



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

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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), which 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.

The terms Global North and Global South refer to lists created by the United Nations. Global North countries are mature economies, wealthy, and politically stable. The Global South countries’ economies are still developing and have faster population growth than the Global North.

## HYPOTHESIS

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

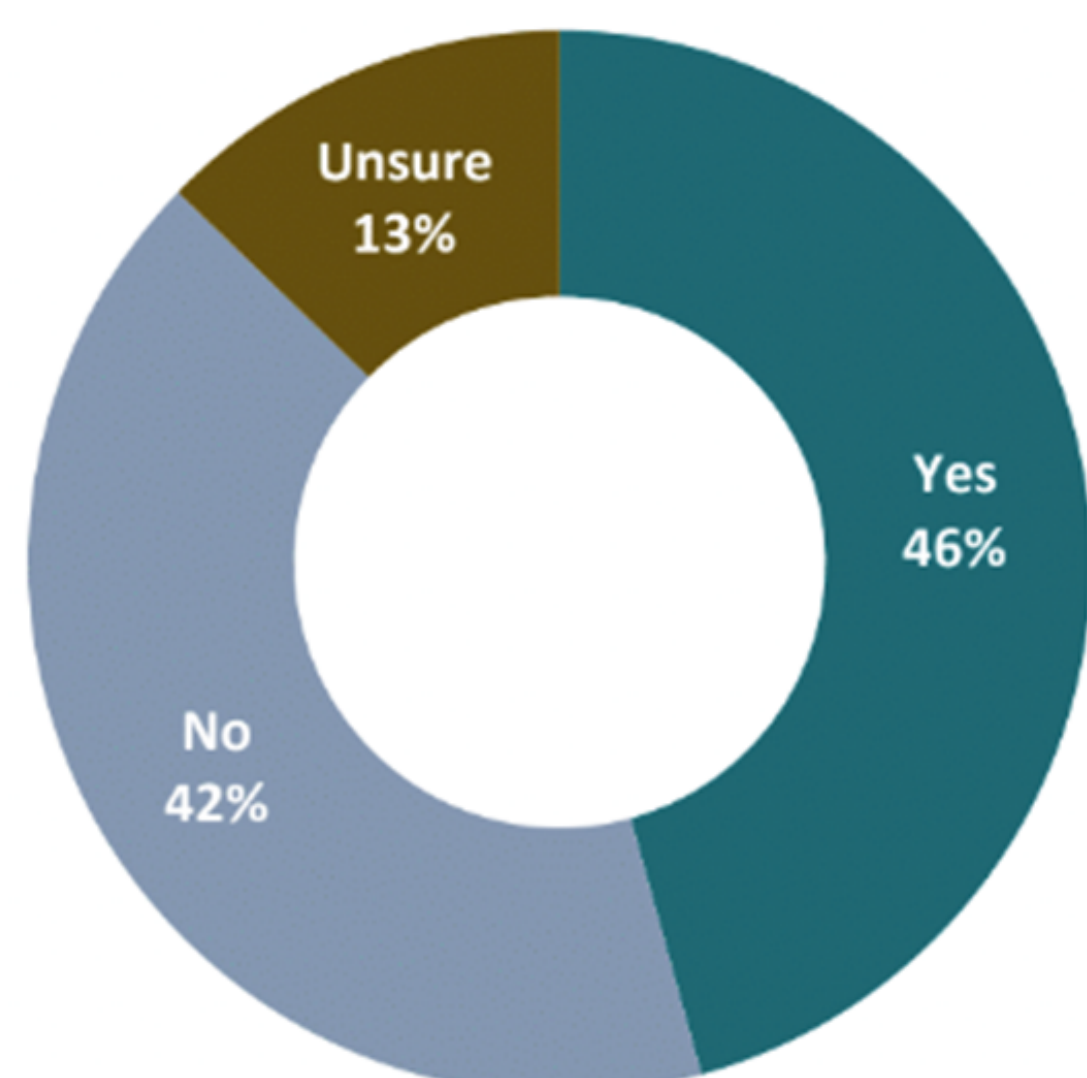
\*Access to a multi-disciplinary clinic is impacted by economic factors as well as geographical factors (rural – urban divide)

\*The relationship between ALS/MND specialists and high-quality care is directly related.

## RESULTS

Multidisciplinary care, as it relates to fundamental right #1, the right to the highest quality care available within their healthcare system.

