Universal Health Coverage

Leave no child behind and Digital Health

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UNICEF, January 2022

Millions of children with disabilities around the globe continue to be left behind,

despite the near-universal ratification of the

- **Convention on the Rights** of the Child, the call for action embedded in the
- **Convention on the Rights of Persons with Disabilities** and the clear mandate set by the
- **Sustainable Development Goals**.

Abandoned in hospital

Often, this neglect is the result of limited data

REGULATION (EU) 2016/679 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL

of 27 April 2016

on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation)

General Data Protection Regulation 2016

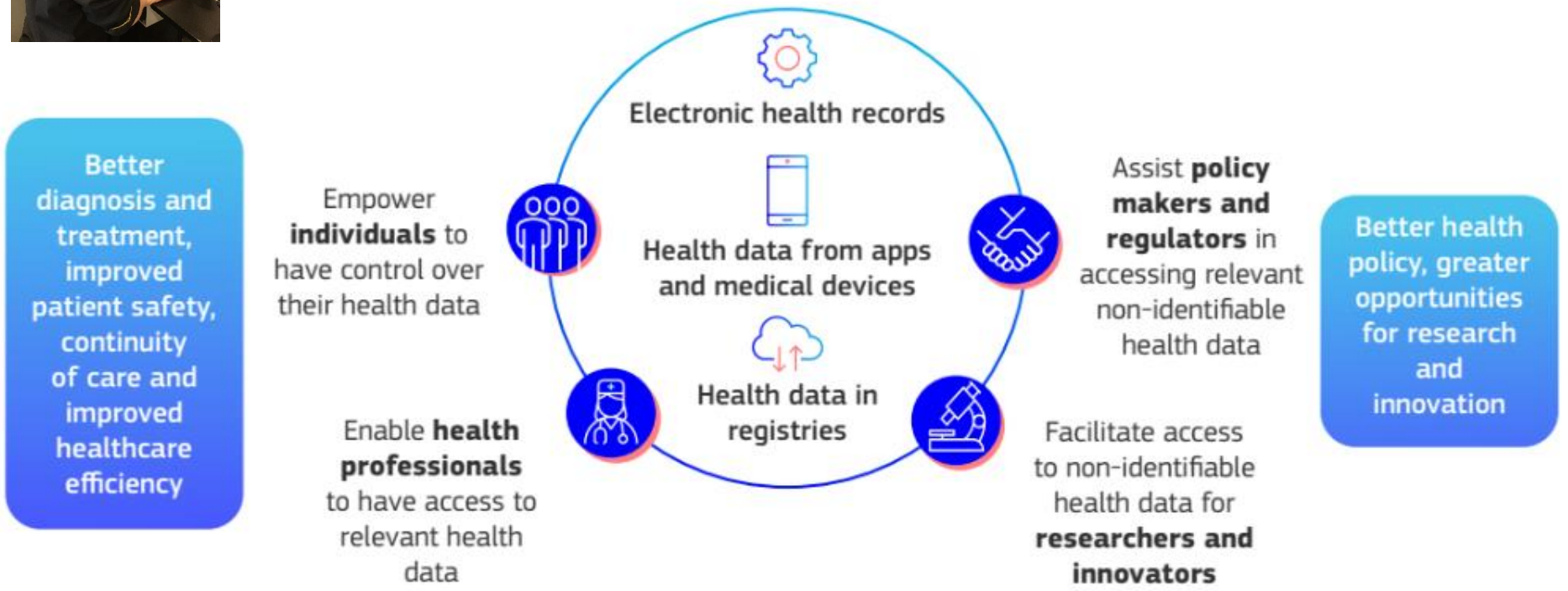
Art. 20 GDPR

Right to data portability

The data subject shall have the right to receive the personal data concerning him or her, which he or she has been provided to a controller, in a **structured, commonly used and machine-readable format** and have the right to transmit those data to another controller without hindrance from the controller to which personal data have been provide….

DigitalHealthEurope recommendations on the European Health Data Space

3 May 2022



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

HL7/ FHIR

ICF
ISO9999

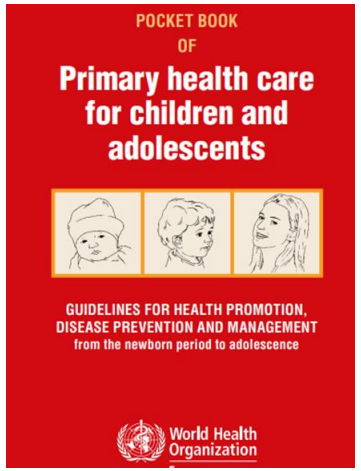
Registry
Data collection with systematically organised computer processable collection medial terms

Guideline
Social services and rehabilitation

World Health Organization

Digital Modelling of Primary Child Health

From home to each health system

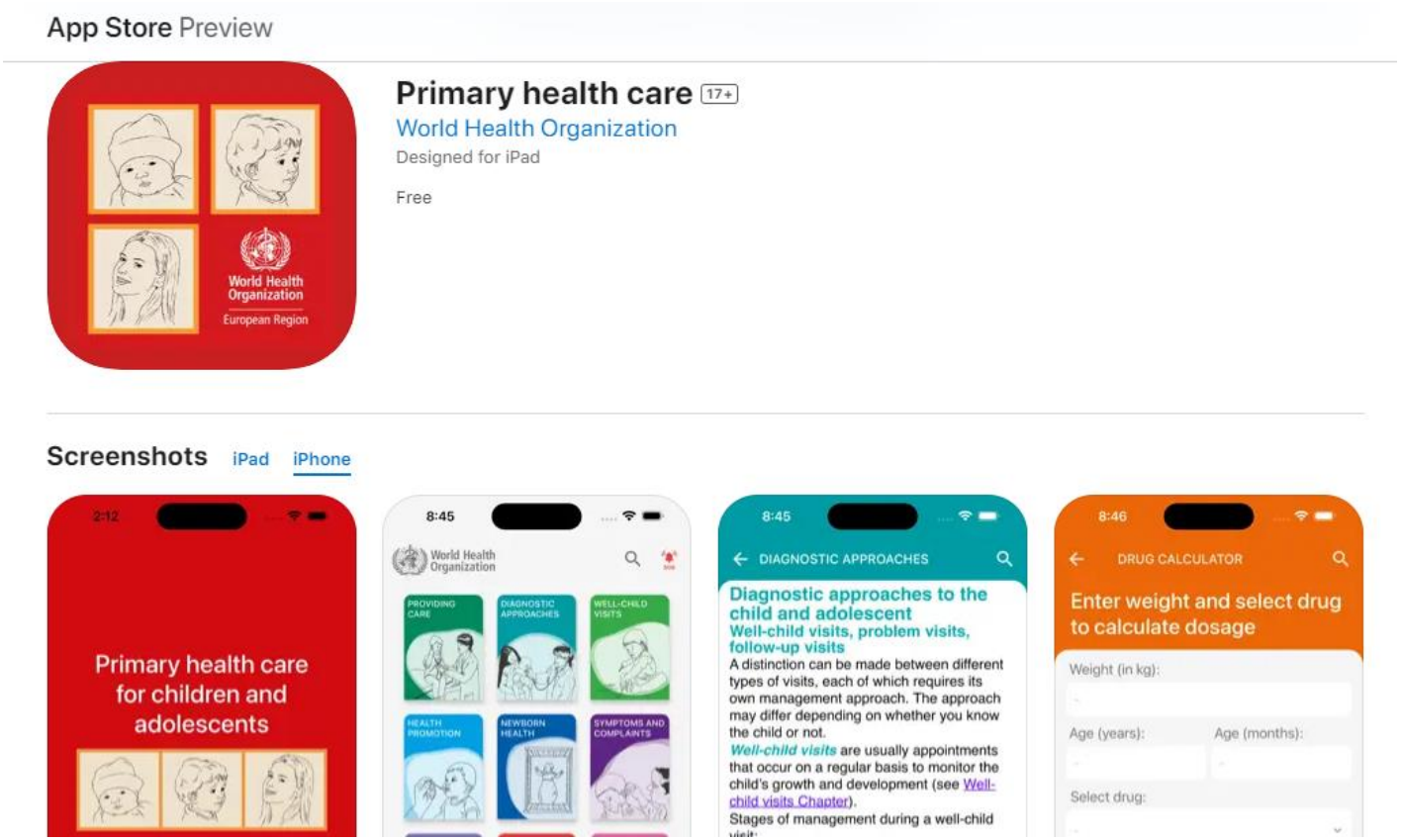


https://www.who.int/europe/publications/i/item/9789289057622

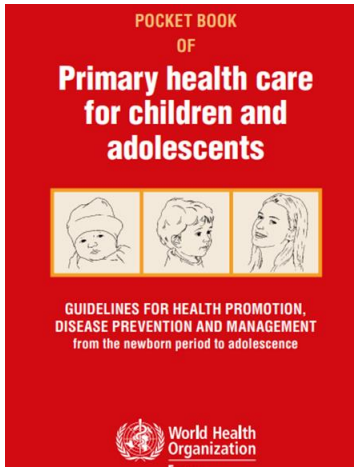
World Health Organization

https://apps.apple.com/es/app/primary-health-care/id6475376267?l=en-GB&platform=iphone

