

Questionnaire for people living with ALS and their carers: Share your experience!

Why participate?

Your contribution will help us...

- **Identify gaps** in care and support
- Capture the **lived experiences and needs** of patients and carers
- Improve and harmonise ALS care across Europe

Who can take part?

- **People living with ALS**
You can respond on behalf of a patient or a patient community
- **Family members or carers** supporting a person living with ALS
- In all European countries (EU or non-EU)

Scan this QR code to access the questionnaire!



Anonymous and **voluntary**

Available in 32 languages

Deadline: **25 May 2026**

Your voice matters

Feel free to share this with others who may be concerned!

This initiative is led by the European Reference Network for Rare Neuromuscular Diseases (ERN EURO-NMD), within the framework of the JARDIN Joint Action (Task 6.2)



European
Reference
Network

for rare or low prevalence
complex diseases



Network
Neuromuscular
Diseases (ERN EURO-NMD)



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