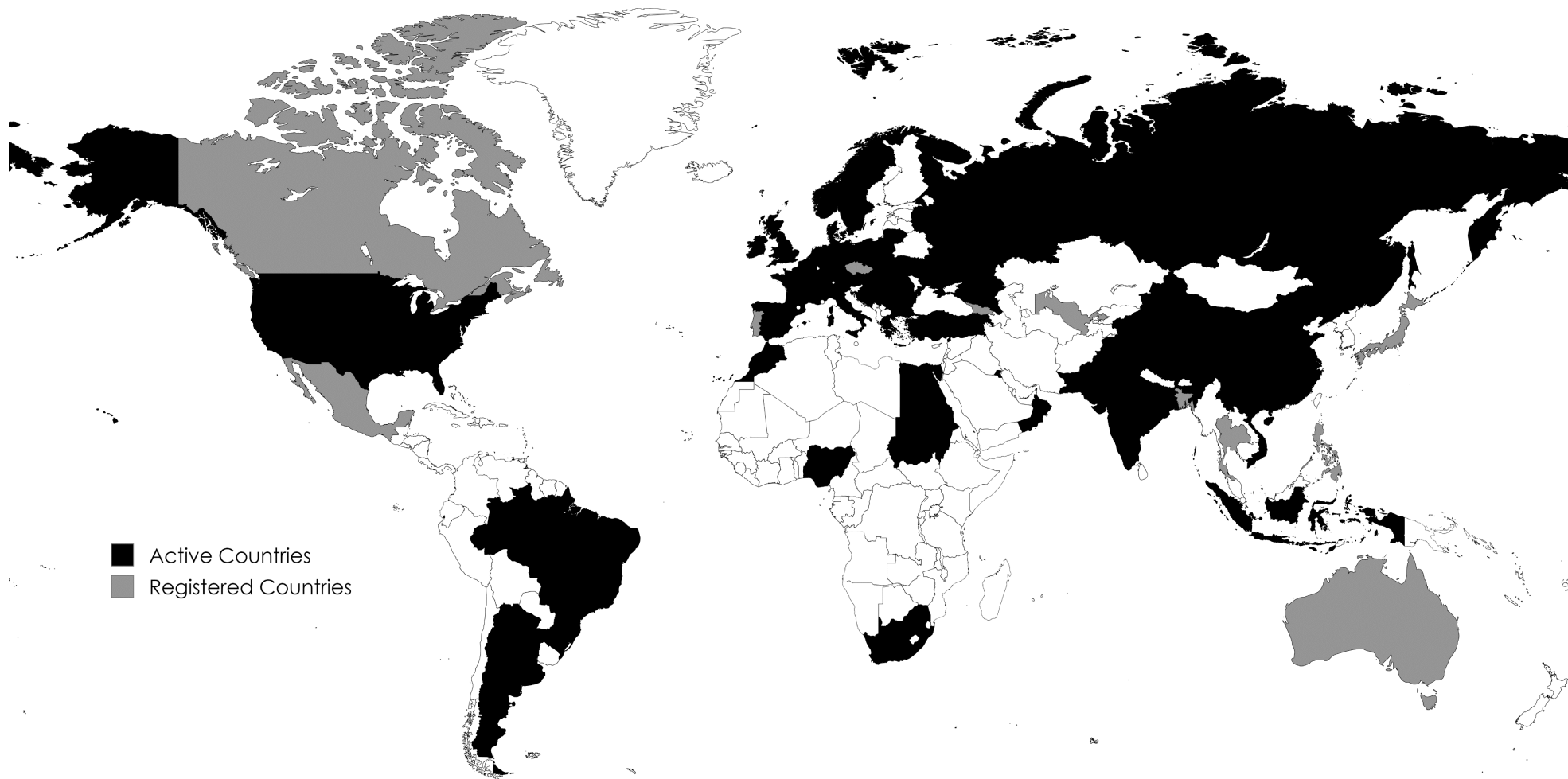


Activity Report June 2024



Wide reach for *SDMregistries* events, education & newsletters

