

Sex Development & Maturation (MTG7)

Endo-ERN General Assembly 2026

Chairs: Hedi Claahsen, Claus Gravholt, Lexi Breen, Manuela Brösamle



Funded by
the European Union

Discussion – Athletes with DSD

Discussion leads: Sabine Hannema & Susan O’Connell

Desired Outcome: Form basis for public statement to be published on behalf of MTG7 experts in Endo-ERN

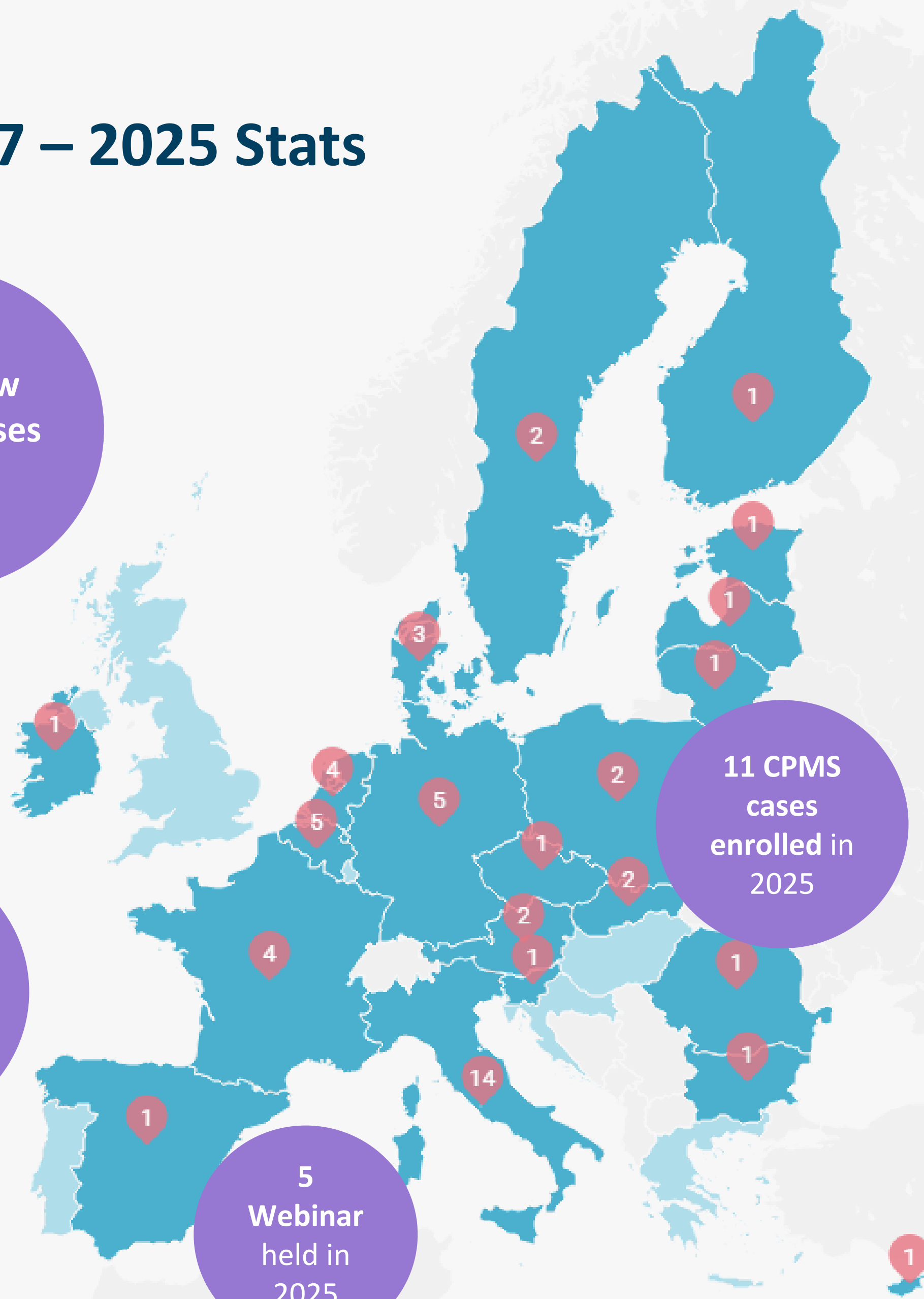
MTG7 – 2025 Stats

**3,242 new
patient cases
in 2025**

14
publications
with at least 2
member
states in 2025

5
Webinar
held in
2025

**11 CPMS
cases
enrolled in
2025**

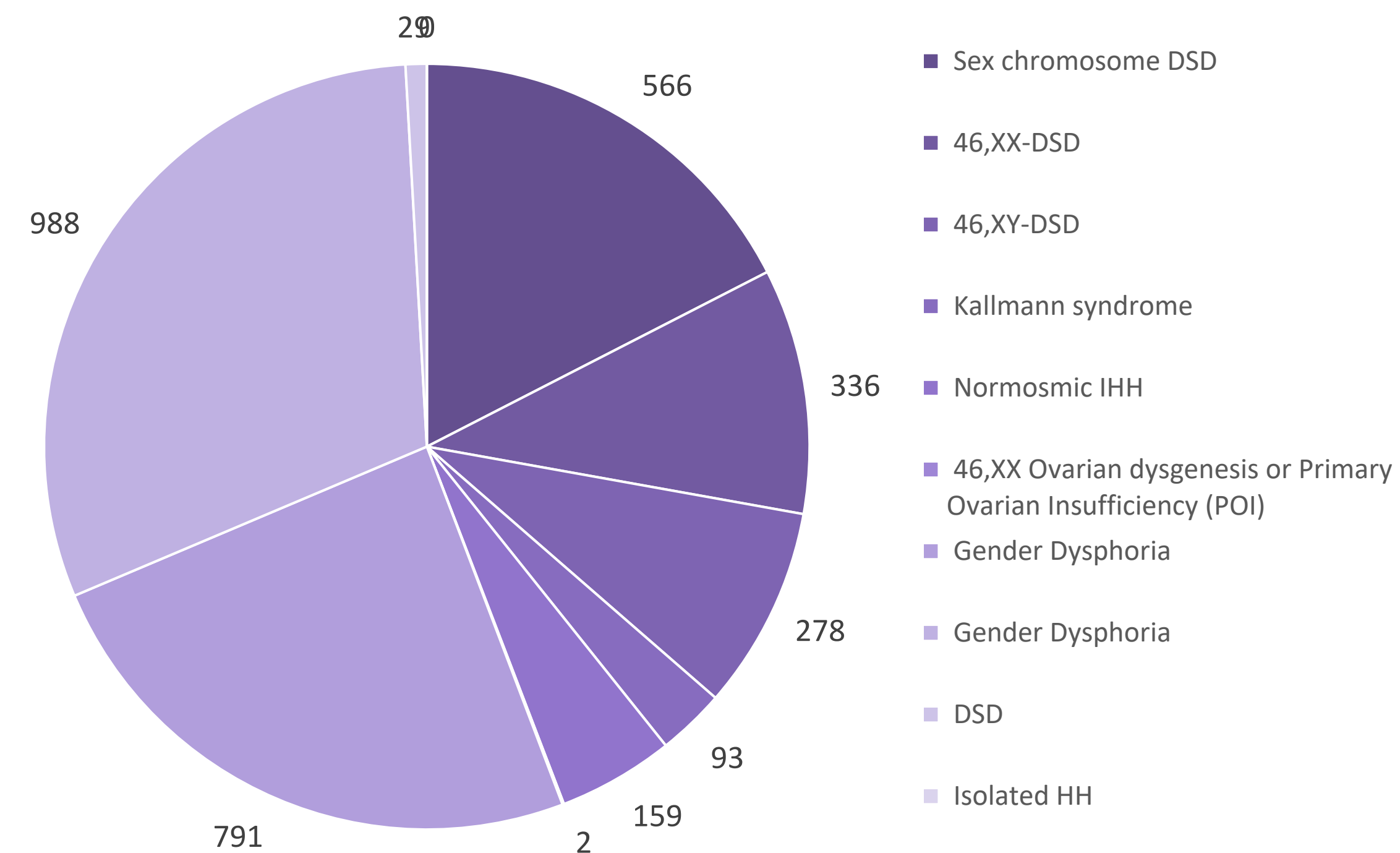


European
Reference
Network

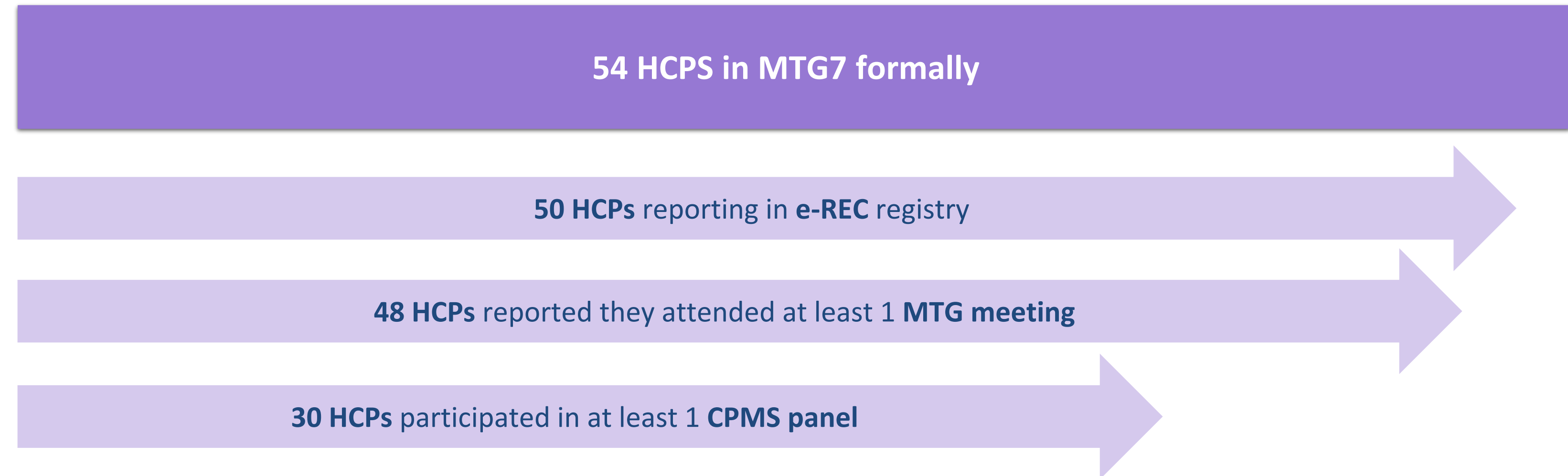


Endo-ERN

No. of new patients per MTG7 sub thematic area
of new patients



MTG7 HCPS - 2025 Stats



- 41 HCPS have **different** EC & e-REC totals
- 8 HCPS **do not have** Endo-ERN logo/url at their website
- 14 HCPS who did not measure patient satisfaction – this is based on your HCP **NOT your department** usually

Registries

31 HCPs report to the SDM Registries
