

2023 Fundamental Rights for People Living with ALS/MND & Caregivers of People Living with ALS/MND Survey Report



INTERNATIONAL ALLIANCE
OF ALS/MND ASSOCIATIONS

TABLE OF CONTENTS

Introduction	1
Methods & Definitions	2
Fundamental Rights for People Living with ALS/MND (PALS)	3
Overall Results	6
Right #1 & Key Takeaways	10
Right #2 & Key Takeaways	13
Right #3 & Key Takeaways	17
Right #4 & Key Takeaways	20
Right #5 & Key Takeaways	22
Right #6 & Key Takeaways	25
Right #7 & Key Takeaways	27
Right #8 & Key Takeaways	30
Right #9 & Key Takeaways	33
Right #10 & Key Takeaways	35
Right #11 & Key Takeaways	38
Fundamental Rights for Caregivers of People Living with ALS/MND (CALS)	41
Overall Results	43
Right #1	45
Right #2	46
Right #3	47
Right #4	48
Key Takeaways	49
Conclusion	53
Acknowledgements	54

INTRODUCTION



The Fundamental Rights for People Living with ALS/MND (PALS) and the Fundamental Rights for Caregivers of People Living with ALS/MND (CALS) outline the aspirational rights of the global ALS/MND community. These documents guide the work of the International Alliance of ALS/MND Associations.

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 CALS Advisory Council.

In 2021, the previously melded PALS and CALS rights became separate documents.

Although the Alliance and its representatives understand that some of these conditions might not be immediately attainable, these rights represent what 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 was launched to benchmark against the data captured in its first version.

METHODS & DEFINITIONS



The survey was launched through our member organizations and on social media in May 2023 and supported by Bramm Research, an independent third-party research company. It was in the field for 60 days and we received close to 2,000 responses from 54 countries: 903 (47%) of the respondents were PALS and 1,024 (53%) were CALS. The survey was available in 16 different languages.

GLOBAL NORTH & GLOBAL SOUTH

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

The highest number of survey responses came from Brazil (277), Turkey (250), and Colombia (186). The languages most represented are Spanish (27%), English (22%), Portuguese (14%), and Turkish (13%).



SURVEY RESPONSE

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



FUNDAMENTAL RIGHTS FOR PEOPLE LIVING WITH ALS/MND (PALS)



FUNDAMENTAL RIGHTS FOR PALS

PALS have the right to:

- 1) The highest quality care available within their healthcare system.
- 2) The highest quality treatment available within their healthcare system.
- 3) Information and education that will enable them to play an active role in making decisions.
- 4) Choice with respect to:
 - health and support workers who are providing treatment or advice;
 - the location where care takes place; and
 - the type of treatment or support that is provided.
- 5) End-of-life choices, which include the right to accept, refuse or discontinue treatment or intervention within the legal framework of their own country.
- 6) Provide input on the healthcare and support systems, including policymaking, care delivery, and the implementation of medical research procedures and protocols.
- 7) The liberty to live the best quality of life possible.
- 8) Live without discrimination.
- 9) Confidentiality and privacy regarding their personal information.
- 10) Receive any available governmental or other economic remuneration, benefits and entitlements.
- 11) Have access, upon diagnosis (or likely diagnosis), to:
 - up-to-date education about clinical genetics in ALS/MND;
 - genetic counselling;
 - genetic testing;
 - safeguards against genetic discrimination; and
 - subject to education and counselling, blood relatives should also be given the same access, where relevant.



UNITED NATIONS CONVENTION ON THE RIGHTS FOR PEOPLE WITH DISABILITIES



The PALS and CALS Advisory Council and the Alliance support the “Convention on the Rights of Persons with Disabilities” as brought forward by the United Nations. The Convention supports the global promotion and protection of all human rights and fundamental freedoms for all people with disabilities, including those living with ALS/MND. Of note, the Alliance emphasizes the importance of Articles 9 and 19 surrounding a person’s independence and their rights to equal accessibility and participation in daily living and enjoyment of life.

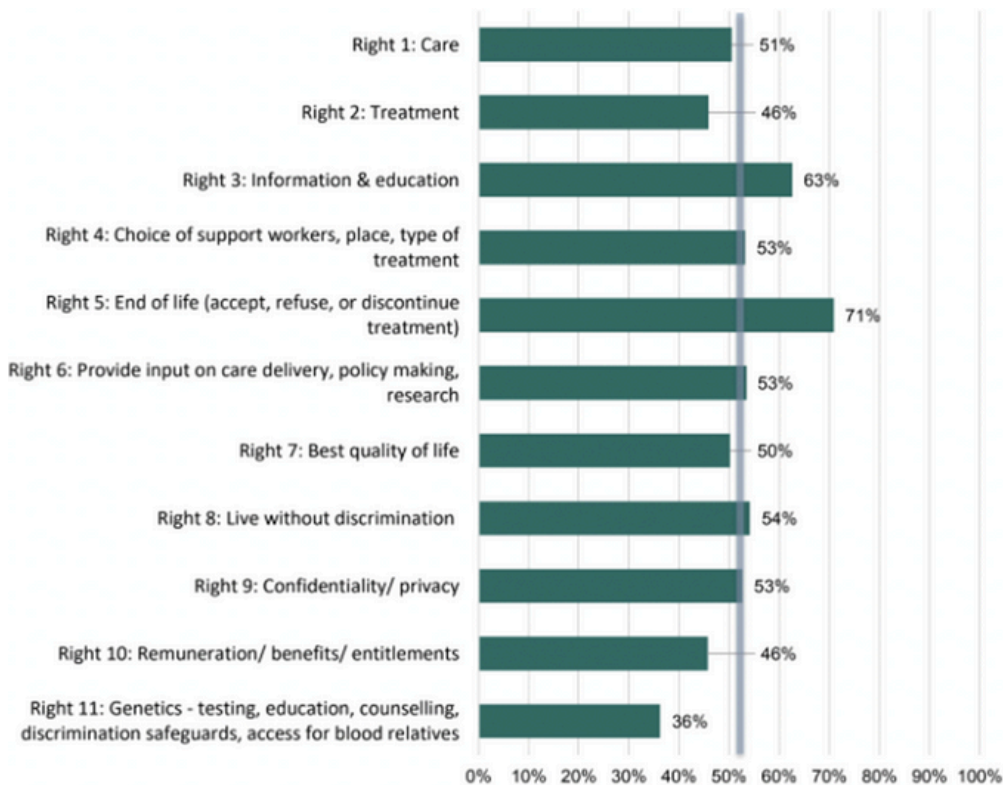
By providing equal access to all aspects of daily living and services, people living with ALS/MND can live autonomously and independently. This means people living with ALS/MND can make their own choices about their daily living, living arrangements, healthcare provision, and community involvement. Global provision of equal access to services such as transportation, housing, workplace environment, medical facilities, and information services can support both enjoyment and quality of life and support for a person’s independence.

In addition to supporting the Convention, these rights as they pertain to people living with ALS/MND are extrapolated into the Fundamental Rights for People Living with ALS/MND.

OVERALL RESULTS



The chart shows the percentage of PALS respondents who strongly agree or agree with each right being met. The global average is 52%.



KEY TAKEAWAYS

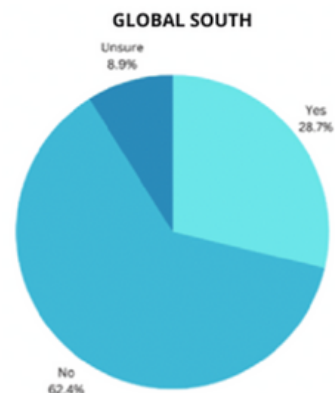
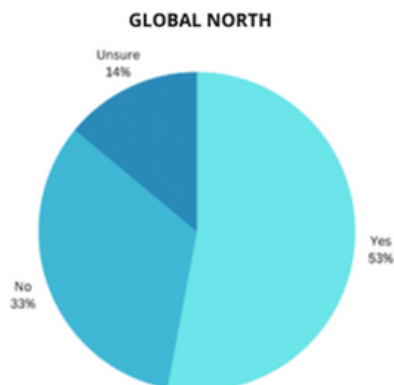


GLOBAL NORTH VS. GLOBAL SOUTH RESULTS

There are still major discrepancies in respect for the Fundamental Rights between the Global North and the Global South. Agreement with rights being met is higher in the Global North for every right except one: the confidentiality and privacy of personal information (Global South agreement is 59% vs. 50% in the Global North).

