



# On Your Own Feet

**Research Project For & With Adolescents with Chronic Conditions**  
**Short General Introduction**

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transition of adolescents with chronic conditions from pediatric care to adult care: one of the biggest challenges for pediatrics




# On Your Own Feet

- large practice-based academic project: mixed methods research
- setting: biggest children’s hospital in Netherlands
- active involvement and participation of youth, nurses and healthcare providers
- continuation with a national implementation programme to improve current adolescent care




[www.oepenbenen.NU](http://www.oepenbenen.NU)

**Aim:** to explore preferences and competencies for self-care in order to improve preparation of adolescents with chronic disorders for transition to adulthood & to adult services


**Methods:**  
 mixed methods design: extensive qualitative research in two phases followed by web-based survey among youth and parents

## qualitative research: methods (phase I)




**phase I:**  
**youth’s world**

- interviews with 31 youth at home (nursing students as co-researchers)
- Q-methodology
- youth as co-researchers: disco-party: 34 interviews with peers (fellow patients)




## qualitative research: methods phase II



**phase II:**  
**professionals’ world**

- 30 observations of 39 consultations with youth / parents (nurse specialists as co-researchers)
- 3 focus group discussions with 27 healthcare professionals (doctors, nurses, paramedics)



## quantitative research: methods



### web-based survey

#### youth with chronic conditions / parents

- general questions
- health-related quality of life (Kidscreen)
- impact disease (Disabkids)
- preferences for healthcare (incl. Q-study)
- competencies for healthcare / self-efficacy

1039 youth (response rate 29%)

778 parents (response rate 21%)



### Four papers

13th Research Conference of the  
Workgroup of European Nurse Researchers (WENR)  
Vienna 2008

1. Quality of Life of Adolescents With Chronic Disorders: An Optimistic View
2. From Spectator to Principal Character: Adolescents with Chronic Conditions in Medical and Nursing Consultations
3. Identifying Adolescents with Chronic Disorders at Risk for Self-management Failure: Care-Related Preference Profiles and their Contribution
4. Participatory Research: Adolescents with Chronic Disorders Interviewing Fellow Patients About Health Care Preferences