



EURORDIS Mental Health & Wellbeing Partnership Network

Network Terms of Reference

July 2023

Introduction

People living with a rare and undiagnosed condition experience an accumulative impact on their mental health and wellbeing. At an individual level, people living with a rare disease (PLWRD) can have an associated mental health co-morbidity, whereas at a population level, the community lives with the increased psychological impact associated with the rare diseases journey across all stages of life. In addition, PLWRD and their families have increased exposure to social inequalities and discrimination, which are risk factors and determinants for poor mental wellbeing.

EURORDIS has established a Mental Health & Wellbeing Partnership Network in order to take action to the rare disease community call to look beyond the physiological symptoms of a rare condition, with a specific focus on fostering increased access to psychological support as a fully integrated part of the coordination of care and ensuring it is routinely available at diagnosis and throughout the following care pathway.

Purpose

The EURORDIS Mental Health & Wellbeing Partnership Network (Partnership Network) will bring together experts and stakeholders to drive a community action on mental health and wellbeing for PLWRD, their families and caregivers.

Specifically, the Partnership Network will unite and empower the rare disease community to come together, learn, take action and tailor recommendations to the specific needs of PLWRD in all policy areas, to ensure that the mental health and wellbeing of the rare disease community is improved. The findings of the Network will feed into EURORDIS' work across all policy areas, specifically through:

- increased access to quality preventative measures, early detection and treatment services, improving health promotion, and ensuring more people recover.
- tackle inequalities, stigma and discrimination among the rare disease community experiencing poor mental health and wellbeing.
- taking action to contribute to addressing the underpinning socio-economic and environmental determinants on mental health in the rare disease community.

Mission

Through collaboration of experts – medical, research and by lived experience, the Partnership Network will harness the collective evidence, innovations, best practices, tools and resources, and level up the capacities to shape policies and promote practices that reduce the impact of rare diseases on mental health.



General Objectives

The Partnership Network has been established to unite and empower the rare disease community to come together and take actions that promote good mental health and prevention of mental health distress and challenges, specifically to:

- network and share expertise and knowledge to better understand the relationship between rare diseases and mental health.
- provide input to EURORDIS work on addressing the health and social determinants of mental health and tackling stigma and discrimination.

Specific Objectives

The Network specific objectives are to foster a peer learning environment to lead on key actions and deliverables agreed under the EURORDIS Mental Health & Wellbeing Initiative (Initiative), specifically:

- harness the community's expertise and experience, to build knowledge on the intersectional mental health and rare diseases needs and to strengthen systems locally in all sectors.
- engage the rare disease and mental health communities and survey the population needs related to mental health and wellbeing.
- increase awareness of the complexities and increased vulnerabilities of living with a rare disease and the associated impact of mental health and wellbeing on individuals and families.
- build competencies and empowerment of rare disease advocates, through peer learning training to engage in actions in all policies that address rare diseases and the mental health needs of the community.
- identify best practice and evidence-based approaches and develop a psychological wellbeing toolkit and standardised protocols that can be leveraged to prevent mental health co-morbidities through access to health promotion and prevention interventions.
- strengthen health system capacities to understand the intersectoral needs between rare diseases and mental health, to optimise policies, practices and interventions.

In addition, in collaboration with EURORDIS policy work, advise on the following issues:

- scientific and research aspects of the Initiative.
- strategies and position statements related to rare diseases and mental health.
- addressing the risk factors and determinants of mental health.
- dissemination of the findings to the wider community.

The Partnership Network will connect and partner with social, educational and employment experts from EURORDIS' Social Pillar Advisory Group and other EURORDIS Task Forces and Working Groups.



Composition of the Partnership Network

The composition of the Partnership Network will be approximately 50 members, from within both the rare disease community and the mental health sectors and associated fields.

