Thalassemia, world wide

The times they are a-changing' Bob Dylan 1964

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Building the Rare Disease knowledge and information ecosystem through better connections
A vision for equity and optimised care globally to people living with a rare disease locally

Worldwide more persons are diagnosed with a rare condition.

International medical prevention and treatment guidelines ensure a common practice.

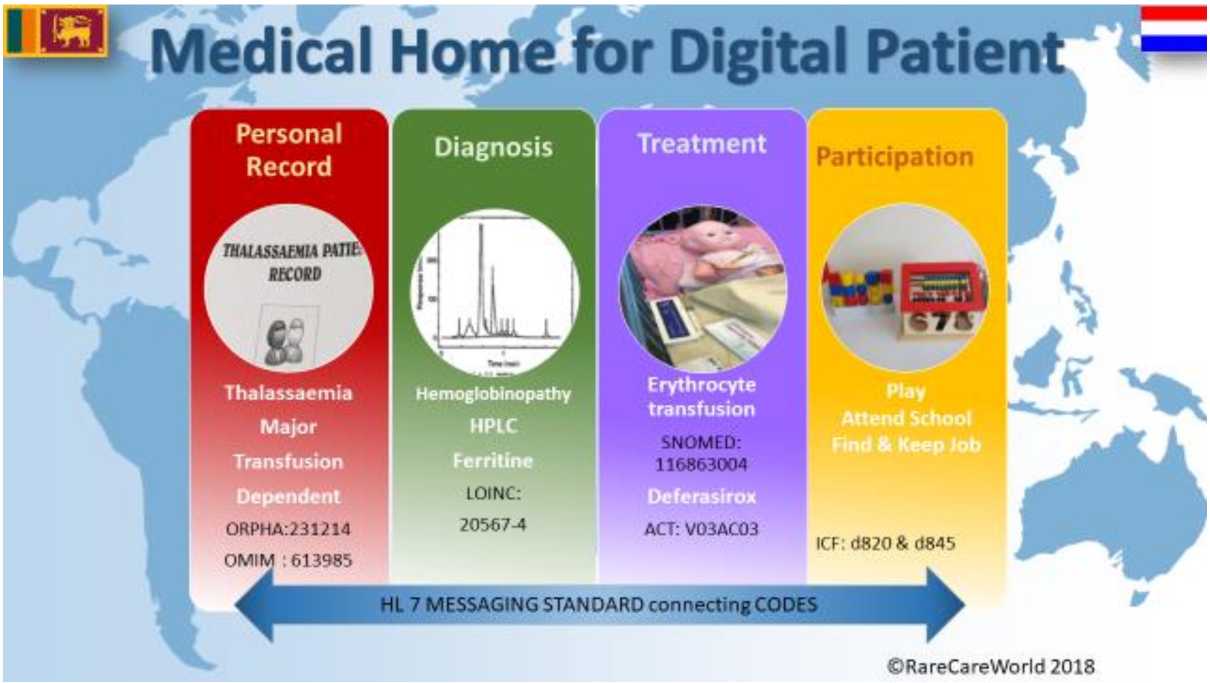
Medical and social care are often regarded as separate financial and organizational entities.

The need of a universal framework for holistic care is warranted more urgently.

The use of international classification and standards help surveying measures to overcome health and social disparities.

Individuals with a rare condition wish to be healthy and enjoy a worthy place in society.

Thalassemia is an inherited blood disorder caused by mutated globin genes which encodes for haemoglobin. Dutch patient organizations collaborated with thalassemia experts in Sri Lanka to build elements for one universal interoperable management model:



In Sri Lanka, patients and families hold their personal records as original documents and written files.
In The Netherlands patient data are locked into numerous vendor and health provider dependent IT systems.
Governmental recommendation on Data Interchange Standards are similar in both states.

http://www.health.gov.lk/enWeb/publication/NeGS_v_1.pdf
https://www.medmij.nl/informatiestandaarden/

Poster ECRD Vienna, May 2018