### I have access to a multidisciplinary clinic.



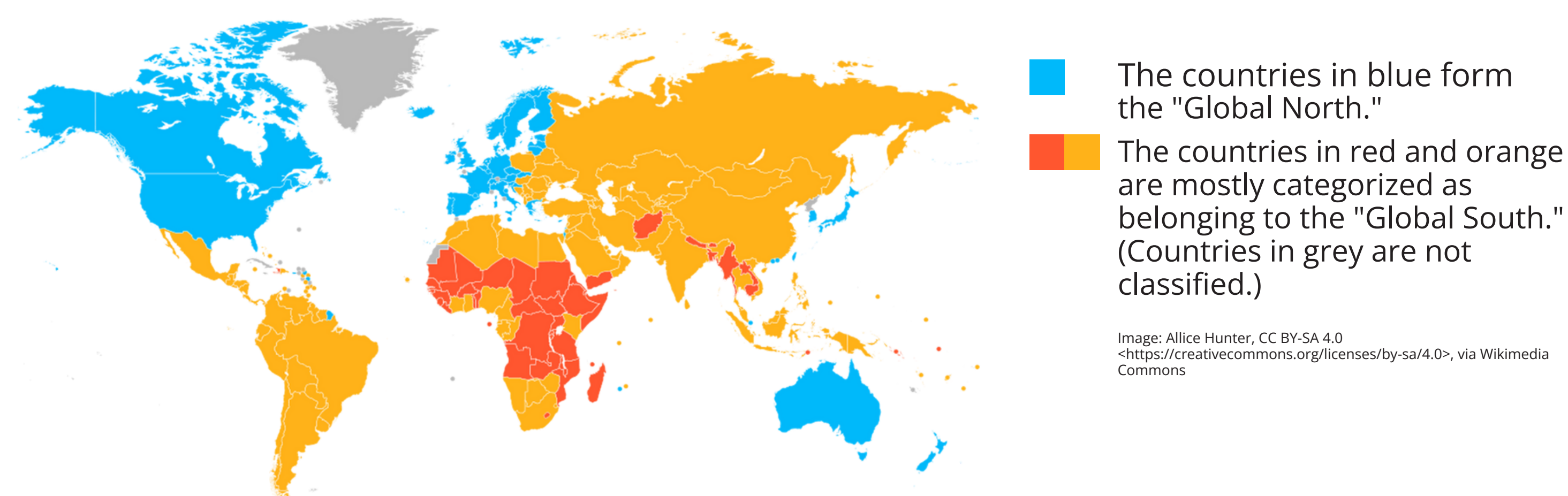
**Figure 1.** Nearly half of all PALS respondents reported having access to a multidisciplinary clinic, the same as in 2021. Meanwhile, two of every five respondents said they did not have access to a multidisciplinary clinic.

### I receive care from:



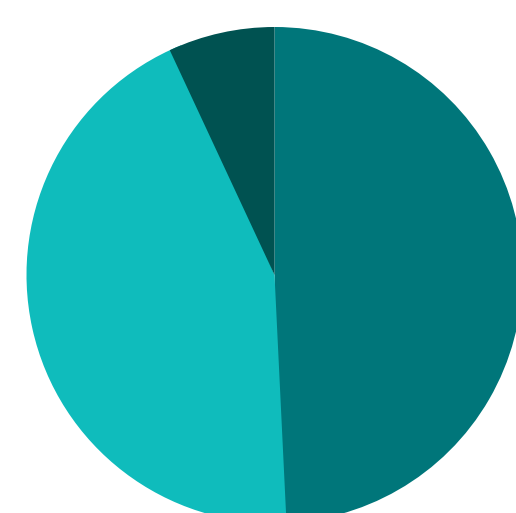
**Figure 4.** Having access to various health care specialists, including a social worker or psychologist, is directly connected to strongly disagree or strongly agree with whether or not PALS feels they are receiving high quality care. Respondents who strongly disagreed with access to high quality care did not have access to a multidisciplinary clinic.