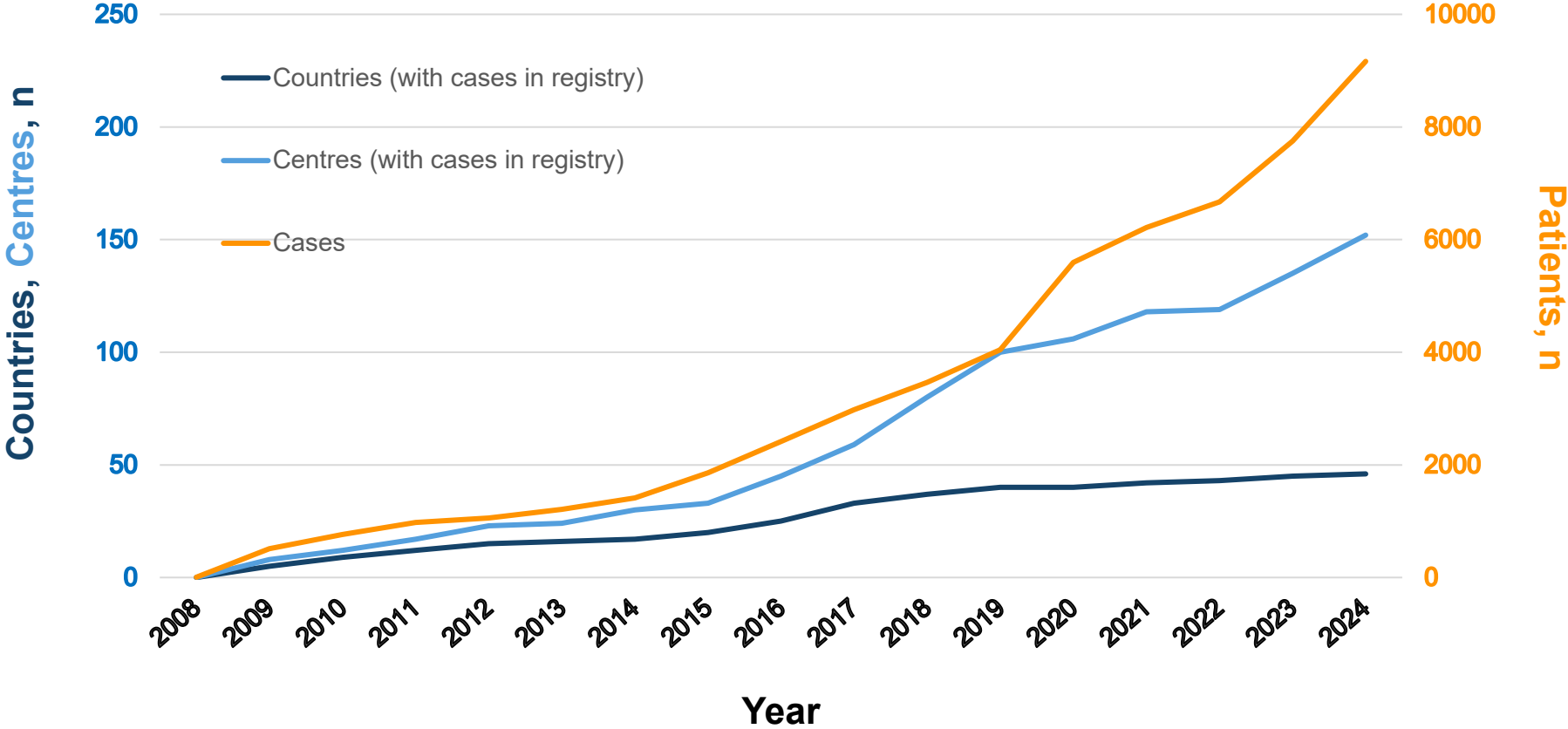


June 2024 – 9165 cases
152 centres from 46 countries with cases
Additional 46 centres from 11 countries in dissemination list

