



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

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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.

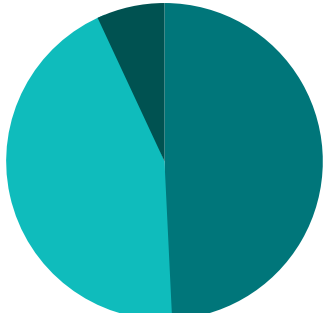
In April 2021, the Alliance created a survey to ascertain the level of agreement that these rights were being respected for PALS and CALS. In May 2023, the second survey of its kind was launched to benchmark against the data captured in its first version.

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, and Global South countries’ economies are still developing. They have faster population growth than the Global North.

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

RESULTS

The analysis plan was informed by the results of the 2021 Fundamental Right Survey. The results aim to benchmark and track progress and trends over the last couple of years to give an accurate snapshot of the reality of PALS, as well as help identify opportunities for improvement. Of the thirteen rights that could be tested against 2021 results, agreement levels for seven have increased in 2023.

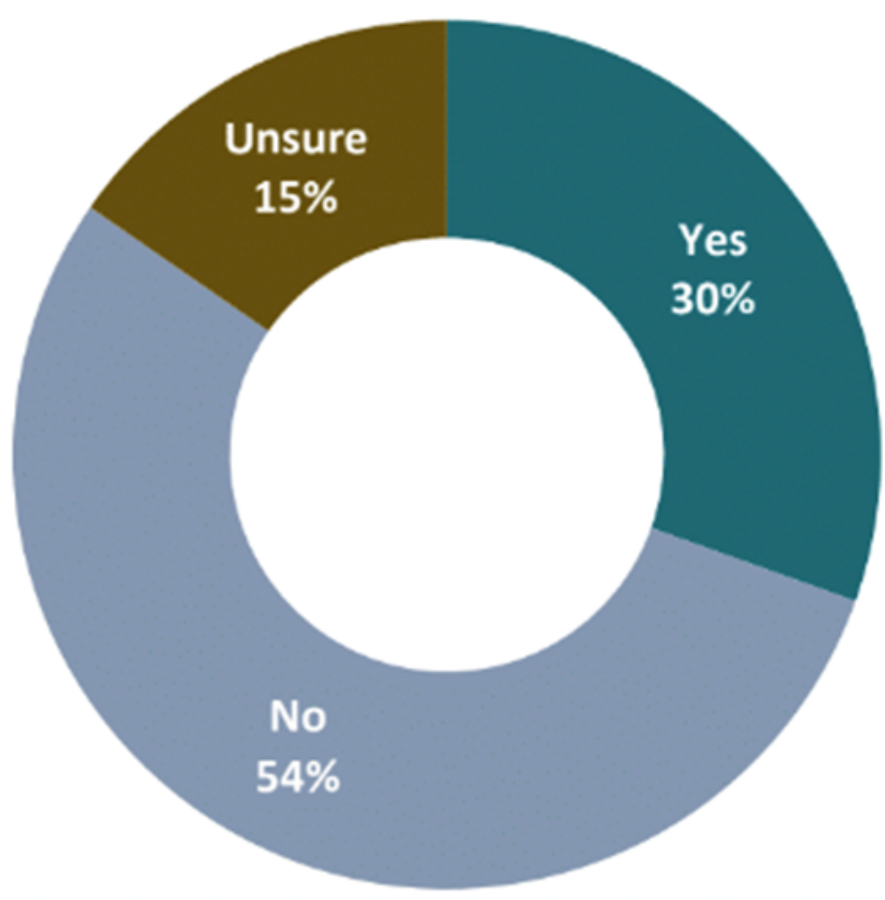
Hypothesis 1
Having access to an ALS MND Association provides better respect of all 11 Fundamental Rights.
TRUE: Agreement levels for respondents with Association access high higher for every measured right, especially for end-of-life choice.

Hypothesis 2
The right to information and education is better respected in countries where English is spoken.
TRUE: The proportions of English-speaking PALS respondents (87% vs. 54% non-English speaking) who agree or strongly agree to having access to information and education.

TOTAL RESPONDENTS
Agree/ Strongly Agree
Strongly Agree
Agree
Disagree
Strongly Disagree
Disagree/ Strongly Disagree
Does Not Apply/ No Opinion

2023	2021	Respondent Language			
		%	%	English	< > Not English
898	404	228			670
63%	59%	87%	>		54%
22%	19%	46%	>		14%
40%	40%	40%			40%
24%	24%	10%	<		28%
13%	15%	3%	<		16%
36%	39%	13%	<		44%
1%	2%	0%	<		2%

With regard specifically to your ALS/MND experience, have you experienced discrimination?

