



ERICA

European Rare Disease Research
Coordination and Support Action

JARDIN & ERN Research

ERN-Bond/Jardin

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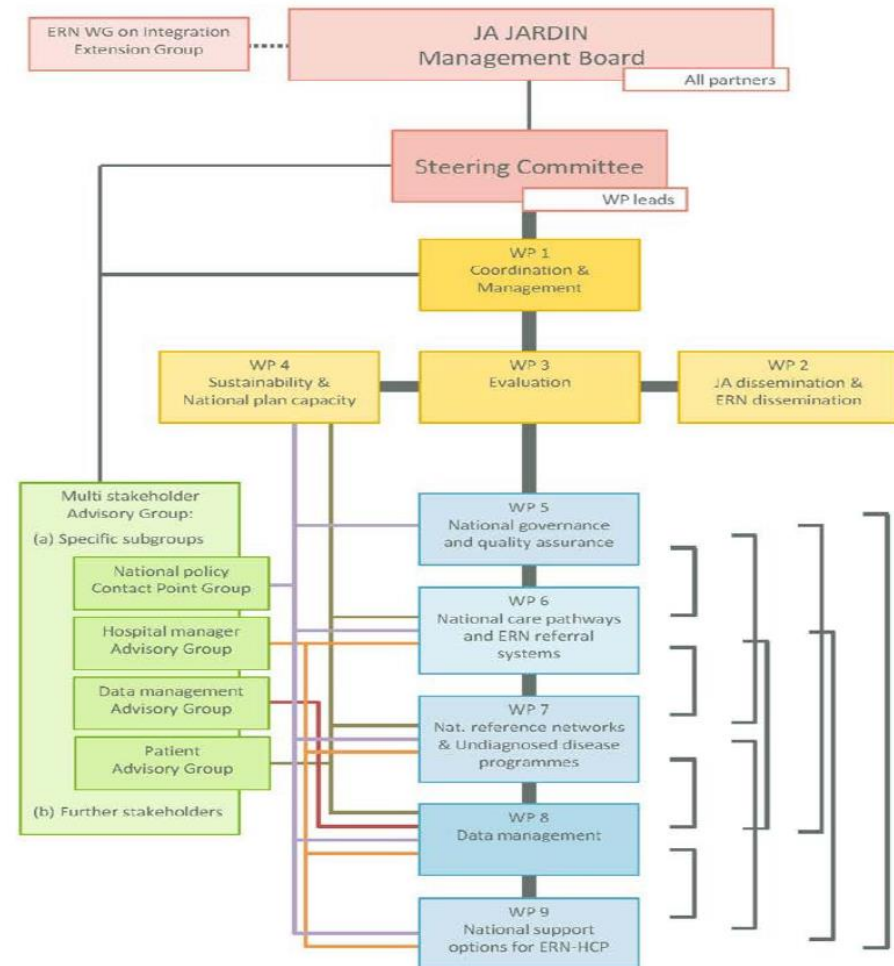
Friday, December 13th 2024

Joint Action JARDIN

Basic figures:

- » 60 partner institutions
 - » 29 Member States
 - » 28 Competent authorities (CA)
 - » 31 Affiliated Entities (AE)
 - » 1 Associated partner
- » Funding
 - » Exceptional utility rule

» EU:	15.000.000,00
» MS:	3.750.000,00
» Total:	18.750.000,00
» (DK):	266.000,00



JARDIN WP complementarities with ERDERA

- WP4: Sustainability of outcomes and outputs of the Joint Action
- WP5: National governance and quality assurance models
- WP6: National care pathways and ERN referral systems
- WP7: National reference networks and undiagnosed disease programmes or equivalent strategies interlinked with ERN
- WP8: Data management

JARDIN WP5 tasks complementarities

5.1 Mapping of existing national governance models for ERN-HCPs and care pathways in MS for a complete understanding of national governance systems and RD policies

5.2 Identification of existing best practices, gaps, and deficiencies

5.3 Identification of elements and means to align national and European ERN policies

5.4 Definition of possible systems that could be applied to different national contexts

5.5 Mapping of national quality assurance models and good practices in rare and complex diseases in MS

5.6 Identification and elaboration of selected and meaningful indicators for a national monitoring of rare and complex diseases primarily focussing on care pathways

5.7 Development of a framework for the collection of national monitoring data

5.8 Collection of national indicators

5.9 Development of monitoring indicators for ERN integration

5.10 Implementation of the integration indicators into different MS

Overlap with **JARDIN WP4 WP5**

ERDERA WP25, T25.4 Global Collaborations

Objective: To establish international partnerships that will benefit ERDERA and promote sharing of resources, expertise, and research findings which will address issues of resource fragmentation, harness collective knowledge and expertise, and facilitate exchange of information and data, ultimately leading to improved diagnosis and the development of new and innovative treatments for RDs.