### GLOBAL NORTH AND SOUTH



## METHODS

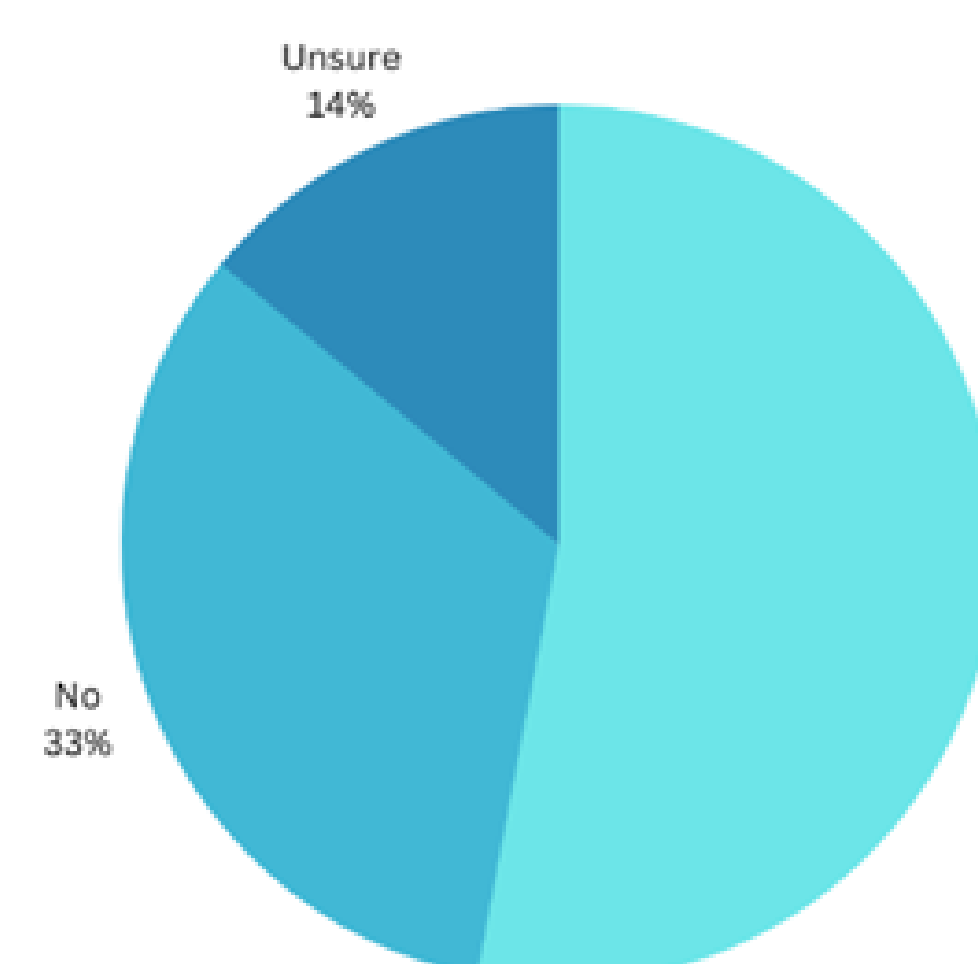
The survey was done by Bramm Research an independent third party and it was launched both through our member organizations and on social media in May 2023. It was in the field for 60 days. We received responses from 54 countries. The survey was available in 16 different languages.



