

Mental Wellbeing Update

CNA Meeting, 07.09.2023



Iris, Ehlers-Danlos syndrome, chronic paroxysmal hemicrania, cluster headaches

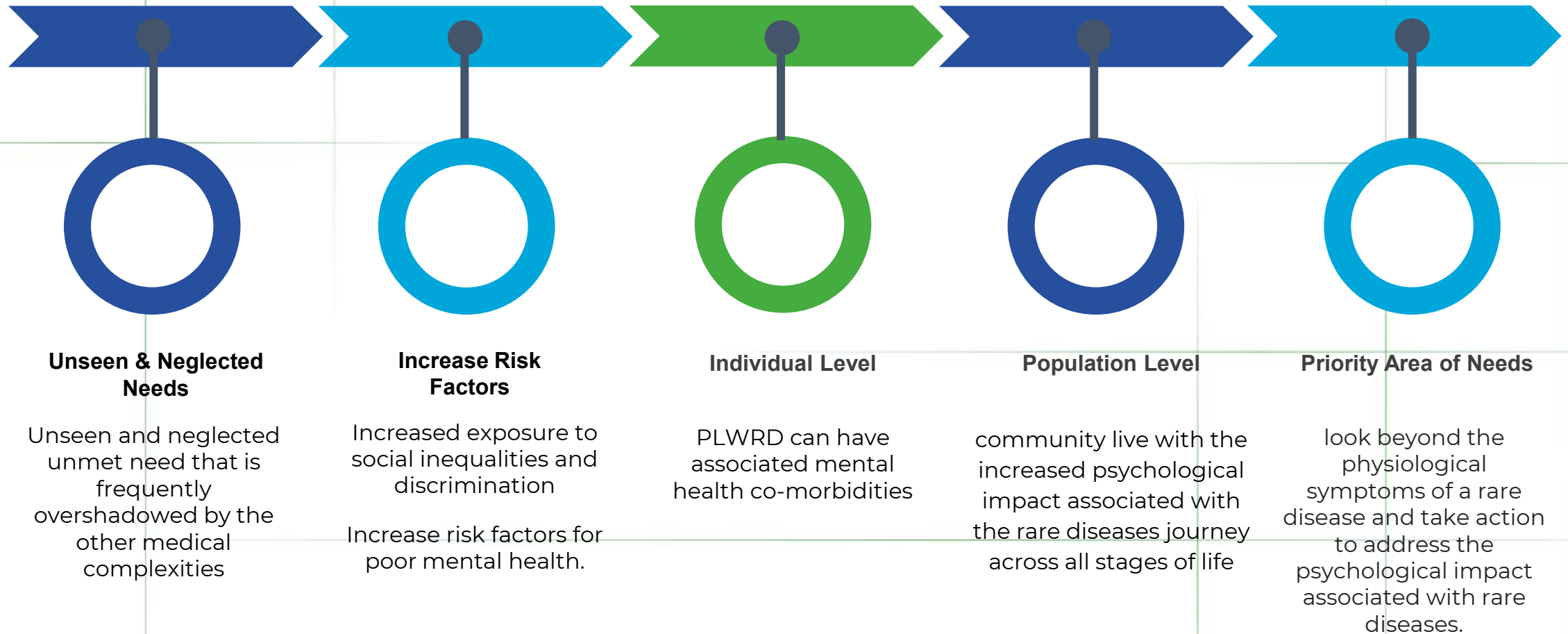


Rare Disease
Research Partners

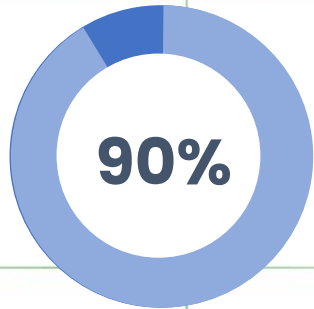
Impact of Rare Diseases on Mental Health & Wellbeing



Accumulative Impact on Wellbeing



Evidence-base



>90% of PLWRD surveyed

felt worried, anxious, stressed and/or depressed and 19% had suicidal thoughts.

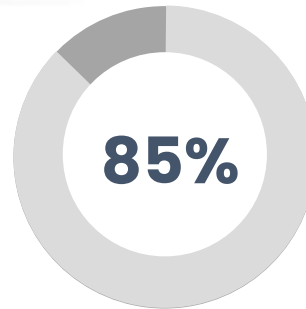
(Spencer-Tansley 2022)



>1/3 of parents of a child

of a child with an undiagnosed disease meet clinical criteria for mild to moderate depression or anxiety.

(McConkie-Rosell 2018)



85% PLWRD

declared that the rare disease impacts upon several aspects of their physical and mental health and everyday life.

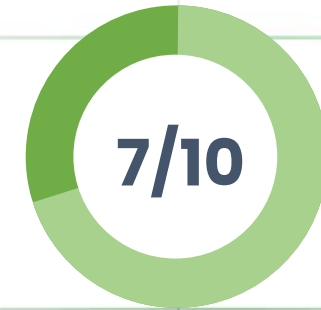
(Coubier et al. 2017)



PLWRD & their families

PLWRD and their families report being x3 times more unhappy and depressed compared with the general population.

(Coubier et al. 2017)



7 out of 10 patients & carers

7 out of 10 patients and carers must reduce or stop their professional activity due to the rare disease and associated burden.

(Coubier et al. 2017)

The diagnosis of a rare disease has a significant psychological impact upon the whole family, not just the affected individual (Kenny 2022)

Iris, Ehlers-Danlos syndrome, chronic paroxysmal hemicrania, cluster headaches



EURODIS Advocacy

A photograph of Commission President Ursula von der Leyen speaking at the European Parliament. She is wearing a light pink jacket and has her hands raised in a gesture. The background shows the interior of the parliament with other people seated.

Commission Communication on the Comprehensive Approach to Mental Health

- Mental health is now being recognised as a public health priority in the European Union, notably in Commission President von der Leyen’s State of the Union speech at the European Parliament on the 14 September 2022.
- The new Communication Communication was published on 7 June 2023.
- Our specific goal is that rare diseases are seen as a vulnerable population requiring specific attention in the new Communication.

European Commission Communication on a Comprehensive Approach to Mental Health

x20 Flagship Initiative with a budget: **EUR 1.23 billion**

x6 priorities:

1. Integrating mental health across policies
2. Promoting good mental health, prevention and early intervention for mental health problems
3. Boosting the mental health of children and young people
- 4. Helping those most in need**
5. Tackling psychosocial risks at work
6. Reinforcing mental health systems and improving access to treatment and care

EURORDIS recognises that the new Communication is an important first step in a new comprehensive approach to address mental health, coordinating action across all policy areas, but needs to be inclusive of all populations in vulnerable situations.

Helping those most in need

People in Vulnerable Situations

- **Children & Young People**
- Older People
- **Cancer patients and survivors**
- **People living with disabilities**
- Migrant and refugee populations
- Ethnic minorities
- People from lower socio-economic backgrounds
- LGBTIQ+ people
- **People with chronic diseases and co/multi-morbidities**
- Women
- Victims of gender-based violence
- Victims of trafficking in human beings
- Victims of crimes
- Roma
- People living in rural or remote areas

People living with a rare disease have multiple 'intersectional' needs including:

- Children & Young People
- Women
- Older People
- Living with a disability
- **Chronic Diseases & Multi-comorbidities**
- Cancer

