

Patient Perspectives in the LightCure Project



16TH NOV 2024 | LIVERPOOL | FAMILY CONFERENCE

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Funded by the European Union
LightCure - 101080327



Rare Chronic Diseases

Impact on daily life of **Individuals** and Caregivers

Changes in daily life and future plans



Experienced restrictions/limitations



Burdens due to increased care



Stigmatization (impairs self-esteem)



Increased risk of mental disorders and behavioral problems



Rare Chronic Diseases

Impact on daily life of Individuals and **Caregivers**

Diagnosis
shock



Helplessness and
excessive demands,
farewell to the
"perfect" child



Need to make
decisions



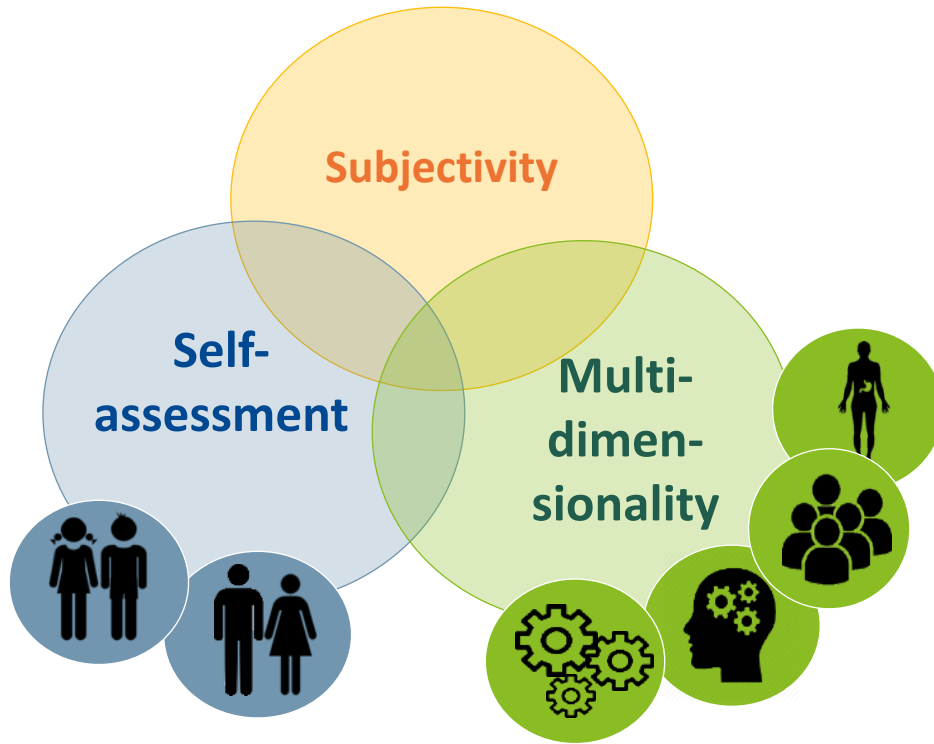
Intensive
(medical) care/
responsibility



