

Current medical care of children and adolescents with disorders of sex development in Switzerland

Grit Sommer^{1,2}, Daniel Konrad³, Beatrice Kuhlmann⁴, Dagmar L' Allemand⁵, Franziska Phan-Hug⁶, Michael Hauschild⁷, Valerie Schwitzgebel⁸, Paolo Tonella⁹, Melanie Hess¹⁰, Urs Zumsteg¹⁰, Anna Lauber-Biason¹¹, Christa E. Flück²,
for the Working Group DSD of the Swiss Society for Pediatric Endocrinology and Diabetology (AG DSD SGPED)

¹Institute for Social and Preventive Medicine, University of Bern, Switzerland; ²Department of Pediatrics, Division of Pediatric Endocrinology, Diabetology and Metabolism, Inselspital Bern University Hospital, University of Bern, Switzerland; ³Division of Pediatric Endocrinology and Diabetology, University Children's Hospital, Zurich, Switzerland; ⁴Department for Children and Adolescents, Kantonsspital Aarau, Aarau, Switzerland; ⁵Department of Endocrinology, Children's Hospital of Eastern Switzerland, St Gallen, Switzerland; ⁶Ensemble Hospitalier de la Côte, Hospital of Morges, Switzerland; ⁷Pediatric Endocrinology, Diabetology and Obesity Unit, Lausanne University Hospital, Lausanne, Switzerland; ⁸Pediatric Endocrine and Diabetes Unit, Department of Pediatrics, University Hospitals of Geneva, Geneva, Switzerland; ⁹Division of Pediatric Endocrinology and Diabetology, Cantonal Hospital of Lucerne, Children's Hospital, Lucerne, Switzerland; ¹⁰Division of Pediatric Endocrinology and Diabetology, Department of Pediatrics, University of Basel Children's Hospital, Basel, Switzerland; ¹¹University of Fribourg, Division of Endocrinology, Fribourg, Switzerland.

Introduction and objectives

In Switzerland, persons with DSD asked for better care. It is unclear how many persons are diagnosed with DSD each year in Switzerland and whether medical care meets current international guidelines for DSD.

We aimed to estimate how many children and adolescents have a DSD diagnosis according to Chicago consensus [1] and to describe the current medical care of DSD.

Methods

In Fall 2017, we sent a questionnaire to pediatric endocrinologists of 8 Swiss children's hospitals asking them:

- To estimate numbers of treated DSD patients
- To indicate specialists involved in DSD care and
- To report research activities.

Results

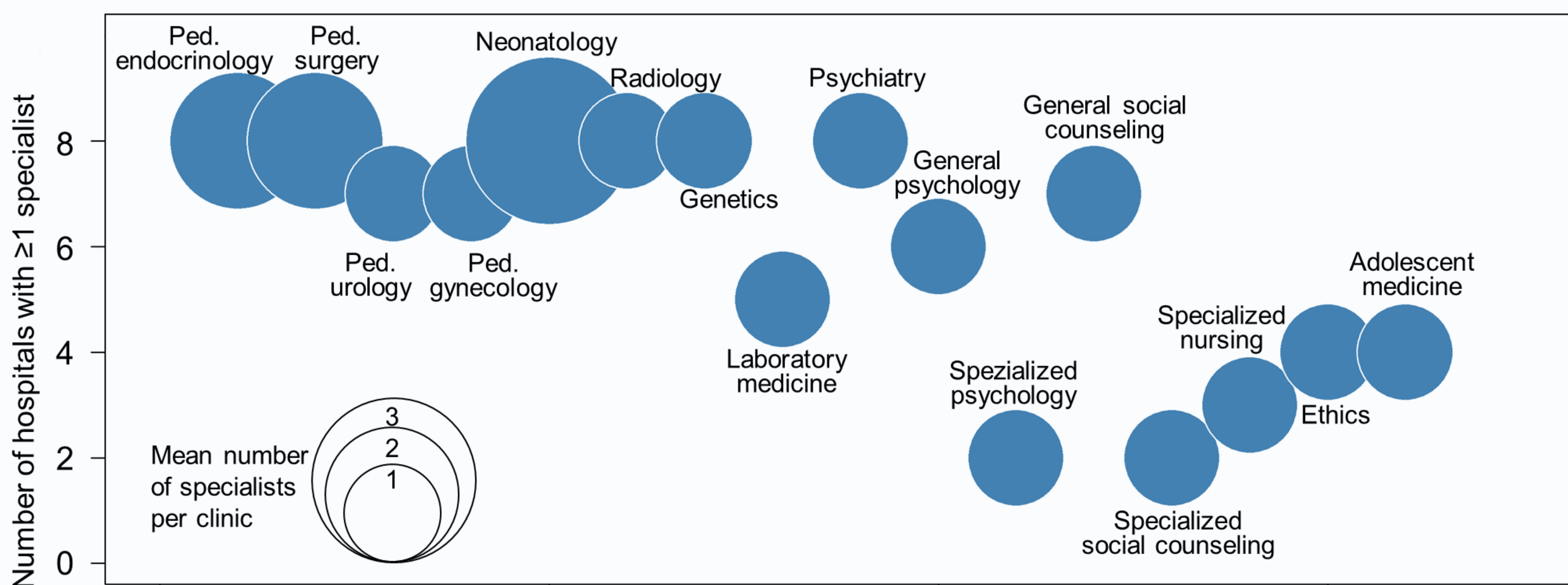
The 8 children's hospitals cover >85% of newborns in Switzerland and treat ~750 children with DSD (Table 1). Each year, ~24 newborns and 24 patients aged 1-17 years were diagnosed with complex DSD (ambiguous genitalia).

Most hospitals used international guidelines [2] and had interdisciplinary DSD teams (Fig.1). Transition to adult medicine was between 16-25 years, but adult physicians specialized on DSD were lacking. All hospitals participate in the new Swiss DSD cohort study.

Table 1: Estimated number of children with DSD [1], aged <17 years and treated in 8 participating children's hospitals.

	N	N per clinic (mean)	Range
Total DSD diagnoses	748	94	23-200
Complex DSD	90	11	3-23
Congenital adrenal hyperplasia	127	16	4-35
Ullrich-Turner Syndrome	134	17	9-35
Other DSD diagnoses, incl. Klinefelter Syndrome	397	50	0-174

Fig.1: Number of specialists per medical speciality in 8 participating children's hospitals.



Conclusion

Incidence and prevalence of DSD are unknown in Switzerland. Most children's hospitals had established interdisciplinary DSD teams, which treat children with DSD and their families according to international guidelines, but specialized DSD psychologists and adult DSD specialists were lacking. The new Swiss DSD cohort study will allow to assess reliable data of DSD, facilitate communication among physicians and with advocacy groups, and provide a basis for research.

References:

- [1] Hughes, IA *et al.*, Consensus statement on management of intersex disorders. Arch Dis Child, 2006.
[2] Ahmed, SF *et al.*, UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development. Clin Endocrinol (Oxf), 2011.

Contact: Grit Sommer, grit.sommer@dbmr.unibe.ch

Funding: Swiss Society for Endocrinology and Diabetology (SGED) and Boveri Foundation, Zurich