



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

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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 Alliance, through collaborations in regions where there is no access to voice preservation, seeks to establish a broader understanding of the current state of the art service and availability for this technology with the objective of designing and developing a sustainable foundation on which everyone worldwide who would benefit will have access to it.

This topic is new to the 2023 survey. Voice Preservation involves recording samples of a person’s speech in order to preserve their natural voice and acoustic identity in the event that they were to lose their ability to speak at some stage in the future. Message and voice banking are two of the main ways that a person may wish to preserve their voice.

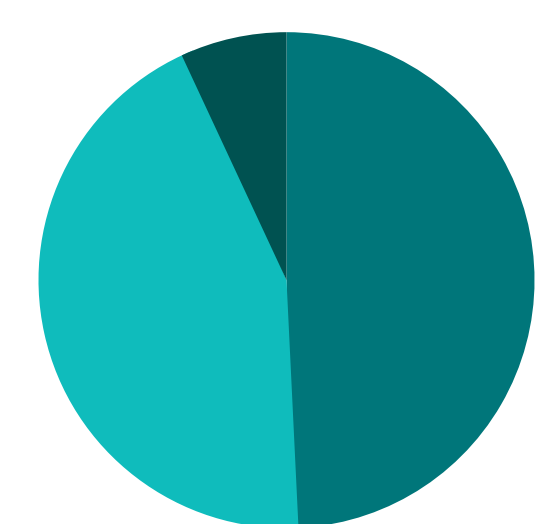
## HYPOTHESIS

\*The biggest issue with regards to assistive devices is access.

\*Factors like geography and language play a role in awareness of and access to voice preservation.

## 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

Voice preservation is an aspect of technology used among PALS which in turn contributes to fundamental right #7, the right to the best quality of life possible. Access to assistive devices may not be the main issue among respondents. More basic than that, there is a general lack of awareness of such technologies and services.

