



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

Jessica Mabe^{1, 2}, Catherine Cummings³

¹ International Alliance of ALS MND Associations

BACKGROUND

A guiding document for the Alliance is the Fundamental Rights of People Living with ALS/MND 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 are updated each year by the Alliance’s PALS and CALS Advisory Council. In February of 2021, it was identified that the previously melded CALS and PALS rights needed to be in separate documents as the pandemic had exacerbated the Caregiver burden to the point where it was important to consider these rights separately. Therefore in 2021 the Fundamental Rights of Caregivers of People Living with ALS/MND was launched.

In addition, it was recognized that there needed to be a right added around Genetic Counseling and Testing which we now recognize is an important element to be considered at or near diagnosis. In 2023, a further review made further changes to the wording and made the first right “access to treatments”. Caregivers rights were expanded with the rights to ask for support when needed, to have direct communication with the medical team, and be able to stay with the PALS when admitted to medical facilities.

These fundamental rights represent the ideal for individuals living with ALS/MND (PALS) and Caregivers (CALS) worldwide. Although the International 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 organisations should adopt and promote as conditions, systems and resources allow.

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

RESULTS

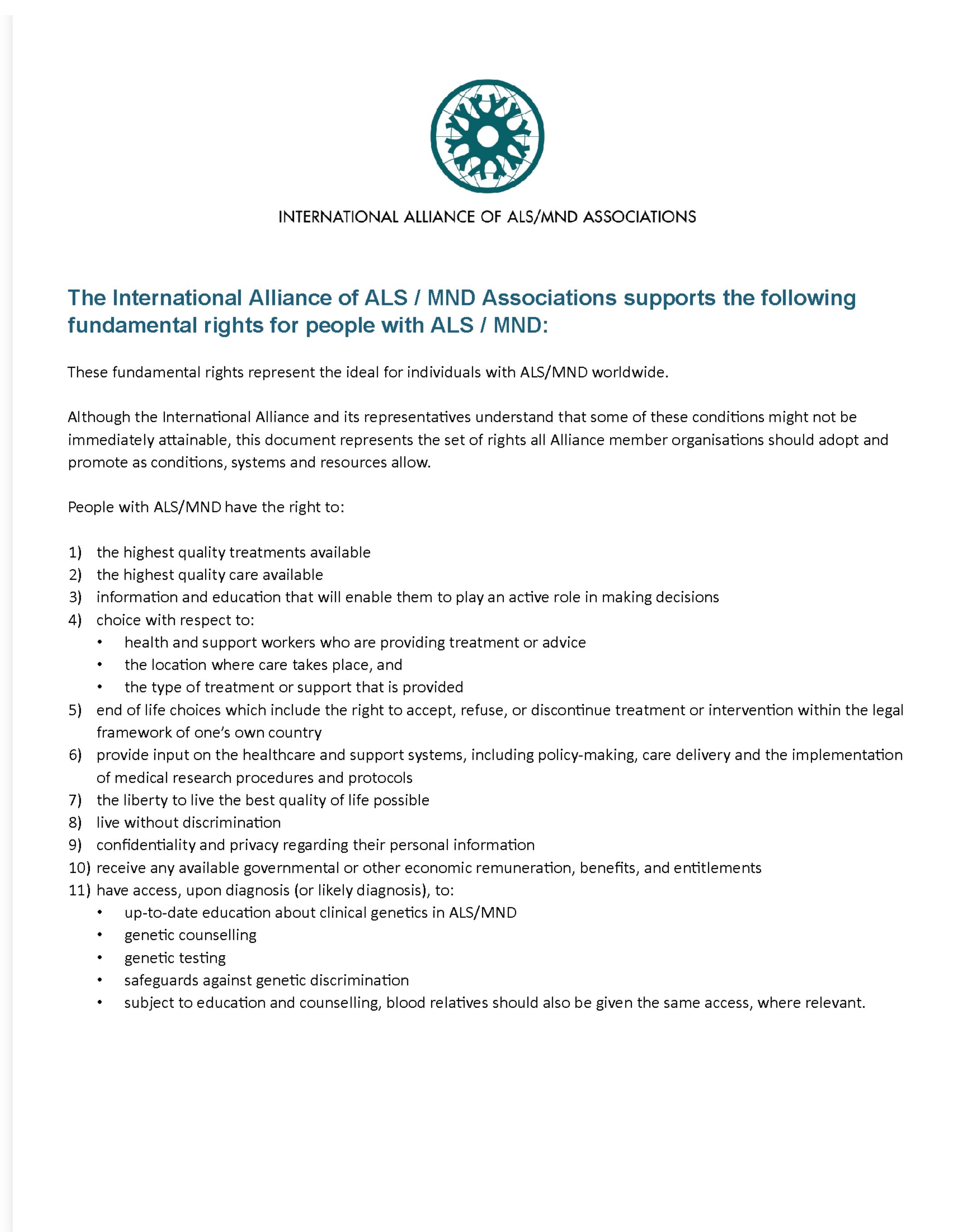


Figure 1. The Fundamental Rights of People Living with ALS/MND

DISCUSSION

Overall the figures are low with a median of 52% of Fundamental Rights being respected for people living with ALS/MND, and similarly for caregivers with a low median of 36%. Some specific findings that merit discussion are:

