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Respondent

2 Anonymous

09:49
Time to complete

Participation Agreement (GDPR)

This form is specifically dedicated to collect information for the purpose of the European Rare Diseases Research Alliance (ERDERA), ***Task 25.4 Alignment with the Research strategies of the European Reference Networks.*** *We collect Personal Data freely provided by the user including (but not limited to): name, email address, and any other details specifically asked in this forms. ERDERA does not share personally identifiable information with unrelated Third Parties. However, we may disclose, transfer or share your Personal Data - anonymized or in its original format - with certain third parties in compliance with the GDPR provisions without further notice to you, only for the organization and follow up of this task.*

Information collected on this form will be held in compliance with the General Data Protection Regulation (EU Regulation 2016/79) (GDPR) of the European Parliament and of the Council as of 27 April 2016 on the protection of natural persons with regards to the processing of personal data and on the free movement of such data. Data will be processed and stored, on ERDERA secured Collaborative Platform, for at least at least five years after ERDERA ends (i.e., final payment).

If you want to have more information on data processing, for example know how your personal data is being processed, or if you want to exercise your right according to Articles 15-22 of the GDPR, or if you notice a personal data breach according to Articles 33-34, please contact the data controller who determines the purpose and means of the processing of personal data.

Contact details *: coordination@erdera.org*
More information on ERDERA: *https://erdera.org/about/*

1. Participation Agreement (GDPR) *

- ( ) I agree

This question is required.

2. First Name *

Alexis

3. Last Name *

ARZIMANOGLOU

4. Organisation *

EPICARE

5. email *

aarzimanoglou@orange.fr

6. **Name of the ERN with which you are most closely associated (Select one or more if applicable)** *

- [ ] ERN BOND
- [ ] Endo-ERN
- [x] ERN EpiCARE
- [ ] ERKNet
- [ ] ERN LUNG
- [ ] ERN Skin
- [ ] ERN EURACAN
- [ ] ERN EuroBloodNet
- [ ] ERN EURO-NMD
- [ ] ERN GENTURIS
- [ ] ERN GUARD-HEART
- [ ] MetabERN
- [ ] ERN PaedCan
- [ ] ERN RARE-LIVER
- [ ] ERN TRANSPLANT-CHILD
- [ ] ERN-RND
- [ ] ERNICA
- [ ] ERN eUROGEN
- [ ] VASCERN
- [ ] ERN ReCONNET
- [ ] ERN RITA
- [ ] ERN ITHACA
- [ ] ERN EYE
- [ ] ERN CRANIO

7. **Your role in the ERN** *

- [x] ERN coordinator (I am the Coordinator, or else am completing this as a Chair of a relevant Working Group, or else I have surveyed the network at large to the point where I feel comfortable speaking on behalf on 'the ERN')
- [ ] HCP member (I am the HCP representative, or else I have surveyed the HCP at large to the point where I feel comfortable speaking on behalf on 'the HCP')

8. **Do you know what ERDERA is ?** *

- (●) Yes
- ( ) No

9. **Is your ERN as a network involved in the ERDERA project?** *

- (●) Yes, please specify
- ( ) No
- ( ) I do not know

10. Please specify below

Co-chair of T25.4

11. **Is your medical team involved in ERDERA activities?**

- ( ) Yes, please specify
- (●) No

ERN Research activities

12. **Does your ERN/HCP has a transversal Working Group for research?** *

- (●) Yes, please specify
- ( ) No

13. Please specify (list all here below)

Clinical Trials; A list of Labs attached or collaborating with EPiCARE members

14. **What type of research activities are currently ongoing in your ERN/HCP?** *

- ( ) Basic
- ( ) Diagnostic Research Studies
- (•) Observational Clinical Studies
- ( ) Interventional Clinical trials
- ( ) Outcome measures
- ( ) Other

15. Please specify here

16. **What plans or strategies has your ERN/HCP developed to advance clinical research in your field?** *

We ddfined 5 priority domains. Publication submitted

17. **What do you think are the most eminent topics for ERN research in the coming 5 years (rank at least top 3)** *

1 Investigator initiated trial planning & execution
2 Patient-centred outcome measures
3 Pragmatic (registry based) clinical trials
4 Harmonized data capture (incl. collection/storage and data FAIRification)
5 Genomic diagnostic expertise sharing
6 Patient involvement in clinical trials
7 Omics / biomarker research expertise sharing
8 Legal issues (data protection, Informed Consent)
9 Creation of biorepositories
10 Advanced experimental therapies

