)*			LA33-6
No © *http://snomed.info/sct ID:373067005 No (qualifier value)*			LA32-8
Unknown © *http://snomed.info/sct ID:261665006 Unknown (qualifier value)*			LA4489-6

Problems (including diagnoses)

Juvenile Cataract



3.3 Well-child visit: 1 week

- Look for congenital diseases and jaundice
- Follow up weight gain and vaccinations
- Support caregivers and counsel on feeding, activity and safety

History

- Care situation and exceptional burdens in the family
- Feeding difficulties
- Abnormal crying
- Congenital disorders in the family, e.g. hip problems, eye conditions

Examination

- Perform a complete physical examination (p. 116). Look for signs of acute illness or congenital conditions:
  - **Growth:** measure body weight, length and head circumference (p. 21) and confirm the z-score according to the WHO growth charts (Annex 3). Newborn typically lose up to 10% of their birth weight during the first days of life and regain it within 10–14 days. If weight loss exceeds 10% of birth weight, see p. 119.
  - **Skin:** pallor, cyanosis, jaundice (p. 148), rashes (p. 143), hydration
  - **Head and neck:** bulging fontanelle (p. 128), crepitations, cleft palate (p. 129), caput succedaneum (p. 126), ptosis (p. 134), absent red eye reflex (p. 133), coloboma (p. 133), nystagmus, ear deformities (p. 131)

Cloudy lens or absent red reflex

A lens opacity (grey-white clouding of the lens) or absence of the red reflex, during the red reflex examination (p. 119), can be a sign of both congenital cataract (p. 459) and early retinoblastoma (p. 459).

- Refer newborns with an absent red reflex or a cloudy lens immediately to an eye specialist. Early detection and treatment are essential.

A Month old at PCH

PCH

Child comes for a regular screening at PCH

Physical exam

Red eye reflex

Referal to ophtalmologist

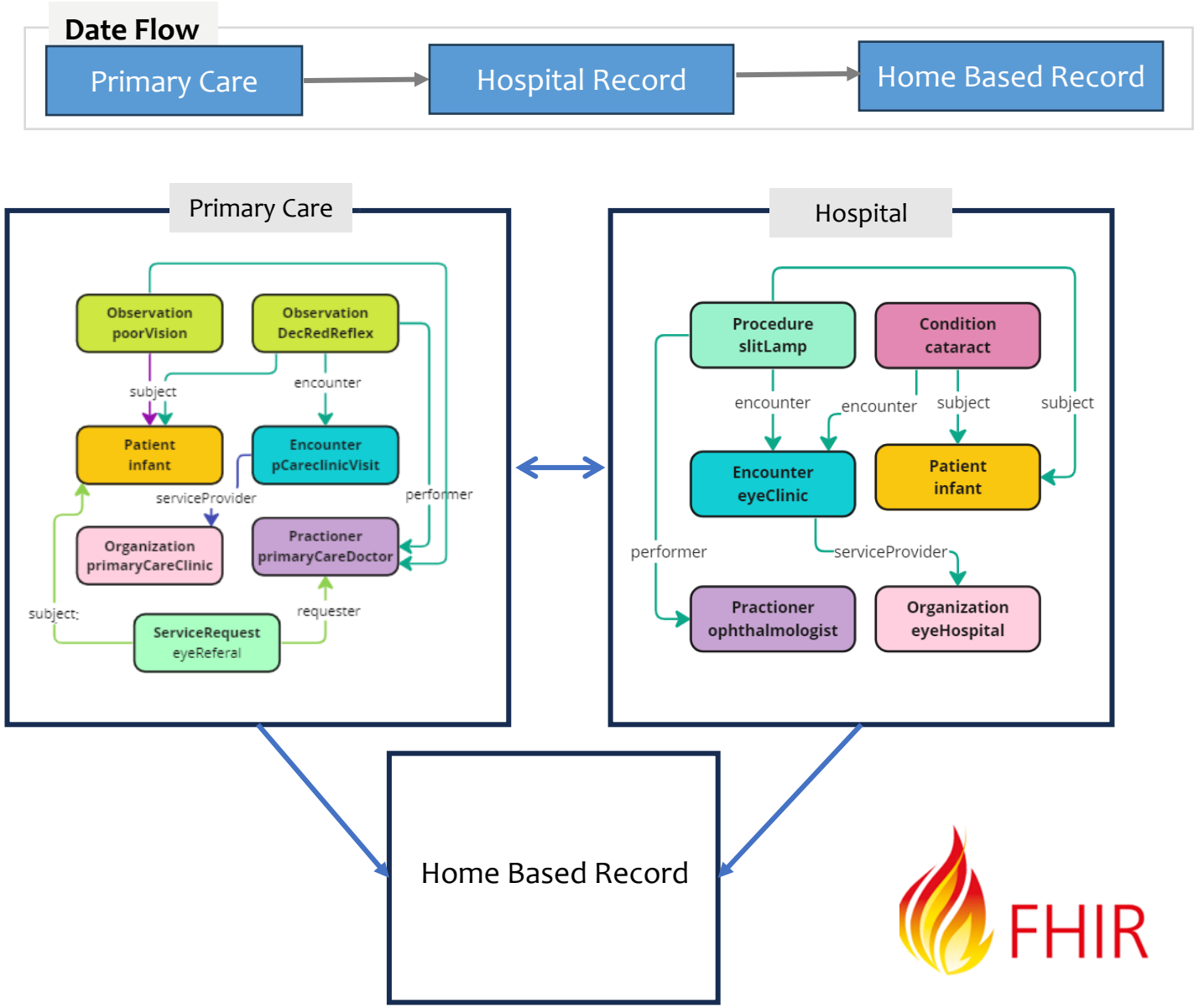
Observation:

Study observation Left optic lens Slit lamp biomicroscopy Ophtalmol >

Diagnosis : Infantile cataract



Cataract > HL7 FHIR modeling



Terminologies

Red reflex absent	SNOMED CT	247079003
Abnormal vision	SNOMED CT	7973008
Study observation Left optic lens Slit lamp biomicroscopy	LOINC	79866-0
Congenital Cataract	ICD 10	Q 12.0