Members can be from:

- Patient Organisations
- Hospital and Academic Institutions
- Research Groups and Networks
- Social Care Sector Organisation
- Education and Employment Institutions
- Non-Governmental Organisations
- National and Local Authorities & Policy Institutions

Membership is on a voluntary basis.

Members can be existing members of established EURORDIS advocacy groups, such as the Social Pillar Advisory Group, ERN Steering Committee or Task Forces. These can be formal or informal members of the Partnership Network. EURORDIS may co-opt additional members, as appropriate.

Members of the Partnership Network will act on an individual capacity. Members may nominate substitutes to attend meetings to contribute to an active and full capacity.

Partnership Network members agree to:

- adhere to the Terms of Reference of the Partnership Network and Charter of the EURORDIS Volunteers.
- commit to liaising with their organisation in order to provide the position of their organisation on the topics to be addressed and to inform their organisation about the activities of the Partnership Network.
- actively participate in Network meetings and working groups and support the network to achieve its objectives, activities and outcomes.
- represent the views of the rare disease community and patient groups to the network activities.
- share knowledge, expertise and information, such as resources, evidence, best practices and case studies, with other participants.
- prepare ahead of the meetings, including reading in advance the papers provided for the meeting, so as to meaningfully contribute to the meetings.

Mental Health & Wellbeing Champions will be identified from the membership of the Partnership Network and who would be recognised as EURORDIS volunteers and represent EURORDIS in key events and conferences.



Co-chairs

EURORDIS will coordinate the function for the Partnership Network and will have two co-chairs, one from the EURORDIS Board of Directors and the other to be the EURORDIS Mental Health & Wellbeing Lead.

The co-chairs will be responsible for ensuring that the Partnership Network operates in such a way as to deliver its key function and report progress on the Networks activities to the EURORDIS Board of Directors.

Structure of the Partnership Network

The structure of the Partnership Network will consist of a **Steering Group** and **Working Group(s)**.

- A Steering Group will provide leadership and support to ensure successful delivery of the Partnership Network. The co-chairs will jointly chair the Steering Group.
- Working Groups can be established when required to support operational implementation of the annual work plans.

Please see Annex I for the role and function of the Steering Group, including the composition, responsibilities and processes for establishing the group.

The Partnership Network will connect and partner with social, educational and employment experts from EURORDIS Social Pillar Advisory Group and other EURORDIS Task Forces and Working Groups.

(a) Steering Group

The Steering Group will oversee the strategic development of the network and the implementation of the annual work plan and advise on advocacy and strategic issues and future priorities. The Steering Group will promote the adoption of a human rights approach, advancing equality and tackling inequalities, and ensure a full life course approach across all the activities of the Mental Health & Wellbeing Initiative.

(b) Working Groups

Working Groups may be created to undertake specific tasks of the Partnership Network work plan. Each group will designate a lead and co-lead who will chair the meetings and report back to the Steering Group.

Meeting Frequency

The Partnership Network will meet a 3 times per year to review the annual work plan, serve as a platform for knowledge sharing among participants and discuss key issues. Additional workshop sessions may take place to allow for focussed debate on key issues. Meetings will primarily be on a virtual basis to facilitate wider attendance and reduce travelling times.



The agenda and relevant documents of each Network Partnership meeting will be sent to members in advance of the meeting to allow for preparation. Only agreed actions and decisions will be recorded at the meeting by one of the co-chairs or lead. These will be made available to the members of the Partnership Network within 2 weeks of the meeting.

The Steering Group will meet as a minimum once a year, to report on progress of the Working Groups, discuss issues and revise the work plan. The Steering Group will make recommendations that will be validated, where appropriately, by the EURORDIS Board of Directors. In the event that a consensus is not reached by the Steering Committee, the co-chairs of the Network will make the casting decision.

Each Working Group will have meetings, attended by Working Group participants. The frequency of working group meetings will be determined by the lead and co-lead of the respective Working Group.

The structure and frequency of the meetings will be kept under review to ensure that the Partnership Network remains effective.

