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

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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: