

Mental health is a family issue in rare disease

- 3× higher risk of depression
- Diagnostic odyssey → uncertainty
- Caregiver burden
- Siblings often invisible
- Fragmented detection of distress

Psychological vulnerability accumulates across the family system

REFERENCE

Dubief J., Faye F. (June 2026).
Improve Our Mental Health! Key findings from a Rare Barometer survey on the mental health of people with rare diseases.
EURORDIS–Rare Diseases Europe.
<https://doi.org/10.70790/MHFS2026>



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FAMILY-CENTRED AI-SUPPORTED VOICE MONITORING TO ADDRESS UNMET PSYCHOSOCIAL NEEDS IN RARE DISEASE

FAMILY VOICE IN RARE DISEASE (FAVOUR-RD)

INNOVATIONS TO ADDRESS UNMET NEEDS



From detection ... Innovation in psychosocial support

- Support for patients and families
- Coordination of care pathways
- Interdisciplinary training in health, social and educational fields
- Public awareness
- Expertise for policy and funding decisions

Moving beyond disease-specific silos: a pioneering canton-level patient organization model supporting all rare disease families – including those without a diagnosis



... to the voice ... AI technological innovation

- Voice sample (short recording 30s)
- AI analysis (prosody, rhythm, pauses, intonation)
- Vocal biomarkers
- Validated questionnaires (anxiety and depression measures)
- Early detection of psychological vulnerability

A non-invasive, location-independent and scalable AI-based voice analysis approach for early identification of psychological vulnerability



... to care Innovation in healthcare

- Rapid home-based response
- Care delivered in the patient's daily environment
- Specialised multidisciplinary psychiatric support
- Care coordination and system navigation support
- Support covered by social insurances

Ensuring that early detection leads to timely, coordinated and real-life psychiatric care at home



Why it matters

- Early detection at family level
- Integrated psychosocial pathway
- Real-world implementation
- Scalable model for rare disease ecosystems
- Technology strengthens early recognition – care remains human

ADDRESSING UNMET PSYCHOSOCIAL NEEDS WHERE THEY ACCUMULATE MOST: THE FAMILY SYSTEM