Global Data, Local Care: Advancing Smarter Standards



Well child visits- Vaccination- Disease

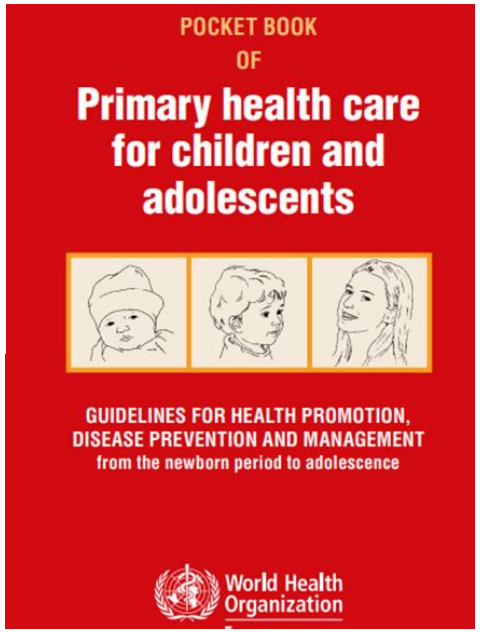
Care Plan

Immunization
(Vaccinations)

4.2 Vaccinations

Vaccines reduce suffering and save lives. Over half of the 30% drop in childhood mortality in the world since 1990 is attributable to immunization.

Make sure that the child receives vaccines at the recommended age according to the national vaccination schedule.



International Birth And Child Model Implementation Guide
1.0.0 - STU 1

HL7 FHIR

LOINC®

39294-4
Children's preventive health services attachment Set

39235-7	Immunization data Set CPHS	0..*	
39236-5	Vaccine code (CPT) CPHS	1..1	
39237-3	Immunization status CPHS	1..1	
30973-2	Dose number	0..1	
30957-5	Manufacturer name [Identifier] Vaccine	0..1	
30959-1	Lot number [Identifier] Vaccine	0..1	
3141-9	Body weight Measured	1..1	[lb_av];kg
3137-7	Body height Measured	1..1	[in_us];cm;m
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8480-6	Systolic blood pressure	1..1	mm[Hg]
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9843-4	Head Occipital-frontal circumference	0..1	cm
8339-4	Birth weight Measured	0..1	[lb_av];kg;g

SNOMED
SCTID: 1252708008
Vaccine product containing only Streptococcus pneumoniae Danish serotype 1, 3, 4, 5, 6A, 6B, 7F, 9V, 14, 18C, 19A, 19F, 22F, 23F, and 33F capsular polysaccharide conjugated antigens (medicinal product)
15-valent



ATC J07AL02

Which vaccines are available for children free of charge at Chaika Tbilisi?

— **Hexaxim**

A combined vaccine against six infections: hepatitis B, pertussis, diphtheria, tetanus, poliomyelitis, and Haemophilus influenzae type B.

Used for vaccination of children from 6 weeks to 24 months of age.

Schedule: 3 doses with an interval of at least 4 weeks (usually at 2, 3, and 4 months).

— **Rotarix**

Vaccine against rotavirus infection, available as sweet oral drops.

Schedule: 2 doses — at 2 and 3 months.

Note: The second dose must be given before the child reaches 24 weeks (6 months).

— **Prevenar 13**

ATC J07AL02

Vaccine against pneumococcal infection.

Schedule: at 2, 4, and 12 months.

— **MMR**

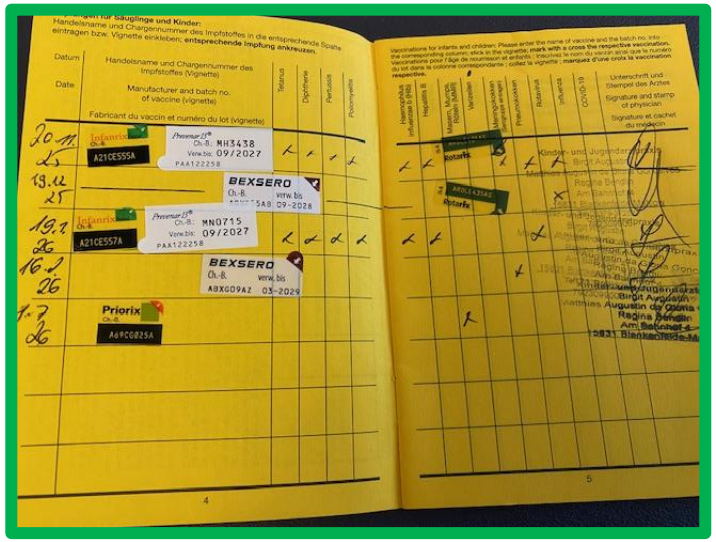
Vaccine against measles, mumps, and rubella.



SNOMED

SCTID: 51451000087105

Vaccine product containing only Streptococcus pneumoniae Danish serotype 1, 3, 4, 5, 6A, 6B, 7F, 9V, 14, 18C, 19A, 19F, and 23F capsular polysaccharide antigens conjugated (medicinal product)







BCG vaccine
Administered: 05.03.2024

Chickenpox vaccine
Administered: 21.01.2025

DTaP-IPV vaccine
Administered: 12.02.2026

DTaP-IPV-HiB vaccine
Administered: 26.06.2024, 29.04.2024

DTaP-IPV-HIB-hepatitis B vaccine
Administered: 15.01.2025

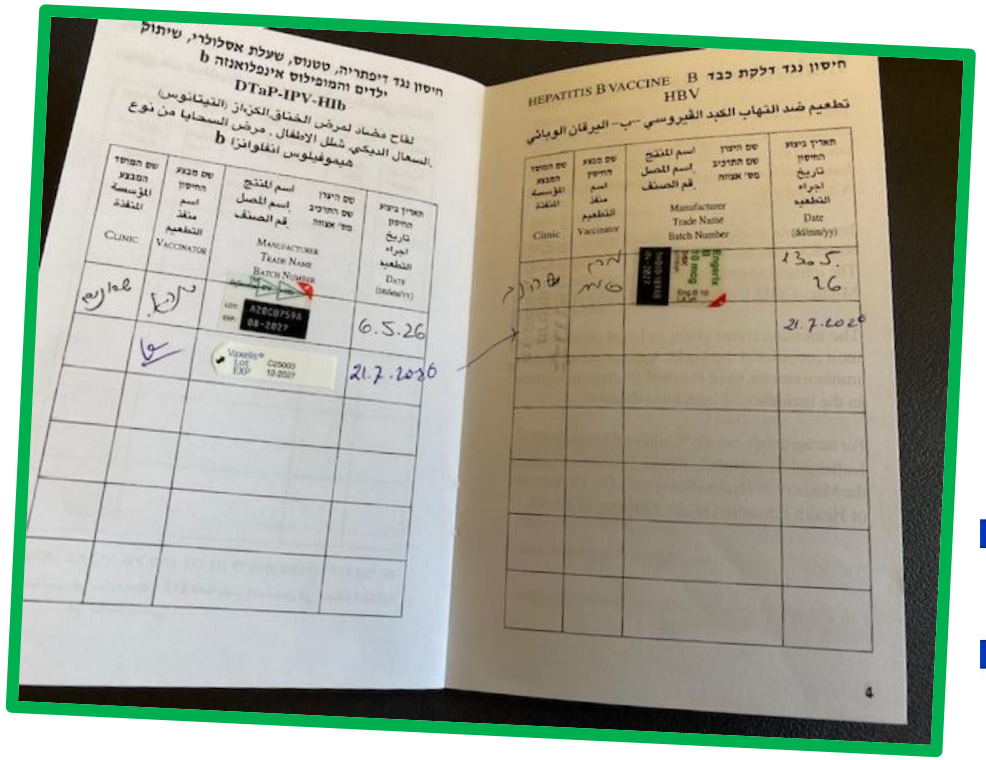
Hepatitis A and B vaccine for children
Administered: 12.02.2026

