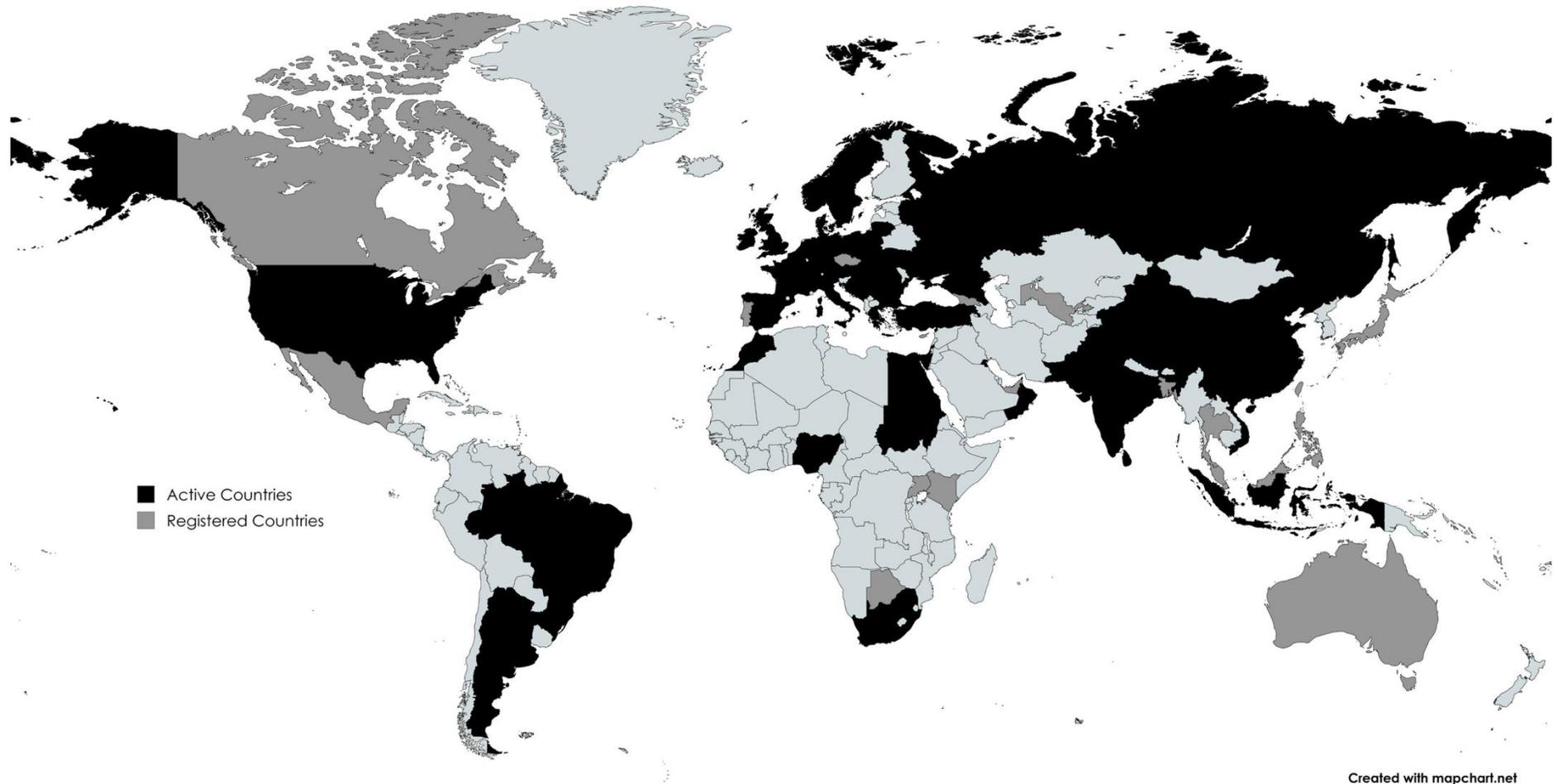


## Activity Report June 2025



## Wide reach for *SDMregistries* events, education & newsletters

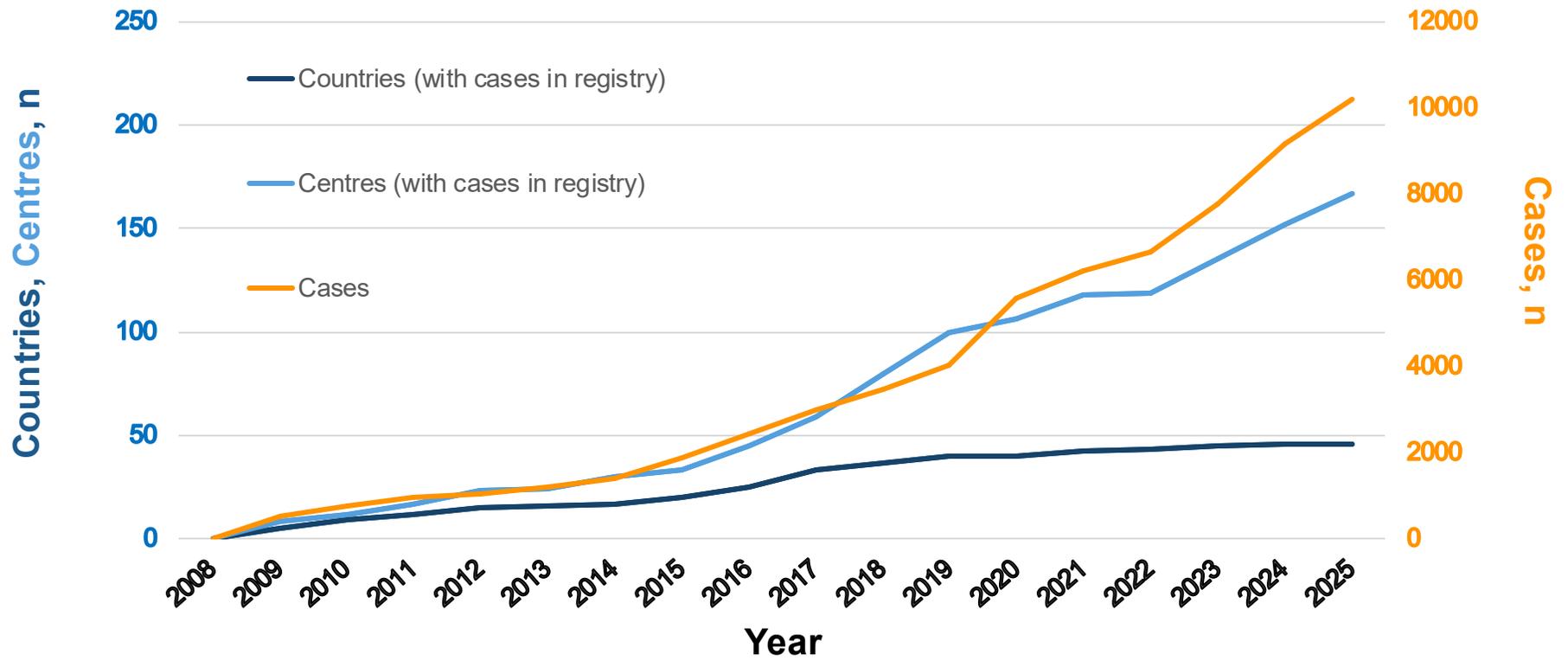


**June 2025 – 10,179 cases**  
**167 centres from 46 countries with cases**  
**Additional 72 centres from 37 countries in dissemination list**

