



EUROPEAN MEDICINES AGENCY  
SCIENCE MEDICINES HEALTH

# Enpr-EMA Annual Report 2019-2020

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



Pirkko Lepola, Chair, Enpr-EMA

28September2020

An agency of the European Union





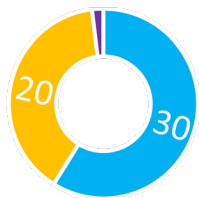
	<b>Meetings</b>	<b>February</b> (CG+Networks), <b>June</b> (CG+Networks), <b>September</b> (CG+Networks)
	<b>New CG Members &amp; Networks</b>	<b>New members of CG:</b> Alessandra Nardone: PENTA, Cecile Ollivier – EUCOPE, and due to UK’s departure from the EU; Sabine Scherer – PDCO, Anette Solli Karlsen – PDCO (observer), <b>Network to CG;</b> TEDDY - 04/2020
	<b>Mandates</b>	Coordinating Group Mandate update and adoption 09/2020
	<b>Support Letters</b>	COMET; Core Outcome Measures in Effectiveness Trials 05/2020 CGTA-4LL, Horizon2020; Reliable and Accessable information on cell- and gene-based therapies 06/2020
	<b>Public Consultations</b>	Docket No. FDA-2019-N-5464 for “Rare Disease Clinical Trial Networks” 07/2020 EU Commission; Pharmaceutical Strategy - Timely patient access to affordable medicines - Individual contributions 09/2020
	<b>Deliverables &amp; Publications</b>	Preparedness of medicines’ clinical trials in paediatrics: Recommendations by the Enpr-EMA 09/2020
	<b>Information Sharing Related to COVID-19</b>	Several centrally distributed regulatory and registry –related up-date information, clinical trials and studies on COVID-19, and discussions between the networks and other collaborative stakeholders during the meetings
	<b>Global Collaboration</b>	MRCT (Multi-Regional Clinical Trials Center of Brigham and Women’s Hospital and Harvard) and regulatory collaboration
	<b>Presentations</b>	1. EPTRI Stakeholders Roundtable – Virtual meeting - July 9th, 2020 2. EFGCP & DIA Better Medicines for Children Conference, October 12-13, 2020, Virtual Conference 3. EAPS European Academy of Paediatric Societies, October 16-19, 2020, Virtual Congress
	<b>WG International</b>	<i>Deliverable to be finalized</i>
	<b>WG Research Nurses</b>	<i>New plans for activities</i>
	<b>WG Ethics</b>	<i>EMA Review &amp; feedback recieved 07/2020</i>
	<b>WG Labelling</b>	<i>Manuscript under development 09/2020</i>



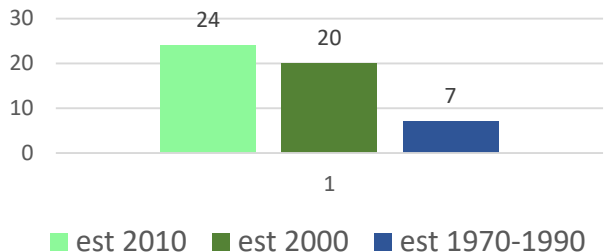
# Enpr-EMA member networks 2020

### Network type (n=51)

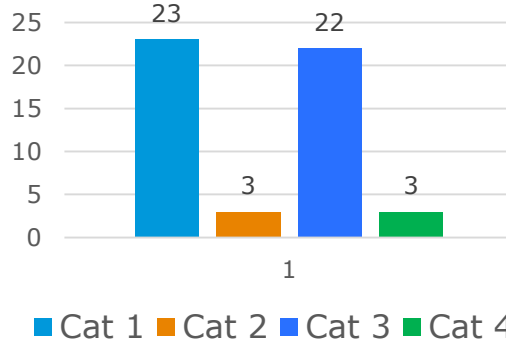
■ Specialty ■ Patient advocacy ■ Multispecialty



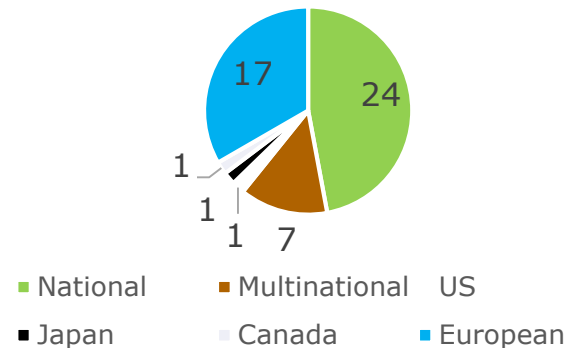
### Member networks - establishment decade



### Enpr-EMA Member network Category (1-4)



### Network operational area (n=51)



### Network (=51) patient groups

