Netherlands CP register for children with cerebral palsy: an innovative model for personalized care with patient participation

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Introduction

Much is still unknown about the optimal treatment in children with cerebral palsy. With the innovative Netherlands CP register, initiated in 2016 and set up in ten pilot centers, we combine a follow up register/program and a treatment register. We collect data from practitioners and children with CP and their parents.

OBJECTIVES:
1) Prevention of secondary problems of CP
2) Personalized care
3) Meaningful care

Patient participation

• Panel of patients/parents: a consultation group for the focus of the register
• Patient Reported Outcome Measures (PROMs) for monitoring and evaluation of treatments: PEDI-CAT, a computer adapted testing questionnaire for the assessment of daily functioning CPCHILD for the assessment of quality of life SDQ for screening of psychosocial problems
• Active participant in care: shared goal setting & providing feedback through a portal

Conclusions:

The Netherlands CP register is an innovative model of a follow up register/program and treatment register. The register has been developed in a unique collaboration between children with CP, their parents, researchers and health care professionals. Patient participation was integrated from the start of the project. PROMs are used in making treatment decisions and for evaluation of treatment.