

CALL FOR ABSTRACTS 2026

Joint Patient Representatives–Clinicians Workshop

Showcasing Best Collaboration Stories

Date	December 1 st 2026
Location / format	Paris, France [hybrid format]

Submission deadline oct 31, 2026

About the workshop

The ERN ITHACA network is pleased to announce a call for abstracts for the 2026 Learning From Each Other Workshop, held as a joint workshop for patient representatives and clinicians of ERN ITHACA. The workshop will provide a collaborative space for patient representatives (ePAGs) and clinicians to share practical experiences, reflect on successful cooperation and inspire new approaches across the ERN ITHACA community. In 2026, the focus moves beyond showcasing the ePAGs projects and activities alone: the call seeks collaboration stories around ERN ITHACA that demonstrate how patient representatives (ePAGs) and clinicians in the ERN ITHACA network worked together to address challenges, improve care, strengthen research or education, and support people living with rare congenital malformation and intellectual disability syndromes, including diagnosed and undiagnosed conditions.

Who can submit?

- Joint submission of patient representative–clinician teams in the scope of ERN ITHACA.

A collaboration story may be submitted by one author on behalf of a wider partnership, provided that the roles and contributions of the collaborating patient representatives/ePAGs and clinicians are clearly described.

What kind of stories are invited?

The call welcomes abstracts describing completed, ongoing or recently initiated collaborations. Examples include, but are not limited to:

- Co-design or improvement of clinical pathways, services or models of care.
- Collaboration in diagnosis, referral, transition or multidisciplinary care.
- Joint involvement in research, registries or data collection.
- Joint development of educational resources, training activities or health-literacy initiatives.
- Co-production of guidelines, recommendations, information materials or decision-support tools.
- Collaboration supporting undiagnosed patients and families.
- Patient involvement in ERN ITHACA working groups, governance or quality-improvement activities.
- Joint advocacy, awareness-raising or policy activities.
- Use of digital tools, telemedicine or other innovative approaches to improve communication and access to expertise.
- Initiatives that strengthen trust, communication and shared decision-making between patients and healthcare professionals.
- Stories do not need to describe large or formally funded projects. Small-scale initiatives, lessons from practice and honest accounts of what worked, what was challenging and what was learned are equally welcome.

Suggested abstract content

1. Title and authors: Provide a concise title and list all authors, roles and organisations. Identify whether each author is a patient representative/ePAG member, clinician or another stakeholder.
2. Background and challenge: Explain the need, problem or opportunity that prompted the collaboration.
3. Aim: State what the patient representative/ePAG and clinician partners sought to achieve together.
4. Collaboration approach: Describe how the partners worked together, including their respective roles, responsibilities and contributions to decision-making or implementation.
5. Outcomes and added value: Present results achieved so far, or expected benefits if the collaboration is ongoing. Where possible, include feedback, examples, indicators or other evidence of change.
6. Learning and reflection: Explain what made the collaboration effective, what challenges were encountered and how these were addressed.
7. Transferability: Describe what other ERN ITHACA teams, rare disease communities or regions could learn and how the approach could be adapted.
8. Corresponding author: Include the email address of the author who can be contacted for further information.

Submission guidelines

- Abstracts must be no longer 250- 300 words, including the title and authors.
- Steps : Background/Introduction; Methods; Results; Conclusion
- Identify the patient representative/ePAG and clinician perspectives represented in the collaboration.
- Submitted online on ITHACA's web site, deadline by Oct 31, 2026

<https://ern-ithaca.eu/events-news/upcoming-events/ern-ithaca-board-meeting-4/>

Criteria for selection

- Meaningful collaboration: The story demonstrates genuine cooperation between patient representatives/ePAGs and clinicians, with clearly described and valued contributions from both perspectives.
- Relevance to ERN ITHACA: The collaboration addresses issues relevant to rare congenital malformation and intellectual disability syndromes, diagnosed or undiagnosed conditions, or the work of the ERN ITHACA network.
- Impact and added value: The collaboration has improved, or has clear potential to improve, care, research, education, communication, patient experience or outcomes.
- Learning potential: The abstract provides practical insights, lessons learned or recommendations useful to other teams and organisations.
- Innovation: The collaboration applies a creative, new or particularly effective approach to addressing a challenge.
- Evidence of success or potential: The story provides evidence of positive change or presents a credible pathway towards impact.
- Transferability: The approach can be adapted, scaled or applied in other rare disease contexts, settings or regions.
- Balance and inclusiveness: The abstract reflects respect for different forms of expertise and demonstrates an inclusive approach to partnership.

Presentation format

Selected abstracts will be presented during the Workshop in Paris, December 1st 2026. Presentations should focus on the story of the collaboration: the challenge, the partnership, the actions taken, the results and the lessons that others can apply.

The ideal presentation would include a joint presentation (ePAG+clinician), but the type (in-person, remote) can be adapted to different settings (also one presenter in-person, one presenter remote is a possible setting). If not possible that both sides of the team are present, this will be discussed separately with the organization team. Further information about presentation length and format will be communicated to selected authors.

Key dates

Milestone	Date
Call for abstracts opens	Sept 21, 2026
Submission deadline	Oct 30, 2026
Notification of results	Nov 14, 2026
Joint ERN ITHACA Patient Representatives–Clinicians Workshop	December 1 st 2026, on site in Paris and online

Invitation

ERN ITHACA welcomes collaboration stories from across its network, whether they describe an established partnership, an emerging initiative or an experience that generated important lessons. The 2026 workshop will offer an opportunity to recognise effective patient representative–clinician collaboration, exchange practical knowledge and identify approaches that can strengthen person-centred care, research and support for people and families living with rare diseases.

Please submit your abstract by oct 31 2026

Contact ERN ITHACA's Project Manager anne.hugon@aphp.fr