



# An Assessment of Fundamental Rights of People Living with ALS/MND Worldwide: Genetics

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## BACKGROUND

A guiding document for the International Alliance of ALS/MND Associations is the Fundamental Rights of People Living with ALS/MND (PALS) that states the aspirational rights of the global community. Originally conceived in the late 1990s as the “Baseline of Services for People Living with ALS/MND”, these rights represent the ideal for individuals living with ALS/MND and caregivers worldwide.

They are updated each year by the Alliance’s PALS and Caregivers of People Living with ALS/MND (CALS) Advisory Council.

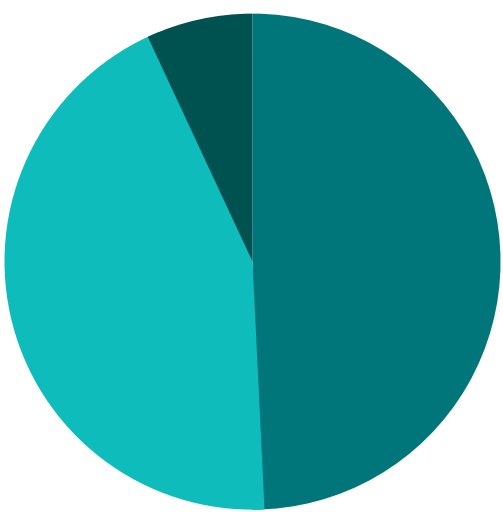
Although the Alliance and its representatives understand that some of these conditions might not be immediately attainable, this document represents the set of rights all Alliance member organizations should adopt and promote as conditions, systems, and resources allow.

In April 2021, the Alliance created a survey to ascertain the level of agreement that these rights were being respected for PALS and CALS. In May 2023, the second survey of its kind was launched to benchmark against the data captured in its first version.

## METHODS

The survey was done by Bramm Research, an independent third party, and it was launched both through our member organizations and on social media in May 2023. It was in the field for 60 days. We received responses from 54 countries. The survey was available in 16 different languages.

### SURVEY RESPONSE



- Person living with ALS/MND
- Current or former caregiver of person living with ALS/MND
- Other

## HYPOTHESIS

\*Access remains the biggest issue for genetic testing and counselling, and it remains unbalanced between the Global North and Global South.

## RESULTS

Genetics are a key part of understanding ALS/MND. This topic relates to fundamental right #11, the right to have access, upon diagnosis, to: up-to-date education about clinical genetics in ALS/MND, genetic counselling, genetic testing, safeguards against genetic discrimination, and subject to education and counselling, blood relatives should also be given the same access, where relevant.

Summary of those who Agree or Agree Strongly

Upon diagnosis, I have access to:

