ERDERA
European Rare Diseases
Research Alliance

Navigating Rare Disease Research: Data, Ethics and AI

Webinar 0: Introductory webinar

Gemma Rodríguez, Marta Campabadal, Roseline Favresse (EURORDIS-Rare Diseases Europe)
Dimitrios Athanasiou (World Duchenne Organization)
Elvina Sakellariou (Duchenne Data Foundation)
Friday 17 January - 12:30-13:30 CET

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Meet the team

Gemma Rodríguez
Open Academy Training Manager (EURORDIS)

Marta Campabadal
Open Academy Senior Manager (EURORDIS)

Roseline Favresse
Research Policy and Initiatives Director (EURORDIS)

Dimitrios Athanasiou
Board Member (WDO)

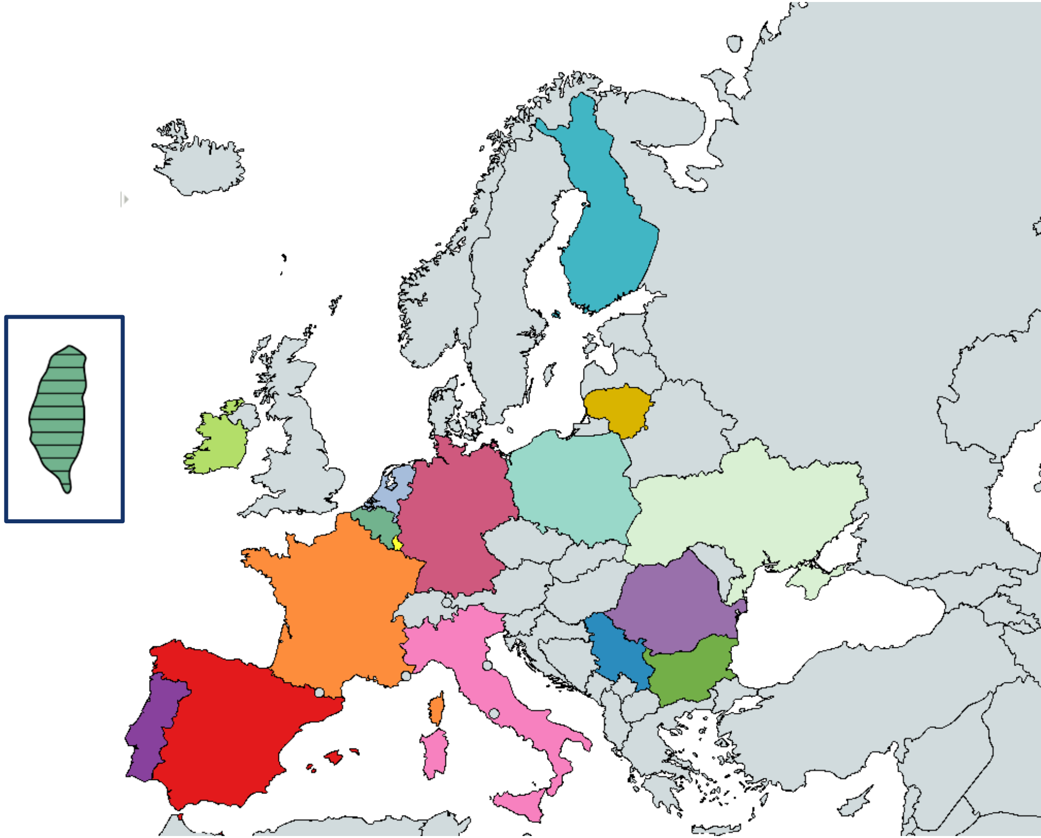
Elvina Sakellaroiu
Operations Officer, Research Project Manager(DDF)

Meet the participants

31 participants

17 countries

25 Rare Diseases



Meet the participants

1

What is your name?

2

Where are you from?

3

What is your organisation? What disease are you representing?

Introduction

- 1st edition!
- From January to July 2025
- Training programme targeted to patient advocates and young researchers
- 18h and 24h hours of training (12 webinars)
- This training programme covers topics such as: Introduction to research and data sources; health data in rare disease research; benefits and challenges of data sharing; data processing and actors involved; ethical and regulatory frameworks; patient perspectives and AI applications; and advanced topics in data use.
- Interactive webinars: lecturing by expert speakers, case studies, in-webinar discussions, tools exploration, inspiring practices, etc.

