



## **dsd-LIFE ABSTRACT FOR THE GENERAL PUBLIC**

### **Title**

**Quality of life in adults with disorders/differences of sex development (DSD) compared to country specific reference populations**

### **Authors**

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### **What did we want to know?**

People with disorders/differences of sex development (DSD) have health problems and chronic physical and mental diseases both related or unrelated to the specific DSD diagnosis. The update of the Consensus Statement endorsed quality of life (QOL) as a major outcome in health care with the objective to reach the best possible quality of life for everybody. Previous studies on QOL in people with DSD have been restricted to subpopulations of the condition or single centre reports and were often lacking comparison to people without DSD or other chronic health conditions. We describe QOL in adult persons with DSD compared to country specific references and assess the impact of the diagnosis itself on QOL.

### **What is quality of life (QOL)?**

QOL is a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of one's own life. The World Health Organisation defined QOL as 'an individual's perception of their position in life in context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns.'

### **What did we do?**

We initiated a study in 14 European medical centers (in France, Germany Poland, the Netherlands, United Kingdom, and Sweden). We asked 1040 persons (717 identifying as females, 311 identifying as males, and 12 persons identifying with another gender) with medically confirmed diagnoses about their QOL using the WHOQOL-BREF with its domains 'physical health, psychological, social relationships and environment. Then we compared our study participants to the general population and comparisons between diagnoses groups.

### **What were the main results?**

The WHOQOL-BREF can be used as a QOL measurement in all people with DSD. QOL is only reduced in the domain of social relationships compared to healthy reference populations. Across all conditions, contemporary health status was highly associated with QOL. Often the health status is not directly related to the condition itself but indicates co-

morbidity and a high burden of disease. Surprisingly, the DSD diagnosis does not explain differences in QOL among the participants.

**What does that mean?**

Except for social relationships, most people with DSD adapt well to their life circumstances and report a good QOL. Not diagnosis, but the individual's health status is much more important than previously thought. Therefore care for people with DSD should focus more on chronic physical or mental health problems both related and unrelated to the diagnosis itself. This finding has major impact on the organization of care; individuals affected need both highly specializing medical care as well as a medical home comprehensively addressing all issues of health and collaborating with subspecialists.

Reference:

Rapp M, Mueller-Godeffroy E, Lee P, Roehle R, Kreukels BPC, Köhler B, Nordenström A, Bouvattier C, Thyen U; dsd-LIFE group. Multicentre cross-sectional clinical evaluation study about quality of life in adults with disorders/differences of sex development (DSD) compared to country specific reference populations (dsd-LIFE). *Health Qual Life Outcomes*. 2018 Apr 3;16(1):54. doi: 10.1186/s12955-018-0881-3.