Launched 29 april 2024 by WHO



Digital Modelling of Primary Child Health

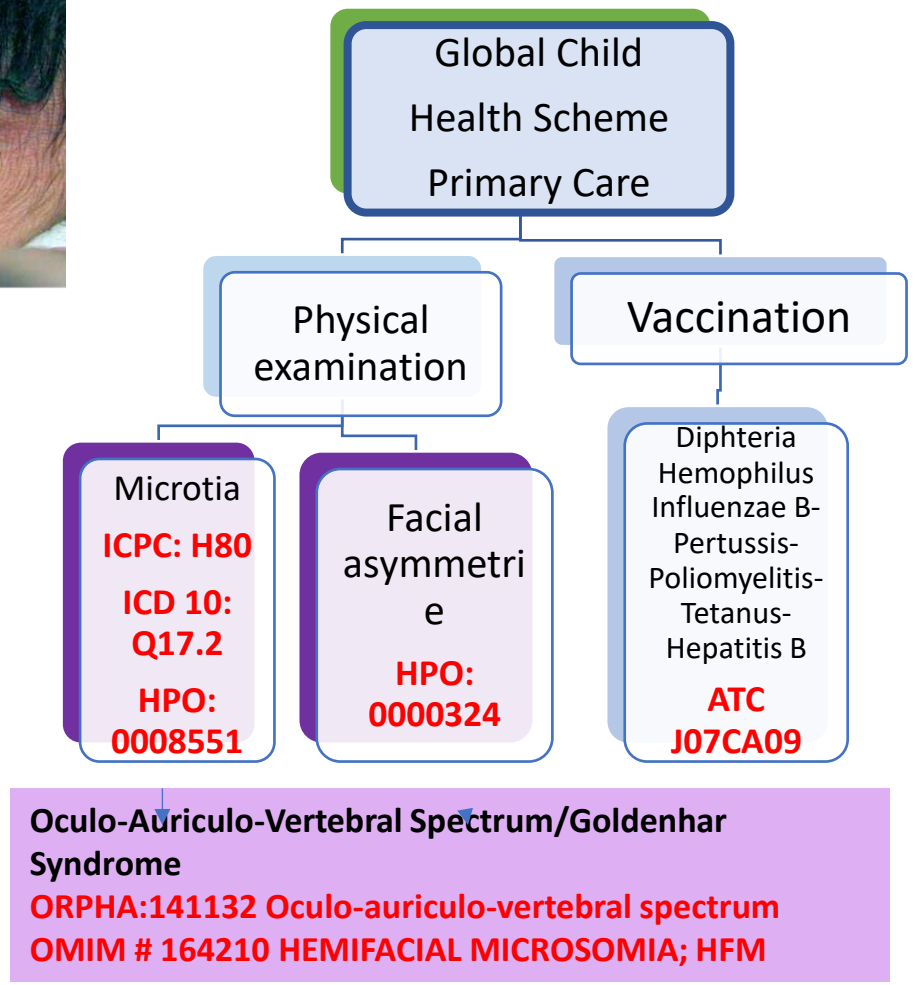


- Illustrative cases from The WHO Pocket Book on Primary health care for Children and Adolescents (WHO Europe, 2022)
- Proof of concept for a comprehensive implementation guide that harnesses the digital terminologies and HL7/FHIR standards
- Facilitating the seamless integration of WHO's quality healthcare standards into diverse primary care environments for children and adolescents.

Modern pediatrics *leaving no child behind*

- ✓Dissemination and generation of knowledge on diseases in children depends on the availability and interoperability of primary child health data.
- ✓Implementing structured set of interoperable international data terminologies such as the International Classification of Diseases (ICD) and International Classification of Function (ICF) as well as the numerical Logical Observation Identifiers Names and Codes (LOINC).

International terminologies as a tool for interoperability in child health



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

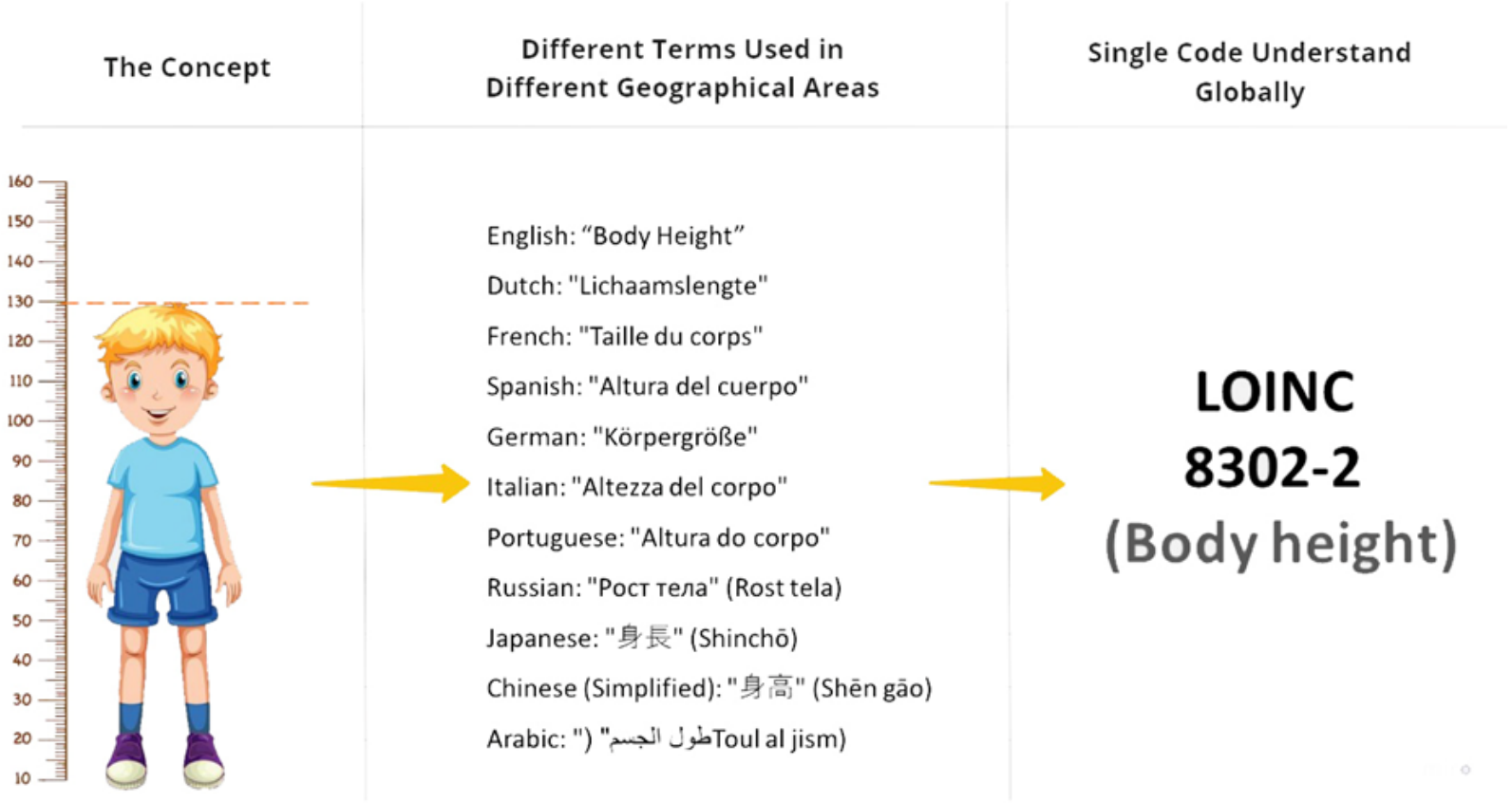
ATC: Anatomical Therapeutic Chemical Classification System

ORPHA: Classification of rare diseases

OMIM: Catalog of Human Genes and Genetic Disorders

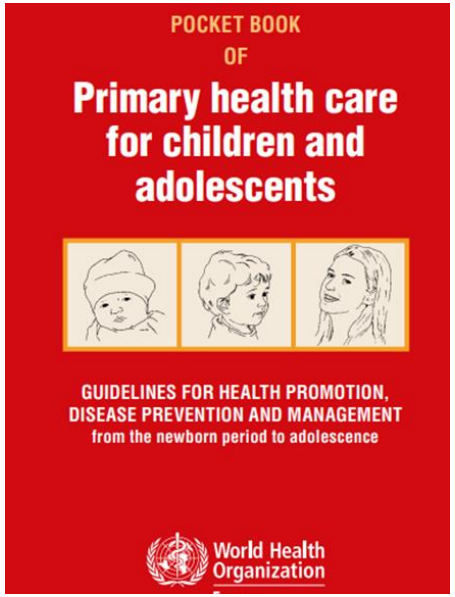
Use of terminologies enables semantic interoperability between systems using HL7 CDA and FHIR

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 Reali and Zachi Grossman, published in "Frontiers in Pediatrics-Children and Health".



Author Figure S.D. Perera, University Colombo, Sri Lanka

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

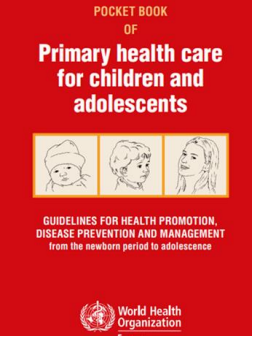
3.2 Well-child visit: birth – 72 hours

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

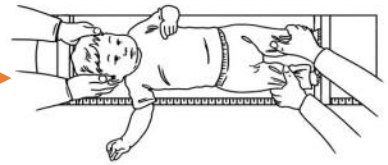


Short Stature
Real time evidence

3.1 Growth monitoring

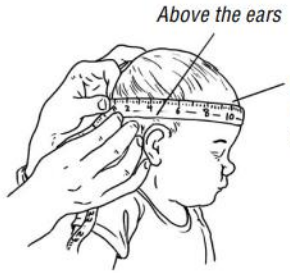
Measuring the child's growth is an essential part of every well-child visit:

- Regularly assess the following parameters to classify the nutritional status: measure the weight, length (from birth to 2 years), height (from 2 years) and head circumference of children with age-appropriate and well-adjusted scales and stadiometers.
- Calculate weight-for-age, length-for-age or height-for-age; weight-for-length or weight-for-height and body mass index (BMI = kg/m²: weight in kilograms/height in metres squared).
- Plot the measurements (with the date) and any available previous measurements on the same growth chart for the same child so that any abnormal growth becomes visible over time.

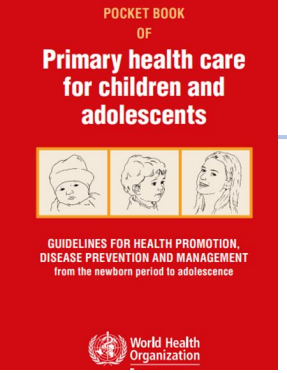


Length measurement from birth to 2 years of age

Height measurement in children from 2 years of age



Head circumference measurement



Case Maternal Achondroplasia

Vitamin K

— 1 mg vitamin K IM within the first hour of birth (during initial breast-feeding while the infant is in skin-to-skin contact with the mother) **or**

— 3 doses of 2 mg vitamin K orally: at birth, at 4 to 6 days, and at 4 to 6 weeks.

— Preterm newborns should receive a lower dose 0.4 mg/kg IM.

Vitamin D

— Daily dose of 400 IU vitamin D starting within days after birth for at least the first 12 months of life.

History

Take a thorough medical history including:

- **Baby's progress since birth:** any parental concerns, feeding, problems in passing urine (usually within 24 hours of birth) and meconium (usually within 48 hours of birth) (p. 150).
- **Maternal history:** age, social background, chronic maternal diseases, medical treatments and drugs, recreational drugs including alcohol and smoking.
- **Family history:** father's age, genetic conditions, consanguinity of parents, previous pregnancies and health of siblings.
- **Present pregnancy:** medical conditions that may have influenced the pregnancy (e.g. gestational diabetes), complications, screening tests and special diagnostic procedures, exposure to maternal infectious diseases such as hepatitis B (p. 168), HIV (p. 167), cytomegalovirus (p. 163), syphilis (p. 164) or toxoplasmosis (p. 165) during pregnancy or delivery.
- **Labour and delivery:** mode of delivery, length of labour, signs of fetal distress, drugs and/or anaesthesia given, APGAR score (p. 24).
- **Risk factors for neonatal infections:**
  - — Premature rupture of membranes (> 18 h before delivery)
  - — Maternal fever > 38 °C before delivery or during labour
  - — Foul-smelling or purulent (chorioamnionitis) amniotic fluid
  - — Maternal colonization with Group B streptococcus
  - — Preterm delivery.

Pregnant woman visit PCH at 22 weeks pregnancy

Mother : Diagnosed with achondroplasia (data academic hospital)

Pregancy & **Fetus :** Short femur by ultra sound observations at 22 weeks of pregnancy

PCH officer considers child has achondroplasia & Refer to academic hospital

Child at birth : Macrocephaly and short stature at birth

After birth:

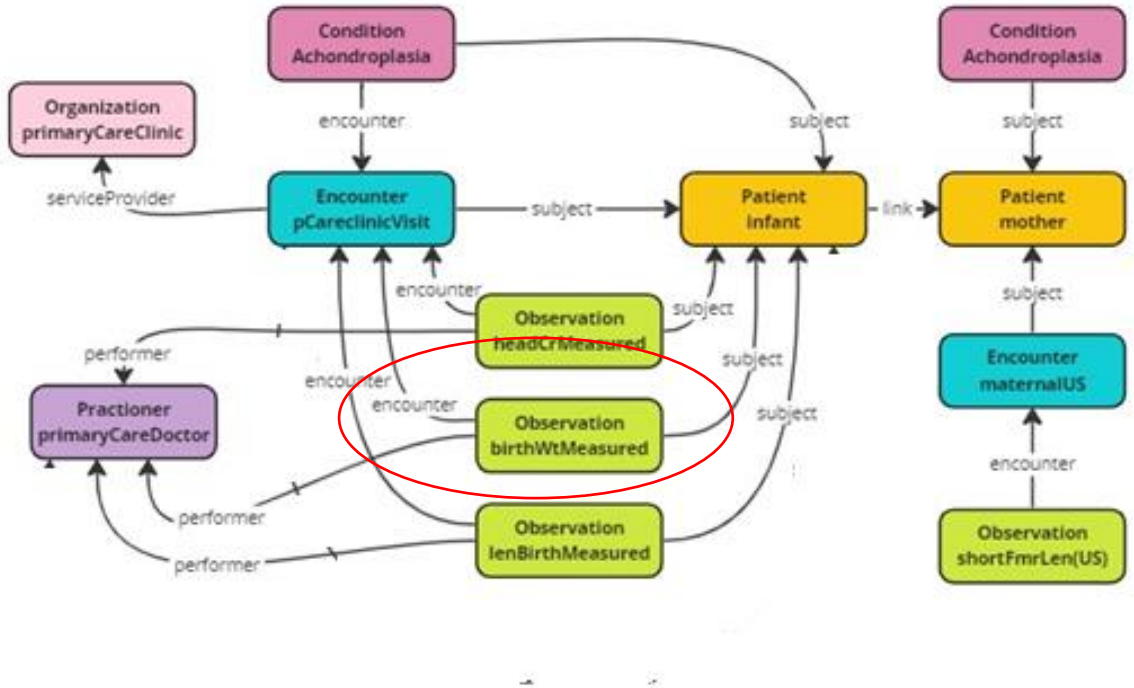
Child head circumference, body length and weight are followed according to achondroplasia growth curves

Maternal Achondroplasia

Integration in electronic health records

Date Flow HL7

Maternal Record → Home Based Record



Terminologies

Femur Length US	LOINC	11963-6
Head Occipital-frontal circumference by Tape measure	LOINC	8287-5
Birth weight Measured	LOINC	8339-4
Body height Measured --at birth	LOINC	89269-5
Achondroplasia	ICD 10	Q77.4

