



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

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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 CALS. In May 2023, the second survey of its kind was launched to benchmark against the data captured in its first version.

## HYPOTHESIS

\*Participation in activities of arts, culture, and sports improve the quality of life of PALS.

## RESULTS

These results represent right #7, the right to the best quality life possible.

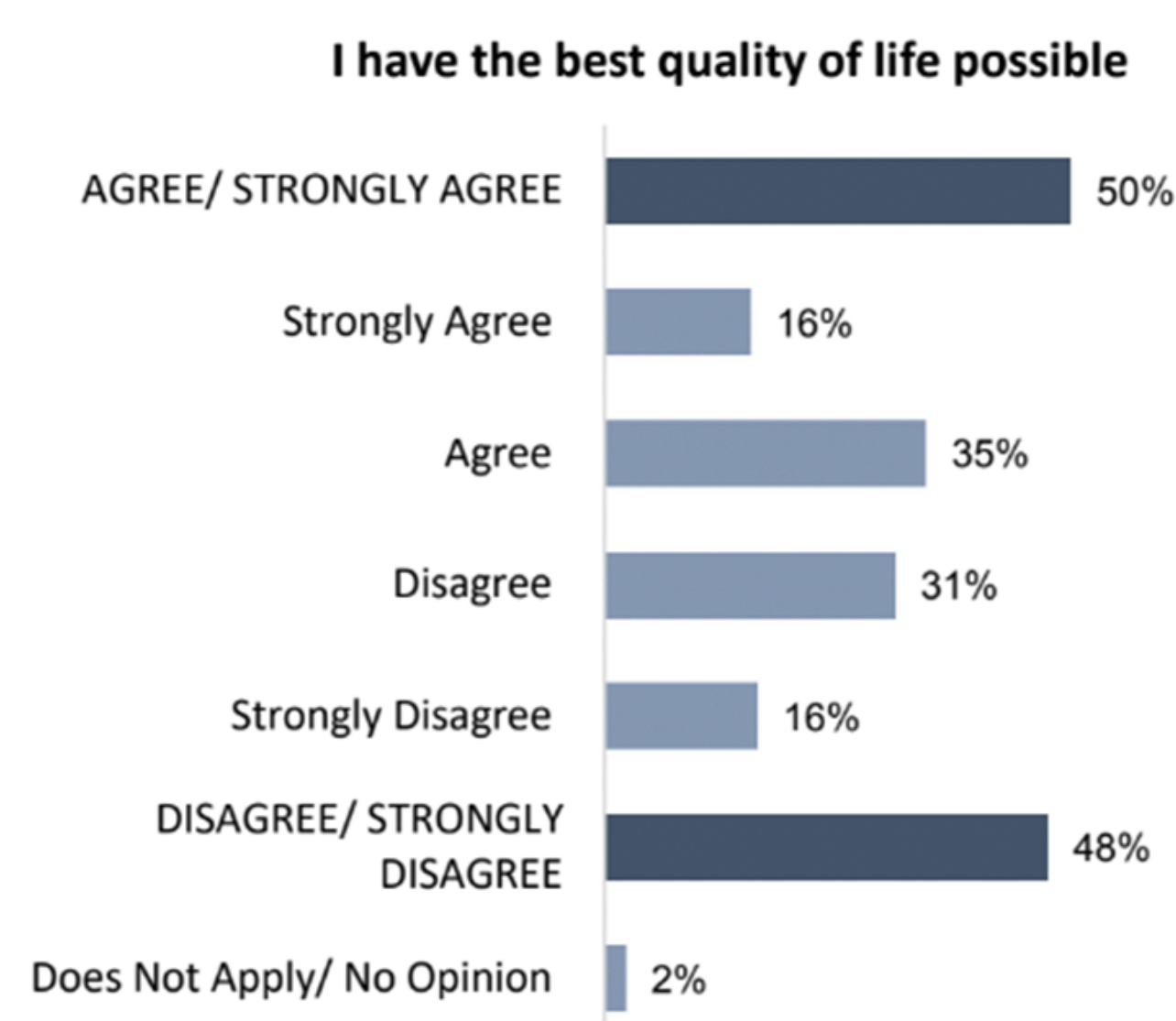


Figure 1. The percentages of respondents agreeing and disagreeing with quality of life are statistically equal, though there is large variation in agreement between English and non-English speakers (75% vs. 42%).