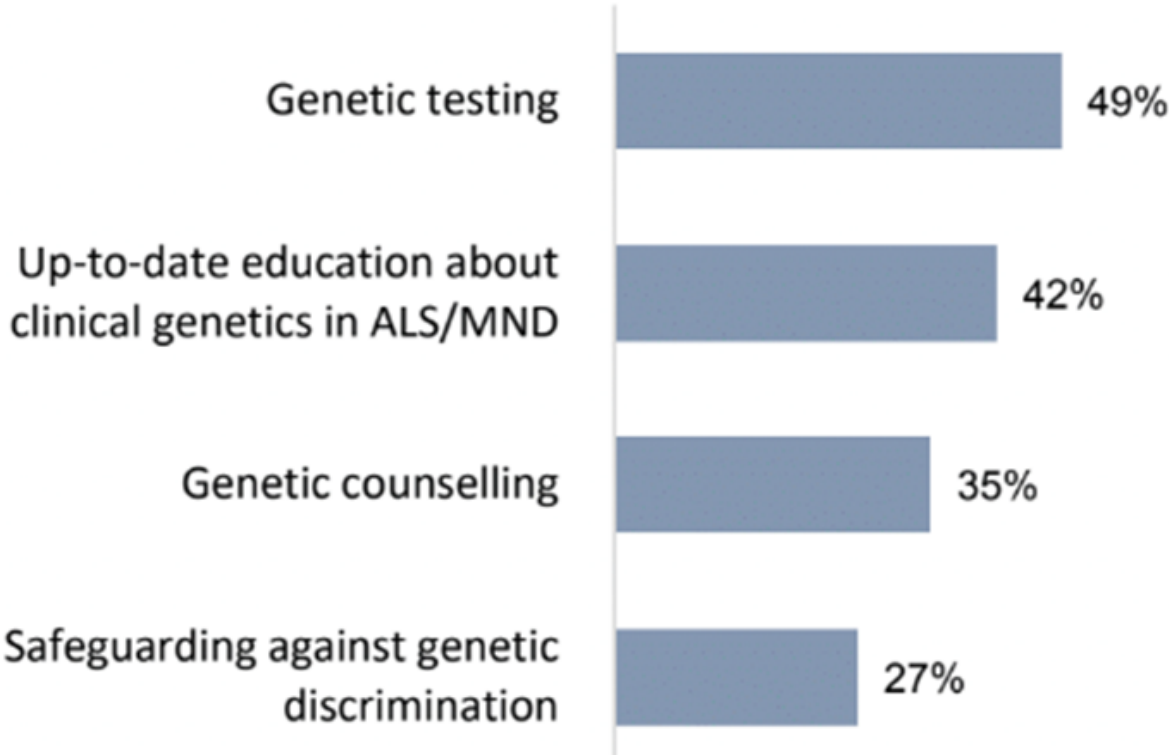


Figure 1. While almost half of respondents have access to genetic testing, only 27% have safeguarding against genetic discrimination.