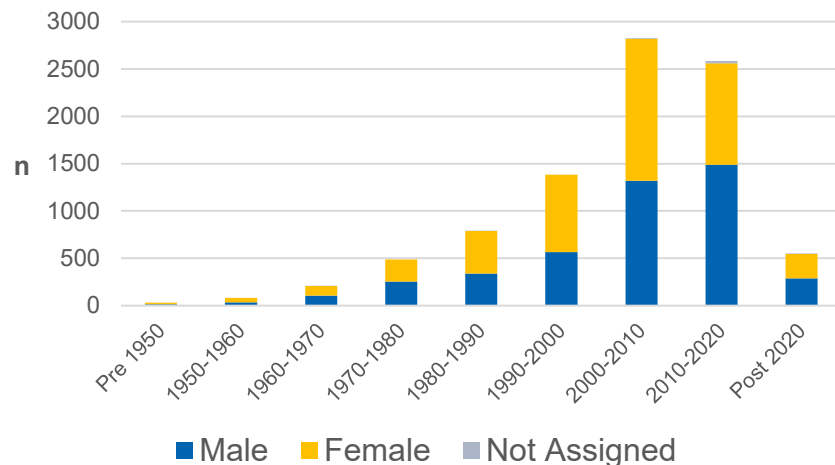
Newborn to 96 yrs
Median Age – 18 yrs

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

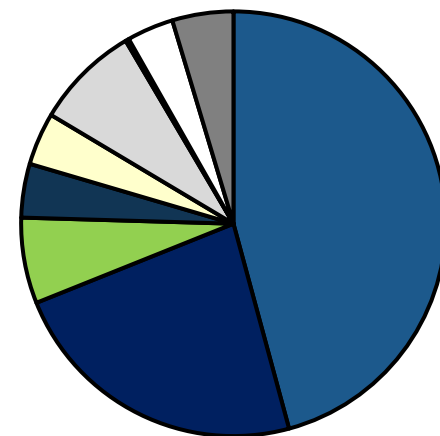
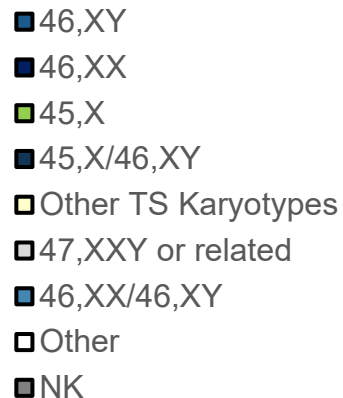
Countries, Centres & Patients