Learning outcomes

IDENTIFY

Different types of data relevant to rare diseases (clinical, genomic, real-world data) and reliable data sources

EXPLAIN

the significance of health data in rare diseases research, focusing on patient registries, regulatory processes, and the role of real-world data

DISCUSS

the roles and responsibilities of key stakeholders in data processing, including clinicians, researchers, institutions, and patient advocates

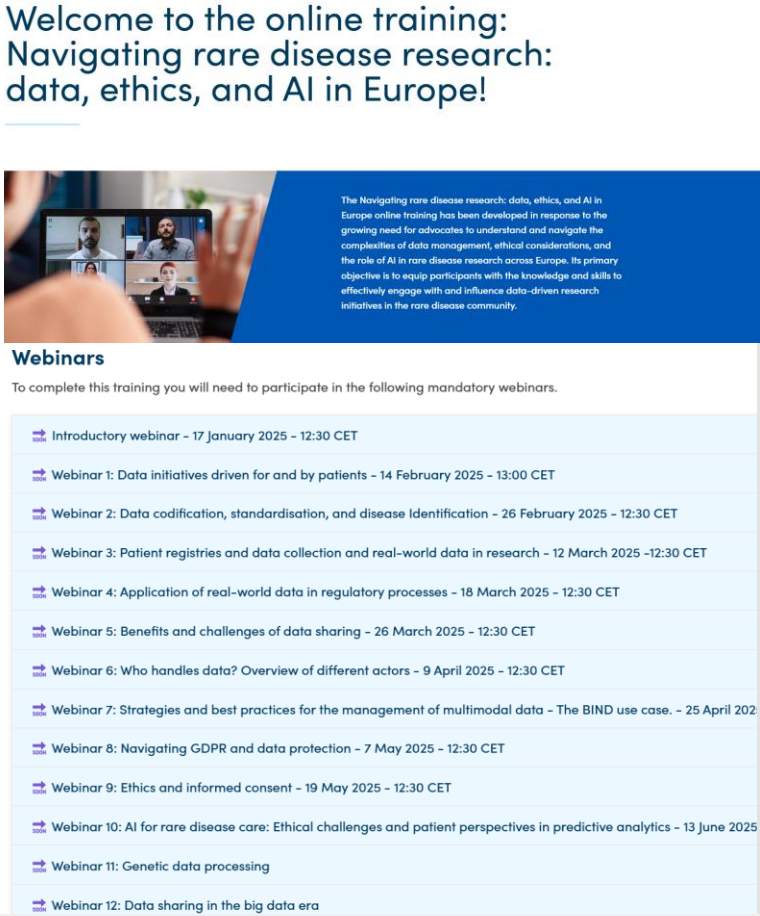
ASSESS

the challenges and ethical considerations related to health data use in rare diseases, including data codification, standardization, privacy concerns, and the impact of AI in research.

Calendar and website

- Navigating Rare Disease Research: Data, Ethics and AI website: https://openacademy.eurordis.org/navigating-rare-disease-research-data-ethics/

- On this website you will find information about:
  - Webinars (calendar, speakers, zoom link)
  - E-learning
  - Programme
  - Faculty



Welcome to the online training: Navigating rare disease research: data, ethics, and AI in Europe!

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

Webinars

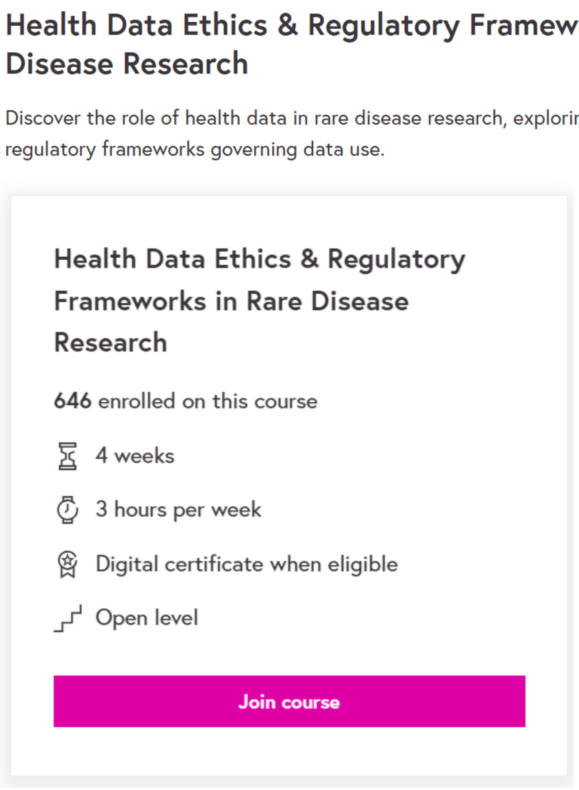
To complete this training you will need to participate in the following mandatory webinars.

- Introductory webinar – 17 January 2025 – 12:30 CET
- Webinar 1: Data initiatives driven for and by patients – 14 February 2025 – 13:00 CET
- Webinar 2: Data codification, standardisation, and disease Identification – 26 February 2025 – 12:30 CET
- Webinar 3: Patient registries and data collection and real-world data in research – 12 March 2025 -12:30 CET
- Webinar 4: Application of real-world data in regulatory processes – 18 March 2025 – 12:30 CET
- Webinar 5: Benefits and challenges of data sharing – 26 March 2025 – 12:30 CET
- Webinar 6: Who handles data? Overview of different actors – 9 April 2025 – 12:30 CET
- Webinar 7: Strategies and best practices for the management of multimodal data – The BIND use case. – 25 April 202
- Webinar 8: Navigating GDPR and data protection – 7 May 2025 – 12:30 CET
- Webinar 9: Ethics and informed consent – 19 May 2025 – 12:30 CET
- Webinar 10: AI for rare disease care: Ethical challenges and patient perspectives in predictive analytics – 13 June 2025
- Webinar 11: Genetic data processing
- Webinar 12: Data sharing in the big data era

FOUNDATION FOR Rare Diseases

EUROPEAN JOINT PROGRAMME RARE DISEASES

Pre-training



Health Data Ethics & Regulatory Frameworks in Rare Disease Research

Discover the role of health data in rare disease research, exploring the ethics and regulatory frameworks governing data use.