MMR vaccine
Administered: 21.01.2025

Pneumococcal conjugate vaccine, PCV10
Administered: 15.01.2025, 26.06.2024, 29.04.2024

Rotavirus vaccine
Administered: 26.06.2024, 29.04.2024, 22.03.2024

MyChart® licensed from Epic Systems Corporation© 1999 - 2026





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



maternal pertussis vaccination in Netherlands

In the Netherlands children's first year pertussis vaccination scheme has two variants at in months of age depending on several data of mother, her 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

DPT vaccination ATC and SNOMED CT

Anatomical Therapeutic Chemical (ATC) Classification

Date and Place vaccination

Bacterial and viral vaccines, combined

- J07CA01 : Diphtheria-poliomyelitis-tetanus
- J07CA02 : Diphtheria-pertussis-poliomyelitis-tetanus
- J07CA03 : Diphtheria-rubella-tetanus
- J07CA04 : Hemophilus influenzae B and poliomyelitis
- J07CA05 : Diphtheria-hepatitis B-pertussis-tetanus
- J07CA06 : Diphtheria-hemophilus influenzae B-pertussis-poliomyelitis-tetanus
- J07CA07 : Diphtheria-hepatitis B-tetanus
- J07CA08 : Hemophilus influenzae B and hepatitis B
- J07CA09 : Diphtheria-hemophilus influenzae B-pertussis-poliomyelitis-tetanus-hepatitis B
- J07CA10 : Typhoid-hepatitis A
- J07CA11 : Diphtheria-Hemophilus influenzae B-pertussis-tetanus-hepatitis B
- J07CA12 : Diphtheria-pertussis-poliomyelitis-tetanus-hepatitis B
- J07CA13 : Diphtheria-hemophilus influenzae B-pertussis-tetanus-hepatitis B-meningococcus A + C

SNOMED CT
The global language of healthcare

	Corynebacterium diphtheriae antigens (procedure)
First diphtheria, pertussis, and tetanus vaccination	Administration of first dose of vaccine product containing only Bordetella pertussis and Clostridium tetani and Corynebacterium diphtheriae antigens (procedure)
Third diphtheria, pertussis, and tetanus vaccination	Administration of third dose of vaccine product containing only Bordetella pertussis and Clostridium tetani and Corynebacterium diphtheriae antigens (procedure)
Second diphtheria, pertussis, and tetanus vaccination	Administration of second dose of vaccine product containing only Bordetella pertussis and Clostridium tetani and Corynebacterium diphtheriae antigens (procedure)
Requires diphtheria, tetanus and pertussis vaccination	Requires diphtheria, tetanus and pertussis vaccination (finding)

Administration of first dose of vaccine product containing only Bordetella pertussis and Clostridium tetani and Corynebacterium diphtheriae antigens (procedure)

SCTID: 866158005

866158005 | Administration of first dose of vaccine product containing only Bordetella pertussis and Clostridium tetani and Corynebacterium diphtheriae antigens (procedure) |

en Administration of first dose of vaccine product containing only Bordetella pertussis and Clostridium tetani and Corynebacterium diphtheriae antigens (procedure)

en Administration of first dose of diphtheria, pertussis, and tetanus vaccine

en Administration of first dose of

tional User Guide Contact Us



Global Data, Local Care: Advancing Smarter Standards



Well child visits- Vaccination- Disease

Problems (including diagnoses)

7. Diseases and Conditions
12.Cystic Fibrosis

7.12 Cystic fibrosis

Cystic fibrosis is the most common chronic, progressive genetic disease. Children and adolescents with cystic fibrosis require lifelong treatment and care. Although the disease is severely life-limiting, advances in the therapy of cystic fibrosis and a range of new drugs have led to significant improvements in quality of life and greater life expectancy. While most children are diagnosed at birth through newborn screening programmes, some get diagnosed later in infancy or childhood.

Signs and symptoms

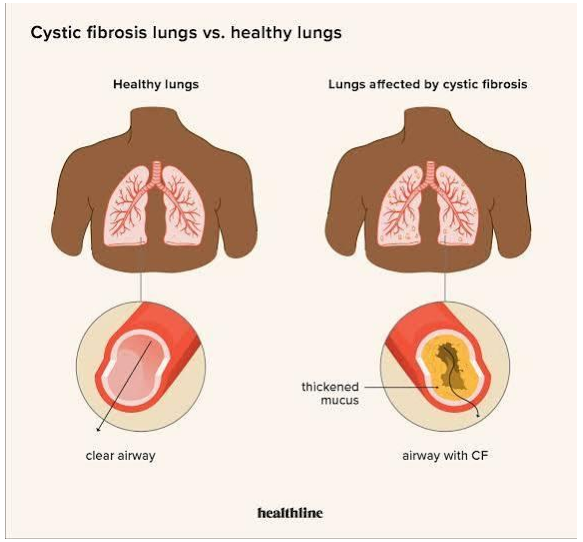
Children and adolescents with cystic fibrosis have thick viscous secretions in the lung, pancreas, liver, intestine and reproductive tract, leading to multiple symptoms.

