

***ALS/MND
Fundamental Rights Survey 2025
Final Report for Türkiye***

Prepared By:



**INTERNATIONAL ALLIANCE
OF ALS/MND ASSOCIATIONS**

April 2026

ALS/MND Fundamental Rights Survey 2025 - Final Report for Türkiye -

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ALS/MND Fundamental Rights Survey 2025 - Final Report for Türkiye -

Background

The International Alliance of ALS/MND Associations supports fundamental rights for people living with ALS/MND (PALS) and their Caregivers (CALs). A guiding document for the Alliance is the Fundamental Rights of PALS and CALs 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 CALs Advisory Council.

This 2025 version of the survey is its third iteration after 2021 and 2023. The survey was based on these ideal rights and respondents were asked to answer questions based on their experience in their countries and with regard specifically to their ALS/MND experience. New in this version of the survey is a section for blood relatives.

Data collection began with a soft launch on Wednesday, August 27th and then was rolled out fully on Tuesday, September 2nd. Respondents were invited directly to complete the online survey via direct link through Alliance members and social media. Those arriving via social media were screened via a CAPTCHA (Completely Automated Public Turing test to tell Computers and Humans Apart) interface. Data collection closed in the morning on Monday, December 8th.

The survey was available 16 in Chinese (Taiwan), Danish, Dutch, English, French, German, Hindi, Italian, Japanese, Korean, Norwegian, Brazilian Portuguese, Spanish, Swahili, Turkish, and Vietnamese. We are very grateful to our members who worked hard on these translations.

The survey was run by Bramm Research, an independent third party. We received 2,232 responses (PALS 42%, CALs 38%, and blood relatives 40%) from 51 countries.

Key objectives of the survey were:

Survey design	Achieve meaningful results
<ul style="list-style-type: none"> • Improve global participation <ul style="list-style-type: none"> ◦ Reach underrepresented regions • Include blood relatives • Clarify and simply language • Better understand barriers to access • Drill-down areas: diagnosis, assistive devices, genetics • Addition of gender filter 	<ul style="list-style-type: none"> • Find strengths and weaknesses at a global level • Highlight areas of strategic importance • Compare results with previous surveys • Fulfil the analysis plan <ul style="list-style-type: none"> ◦ Quality of Life/right correlation • Expand languages <ul style="list-style-type: none"> ◦ first African language (Swahili) ◦ Two new Asian languages (Vietnamese and Chinese (Taiwan)) • Global North and South



A note about base sizes (the number of respondents per question)

For each section (i.e. Person with ALS/MND, Caregiver, and/or Blood Relative), the number of respondents is provided within the section title. If the base size drops significantly from that given in the section header, it will be reported in the legend of the question's chart. For example, if 75 people from a given country said that they were Caretakers, but only 37 of them answered a certain question (because others rightly skipped it), then the country label in the chart for that question would include the label: (N=37). One such question is "*Reasons for Not Receiving Genetic Counselling.*" That question will always be answered by a significantly lower proportion of respondents.

Fundamental Rights of People Living with ALS/MND and Caregivers

These fundamental rights represent the ideal for people 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 with ALS/MND (PALS) have the right to:

- 1) the highest quality treatments available
- 2) the highest quality care available
- 3) information, resources, education, and training that will lead to health literacy about ALS/MND
- 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 one's 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 and the ability to assign consent to communicate on behalf of the individual with ALS/MND
- 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
 - subject to education and counselling, blood relatives should also be given the same access, where relevant.

Caregivers have the right to:

1) be treated by all with respect and regarded as experienced in managing the care of their person with ALS/MND.

2) receive support in all areas, including:

- counseling
- emotional, social and/or respite care programs
- time to take care of themselves and to seek help as and when they need it
- palliative care and bereavement advice and services

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

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

- participate in information, resources, education and training that lead to health literacy about ALS/MND
- to stay with the person with ALS/MND when admitted to medical facilities
- timely appointments and treatments for the person with ALS/MND
- to ask for a professional support person in all living and care activities
- having direct communication with the medical team on behalf of their person with ALS/MND with prior consent from the person with ALS/MND

5) 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 with ALS/MND and themselves.

Read the [2023 Survey Report](#) for a detailed assessment of how these rights are being met worldwide.

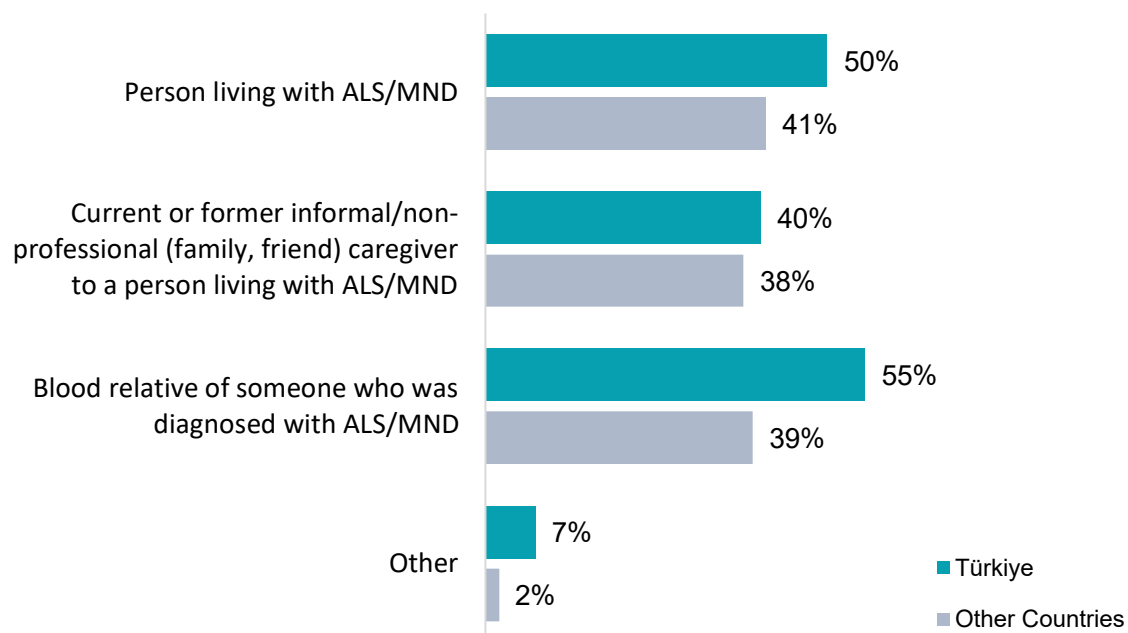
We thank our generous sponsors for their support of the 2025 Fundamental Rights survey.