T25.4 align research strategies within the ERNs and with ERDERA. A platform "ERNs Living Lab" will be created to foster new cross-fertilizing communication and avenues across ERNs and stakeholders to accelerate patient-relevant advancements and discuss the alignment of research strategies and implementation of the acquired knowledge in activities of ERDERA and beyond.

Overlap with **JARDIN** WP4 WP5

ERDERA WP23 – NMGs promotion and national alignment

Objective: ensure the alignment of European and national RD research policies and activities by supporting the deployment, the operations, and the synergies of and between the **National Mirror Groups** (NMGs) in all participating countries.

An **NMG** is a group created – or designated - in each country, benefiting from the ERDERA to bring together the expertise and knowledge of the RD community of a specific country. The objectives of a NMG are to identify national needs that should be discussed and addressed, if possible, within the framework of the ERDERA activities; to coordinate national stakeholders and promote national alignment with the European RD research strategy, to revitalize the national RD plans/strategies and to collect and share lessons learned and good practices. NMGs will also be solicited to help with liaising with the national stakeholders, including but not limited to funders, to manage lessons learned from the cancer field and organise, when relevant, joint activities (like common or complementary funding opportunities).

- Jardin's aim on *national alignment* aspects and NMGs in ERDERA are directly connected

Overlap with JARDIN WP7 National reference networks and undiagnosed disease programmes or equivalent strategies interlinked with ERN

ERDERA WP6 Diagnostic data availability

Objective: Establish a network of diagnostic research centres in underrepresented countries based on NMGs, ERNs, Joint Action JARDIN, and 1+MG.

Overlap with JARDIN WP8 Data management (Ana Rath)

ERDERA Data Services Hub: WP13, WP 14, WP15, WP16

Objective. Data Services Hub to facilitate global data collection, integration, analysis, and sharing at a global scale:

- WP13: RD-VP: finding & accessing data ecosystem
- WP14: Data readiness services
- WP15: Data sharing and analysis services
- WP16: Knowledge bases, ontologies & semantic models for RD research

Overlap with **JARDIN WP8** Data management (Marco Roos)

ERDERA WP14 Data Readiness Services

Objective To expand the use of services by which RD partners contribute to ERDERA's robust infrastructure of data, resources, and expertise (SRIA OO2) to accelerate the automated ethical and legal exploitation of the healthcare and research data from their projects (based on guidance from WP1 and WP17-19), boosting scientific and regulatory evaluation and healthcare delivery (SRIA SO2).

Overlap with JARDIN WP8 Data management, **Task 8.1** ‘Identification of current barriers to RD data sharing and inventory of existing solutions’ and 8.3 ‘Propose and develop solutions to overcome organisational, technical, and legal barriers to integration of national health systems and ERN data management’) (Franz Schaefer).

ERDERA WP 9 Real World Data

ERDERA WP 11 Task 11.1 ATMP Prioritization

Objective WP9 To augment the trial readiness of real-world data available to the CRN partners.

Objective WP11 T11.1 Identify and rank disease indications requiring ATMPs. A multistakeholder survey will be performed across the ERDERA. First, general criteria for ATMP treatment suitability will be pre-defined by experts

Overlap with JARDIN WP8 Data management **Task 8.3**, Propose and develop implementable solutions to overcome organisational, technical, and legal barriers to integration of national health systems and ERN data management

ERDERA WP9 Real World Data

Objective. WP9 Task 9.1, Use of primary healthcare data for RD outcome research (M1-M60) TL: SRUMC; Contributors: VHIR, APHP, Erasmus MC, UPM, LMU, KUM. Structured and unstructured EHR data will be extracted and prepared for re-use in registries and outcome research projects.