### I have an assistive technology device that helps me communicate.

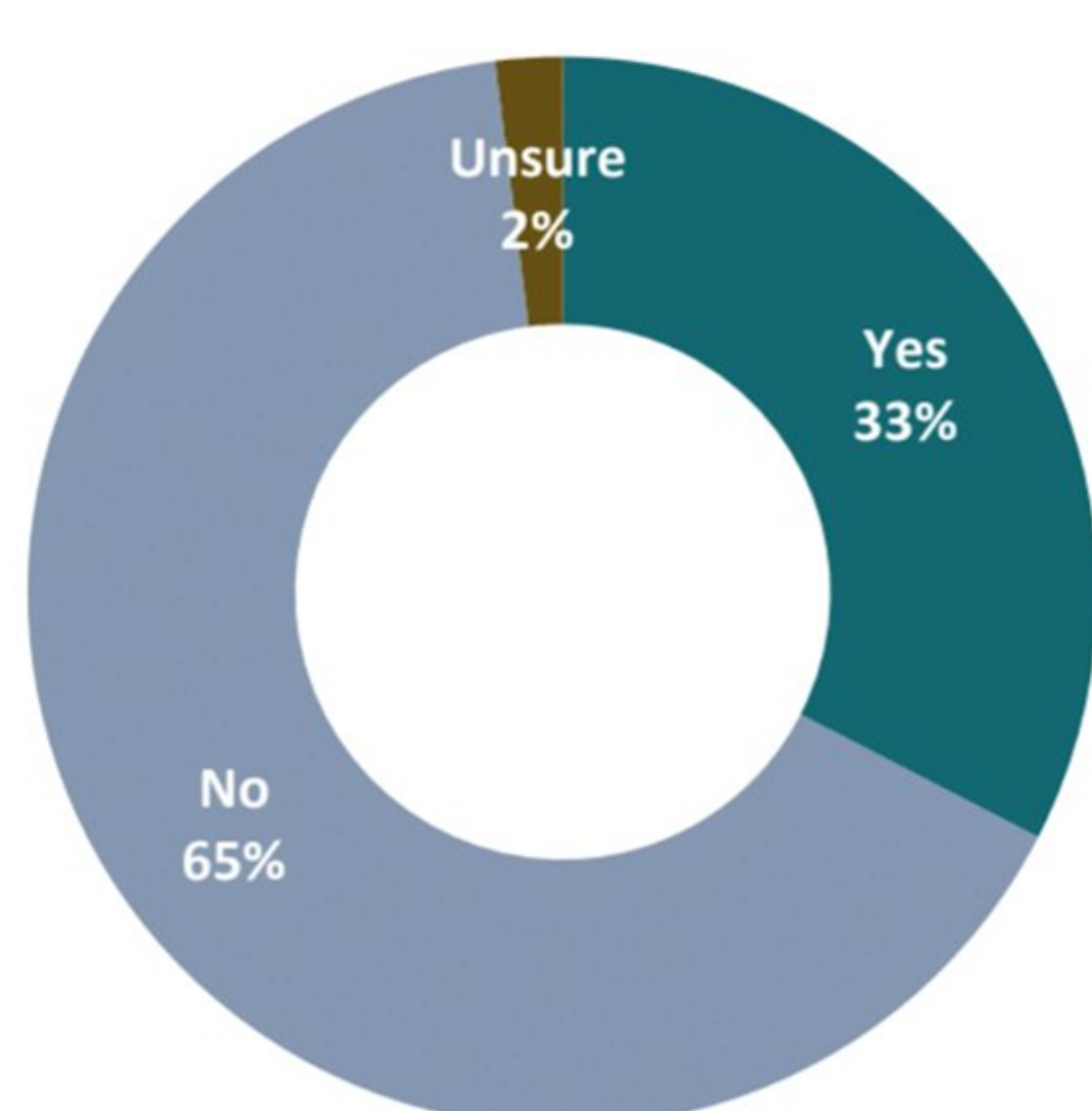


Figure 1. Two-thirds of respondents do not have assistive technology that helps them communicate.