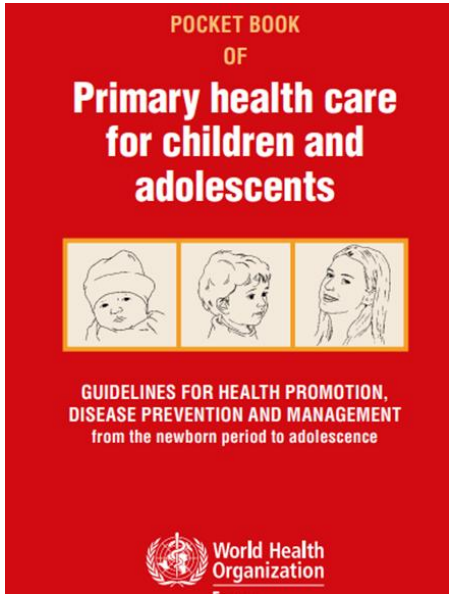
Onset of signs and symptoms is often in early infancy:

- Meconium ileus (p. 150)
- Congenital intestinal atresia
- Respiratory symptoms
- Failure to thrive.

In milder cases, signs and symptoms may develop in later childhood:

- Chronic and recurrent pulmonary disease: recurrent lower respiratory tract infections, chronic wet or productive cough
- Chronic sinus disease: chronic sinusitis, headache, nasal polyposis
- Pancreatic insufficiency: loose greasy stools, malabsorption, anaemia, vitamin deficiencies (A, D, E and K)





Problems (including diagnoses)

Shwachman Diamond Syndrome From Feature to Medical Guideline

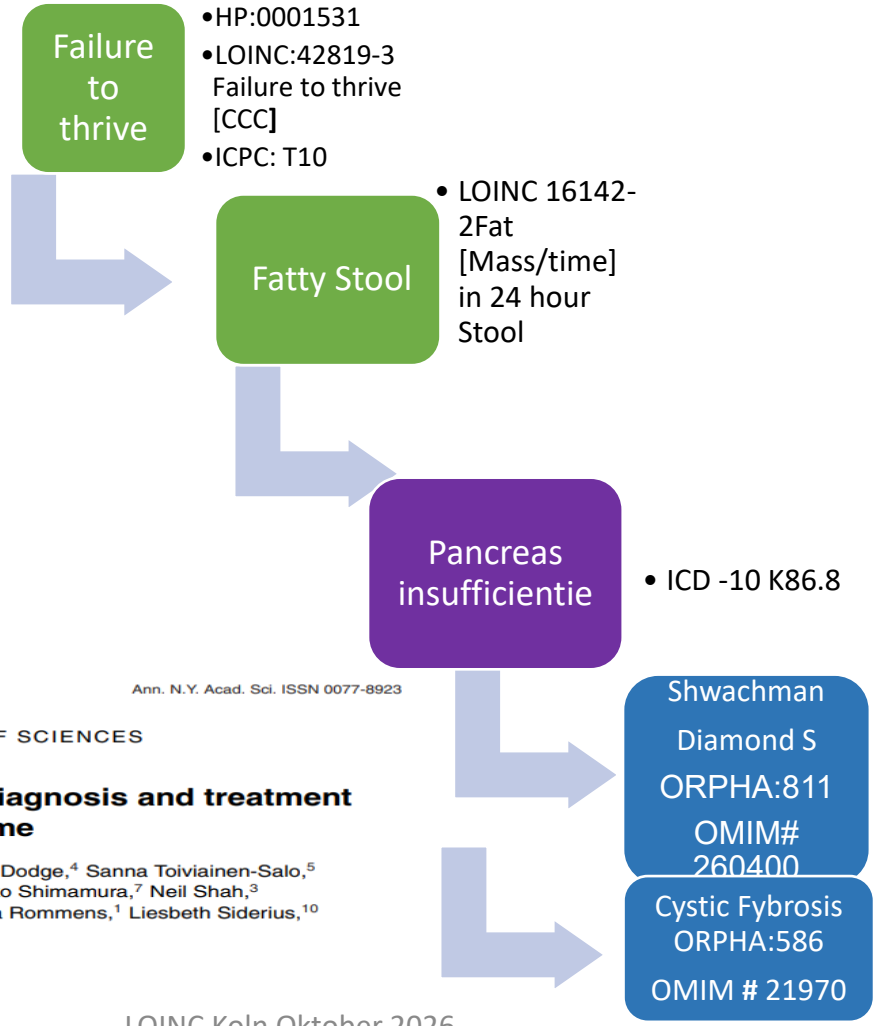
Feature

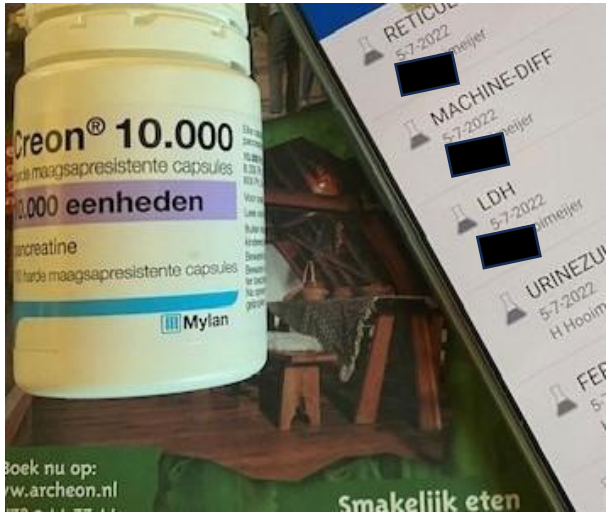
- Fatty Stool
- Growth Retardation
- Common infections

Shwachman Diamond Syndrome-

Management

- Pancreas insufficiency
- Neutropenia
- Skeletal Dysplasia
- Autisme like





Ann. N.Y. Acad. Sci. ISSN 0077-8923

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

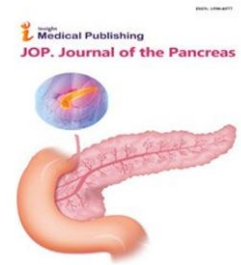
Draft consensus guidelines for diagnosis and treatment of Shwachman-Diamond syndrome

Yigal Dror,[1] Jean Donadieu,[2] Jutta Koglmeier,[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 Kuijpers,[9] Peter Durie,[1] Johanna Rommens,[1] Liesbeth Siderius,[10] and Johnson M. Liu[11]

HL7® FHIR®

Problems (including diagnoses)