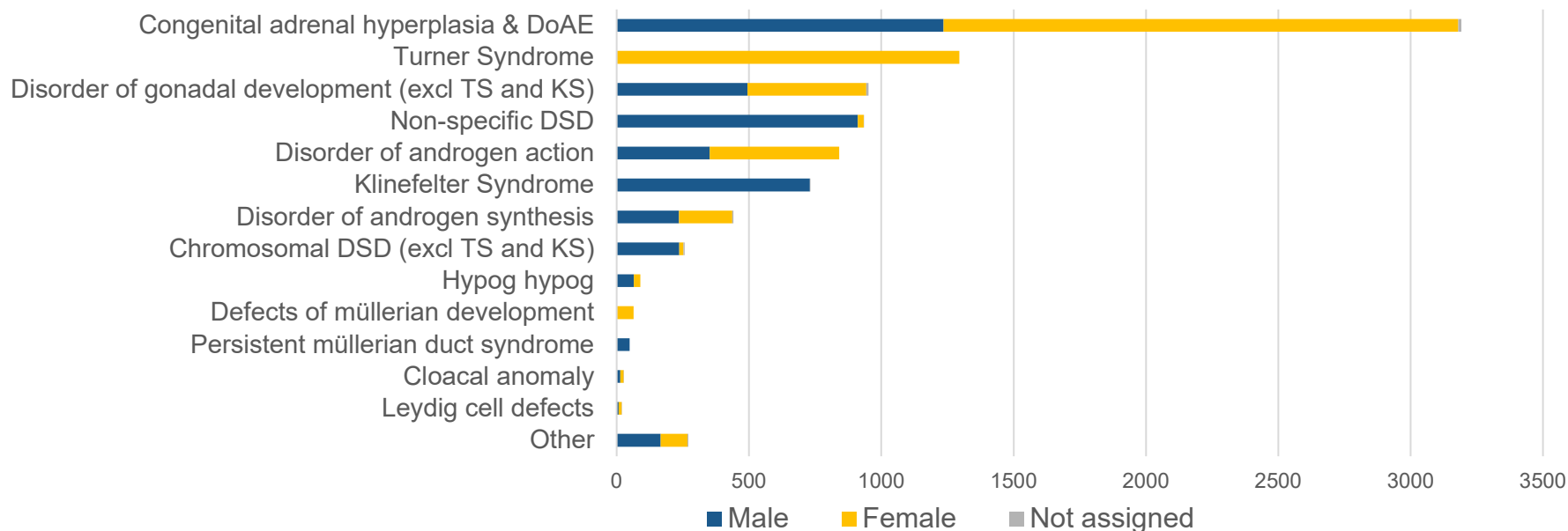
Year of Birth



Karyotypes

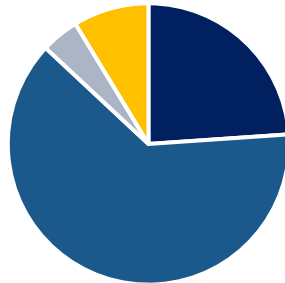


Diagnoses & Sex



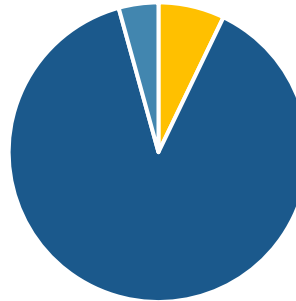
<https://sdmregistries.org/research-output/>

Projects approved n,78



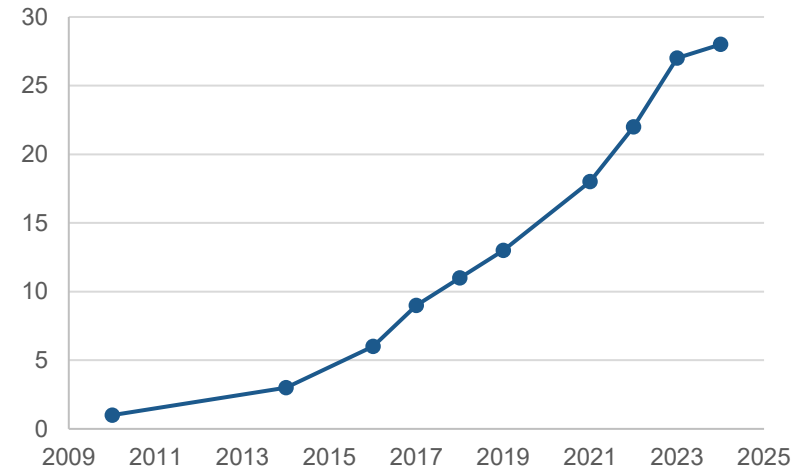
- No activity & no patient data supplied
- Patient level data supplied
- Quality assessment
- Surveys of practice