- For those with access to a multidisciplinary care centre, approximately 1 in 3 (30%) find the centre difficult to access. The rate climbs to 49% for Global South countries. Access is highest among English-speaking respondents (76%) and in the Global North (53%).
- PALS reported very low support in emotional support programs (16%), palliative care and bereavement advice and services (13%) and hospice care (8%).
- Access remains the biggest issue for treatments (Clinical Trials, Approved Drugs), Assistive Devices and Genetic counselling. It is unbalanced between the Global North and the Global South. There is a relationship between access to clinical trials and access to the best possible treatment outcomes. Respondents who agree that they have access to quality treatments are significantly more likely to be participating in a clinical trial or to have participated in one in the past.
- Only 36% of caregivers report being able to have time to take care of themselves.
- Only 1 in 3 caregivers agree about receiving social or respite support.
- Rates of support for caregivers in the Global South (34%) were higher than in the Global North (21%).

HYPOTHESIS

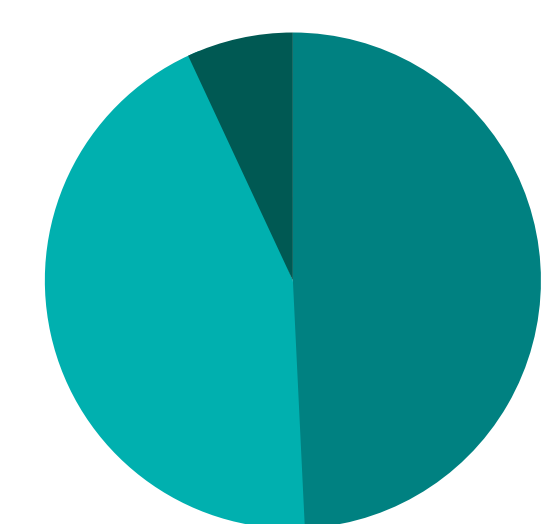
*Access to and respect of these Fundamental Rights is inconsistent around the world and is dependent on multifactorial inputs such as economics, healthcare systems and professionals, and culture which leads to inconsistent quality of life for people living with ALS/MND.

*Access to highest quality of care remains globally unbalanced between the Global North and the Global South.

*Caregivers rights remain inconsistent around the world, with very low support available to them in all areas.