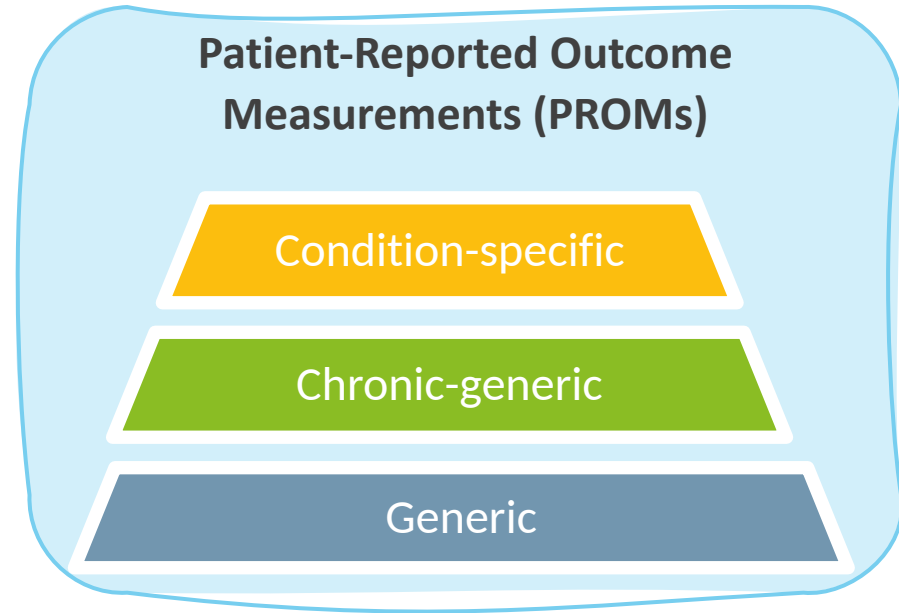
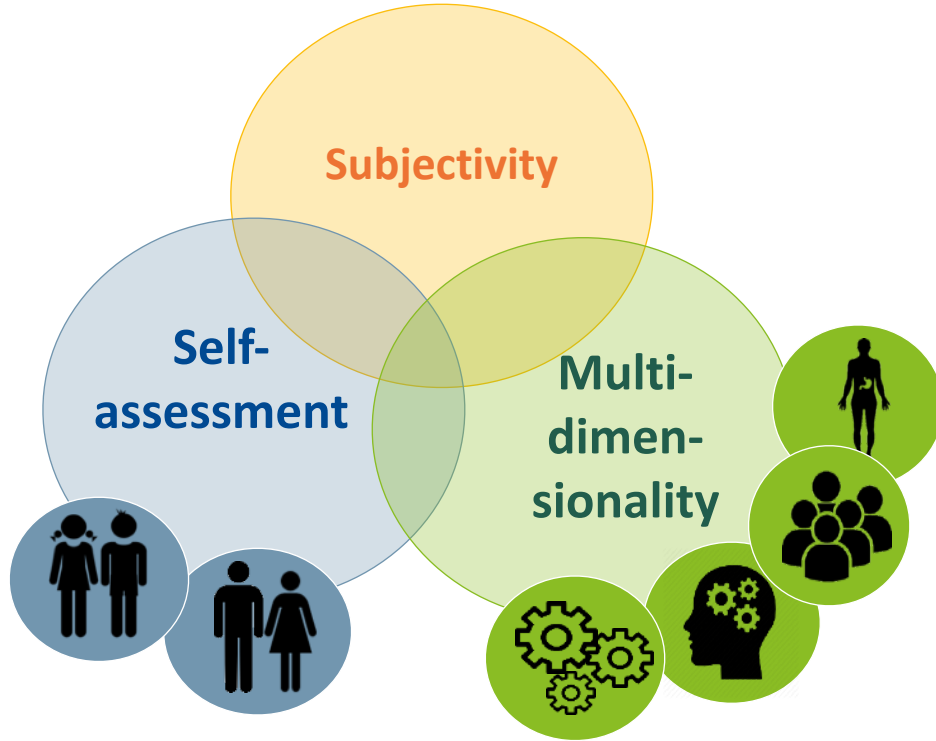
Changes of
future plans



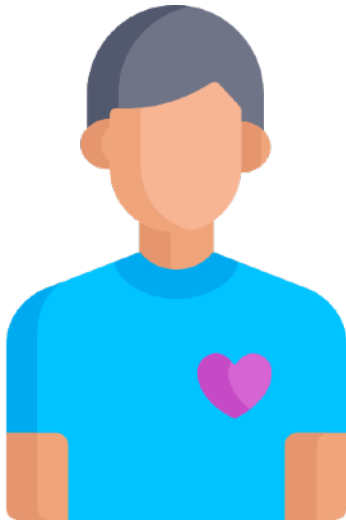
Health-related Quality of Life (HrQoL)



Health-related Quality of Life (HrQoL)



LightCure: Inclusion of the Patient Perspectives



Task 1: Development and validation of a **condition-specific PROM** to measure HrQoL in patients with CHI



Task 2: Shared decision-making (tools for individuals and families, information for professionals)



