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CONFERENCE ABSTRACT

# Healthcare quality for people with Down Syndrome: the patient perspective

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Francine A. van den Driessen Mareeuw[1,2], Antonia M.W. Coppus[3,4], Diana M.J. Delnoij[1,5], Esther de Vries[1,2]

1: Tilburg University, The Netherlands;
2: Jeroen Bosch Hospital, The Netherlands;
3: Dichterbij, The Netherlands;
4: Radboud University Medical Center, The Netherlands;
5: National Health Care Institute, The Netherlands

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**Introduction**: Down Syndrome (DS) is the most prevalent chromosomal anomaly among people with intellectual disability. Because DS is associated with a large variety of chronic comorbidities, people with DS need lifelong healthcare with many different professionals involved. In the past decades, many DS-specialized healthcare initiatives have been introduced. However, little is known about their quality, which hampers monitoring and improvement, and reduces transparency for people with DS and their parents.

Quality indicators (QIs) can provide insight into healthcare quality, unhide opportunities for improvement, and increase transparency. Our study aims to identify starting points for QIs by exploring how qualitative good healthcare contributes to a good life quality of people with DS, thereby answering the question how healthcare quality for this group with special healthcare needs can be measured best. Healthcare quality is increasingly described in terms of outcomes adding value for patients. Our current study focuses on adding value for patients by exploring the patient perspective on healthcare quality for people with DS. This is done by involving people with DS and their parents/family members. Their professional carers (in case of residential care) will be involved later, because they also play an important role in the lives of people with DS.

**Methods**: The study has a qualitative design including semi-structured individual interviews with people with DS (n=18) and parents (n=15). Topics discussed during the interviews included experiences with received healthcare, influence on life quality and healthcare improvement.

**Results**: According to interviewed people with DS (^) and parents (*):

Healthcare quality is:

Patient-centered care: Optimal functioning of the person with DS is central*; Taking context and life stage of the person with DS into account^*; Respectful doctor-patient communication adapted to the abilities of the person with DS^*.

Effective, efficient and accessible care: Care providers with DS-expertise nearby^*; Information about available care*.

Multidisciplinary care including actors outside healthcare (e.g. school, work) and good coordination and integration*: Information sharing (between providers); Synchronized planning of consultations.

Healthcare largely contributes to wellbeing^*.

In the Netherlands, healthcare to people with DS is quite good, although transition from paediatric to adult care needs improvements^*. Parents experience more problems with finding appropriate developmental/social support*.

**Discussion**: To our knowledge, this is the first research project developing QIs for DS healthcare, and the first involving patients and their carers. By focusing on the patient perspective we expect to develop QIs which enable healthcare improvements that are truly relevant to people with DS, add value to their lives, and enhance efficiency within the healthcare system.

**Conclusion**: The issues mentioned by people with DS and parents (above) will be used as starting point for the development of QIs measuring healthcare quality for people with DS.

**Lessons learned**: Involving people with DS by interviewing them is challenging but worthwhile.

**Limitations**: Interviewing people with DS may influence the validity of our findings. However, we minimised this influence by adapting the interviews to the abilities of the interviewees.

**Suggestions for future research**: A next step should be to involve care providers.

**Keywords:** healthcare quality; patient perspective; indicators; down syndrome; multidisciplinary care