

# ERN eUROGEN update

The European Reference Network for Rare Uro-Recto-Genital Diseases and Complex Conditions

Lotte Boormans, ERN eUROGEN Registry Manager

18 June 2026    EPSU congress 2026    10:45-10:50



Interested?  
Email us!



European  
Reference  
Network

ERN eUROGEN  
Rare Uro-Recto-Genital Diseases  
& Complex Conditions



Funded by  
the European Union

Radboud University



Radboudumc  
university medical center

# The ERNs in a nutshell

## European Reference Networks for rare diseases and complex conditions

- Virtual networks of specialised Health Care Providers
- Connecting clinicians to improve patient care
  
- 24 ERNs for various groups of rare diseases
- ERN eUROGEN for rare uro-recto-genital diseases and complex conditions

# ERN eUROGEN overview

- Expertise Area coverage
  - 3 Workstreams (WS)
    - **WS1: Congenital anomalies,**
    - WS2: functional conditions requiring highly specialised surgery
    - WS3: urological tumours
  - Divided into several Expertise Areas
    - 1.1 Complex genital reconstructions (DSDs)
    - 1.2 Bladder exstrophy/epispadias
    - 1.3 Rare urological stone & kidney diseases
    - 1.4 Non-syndromic uro-recto-genital tract malformation
    - 1.5 Posterior urethral valves
    - 1.6 Posterior hypospadias
    - 1.7 Urorectal/anorectal malformations



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# ERN eUROGEN overview

- Expertise Area coverage
  - 3 Workstreams (WS)
    - **WS1: Congenital anomalies,**
    - WS2: functional conditions requiring highly specialised surgery
    - WS3: urological tumours
  - Knowledge sharing
    - CPMS 2 per month
    - Webinars 2 per month
    - Guidelines 3 finished, 7 in progress
    - Registry 1800 patients



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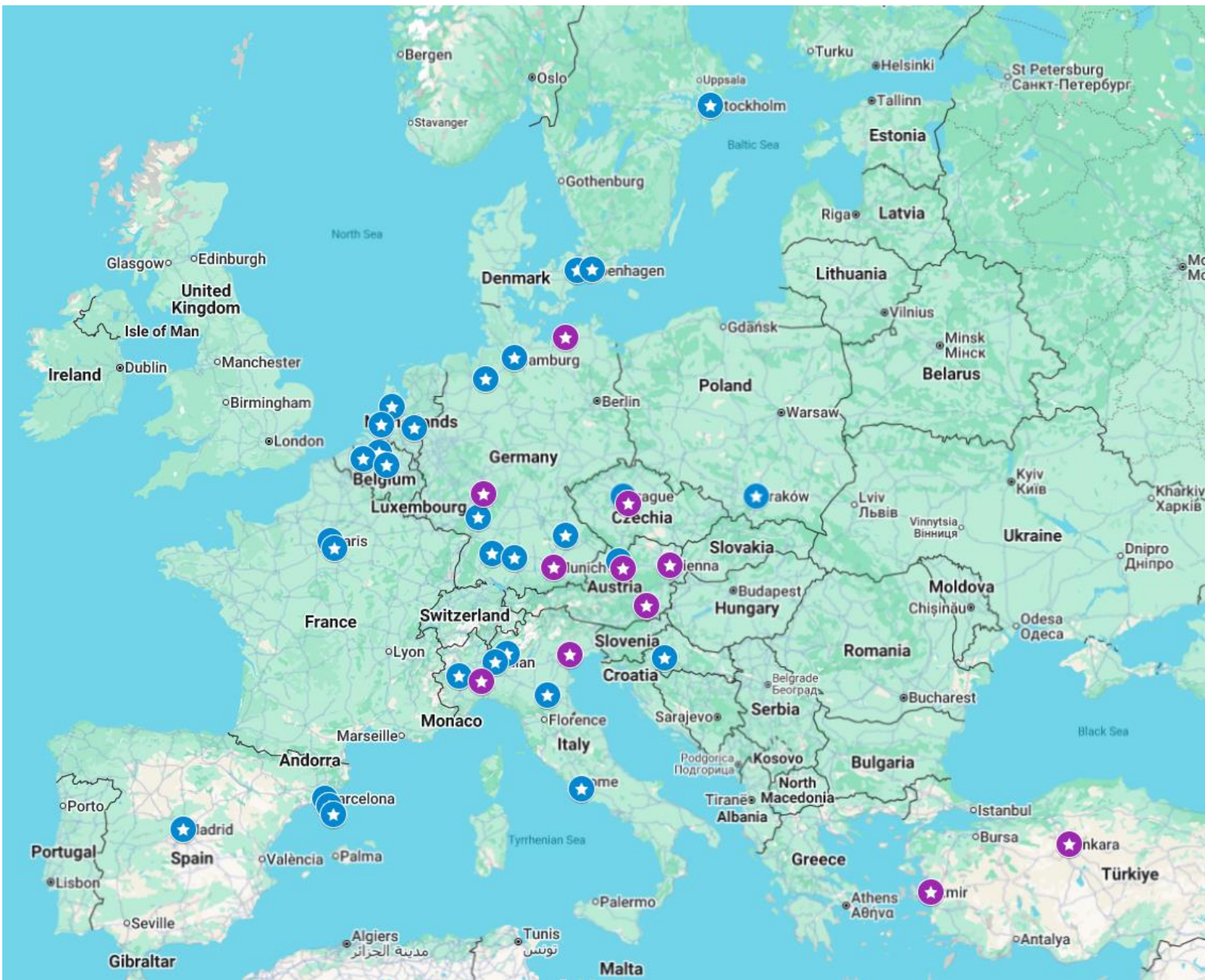
# ERN eUROGEN registry