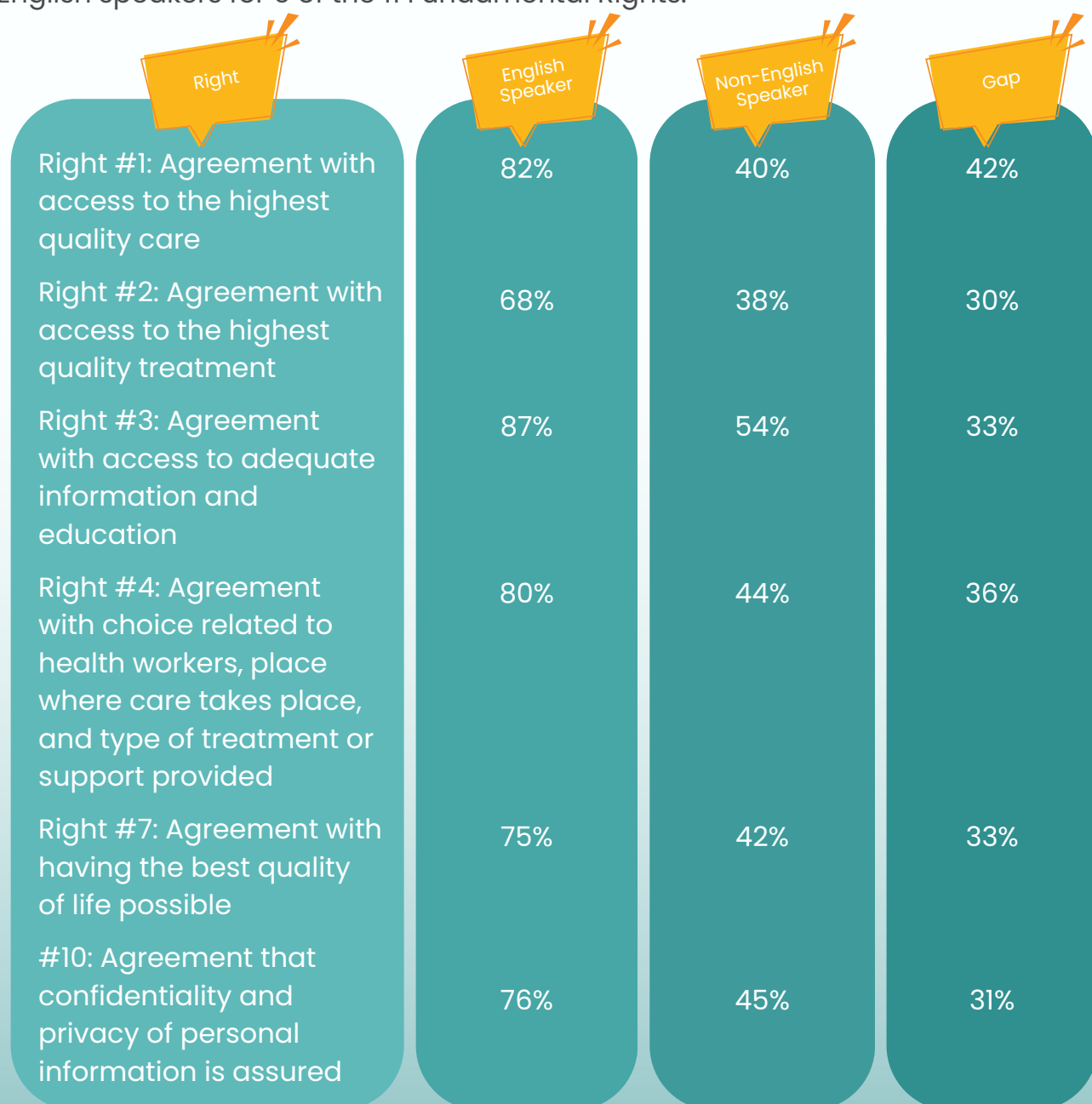
The same Global North advantage trend also applies to various drill-down question results, including access to an ALS/MND association, access to a multidisciplinary clinic, access to and participation in clinical trials, and awareness of voice preservation. Interestingly, willingness to participate in clinical trials is higher in the Global South.

One example of the gap between Global North and Global South is illustrated below, showing responses to the question: I have access to a multidisciplinary clinic.



ENGLISH SPEAKING VS. NON-ENGLISH SPEAKING RESULTS

Similar to geographic categorization, the data show that English-speaking respondents generally have greater agreement with access to a given right. Very large gaps in agreement of 30% or more exist between English and non-English speakers for 6 of the 11 Fundamental Rights:



The English cohort was defined by the language in which the survey was completed, which was recorded automatically by the survey platform.

DRIVERS FOR HIGHEST QUALITY CARE

Our results were analyzed in order to better understand what factors influence respondents' agreement with having access to the highest quality care.

Respondents who strongly agreed with having access to high quality care were represented in higher proportions in the following categories:

- Receiving care from an **occupational therapist**
- Receiving support with **voice banking** at or near diagnosis
- Receiving care from a speech therapist
- Receive care from a **genetic counsellor**

Respondents who strongly disagreed with high quality care had much higher representations in these selections:

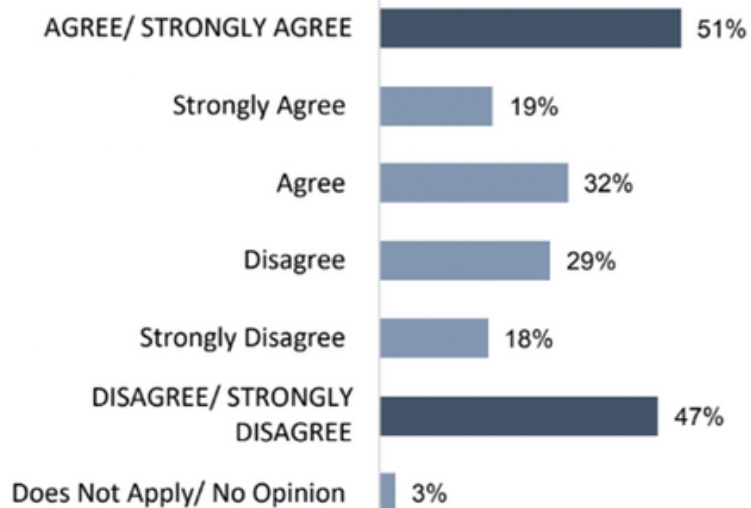
- Not receiving care from **any ALS/MND specialist**
- Not receiving support in any area
- Not having access to a **multidisciplinary clinic**



RIGHT #1

The right to the highest quality care available within their healthcare system.

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



Globally, slightly more respondents agreed that they have access to the highest quality healthcare, not significantly different from 2021. Respondents who agree were proportionally higher among English speakers (82%) and in the Global North (59%). These two groups also had greater access to a multidisciplinary clinic than non-English speakers and those in the Global South.

KEY TAKEAWAYS - RIGHT #1



The right to the highest quality care available within their healthcare system.



What stands out in the data?

A concerning high number of respondents (around 50%) disagree with having access to the highest quality care, suggesting significant dissatisfaction with current healthcare systems.

The role of caregivers is crucial and often under-resourced. **"Without carers you have nothing!"** which highlights the lack of access to paid carers, who are often essential for survival and quality of life.

Mental health support is critical in ALS/MND and yet is low globally for emotional support, family counselling, palliative care. Only one third of PALS receives care from a psychologist or social worker.

Access to ALS/MND Associations has decreased from 2021 to 2023.



What are the next questions that should be answered?

Are PALS able to access care in their care in their community or home?

How can we improve mental and emotional health support worldwide?

How can we apply this to all areas of the world, where some specialties, services, or resources do not exist?

KEY TAKEAWAYS - RIGHT #1



The right to the highest quality care available within their healthcare system.



How can we improve access to this right?

Mental Health and Support

Prioritize the integration of mental health support into ALS/MND care to address PALS needs. This will contribute to the reduction of isolation and destigmatization of mental health care.

Explore the development of community-based programs to provide accessible and culturally appropriate mental health support.

Multidisciplinary Care

Develop best practices for delivering multidisciplinary care, including frequency of visits and communication protocols, even in areas where many specializations do not exist.