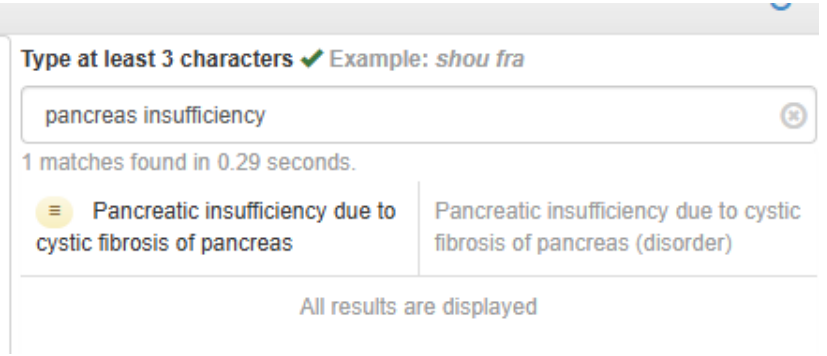
Pancreas insufficiency

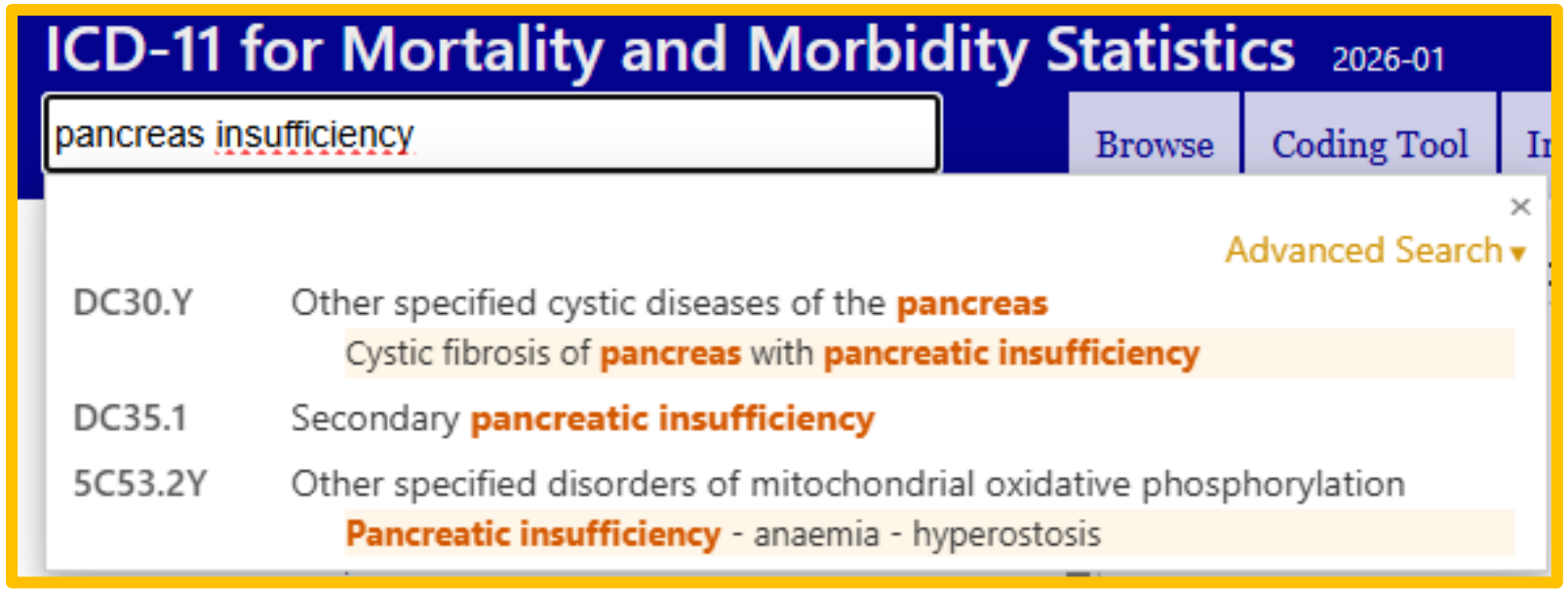


Exocrine pancreatic insufficiency (EPI) is the inability to properly digest food due to a lack of digestive enzymes made by the pancreas.

EPI is found in
cystic fibrosis
Shwachman–Diamond syndrome
Johanson-Blizzard Syndrome

SNOMED CT





Pancreatic insufficiency due to cystic fibrosis of pancreas (disorder)
SCTID: 707450006
707450006 | Pancreatic insufficiency due to cystic fibrosis of pancreas (disorder) | *en* Pancreatic insufficiency due to cystic fibrosis of pancreas (disorder)
en Pancreatic insufficiency due to cystic fibrosis of pancreas

Results

Guideline Cystic Fibrosis

Author Manuscript

HHS Public Access
Author manuscript
Pediatrics. Author manuscript; available in PMC 2025 January 30.

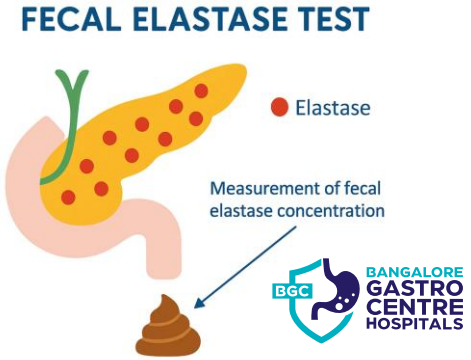
Published in final edited form as:
Pediatrics. 2024 May 01; 153(5): . doi:10.1542/peds.2023-064657.

Cystic Fibrosis Foundation Evidence-Based Guideline for the Management of CRMS/CFSPID

Laboratory Testing

9 The CFF recommends, for people with CRMS/CFSPID, that measurement of fecal elastase (FE) should be performed at the initial assessment. Further testing of FE can be provided when clinically appropriate (Grade B).

10 The CFF recommends against routine laboratory evaluations, including fat-soluble vitamin testing, liver function testing, glucose monitoring, and blood counts for people with CRMS/CFSPID (Grade D).