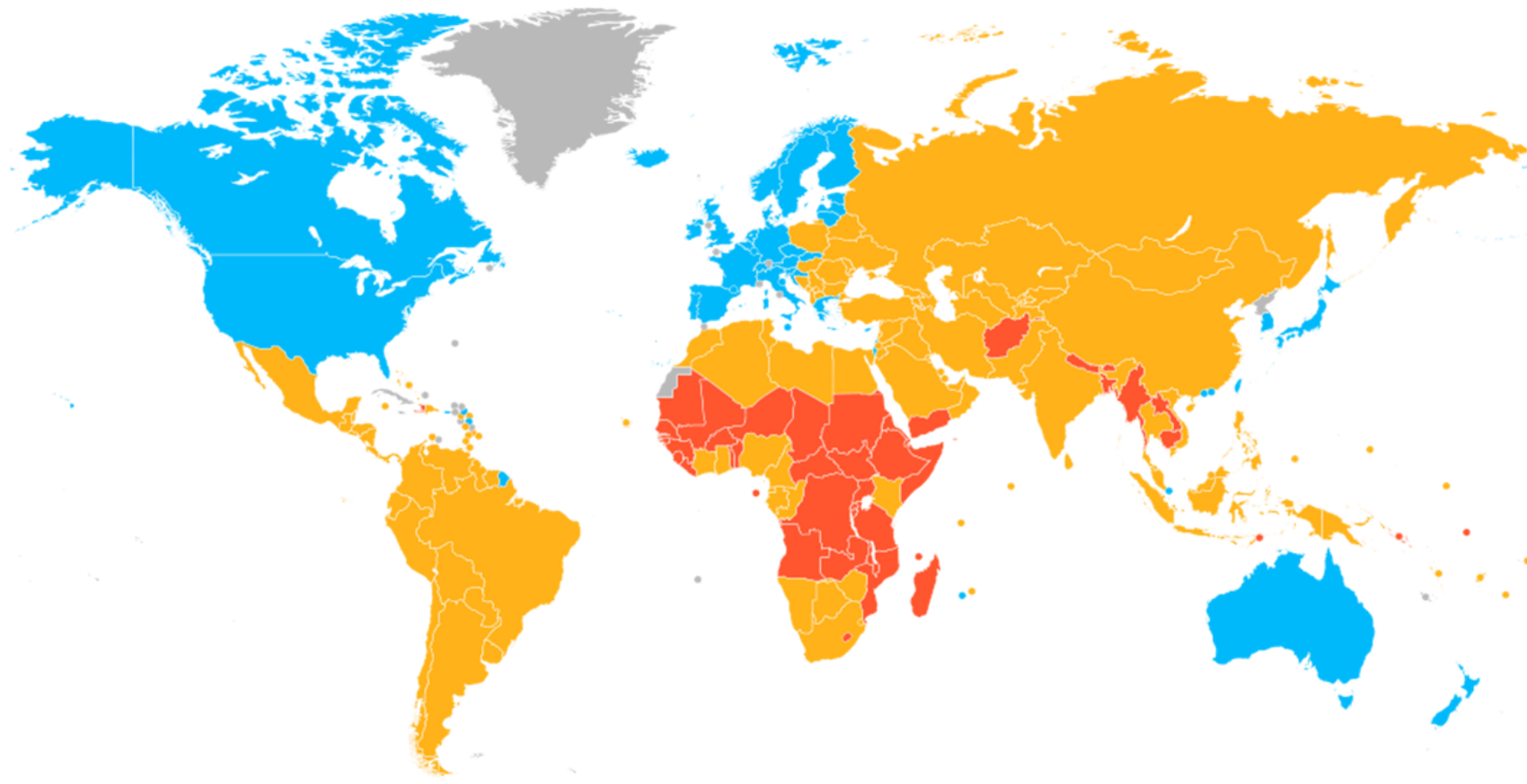


Hypothesis 3
Discrimination happens in the ALS/MND community.
TRUE: 30% of PALS respondents have experienced discrimination, the results as in 2021. Those in the Global South reported a higher rate (39%) as compared to the Global North (27%).