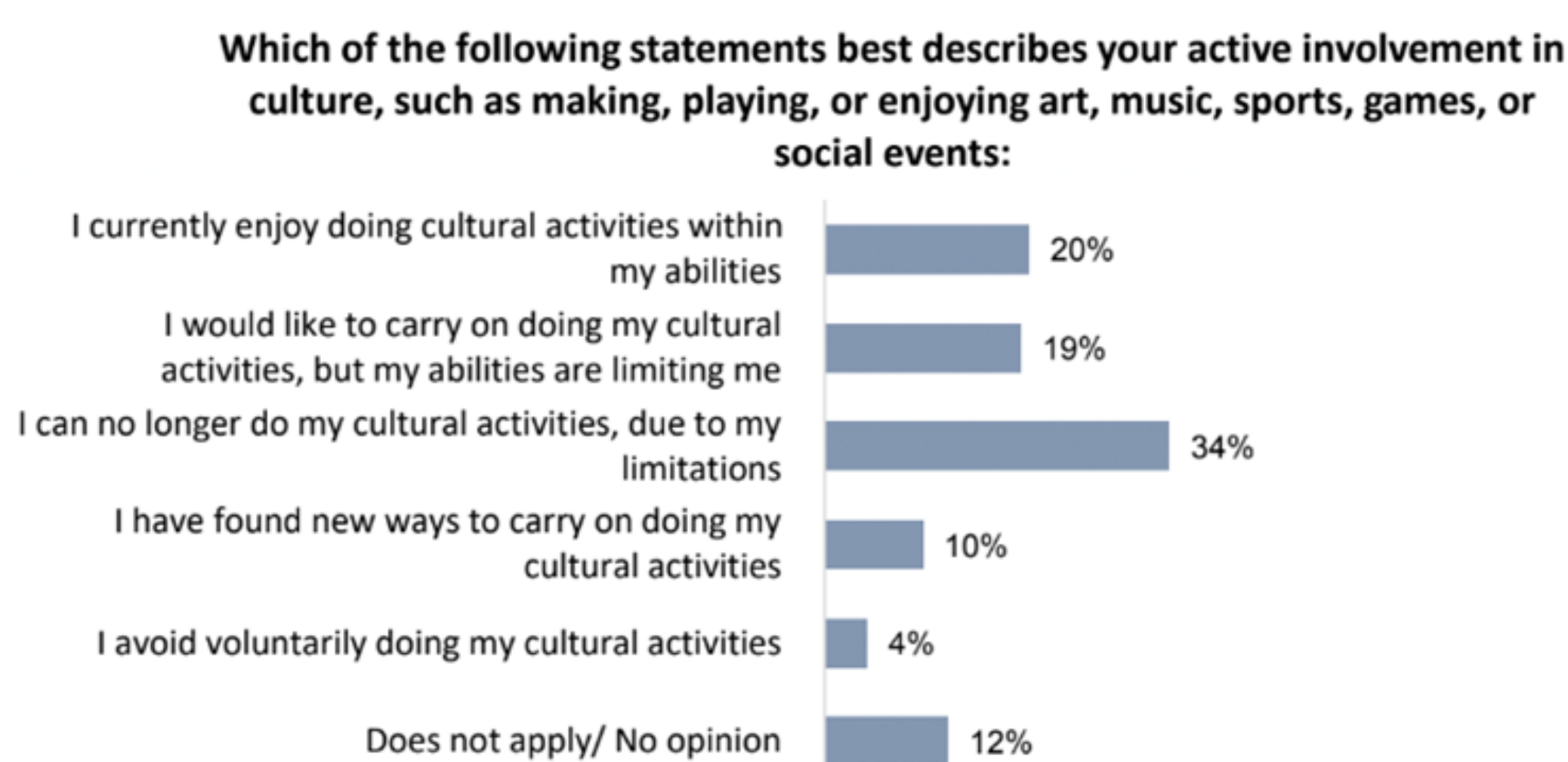


Figure 2. Due to limitations, 34% of PALS respondents can no longer participate in cultural activities.

## DISCUSSION

\*Participation in cultural activities such as art, music, games, sports, and social activities directly impact quality of life for PALS.

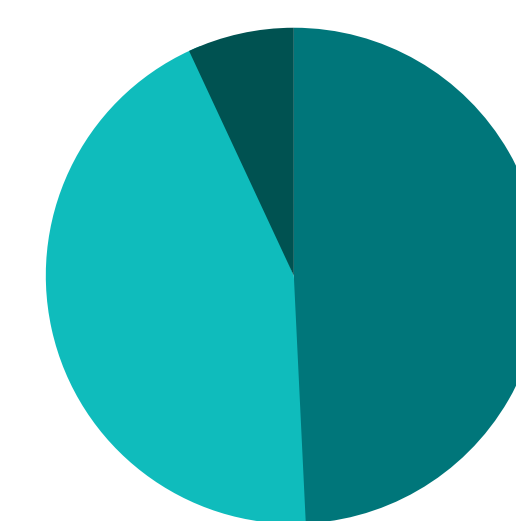
\*Limitations impacting ability to participate in cultural activities impact over half (53%) of the respondents.

\*1 in 5 PALS continues to enjoy cultural activities, which contributes to best quality of life.

## 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

	2023	2021	Quality of Life	
	%	%	Agree/ Strongly Agree	Disagree/ Strongly Disagree
<b>28. Which of the following statements best describes your active involvement in culture, such as making, playing, or enjoying art, music, sports, games, or social events:</b>				
<b>TOTAL RESPONDENTS</b>	<b>894</b>	<b>n/a</b>	<b>447</b>	<b>421</b>
I currently enjoy doing cultural activities within my abilities	20%	n/a	27%	> 14%
I would like to carry on doing my cultural activities, but my abilities are limiting me	19%	n/a	21%	35% 17%
I can no longer do my cultural activities, due to my limitations	34%	n/a	22%	< 47%
I have found new ways to carry on doing my cultural activities	10%	n/a	14%	> 5%
I avoid voluntarily doing my cultural activities	4%	n/a	5%	3%
Does not apply/ No opinion	12%	n/a	11%	13%

Figure 3. Respondents who can no longer do cultural activities have report lower quality of life. These results are new from the 2023 survey.

## 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](http://als-mnd.org).