Measuring FE at the initial assessment is important to evaluate for exocrine pancreatic function because pancreatic insufficiency is a clinical feature of CF. FE levels can fluctuate in the first year of life; therefore, a single abnormal FE level should be interpreted cautiously, and repeat testing may be warranted[43] if symptoms of steatorrhea or failure to thrive develop. Most people with CRMS/CFSPID exhibit normal growth and nutrition and are pancreatic sufficient; thus, the presence of pancreatic insufficiency would strongly support reclassification to CF.[35,44,45]

Results

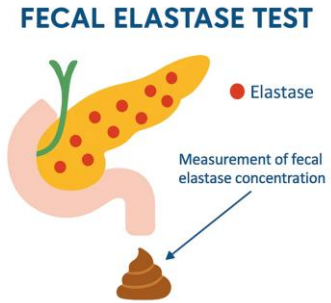
Guideline Shwachman diamond syndrome

Hematologic	
Peripheral blood cytopenias	CBC with differential
	Reticulocyte count
BMF	Bone marrow aspirate and biopsy
	Immunophenotypic analysis by flow cytometry
	Conventional karyotype and FISH
	Somatic myeloid NGS panel
MDS/AML	Cytoreductive therapy as clinically indicated
	HLA-typing and evaluation for stem cell transplant as indicated
Immune dysregulation	Serum immunoglobulins (IgG, IgM, IgA, IgE)
	Lymphocyte subsets (T-cell subsets, B cells, natural killer cells)
Coagulopathy	Prothrombin time
Nonhematologic	
Exocrine pancreatic dysfunction	Serum pancreatic isoamylase
	Fecal elastase
	Serum levels of vitamins A, D, E, and K, copper, and selenium
	Pancreatic enzyme supplementation

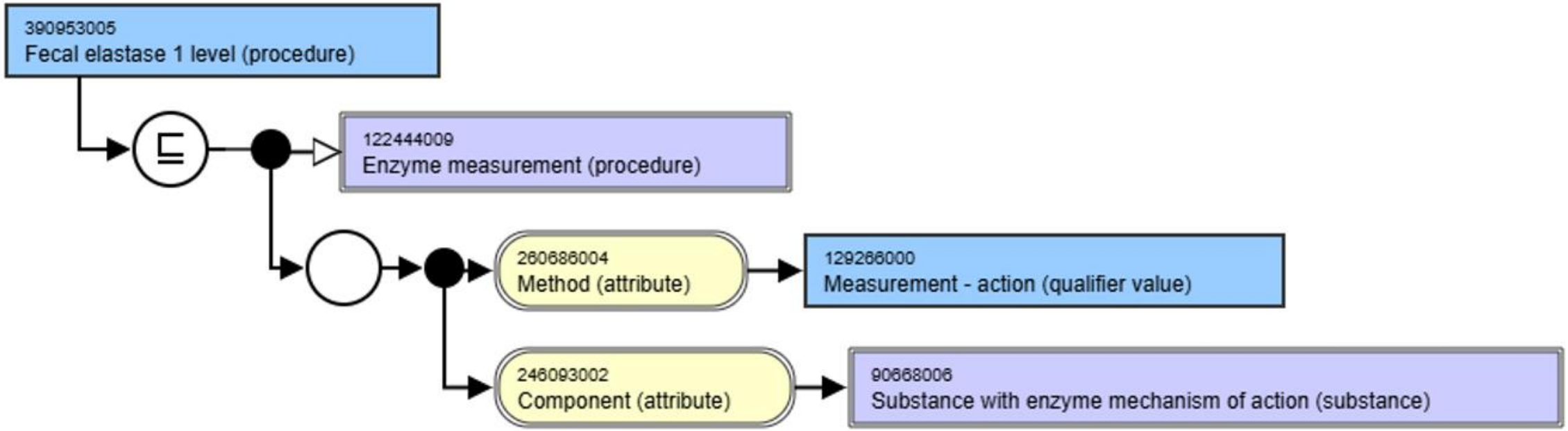


From Table 1 Reilly CR, Shimamura A. Predisposition to myeloid malignancies in Shwachman-Diamond syndrome: biological insights and clinical advances. Blood. 2023 Mar 30;141(13):1513-1523. doi: 10.1182/blood.2022017739. PMID: 36542827; PMCID: PMC10082379.

Status	LOINC	Long Common Name	Component	Property	Timing	System	Scale	Method	Class	Type	Example UCUM Units
	25907-7	Elastase.pancreatic [Mass/mass] in Stool	Elastase.pancreatic	MCnt	Pt	Stool	Qn		CHEM		ug/g



SNOMED CT
The global language of healthcare



https://www.bangaloregastrocentre.com/blog/fecal-elastase-test-the-complete-guide-to-pancreatic-function-testing/

Cystic Fibrosis relation PI to gene mutation

Cystic fibrosis transmembrane conductance regulator (*CFTR*) gene mutations in pancreatitis

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Mutation	Canadian Consortium for CF Genetic Studies			Mutation class
	Total PI	Total PI+PS	PIP score	
621+1G>T	96	96	1.00	Classes I - III
711+1G>T	36	36	1.00	Classes I - III
R553X	24	24	1.00	Classes I - III
I507del	34	34	1.00	Classes I - III
G542X	74	75	0.99	Classes I - III
F508del	1276	1324	0.96	Classes I - III
1717-1G>A	20	21	0.95	Classes I - III
W1282X	19	20	0.95	Classes I - III
N1303K	45	48	0.94	Classes I - III
R1162X	12	13	0.92	Classes I - III
G551D	59	67	0.88	Classes I - III
G85E	16	22	0.73	Classes I - III
A455E	18	37	0.49	Classes IV - V
2789+5G>A	6	16	0.38	Classes IV - V
R334W	1	10	0.10	Classes IV - V
3849+10kbC>T	2	22	0.09	Classes IV - V
R117H	1	25	0.04	Classes IV - V

Table 1

The PIP score for a specific mutation is the ratio between the **pancreatic insufficient patients carrying the mutation (Total PI)** and all pancreatic insufficient and sufficient patients (Total PI+PS) carrying the same mutation in a homozygous state or heterozygous in a combination with a severe mutation such as: F508del, G551D or a Class I mutation. For example,