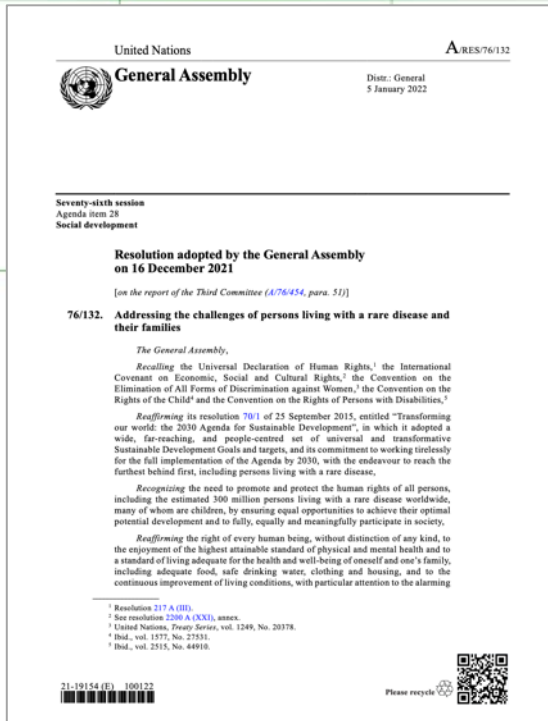
Shift in definition since the publication of Communication



Two Flagship Initiatives:

- Protecting Victims of Crime (11)
- Cancer Mission: Platform for Young Cancer Survivors (12)

UN & WHO Recognition



UN General Assembly Resolution A/RES/76/132 Addressing the challenges of persons living with a rare disease and their families:

10. Urges Member States to implement effective programmes to promote mental health and psychosocial support for persons living with a rare disease, and to promote policies and programmes that enhance the well-being of their families and caregivers.

World Health Organisation, 2022:

The World Health Organization (WHO) recognized “people with an existing health condition” as one of the main vulnerable groups who were more likely to develop symptoms of mental disorders following the pandemic, along with young people and women ([WHO 2022](#)).



Overview of EURORDIS' Advocacy Activity in 2023

Q1, 2023

- MEP Key Ask on Mental Health, RDW
- Gathering Evidence
- Submitted Call for Evidence on RD & MH
- Attended EP Policy Event
- Submitted a Poster of a Concrete Action
- Developed EURORDIS Mental Wellbeing Initiative
- Joined the EC MH Advocacy Platform



Q3, 2023

- New Webpage on Mental Wellbeing
- Launched a call to join new Partnership Network
- 1st Webinar on Impact of RD on Mental Wellbeing
- 2nd Webinar on Living with Uncertainty & Dealing with Trauma
- ERTC Webinar on Mental Wellbeing
- Submission of Best & Promising Practice on RD & MH
- Contribution to MEP Own Initiative (INI) Report
- RBV Factsheet on Mental Health & Wellbeing



- Rare on Air Podcast & Blog
- EMM Satellite Workshop on Mental Wellbeing, Stockholm
- EURORDIS became a member of Mental Health Europe (MHE)
- Developing strategic partnerships with GAMIAN Europe and MHE
- Approval of Terms of Reference for EURORDIS Partnership Network
- EC publish new Communication Mental Health
- Published a Media Statement & submitted Full Response on the new Communication

Q2, 2023




Q4, 2023

- World Mental Health Day
- Launch new EURORDIS Partnership Network
- Mental Health Session at WODC
- EP Policy Event on People in Vulnerable Situations

EURORDIS Key Ask on Mental Health

Our key ask is that people living with a rare diseases are recognised as a population living in vulnerable situations, due to the multiple intersectional needs, requiring specific attention in the new Communication.



Call for Evidence: A Comprehensive Approach to Mental Health
Response from EURORDIS-Rare Diseases Europe
 On behalf of the 30 million people living with a rare disease in Europe
 February 2023

EURORDIS-Rare Diseases Europe (EURORDIS) welcomes the European Commission (EC) procedure to establish a new Communication on a Comprehensive Approach to Mental Health and would like to offer the following input to ensure that all vulnerable groups with higher risk to mental health and well-being are included in the future Communication, leaving no one behind.

