



Sophia
REVALIDATIE

Participate?!

study of 4-25 years old ABI patients & their families

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Pediatric acquired brain injury (ABI)



Sophia
REVALIDATIE

Past research: persistent and long term restrictions in participation [de Kloet]

Factors consistently found to be associated with **more** participation restrictions were:

- greater severity of ABI
- impaired motor, cognitive, behavioural and/or sensory functioning
- limited accessibility of the physical environment
- worse family functioning

Pediatric ABI (2)

Fewer participation problems were associated with:

- a supportive/nurturing parenting style
- higher household income
- acceptance and support in the community
- availability of special programmes



Aim



- To better match rehabilitation treatment for ABI youth with demands / development of child and family
- Combine research and healthcare
- Implement relevant outcome measures & medical-neurological standard assessment (PSOM-SNE)

T0 → **T1** (12 mo later) → **T2** (24 mo later)

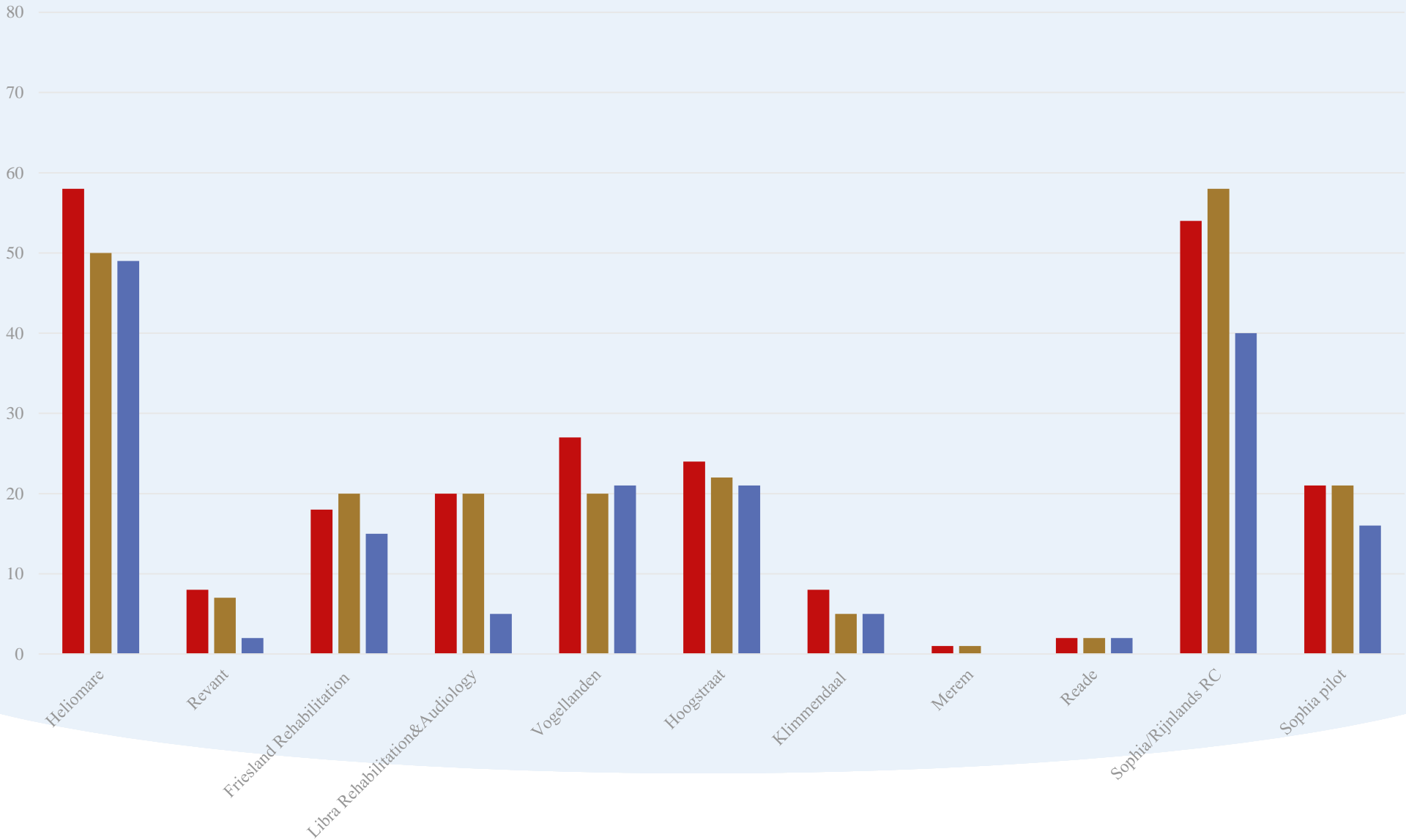
Multi center study



Sponsored by



Inclusion as of June 2018



Methods



- pilot of a larger, prospective, observational study
- youth (14-25 yrs) referred to rehab with ABI diagnosis
- online questionnaires: youth & parent version
 - PedsQL Core Set
 - PedsQL Multidimensional Fatigue Scale
 - PedsQL Family Impact Module
 - CASP, CAFI, CASE
- medical neurological screening
- PIF during 1st consult

Sneak preview of first results



Pilot & T0 Sophia Revalidatie

	Total group n=65	TBI= 46	NTBI=19	
Sex, male, nr (%)	32 (49%)	21 (46%)	11 (58%)	p=0.37
Age at injury, years; mean (SD)	15.7 (5.3)	16.7 (4.1)	13.1 (6.8)	p= 0.01 *
Time since injury, years; mean (SD)	2.5 (4.2)	1.6 (2.9)	4.9 (5.9)	p< 0.01 *
Current age, years; mean (SD)	18.2 (2.7)	18.3 (2.8)	18.0 (2.6)	p=0.68

Youth with TBI and their parents median (interquartile range)

	Youth	Parents	
PedsQL 4.0 General Core Scales	60.9 (44.6, 78.0)	61.4 (46.7, 75.3)	p=0.10
PedsQL MFS	44.4 (33.7, 56.9)	47.9 (37.2, 63.9)	p=0.38
CASP Total Score	80.5 (67.2, 93.1)	90.4 (79.9, 97.3)	p<0.01
PedsQL FIM		72.9 (62.5, 83.2)	

Youth with NTBI and their parents

	Youth	Parents	
PedsQL 4.0 General Core Scales	67.4 (55.7, 79.1)	65.3 (48.9, 78.8)	p=0.93
PedsQL MFS	53.5 (31.6, 63.9)	44.4 (27.8, 65.3)	p=0.38
CASP Total Score	86.4 (71.8, 92.1))	91.1 (80.2, 96.9)	p=0.85
PedsQL FIM		61.8 (51,4, 87,2)	

Future analyses

- Exploring relationships between participation, fatigue and QoL
- Comparing data to earlier hospital cohort



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