



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

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BACKGROUND

A guiding document for the Alliance is the Fundamental Rights of People Living with ALS/MND 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 are updated each year by the Alliance’s PALS and CALS Advisory Council. In February of 2021, it was identified that the previously melded CALS and PALS rights needed to be in separate documents as the pandemic had exacerbated the Caregiver burden to the point where it was important to consider these rights separately. Therefore in 2021 the Fundamental Rights of Caregivers of People Living with ALS/MND was launched.

In addition, it was recognized that there needed to be a right added around Genetic Counseling and Testing which we now recognize is an important element to be considered at or near diagnosis.

These fundamental rights represent the ideal for individuals living with ALS/MND (PALS) and Caregivers (CALS) worldwide.

Although the International 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 organisations should adopt and promote as conditions, systems and resources allow.

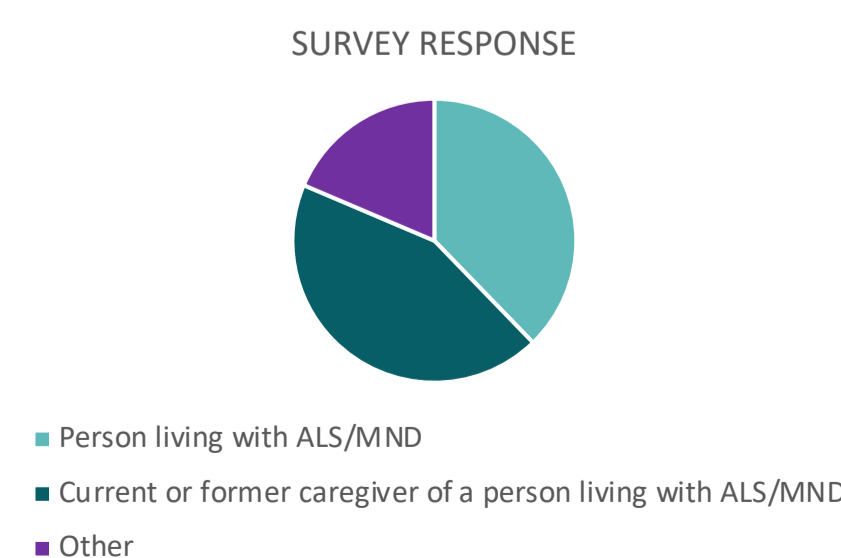
In April 2021, at the conclusion of the update the Alliance decided to do a benchmark survey to ascertain the level of agreement that these rights were being respected for both PALS and CALS.

HYPOTHESIS

Access to and respect of these Fundamental Rights is inconsistent around the world and is dependent on multifactorial inputs such as economics, healthcare systems and professionals, and culture which leads to inconsistent quality of life for people living with ALS/MND.

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 August and it was in the field for 40 days. We received responses from 32 countries. The survey was translated into 10 different languages.



RESULTS

The International Alliance of ALS/MND Associations supports the following fundamental rights for people living with ALS/MND:

These fundamental rights represent the ideal for individuals living with ALS/MND worldwide.

Although the International 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 organisations should adopt and promote as conditions, systems and resources allow.

People living with ALS/MND have the right to:

- the highest quality care available within their healthcare system
- the highest quality treatment available within their healthcare system
- information and education that will enable them to play an active role in making decisions
- 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
- 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
- provide input on the healthcare and support systems, including policy-making, care delivery and the implementation of medical research procedures and protocols
- the best quality of life possible
- live without discrimination
- confidentiality and privacy regarding their personal information
- receive any available governmental or other economic remuneration, benefits, and entitlements
- have access, upon diagnosis, to:
 - up-to-date education about clinical genetics in ALS/MND
 - genetic counselling
 - genetic testing
 - safeguards against genetic discrimination
 - subject to education and counselling, blood relatives should also be given the same access, where relevant.