ERN eUROGEN HCPs

30 approved

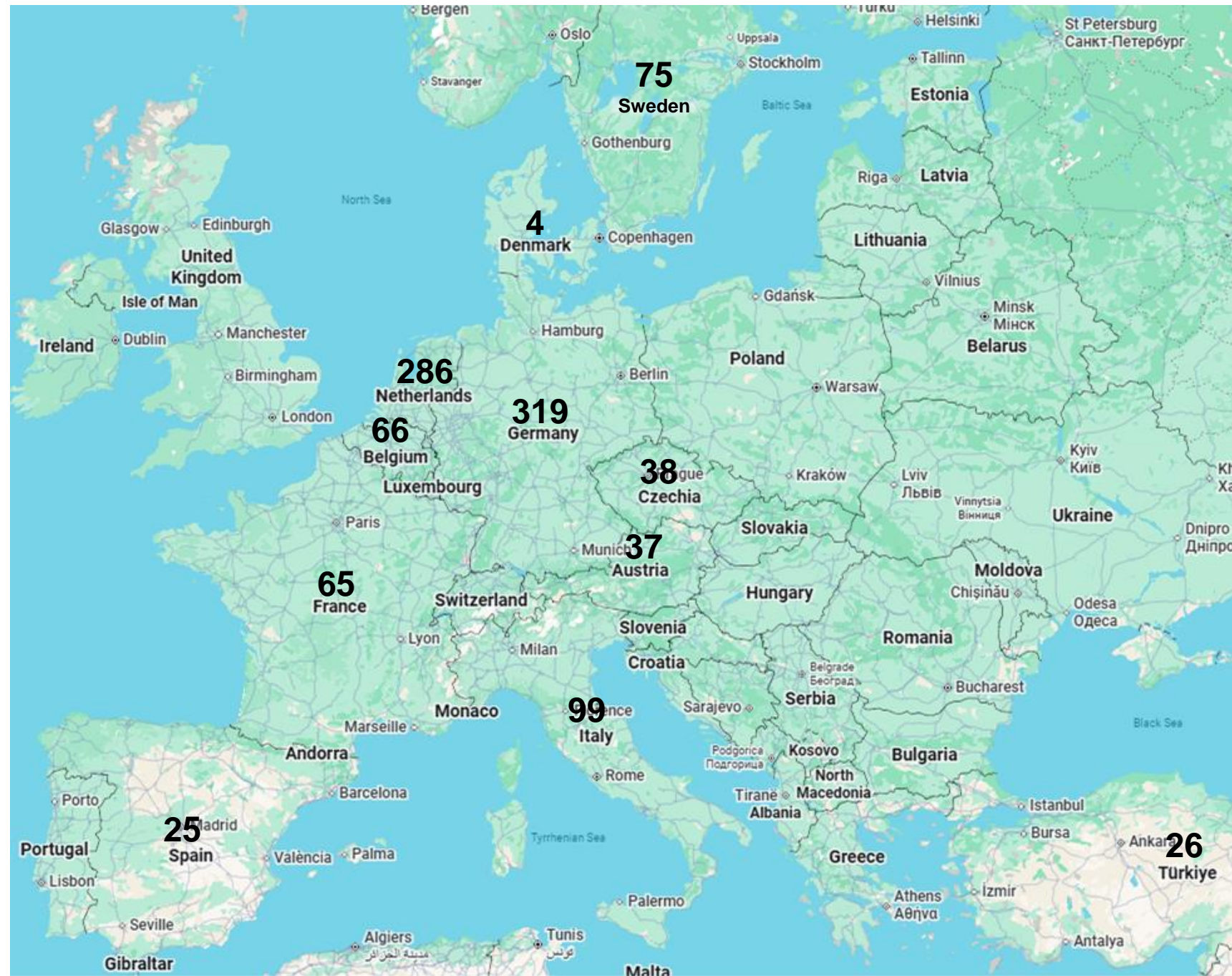
ARM-Net HCPs

12 approved

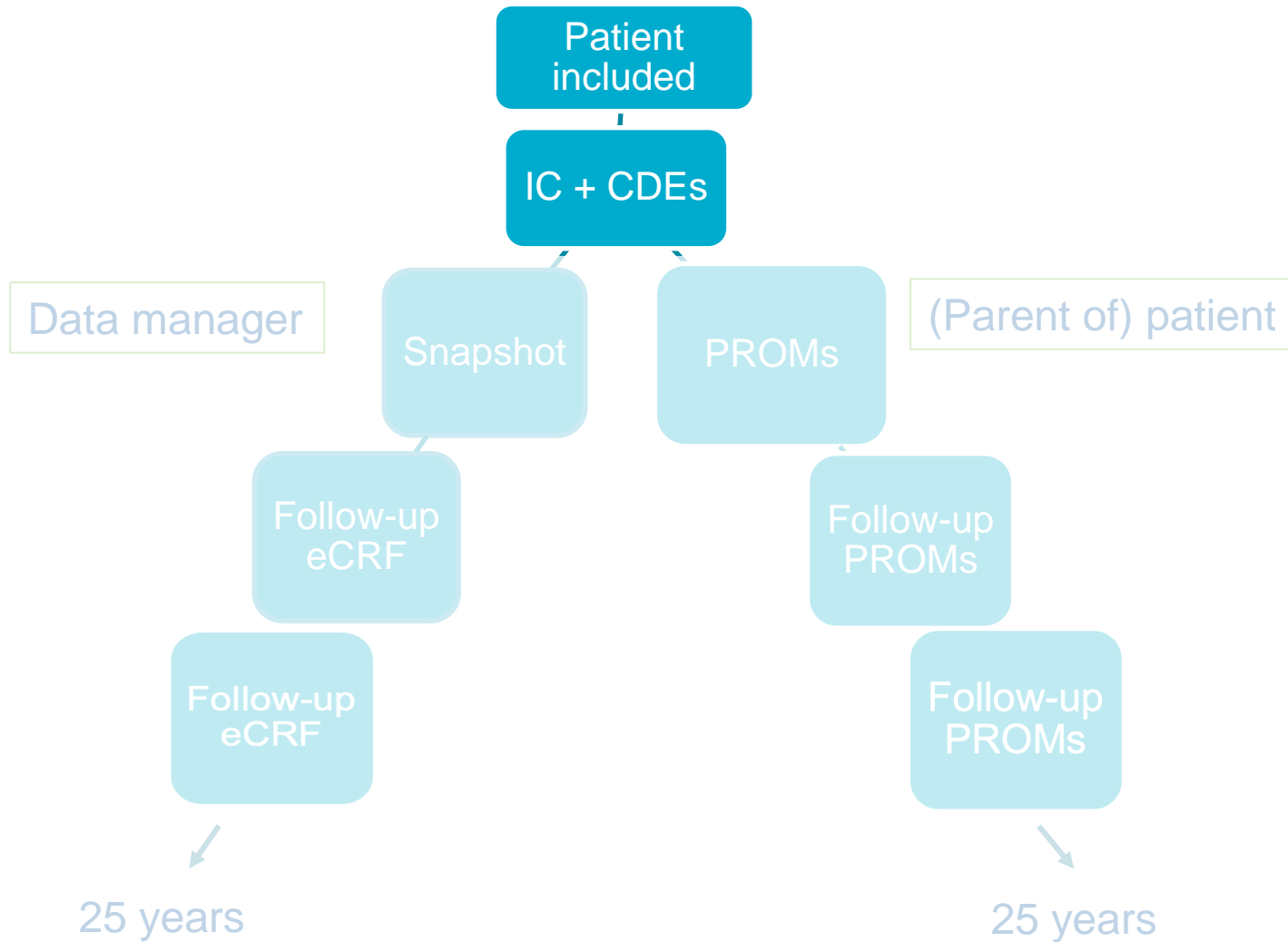


# Current status

Country	Number of cases
Austria	37
Belgium	66
Czechia	38
Germany	319
Denmark	4
Spain	25
France	65
Italy	99
Turkey	26
The Netherlands	286
Sweden	75
<b>Total</b>	<b>1040</b>



# Data elements



## IC options

Answers of participant to IC options



## Common Data Elements

Developed by the JRC  
Used in all ERN registries



## Clinical Practice Snapshots

6 specific clinical subjects per EA  
about the clinical approach  
filled out 1 year after first visit