DISCUSSION

- *ALS/MND associations are valuable for PALS and are linked to higher agreement of agreement with rights.
- *Access to highest quality care remains globally unbalanced between the Global North and the Global South.
- *Access to treatment: although Riluzole has high availability in both the Global North and South, availability of Edaravone and AMX0035 is higher in the North. Access to clinical trials, both currently and in the past, is higher in the North.
- *Only 1/3 of PALS respondents have access to genetic counselling and the proportions are lowest in the Global South (25%).
- *Only a third of the CALS respondents have time to take care of themselves, and 80 % report that their economic situation is affected. 75% of CALS are female.

GLOBAL NORTH AND SOUTH



- The countries in blue form the "Global North."
- The countries in red and orange are mostly categorized as belonging to the "Global South." (Countries in grey are not classified.)

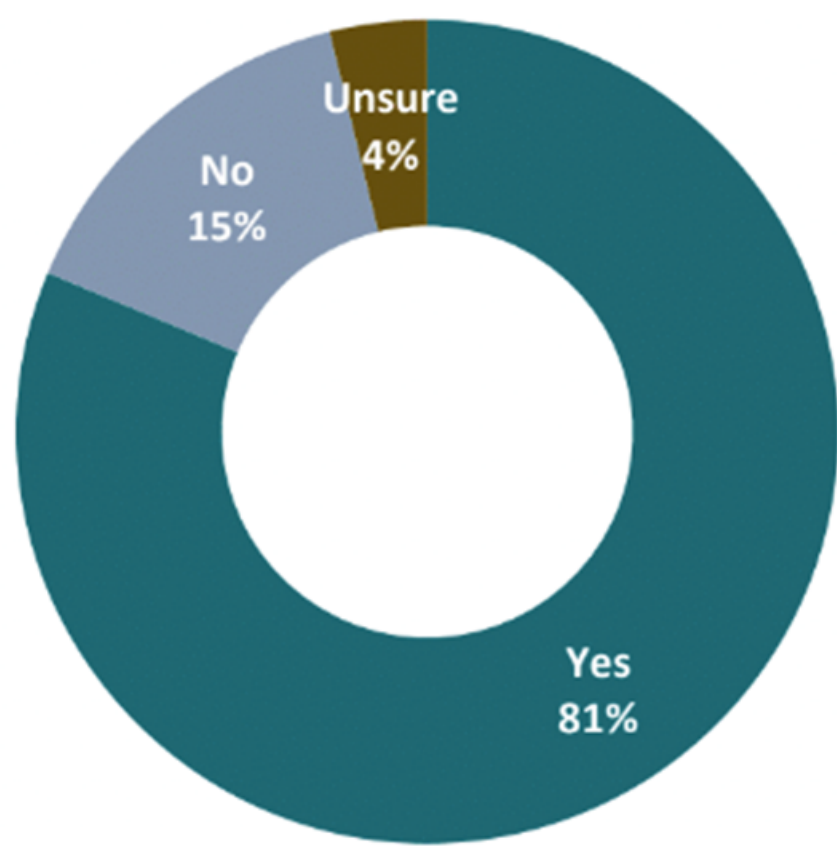
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HYPOTHESIS

The 2023 Fundamental Rights Survey provided an opportunity for the Alliance to test and validate certain hypotheses with regards to the PALS and CALS landscape. These hypotheses were generally based on the results of the 2021 survey and serve to benchmark and compare any progress in certain areas. Several hypotheses were considered as part of the analysis plan, including:

- Having access to an ALS MND Association provides better respect for all 11 Fundamental Rights.
- The right to information and education is better respected in countries where English is spoken.
- Discrimination happens in the ALS/MND community.
- ALS/MND puts families into poverty.
- Access remains the biggest issue several rights including highest quality care, treatments (clinical trial, approved drugs), genetic counselling. Additionally, this access is unbalanced between the Global North and the Global South.
- Respect of the Fundamental Rights of CALS is universally low and inconsistent, lacking support in all areas including access to remuneration, emotional support programs, palliative care, bereavement advice and services, and social support and respite.