Genetic testing

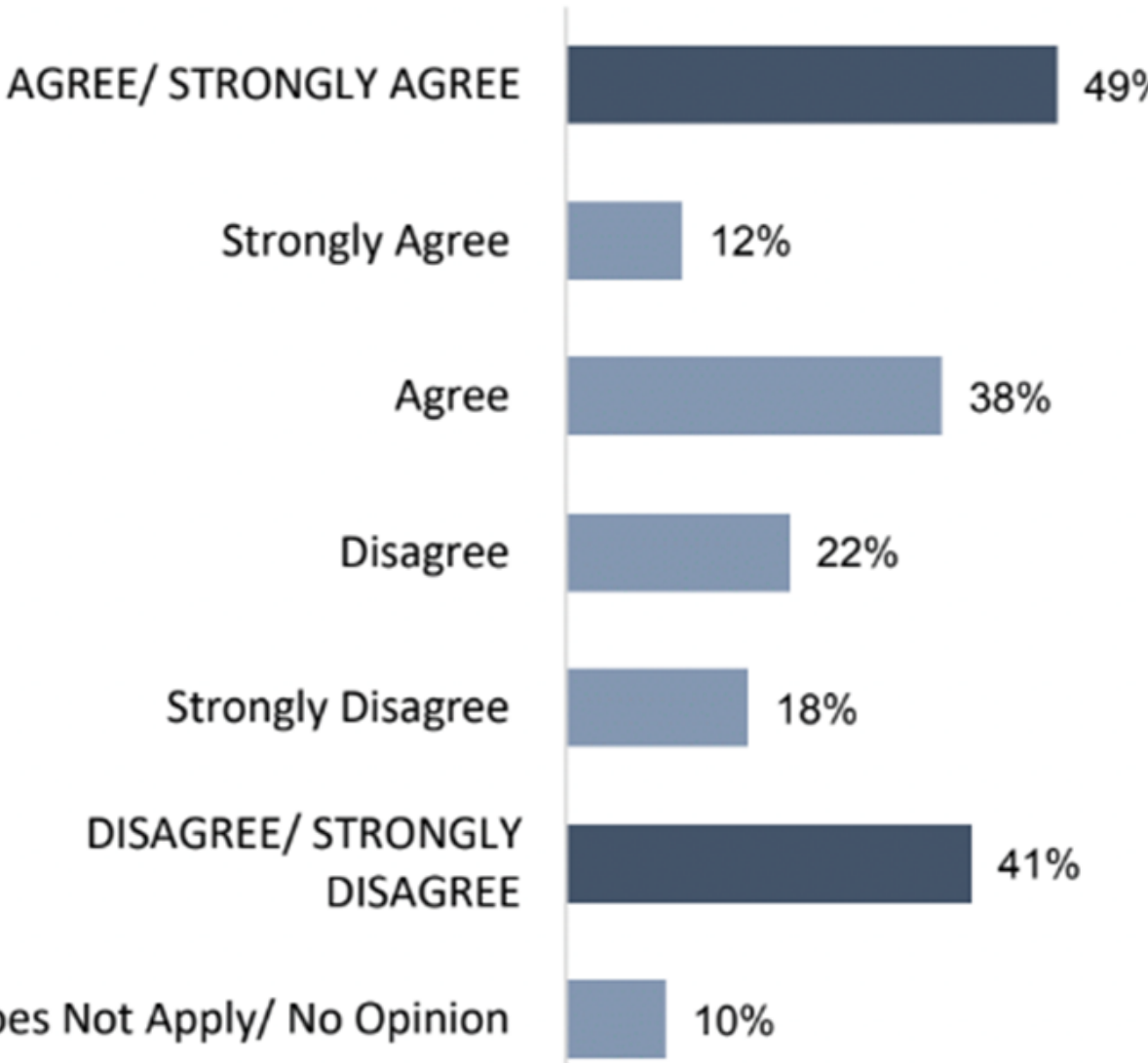


Figure 2. Upon diagnosis, agreement and disagreement to access to genetic testing has not changed significantly from the 2021 results. Unsurprisingly access is greater in the Global North (54% agree vs. 35% disagree) whereas the opposite is true for the Global South (38% agree vs. 55% disagree).