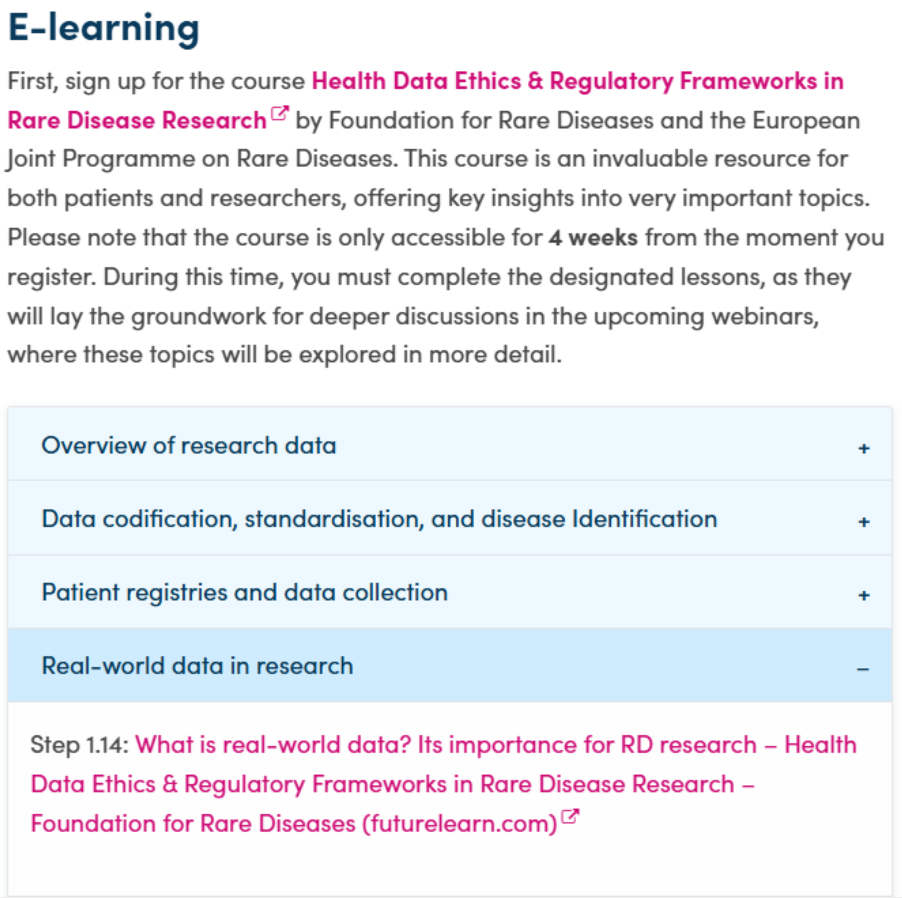
Health Data Ethics & Regulatory Frameworks in Rare Disease Research

646 enrolled on this course

- 4 weeks
- 3 hours per week
- Digital certificate when eligible
- Open level

- Sign up for Health Data Ethics and Regulatory Frameworks in Rare Disease Research by Foundation for Rare Diseases and the European Joint Programme on Rare Diseases
- Key insights on Rare Diseases Research and Data
- **Content available only 4 weeks from the moment you register** (before the first webinar)
- Useful lessons detailed on the website
- Not mandatory but highly recommended

Pre-training



E-learning

First, sign up for the course **Health Data Ethics & Regulatory Frameworks in Rare Disease Research** by Foundation for Rare Diseases and the European Joint Programme on Rare Diseases. This course is an invaluable resource for both patients and researchers, offering key insights into very important topics. Please note that the course is only accessible for **4 weeks** from the moment you register. During this time, you must complete the designated lessons, as they will lay the groundwork for deeper discussions in the upcoming webinars, where these topics will be explored in more detail.

Overview of research data +

Data codification, standardisation, and disease Identification +

Patient registries and data collection +

Real-world data in research –

Step 1.14: What is real-world data? Its importance for RD research – Health Data Ethics & Regulatory Frameworks in Rare Disease Research – Foundation for Rare Diseases (futurelearn.com)

- On the website you'll find the selected lessons where key topics will be explored in more details during future webinars

Assessment methods and criteria

- Students must participate in all the mandatory webinars
- Digital certificate of completion
- A virtual attendance sheet will be available during each session
- If, for any reason, a student can't attend any of the webinars, they must communicate it in advance to gemma.rodriguez@eurordis.org

Next webinar

Webinar 1: Data initiatives driven for and by patients

14 February 2025 13:00 CET

Zoom link available on the school webpage

Elvina Sakellariou
Research Coordinator and
Project Manager at Duchenne
Data Foundation

Holm Graessner
Managing Director of the
Rare Disease Centre at the
University and University
Hospital Tübingen

Q&A