Digital language JSON

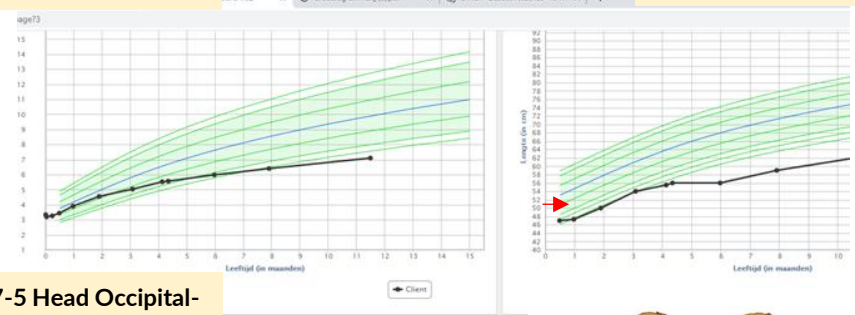
{"resourceType":"Observation","id":"cfsb1704636128883","status":"final","code":{"coding":[{"code":"3141-9","system":"http://loinc.org","display":"Body weight Measured"}]},"valueQuantity":{"value":10,"unit":"kg"},"interpretation":[{"coding":[{"code":"L","system":"http://terminology.hl7.org/CodeSystem/v3-ObservationInterpretation","display":"Low"}]}],"subject":{"reference":"cfsb1704507726008"},"effectiveDateTime":"2024-01-01T00:00:00.000Z"}

Maternal Achondroplasia

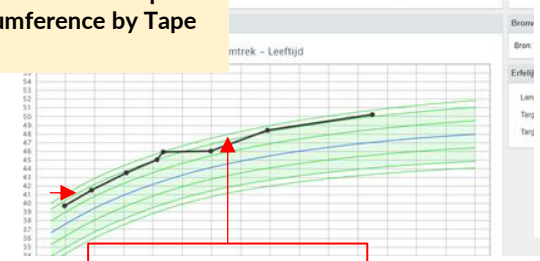
Real life data

LOINC 29463-7 Body weight

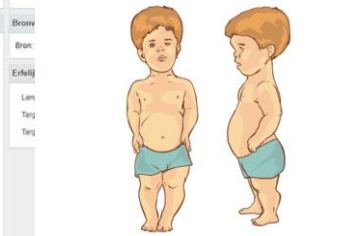
LOINC 8302-2 Body height



LOINC 8287-5 Head Occipital-frontal circumference by Tape measure



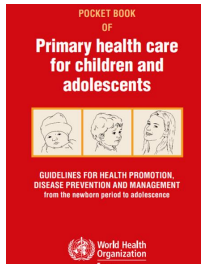
Hydrocephalus Risk



New Treatment

Achondroplasia-growth curve at each primary care visit

The company will price the treatment at roughly $300,000 per year



Diseases and conditions

7.14 Thalassemia

7.3 Autism spectrum disorder

Case Beta Thalassemia Children on the move

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**

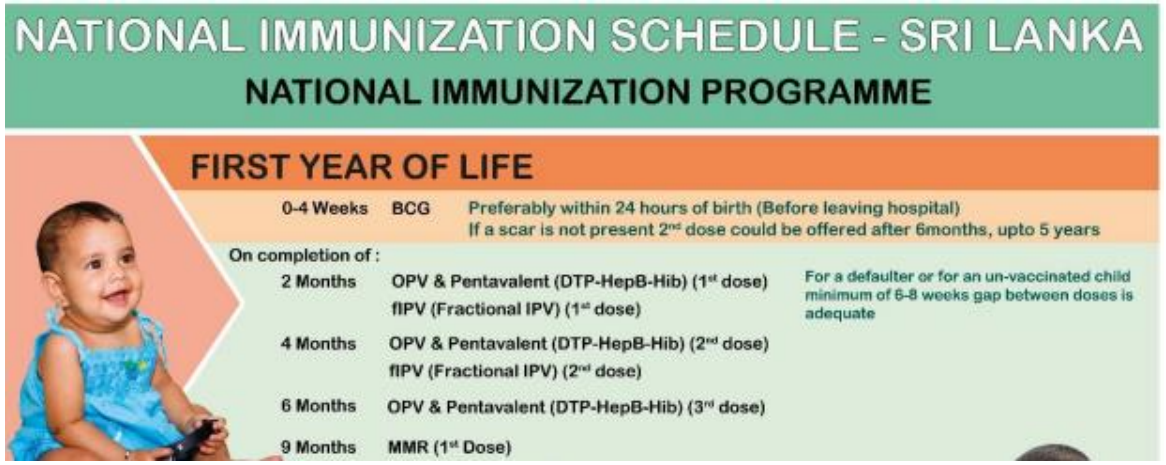
Laboratory test : Hemoglobine | Microcosis red blood cells

Referal to Thalassemia clinic

Parents are advised about routine vaccinations

Cascade Screening of Family

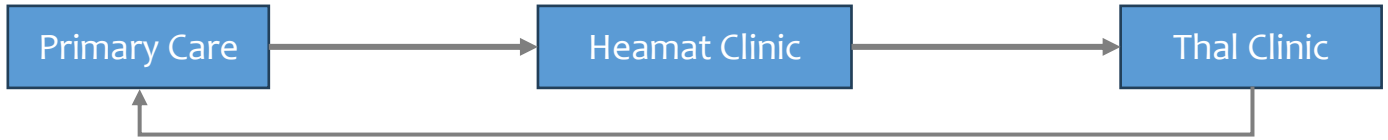
Diagnosis : Beta Thalassemia



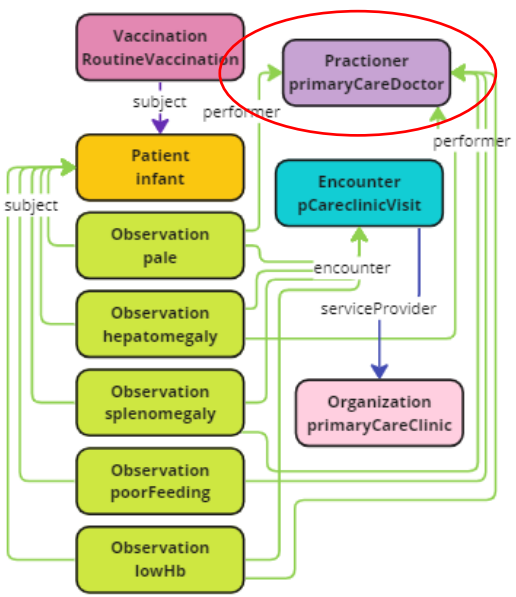
Beta Thalassemia

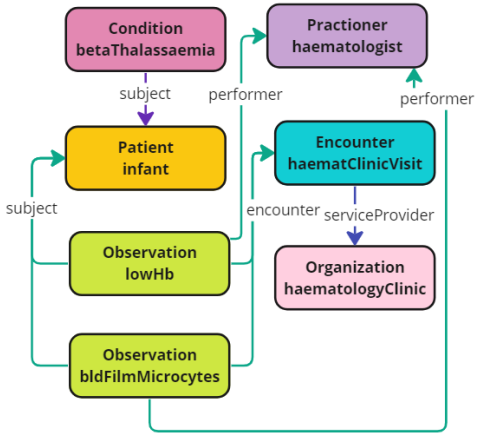
Integration in electronic health records