Develop strategies to prevent caregiver burnout and ensure well-being.

Work towards increasing access to multidisciplinary care teams, including neurologists, nutritionists, occupational therapists, and genetic counsellors, especially in underserved regions.



PALS Say

There is an overall lack of care support.

There is a pressing need for ALS/MND-specialized care/medical professionals.

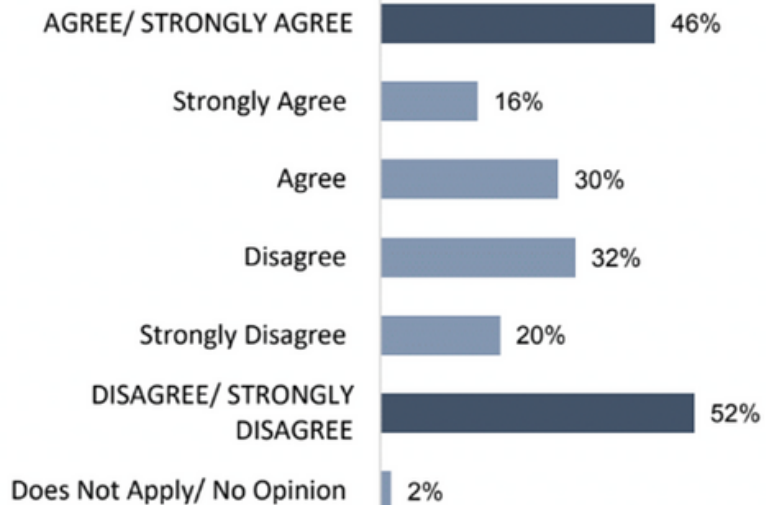
They often experience a lack of empathy, indifference, reduced care/treatment from medical professionals due to the terminal, incurable nature of the disease.

The complexity of caring for individuals with ALS/MND can deter potential paid caregivers, leading to a shortage of qualified professionals and demands for higher wages.

RIGHT #2

The right to the highest quality treatment available within their healthcare system.

I have access to the highest quality treatments within my healthcare system.



Access remains the biggest issue for treatments; it is unbalanced between the Global North (53% agreement) and the Global South (28% agreement), and English (68% agreement) vs. non-English respondents (38% agreement). Although Riluzole has higher availability in both the Global North and South (81% globally have access), availability of Edaravone and AMX0035 is higher in the Global North (20% and 11% respectively globally have access).[1]

Access to clinical trials is perceived to be a driver for agreement to access to highest quality treatments, therefore feedback on that topic is also provided.

[1] This survey was completed in 2023, when AMX0035 was still available in certain markets as treatment for ALS/MND.

KEY TAKEAWAYS - RIGHT #2



The right to the highest quality treatment available within their healthcare system.



What stands out in the data?

There are more than double the responses in 2023 (903) than in 2021 (408), yet no statistical change in the perception of access to treatment: 46% of respondents in 2023 agree or strongly agree with having access to treatments vs. 44% in 2021.

More people with ALS/MND disagreed (52%) than agreed (46%) with having access to the highest quality treatments.

The urban/rural divide is more balanced than expected: agreement for this right is 46% among urban respondents and 47% among rural respondents.

There is willingness of PALS to participate in clinical trials.

Highest levels of current participation in a clinical trial are in the United States and Spain.



KEY TAKEAWAYS - RIGHT #2



The right to the highest quality treatment available within their healthcare system.



What are the next questions that should be answered?

What are the barriers to medication accessibility in countries around the world?

How does the perception of the right to highest quality treatments change over time when living with ALS/MND?

Would the data change if we had a larger sample of respondents?

Should access to drugs in development be part of this right? If so, at what stage?

How can awareness for clinical trials be increased?

What are the motives/barriers to participating in clinical trials?

How can we better understand/provide expanded access to treatment in countries where trials do not occur?



How can we improve access to this right?

Prioritizing High-Quality Research

Allocate resources efficiently to maximize the impact of research efforts in less time to account for the terminal nature of the disease.

Global View

Prioritize efforts to raise the standard of care in the Global South to match the Global North, rather than solely focusing on improving the Global North.

Identify the minimum resources required to provide equitable care for ALS/MND patients worldwide, beyond pharmaceutical treatments.

KEY TAKEAWAYS - RIGHT #2



The right to the highest quality treatment available within their healthcare system.



How can we improve access to this right?

Education and Awareness

Collaborate with professional organizations to educate PALS/CALS and non-specialized healthcare providers about ALS/MND, treatment options, and research opportunities.

Provide training and resources to healthcare providers in underserved regions to improve their knowledge and skills in managing ALS/MND.

Advocate for policies that support access to current and experimental treatments for ALS/MND, including pricing reforms and government subsidies.

Develop educational materials and resources to improve [health literacy](#) around ALS/MND and available treatments.

Clinical Trial Infrastructure and Diversification

Invest in building clinical trial infrastructure, regulatory frameworks, and trained personnel.

Prioritize countries in the Global South that are geographically close to regions with existing clinical trial infrastructure.

Increase the sample size for clinical trials, particularly in the Global South, to obtain more representative and diverse data.

Work with [industry](#) to better understand clinical trial locations and go-to-market strategies to be able to advocate for gene pool diversification.

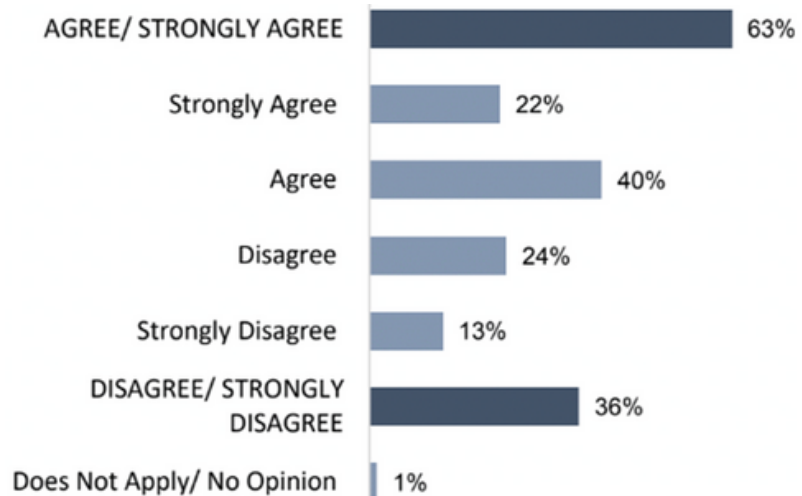
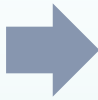
Utilize observational studies to collect valuable data in regions where interventional trials may be challenging to implement. Differentiate non-drug observational clinical trials (ex. respiratory, mental health) from drug trials.

Encourage collaboration between academic institutions in different regions to facilitate cross-border clinical research.

RIGHT #3

The right to information and education that will enable them to play an active role in making decisions.

I have access to adequate information and education that enables me to play an active role in making decisions about my care, treatment, and support.



The highest proportions of those who agreed were English speakers (87%) and rural respondents (73%). Of the 59% of the respondents who agree that they can get resources in their language of choice, 83% are from English-speaking countries.

KEY TAKEAWAYS - RIGHT #3



The right to information and education that will enable them to play an active role in making decisions.



What stands out in the data?

Sixty-three percent of respondents agree they have access to adequate information and education; not statistically different from 2021 despite more digitization of information.

English-speaking countries have the highest level of agreement, followed by the Netherlands and Japan.



What are the next questions that should be answered?

Where are PALS/CALS looking for information and resources?

What do people want to know and how do they want to consume this information?

How can we be better at communicating the right information at the right time, knowing living with ALS/MND is not a linear path?



KEY TAKEAWAYS - RIGHT #3



The right to information and education that will enable them to play an active role in making decisions.



How can we improve access to this right?

Global Standardization and Collaboration

Identify and utilize existing (English) information and resources to avoid duplication of efforts.

Foster collaboration among organizations worldwide to share knowledge, best practices, and resources.

Evaluate the effectiveness of digital information resources and identify strategies for reaching underserved populations.

Create a centralized platform or repository for healthcare information and resources, ensuring quality and accuracy.

Raising Awareness

Conduct public awareness campaigns to inform individuals with ALS/MND about their rights and the resources available to them.

Provide education and support to caregivers, including nurses, to help them navigate the healthcare system and access necessary resources.

