Development and testing of a health related quality of life instrument for non-ambulatory adults with severe disabilities

Gepubliceerd: 24-01-2018 Laatst bijgewerkt: 13-12-2022

The CPCHILD-18+ is sufficiently tested for its psycometric characteristics to be used in clinical practice and research

Ethische beoordeling	Niet van toepassing
Status	Werving nog niet gestart
Type aandoening	-
Onderzoekstype	Observationeel onderzoek, zonder invasieve metingen

Samenvatting

ID

NL-OMON21614

Bron
NTR

Verkorte titel
CPCHILD-18+

Aandoening

health related quality of life of non-ambulatory adults with severe disabilities e.g. cerebral palsy

Ondersteuning

Primaire sponsor: RUG
Overige ondersteuning: applications for funding underway for second phase of the study

Onderzoeksproduct en/of interventie

Uitkomstmaten

Primaire uitkomstmaten

Scores of the health-related quality of life instrument that is tested for its psychometric evaluation

Toelichting onderzoek

Achtergrond van het onderzoek

Rationale: Because of a higher life expectancy of non-ambulatory children with severe disabilities there is a growing need for an adult-specific Health related quality of life-measure

Objective:

Objective 1. Assess the face and content validity of the CPCHILD-18+: Evaluate the suitability of the items of the CPCHILD-DV for use with non-ambulatory adults in a Dutch population, to establish the elimination, modification, or retention of each item and addition of new items (content adaptations) for the CPCHILD-18+; Assess the sensibility of the CPCHILD-18+, namely its comprehensibility, clarity of instruction, suitability of the response scale, and ease of usage in a Dutch population.

Objective 2. Assess the test-retest reliability, internal consistency and known groups-validity of the CPCHILD-18+ in a Dutch population.

Study design: a cross-sectional study

Study population: Direct support persons and/or parents of non-ambulatory adults with severe disabilities.

Doel van het onderzoek

The CPCHILD-18+ is sufficiently tested for its psycometric characteristics to be used in clinical practice and research

Onderzoeksopzet

not applicable

Onderzoeksproduct en/of interventie

not applicable

Contactpersonen

Publiek

T. Zalmstra
Teugestraat 9

Amsterdam 1107 SB
The Netherlands

Wetenschappelijk

T. Zalmstra
Teugestraat 9

Amsterdam 1107 SB
The Netherlands

Deelname eisen

Belangrijkste voorwaarden om deel te mogen nemen (Inclusiecriteria)

Adult primary caregiver (parent or direct support person) of a person:

• with severe disabilities e.g. cerebral palsy, syndromes, profound intellectual and multiple disabilities (

• age from 18 years up

• non-ambulatory (GMFCS level IV or V)

for at least the last six months. The caregiver has to have sufficient understanding of the written Dutch language.

Belangrijkste redenen om niet deel te kunnen nemen (Exclusiecriteria)

Exclusion criteria includes the presence of a progressive neurological disorder or severe concurrent illness or disease in the non-ambulatory adult, not typically associated with the

underlying disability

Onderzoeksopzet

Opzet

Type:	Observationeel onderzoek, zonder invasieve metingen
Onderzoeksmodel:	Anders
Blindering:	Open / niet geblindeerd
Controle:	N.v.t. / onbekend

Deelname

Nederland

Status:	Werving nog niet gestart
(Verwachte) startdatum:	01-02-2018
Aantal proefpersonen:	50
Type:	Verwachte startdatum

Ethische beoordeling

Niet van toepassing

Soort:	Niet van toepassing

Registraties

Opgevolgd door onderstaande (mogelijk meer actuele) registratie

Geen registraties gevonden.

Andere (mogelijk minder actuele) registraties in dit register

Geen registraties gevonden.

In overige registers

Register	ID
NTR-new	NL6576
NTR-old	NTR6962
Ander register	UMCG Research Register : 201700844

Resultaten