

Survey Title: Perception of DSD classification and DSD Care among DSD Patients, Parents/Carers and Patient Advocacy Groups

(for example Androgen insensitivity syndrome, Turner syndrome, Congenital adrenal hyperplasia, Klinefelter syndrome, Complete gonadal dysgenesis, Hypospadias etc.)

What is the purpose of this survey?

The Consensus statement on management of intersex disorders (A Hughes, C Houk, S F Ahmed, P A Lee, and LWPES1/ESPE2 Consensus Group (July 2006)), which includes a revised nomenclature and definition of DSD-related conditions, aims to improve the care of people with DSD. The important goal of this survey is to find out how people subsumed under the diagnosis DSD feel about the term “DSD”, if/how they identify with DSD, have personally experienced changes of socio-political attitudes and/or management and, ultimately, if a revision of the definition and/or nomenclature of DSD would be required.

What is the background of this survey?

Since the publication of the “Consensus statement on management of intersex disorders”, social movements by policy leaders and stakeholders for some DSD-related conditions have changed attitudes towards treatment, especially in relation to surgery. This has led to restrictions on surgery in some countries, dissatisfaction among individuals with DSD who are in favour of surgery and ultimately a social divide among persons with DSD. This situation poses new challenges for clinicians and patients.

What is Endo-ERN?

The European Reference Network on rare endocrine conditions (Endo-ERN) aims to improve access to high-quality healthcare for patients with hormonal disorders. Endocrine conditions are often complex and require lifelong care starting from early age. Endo-ERN aims to provide this care for patients throughout their entire lives and to reduce and ultimately abolish inequalities in care for patients with rare endocrine disorders in Europe, through facilitating knowledge sharing and facilitating related healthcare and research.

Who do we ask to complete this survey?

Patients with the conditions referred by the term DSD or their parents and carers, and related patient organizations.

Who is conducting this investigation?

The Main Thematic Group Sexual Maturation and Development Group within the Endo-ERN.

How will my answers be used?

The responses will be treated anonymously. They are intended to provide information for MTG 7 and other Endo-ERN members. Depending on feedback and evaluation, the benefits of further activities via Endo-ERN will be assessed.

The data in the EU-Survey tool will be stored in the European Commission's data centre for 12 months. Analysis of this data will be conducted by MTG7 researchers as representatives of their respective institutions in Endo-ERN. The data will be downloaded from the EU Survey tool for the purpose of analysis and stored in compliance with local server requirements. Following publication of the analysis and research the data will be stored in the institution of the primary researcher as archival data record for a minimum of 10 years. No identifying details will be stored.