Genetic counselling

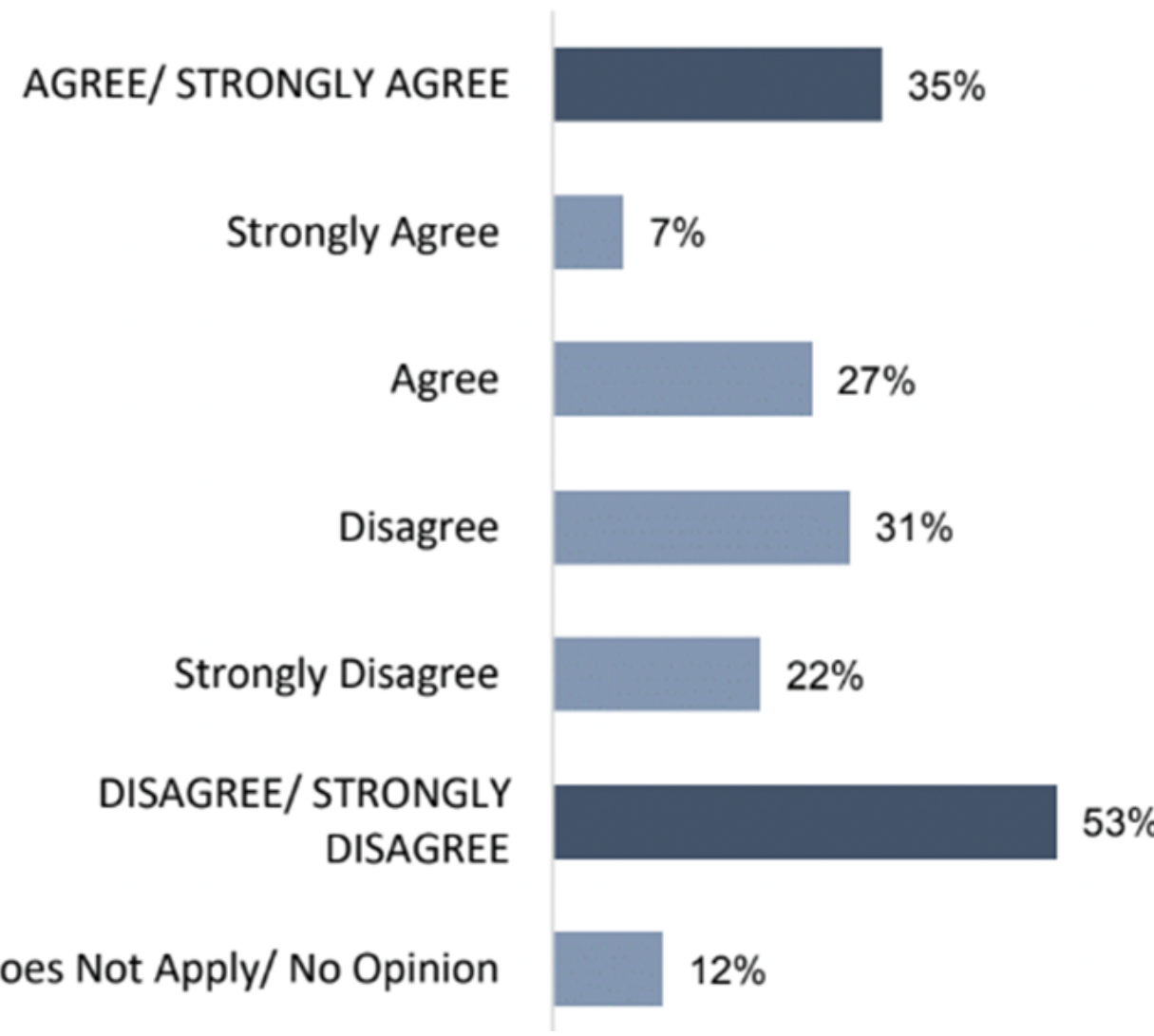


Figure 3. Only one in three PALS respondents have access to genetic counselling upon diagnosis.

