ePAG Steering Committee milestones

- **FEB 2018**: ePAG Steering Committee was set up
- **APR 2018**: ePAG Constitution and Rules of procedure
- **MAY-NOV 2018**: Contribution to the drafting of the 10 Recommendations to anchor ERN into national health systems
- **NOV 2018**: Contribution to the development of the quarterly ePAG exchange of good practices webinars
- **SEP 2022**: Refined mission, role and functioning of WG 2 ePAG Co-Chairs appointed
- **JAN 2022**: New governance templates for patient representation in ERNs
- **JUN 2021**: Paper on ePAG Impact Assessment Framework published
- **SEP 2020**: Discussion and feedback on the Mature ERN paper
- **OCT 2019-MAR 2020**: Development of the ePAG Impact Pilot Framework
- **MAR 2023**: Sharing best practice on ePAG advocates involvement in ERN management
- **JUN 2023**: Workshop on Patient Partnership framework for the ERNs
- **OCT 2023**: Open Letter on ERNs co-signed with ERN Coordinators and EURORDIS
- **NOV 2023**: ePAG SC annual meeting: Monographic 5-year ERNs evaluation
ePAG Research and Registries Working Group milestones

- **NOV 2018**: Call on quality of RD Registries. Practical Guide to develop a Patient registry.
- **DEC 2018**: Call to present plan and Strategy for CHAFA ERNs funded Registries.
- **FEB 2019**: Presentation on the working process and the plan for the ERN working group on research.
- **APR 2019**: Webinar on registries. Presentation on FAIRification of data and the Go FAIR RD Network.
- **SEP 2019**: Presentation of outcome of the EJP WP 20 meeting.
- **FEB 2020**: Brainstorming for the new launch of ePAG Research & Registries WG.
- **JAN 2021**: Call for interest for new members launched.
- **MAR 2021**: Rare Diseases GO FAIR Patient Network: What’s in for you?
- **MAR 2022**: Workshop on ethics and regulatory considerations on RD research.
- **JUN 2022**: Re-launching the WG (scope & objectives) & Introduction of new members ERICA project.
- **MAR 2023**: Call to explore and explain EU funding landscape for RD research.
- **SEP 2023**: Best practice on how to engage patients in clinical trials endpoints. Providing feedback to the Together 4RD initiative.
- **NOV 2023**: Decision to transform WG into a Task Force to develop a patient partnership framework for Clinical Trials.
- **MAR 2022**: The overall progress of ERICA; Data Access Policy.
- **JUN 2022**: Call on quality of RD Registries. Practical Guide to develop a Patient registry.
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 ERN National Coordination Hubs
- **FEB 2023**: ePAG Newsletter #1
- **DEC 2022**: Launch of 1st podcast episode on ERNs and ePAGs
- **SEP 2022**: Recording of the 2nd podcast episode on ERNs and ePAGs
- **JUL 2023**: ePAG Newsletter #3
- **SEP 2023**: Launch of Podcast episode ERNs on Air: not 2 are alike
- **OCT 2023**: ePAG Newsletter #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 Clinical Practice Guidelines & Care Pathways Task Force milestones

**MAR 2021**
Scoping the group and defining priorities

**NOV 2021**
Webinars #1 and #2 on Patient involvement in Clinical Practice Guidelines development

**MAR 2022**
Webinar #3 on Dissemination of Clinical Practice Guidelines

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

**NOV 2022**
Webinars #4, 5 and 6 on Plain language summaries Roadmap to Implement Guidelines Appraisal of Existing Guidelines

**NOV 2022**
 WG agreement on additional areas for training and support for 2023

**JUL 2023**
Peer learning about Literature review for CPG, Writing a Guideline & Implementation

**SEP 2023**
Call on how to translate Guidelines into Care Pathways

**APR 2023**
WG agreement on additional areas for training and support for 2023

**NOV 2023**
Call to discuss methodology on Care Pathways Development

**JUN 2023**
Peer learning about scoping a Guideline, based on sharing experiences
ePAG AMEQUIS Task Force milestones

**MAR 2021**
Call to explain Assessment of ERNs

**JUL 2021**
Call to explain Evaluation of ERNs

**AUG 2021**
Call to explain Monitoring of ERNs ePAG working doc on the future of ERNs

**OCT 2021**
Call to prepare for AMEQUIS workshop

**SEP 2022**
Patient Guide & Q&A Factsheet on AMEQUIS Evaluation

**JUN 2022**
Webinar: Demystifying AMEQUIS

**DEC 2022**
Letter to provide feedback on AMEQUIS proposal

**JAN-FEB 2023**
Individual ePAG Meetings (x24) to prepare for their involvement in the ERN Evaluation process

**MAR 2023**
Debriefing from the Interviews of Patient Leads by the Independent Evaluation Body

**SEP 2023**
Review new ERN Monitoring Indicators

**NOV 2023**
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 Patient Partnership Framework and preliminary discussion on implementation