



Social Policy Action Group

Terms of Reference

Adopted in September 2023

Introduction

Most people who live with a rare disease face serious everyday challenges and many societal barriers, while also living with visible or invisible disabilities. The barriers they face include the lack of holistic, integrated and lifelong care and support, as well as limited access to social and disability rights, limited participation in education and employment, and reduced income.

Such barriers prevent people living with a rare disease and their families, often the main carers, from living more independently and from fully participating in various areas of society, while also exposing them to a high level of psychological, social, and economic vulnerability.

Purpose

EURORDIS' ambition is to see people with a rare disease and their families integrated in a society that:

- Is aware of their needs and effectively provides timely, high-quality care according to those needs.
- Breaks down barriers in access to care, treatment, education, employment, leisure, psychological support and all aspects of participation in society.
- Enables them to fully enjoy their fundamental human rights, on equal footing with others.

EURORDIS' work to advance this ambition includes:

- Advocating for integrated health and social care, with a lifelong and holistic approach.
- Advocating for non-discrimination and access to social and human rights, i.e., social protection, social and community services, independent living support, education and employment.
- Advocating for the adequate assessment and recognition of the disabilities faced by people living with a rare disease, as well as to improve their access to disability related rights.
- Engaging with EU institutions and partnering with external experts and organisations, to provide input to the design of relevant policies, initiatives and funding instruments.
- Empowering its members and the rare disease community on social and other human rights topics.
- Contributing to the design, implementation, and promotion of relevant good practices.
- Developing or taking part in relevant European projects.
- Contributing to or leading publications on relevant topics.

Mission

The EURORDIS Social Policy Action Group (SPAG) will support EURORDIS' work to shape policies and practices that improve the access of people living with a rare disease and their families to holistic care, social and human rights. The activities of the SPAG will be regularly defined, in line with EURORDIS' mission, strategy and priorities.

Objectives

The mission of the SPAG focuses on the following objectives:

- Informing on and raising awareness of the everyday needs and barriers faced by people living with rare diseases, including rare cancers, and their families.
- Advising EURORDIS to ensure the formulation of person-centric approaches to the different issues related to holistic care, social and human rights.
- Advocating for policies and services that address the unmet needs and societal barriers, at European, national and regional levels; pursuing opportunities to support EURORDIS with influencing high-level decision making.
- Facilitating the participation of people living with a rare disease and their families in relevant consultations by sharing and collecting contributions from individuals and their organisations.
- Enabling EURORDIS to bring the voice of people living with a rare disease and their families to specific projects and initiatives.
- Empowering their organisations and the rare disease community to advocate for holistic care, and for the social and human rights of people living with a rare disease and their families.

Composition

The SPAG is composed of 10 to 15 members, representing a diversity of European countries, rare diseases, disabilities, ages, and backgrounds.

The SPAG members are:

- Individuals living with a rare disease, family members or other representatives of an organisation representing people living with rare diseases.
- Other experts with experience in social policy, social services, education, employment, disability, independent living, integrated care or other relevant fields.

Mandate

The members of the SPAG are nominated for a term of 3 years, from November 2023 to October 2026.

Following a review of the achievements and continued need for the SPAG, EURORDIS' Board of Directors could approve a renewal of the SPAG.

There have been two previous SPAG mandates, from 2015 to 2022, with distinct members and objectives¹.

¹ In its first mandate (2015-2018), the SPAG was designated as Social Policy Advisory Group and composed of 10 representatives. It was then renamed to Social Policy Action Group, for its second mandate (2019-2022), when it was composed of 9 representatives. The work of the SPAG directly supported several important milestones for the rare disease community, many of which are listed in the "useful resources" section of these Terms of Reference (page 4).



Status and Code of Conduct

The SPAG is an informal network hosted by EURORDIS. Membership is voluntary.

SPAG members are EURORDIS volunteers who must adhere to these Terms of Reference and to the [EURORDIS Charter of Volunteers](#).

The responsibilities of the SPAG include a commitment to participate actively in the work of the group.

SPAG members are responsible for liaising with their organisation, and for informing their organisation about the activities of the SPAG and their own membership.

Confidentiality and Potential Conflict of Interest

Members are expected to respect the confidentiality of meetings. When there is a potential conflict of interest, members are expected to notify the EURORDIS staff member responsible for coordinating and supporting the SPAG and to exclude themselves from the specific agenda items for which there is a potential conflict of interest.