Funding of projects that were activated n,70

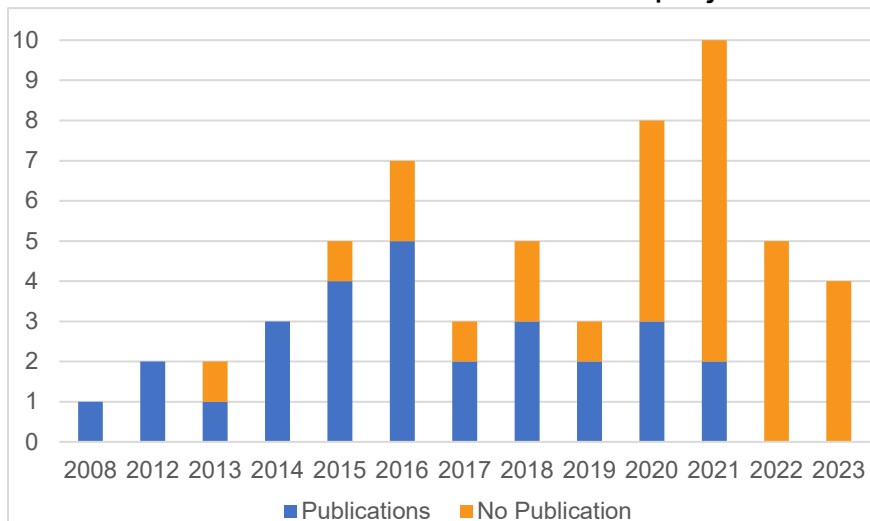


- Industry (feasibility)
- Public/University
- Public/University/Industry

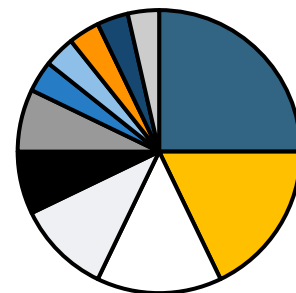
Cumulative outputs – original data publications



Outcome of activated research projects

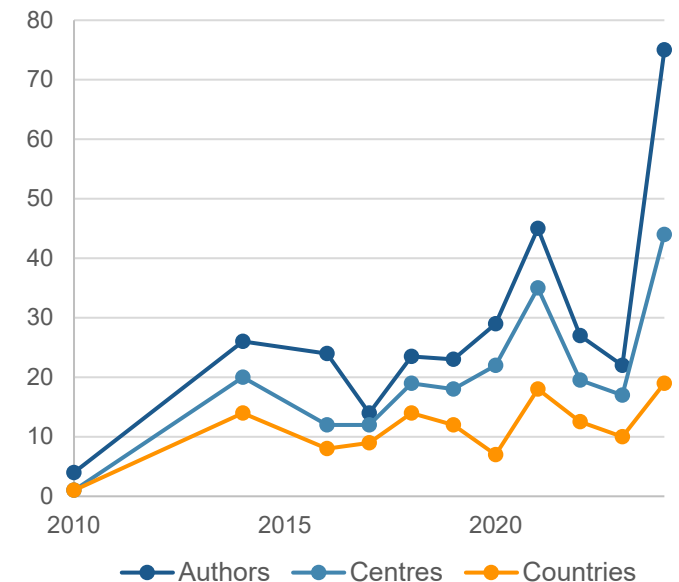


Destination of original data publications



- JCEM
- EJE
- OJRD
- Pediatr
- Endocrine
- WJPS
- Sex Dev
- HRP
- Clin Endo
- BMJ Open
- eBioMed

Extent of Partnership



Median lag between study launch and publication = 2 yrs (1, 9)

In 2024 Research Participation Awards were conferred on centres that were in the top quintile for (a) the number of studies they participated in and that led to a publication in 2022-2023 and (b) for contributing the largest number of cases into these studies. Those centres that were in the top quintile for both criteria were awarded a Gold Award and those that achieved one criterion were awarded a Silver Award.



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

**4th I-DSD 2013
Glasgow**



**5th I-DSD 2015
Ghent**



**6th I-DSD 2017
Copenhagen**



**7th I-DSD 2019
Sao Paulo**



**8th I-DSD 2021
Webinar**



**9th I-DSD 2022
Bern**



**10th I-DSD 2023
Webinar**



**11th I-DSD 2024
Stockholm**



**1st PG Course 2022
Bern**



**2nd PG Course 2024
Stockholm**

