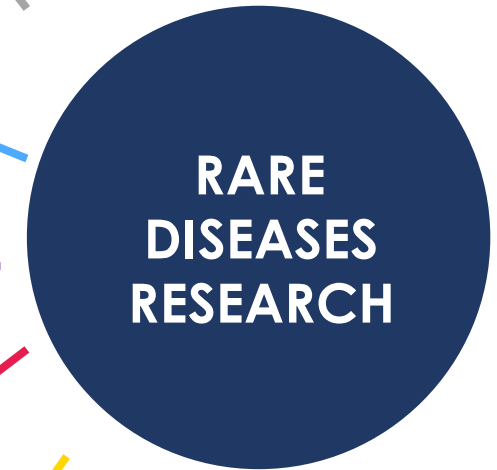
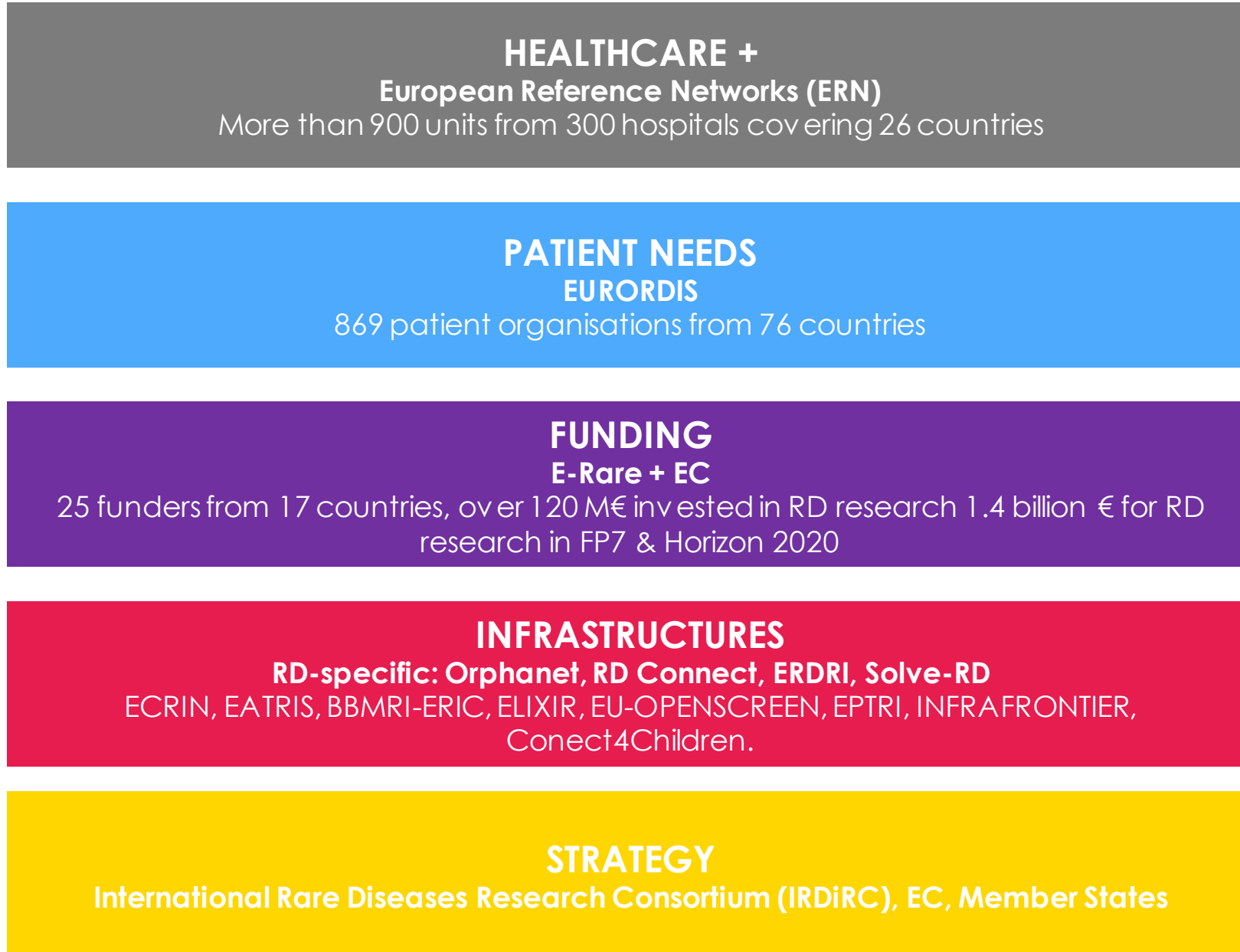