Figure 1. The Fundamental Rights of People Living with ALS/MND

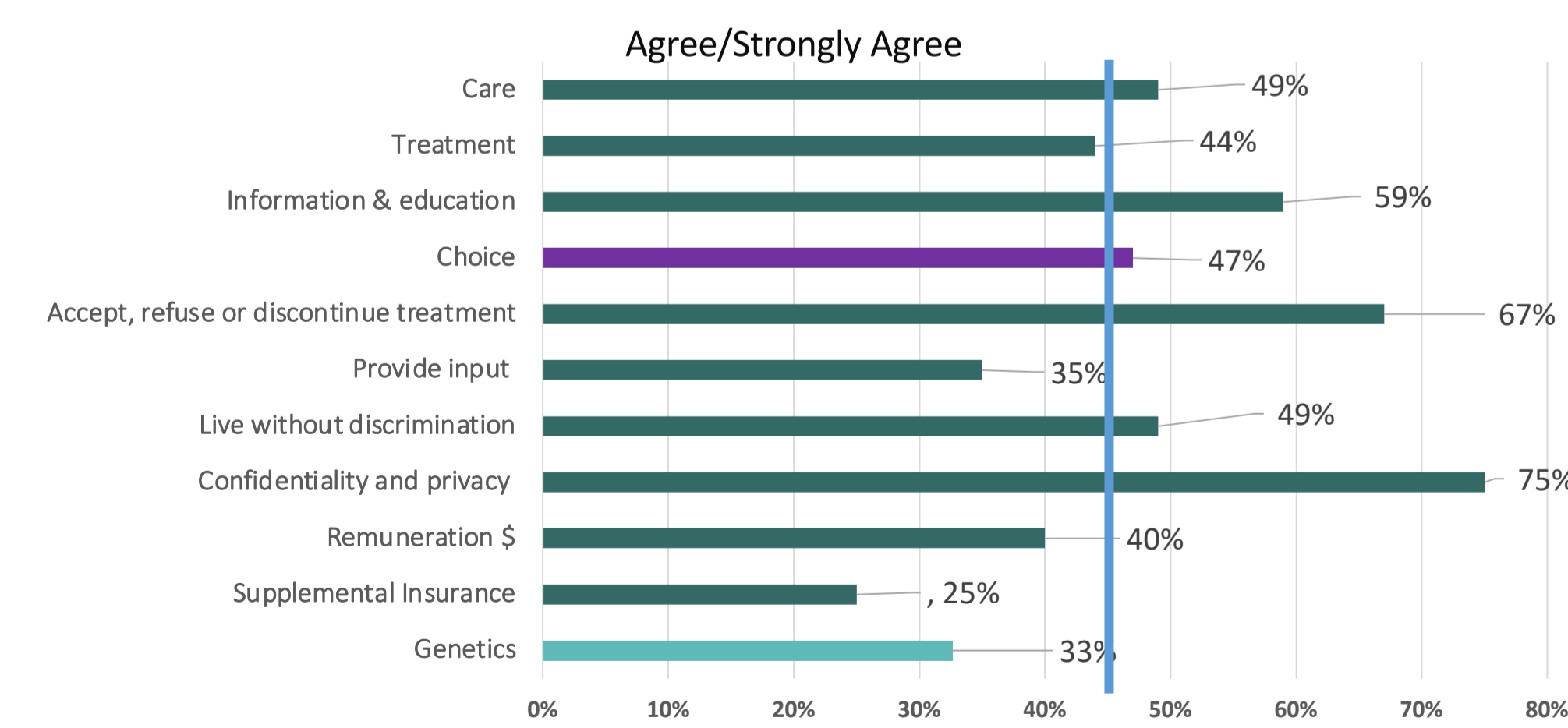


Figure 2. The assessment of PALS rights indicates that they are not well respected globally with the median at 45%.