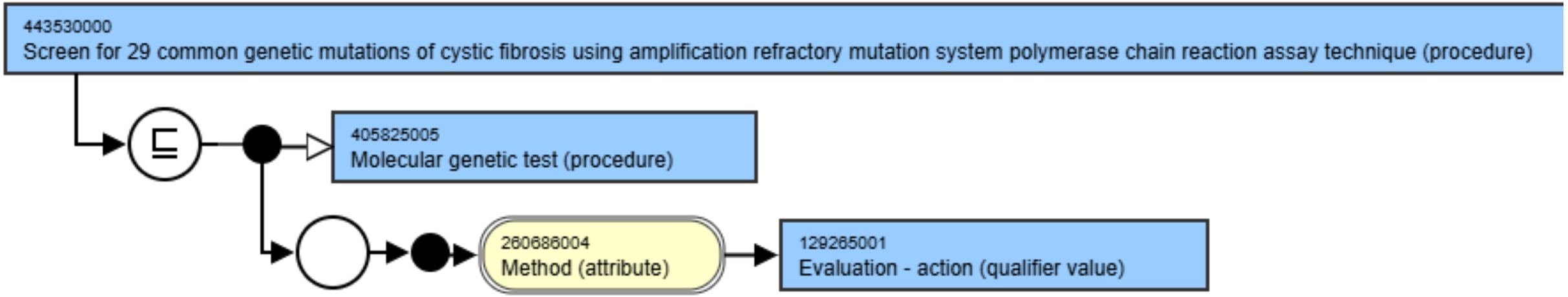
- a ratio of 1.00 indicates that all patients with 621+1G>T are PI when associated with a severe mutation on the other allele.
- a ratio of 0.1 demonstrates that 10% of subjects with R334W are PI.

Adapted from Ooi et al.

Results

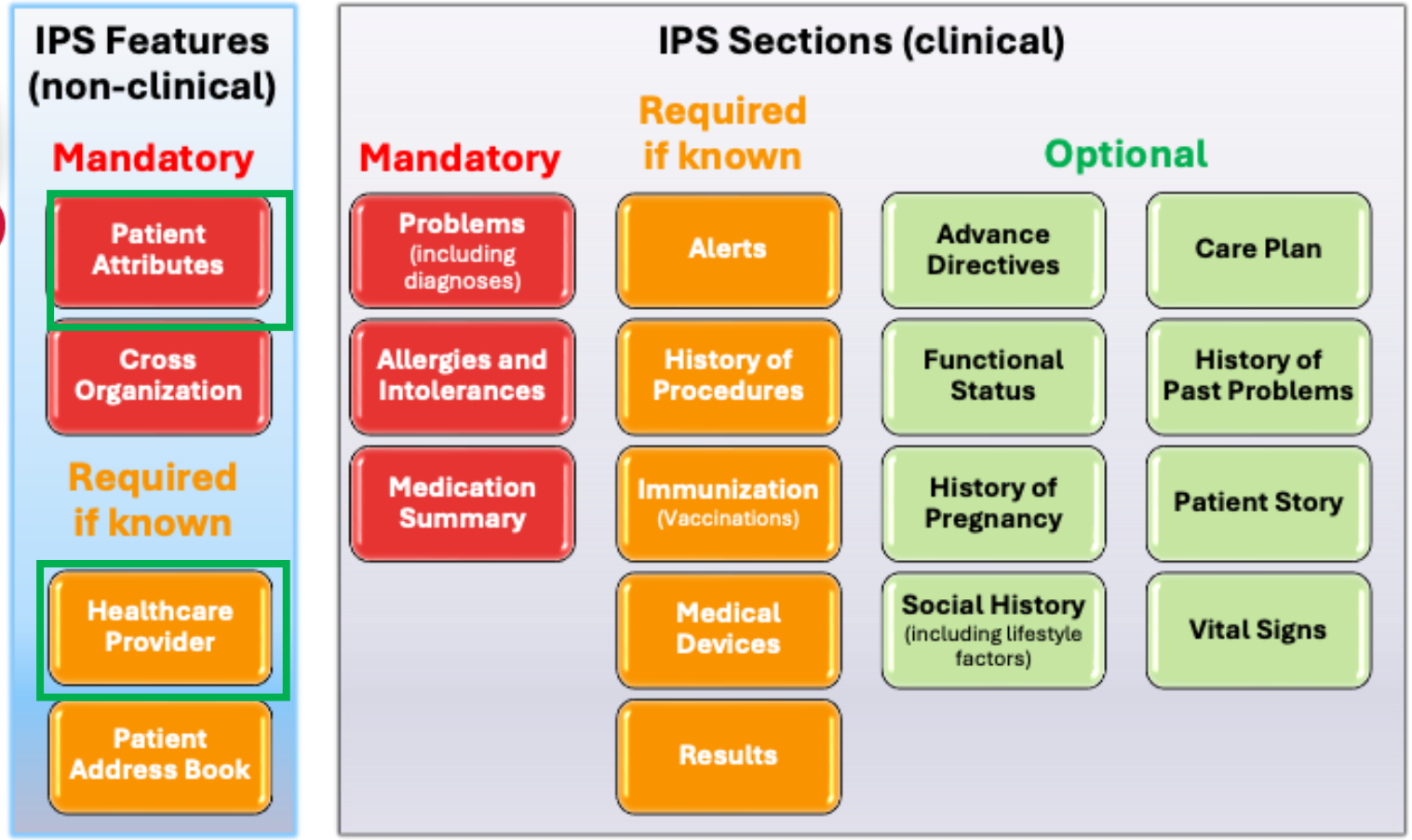
Cystic Fibrosis ‘common genetic mutation

Which 29 common mutations?



International Patient Summary updated October 2025

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



- Child Health
- Vaccination
- Chronic disease

What means a EHDS Health Professional ?

15.28.1 Logical Model: Immunisation model

Official URL: `http://www.xt-ehr.eu/fhir/models/StructureDefinition/EHDSImmunisation`	*Version*: `0.3.0`
Draft as of 2026-02-06	*Computable Name*: `EHDSImmunisation`

Model describes the administration of immunisation products, including vaccines and immunoglobulins, covering active and passive immunisations. It focuses on immunisation as a clinical procedure rather than the resulting immunity. The model supports routine immunisations at standard doses and may overlap with medication summaries or prescription lists. Natural immunity, immunisation outcomes, refusals, and administration or planning details are out of scope.



Usages:

- Use this Logical Model: Laboratory report model and Patient summary model

You can also check for usages in the FHIR IG Statistics

15.28.1.1 Formal Views of Profile Content

Description of Profiles, Differentials, Snapshots and how the different presentations work.