### What access to technology do you have?

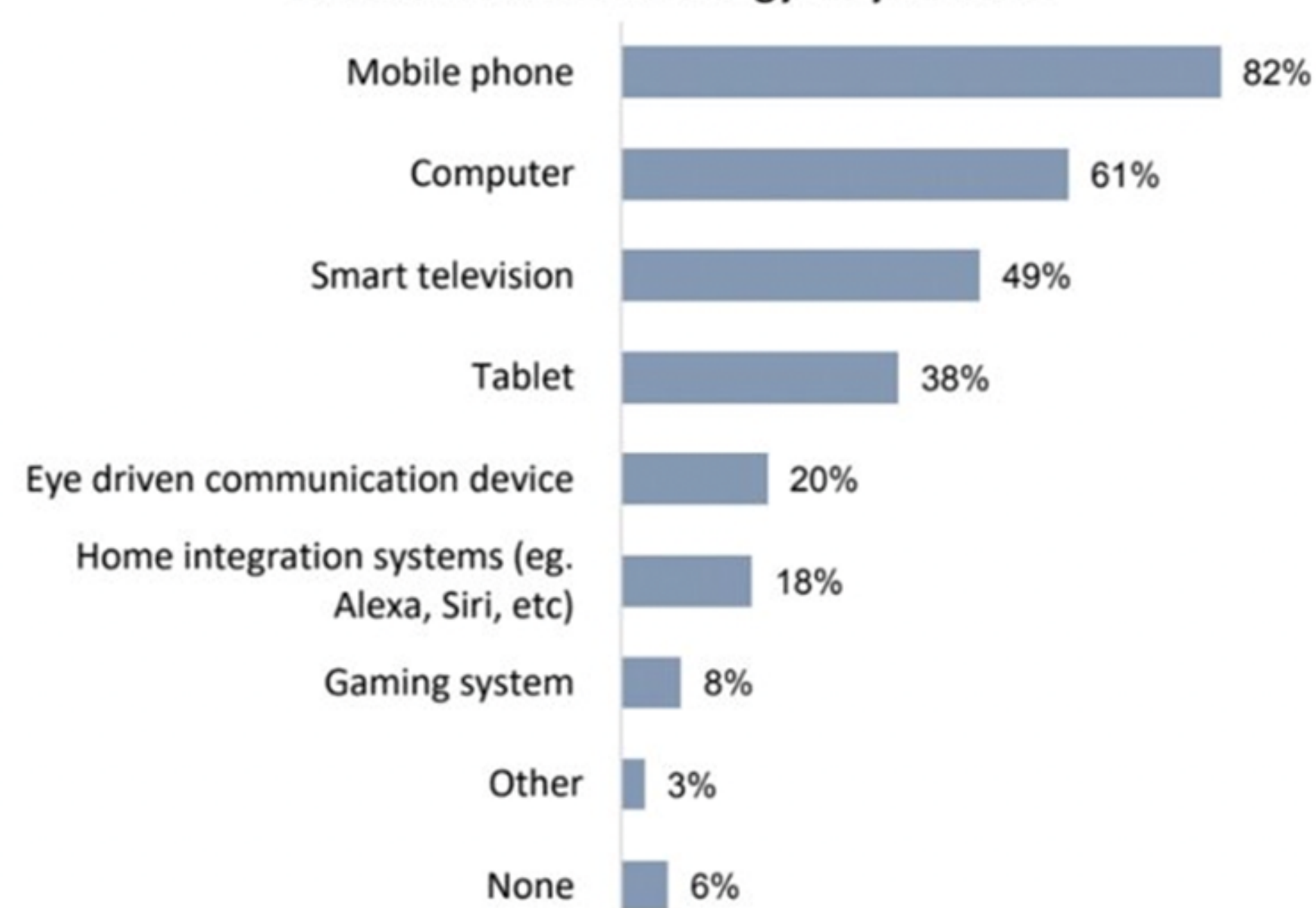


Figure 2. Mobile phone is the most ubiquitous technology among PALS respondents, regardless of geography and spoken language.