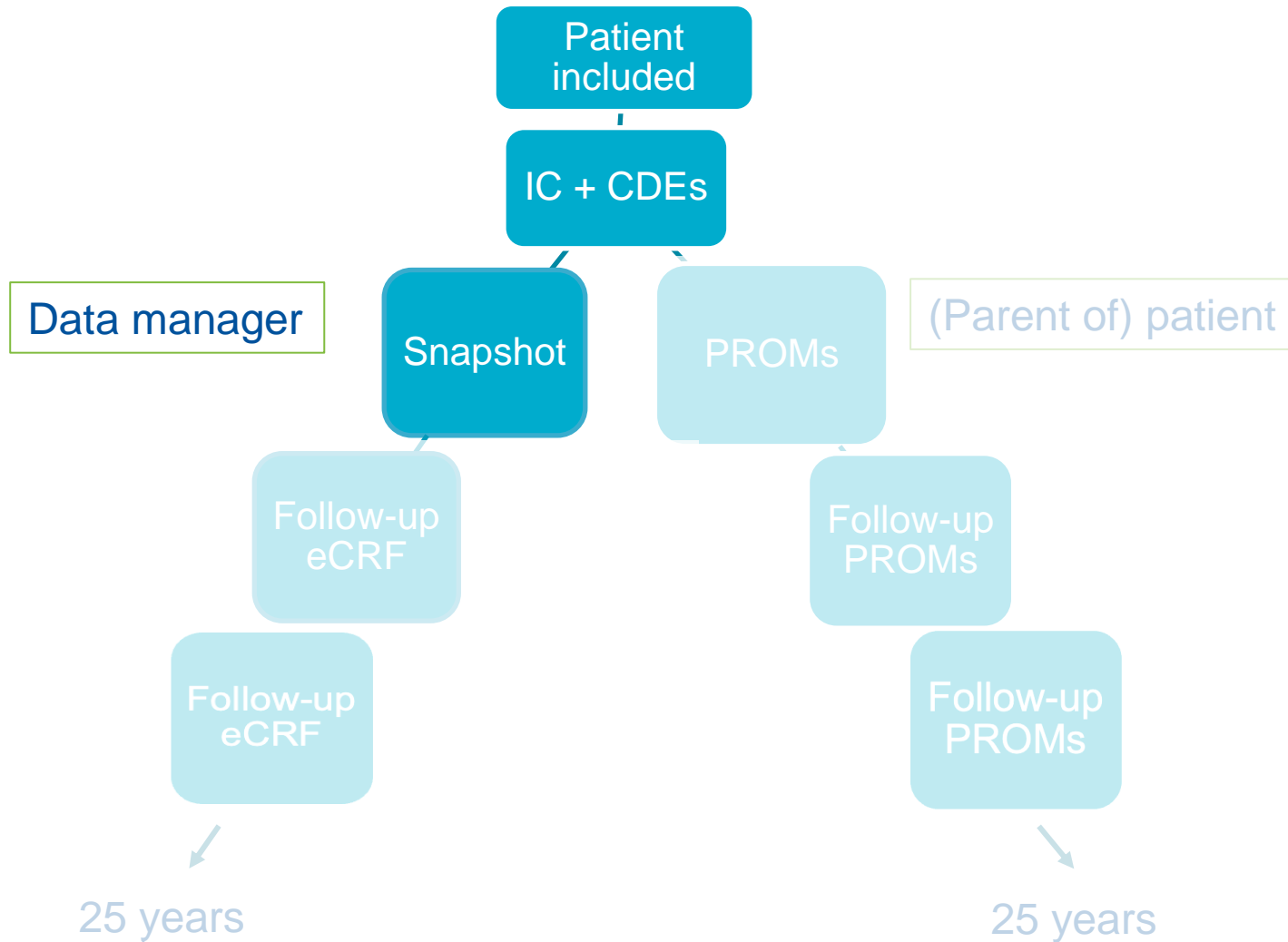
## Follow-Up eCRFs

about further clinical approach,  
care consumption and outcome measures  
multiple eCRFs

## PROM Questionnaires

Questions regarding quality of life and  
satisfaction with care process & outcomes  
multiple questionnaires