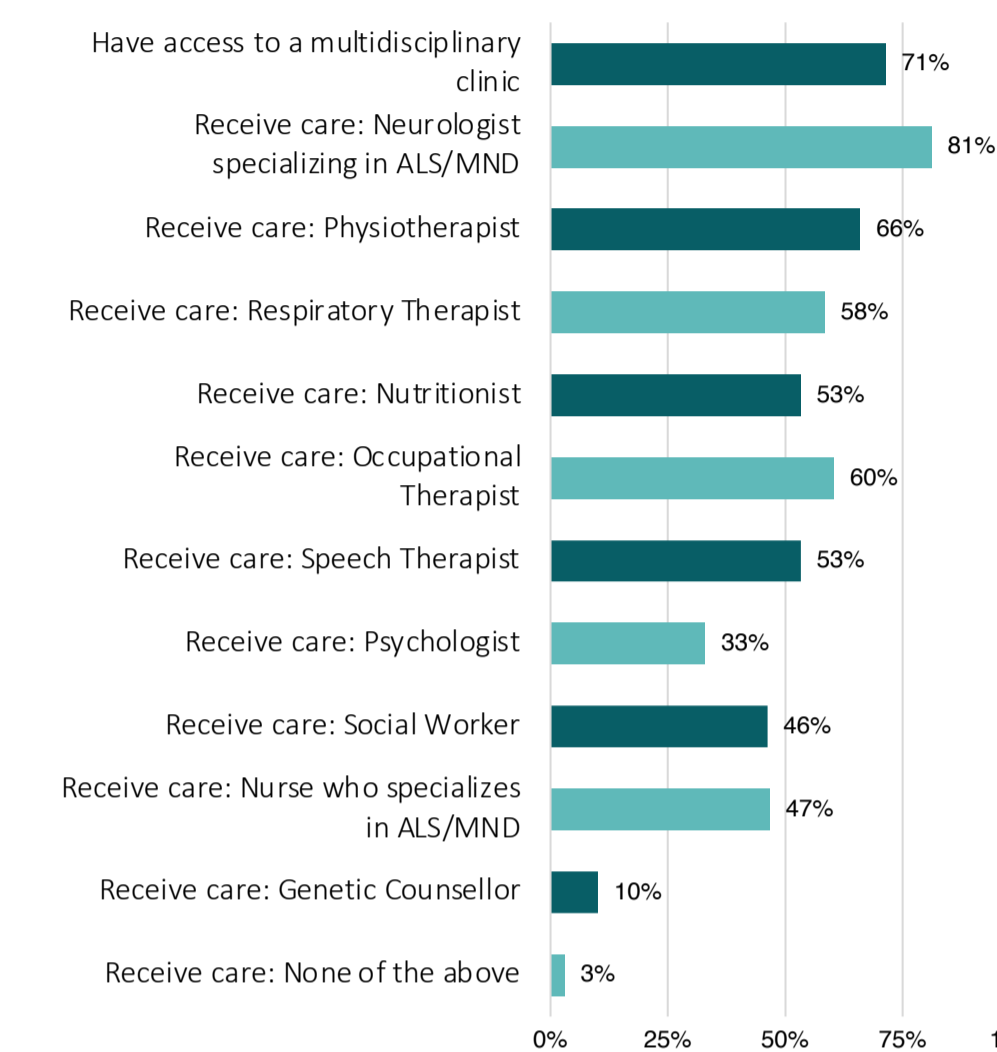


Figure 3.

There is a strong co-relation between agreement to the highest quality healthcare and the multidisciplinary teams that they have access to. PALS were more likely to indicate this right was being respected if they had access to a multidisciplinary clinic and allied health professionals who specialized in ALS/MND.

Over half (52%) disagreed that they can provide input on their healthcare and support systems. Coupled with the 13% that said that they have no opinion on this or that it does not apply to them it seems that there is a large percentage of our community that feels they have no voice and cannot advocate for themselves.

