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

No registrations found.

Ethical review	Not applicable
Status	Pending
Health condition type	-
Study type	Observational non invasive

Summary

ID

NL-OMON21614

Source
NTR

Brief title
CPCHILD-18+

Health condition

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

Sponsors and support

Primary sponsor: RUG
Source(s) of monetary or material Support: applications for funding underway for second phase of the study

Intervention

Outcome measures

Primary outcome

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

Secondary outcome

not applicable

Study description

Background summary

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.

Study objective

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

Study design

not applicable

Intervention

not applicable

Contacts

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Eligibility criteria

Inclusion criteria

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.

Exclusion criteria

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

Study design

Design

Study type:	Observational non invasive
Intervention model:	Other
Masking:	Open (masking not used)
Control:	N/A , unknown

Recruitment

NL

Recruitment status:	Pending
Start date (anticipated):	01-02-2018
Enrollment:	50
Type:	Anticipated

Ethics review

Not applicable

Application type:	Not applicable

Study registrations

Followed up by the following (possibly more current) registration

No registrations found.

Other (possibly less up-to-date) registrations in this register

No registrations found.

In other registers

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

Study results