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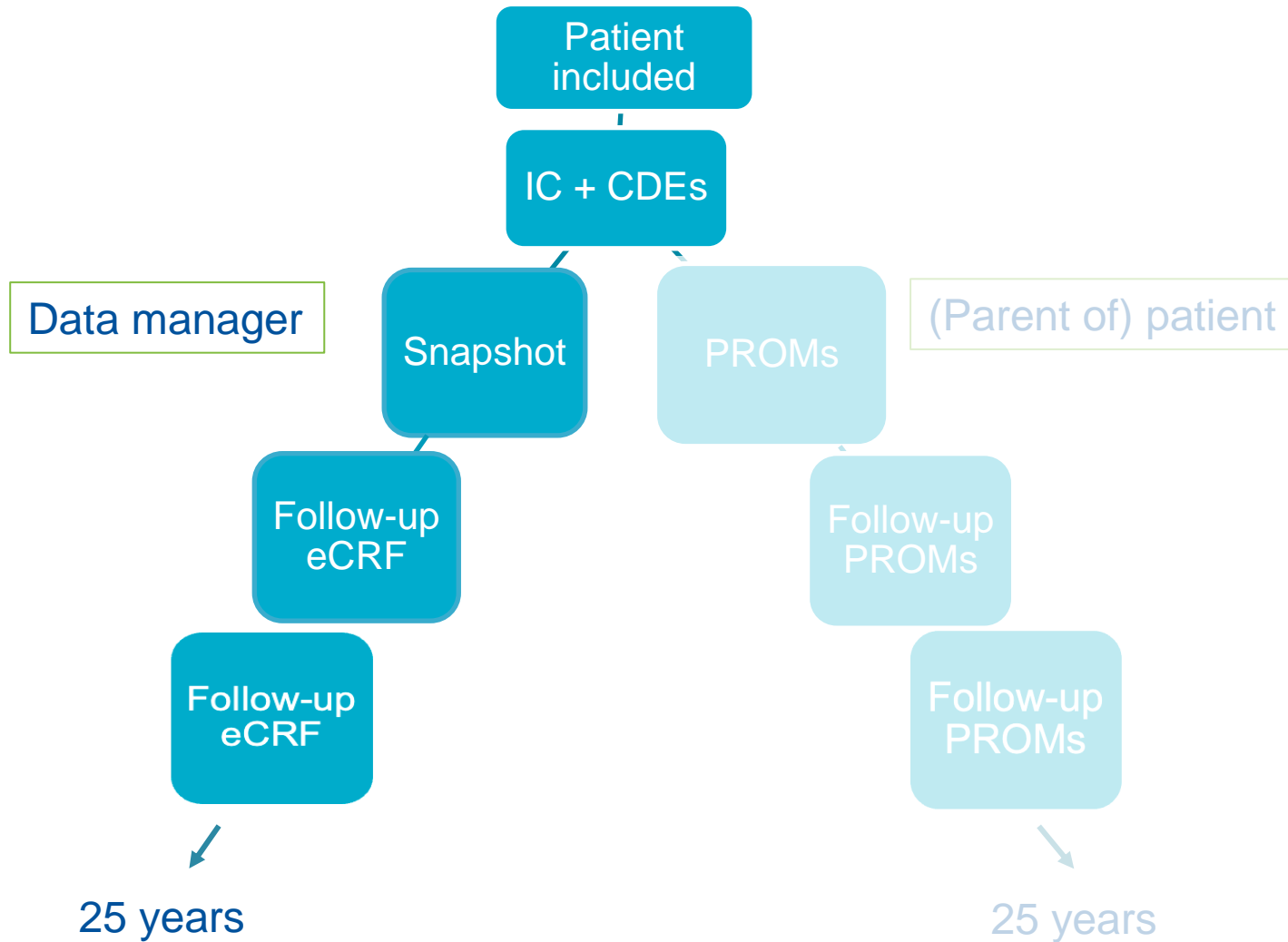
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