

Voucher project “ Strengthen the Voice of the Patient”

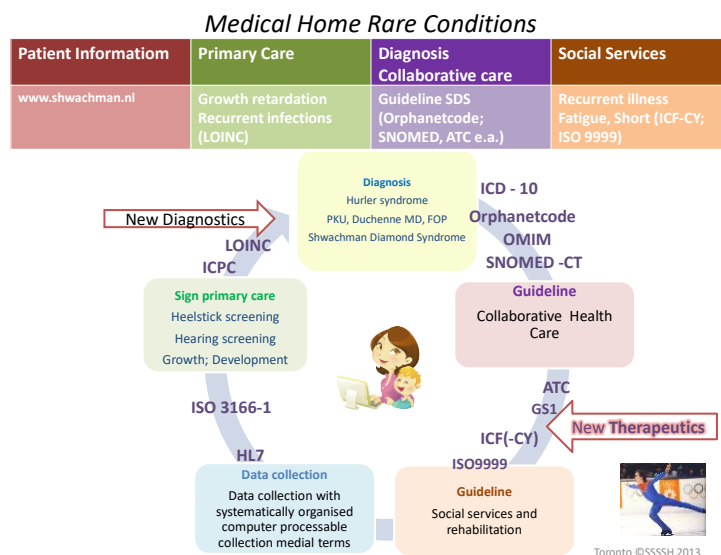
Het voucher project “Versterken Stem van de Patiënt”

Collaborating patient organizations, representing individuals with a rare condition and their families, have taken the initiative to foresee in a web- based portal bringing together information on early recognition, medical care and social support.

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Rare conditions are often a combination of by itself not so rare congenital anomalies or diseases presenting at different ages. Sometimes characteristic features are present but unrecognized. Once a diagnosis is established, different specialist need to collaborate and with primary care providers, the patients and their families.

Health and Internet Technology is the key to a medical home, as a network of health care providers and services sharing information with patients and families regardless of location. Still most patient data are locked in IT systems and there is little harmonization of interoperable data exchange. Regardless of the nature of the condition, for each disease set international codes can be aligned to record features, diagnosis and diagnostics as well as therapies and social services.



‘The voice of the patient’

Individuals with a rare condition do not regard themselves as patients. They are persons with common needs, and wish to be common. To learn, to participate, to speak for themselves. Seven diseases will serve as the example on how these conditions can fit in one ‘ medical home ’ or chronic care model: care close by home when possible, specialist care when needed and self- management when wanted.

Thanking initiating patient organizations, partner in project S06500 and project partners in ‘ Vroegsignaleren’



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