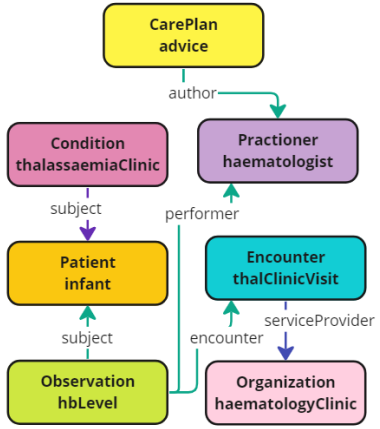
Date Flow HL7



FHIR







Terminologies

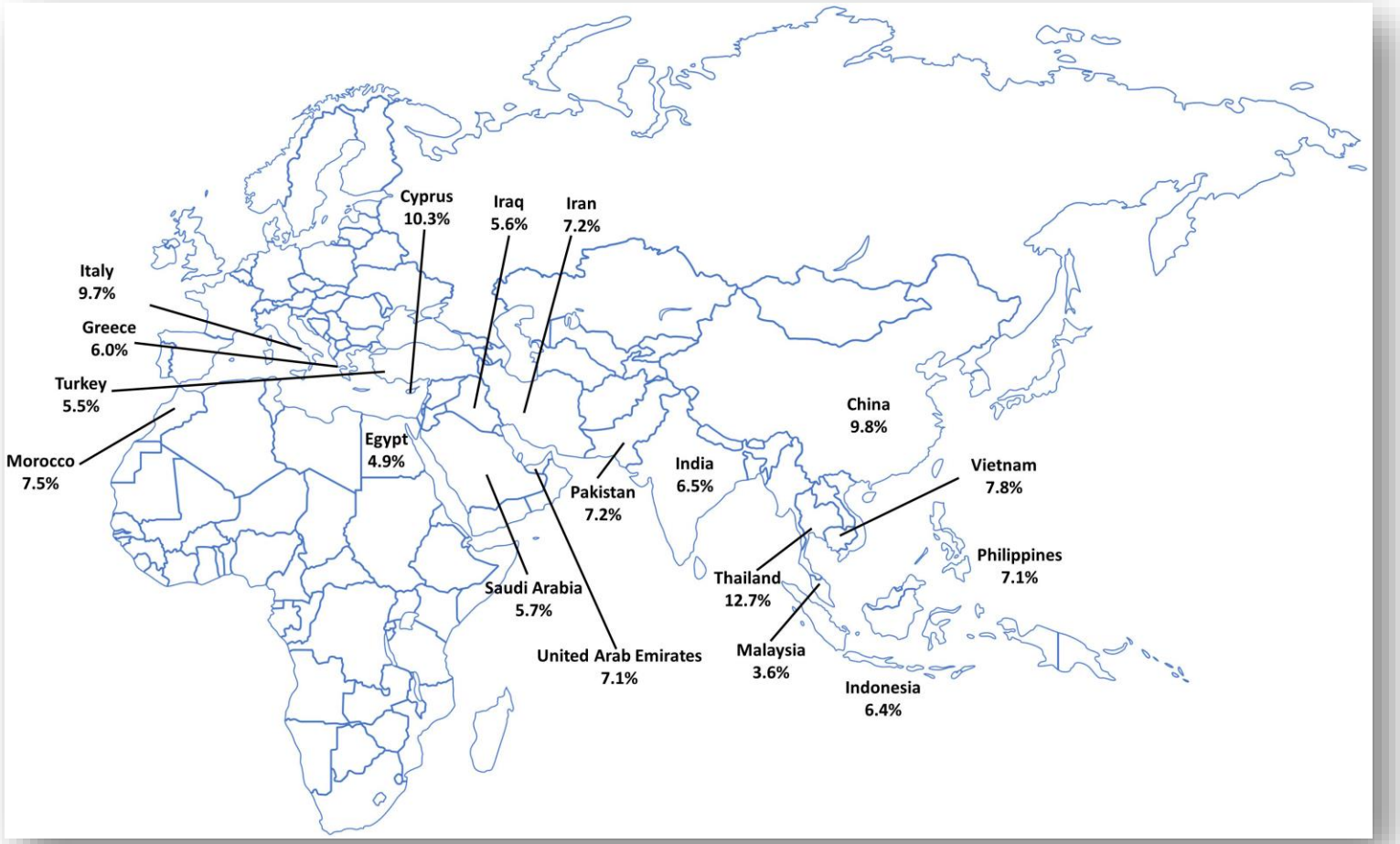
diphtheria-poliomyelitis-tetanus	ATC	J07CA01
Pallor	SNOMED CT	1237486008
Hepatomegaly	SNOMED CT	80515008
Splenomegaly	SNOMED CT	16294009
Haemoglobin concentration in blood	LOINC	718-7
Microcytes in blood film	LOINC	741-9
Feeding disorder of infancy and childhood	IDC 10	F98.2
Beta Thalassaemia	ICD 10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

Digital Language JSON

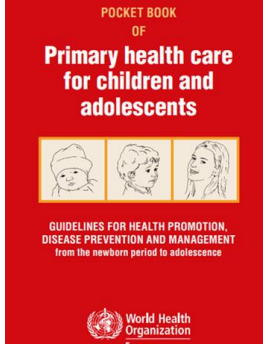
{"resourceType":"Practitioner","id":"cfsb1704509045558","name":[{"text":"Doctor Practioner","given":["Doctor"],"family":"Practioner"}],"telecom":[{"system":"email","value":"xxx@xxx.com","use":"work"},{"system":"phone","value":"0771111111","use":"work"}],"address":[{"text":"No x, Stree x, City X","use":"work","type":"both","line":["No X"],"city":"CIty X","country":"XXX"}]}

Beta Thalassemia

Carrier rate of β-thalassemia in endemic countries. Data taken from the global burden of disease collaborative network.



Front. Hematol., 20 June 2023
Sec. Red Cells, Iron and Erythropoiesis Volume 2 - 2023 | https://doi.org/10.3389/frhem.2023.1187681



Case Skin
Autism Spectrum Disorder

SKIN

5. NEWBORN HEALTH

Congenital dermal melanocytosis ("Mongolian spot")

- Small to large patches of blue or black pigmentation, oval or irregular in shape, mainly in the lumbosacral region. Lesions are sometimes mistaken for bruises.
- Common in children of African or Asian ethnic background.
- ▶ Provide reassurance as most will fade in early childhood.

Brown (café-au-lait) spots

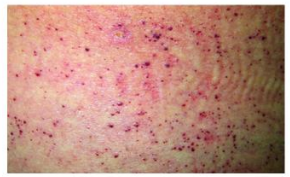
- Tan or light brown patches with well-defined borders.
- ▶ If fewer than six in number: reassure parent that the patches have no pathological significance and do not require any treatment.
- ▶ Refer if 6 or more: may be a sign of neurofibromatosis.

Infantile haemangioma (strawberry haemangioma)

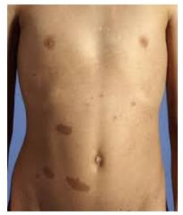
Infantile haemangioma, also known as a strawberry naevus, is the most common benign vascular skin tumour, that affects 4% of all infants with increased prevalence in preterm newborns. It can be present at birth but mostly appears within the first weeks of life, increases in size until the age of 6 to 9 months then regress: 95% will disappear by puberty.

- Dark red marks, found anywhere on the body

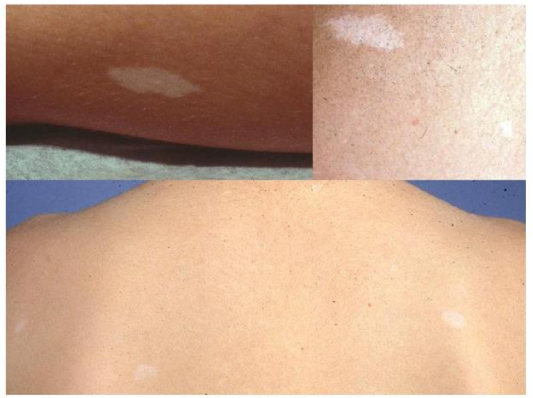
HP:0008066
Abnormal blistering of the skin