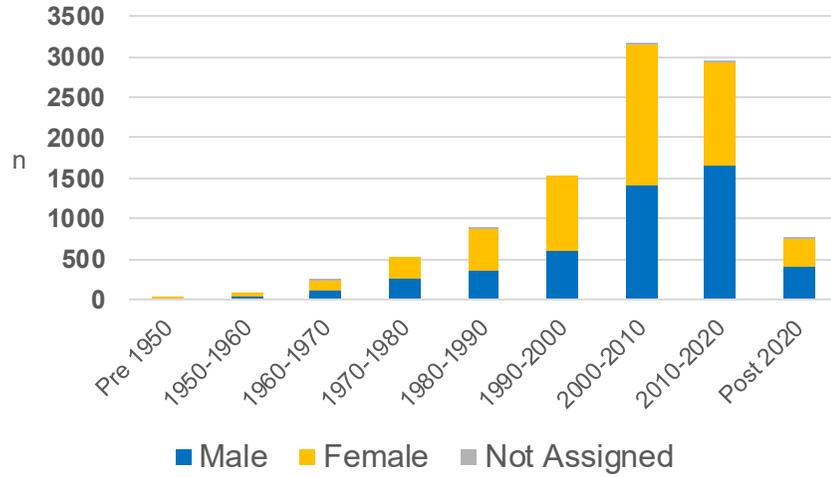
**Newborn to 98 yrs**  
**Median Age – 19 yrs**