Meetings

The SPAG will meet a 3 times per year. The meetings will serve as a platform for knowledge sharing among participants and to discuss key issues.

Additional workshop sessions may take place to allow for focussed debate on key issues.

Meetings will primarily be virtual, to facilitate participation and reduce travel times and costs.

The agenda and relevant documents of each SPAG meeting will be sent to members in advance of the meeting. Only agreed actions and decisions will be recorded at the meeting. These will be made available to all members of the SPAG within 2 weeks of the meeting.

All meetings and communications will be in English.

Other activities

Specific activities for the SPAG will be regularly defined, in line with EURORDIS' mission, strategy, and priorities.

Besides the regular SPAG meetings, SPAG members may be involved in any of the following activities:

- Contributing to EURORDIS' positions and supporting its contributions to consultations by the European Commission or other relevant EU and international institutions.
- Identifying key issues to be discussed and addressed within the scope of the SPAG's mission.
- Presenting at national or European events.
- Elaborating short reports on relevant barriers or policies in their country.
- Translating short summaries of key advocacy position documents.
- Contributing to dissemination and advocacy activities.
- Providing input to the delivery of projects and supporting the identification of opportunities to participate in projects and access grants.

Conferences

When participating in conferences or forums not specifically on behalf of the SPAG, members shall make clear that the views expressed are their own views and not those of EURORDIS and the SPAG.

When being invited as a EURORDIS-SPAG representative, members must inform the EURORDIS staff member responsible for coordinating and supporting the SPAG, who will appreciate whether it is appropriate for the member to participate and represent the SPAG. In this case, the SPAG members shall:

- Ensure that the views expressed are those of EURORDIS.
- Identify with their affiliations to their organisation as well as to EURORDIS.
- Report back to the SPAG on the outcomes and relevant aspects of the meeting.

Contact

EURORDIS will designate a EURORDIS staff member to coordinate and support the SPAG, who reports periodically to the Board on the activities of the SPAG. The specific contact will be shared in the Call for Expressions of Interest and on the EURORDIS' website SPAG page.

EURORDIS shall:

- Coordinate the work of the SPAG.
- Provide technical and scientific support.
- Organise meetings of the SPAG, ensuring timely circulation of meeting documents.
- In relation with a SPAG member, assist the preparation of agendas and minutes of SPAG meetings.
- Contribute to the identification of the experts.

Application Process

A Call for Expressions of Interest will be launched in 2023. A standardised form and online application process will be developed by EURORDIS.

The applications will be reviewed by the EURORDIS Social Policy and Initiatives Director. A maximum of 15 applicants will be selected and endorsed by the EURORDIS Board of Directors.

Useful resources

1. [EURORDIS Position Paper: Achieving Holistic Person-Centred Care to Leave no One Behind](#) (2019).
2. European survey [Juggling care and daily life: The balancing act of the rare disease community](#) (2017).
3. UN Resolution on [Addressing the Challenges of Persons Living with a Rare Disease and their Families](#) (2022).
4. EURORDIS [Answer to the EC Consultation on the European Pillar of Social Rights](#) (2016).
5. EURORDIS [contribution to the EC consultation on the Disability Rights Strategy for 2021-30](#) (2021).
6. EURORDIS [contribution to the EC call for evidence on the EU Disability Card](#) (2023).
7. EURORDIS [Contribution to the EC call for evidence on the proposal for a European Care Strategy](#) (2022).
8. EURORDIS [Factsheet: Work-life Balance Directive](#) (2019).
9. [Results of the EU-funded INNOVCare project](#), on integrated care for rare diseases (2015-2018).
10. Castro, R. *et al.* (2021). [Rare Diseases](#). In: Amelung, V., Stein, V., Suter, E., Goodwin, N., Nolte, E., Balicer, R. (eds) Handbook Integrated Care. Springer, Cham. https://doi.org/10.1007/978-3-030-69262-9_44
11. Castro R. *et al.* [Bridging the Gap between Health and Social Care for Rare Diseases: Key Issues and Innovative Solutions](#). Adv Exp Med Biol. 2017;1031:605-627. doi: https://doi.org/10.1007/978-3-319-67144-4_32. PMID: 29214594.