ERN eUROGEN European Patient Advocacy Group

Strategy 2025

1. OVERALL STRATEGY

The ERN eUROGEN European Patient Advocacy Group (ePAG) brings together patient representatives for rare uro-recto-genital diseases and complex conditions to actively participate in the European Reference Network (ERN), working in partnership with clinicians and researchers. EURORDIS (Rare Diseases Europe) supports the group in its activities.

The ERN eUROGEN ePAG aims to empower patients to advocate for their needs by amplifying the patient voice within the network and ensuring patient-centricity across all activities. The ePAG representatives' input helps shape healthcare services, training, and research to better address patient needs.

Key responsibilities:

- **Advocating for Patients**: Ensuring the network's activities align with patient needs and perspectives.
- **Participating in Decision-Making**: Joining strategic board, workstreams, and other meetings.
- **Developing Resources**: Collaborating on creating patient-friendly materials.
- **Disseminating Information**: Sharing updates, guidelines, and resources with patient communities.
- **Feedback and Monitoring**: Providing feedback on initiatives and monitoring their impact.

2. THE PATIENT PARTNERSHIP FRAMEWORK

Aligned with **EURORDIS Rare Disease Europe's Patient Partnership Framework for ERNs** (2023), the ERN eUROGEN ePAG aims to:

- Foster a shared understanding of patient partnership, ensuring patients and healthcare professionals collaborate as equal partners.
- Emphasize transparency, shared leadership, teamwork, and continuous engagement.
- Define desired outcomes and align activities with stakeholder motivations.
- Tailor engagement strategies to accommodate the diverse needs, preferences, and characteristics of patient communities.
- Address accessibility barriers, such as language, cost, and logistical challenges, to ensure inclusive participation.
- Facilitate effective dissemination of information.
- Implement structured evaluation mechanisms to assess the impact of patient engagement and iteratively improve activities.
- Support patient representatives in capturing and analysing community perspectives.
- Encourage collaborative selection of engagement methods, ensuring alignment with activities such as guideline development, education, or data management.
- Provide training and resources to empower patients for meaningful engagement.
- Establish support structures that enhance the capacity of patient representatives for effective collaboration.

2.1. Defining Patient Partnership in ERNs

Patient partnership within ERNs is a collaborative relationship where patients, caregivers, and healthcare professionals work together as equal stakeholders in all network activities. This partnership ensures that both the experiential knowledge of patients and the clinical expertise of healthcare professionals are equally valued in decision-making, co-design, and implementation.

Key principles of true patient partnership:

- **Shared Decision-Making**: Patients and healthcare professionals contribute equally to discussions, with each voice carrying weight.
- **Mutual Respect and Trust**: Recognizing patients as experts by lived experience and professionals as experts by training.
- **Co-Creation and Collaboration**: Patients actively shape policies, guidelines, and healthcare improvements.
- **Transparency and Accountability**: Clearly defined roles and responsibilities prevent token representation.
- **Continuous Learning and Adaptation**: Ongoing dialogue, training, and feedback refine collaboration over time.

This approach shifts healthcare from being "for" patients to being "with" patients, ensuring rare disease networks are shaped by those who live with these conditions.

2.2. Ensuring Accessibility, Inclusivity, and Diversity

- Patient representatives are encouraged to disclose any accessibility needs for meetings.
- Most meetings allow remote participation, and reimbursement is provided for in-person attendance.
- Flexible scheduling is facilitated through polling patient representatives.
- ERN eUROGEN actively recruits patient representatives from diverse backgrounds and partners with patient organizations to amplify underrepresented voices.

2.3. Fostering Meaningful Engagement

- ERN eUROGEN ePAG establishes outcome-based goals and holds bi-monthly progress meetings to define and communicate objectives.
- Structured processes ensure meaningful patient involvement (e.g., clear roles, responsibilities, and recognition of contributions) to prevent tokenism.
- Patient representatives are regularly invited to provide feedback on their engagement experiences.

2.4. Supporting Collaboration and Training

- A welcome guide has been developed for new patient representatives, outlining collaboration processes, roles, and available training resources.
- EURORDIS provides additional task-specific guides for engagement in activities such as registries and clinical practice guidelines.

2.5. Dissemination and Knowledge-Sharing

- Successes are celebrated by recognising contributions from patient representatives.
- Outcomes of effective patient engagement are disseminated in order to share knowledge.

2.6. Evaluation and Continuous Improvement

- The annual ePAG strategy enables systematic evaluation of patient engagement effectiveness.
- Evaluation includes achievement of deliverables, satisfaction surveys, participation rates, and impact assessments.
- Periodic reviews ensure alignment with strategic goals, incorporating patient feedback into future strategies.

3. SPECIFIC STRATEGY GOALS FOR 2025

3.1. Strengthening Patient-Clinician Communication

3.1.1 Pre-Appointment Questionnaire

Developing a standardised pre-appointment questionnaire/checklist to help patients articulate their needs and expectations during clinical visits.

3.1.2 Guidance for Clinicians

Providing training and resources for healthcare professionals on effective communication with rare disease patients, particularly those transitioning from paediatric to adult care. Potential delivery formats include webinars or written guidelines based on best practices (e.g., Sant Joan de Déu guidance).

3.2. Patient-Centred Clinical Decision-Making (CPGs and CDSTs)

3.2.1 Bladder Pain Syndrome/Interstitial Cystitis

Providing patient input on Clinical Practice Guidelines & Clinical Decision Support Tools covering conditions such as eosinophilic cystitis, ketamine cystitis, glandular cystitis, radiation cystitis, follicular cystitis, cystitis cystica, and haemorrhagic cystitis (ERN eUROGEN Direct Operational Grant 2023-2027 Work Package 7, Deliverables 7.10-17).

3.2.2 Penile Cancer

Contributing patient input to the Clinical Decision Support Tool for centralisation of penile cancer (ERN eUROGEN Direct Operational Grant 2023-2027 Work Package 7, Deliverable 7.18) and continuing efforts to promote the centralisation of penile cancer and other rare diseases in collaboration with EAU and the Penile Cancer Guidelines Panel.

3.3. Empowering Patients Through Advocacy & Support

Empowering patients by raising awareness and helping others find their voice through collaboration and advocacy.

3.3.1 Patient Journeys

1. Developing a patient journey relating to common needs in uncommon uro-recto-genital conditions, emphasising the importance of empowerment to help patients move from isolation to advocacy.
2. Developing a patient journey on Klinefelter syndrome (KS/XXY).

3.3.2 EURORDIS Mental Health & Wellbeing Partnership Network

Continuing participation in the EURORDIS Mental Health & Wellbeing Partnership Network to raise awareness and advocate for policy improvements.

3.3.3 Penile Cancer Patient Survey

Continuing the Penile Cancer Patient Survey to assess patient experiences, identify best practices, highlight areas for improvement, and share findings with patients and clinicians to drive enhancements in service quality and patient outcomes.

3.4. Advancing Centralisation of Care

3.4.1 Advocacy for Centralisation

Exploring advocacy opportunities to lobby national health ministries in policy change.

3.4.2 Collaborative Position Statement

Potentially developing a cross-ERN/EURORDIS document supporting centralisation efforts.

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ERN eUROGEN is a European Reference Network (ERN) approved by the ERN Board of Member States (BoMS). For more information about the ERNs and the EU health strategy, please click here. The ERNs are funded by the European Union.