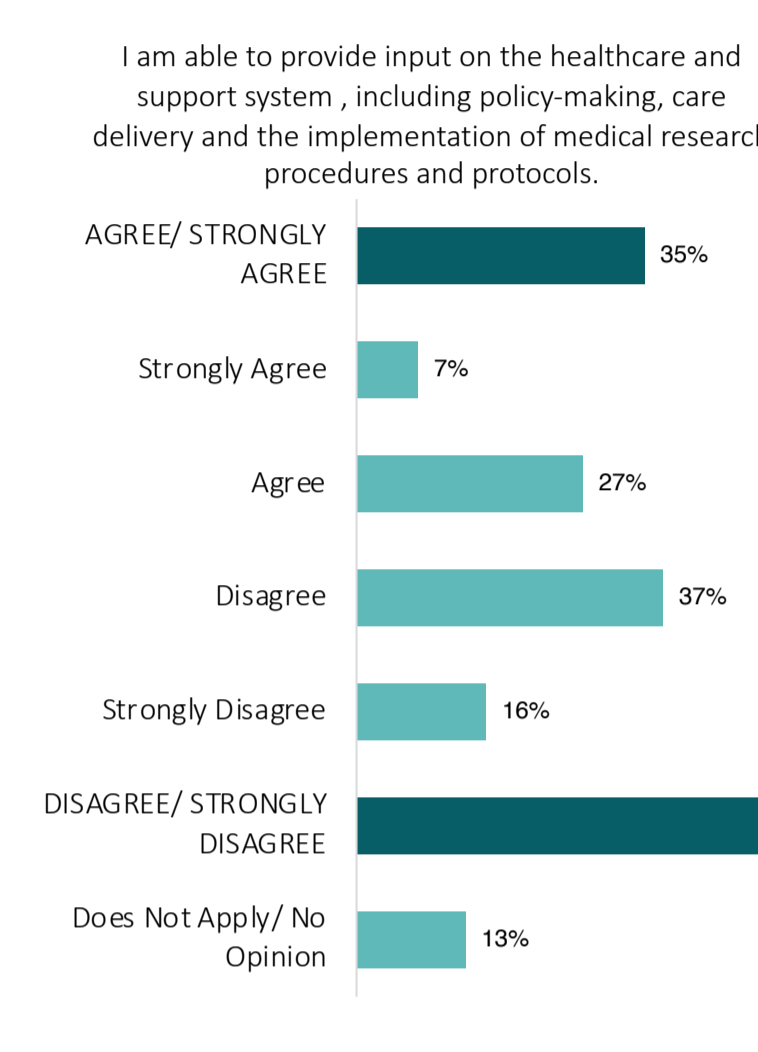


Figure 4.

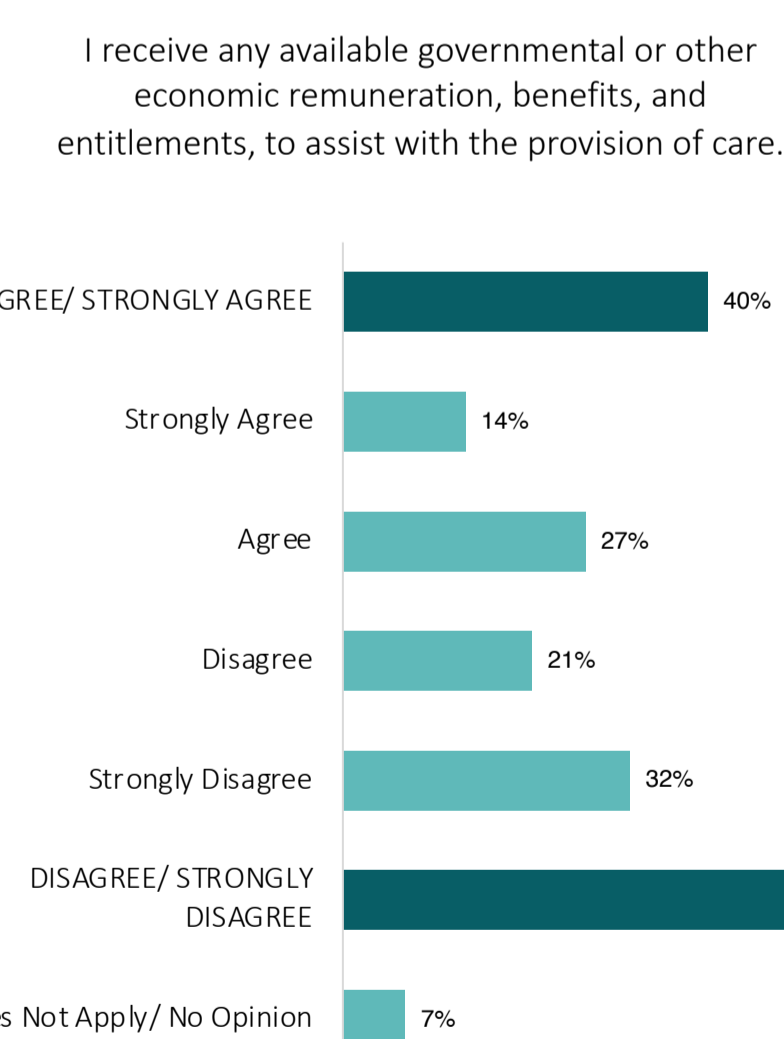


Figure 5.

Overall, more persons with ALS/MND disagreed (53%) than agreed (40%) that they receive economic support for their care. In addition, almost 2 out of 3 respondents said that they did not have supplemental insurance to support them.