**Approved by ethics to store routinely collected clinical data following informed consent**

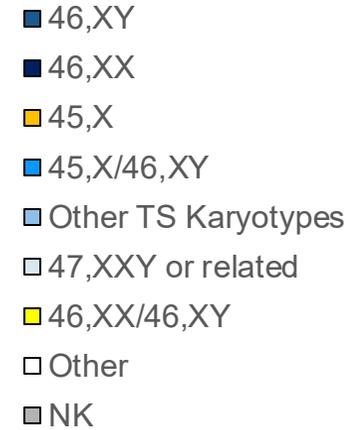
## Countries, Centres & Patients



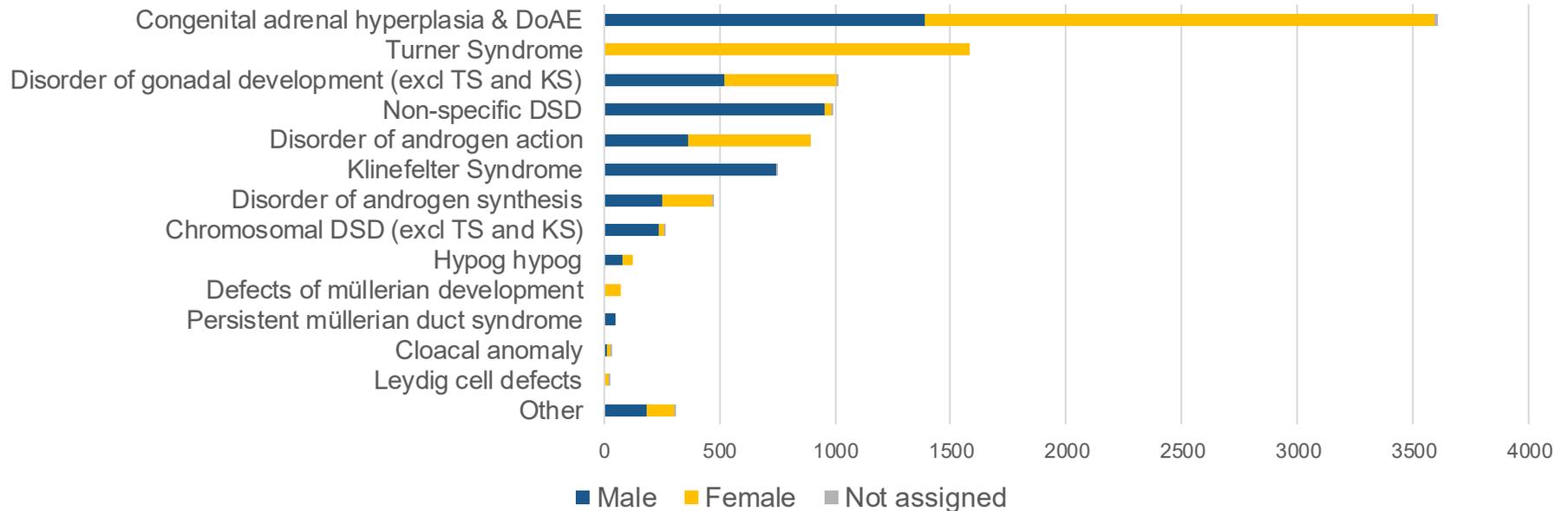
## Year of Birth



## Karyotypes

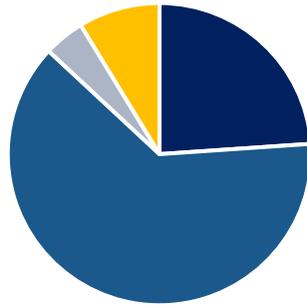


## Diagnoses & Sex



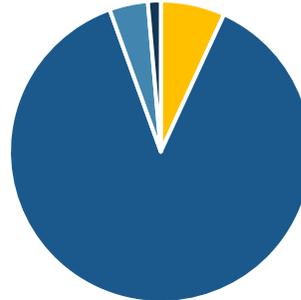
<https://sdmregistries.org/research-output/>

Projects approved n,83



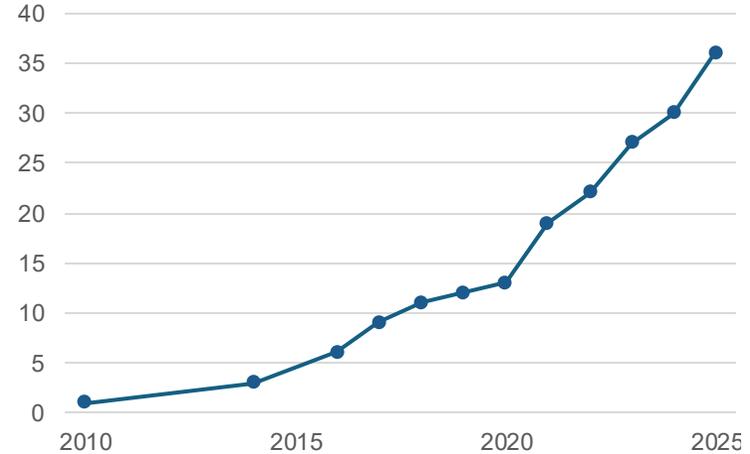
- No activity & no patient data supplied
- Patient level data supplied
- Quality assessment
- Surveys of practice

Funding of projects that were activated n,73

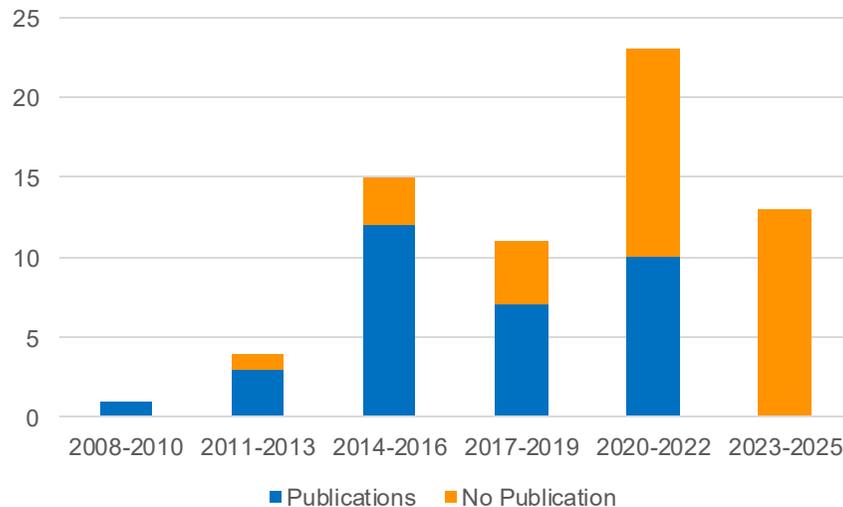


- Industry (feasibility)
- Public/University
- Public/University/Industry
- Public/University/Patient organisation

