ePAG Research and Registries Working Group milestones

**NOV 2018**
ePAG Research & Registries WG was set up; Recommendations for *Improving the Quality of Rare Diseases Registries; Practical Guide to develop a Patient registry*

**DEC 2018**
EuRECA, Plan and Strategy for CHAFEA Funded Registries; European Joint Programme on Rare Diseases

**FEB 2019**
Presentation on the working process and the plan for the ERN working group on research

**APR 2019**
Outcomes of the EJP WP 20 meeting

**SEP 2019**
Registries webinars - Discussions on future plans and organisation Presentation on FAIRification of data and the role of the Go FAIR RD Network

**MAR 2021**
Re-launching the WG (scope & objectives) & Introduction of new members ERICA project

**FEB 2021**
Call for interest for new members launched

**JAN 2021**
Brainstorming for the new launch of ePAG Research & Registries WG

**SEP 2021**
Rare Diseases GO FAIR Patient Network: What's in for you?

**MAR 2022**
The overall progress of ERICA; Data Access Policy

**SEP 2022**
Exploring the EU Funding landscape: Overview of research funding opportunities Case study on getting funding for doing research on an ultra-rare disease

**JUN 2022**
Workshop on Ethics and regulatory considerations paper

**MAR 2023**
Providing feedback to ERICA project (Jan-Jun)

**SEP 2023**
GARDIAN Registry: Engaging patients in clinical trials endpoints Providing feedback on the Together 4RD initiative, Member States Statement on ERN Collaboration with Industry & Pilot projects

End of Working Group
ePAG Clinical Practice Guidelines & Care Pathways Task Force milestones

- **MAR 2021**
  - ePAG Clinical Practice Guidelines Task Force
  - Webinar #1 on scoping the group and defining priorities

- **MAR 2022**
  - Webinar #4 on Dissemination of Clinical Practice Guidelines

- **JUN 2022**
  - Launch of the Guide on patient involvement in Clinical Practice Guidelines development

- **SEP 2023**
  - Webinar #12 on methodology on Care Pathways Development to inform the Joint Action on Integration

- **JUL 2023**
  - Webinar #10 on peer learning on Research, Writing a Guideline & Implementation, based on sharing experiences in guideline development

- **AUG 2023**
  - Care Pathway Development Methodology – Summary drafted

- **SEP 2023**
  - Webinar #11 on translating Guidelines into Care Pathways

- **NOV 2023**
  - Webinar #13 on roadmap to Implement Guidelines

Connecting ePAGs to patients Working Group milestones

- **FEB 2021**: Connecting Patients with ERNs WG was set up
- **OCT 2021**: Publication of the Factsheet “Patient engagement in European Reference Networks”
- **APR 2022**: Creation of the video and slide deck “ePAGs and ERNs 101”
- **MAY 2022**: Publication of the “Thinking to become an ePAG advocate Guide”
- **JUN 2022**: Concept development of podcast episodes on ERNs and ePAGs
- **MAY 2023**: Webinar on approaches to involve patients in RD National Networks and similar initiatives; ePAG Newsletter published #2
- **FEB 2023**: ePAG Newsletter published #1
- **DEC 2022**: Launch of 1st podcast episode on ERNs and ePAGs
- **SEP 2022**: Recording of the 2nd podcast episode on ERNs and ePAGs
- **AUG 2022**: Recording of the 1st podcast episode on ERNs and ePAGs
- **JUL 2023**: ePAG Newsletter published #3
- **SEP 2023**: Launch of Podcast episode ERNs on Air: not 2 are alike
- **OCT 2023**: ePAG Newsletter published #4
- **NOV 2023**: Launch of podcast episode ERNs on Air: giving back to your community
- **DEC 2023**: FAQs on ePAGs and EURORDIS published on website
ePAG AMEQUIS Task Force

milestones

**Workshop #1** on Assessment of ERNs
**Workshop #2** on Evaluation of ERNs
**Workshop #3** on Monitoring of ERNs
**Workshop #4** on Preparation
**Workshop #5** on Advocacy
**Workshop #6** on Advocacy
**Workshop #7** on Advocacy

**Draft** letter on AMEQUIS proposal

**Individual ePAG Meetings (x24)** to prepare the ERNs and ePAG advocates for their involvement in the ERN Evaluation process

**Capacity building recording** for patient representatives taking part in the interview process

**Debriefing from the Interviews of Patient Leads** by the Independent Evaluation Board (IEB)

**Draft Reports** for the ERNs are expected to have been shared with the Networks for comments

**Review new ERN Monitoring Indicators**

**Development of advocacy on the outcome of the ERN 5 Yr Evaluation and dissemination.**
ePAG Patient Partnership Working Group milestones

- **MAR 2023**: Initial discussion on Patient Partnership Framework - objectives, concept and methods
- **JUN 2023**: Patient Partnership Framework workshop
- **OCT 2023**: Analysis of patient partnership survey results and feedback on Patient Partnership Framework
- **NOV 2023**: Presentation of final version of Patient Partnership Framework and preliminary discussion on implementation