

Open Academy Schools



Navigating rare disease research: data, ethics, and AI in Europe

This specialised online training is designed for 20 rare disease advocates from Europe and will consist of 18 hours of virtual instruction spread over six months (January to June). The program will include e-learning, webinars, and assignments.

What will you learn?

- Understand various types of research data relevant to rare diseases and identify reliable sources.
- Explain the role of health data in rare diseases research, particularly in patient registries, regulatory processes, and real-world data usage.
- Identify and analyze the roles of different actors in data processing, such as researchers, institutions, and patient advocates.
- Recognize key challenges in using health data for rare diseases research, including data codification, standardization, and researching ultra-rare diseases.
- Discuss the principles, benefits, and challenges of data sharing, including the application of FAIR principles and international complexities.
- Navigate the ethical, regulatory, and data protection frameworks, including GDPR, informed consent, and ethics approvals.
- Evaluate the perspectives of key stakeholders in data processing, focusing on patient concerns about data sharing.
- Develop a comprehensive understanding of AI's role in rare diseases research and its integration into current research methodologies.

This training has been developed in response to the growing need for advocates to understand and navigate the complexities of data management, ethical considerations, and the role of AI in rare disease research across Europe. Its primary objective is to equip participants with the knowledge and skills to effectively engage with and influence data-driven research initiatives in the rare disease community.



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Programme features

- **Program level:** intermediate
- **Format:** online webinars + assignments
- **Target Audience:** patient advocates and young researchers (PhD and PostDoc)
- **Duration:** from January until end of June (**minimum 3 hours per month**)
- **Participants:** 20
- **Total Hours:** 18-24 hours

Topics:*

- Introduction to research and data sources
- Health data in rare disease research
- Data sharing: benefits, challenges and ethics
- Ethical and regulatory frameworks
- Data processing and actors involved
- Advanced topics in data use
- Patient perspectives and AI applications

Starting in January, participants in this new online programme will be required to complete an online course within the first 4 weeks, followed by monthly webinars from January to June.

This training programme is not definitive and is subject to change.

Criteria

To take part, **you must be a rare disease patient advocate or PhD/up to 2yrs post PhD researcher**. As all training is conducted in English, a good level of the language is required. Patient representatives don't need to be a member of EURORDIS but must represent a patient organisation to apply. Researchers must represent a research institute or hospital.

The Open Academy Schools 2025 have been developed in collaboration with:



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