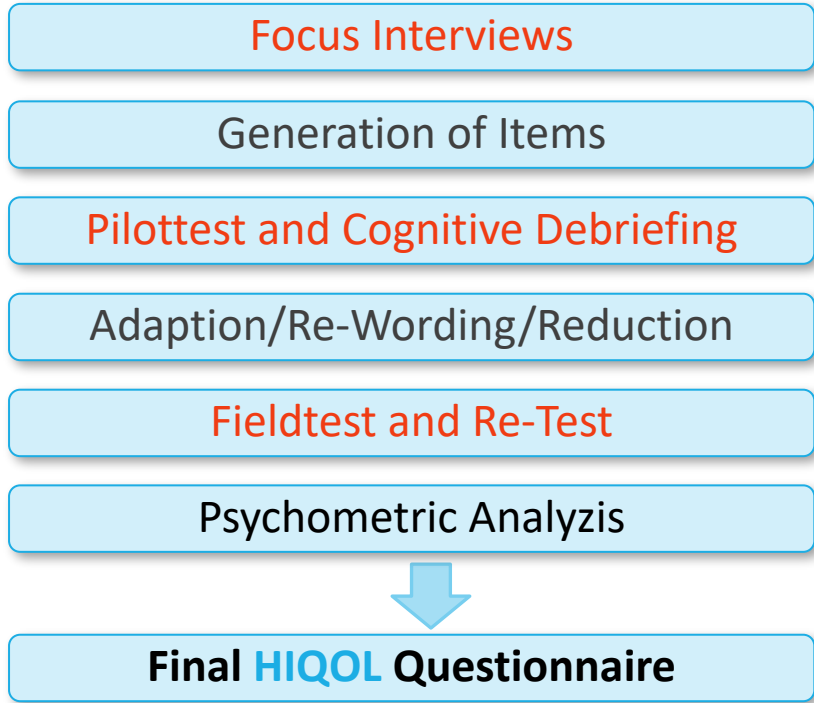
Aim: Improving Person-Centered Care



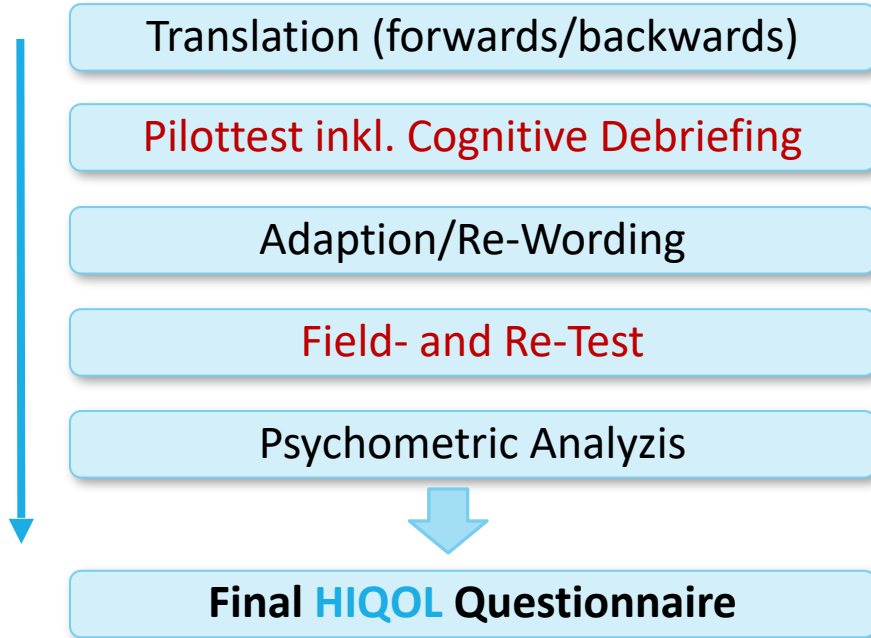
Task 1: Development and Validation of a condition-specific PROM to assess HrQoL | **HyperInsulinism Quality Of Life (HIQOL)**



Individuals with CHI aged 0-99 years and parents of
Individuals with CHI aged 0-26 years

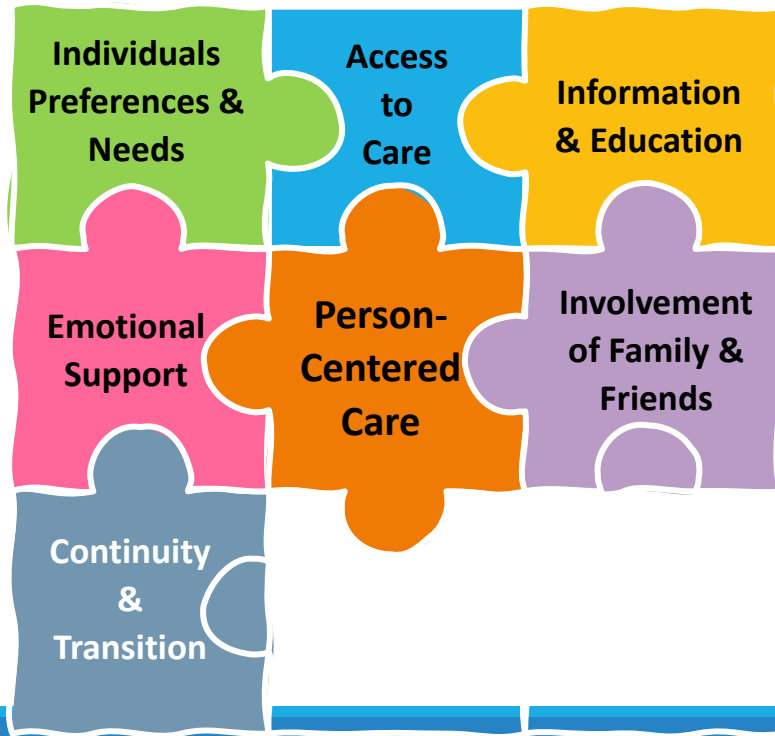


Task 1b: Validation for further countries/language HIQOL



Task 2: Development of a Material for Shared Decision-Making

Collaborative Hyperinsulinism Options for Informed Clinical Engagement - CHOICE



- Assessment of experiences, preferences & needs (individuals, parents and healthcare providers)
- Development of training programs for healthcare providers (e.g., e-learning modules)
- Development of person-centered information for shared decision-making (e.g., videos, brochures)





Your voice is
important!

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Scan me!