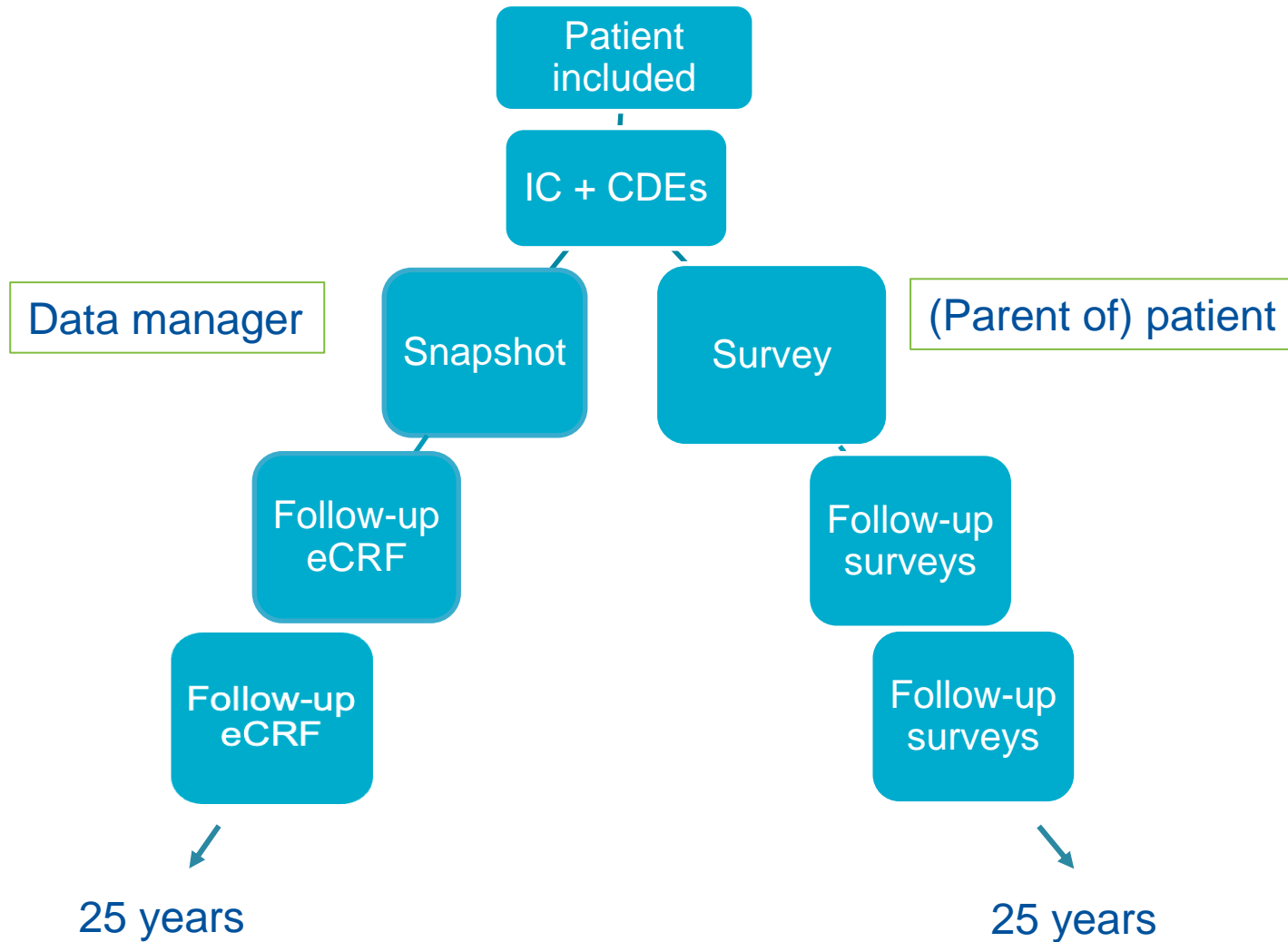
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## Follow-up surveys