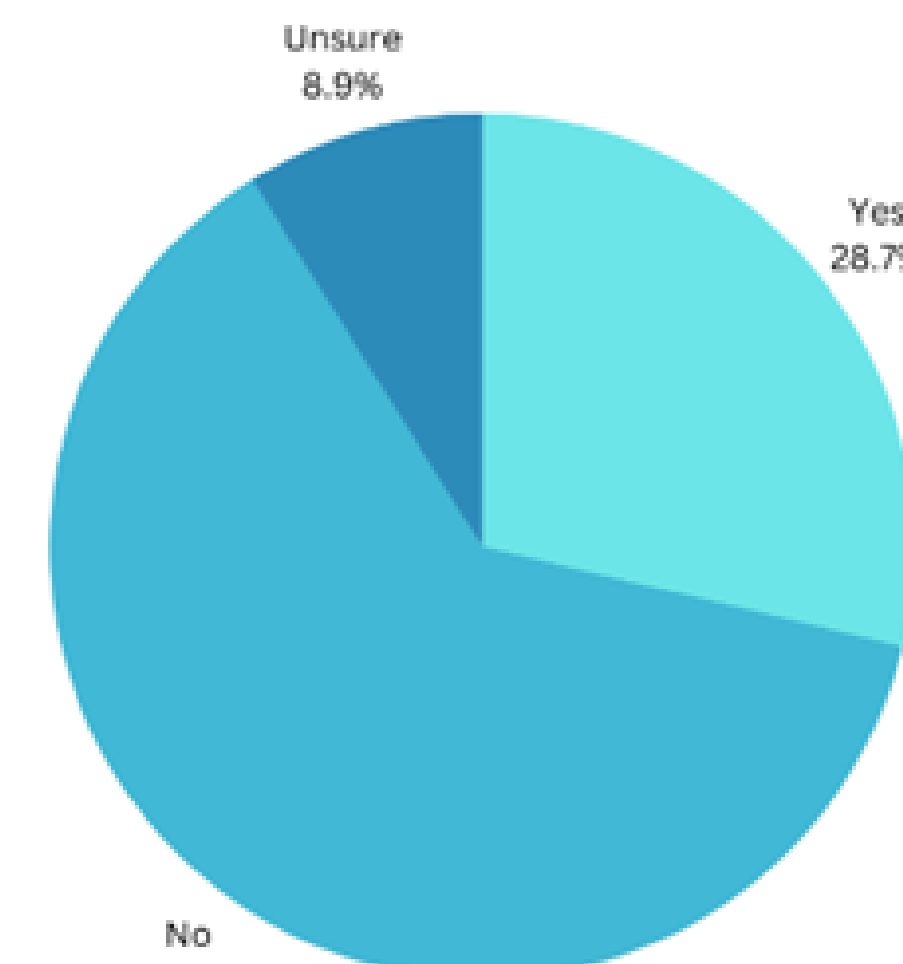
### SURVEY RESPONSE

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

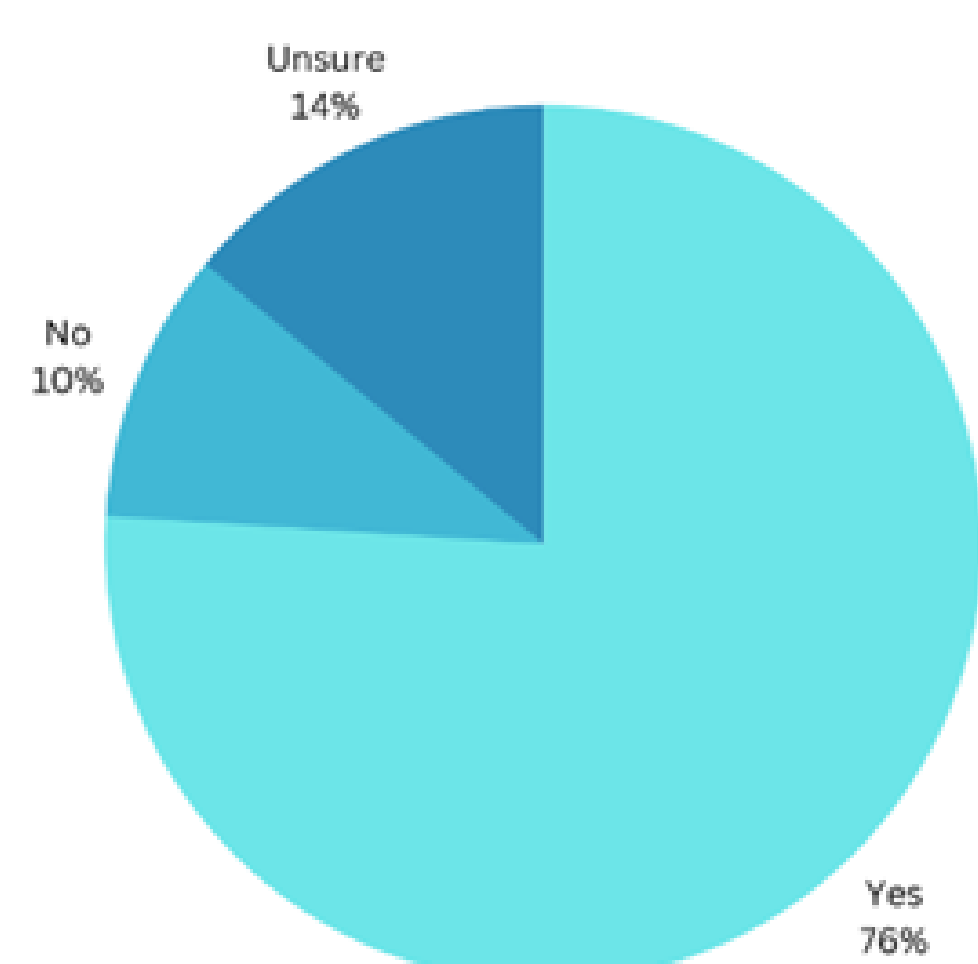
### GLOBAL NORTH



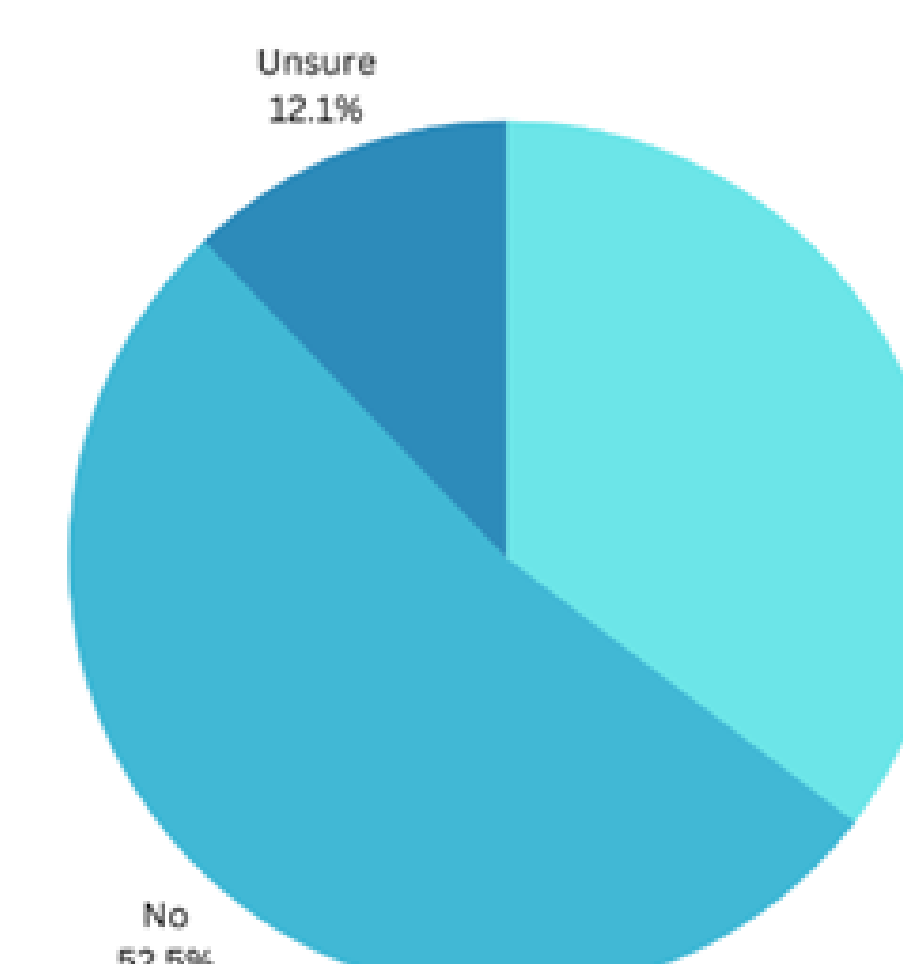
### GLOBAL SOUTH



### ENGLISH SPEAKING



### NON-ENGLISH SPEAKING



**Figure 2 and 3.** Unsurprisingly, access to multi-disciplinary care is primarily in the Global North (53%) and among English-speaking respondents (76%). Interestingly, access from urban and rural respondents is approximately equal.

## DISCUSSION

The services offered at multidisciplinary clinics are part of the quality of care that a PALS is able to receive. There are some noteworthy points:

\*Access to multidisciplinary clinics remains significantly higher in the Global North and in English speaking countries due to economic and geographical factors. Additionally, these results are the same as in 2021.

\*Urban versus rural location did not have a significant impact on data results, despite the hypothesis that urban respondents would have greater access.

\*Access to health care specialists is highly connected to strongly disagreeing or strongly agreeing with whether or not PALS feel they're receiving high quality care.

\*Access to various healthcare specialists plays a significant role in how PALS perceive the quality of the care they are receiving. The main specialists mentioned as providing care are neurologists (76%), physiotherapists (57%), and respiratory therapists (45%).

\*Having access to social workers and psychologists is a driver of the perception of highest quality care available.

## 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](mailto:alliance@als-mnd.org) or visit us at [als-mnd.org](https://als-mnd.org).