

A SEMANTIC INFORMATION STANDARD FOR GLOBAL CHILD HEALTH

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Introduction

The United Nations Sustainable Development Goals (SDG) “ensure healthy lives and promote well-being for all ages”. - To meet the challenge of sustainable healthcare, communication and cooperation between all involved in child health should be supported. - Information systems, providing interoperability between public health, medical- and social care, generate data to improve health. - To establish a semantic interoperable child health record, efficient management and publishing of terminologies is a precondition.

Methods

A core set of terminologies was identified:
 -ICPC International Classification of Primary Care
 -HPO Human Phenotype Ontology
 -LOINC Standard for identifying health measurements, observations, and documents

- ICD International Classification of Diseases
- ORPHAnet Classification of rare diseases
- OMIM Catalog of Human Genes and Genetic Disorders
- ATC Anatomical Therapeutic Chemical Classification System
- SNOMED Clinical health terminology
- ICF International Classification of Functioning, Disability and Health

Some terminologies are already connected (ORPHAnet, OMIM, HPO), others (LOINC, ICF, ATC) need to be aligned to complete the health record. Recognizable features, diagnostics, therapies, and disabilities of six chronic diseases were aligned with the terminologies to demonstrate the feasibility of a universal child health record (figure, Unified Modeling Language).

of Thalassaemia, Sickle Cell Disease, Fibrodysplasia Ossificans Progressiva, Goldenhar-, Treacher Collins- and Shwachman Diamond syndrome.

The ICPC, HPO and LOINC are useful as a diagnostic tool. After diagnosis, disease modules aligned with OMIM, ORPHAnet, ICD, LOINC, ATC and ICF could simplify the care for children with complex and disabling conditions. A tight integration of all terminologies for these conditions is possible and yields a promising model for earlier recognition and better care. <https://rarecare.world/>

Conclusion

One integral international e-health concept based on common terminologies could help to work towards universal integrated child health care, including the disabled child. Thus generating data to follow up on the SDG targets.

Results

A sub-set of terminologies was connected with medical guidelines

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Figure Unified Modeling Language