RIGHT #4

The right to choice with respect to: a) health and support workers who are providing treatment or advice; b) the location where care takes place; and c) the type of treatment or support that is provided.

I have a choice with respect to:



Health and support workers who are providing treatment or advice

55%

The place where care takes place

52%

The type of treatment or support that is provided

52%

Slightly over half of the respondents agree with all three statements about treatment and care choices, up an average of 6% from 2021. The highest levels of agreement are in the Global North and among English speakers.

KEY TAKEAWAYS - RIGHT #4



The right to choice with respect to: a) health and support workers who are providing treatment or advice; b) the location where care takes place; and c) the type of treatment or support that is provided.



What stands out in the data?

Australia has the highest average agreement rate (93%), while Turkey, Brazil, Colombia, and (surprisingly, as a Global North country) Denmark all have agreement averages under 40%.

Responses may be influenced by:

- The stage of disease progression
- The care choices available in various countries
- The concept of choice and its meaning in different cultural and socioeconomic contexts.



What are the next questions that should be answered?

What barriers restrict choice with regards to care specialists, location, and type of treatment?

Does access to (multidisciplinary) care impact perception of choice?

How can we, as a global community, help countries where agreement with this right is low?



How can we improve access to this right?

Empowerment and Advocacy

Leverage the experience in Global North and English-speaking countries to drive change in other regions.

Global advocacy and implementation of measures to reduce financial barriers to accessing care, such as insurance reforms or government subsidies will give PALS more choice.

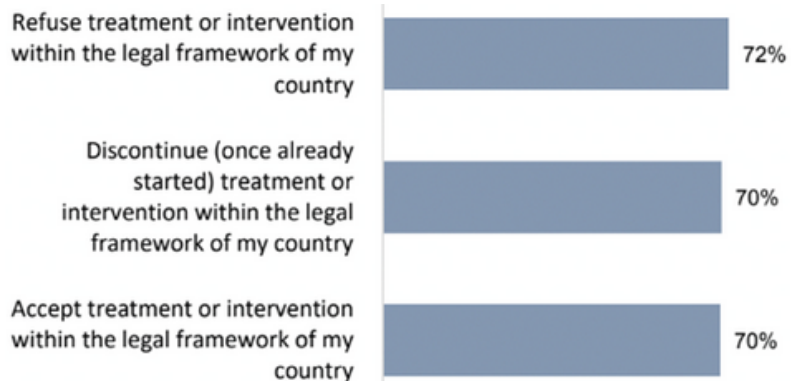
Consider cultural and contextual factors when designing and implementing programs to improve choice.

Educate PALS about their rights and empower them to advocate for their preferred care choices.

RIGHT #5

The right to end-of-life choices, which include the right to accept, refuse or discontinue treatment or intervention within the legal framework of one's own country.

I have a choice with respect to:



Agree/disagree variation between countries was very high for each statement in this right. The highest levels of agreement, including for end-of-life decisions and formal advanced care processes, were among English speakers and in the Global North.

KEY TAKEAWAYS - RIGHT #5



The right to end-of-life choices, which include the right to accept, refuse or discontinue treatment or intervention within the legal framework of one's own country.



What stands out in the data?

Religion and stigma may influence agreement with this right, especially regarding end-of-life decisions.

100% of Canadian respondents agree they have the right to choose to refuse treatment or intervention within the national legal framework.

The average variance gap between agreement and disagreement with the topics in this right is significant at 47%.

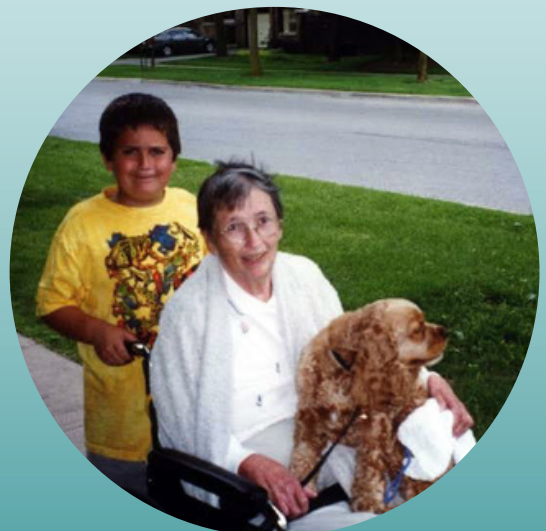


What are the next questions that should be answered?

What are the main barriers to access to end-of-life choices?

How can we destigmatize these topics?

How much is this subject being addressed by health care providers in each country?



KEY TAKEAWAYS - RIGHT #5



The right to end-of-life choices, which include the right to accept, refuse or discontinue treatment or intervention within the legal framework of one's own country.



How can we improve access to this right?

Legalities

Increase awareness to inform individuals about their rights and options related to end-of-life care.

Address concerns among healthcare professionals regarding legal liability and potential prosecution.

Advocate for the development of clear and accessible legal frameworks that support individual autonomy in end-of-life decision-making.

Religious and Cultural Factors

Consider the role of religion and culture in shaping attitudes towards end-of-life care and develop culturally sensitive approaches.

Support

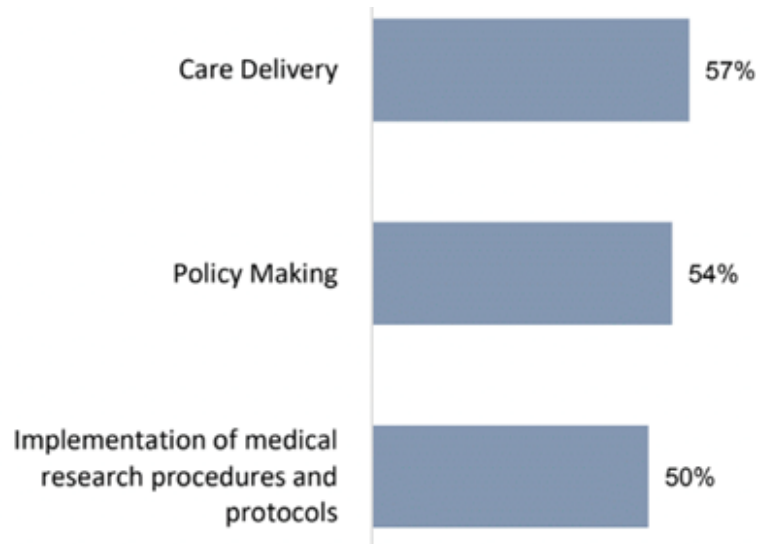
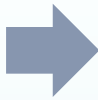
Provide resources and support to families facing end-of-life decisions to help them navigate the process and make informed choices.

Help from patient advocacy organizations: create education and advocacy opportunities, peer support groups to discuss end-of-life choices, including advance care directives.

RIGHT #6

The right to provide input on the healthcare and support systems, including policymaking, care delivery and the implementation of medical research procedures and protocols.

I am able to provide input (by personal advocacy or involvement in an ALS/MND group) on the healthcare and support system including:



There is much variance between the main country cohort with regards to this right. Slightly over half of respondents agree with being able to provide input on policy and care choices.

KEY TAKEAWAYS - RIGHT #6



The right to provide input on the healthcare and support systems, including policymaking, care delivery and the implementation of medical research procedures and protocols.



What stands out in the data?

Statistically significant European countries (Spain, the Netherlands, Denmark) have relatively low agreement levels compared to their Global North counterparts.

Australia, Japan, the United States had the highest levels of agreement across all three topics.



What are the next questions that should be answered?

How many people do not have access to care in their country, and consequently have no opportunity to provide input into the systems?

How can countries that provide many opportunities for advocacy support countries that do not?



How can we improve access to this right?

Regional Disparities

Develop targeted strategies to support ALS/MND communities in South America and improve their access to rights.

Analyze the reasons for the discrepancies in agreement levels within European countries.

Create resources and tools that provide individuals with ALS/MND and their supporters with clear information and guidance on advocating for policy changes.