18. Any other topics that are relevant and not listed above

19. **Reflecting on the past 5 years, in which research areas has your ERN/Medical Team made the most progress or invested the most effort?** *

As an ERN in defining research priorities. EpiCARE has a dedicated Research Council. A procedure is in process to identify mid-career leaders in the field to drive research

20. **If resources were not a limiting factor, what research areas or projects would your ERN/Medical Team prioritize in the coming years?** *

Natural History Studies; Identification of Biomarkers; Precision/Targeted therapies

21. **Does your ERN/Medical Team currently have any concrete tools or resources (e.g., expertise in small population trial design, clinical research-ready databases or registries, SOPs, or infrastructure supporting site readiness or research projects) that could support future clinical research or trial activation — either at the planning or implementation stage?** *

- (●) Yes
- ( ) No

22. ***Please rate the relevance (from very low impact to very high impact) of the following obstacles/barriers, in terms of hindering clinical research in your ERN.*** *

	Very low	Low	Neutral	High	Very high
Challenges in defining outcomes	○	○	◉	○	○
Challenges in building relationships with industry	○	○	◉	○	○
Challenges in building relationships with regulatory agencies/authorities	○	○	○	○	◉
Challenges in conducting clinical research that complies with regulatory requirements	○	○	○	◉	○
Independent Ethics Committee issues	○	○	○	◉	○
Lack of suitable PROMs & PREMs	○	○	○	◉	○
Challenges in seeking patient input for research priorities	○	○	◉	○	○
Challenges in seeking patient input for clinical trial protocol design	○	○	◉	○	○
Challenges in seeking patient input for clinical trial conduction and monitoring	○	○	◉	○	○
Challenges in enrolling patients	○	○	◉	○	○
Challenges in identifying and involving HCPs	○	○	◉	○	○
Issues around clinical data management	○	○	○	○	◉
Lack of funding	○	○	○	◉	○

23. Other, please specify

24. **Have you encountered any obstacles in implementing research projects ?** *

- (●) Yes
- ( ) No

Obstacles and Proposed Solutions

25. *Challenges in clinical trials*

Regulatory issues

26. *Solutions for clinical trials*

27. *Challenges in Natural history studies*

Funding

28. *Solutions for Natural history studies*

29. *Challenges in Registries*

Data sharing issues

30. *Solutions for Registries*

31. **Does your ERN/Medical Team foster the involvement of patient organisations and/or patients in research activities?** *

- (●) Yes
- ( ) No

32. **Any additional comments regarding ERNs (as network) added value in research, or suggestions for improving patient involvement in clinical research?**

Cross-ERN & Multicenter Research Projects

This section aims to explore current and future opportunities for collaborative research across clinical centers and European Reference Networks (ERNs). With 24 ERNs covering a wide range of rare and complex diseases, fostering translational research across networks is essential to address shared challenges and leverage collective expertise. We seek to gather insights from ERN members (both individually and as part of their networks) regarding their involvement in multicenter projects, cross-ERN research initiatives, and the tools or resources needed to support these efforts.
Our objectives include:

- Identifying existing and potential **translational research collaborations** across ERNs.
- Developing a **dedicated digital platform, using existing ERICA ERN website** to streamline and facilitate ERN-based cooperation.

Ensuring that the ERN Living Lab (ERN-LL) fosters **cross-fertilization between researchers and clinicians** across disease areas.

33. **Are you currently coordinating in a multicenter research project involving other members of your ERN?** *

- ( ) Yes
- (•) No

34. **Are you currently participating in a multicenter research project involving other members of your ERN?**

- (•) Yes
- ( ) No

35. If Yes, The name of project & Principal Investigator of the project with his contact information

Grant Applications & Funding

36. **Have you applied for research grants (EU Grants or International) related to research studies in the past 3 years?**

- (•) Yes, on behalf of the ERN as a network
- ( ) Yes on behalf of my medical team
- ( ) No

37. **If yes, please provide details:**

- Grant (s) Name (s)
- Funding Agency (ies)
- Year of Application (s)
- Was the grant approved for funding? (Yes / No / Pending decision):

38. **Anything else you like to comment or share with us:**