Cumulative outputs – original data publications

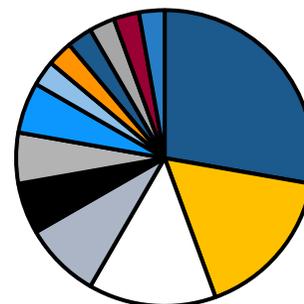


Outcome of activated research projects



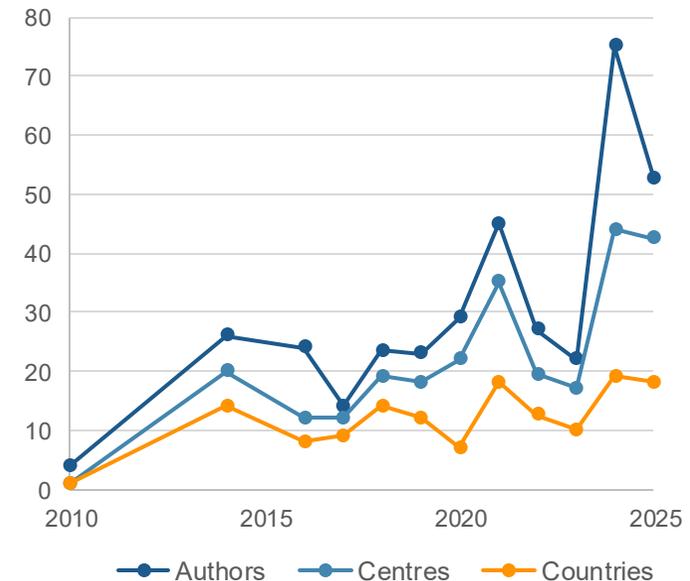
Median lag between study launch and publication = 3 yrs (1, 9)

Destination of original data publications



- JCESM
- Sex Dev
- OJRD
- eBioMed
- BMJ Open
- Endocrine
- Endo Con
- EJE
- HRP
- Clin Endo
- Pediatr
- JES
- WJPS

Extent of Partnership



In 2024, Research Participation Awards were conferred on centres that ranked in the top quintile for: (a) the number of studies they participated in that led to a publication in 2022–2023, and (b) the number of cases they contributed to those studies. Centres that ranked in the top quintile for both criteria received a Gold Award, while those that met one criterion received a Silver Award. The next award ceremony will take place in Lübeck in July 2026 at the next I-DSD Symposium.



Federico Baronio, Bologna



Rodolfo Rey, Buenos Aires



Ajay Thankamony, Cambridge



Martine Cools, Ghent



Faisal Ahmed, Glasgow



Tulay Güran, Istanbul



Sükran Poyrazoğlu, Istanbul



Tania Bachega, São Paulo



Uta Neumann, Berlin



Heba Elsedfy, Cairo



Ayla Güven, Istanbul



Walter Bonfig, Munich



Hedi Claahsen, Nijmegen



Eduardo Correa Costa, Porto Alegre



Theo Sas, Rotterdam



Renata Markosyan, Yerevan

## I-DSD 2013 Glasgow



## I-DSD 2015 Ghent



## I-DSD 2017 Copenhagen



## I-DSD 2019 Sao Paulo



## I-DSD 2021 Webinar



## I-DSD 2022 Bern



## I-DSD 2023 Webinar



## I-DSD 2024 Stockholm



## I-DSD 2025 Webinar



## I-DSD 2026 Lübeck



## PG Course 2022 Bern



## PG Course 2024 Stockholm



## PG Course 2026 Lübeck