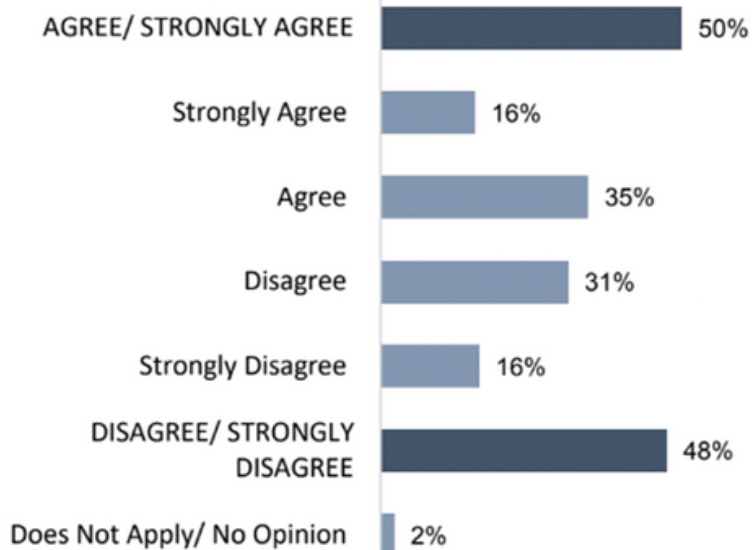
Barriers

Conduct qualitative research or surveys with individuals who disagree with policy influence to understand the barriers they face.

RIGHT #7

The right to the best quality of life possible.

I have the best
quality of life
possible:



There is a large gap in agreement between English and non-English speakers (75% vs. 42%). The same conclusion applies to results regarding involvement in cultural activities (making/playing music, art, sports, games, or social events). Thirty-four percent of respondents can no longer participate in cultural activities due to their limitations with ALS/MND. This right also includes assistive devices for communication and voice preservation.

KEY TAKEAWAYS - RIGHT #7



The right to the best quality of life possible.



What stands out in the data?

Australian PALS have the highest agreement level with this right at 88%.

65% of respondents do not use an assistive technology device that helps them communicate.

The lack of awareness for voice preservation is greater in the Global South and among non-English speakers compared to the Global North, and English-speakers.

PALS who completed voice preservation are almost exclusive to the United States, Japan, and Australia.



What are the next questions that should be answered?

What are the main barriers for PALS not doing cultural activities?

What are some of the greatest challenges with regards to travel and accommodation?

How can we learn more about health providers restricting PALS from travelling or leaving home?



How can we improve access to this right?

Impact of Geography and Disease Stage

Recognize the influence of weather and geography on the quality of life for individuals with ALS/MND.

Anticipate the impact of disease progression, especially changes in communication abilities, on quality of life.

KEY TAKEAWAYS - RIGHT #7



The right to the best quality of life possible.



How can we improve access to this right?

Voice Preservation and Assistive Devices

Implement strategies to ensure early access to voice preservation services upon or shortly after diagnosis.

Broaden the discussion of assistive technology to include mobility aids and devices that enhance overall quality of life.

Promote awareness of voice preservation technologies and their benefits in regions where they are less prevalent. Currently, it is most common in English-speaking countries.

Address technology issues around languages and accents to make voice preservation more accessible.

Address the challenges of cost and accessibility for assistive technologies in different regions.



PALS Say

Their quality of life is reduced in the following ways:

Accessibility challenges with building entrances, toilet height, cultural activities, lack of public transportation for wheelchair users, taxis/hotels/airlines not wanting to provide service/accommodations due to wheelchair/disability, using a service door to access places rather than the main door.

Communication:

- Being interrupted when using communication devices which can take longer to use.
- Difficulty accessing appointments due to reliance on phone-only scheduling systems, which can be problematic for individuals with speech impairments.

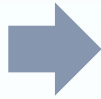
Limitations on mobility and the ability to leave home.

Insufficient consideration of the physical limitations of individuals with ALS/MND, leading to long wait times and challenges with basic needs like using the bathroom.

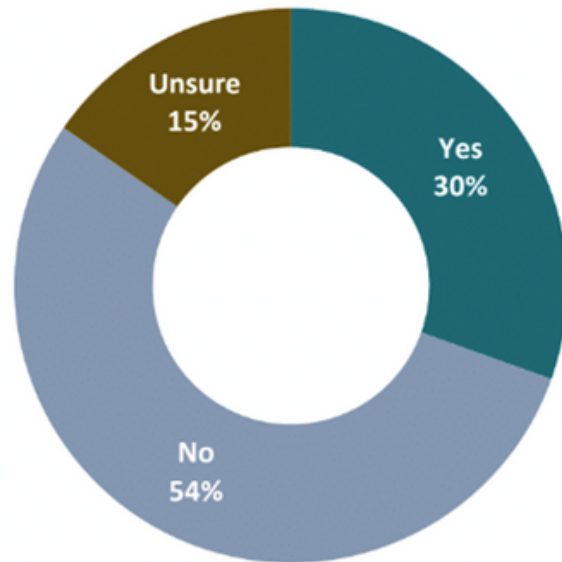
RIGHT #8

The right to live without discrimination.

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



*Discrimination means any distinction, exclusion, or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including the denial of access to adequate accommodation, public transport, buildings, or interaction problems due to speech or mobility symptoms.



One in three PALS respondents has experienced discrimination; the highest proportions are in the Global South (39%) and among non-English speakers (35%).

KEY TAKEAWAYS - RIGHT #8



The right to live without discrimination.



What stands out in the data!

Surprisingly, 54% of respondents report not experiencing discrimination.

South Korea had the highest level of discrimination at 57%.

The perception of discrimination can vary among individuals, for some it is related to limited accessibility, while for others it can be explicit negative treatment. This may depend on cultural and regional differences.



What are the next questions that should be answered?

What can we do to reduce discrimination?

Could lobbying the transportation industry internationally be helpful for improving access to this right?



KEY TAKEAWAYS - RIGHT #8



The right to live without discrimination.



How can we improve access to this right?

Accessibility

Implement universal design principles in public spaces, transportation, and buildings to ensure accessibility for individuals with disabilities.

Study countries where respondents feel less discriminated against to identify successful strategies for improving accessibility.

Support Services

Offer legal assistance and other support services to individuals who experience discrimination due to ALS/MND.



PALS Say

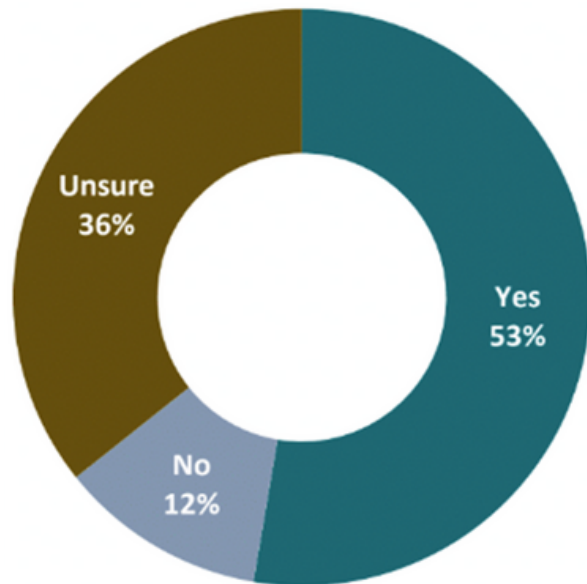
They often feel unheard, disrespected, and treated as cognitively impaired and incapable of making decisions. Some examples of discrimination they report experiencing are:

- Based on how they look
- By employers based on productivity
- Based on age for diagnosis (too young)
- Based on age for health insurance coverage
- Based on race that is less commonly associated with ALS/MND
- Denial of alcoholic beverage due to speech changes
- Exclusion from social/family events, work
- Ability/accessibility to vote

RIGHT #9

The right to confidentiality and privacy regarding their personal information.

I am assured of confidentiality and privacy regarding my personal information.



Just over half of PALS respondents feel assured of confidentiality and privacy (53%), higher among English speakers (76%) versus non-English speakers (45%), and slightly higher in the Global South (59%) versus Global North (50%). Interestingly, over one third of respondents are unsure.

KEY TAKEAWAYS - RIGHT #9



The right to confidentiality and privacy regarding their personal information.



What stands out in the data!

Privacy laws are not well respected worldwide.

The highest rates of “unsure” responses are from the Netherlands (92%) and Turkey (70%).



What are the next questions that should be answered?

What specific aspects of confidentiality and privacy do PALS feel have been violated?

Would cultural differences/approaches impact responses?



How can we improve access to this right?

Laws

Implement and enforce stronger privacy laws that align with international standards.