Up-to-date education about clinical genetics in ALS/MND

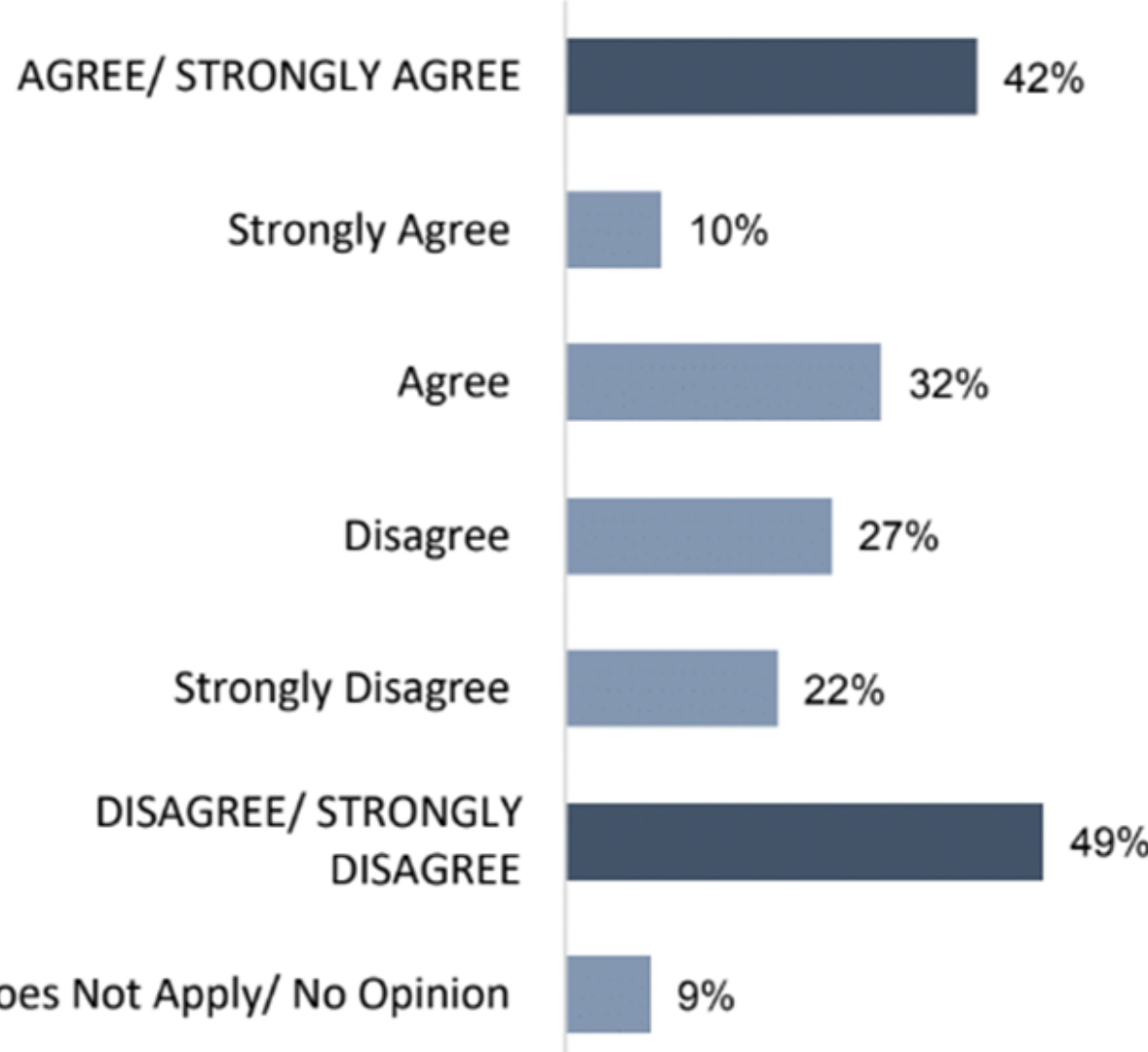


Figure 5. Although still relatively low at 42%, the proportion of those agreeing with having access to education has increased, vs. 36% in 2021. The highest level of agreement was among English speaking respondents (69%). The highest level of disagreement was among respondents from the Global South (63%).