### Which of the following statements best describes your situation as it relates to voice preservation.

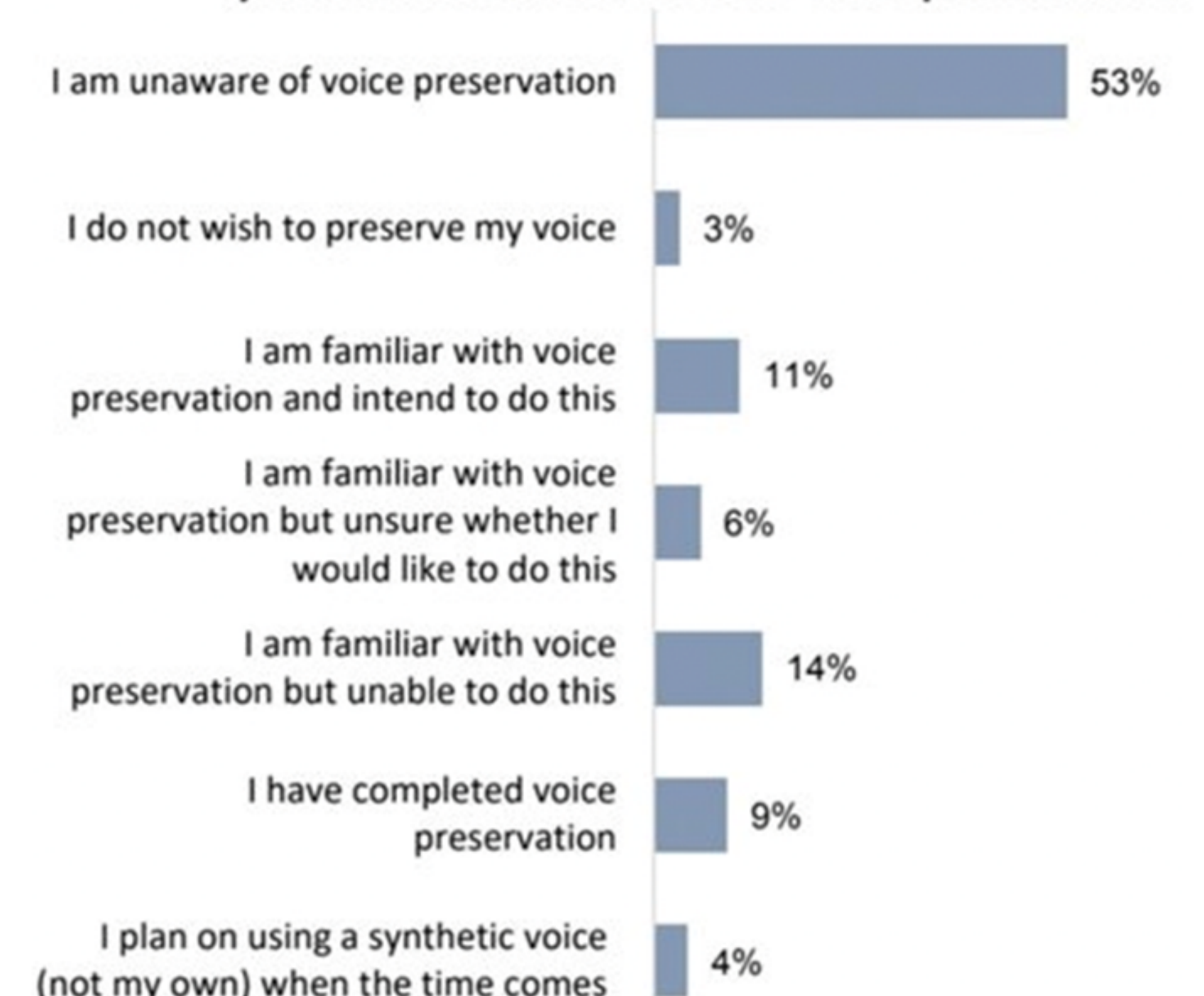


Figure 2. Over half of the respondents are unaware of voice preservation. Conversely, almost 10% of respondents have completed voice preservation, and over 10% of respondents plan to do so.

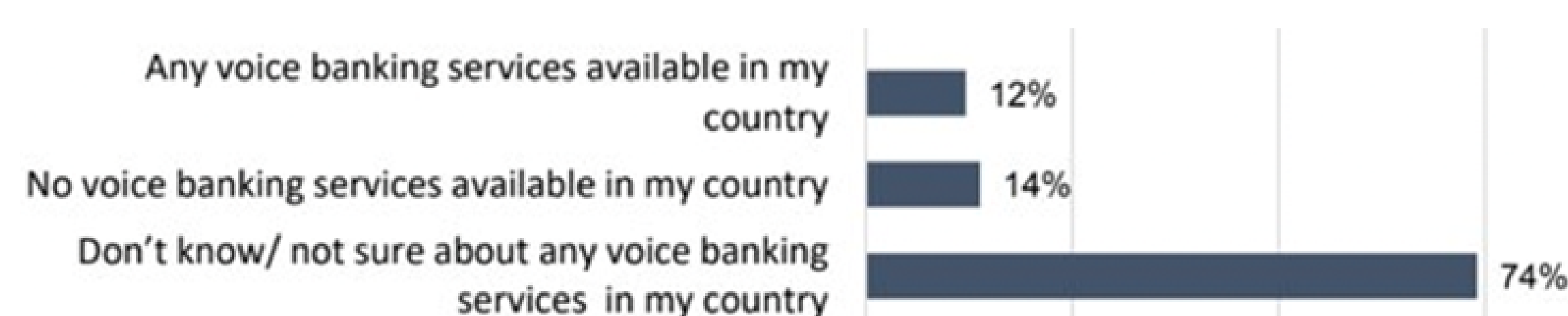


Figure 4. 88% of respondents report no voice banking services or are unsure about them in their country.

## DISCUSSION

Voice preservation is a fairly recent innovation therefore awareness and accessibility are the main issues regarding this topic. Some interesting points include:

\*Inconclusive results about access being the main issue regarding assistive devices. Awareness seems to be the most important barrier. Over half of the respondents were unaware of voice preservation, 88% could not name a voice banking service, and only one in five PALS has access to eye-driven technology.

\*Global South and non-English speaking countries are significantly less aware of voice preservation compared to the Global North and English-speaking countries nearly two in three respondents respectively).

\*Intent/interest in voice preservation is almost even between Global North (12%) and Global South (9%).

\*Considerations for barriers to voice preservation include socio-economic factors, language, infrastructure availability, technology capabilities, and awareness of health professionals, to name a few.

## 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).