Education

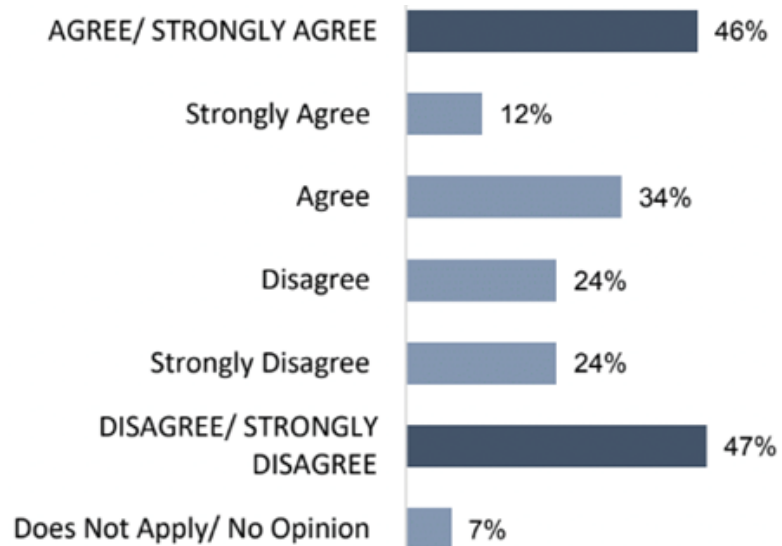
Raise awareness among organizations, corporations, and healthcare professionals about the critical importance of implementing strong data protection measures and maintaining transparency regarding their handling of personal information.

Empower PALS/CALS to know and understand their rights with regards to privacy and confidentiality.

RIGHT #10

The right to receive any available governmental or other economic remuneration, benefits, and entitlements.

I receive any available governmental or other payments, to assist with the provision of care.



Agreement and disagreement with receiving governmental assistance are almost equal; however, significantly more favourable in the Global North (54% vs. 26% in the Global South), and among English-speakers (61% vs. 41% non-English speakers). Additionally, 72% of PALS respondents globally disagree with having supplemental insurance that can assist with the provision of care. Unsurprisingly, 4 out of 5 respondents report being economically affected by ALS/MND.

KEY TAKEAWAYS - RIGHT #10



The right to receive any available governmental or other economic remuneration, benefits, and entitlements.



What stands out in the data?

Agreement with this right is highest in Japan (86%), Australia (82%), and lowest in Colombia (7%).

Thirty-seven percent of respondents had to leave their job, while only 7% stayed in the job they had before their ALS/MND diagnosis.

ALS/MND puts families into poverty. The most economically affected countries are Colombia, South Korea, and Turkey. The least affected are Canada, Australia, and Denmark.



What are the next questions that should be answered?

Who pays for PALS care and medications?

What specific types of financial support or benefits are most lacking, and how can they be improved to better support families affected by ALS/MND?

Are PALS dependent on their national health service (as only 23% of PALS responded yes to having supplemental insurance)?

KEY TAKEAWAYS - RIGHT #10



The right to receive any available governmental or other economic remuneration, benefits, and entitlements.



How can we improve access to this right?

Awareness

Pinpoint specific types of financial support, benefits, and potential solutions that are lacking for families affected by ALS/MND.

Better understand the costs associated with ALS/MND in different countries to help advocate for enhanced government support and policy changes. This information can also shed light on how financial challenges can impact disease progression and decision-making, including end-of-life care.

CALS

Understand the ripple effect of how the lack of financial support impacts CALS.



PALS Say

With regards to financial support

People with disabilities are more likely to experience financial hardship due to increased costs and lower incomes compared to those without disabilities.

There is inadequate public support for healthcare costs, limited insurance coverage, and restricted access to necessary treatments.

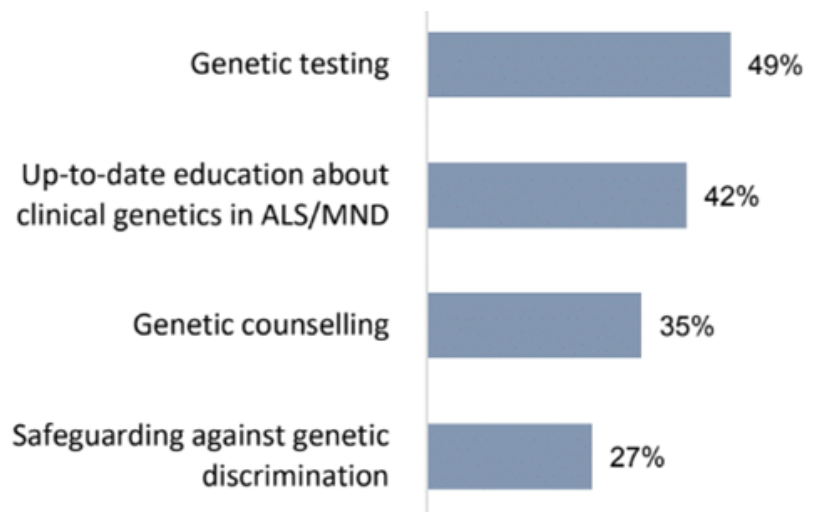
There is limited access to essential medications and devices due to restrictions imposed by public health insurance.

They often face lengthy wait times for medication payment approval.

RIGHT #11

The right to have access, upon diagnosis, to: a) up-to-date education about clinical genetics in ALS/MND; b) genetic counselling; c) genetic testing; d) safeguards against genetic discrimination; and e) subject to education and counselling, blood relatives should also be given the same access, where relevant.

Upon diagnosis, I have access to:



While almost half (49%) of PALS respondents have access to genetic testing, only 27% have safeguarding against genetic discrimination. Only one in three PALS report having access to genetic counselling, the healthcare provider perceived as the most specialized in ALS/MND. A mere 6% of respondents report receiving care from a genetic counsellor. Again, these results are unbalanced between the Global North/English speakers (who report having more access) and the Global South/non-English speakers.

KEY TAKEAWAYS - RIGHT #11



The right to have access, upon diagnosis, to: a) up-to-date education about clinical genetics in ALS/MND; b) genetic counselling; c) genetic testing; d) safeguards against genetic discrimination; and e) subject to education and counselling, blood relatives should also be given the same access, where relevant.



What stands out in the data?

Since 2021, there has been an increase in each of the topics in this right, although none are significant (6% is the highest change in education about clinical genetics in ALS/MND).

Access to genetic counselling (35%) is not matched with genetic testing (49%).

Although the genetics numbers are low globally, the highest scores generally are from respondents in the United States and the Netherlands.



What are the next questions that should be answered?

What are the main barriers to accessing a) genetic counselling and b) genetic testing?

How can we expand access worldwide, especially to underrepresented groups?

What are the financial barriers for genetic counselling and testing?

How can access to genetic counsellors be improved?

Other than a genetic counsellor, who provides the genetic counselling?

How can we reduce genetic discrimination?

What are the main sources of genetics education for PALS/CALS?

Is genetic information:

- out of date?
- not translated often enough?
- not in easy-to-understand language?

KEY TAKEAWAYS - RIGHT #11



The right to have access, upon diagnosis, to: a) up-to-date education about clinical genetics in ALS/MND; b) genetic counselling; c) genetic testing; d) safeguards against genetic discrimination; and e) subject to education and counselling, blood relatives should also be given the same access, where relevant.



How can we improve access to this right?

Improving Access to Services: Despite various jurisdictional, liability, and licensure challenges, establish a global network for genetic counselling and testing to make genetics services more accessible.

Encourage healthcare providers to recommend genetic counselling and testing as a default step in the diagnosis, and at the same time, educate PALS/CALS about its importance.

Lobby for policies that support increased access to genetic counselling and testing, including funding, regulatory reforms, discrimination laws, and professional training.

Although differences in standards may exist between clinical and research genetic testing, utilize university-based programs to expand access to genetic services.

Addressing Discrimination: Stronger legal protections against genetic discrimination are needed to ensure individuals are not disadvantaged based on their genetic information.

Healthcare providers should be trained in the importance of confidentiality and non-discrimination in genetic counselling and testing.

Workforce: Aim to increase the number of genetic counsellors (who specialize in ALS/MND).

Optimize the use of genetic counsellors and streamline education as much as possible when there is a shortage of these professionals.

Education and Awareness: Identify opportunities to streamline the genetic counselling and testing process and reduce barriers to access.

Create virtual meetings where specialists can share genetics knowledge to other healthcare providers.