(formerly known as I-DSD/I-CAH/I-TS)

Orphacodes in DSD – Agree on all*?

Orphacode – sub theme area	Condition	Individual Oprhacodes in subtheme	ICD-10
90771, 174590	DSD	90771, 2982, 98085, 325546	
90771, 174590	IHH	432, 478	Q87.8, Q71.8
90771, 174590	Gender dysphoria		F64
90771, 174590	Premature ovarian insufficiency	95709	E8.3

*Full core registry list within the subthematic groups given :
[Core_registry_diagnosis_and_conditions_dictionary_v10-24.05.25.xlsx](#)

CAH care pathway update

Thank you to all who gave feedback on this care pathway!

- Feedback has been incorporated
- The latest version is currently under review by eUROGEN experts
- Next steps focus on finalizing and **Implementation** of care pathway

Thoughts/ reflections on this?

ENDO-ERN Opinion / Perspective Paper: CAIS



*A Clinically-Oriented Roadmap for Transition and Adult Care in DSD – The Case of **CAIS***

What: Emphasize key gaps in research that should be highlighted in a roadmap within CAIS care during transition of care

Who: Endocrinologists, paediatric endocrinologists, transition of care WG, patient representative, psychologist/ psychiatrist

When: Proposed during MTG7 meeting, kick off November 2025

Current status: Ongoing writing and discussion of key points

Other developemnts in 2025

[ENDO-ERN expert opinion: addressing the endocrine needs in considering genital surgery in disorders/differences in sex development individuals in Europe | European Journal of Endocrinology | Oxford Academ](#)

[Enhancing transition care for adolescents and young adults with adrenal insufficiency in the Netherlands: a holistic model for improved patient outcomes in: Endocrine Connection](#)

[Continuity of care in Klinefelter syndrome: age-adapted modules for standardized clinical data collection \(I-KS\) - PubMeds Volume 14 Issue 10 \(2025\)ic](#)

EURREB Modules:
[Women's Reproductive Health - EuRREB](#)
[Gender Incongruence - EuRREB](#)





AOB?

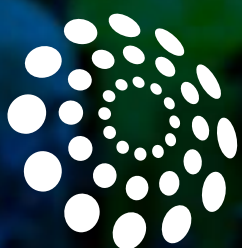


European
Reference
Network



Endo-ERN





European
Reference
Network



Endo-ERN