We call for the EC Communication on a Comprehensive Approach to Mental Health to recognise the 30 million people living with a rare disease (PLWRD) in the EU as a vulnerable population living with a 'triple burden' on their mental health and well-being, and to promote actions in all policy areas beyond the health system. Most rare diseases appear in childhood, the mental health impact on these children is very high as well as on their siblings and parents.

Risk factors for poor mental health are strongly associated with social inequalities. Indeed, the World Health Organization (WHO) recognises that the greater the level of inequality, the higher the risks to mental health and well-being (Social Determinants of Mental Health, WHO, 2014). People with rare diseases live with the accumulative effect of:

- Multiple co-morbidities that impact on mental health and wellbeing (Health-Related QoL Study 2022)
- Increased psychological impact across all stages of life (Coubrier et al. 2017)
- Increased exposure to social inequalities and discrimination (EURORDIS Foresight Study)

This triple burden supports the call to recognise people affected by rare diseases and their families as a vulnerable population with a higher risk to poor and mental health and detrimental impact on their well-being.

Summary of the Evidence:

- 79% of PLWRD surveyed felt worried, anxious, stressed and/or depressed and 19% had suicidal thoughts (Spencer-Tanley 2022)
- 1/3 of parents of a child with an undiagnosed disease meet clinical criteria for mild to moderate depression or anxiety (McConkie-Rosell 2018)
- The diagnosis of a rare disease has a significant psychological impact upon the whole family, not just the affected individual (Kenny 2022)
- 81% PLWRD declare that the rare disease impacts upon several aspects of their physical and mental health and everyday life. (Coubrier et al. 2017)
- PLWRD and their families report being 3x times more unhappy and depressed compared with the general population. (Coubrier et al. 2017)
- 7 out of 10 patients and carers must reduce or stop their professional activity due to the rare disease and associated burden. (Coubrier et al. 2017)

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EURORDIS Response to the EC Call for Evidence, 2023



A COMPREHENSIVE APPROACH TO MENTAL HEALTH
 #MentalHealth #HealthUnion

BACKGROUND

Increased mental health risks are a reality for a range of vulnerable populations including youth, elderly, women, people with pre-existing health conditions* (such as chronic conditions and rare diseases) or disabilities, migrants, ethnic minorities, LGBTQIA+. Without mental health promotion, prevention and support, the psychological burden and mental health co-morbidities detrimentally impact on vulnerable populations' participation in society. The Comprehensive Approach to Mental Health needs to include all vulnerable populations and detail actions that are holistic, flexible and can be tailored to the specific needs of each population, across all policy areas.

Evidence demonstrates the link between physical health and mental wellbeing, with a correlation between the severity and complexity of a physical medical condition and the impact on mental health and wellbeing**. This is true for chronic conditions and rare diseases, with an increased psycho-social vulnerability in these populations. Rare diseases are complex, chronic, and often debilitating disorders with multiple intersectional unmet needs. Frequently affecting children, rare diseases lead to social exclusion and discrimination, impacting access to education and employment. The accumulative impact of living with increased co-morbidities, psychological stressors, and social inequalities results in a higher prevalence of depression and anxiety disorders.

CONCRETE ACTION

Idea: To strengthen the capacities and empowerment of vulnerable groups to become mentally healthy communities, by developing a Mental Health & Wellbeing Toolkit for Vulnerable Populations. This toolkit can be **gender** identifying best practices and evidence-based tools that can be **tailored** by each vulnerable population to address their specific needs.

EU added value and potential benefits: Addressing the needs of vulnerable populations present an area of added value for the European Union where EU community actions help to strengthen national measures. It is reported that each vulnerable population comprise a significant sized community – young people (87 million), older people (24 million), chronic diseases (50 million) and rare diseases (30 million).

There is a large discrepancy in health and social services available across EU countries to support these vulnerable populations. The development of a Mental Health & Wellbeing Toolkit for Vulnerable Populations would help address these gaps by strengthening the capacity of patient organisations and Civil Society Organisations (CSOs) with EU-shared best practices and tools to support their respective communities, reducing avoidable downstream health, social and economic costs.