FUNDAMENTAL RIGHTS FOR CAREGIVERS OF PEOPLE LIVING WITH ALS/MND (CALs)



FUNDAMENTAL RIGHTS FOR CALS

CALS have the right to:

1

Receive support in all areas, including:

- counselling;
- emotional, social and/or respite care programs;
- time to take care of themselves and to seek help as and when they need it;
- planning for their own future, and;
- palliative care and bereavement advice and services.

2

Have access to all elements and mechanisms that will facilitate and help their efforts as caregivers, including:

- information and education that will enable them to play an active role in making decisions about care and support;
- regular training and resources to be better able to provide for the person living with ALS/MND at home, and;
- timely appointments and treatments for the person living with ALS/MND.

3

Receive any available governmental or other economic remuneration, benefits, and entitlements to assist with the provision of care to the person living with ALS/MND.

4

Provide input on the healthcare and support systems, including policymaking, care delivery and the implementation of medical research procedures and protocols that affect both the person living with ALS/MND and themselves.

OVERALL RESULTS

Respect of the Fundamental Rights for CALS is universally low and inconsistent, lacking support in all areas, especially access to remuneration, emotional support programs, palliative care, bereavement advice and services, and social support and respite.

There has been little improvement in the CALS rights situation between 2021 and 2023.



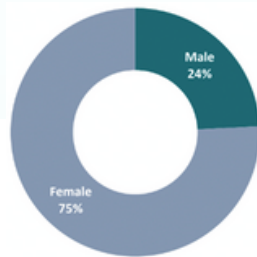
CALS Say

It is difficult for people to understand what ALS/MND is.

We cannot find caregivers to care for patients with acute ALS/MND.

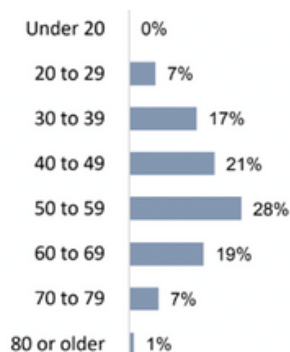
The time required to care for a person diagnosed with ALS/MND is full time and it would not be possible to work and care at the same time.

GENDER & AGE



GENDER BREAKDOWN

75% of CALS respondents are female.



AGE DISTRIBUTION

68% of CALS respondents are between the ages of 40-69 years. This data generally corresponds to the ages of the PALS respondents. However, there are slightly higher percentages of CALS in the 30-39 and 40-49 age ranges.

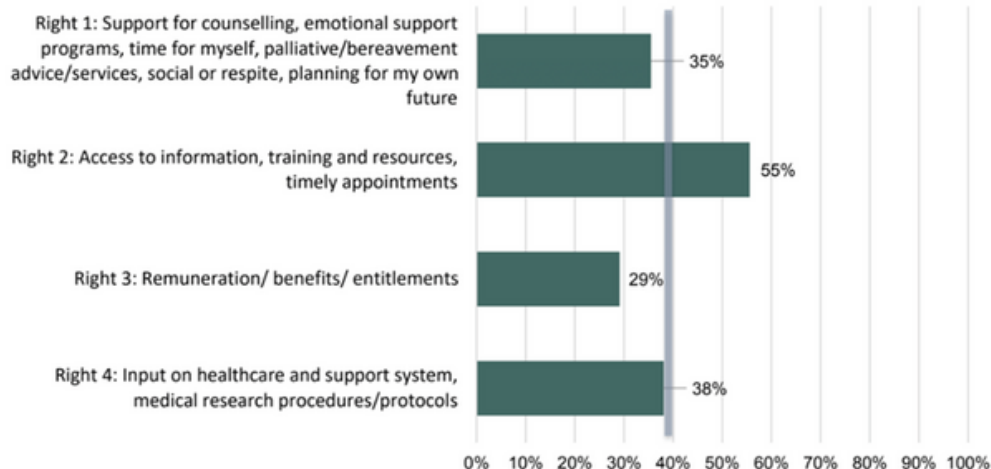
The average age of caregivers in the Global North is higher than in the Global South: 54 years vs. 47 years.

AGREEMENT WITH RESPECT FOR THE CALS RIGHTS



This graph shows the percentage of CALS respondents who strongly agree or agree with each right being met. The global average is 39.5%.

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



RIGHT #1

THE RIGHT TO RECEIVE SUPPORT IN ALL AREAS

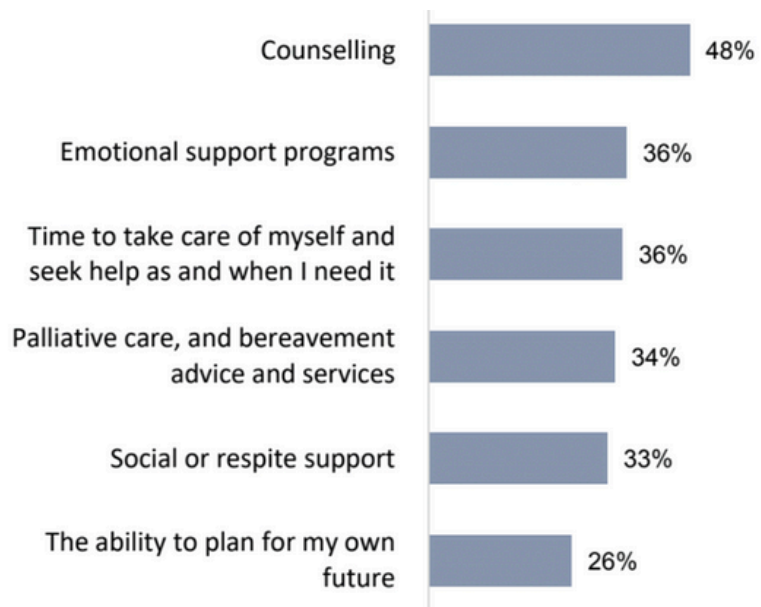
Including:

- counselling;
- emotional, social and/or respite care programs;
- time to take care of themselves and to seek help as and when they need it;
- planning for their own future, and;
- palliative care and bereavement advice and services.

I am receiving support in these areas.



CALS support rates are higher in 2023 compared to 2021 across all categories but remain low in all parts of the world. These support rates are higher in the Global South vs. the Global North.



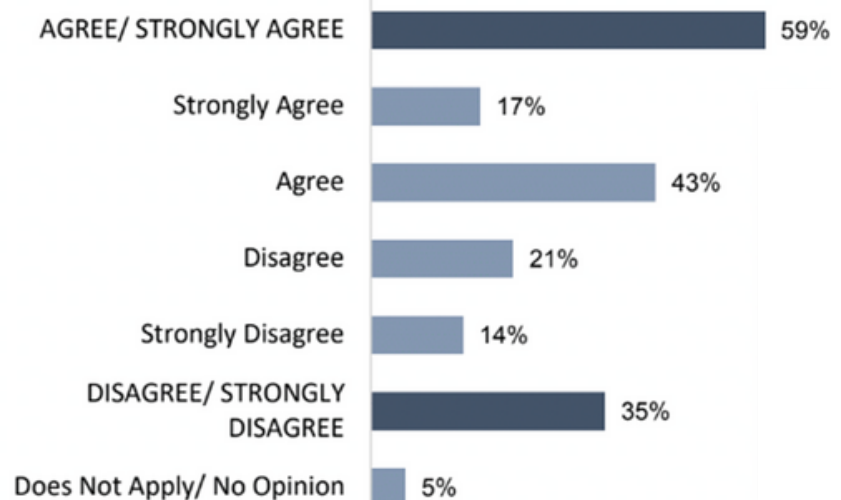
RIGHT #2

THE RIGHT TO HAVE ACCESS TO ALL ELEMENTS AND MECHANISMS THAT WILL FACILITATE AND HELP THEIR EFFORTS AS CAREGIVERS

Including:

- information and education that will enable them to play an active role in making decisions about care and support;
- regular training and resources to be better able to provide for the person living with ALS/MND at home, and;
- timely appointments and treatments for the person living with ALS/MND.