Key Elements Table | Differential Table | Snapshot Table | Statistics/References | All

Name	Flags	Card.	Type	Description & Constraints
EHDSImmunisation		0..*	EHDSDataSet	Immunisation model Elements defined in Ancestors:header
header		1..1	Base	Basic metadata for this information
subject		1..1	EHDSPatient	Patient/subject information
identifier		0..*	Identifier	Business identifier for the object, unique within its system. Supporting disambiguation between different contexts (systems/countries).
author[x]		0..*		The author of the immunisation statement.
authorEHDSHealthProfessional			EHDSHealthProfessional	

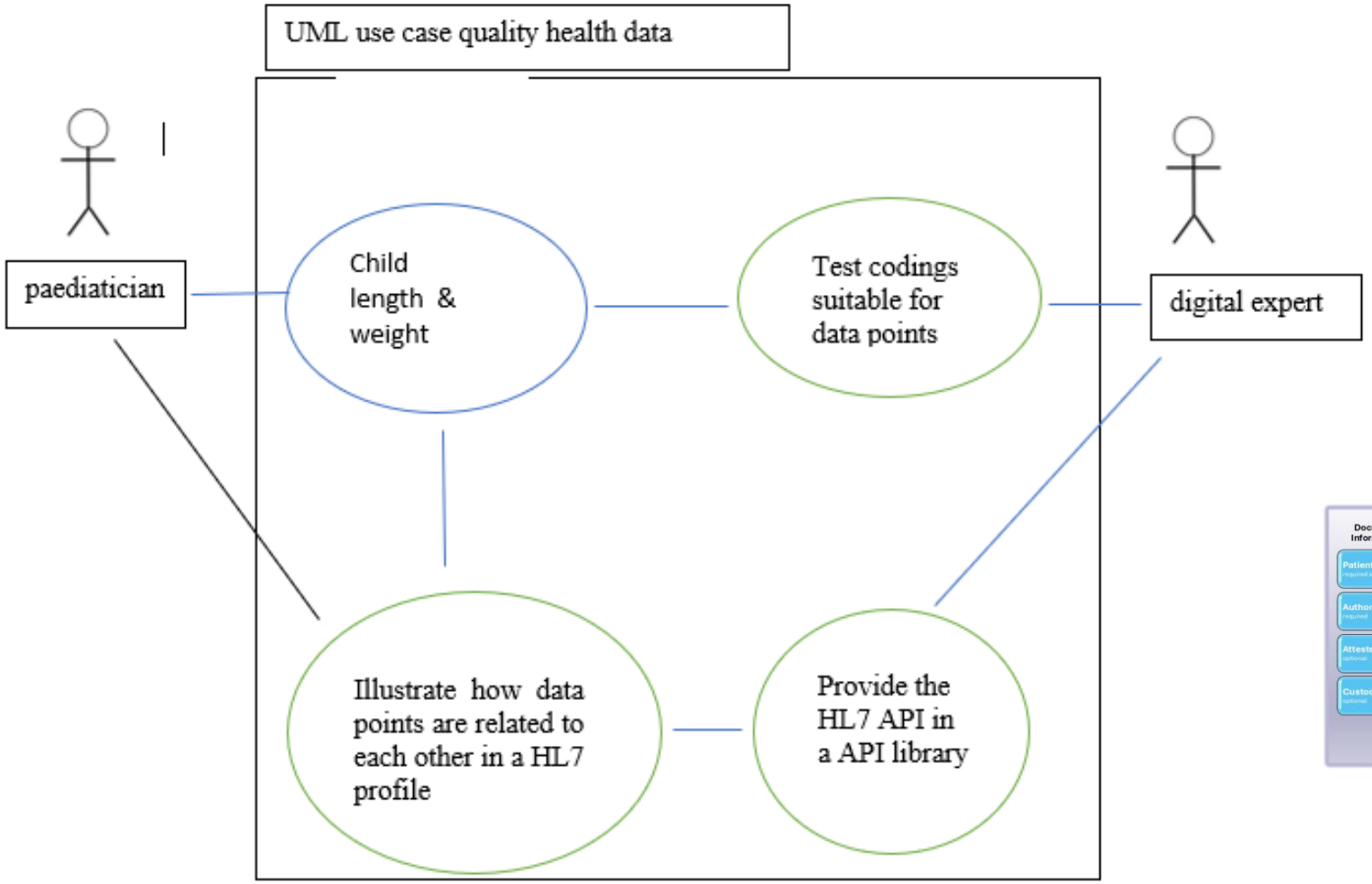
Care Plan

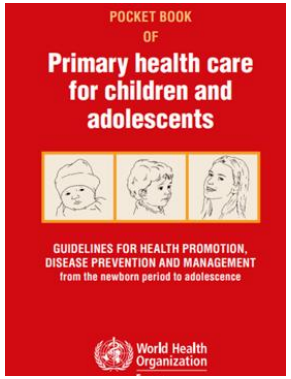
Results

Immunization
(Vaccinations)

Problems
(including diagnoses)

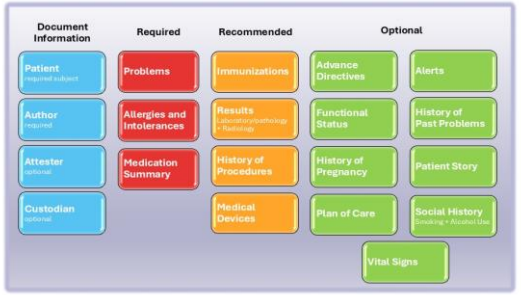
Lenght and weight in child health





HL7 FHIR

The IPS Composition



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)

Stichting Shwachman syndroom | Support Holland

New Diagnostics

HPO
LOINC
ICPC

Diagnosis
Hurler syndrome
PKU, Duchenne MD, FOP
Shwachman Diamond Syndrome

ICD - 10
Orphacode
OMIM

SNOMED -CT
DCOM

Sign primary care
Heelstick screening
Hearing screening
Growth; Development

Guideline
Collaborative Health Care

Interoperable data model

ISO 3166-1



ATC

New Therapeutics

ICF
ISO9999

HL7/ FHIR



Registry
Data collection with systematically organised computer processable collection medial terms

Guideline
Social services and rehabilitation



©SDSS Holland

Thank you

- European Pediatric Disease Network

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David Neubauer, Slovenia
Arunas Valiulis, Lithuania
Lina Jankauskaite, Lithuania
Jola Wierzba, Poland
Jernej Zavrsnik, Slovenia

- Consensus in Pediatrics and Child Health

Manual 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
Robert Stegwee, IT Expert, Netherlands

- People with a rare condition and their families

Shwachman Diamond Syndrome Support Holland, Netherlands
Paulo Gonçalves, Portugal



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