Rare Diseases as an European Priority

Daria Julkowska

Coordinator of the European Joint Programme on Rare Diseases
INSERM, France

Rare Diseases Research Landscape in Europe in 2018



750
people
650 Scientifics
100 Admin

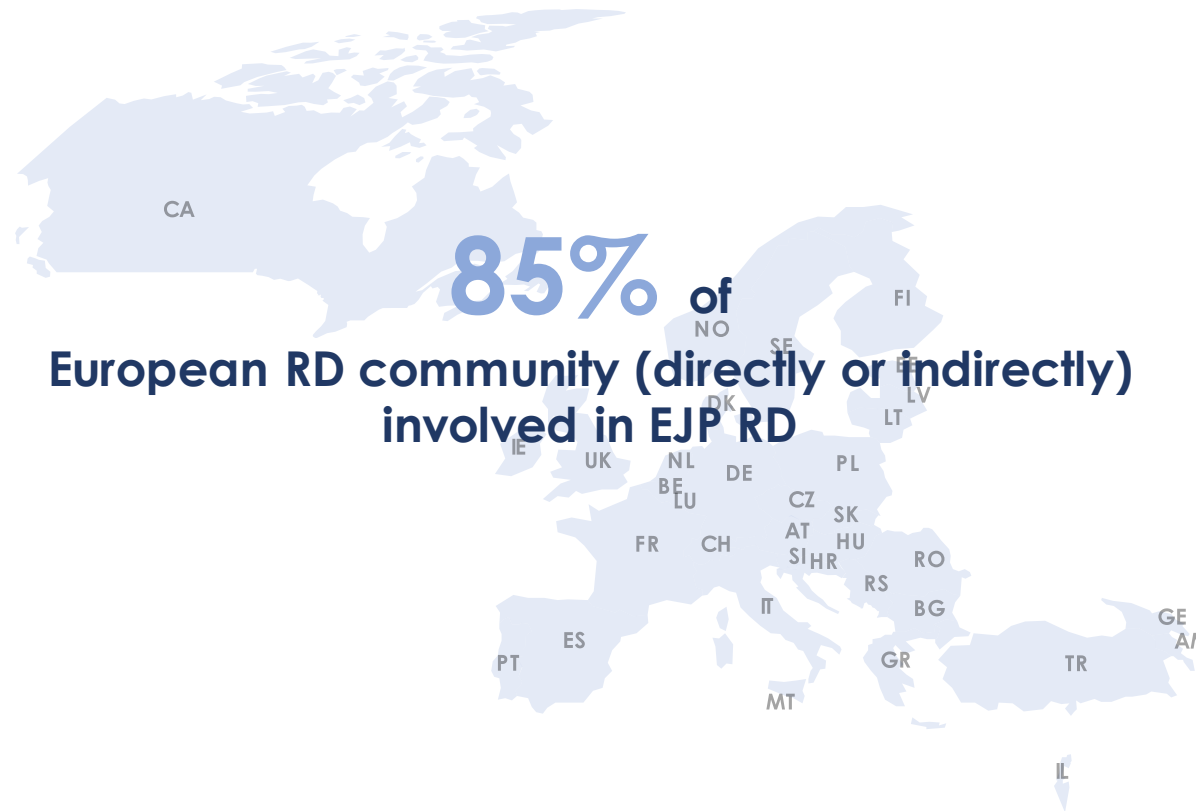
35 participating countries

26 EU MS, 7 associated (AM, CH, GE, IL, NO, RS, TK), UK and CA

101 M€
Budget

Union contribution: 55 M€ (70% reimbursement rate)

EJP RD in numbers



87
beneficiaries

9 hospitals
12 research institutes
31 research funding bodies/ministries
24 universities/hospital universities
5 EU infrastructures
5 charities/foundations
EURORDIS