Overlap with JARDIN WP7 National reference networks and undiagnosed disease programmes or equivalent strategies interlinked with ERN

ERDERA WP6 Diagnostic data availability

Objective Establish a network of diagnostic research centres in underrepresented countries based on NMGs, ERNs, Joint Action JARDIN, and 1+MG.

NEXT:

January 8th 2024, ERDERA-JARDIN collaborative workshop

Thank you

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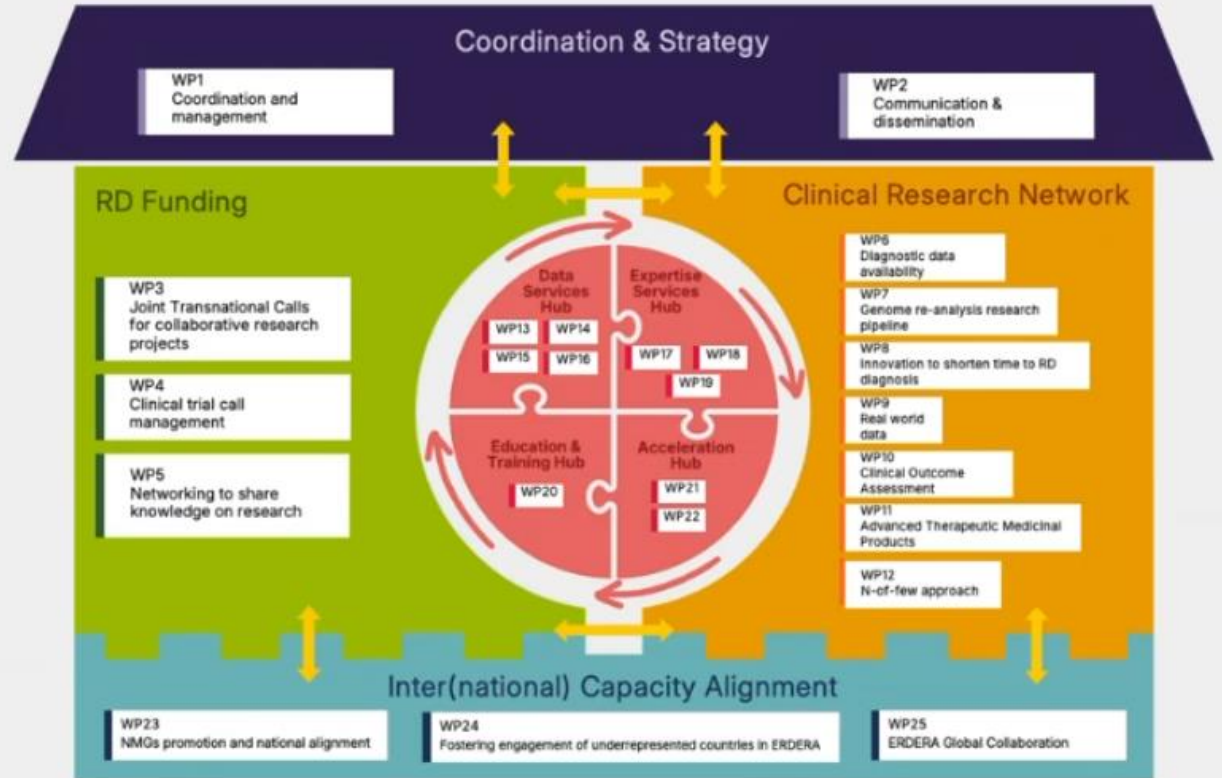
ERDERA

European Rare Diseases Research Alliance

- 178 Organisations**
- 40 funders**
- 81 research performing organisations**
- 9 patients' organisations**
- 3 research infrastructures**
- 22 private for-profit partners (industry & SME)**
- 23 other (univ, hospital, non-profit, public administration)**

- 37 Countries**
- 26 EU member states**
- 8 associated countries***
- 3 non-EU***

*at the time of ERDERA proposal submission



- WP13 Rare Diseases-Virtual Platform (RD-VP): Finding and accessing the data ecosystem
- WP14 Data readiness services
- WP15 Data sharing and analysis services

- WP16 Knowledge bases and ontologies for RD research
- WP17 Mentoring and consultancy
- WP18 Regulatory support service

- WP19 Methodological Support
- WP20 Education and training in rare diseases research
- WP21 Technology accelerator

WP22 Public-Private Collaboration Accelerator