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

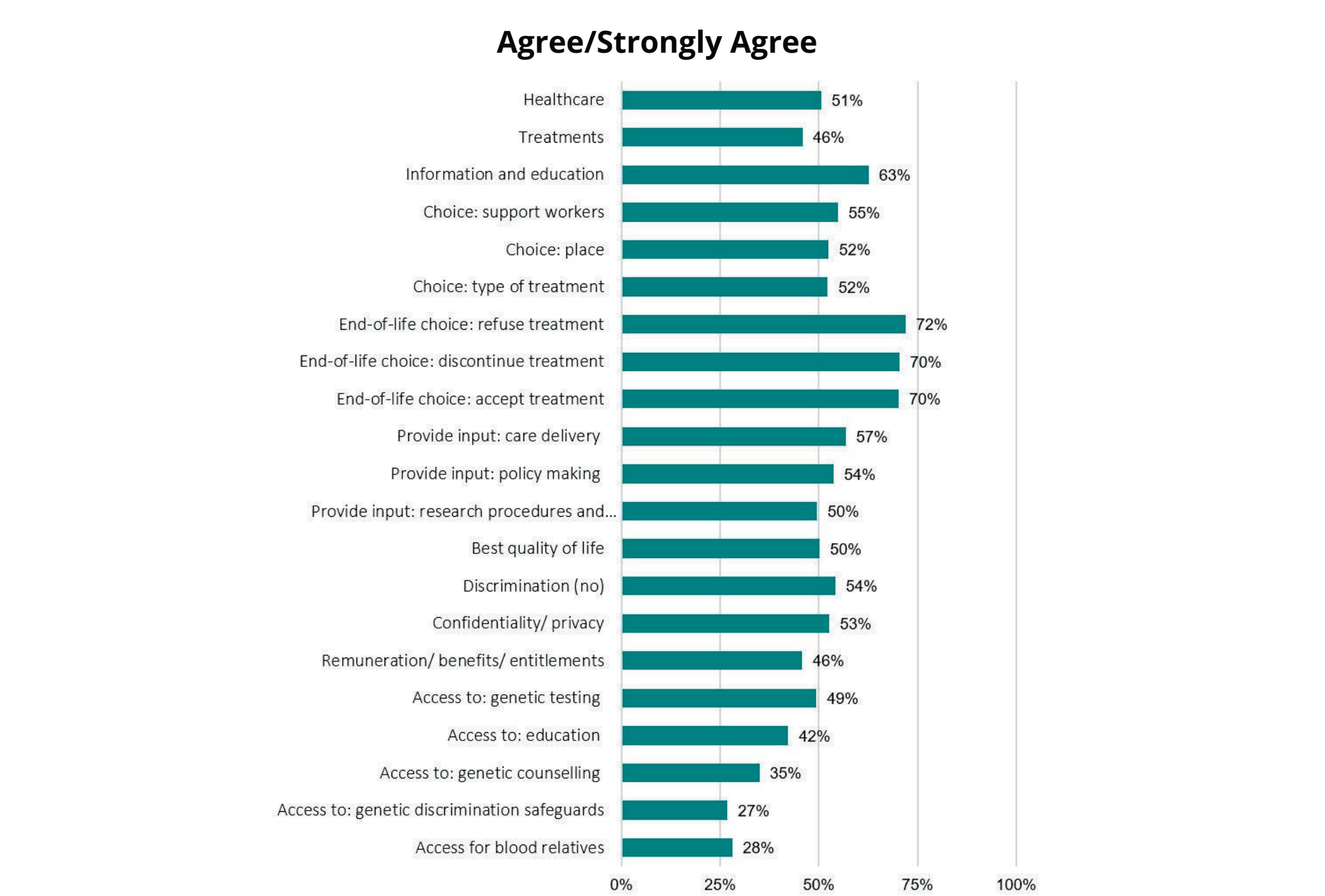


Figure 2. The assessment of the PALS rights indicates that they are not well respected globally with the median at 52