HP:0100585
Teleangiectasia of the skin

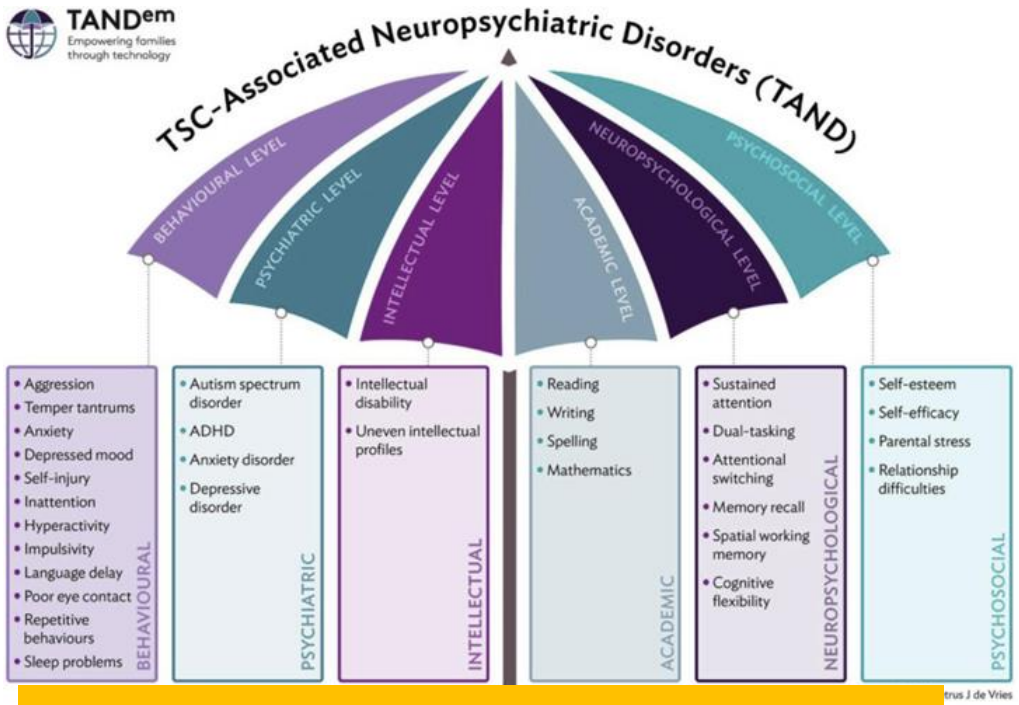


HP:0000995
Melanocytic nevus



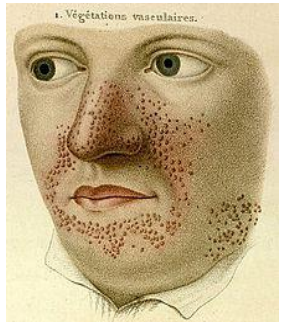
HP:0009719
Hypomelanotic macule

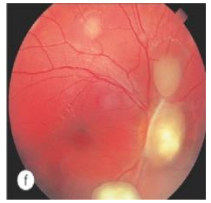
Digital Child Health Skopje April 2024

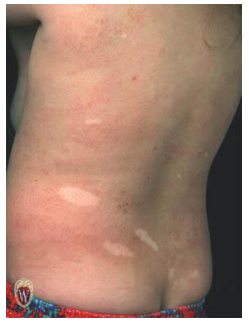


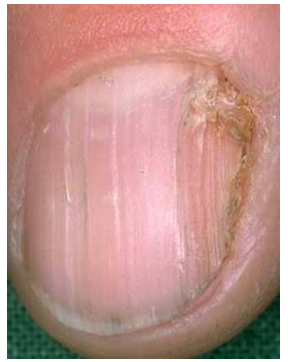
Autism Spectrum Disorder

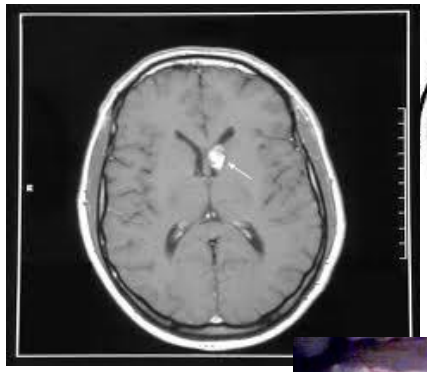
Tuberous sclerosis complex

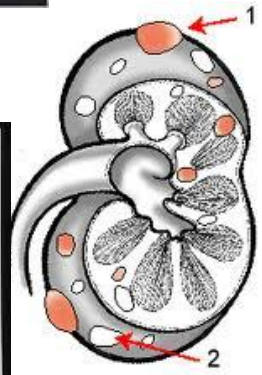












Northrup H, Aronow ME, Bebin EM, Bissler J, Darling TN, de Vries PJ, Frost MD, Fuchs Z, Gosnell ES, Gupta N, Jansen AC, Jóźwiak S, Kingswood JC, Knilans TK, McCormack FX, Pounders A, Roberds SL, Rodriguez-Buritica DF, Roth J, Sampson JR, Sparagana S, Thiele EA, Weiner HL, Wheless JW, Towbin AJ, Krueger DA; International Tuberous Sclerosis Complex Consensus Group.
Updated International Tuberous Sclerosis Complex Diagnostic Criteria and Surveillance and Management Recommendations. Pediatr Neurol. 2021 Oct;123:50-66. doi: 10.1016/j.pediatrneurol.2021.07.011. Epub 2021 Jul 24. PMID: 34399110.

From Feature to Medical Guideline

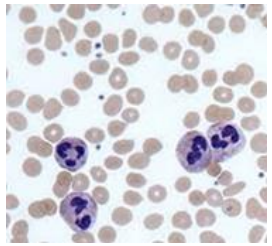
Feature

- **Fatty Stool**
- **Failure to thrive**
- **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

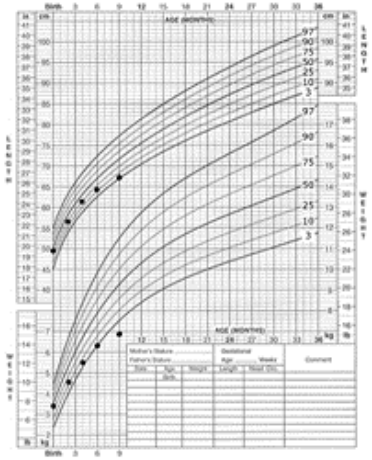
Yigal Dror,[1] Jean Donadieu,[2] Jutta Koglmeier,[3] John Dodge,[4] Sanna Toiviainen-Salo,[5] Outi Makitie,[5] Elizabeth Kerr,[1] Cornelia Zeidler,[6] Akiko Shimamura,[7] Neil Shah,[3] Marco Cipolli,[8] Taco Kuijpers,[9] Peter Durie,[1] Johanna Rommens,[1] Liesbeth Siderius,[10] and Johnson M. Liu[11]

Failure to thrive

- HP:0001531
- LOINC:42819-3 Failure to thrive [CCC]
- ICPC: T10

Fatty Stool

- LOINC 16142-2Fat [Mass/time] in 24 hour Stool



Pancreas insufficientie

- ICD -10 K86.81

Shwachman Diamond S
ORPHA:811
OMIM# 260400

Cystic Fybrosis
ORPHA:586
OMIM # 21970

Growing up with Shwachman Diamond syndrome
International Classification of Function (ICF)

Materials & Methods

Representatives of the Dutch SDS patient organisation selected 12 categories from the domain activities and participation of the ICF core-set autism brief and included these items in a questionnaire.

Results

The table shows ICF ≥6 quotations from ≥ 3 respondents; the most frequent are on top. Not only activities and participation categories were used frequently, but also functions and environmental factors

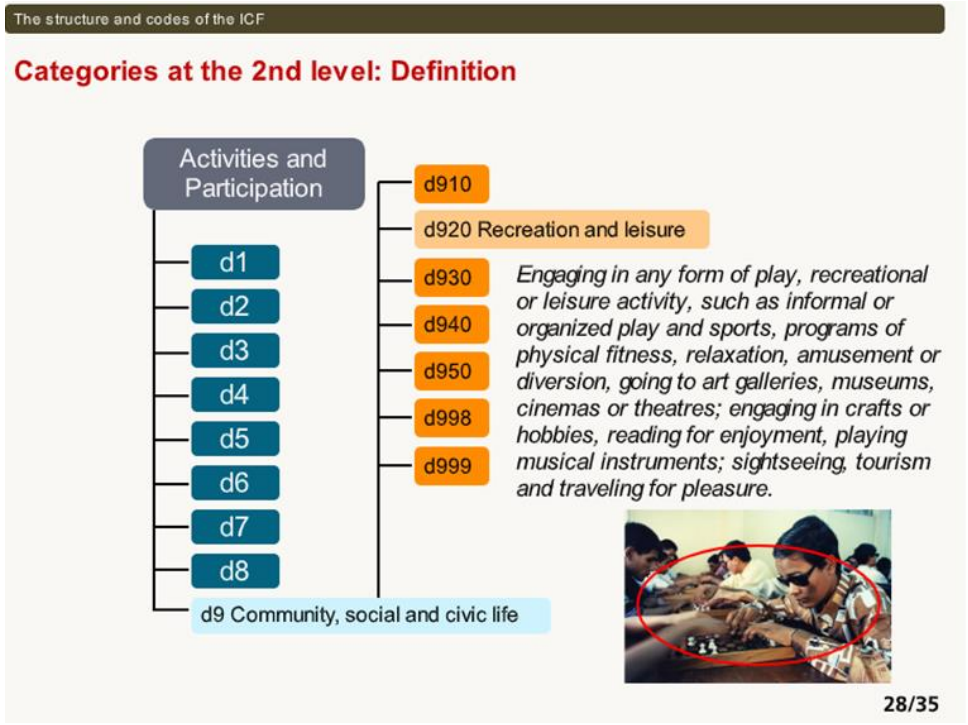
Activities and participation	Functions
d920 Recreation & leisure	b152 Emotional functions
d240 Handling stress and other psychological demands	b126 Temperament and personality functions
d850 Remunerative employment	b455 Exercise tolerance functions
d570 Looking after one's health	b125 Dispositions and intra-personal functions
d475 Driving	
d310 Understand spoken messages	**Environmental factors**
d720 Complex interpersonal interactions	e310 Immediate family
d610 Acquiring a place to live	e330 Peoples in positions of authority
d750 Informal social relationships	e355 Health professionals
d640 Doing housework	e360 Other professionals
d710 Basic interpersonal interactions	e120 Transportation
d230 Carrying out daily routine	
d210 Undertaking a single task	

