Timeline of the ePAG Steering Committee Working Group milestones

1. ePAG Steering Committee was set up - February 2018
2. Co-developed the ePAG Constitution/Rules of procedure - April 2018
3. Co-created the concept of the ePAG Steering Committee annual meeting - May 2018
4. Contributed to the drafting of the 10 Recommendations to anchor the ERN into national health systems - May – November 2018
5. Co-developed the concept of ePAG induction call - June 2018
6. Contributed to the development of the quarterly ePAG exchange of good practices webinars - November 2018
7. Co-produced the updated definition of ePAG Advocate role - May 2019
8. Participated in the development of the ePAG Impact Pilot Framework - October 2019 – Ongoing
9. Promoted the involvement of ePAGs in the assessment of the HCP Applicants - March 2020
10. Contributed to the refinement of the Mature ERN paper - September 2020
11. Created a participatory approach (based on an online questionnaire) to develop a position on ePAG compensation - March 2021 – ongoing
12. Assisted in the development, testing and refinement of patient-clinician team building training, including the patient-clinician reflection sessions - May – September 2022
13. Supported the reshaping of the ePAG Steering Committee role and mission
14. Co-led the restructuring of the ePAG Steering Committee role and meeting

Timeline of the ePAG Training Needs Working Group milestones

2. Members of the ePAG Training & Capacity Working Group participate in the ERN Knowledge Generation WG - 2021
3. Design of joint patient-clinician teambuilding sessions to strengthen collaboration and patient partnerships in the ERNs - January 2021
4. Develop ePAG Training Needs Survey - May 2021
5. Launch of ePAG Training Needs Survey - October 2021
6. Analysis of the results of the ePAG Training Needs Survey - January 2022
7. Communication of ePAG training needs to ERN Coordination teams - February 2022
8. Implementation of pilot patient-clinician team building sessions in 3 pilot ERNs - June December 2022
Timeline of the Connecting Patients with the ERNs Working Group milestones

1. Set up of the Connecting Patients with ERNs WG
   - February 2021

2. Publication of the Factsheet "Patient engagement in European Reference Networks"
   - October 2021

3. Creation of the video and slide deck "ePAGs and ERNs 101"
   - April 2022

4. Publication of the "Thinking to become an ePAG advocate Guide"
   - May 2022

5. Concept development of podcast episodes on ERNs and ePAGs
   - June 2022

6. Recording of the 1st podcast episode on ERNs and ePAGs
   - August 2022

7. Recording of the 2nd podcast episode on ERNs and ePAGs
   - September 2022

Timeline of the ePAG Research and Registries Working Group milestones

1. Setting up the ePAG Research & Registries WG
   - November 2018

2. Recommendations for Improving the Quality of Rare Diseases Registries
   - December 2018

3. Practical Guide to develop a Patient Registry
   - April 2019

4. EuRRECa, Plan and Strategy for CHAFEA Funded Registries
   - January 2021

5. European Joint Programme on Rare Diseases
   - February 2021

6. Presentation on the working process and the plan for the ERN working group on research
   - March 2021

7. Outcomes of the EJP WP 20 meeting
   - February 2021

8. Registries webinars - Discussions on future plans and organisation
   - September 2019

9. Presentation on FAIRification of data and the role of the Go FAIR RD Network
   - September 2019

10. Brainstorming for the new launch of ePAG Research & Registries WG
    - March 2021

11. Call for interest for new members launched
    - June 2022

12. Re-launching the WG (scope & objectives) & Introduction of new members
    - March 2021

13. ERICA project
    - June 2022

14. RDs GO FAIR Patient Network: What’s in for you?
    - March 2022

15. Workshop on Ethics and regulatory considerations paper
    - March 2022

16. The overall progress of ERICA
    - March 2022

17. Data Access Policy
Timeline of the ePAG AMEQUIS task force milestones

1. ePAG AMEQUIS Task Force first workshop (Preparation) - March 2021
2. ePAG AMEQUIS Task Force second workshop (Evaluation) - July 2021
3. ePAG AMEQUIS Task Force third workshop (Monitoring) - August 2021
4. Draft letter on ERN Monitoring & Evaluation - August - October 2021
5. ePAG AMEQUIS Task Force fourth workshop (Preparation) - October 2021
6. ePAG AMEQUIS Task Force fifth workshop (Advocacy) - November 2021
7. Draft Letter on AMEQUIS Proposal - November 2021 - February 2022
8. ePAG AMEQUIS Task Force sixth workshop (Advocacy) - February 2022
9. ePAG AMEQUIS Task Force seventh workshop (Advocacy) - April 2022
10. Demystifying AMEQUIS Webinar - June 2022
11. ePAG AMEQUIS Task Force eighth workshop (Advocacy) - September 2022
13. ERN Evaluation Webinar
14. One-on-one supporting and reflection sessions to prepare the ERNs and ePAG advocates for their involvement in the ERN Evaluation process