



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

### **Participation of adults with disorders/differences of sex development (DSD) in the clinical study dsd-LIFE: design, methodology, recruitment, data quality and study population.**

#### **Authors**

Robert Röhle, Katharina Gehrmann, Maria Szarras-Czapnik, Hedi Claahsen-van der Grinten, Catherine Pienkowski, Claire Bouvattier, Peggy Cohen-Kettenis, Anna Nordenström, Ute Thyen, Birgit Köhler, on behalf of the dsd-LIFE group

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

Many persons with a diagnosis included in the medical umbrella term DSD (disorders/differences of sex development) receive medical treatments and face different health issues which might have an impact on their well-being. The aim of dsd-LIFE is to improve health care and well-being for persons with DSD conditions. The aim of this paper is to describe the method and participants of the study.

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

We collected information from 1040 persons with DSD conditions in 6 European countries (Germany, France, the Netherlands, Poland, Sweden and the UK) through an online questionnaire about their physical, psychological and sexual well-being, their experiences with the different medical treatments and health care. Moreover, data based on medical interview, physical exams and lab investigations were collected.

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

1040 persons with different DSD conditions with a mean age of 32.4 (+/- 13.6 years) participated in the study. 301 persons with Turner syndrome, 45 with 45,X0/46,XY conditions, 218 with Klinefelter syndrome, 1 with XYY chromosomes and 63 with XY gonadal dysgenesis, 71 with complete androgen insensitivity (CAIS), 35 with partial androgen insensitivity (PAIS), 20 with androgen synthesis impairments, 25 with severe hypospadias, 8 non-classified XY DSD conditions 226 with congenital adrenal hyperplasia (CAH), 21 with XX gonadal dysgenesis and 6 males with XX genes. Additionally, 121 XY male persons with CAH participated

#### **What does that mean ?**

Through the high number of participants, we will be, better than before, able to investigate the medical and psychosocial issues which are important for well-being and improvement of health care.

**Reference:**

Röhle R, Gehrman K, Szarras-Czapnik M, Claahsen-van der Grinten H, Pienkowski C, Bouvattier C, Cohen-Kettenis P, Nordenström A, Thyen U, Köhler B; dsd-LIFE group. Participation of adults with disorders/differences of sex development (DSD) in the clinical study dsd-LIFE: design, methodology, recruitment, data quality and study population. *BMC Endocr Disord.* 2017 Aug 18;17(1):52. doi: 10.1186/s12902-017-0198-y.