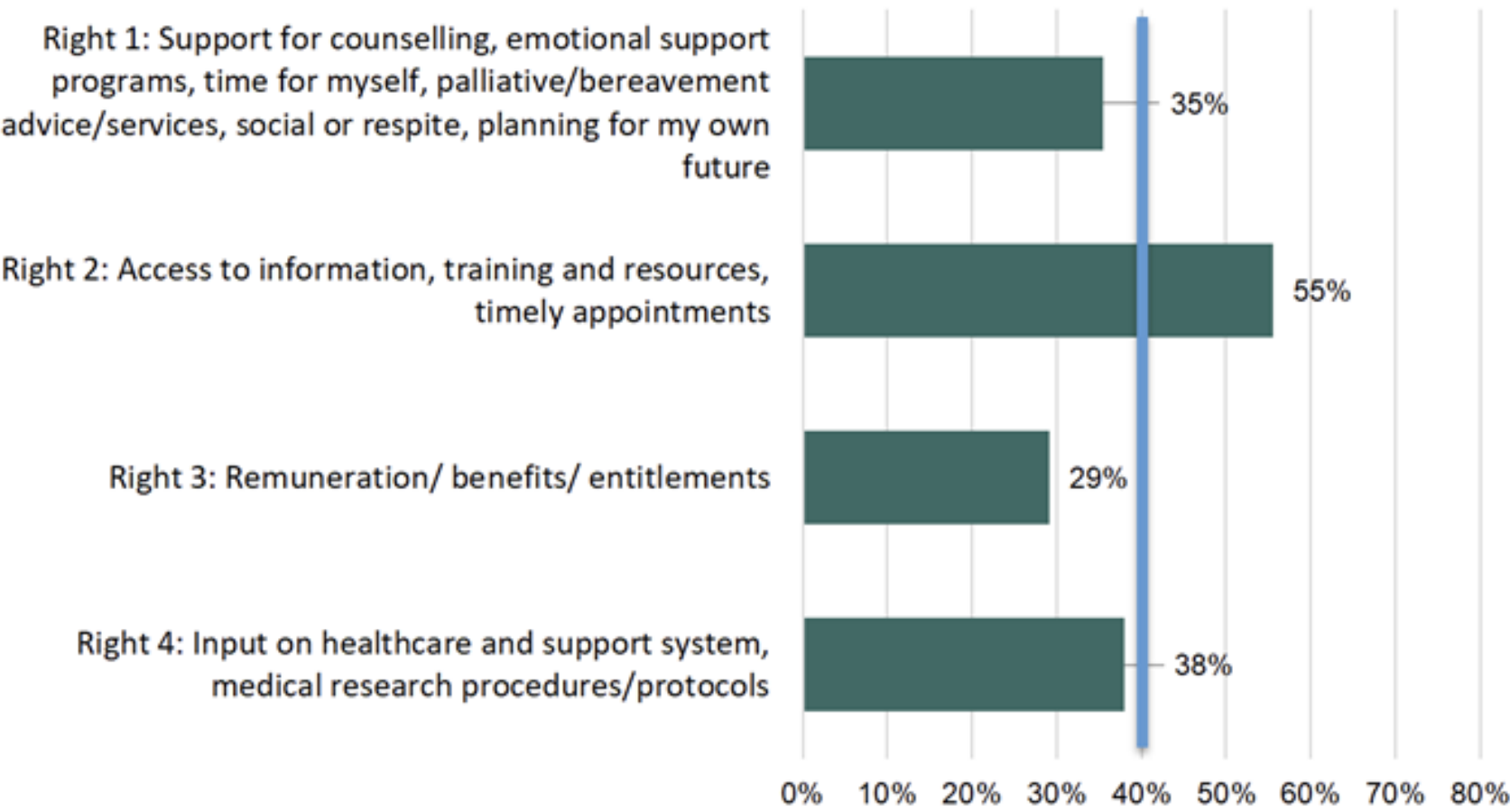
Has ALS/MND affected your economic situation?



Hypothesis 4
ALS/MND puts families into poverty.
TRUE: 4 out of 5 PALS respondents have been affected economically and almost 4 in 10 (37%) have had to leave employment completely. The numbers are high across all cohorts, but especially so with non-English speakers (85% vs. 71% English speakers) in the Global South (88% vs. 79% in the Global North).

2023	2021	Global N. vs. S			
		%	%	North	< > South
900	408	640			260
51%	49%	59%	>		30%
19%	22%	23%	>		8%
32%	27%	35%	>		22%
29%	25%	23%	<		43%
18%	24%	16%	<		23%
47%	49%	39%	<		67%
3%	3%	2%			3%

Current or Former Caregiver of a Person Living with ALS/MND



Hypothesis 6
Respect of the Fundamental Rights of CALS is universally low and inconsistent, lacking support in all areas including access to remuneration, emotional support programs, palliative care, bereavement advice and services, and social support and respite.
TRUE: CALS support rates are slightly higher in 2023 compared to 2021 across all categories but remain low in all parts of the world.

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.