How will this help to strengthen action on mental health at EU level and enhance the mental health of European citizens?

A Mental Health & Wellbeing Toolkit for Vulnerable Populations could be used by patient groups, healthcare professionals and social service providers to build knowledge and understanding of the needs of each vulnerable population and the associated impact on mental health, allowing to better target simple effective psycho-social interventions for different populations.

Increasing resilience and capacities among the civil society organisations and patient groups, can support and empower them to better alleviate the risk factors and drivers of poor mental health, preventing mental health co-morbidities and addressing the high levels of unmet needs of these vulnerable populations.


Specifically:

- Reducing the impact on the lives of the affected individuals and their family members, increasing social inclusion and supporting access to education, employment and independent living.

* World Health Organization - COVID-19 pandemic triggers 25% increase in prevalence of anxiety and depression worldwide, 2022.
 ** The King's Fund - Long term conditions and mental health: the cost of co-morbidities, 2012.

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EURORDIS Poster of a Proposal for a Concrete Action, 2023



Commission Communication on 'A Comprehensive Approach to Mental Health'
 Response from EURORDIS-Rare Diseases Europe
 On behalf of the 30 million people living with a rare disease in Europe
 June 2023

EURORDIS-Rare Diseases Europe welcomes the European Commission Communication on 'A Comprehensive Approach to Mental Health' and stresses the need for recognition of the mental wellbeing challenges specifically impacting the rare disease community. This initiative is a first and important milestone in renewing the political commitment to address the mental health needs of all Europeans.

We strongly agree with the Communication's proposal to identify high-risk groups and target support, resources and tailored policies to meet their specific needs. People living with a rare disease and their families live with severe, progressive and chronic conditions and disabilities. Children, young adults and adults of all ages are impacted by rare diseases, with women being the majority among family caregivers. People living with a rare disease and their families frequently find themselves at the intersection of numerous diverse vulnerable situations, including psychosocial risks at work or school, medical uncertainties, economic hardship, discrimination and stigma. As such, EURORDIS welcomes the Commission's ambition to take a comprehensive approach to addressing the psychosocial and structural determinants to mental health. We also call on the Commission to ensure each of its flagship initiatives is implemented with an intersectional approach.

(A) Integrating Mental Health Across Policies

EURORDIS welcomes the Commission's ambition to take a comprehensive approach to addressing the psychosocial and structural determinants to mental health and calls for a coordinated and integrated approach that promotes mental health across all policies. This is truly an ambitious and innovative approach, one which requires unified and dedicated EC-structures to oversee and guide its implementation across the European Union.

The Communication is an important step in establishing a new, comprehensive approach to address the mental health crisis that has resulted from the significant and accumulated impact of unprecedented crises¹. However, this first step needs to be scaled up to be truly comprehensive, **coordinated under a new EU Mental Health Strategy** and supported with the development of **national plans on mental health in all policy areas** to coordinate and steer meaningful action at both European and national levels, in each EU Member State.

EURORDIS supports the call from Mental Health Organisations, along with the European Parliament Alliance on Mental Health and several other stakeholders, for the Commission to establish a dedicated internal Commission structure and to strengthen action across the European Union under a new EU Mental Health Strategy, supported by the creation of dedicated national action plans on mental health in all Member States.

¹ Including the COVID-19 pandemic, Russia's war of aggression against Ukraine, the cost-of-living-crisis and the worsening planetary crisis (climate change, biodiversity loss and pollution).