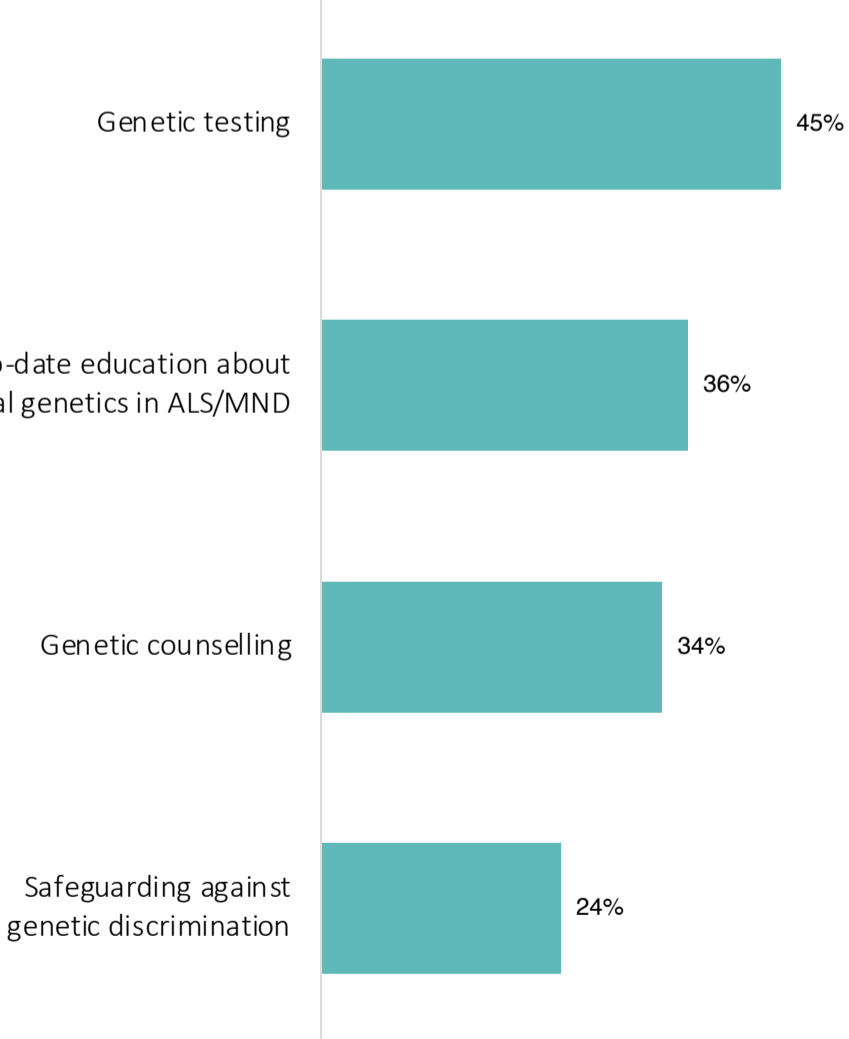


Figure 6.

It is concerning that only 45% of respondents had access to genetic testing worldwide but even more concerning is that only 34% had access to genetic counselling. Genetic counselling should precede and accompany genetic testing.

DISCUSSION

Overall the figures are low with a median of 45% of Fundamental Rights being respected for people living with ALS/MND. Some specific findings that merit discussion are:

- The right to the highest quality of healthcare and treatments are at 49%, 44% respectively, which is concerning that neither are at 50%. What can be done to provide access to multidisciplinary clinics, approved treatments and clinical trials globally?
- The highest drivers of PALS agreeing that they had access to the highest quality healthcare were access to a multidisciplinary clinic with a team of allied health professionals that specialize in ALS/MND. How can we make sure that more people with ALS/MND have access to these highly qualified professionals without adding additional burden to the individuals?
- The right to provide input on healthcare and support systems is very low at 35%. Considering the PALS is the one that knows what they are going through how can we help them advocate within their jurisdiction?
- Right to confidentiality and privacy is high at 75%, but this is an area that is highly legislated through mechanisms such as GDPR. Do other areas need to be legislated to have the right respected?
- ALS/MND can force people into poverty if they do not have access to remuneration (40%) and/or supplemental insurance (25%). This is an area our community has to advocate for! Can we get legislated coverage for remuneration for PALS upon diagnosis so that if the individual with ALS/MND has to leave their paid employment, there is a safety net for them economically?
- The results for genetic counselling and testing are very low at an average of 33%. There is limited access worldwide. What can the Alliance and its member organizations do to increase awareness, provide resources, education and access globally?

ACKNOWLEDGEMENTS

We would like to thank the 1000+ people who responded to the survey, particularly the people living with ALS 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.