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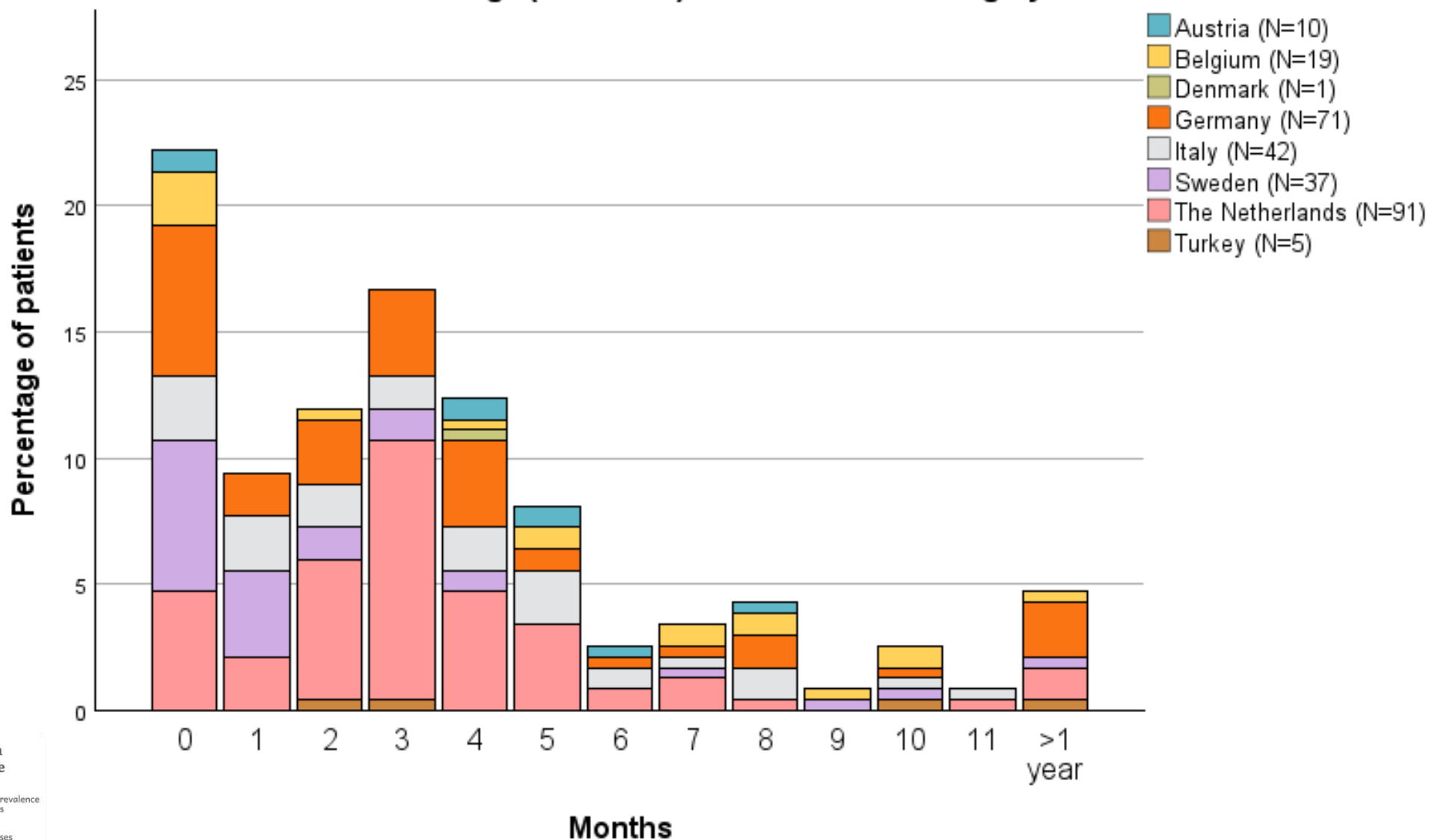
# Use of ERN eUROGEN registry

## Analyses by registry Manager

- Cleaning of data and yearly reports

# Data reports – Anorectal malformations

Age (in months) at reconstructive surgery



# Use of ERN eUROGEN registry

## Analyses by registry Manager

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## Analyses by (external) researchers

- Apply for data use and publish results
- Example: Bladder Exstrophy research – Parmida Anvary



Email us directly for the Bladder Exstrophy study



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## Analyses for development of Clinical Practice Guidelines

- Use registry to gain insight in common clinical practice

# Join the registry!

## Any hospital can join the registry!

### Requirements

- Treatment of patients within our Expertise Area
- Get ethical and legal approval for registry participation
  - Our team will guide you!
  - Contact [loes.vanderzanden@radboudumc.nl](mailto:loes.vanderzanden@radboudumc.nl) or [lotte.boormans@radboudumc.nl](mailto:lotte.boormans@radboudumc.nl)



**Interested?  
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