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EURORDIS Response to the EC Commission Communication on the Comprehensive Approach to Mental Health, June 2023

Mental Wellbeing Communication

<https://www.eurordis.org/mental-wellbeing/>

Home \ Mental Health & Wellbeing

Mental Health & Wellbeing

There is no health without mental health. The relationship between physical and mental health is well established. Increased severity and complexity of a physical health condition, in turn increases the risk to mental health and well-being result in higher rates of depression, anxiety and also where poor mental health can impact on physical health, the capacity to self-care, resilience. (King's Fund¹, Royal College of Psychiatrists & Centre for Mental Health², Mental Health Foundation³).

Mental health is a basic human right. The World Health Organization's definition of mental health⁴, seeing it as something that is strongly linked to opportunities, and participation in the community:

"A state of mental well-being that enables people to cope with the stresses of life, realize their abilities, learn well, (making healthy choice) and work well, and contribute to their community. It is an integral component of health and well-being that underpins our individual and collective abilities to make decisions, build relationships and shape the world we live in. And it is crucial to personal, community and socio-economic development."

Impact of Rare Disease on Mental Wellbeing

People living with a rare and undiagnosed condition have increased vulnerability and risk factors resulting in them experiencing an accumulative impact on their mental wellbeing, specifically at an individual level.

At an Individual Level

Mental health is an associated co-morbidity for many rare diseases.

At a Population Level

Increased psychological impact associated with the rare diseases journey across all stages of life.

Cross-cutting psychosocial determinants

People living with a rare disease and their families have increased exposure to social inequalities and discrimination, which are risk factors and determinants for poor mental wellbeing.

EURORDIS Action to Improve the Mental Wellbeing of the Rare Disease Community

EURORDIS wishes to leverage the opportunity of the new Communication on a Comprehensive Approach to Mental Health to make visible the unmet mental health needs of people living with a rare disease and their families and take affirmative action to address these needs.

Pillar 1
Network & Community Engagement

- New Eurordis MxI Partnership Network
- Community Engagement
- Advocacy in All Policy Areas

Pillar 2
Evidence Generation

- Literature Review on Unmet Needs
- Population Survey
- Targeted Literature on Solutions

Pillar 3
Best Practice & Capacity Building

- Peer Learning Programme
- Sharing Best Practice Platform
- Mental Health Communities Toolkits
- Care Standards & Pathways

Pillar 4
Awareness & Communication

- Public Awareness Campaign
- Communication Strategy
- Communication Activities & Tools

Pillar 5
Management & Stakeholder Engagement

- Management, Monitoring & Impact
- Engagement Strategy
- Funding Opportunities

A new EURORDIS Mental Wellbeing Initiative is planned to be launched in 2023-24, with the overarching objective to **promote the development of a 'mentally healthy community'** that reduces the accumulated impact of rare diseases on mental health and wellbeing among people living with a rare disease and their families.

EURORDIS new Mental Wellbeing Partnership Network

EURORDIS will establish a new EURORDIS Mental Health Partnership Network (Partnership Network) to support and coordination of the development and delivery of community activities in the framework of EURORDIS Mental Wellbeing Initiative.

The Partnership Network will bring together experts and stakeholders to drive a community action on mental health and wellbeing for people living with a rare disease, 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 people living with a rare disease, in all policy areas, to ensure the mental health and wellbeing of the rare disease community is improved. The findings of this network will feed into EURORDIS work across all policy areas.

EURORDIS launched a call for expressions of interest to join the new Partnership Network at a EURORDIS Membership Meeting (EMM 2023) Satellite Working – Enhancing the Mental Wellbeing in the Rare Disease Community held on the 25.05.2023.

Applications for our new Partnership Network are still open! EURORDIS is looking for dedicated volunteers to be active in the Partnership Network.

If the rare disease you represent has an impact on the mental health and wellbeing we would like to hear from you and ensure that your expertise and insights are included to shape the work of the Partnership Network.

[Apply here](#)

Podcast Episode
Mental wellbeing with a rare disease
Rare on Air

Valuing Mental Wellbeing in the Rare Disease Community

May 2023

The recent COVID-19 pandemic was a wake-up call to the importance of the physical health of citizens to both society and the economy. In recent months, the importance of the mental health of citizens, and the population as a whole, has only just started coming to light and being recognised by policy makers, politicians and governments.