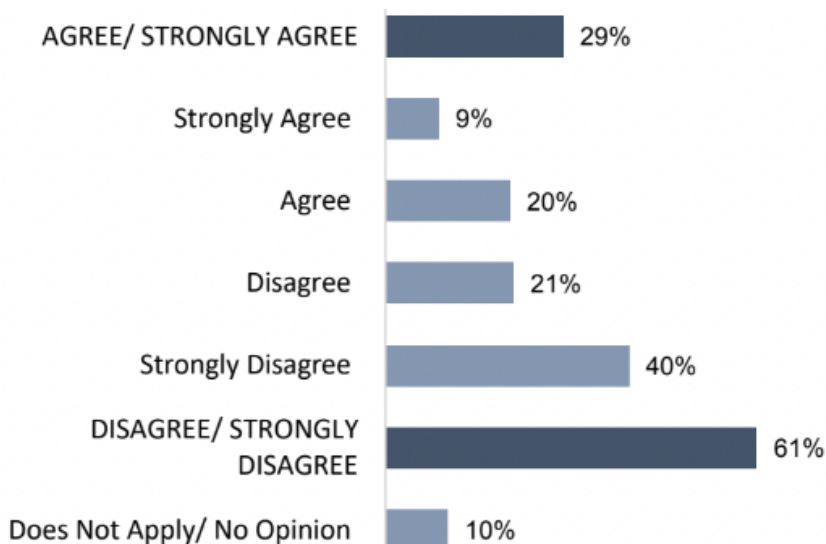
I have access to information and education that enables me to play an active role in making decisions about care and support.



Access to information was reported at higher levels among English speakers (75%) than non-English speakers (56%).

RIGHT #3

THE RIGHT TO RECEIVE ANY AVAILABLE GOVERNMENTAL OR OTHER ECONOMIC REMUNERATION, BENEFITS, AND ENTITLEMENTS TO ASSIST WITH THE PROVISION OF CARE TO THE PERSON LIVING WITH ALS/MND



I receive any available governmental or other economic remuneration, benefits, and entitlements, to assist with the provision of care to the person living with ALS/MND.

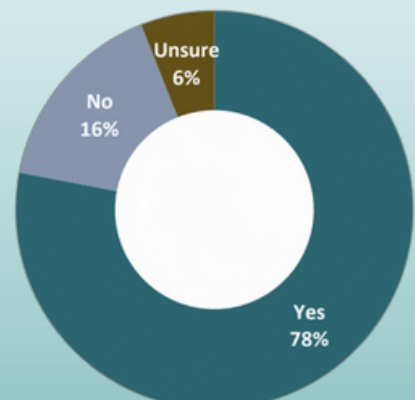


Only 29% of CALS respondents report having government support to assist with care, the same as in 2021. There is a 20% gap in the agreement responses between the Global North (37%) and the Global South (17%).

Has ALS/MND affected your economic situation?

Almost 4 out of 5 caregivers reported having their economic situation impacted by ALS/MND (78%). Caregivers in the Global South (87%) are more affected than those in the Global North (72%). One in 5 caregivers:

- leaves employment, and;
- makes adaptations to their job.



RIGHT #4

THE RIGHT TO PROVIDE INPUT ON THE HEALTHCARE AND SUPPORT SYSTEMS, INCLUDING POLICYMAKING, CARE DELIVERY AND THE IMPLEMENTATION OF MEDICAL RESEARCH PROCEDURES AND PROTOCOLS THAT AFFECT BOTH THE PERSON LIVING WITH ALS/MND AND THEMSELVES.

I am able to provide input (advocacy) in these areas.



Advocacy remains at minority levels in providing input into procedures and protocols that affect both PALS and CALS.

The healthcare and support system, including policy making, care delivery

40%

The implementation of medical research procedures and protocols that affect both the person living with ALS/MND and myself

36%

KEY TAKEAWAYS



WHAT STANDS OUT IN THE DATA?



FINANCIAL BURDEN

The economic situation of caregivers is heavily impacted, with 80% reporting financial strain. A major concern is the lack of remuneration (payment) for CALS, creating financial hardship.



SYSTEM IMBALANCE

Public funds often prioritize paying professional caregivers over supporting family caregivers, creating a financial burden for families.



STRONG VOICE, LIMITED SUPPORT & PLANNING

CALS response rate is over 50%, indicating a strong desire to be heard.

However, there's a lack of improvement in their situation between 2021 and 2023, suggesting their needs aren't being fully addressed.

ALS/MND affects more than just the person living with ALS/MND. For caregivers, the ability to plan for their own future is significantly impacted by the diagnosis.



CULTURAL DIFFERENCES

There might be cultural variations in how acceptable it is for CALS to request help. Interestingly, Global South numbers for receiving support are higher than those in the Global North. Cultural nuances may influence CALS seeking help due to a sense of familial responsibility, which can prevent them from accessing available resources.

KEY TAKEAWAYS



WHAT ARE THE NEXT QUESTIONS THAT SHOULD BE ANSWERED? (1)



CAREGIVER DEMOGRAPHICS & CHARACTERISTICS

Age: Focus on young caregivers (under 20) to understand their specific needs and challenges.

Gender: Analyze gender disparities in survey completion and support access.

Caregiver Journey: Explore the evolution of caregiver needs over time (length of caregiving), as well as how they are doing once their person has passed away.

Relationship to PALS: Examine the family dynamics in the caregiving role and young individuals who might not identify as caregivers.



CAREGIVER SUPPORT & RESOURCES

Remuneration: Investigate the adequacy of financial or in-kind support for caregivers, as well as employment accommodations.

Emotional Support: Explore the types of emotional support programs, barriers to access, and the effectiveness of these programs.

Support Networks: Understand the composition of caregiver support networks and their impact on caregiving experiences. This should include backup plans for care and support to combat isolation.

Information Access: Analyze disparities in access to information and resources based on language, geography, disease progression, and key topics such as clinical trials.

Caregiver Well-being: Assess the impact of caregiving on caregivers' physical and mental health, including addressing their fears around life management and finances.

KEY TAKEAWAYS



WHAT ARE THE NEXT QUESTIONS THAT SHOULD BE ANSWERED? (2)



SYSTEM & POLICY CONSIDERATIONS

Cultural Differences: Explore how cultural factors influence caregiving practices, support seeking behaviours, and the definition of caregiving.

Economic Impact: Examine the financial burden of caregiving, including job changes/accommodations, and economic consequences.

Policy Implications: Identify policy areas that can be addressed to improve caregiver support, such as remuneration, access to services, and caregiver rights.



DATA COLLECTION & ANALYSIS

Comparative Analysis: Compare caregiver experiences across different regions and cultural contexts to identify commonalities and disparities.



KEY TAKEAWAYS



HOW CAN WE IMPROVE ACCESS TO CALS RIGHTS?



ENHANCE INFORMATION ACCESSIBILITY

Provide culturally appropriate information and resources in multiple languages.



STRENGTHEN CAREGIVER RIGHTS

Advocate for caregiver rights on a global scale to ensure legal protections and entitlements.



PRIORITIZE CAREGIVER WELL-BEING

Offer mental health support, financial assistance, and respite care options for caregivers.



INVOLVE CAREGIVERS IN DECISION-MAKING

Give caregivers a stronger voice in medical appointments and care planning.



EMPOWER CAREGIVERS

Equip caregivers with the knowledge and tools to advocate for themselves and their loved ones, including knowledge about the next stages of the disease and care plan. Raise awareness and challenge cultural stigmas around seeking help as a caregiver.



FOSTER COMMUNITY & SUPPORT

Create platforms for caregivers to connect, share experiences, and build support networks.



RECOGNIZE THE IMPACT ON FAMILIES

Offer support and resources to entire families affected by ALS/MND.

CONCLUSION

OVERALL, THESE POINTS HIGHLIGHT THE NEED FOR A MORE BALANCED AND SUPPORTIVE SYSTEM FOR ALS/MND CAREGIVERS WORLDWIDE. FINANCIAL ASSISTANCE, FLEXIBILITY IN PUBLICLY FUNDED CARE, AND RESPECT FOR CULTURAL DIFFERENCES ARE CRUCIAL ASPECTS TO CONSIDER.

By addressing these key areas, we can significantly improve the lives of caregivers and enhance their ability to provide the best possible care for their loved ones living with ALS/MND.

WHAT CALS SAY

Spending more quality time together is a priority.



ACKNOWLEDGMENTS

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. We are equally grateful for the contributions of various expert volunteers from the community who helped provide feedback on interpreting the 2023 data.



INTERNATIONAL ALLIANCE
OF ALS/MND ASSOCIATIONS