

The use of patient reported outcomes in the structure of national quality registries in Sweden for children and adolescents with chronic conditions

How children and young individuals with chronic conditions experience their health and everyday life has not been followed structurally in national quality registry compare to medical outcomes. Until today there has not been any patient reported outcome measures within the national quality registries. Therefore, this project aims to describe and test patient reported outcome measures with focus on health-related quality of life for children and young individuals who has some kind of chronic condition. The first question is which instrument should be used, which is examined in the first two studies. A generic health-related quality of life instrument called DISABKIDS has been chosen and has been evolved into a patient reporting module, which facilitates the ability to answer prior to the visit. The questionnaire is for children from 8 years old. The two last studies will be focused on how to use DISABKIDS questionnaire as a base to discuss health-related issues during the patient encounter. To use the structure of national quality registries offers a unique opportunity to follow the health of children and young individuals during their transition to adulthood and how their lives are affected by their disease.

Project time span

2011 - 2016

Funding

Futurum – akademien för hälsa och vård, Region Jönköpings län

Project Leader

Professor Karin Enskär, karin.enskar@ju.se

For more information, contact:

Christina Peterson, christina.peterson@ju.se