Even in the rare disease community, physical health has long been prioritised over mental health. The quest to secure a diagnosis, access to treatments, and drive research to find a cure have all overshadowed the psychological impact endured by those who have travelled along the rare disease journey.

x3

People living with a rare disease and their families are three times more likely to report being unhappy and depressed compared with the general population.

EURORDIS' Rare Biomarker Juggling Life and Care Survey

When engaging with ePAG Advocates active in the European Reference Networks to map the needs that are specific to their rare disease, one common theme quickly surfaced: the accumulated and detrimental impact on mental health and wellbeing. When faced with living with an undiagnosed or rare disease, it seems we only have two options; either we are in crisis management mode or we are alone.

What is 'mental wellbeing'?

To be able to have this critical and long-overdue conversation about our mental health, we first need to find a common definition of what mental health actually is. Many people use the term to indicate a negative state of being, as opposed to seeing mental health as an integral component of our broader health and wellbeing, which enables us to realise our full potential and participate in society. There is no health without mental health!

Mental health is dynamic and fluid, forever changing, and best seen on a continuum. You can move across the continuum from being in good health to being in distress or dealing with challenges and problems and back again. It can impact our mood, behaviour and cognition, expressed through our stresses, anxiety, perceptions and obsession. When it is persistent and pervasive it can be associated with significant distress and impacts on functioning and daily living. There are many factors that affect mental health and wellbeing, for example brain injury, infection, fever, hormone or neurological problems. Additionally, economic factors can impact your wellbeing, such as cost-of-living-crisis, inability to work and live independently, or social and environmental factors like social media, experiencing prejudice

European Parliament Event

Addressing the Risks and Barriers Faced by People in Vulnerable Situations



European Parliament Policy Event

Addressing the Risks and Barriers Faced by People in Vulnerable Situations

Call for the Comprehensive Approach to Mental Health to be inclusive, leaving no one behind

Concept Note

Date: 28 November 2023
Time: TBC
Where: TBC, European Parliament
Host(s): MEP Tilly Metz, Green Party & MEP Sara Cerdas, Socialist Party
Organiser(s): EURORDIS – Rare Diseases Europe & Mental Health Europe

Overview

Mental health has been recognized as a public health priority in the European Union, notably in Commission President von der Leyen's State of the Union speech at the European Parliament on the 14 September 2022. The Commission Communication - Comprehensive Approach to Mental Health is a first, important step in mainstreaming mental health in all EU policies, adopting a psychosocial model of understanding mental health to address social determinants, structural barriers and provide tailored support.

Today's concerns about mental health will continue to increase without adequate action and earlier intervention. Providing support to those most in need is a central tenet of the new Communication and is the heart of all European action to successfully address today's mental health crisis. Critically, it is important that the comprehensive approach is inclusive of all populations in vulnerable situations and takes into account intersectionality in order to leave no one behind and to prevent those most in need from being further marginalised in society. Coordinated European action is needed, across all policy areas, to effectively address the psychosocial and structural determinants to mental health. A truly comprehensive approach demands a paradigm shift in all sectors and increased agility to bridge different sectors and work cross policies. This new approach needs to be embedded under the next legislative period in the European Union, if the multiple intersectional needs of people in vulnerable situations are to be addressed. Additional support, resources and actions need to be prioritised to address those mental health needs as a human experience, by providing a continuum of adequate prevention and early intervention for all populations in vulnerable situations, adequate engagement and tailored support to the needs of different groups.

Objectives

- To set out what we mean by the psychosocial model of mental health, highlighting the specific and intersectional needs of people in vulnerable situations.
- To look into the future and explore what we want to see developed as part of the implementation of the new Communication to promote and protect the mental health and wellbeing of people in vulnerable situations.
- To identify EU action that can best address the social determinants and intersectionality.

