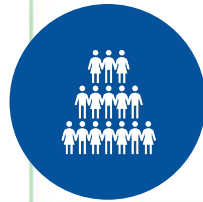


Update on ERNs Affiliated Partners

CNA monthly call
5 Sept 2023



9 Emerging ERN Advocacy Priorities



Securing greater support for HCP members & PO to be active in the ERNs (linked to sustainability, recruitment and retention) in addition to the JA recommendations to support clinicians.



Greater recognition and acknowledgement of the role and contribution of **patient representatives and patient organisations** in the ERNs



Increased cross-ERN MDT disease-specific or disease-cluster working AND cross-ERN collaboration in areas of common interest (transition, development of PREMs, mental health, etc). Greater visibility of current collaboration



Better representation and inclusion of MSs in all ERNs and disease expansion. Open a new process for Affiliated Partners to join targeting only existing geographic gaps. 3rd call for full members to enable disease expansion



Integration of ERNs into the European system for CBHC with a formal role in the decision making (treatment eligibility panels with a binding outcome to access treatment abroad)



Monitoring the impact of the ERNs beyond activities and outputs, and the need for more **outcome and experience-based measures (H-Care)**
Publish results/transparency



Support the development of a **robust evaluation mechanism and methodology to measure the impact of the collaboration** between patient-representatives and clinicians.



Support the development of **pilots** to test different **private-public funding models** for ERNs clinical research activities

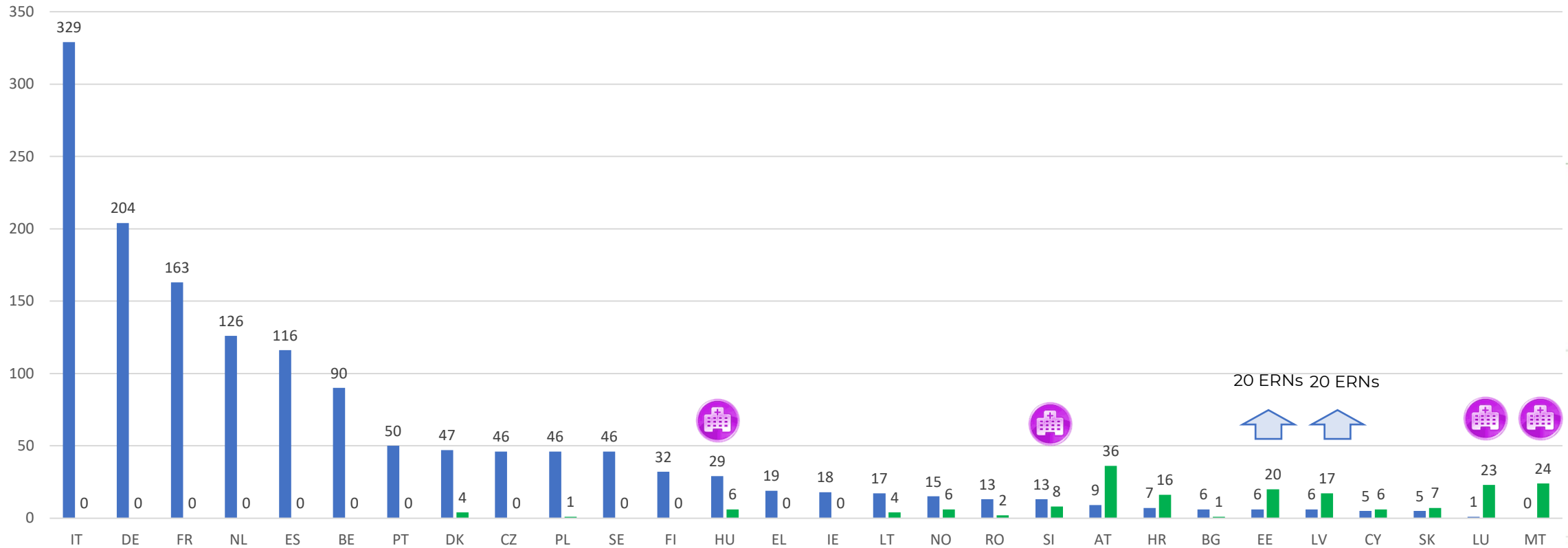


Integration of ERNs into the National Healthcare System – advocate for implementation **after the JA has finished**

ERN Membership (2nd Call)

- 2 calls for Full Membership.
- Affiliation as a means to achieve inclusivity for less experienced centres (associated centres) or set up ERN national Coordination Hubs

Number of HCP Members and Affiliated Partners per Country



Number of Full members and affiliated partners. Source: Presented by Birute Tiumene during the Expert Conference in RD, 25-26 October 2022, Prague



ER national Coordination Hubs

Full Members

Affiliated Partners

11 ERNs

6 ERNs

11 ERNs 9 ERNs



Thank you !

**If you want to know more about ERN National
Coordination Hubs, watch this [webinar](#) -**