Conclusion

Understanding the positive / neutral and negative aspects of living with a rare condition may help parents and communities to support growing up towards a fulfilled life.
Incorporating the **ICF in personal digital health records promotes health and well-being at all ages (Sustainable Development Goal #3, United Nations**)

ICF d 920.0

Recreation and leisure



Indian Mother and Childcare
Kolkata, 2020

ISO/TS 82304-2:2021
Health software Part 2: Health and wellness apps
Quality and reliability

Our FHIR SDK for Android Developers

Android Developers · Follow
Published in Android Developers · 3 min read · Mar 24, 2022

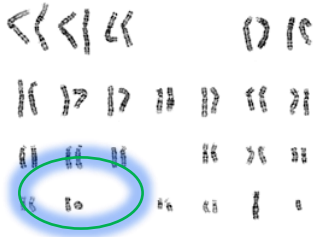
Kolkata, 2020

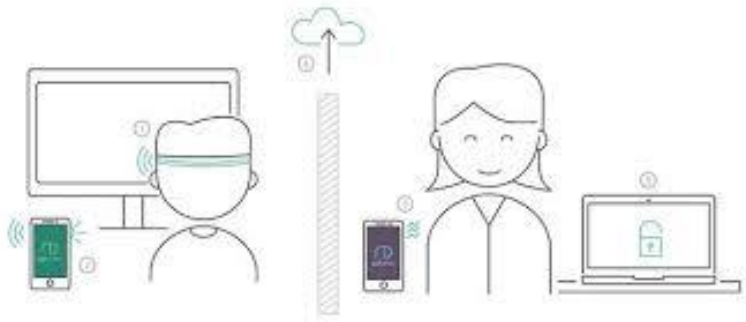
Epilepsy – assistive products- Health Technology Assessment

ICF d132
Acquiring Information

-

Mosaic ring chromosome 20





ICS › 11 › 11.180 › 11.180.01

ISO 9999:2016

Assistive products for persons with disability — Classification and terminology

EPIHUNTER

Health Technology Assessment (HTA)

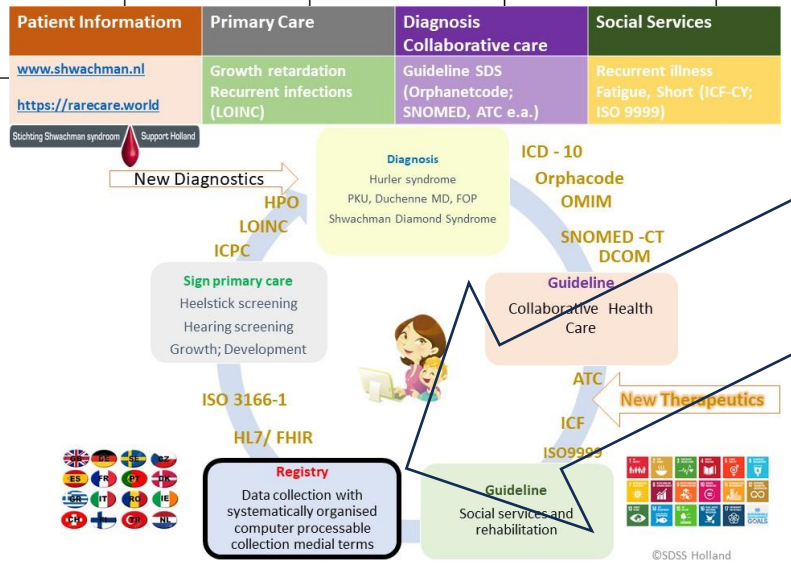
Set of common data elements for rare diseases **registration**

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°	ELEMENT NAME	ELEMENT DESCRIPTION	CODING	COMMENT
1. Pseudonym	1.1.	Pseudonym	Patient's pseudonym	• String	https://eu-rd-platform.jrc.ec.europa.eu/spider
2. Personal information	2.1.	Date of birth	Patient's date of birth	• Date (dd/mm/yyyy)	
	2.2.	Sex	Patient's sex at birth	• Female • Male • Undetermined • Foetus (Unknown)	
3. Patient Status	3.1.	Patient's status	Patient alive or dead	• Alive • Dead • Lost in follow-up • Opted-out	If dead then answer question 3.2
	3.2.	Date of death	Patient's date of death	• Date (dd/mm/yyyy)	
4. Care pathway	4.1.	First contact with specialised centre	Date of first contact with specialised centre	• Date (dd/mm/yyyy)	



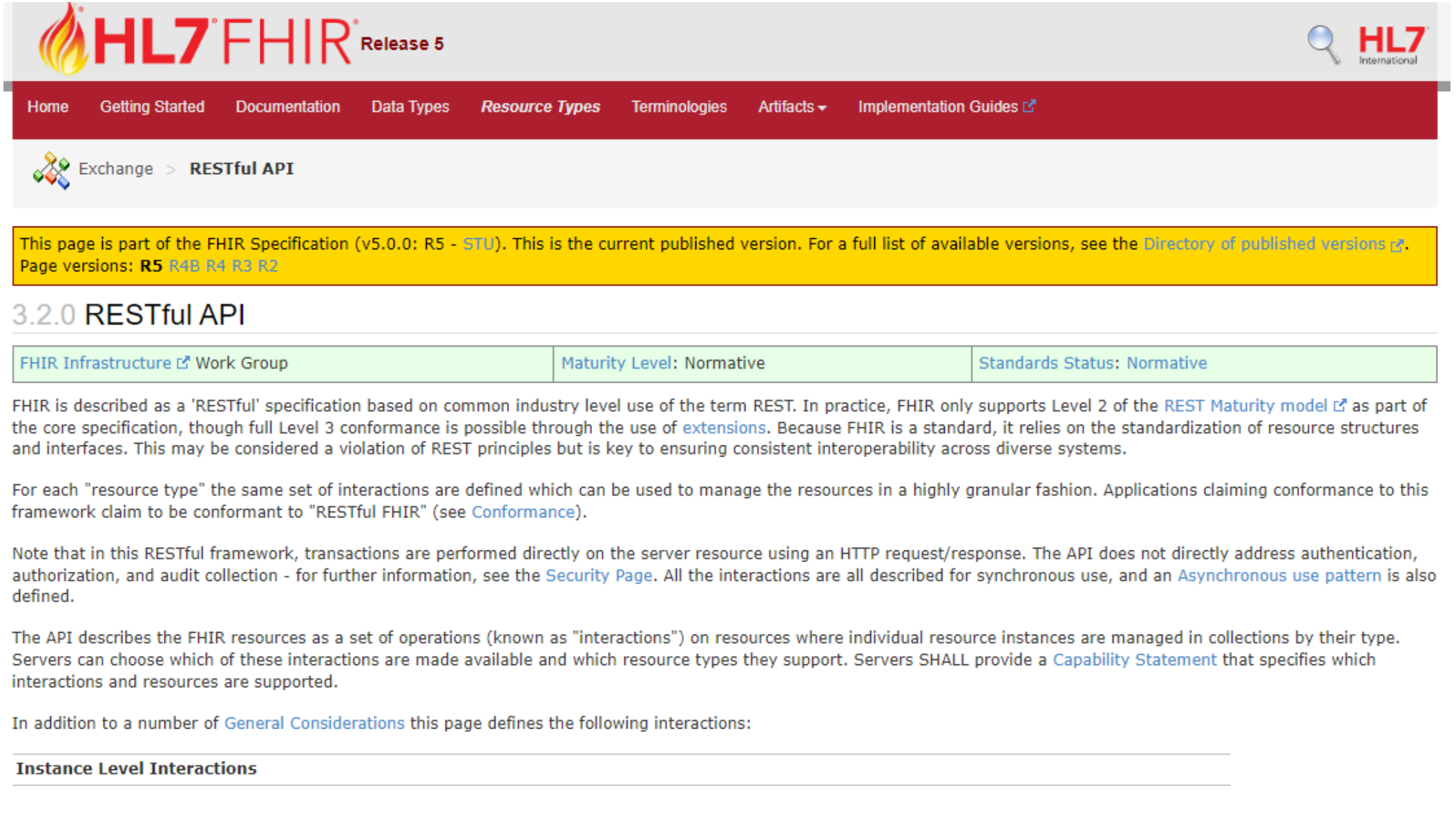
5. Disease history	5.1.	Age at onset	Age at which symptoms/signs first appeared	• Antenatal • At birth • Date (dd/mm/yyyy) • Undetermined	
	5.2.	Age at diagnosis	Age at which diagnosis was made	• Antenatal • At birth • Date (dd/mm/yyyy) • Undetermined	
6 Diagnosis	6.1.	Diagnosis of the rare disease	Diagnosis retained by the specialised centre	Orpha code (strongly recommended – see link) / Alpha code/ ICD-9 code/ ICD-9-CM code / ICD-10 code	
	6.2.	Genetic diagnosis	Genetic diagnosis retained by the specialised centre	International classification of	http://www.hgvs.org
	6.3	Undiagnosed case	How the undiagnosed case i defined		
7. Research	7.1.	Agreement to be contacted for research purposes	Patient's permission exists fo being contacted for researc purposes		
	7.2.	Consent to the reuse of data	Patient's consent exists fo his/her data to be reused fo other research purposes		
	7.3.	Biological sample	Patient's biological sample available for research	• YES • NO	If YES answer question 7.4
	7.4.	Link to a biobank	Biological sample stored in a biobank	• YES (if appropriate use link) • 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)	• Disability profile / Score	