Safeguarding against genetic discrimination

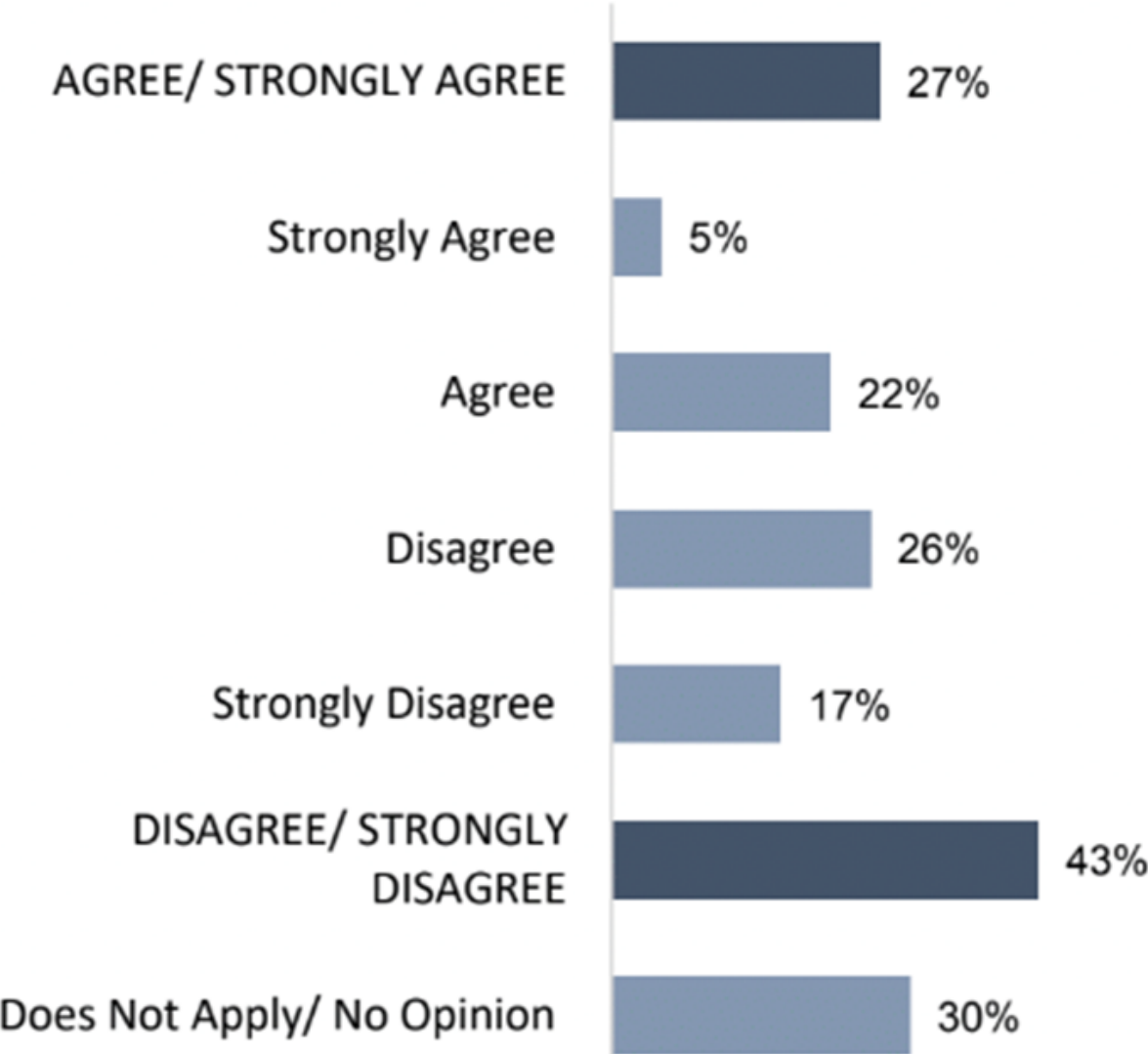


Figure 6. Only one quarter of persons with ALS/MND are safeguarded against genetic discrimination. The proportion is lowest in the Global South (18%).

## DISCUSSION

Genetic testing and counselling can provide PALS with important information to support their journey. Acknowledging the genetic makeup of ALS/MND can help with treatment options and understanding the risk of passing it on to family members. Some interesting points from our 2023 survey are:

- \* Genetic counsellors are perceived to be the most highly specialized professional in ALS/MND at 80% (followed by neurologists at 72% and respiratory therapists at 70%). Access to a genetic counsellor (as well as professionals specialized in ALS/MND) is one of the drivers for respondents who strongly agreed with having access to high quality care (fundamental right #1).
- \*Access to genetic testing and counselling remains lower in the Global South as compared to the Global North.
- \*Access to genetic testing, counselling, and genetic discrimination safeguards has remained the same since 2021, though in 2023 the results are higher with regards to having access to an ALS/MND association provides better alignment with this right.
- \*English speaking respondents are more likely to have access to up-to-date education about clinical genetics in ALS/MND.
- \*Approximately one quarter of PALS respondents reported that their blood relatives are given the same access to genetic counselling and testing.

## ACKNOWLEDGEMENTS

We would like to thank the 1900+ people who responded to the survey, particularly the people living with ALS/MND and their caregivers. We would also like to thank the PALS and CALS Advisory Council of the International Alliance of ALS/MND Associations, whose members provided feedback and guidance on each iteration of this survey as it was developed.

For more information on this project and others please contact us at [alliance@als-mnd.org](mailto:alliance@als-mnd.org) or visit us at [als-mnd.org](https://als-mnd.org).