Contact

The Partnership Network will be coordinated and assisted by Matthew Bolz-Johnson, Mental Health & Wellbeing Lead and Healthcare Advisor. E-Mail: matt.johnson@eurordis.org

EURORDIS shall:

- coordinate the work of the Partnership Network.
- provide technical and scientific support.
- organise meetings of the Partnership Network, ensuring timely circulation of meeting documents.
- in relation with a Partnership Network member, EURORDIS will assist in the preparation of the agenda and minutes of the Partnership Network meetings.
- contribute to the identification of the experts.

Mandate

The duration of the Partnership Network will initially be for 3 years and following a review of the achievements and continued need for the network and, EURORDIS' Board of Directors could approve a renewal of the network.

Status

The Partnership Network is an informal network hosted by EURORDIS. The operations of the Network shall abide by these Terms of Reference as well as other relevant EURORDIS policies, specifically the EURORDIS Charter of the EURORDIS Volunteers.



Confidentiality & Potential Conflicts of Interest

Members will be expected to respect the confidentiality of meetings. Members will be expected to notify the co-chair or lead and exclude themselves from any specific item on the agenda where there is a potential conflict of interest.

Conferences

When participating in international conferences or other forums not specifically on behalf of the Partnership Network, members shall make clear that the views expressed are their own views and not those of the Task Force.

A member of the Partnership Network may participate in international conferences or other forums and represent the Network, upon request or official agreement of the co-chairs of the Partnership Network.

In this case the Network member:

- shall ensure that the views expressed are those of the Network.
- will identify her/himself with its affiliations to her/his patient groups as well as to EURORDIS. The final decision around whether or not it is appropriate for a member to participate and represent the Network will rely entirely on EURORDIS management (President and CEO).

Application Process

Community leaders, representatives and leading experts in their respective fields will be invited to join the Partnership Network on an ongoing basis.

A Call for Expressions of Interest will be launched in 2023. A standardised form and online application process will be developed by EURORDIS. Applicants should be endorsed by their organisation to join the Partnership Network and have experience and expertise in rare diseases and mental health.

Initially, all membership applications will be assessed and approved by the co-chairs of the Network. Following this, membership applicants will be notified of their membership approval (or otherwise) by the co-chairs of the Network. Subsequent applications submitted following the launch of the Network will be assessed and approved by the Steering Group.

Annual Review

The arrangements outlined within these Terms of Reference will be subject to further changes. There will be an annual review of the Terms of Reference.

Annex 1 Steering Group

The Steering Group will oversee the strategic development of the network and implementation of the annual work plan and advise on emerging issues and future priorities.



It will do this by:

- ensuring appropriate engagement of stakeholders including the wider public, people with lived experience, service users, families and carers.
- providing overall strategic direction, including supporting the development of the workplans and strategies to drive implementation for the duration of the EURORDIS Mental Health & Wellbeing Initiative.
- overseeing the work of the Working Group(s) of the Partnership Network, agreeing upon priorities and action, reviewing progress and outcomes, to optimise the Partnership Network impact.
- approving Network membership applications.
- sharing learning and good practices on improving mental wellbeing.
- ensuring that all members are acting as advocates for the broader aims and aspirations of the Partnership Network.

The Steering Group will be comprised of approximately 10 members appointed by EURORDIS for an initial term of 2 years, with the possibility of renewal. These members will consist of the two co-chair of the Partnership Network and the lead and co-lead of the Working Group(s). The selection process to sit on the Steering Group will strive for balanced representation of the Partnership Network participants, with respect to sector and stakeholder group – experts by lived experience, clinicians and policy leads; and connect with social, educational and employment experts from the EURORDIS Social Pillar Advisory Group.

Steering Group decisions will be made through consensus of committee participants. The Steering Group will be chaired by the two co-chairs, one co-chair from the EURORDIS Board of Directors and the other co-chair will be the EURORDIS Mental Health & Wellbeing Lead.