



ERICA

European Rare Disease Research
Coordination and Support Action

Building together the ERN Research Roadmap Continuation of ERN Research Cooperation beyond ERICA

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Current Status of ERN Research

- **30 funded Horizon Europe projects „relevant for ERNs“**
 - 9 from RD-specific call
 - 21 from open calls
 - **3 IHI projects (c4c, Screen4Care, RealiseD)**
 - **28 projects in EJP-RD Joint Transnational Calls**
- > 61 (=10/year) ERN-relevant EU research projects launched

Current Status of ERN Research

Involvement of ERNs in ERDERA (1st period 2024-2027):

WP6-8: Diagnostic pipeline offered to all ERNs

WP9: 8 ERN registries involved in model RWD projects

WP10: 8 ERNs involved in PCOM/App development

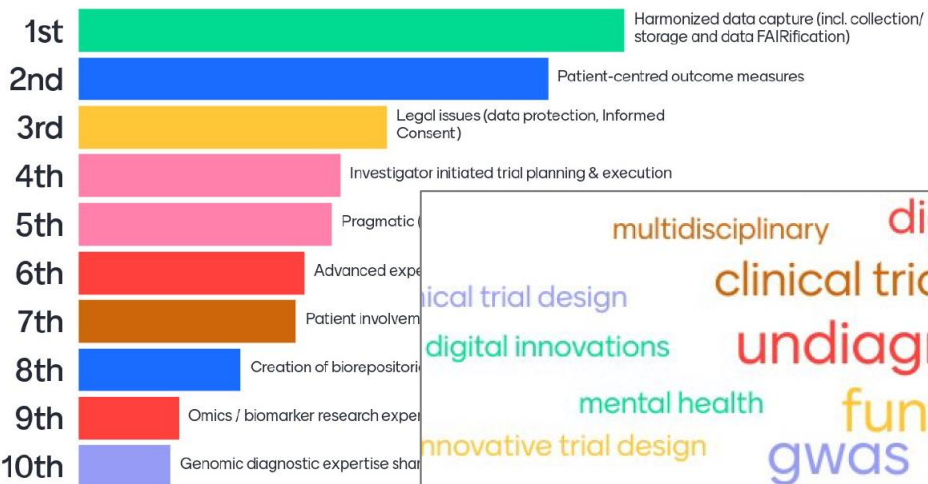
WP11: All ERNs invited to RD prioritization exercise for ATMP development

WP14-15: 11 ERNs represented in, all invited to join ERDERA Virtual Platform

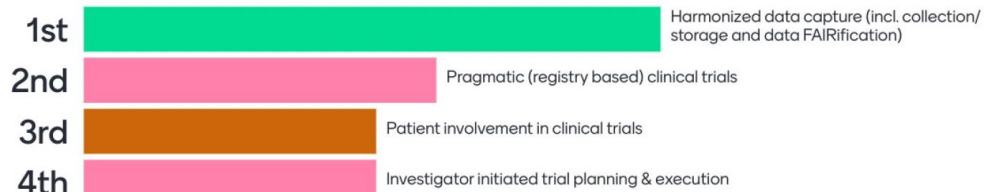
WP25: ERN/ERDERA alignment

Most Eminent RD Clinical Research Themes

2021



2024



ERN Collaborative Research: Strategic Considerations

- **ERN research funding from EU4Health grants:**
 - Coordinative activities, ERN registry support, clinical rather than research exchange grants, patient-centered/patient-driven research
- **ERN-targeted European research calls?**
 - Horizon Europe call for RD topic requiring ERN collaboration?
 - ERDERA: Call for Clinical Trials upcoming
 - ERDERA: ERN-Dedicated Joint Transnational Call(s)?
(e.g. on registry-related topics: exploring RWD by innovative statistical / AI approaches, designing pragmatic trials, genotype-phenotype correlations etc.)
- **Public-Private Research Partnerships?**
 - Registries providing multiple opportunities
 - Paradigm change needed and ongoing

ERN Research: Proposed Post-ERICA Coordination and Activities

- **ERN CG Research Working Group**
 - suspended since start of ERDERA
 - to be reactivated
 - structure?
 - functions?
 - mode of working?

ERN Research: Proposed Post-ERICA Coordination and Activities

- **ERN Research Website**
 - to sustain ERICA website contents
 - to showcase intra/inter-ERN research activities
 - to inform about funding opportunities
 - to include new functionalities (e.g. gene variant database) ?
 - Curation? Funding?
 - Integration into ERDERA website?

ERN Research: Proposed Post-ERICA Coordination and Activities

- **ERN Registry task force**
 - ERICA WP2 legacy
 - to be formed at ERICA Registries @ Heidelberg Workshop, Feb 25

ERN Research: Proposed Post-ERICA Coordination and Activities

- **Annual ERN Research Conference**
 - Needed?
 - Format?
 - Funding?