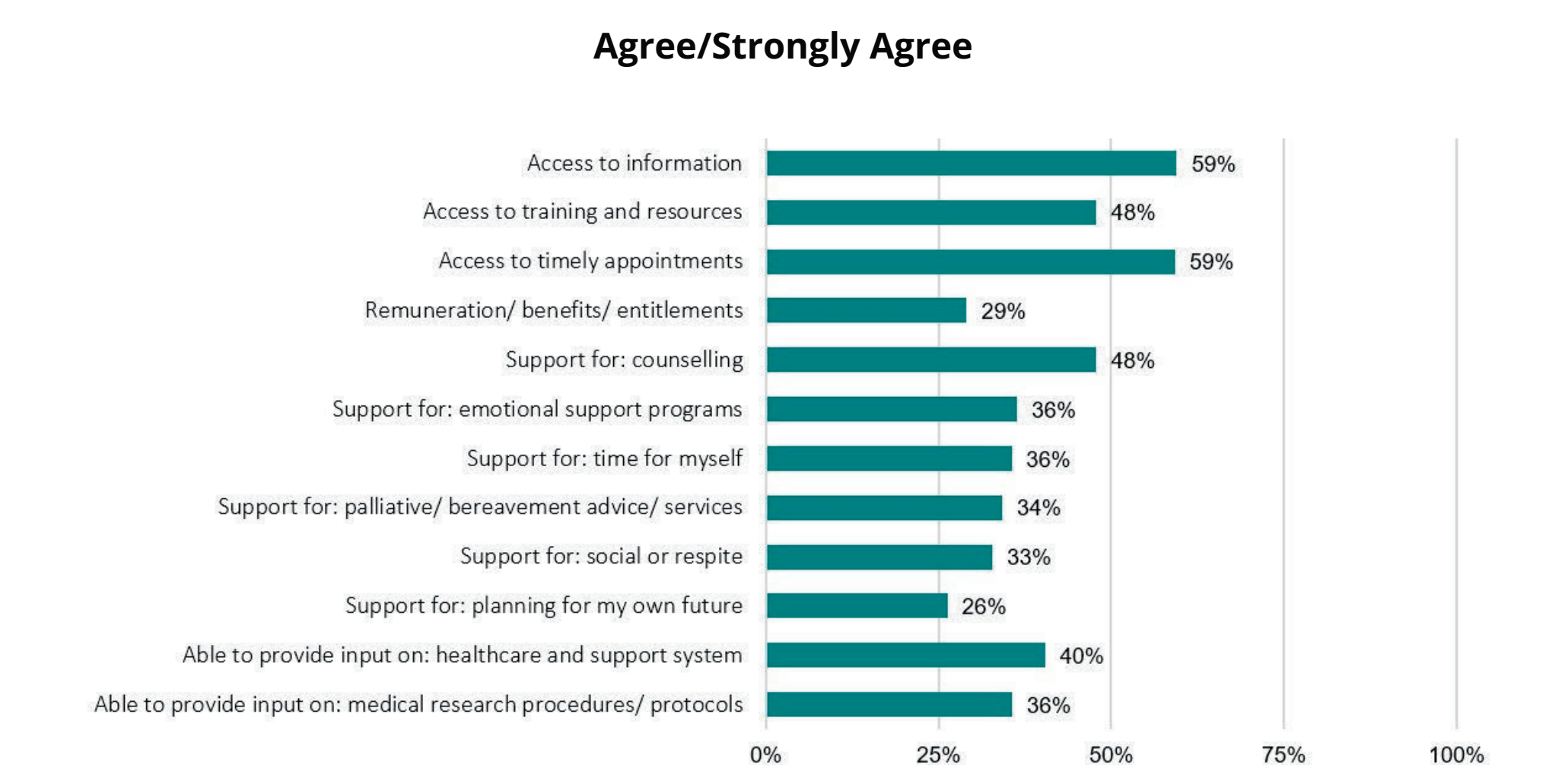


Figure 3. The assessment of the CALS rights indicates that they are not well respected globally with the median at 36