ORPHA
ICD 9
ICD10

HGVS Human Genome Variety
HPO
HGNC Human Genome Nomenclature
OMIM

ICF

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



HL7 FHIR Release 5

HL7 International

Home | Getting Started | Documentation | Data Types | *Resource Types* | Terminologies | Artifacts | Implementation 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

3.2.0 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 specification, though full Level 3 conformance is possible through the use of extensions. Because FHIR is a standard, it relies on the standardization of resource structures and interfaces. This may be considered a violation of REST principles but is key to ensuring consistent interoperability across diverse systems.

For each "resource type" the same set of interactions are defined which can be used to manage the resources in a highly granular fashion. Applications claiming conformance to this framework claim to be conformant to "RESTful FHIR" (see Conformance).

Note that in this RESTful framework, transactions are performed directly on the server resource using an HTTP request/response. The API does not directly address authentication, authorization, and audit collection - for further information, see the Security Page. All the interactions are all described for synchronous use, and an Asynchronous use pattern is also defined.

The API describes the FHIR resources as a set of operations (known as "interactions") on resources where individual resource instances are managed in collections by their type. Servers can choose which of these interactions are made available and which resource types they support. Servers SHALL provide a Capability Statement that specifies which interactions and resources are supported.

In addition to a number of General Considerations this page defines the following interactions:

Instance Level Interactions

Conclusion

- **Evidence based guidelines** are the basis of global child health care
- **Clinical data** points derived from guidelines by clinicians serve as interoperable **terminologies**
- Care delivery is ‘translated’ into **digital language** as JSON
- FHIR enables semantic interoperability in health information exchange standards systems for **clinical and administrative content**
- A defined FHIR profile can be offered as **application programming interface** (API) to enable two or more computer programs to communicate with each other

Open Access FHIR RESTfull API Library

Mother and Child Health

- Growth & Development
- Conditions

Computable clinical guidelines

- Thalassemia
- Shwachman Diamond Syndrome

Immunizations

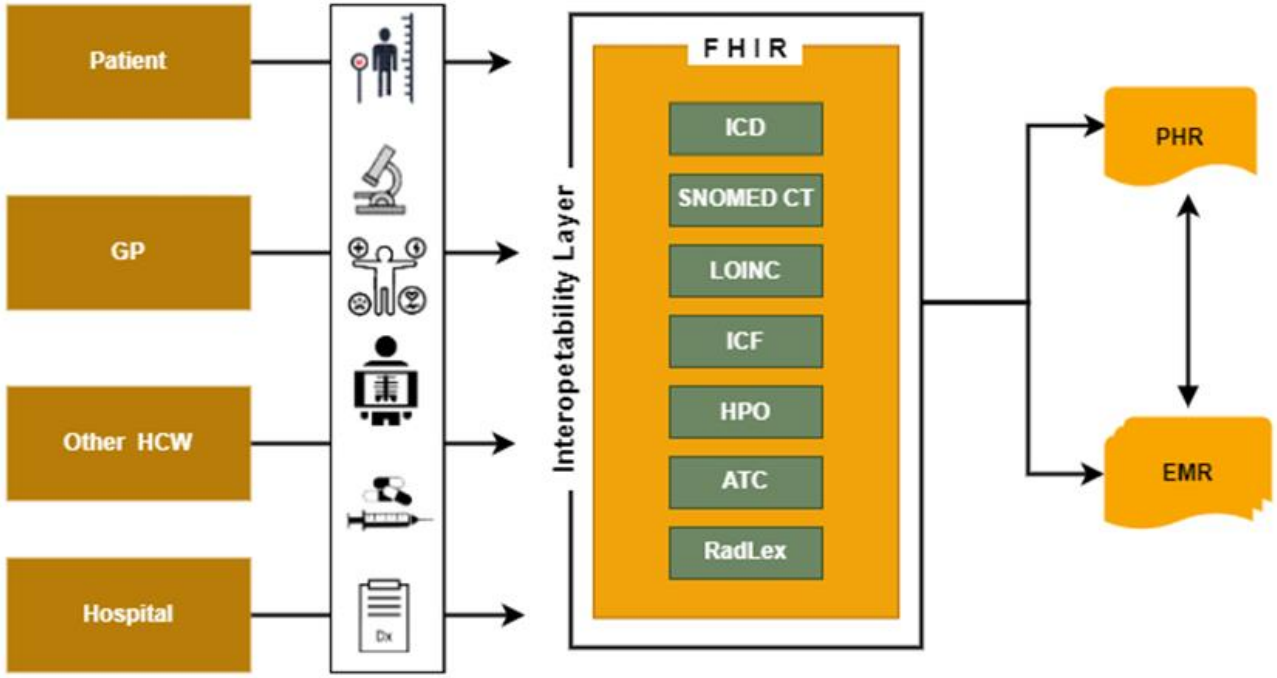
- Vaccination schemes

Social Support

- ICF
- ISO 9999

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 Reali 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



Author Figure S.D. Perera, University Colombo, Srilanka

national health authority

Ayushman Bharat Digital Mission
Building Digital Health Ecosystem

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For Citizens

Citizens or individuals can generate a unique health identifier called the Ayushman Bharat Health Account or ABHA and share their health records. Every individual can generate a unique health identifier called the Ayushman Bharat Health Account or ABHA. ABHA is a 14-digit number that uniquely identifies the citizen as a participant in India's digital healthcare ecosystem. ABHA allows individuals to link and share their health records.

Visit the link to learn more about an ABHA and its benefits to citizens: **https://abha.abdm.gov.in/register**

This section provides access to the IEC and capacity-building resources on ABHA to drive consistent communication and accelerate Ayushman Bharat Digital Mission (ABDM) adoption.

https://datafirst-ailater.health/home

Thank
- European Pediatric Rare Disease Network

John Dodge, U.K.
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David Neubauer, Slovenia
Arunas Valiulis, Lithuania
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Jola Wierzba, Poland
Jernej Zavrsnik, Slovenia

- Consensus in Pediatrics and Child Health

Manual Katz, Israel

- Forum Rare Diseases, Sri Lankan Pediatric Society

Anjan Bhattacharya, ICF expert India
Sahan Damsiri Perera, IT Expert, Sri Lanka
Marc de Graauw, IT Expert, Netherlands
Martin Postma, IT Expert, Netherlands

- People with a rare condition and their families

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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Stichting Shwachman syndroom Support Holland