Outcome

A call to secure continued political commitment to address mental health as a priority under the new European Parliament:

- For the continued prioritisation of mental health, beyond the new Communication, taking a human rights approach to mental health, beyond health, in all policies.
- For future European actions in Mental Health to be inclusive of all people in vulnerable situations, leaving no one behind.

1

MEP co-host:

- MEP Tilly Metz, Green Party
- MEP Sara Cerdas, Socialist Party

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Iris, Ehlers-Danlos syndrome, chronic paroxysmal hemicrania, cluster headaches



EURODIS Position Paper

Structure of Position Paper

1. **Introduction:** Rare disease impact on mental health and wellbeing

2. **Policy Context**

- MH as an EU Public Health Priority under Commission Communication
- World Health Organization (WHO) recognises “people with an existing health condition” as one of the main vulnerable groups
- UN GA Resolution A/RES/76/132 (2021) urges Member States to implement psychosocial support programmes for PLWRD

3. **European Recommendations:** visibility of rare diseases in mental health policy:

- Call for a more inclusive approach of all populations in vulnerable situations
- Dedicated actions with adequate financial support for all vulnerable groups

4. **National Recommendations:** visibility of mental health in rare disease national plans and strategies, specifically to establish psychosocial support programmes through “psychologically informed medical care”

Set out what “psychologically informed medical care” would look like addressing eight common areas of needs, specifically:

(1) family-focused care

(2) coping with uncertainty

(3) empathic communication

(4) practical support

(5) information

(6) psychological support

(7) interdisciplinary care

(8) social support

Approach to develop Position Paper

Position Paper on Mental Wellbeing (2023)

- 1st Draft - Reference document of current advocacy position and existing evidence.
- Engagement with CNA for feedback - online workshop and written feedback
- Internal feedback from EURORDIS Team
- Near-final version: consultation with Partnership Network and EURORDIS Members
- Design and formatting
- Final version completed: Q4 2023



Revised Position Paper (2025)

- Co-created with Partnership Network
- Rare Barometer Survey on mental wellbeing
- Literature review of evidence for both needs and existing solutions to address needs
- Draft Revised Position Paper
- Consult with CNA and EURORDIS Members
- Final version ready for summer 2025

EURODIS Mental Wellbeing Initiative



EURORDIS Mental Wellbeing Initiative

Four-year initiative supported by a new EURORDIS Mental Wellbeing Partnership Network.



Overview of the Initiative

Pillar 1: Network & Community Engagement

New EURORDIS MH Partnership Network

Community Engagement

Advocacy in All Policy Areas

Pillar 2: Evidence Generation

Literature Review on Unmet Needs

Population Survey

Targeted Literature on Solutions

Pillar 3: Best Practice & Capacity Building

Peer Learning Programme

Mentally Healthy Communities Toolkit

Care Standards & Pathways

Pillar 4: Awareness & Communication

Public Awareness Campaign

Communication Strategy

Communication Activities & Tools

Pillar 5: Management & Stakeholder Engagement

Management, Monitoring & Impact

Engagement Strategy

Funding Opportunities

New EURORDIS Mental Wellbeing Partnership Network

Support and reinforce a united and empowered rare disease community affected by mental wellbeing ...

... to come together and be seen, learn, advocate and supported each other.



Terms of Reference



EURORDIS Mental Wellbeing Partnership Network

Network Terms of Reference
Adopted on the 06 July 2023

Introduction

People living with a rare and undiagnosed condition experience an accumulative impact on their mental 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 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 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.

Mission: 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.

Structure: Steering Committee & Working Groups

Meetings: Network will meet x3 per year

Mandate: 3 Year Term & Renewal

Members can be from:

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

EURORDIS Mental Wellbeing Partnership Network

Call to join the Partnership Network ...

... for patient representatives,
medical expertise and
researchers.

1st Round of Registrations: >90 Experts



Thank you!