+ 50 linked third parties
+100% associated networks





EJP RD – single entry point & solutions for all

RESEARCHERS



Funding

Research support services

Training at every stage

Access to resources & tools

Access to extensive network & expertise

CLINICIANS



Clinical studies support services

Support for registries

Access to resources & tools to accelerate diagnosis

Access to extensive network & expertise

Funding

PATIENTS



Access to RD specific expertise

Networking

Training at every stage

Access to resources & tools

Access to extensive network & expertise

Funding

POLICY MAKERS & FUNDERS



Joint funding & strategy

Optimisation of investment in research

Access to support for national RD community

Access to extensive network & expertise

Holistic impact evaluation

INTERNATIONAL PARTNERS

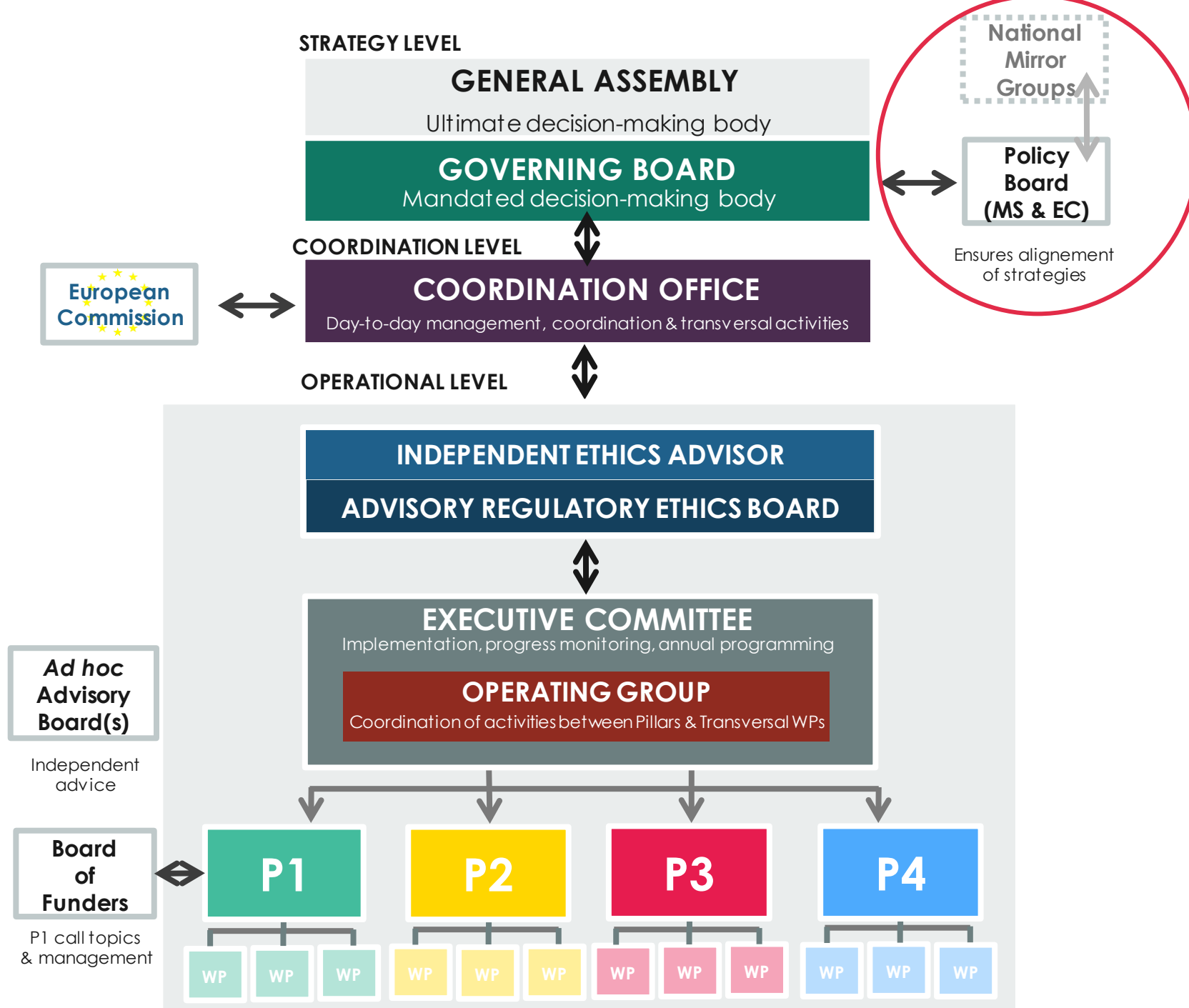


Access to extensive RD network & expertise

Multiple collaboration opportunities

Possibility of alignment

Access to resources & tools



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Follow us on social media



[@EJPRarediseases](https://twitter.com/EJPRarediseases)



The EJP RD initiative has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement N°825575

HEALTHCARE +

PATIENT NEEDS

FUNDING

INFRASTRUCTURES

STRATEGY

**ADVANCING
RESEARCH
FOR RARE
DISEASES**