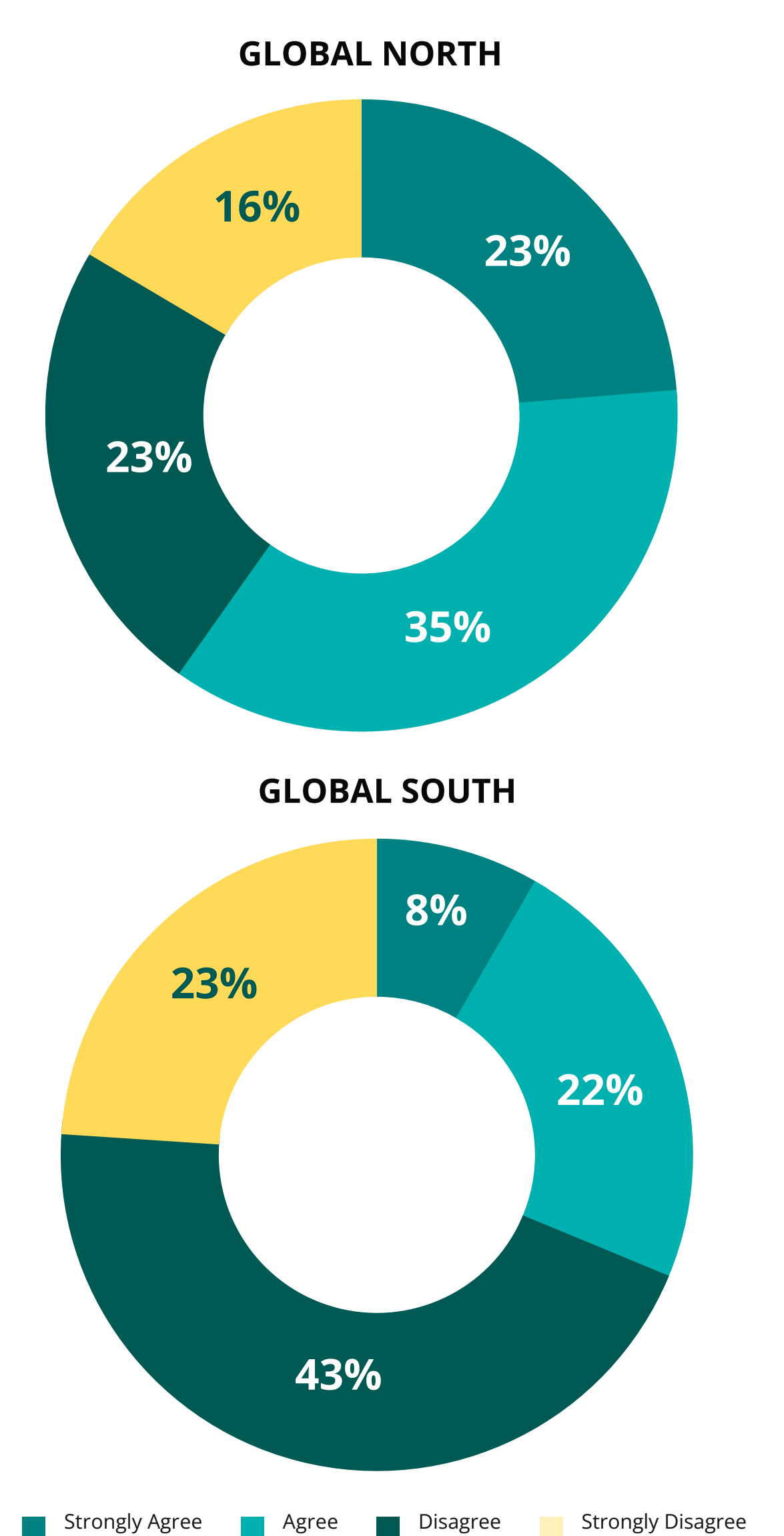


Figure 4. Access to highest quality of care remains globally unbalanced between the Global North and the Global South. The Alliance use the United Nations definition of global north and south for comparison purposes.

Question: I have access to the highest quality care within my healthcare system

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 who 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 or visit us at als-mnd.org.