Overall Profile

Person with ALS/MND, Caregiver, and/or Blood Relative

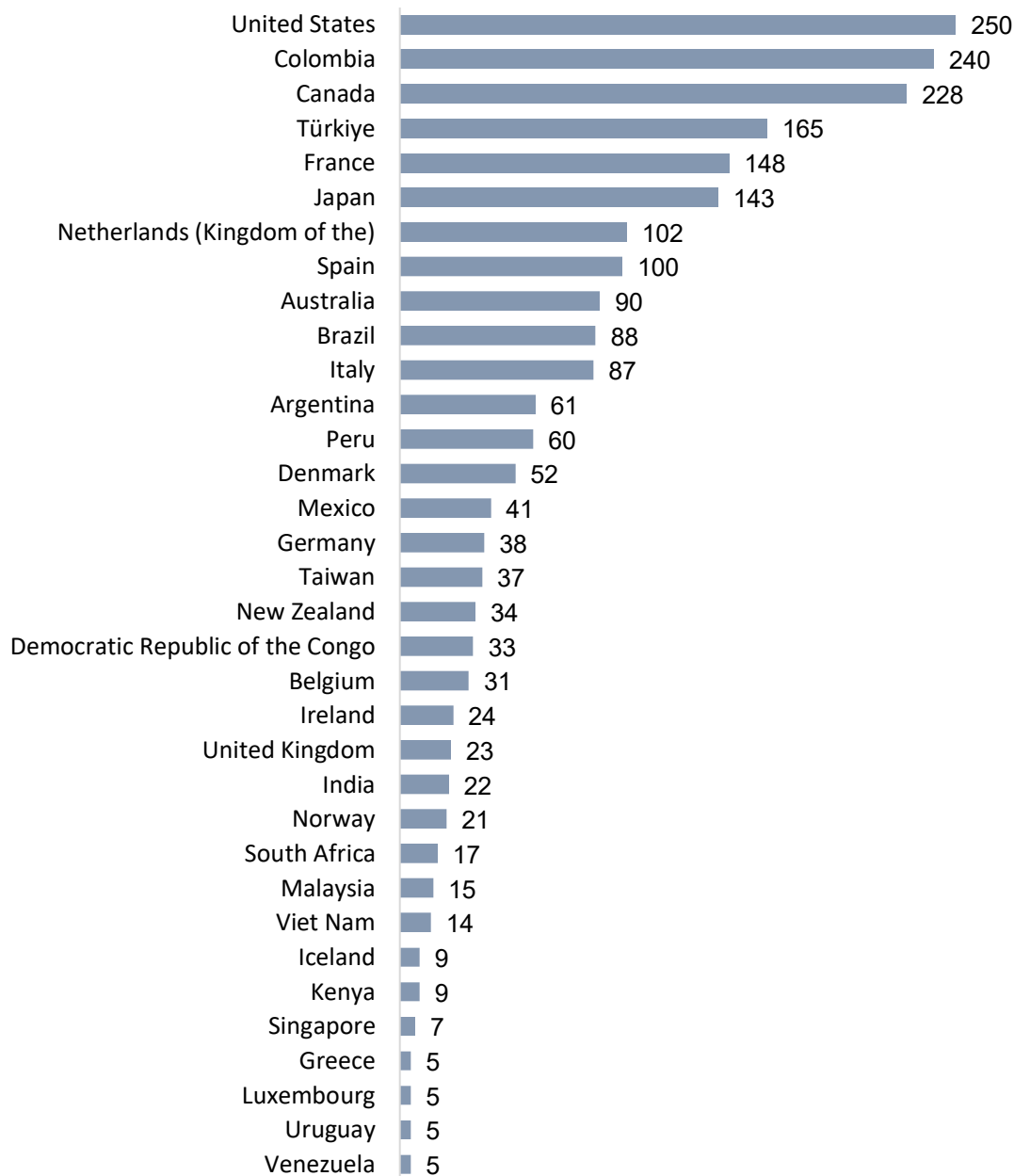
I am a...*



* Respondents could choose more than one category.

Country

What country do you live in?



The following countries were represented by two completions:

Ecuador	Republic of Korea	Sweden
Portugal	Romania	Switzerland

The following countries were represented by one completion:

Afghanistan	Indonesia	Libya	Oman
Botswana	Iran (Islamic Republic of)	Myanmar	Serbia
Guatemala	Kuwait	Nigeria	



Survey Language [Türkiye completions only]

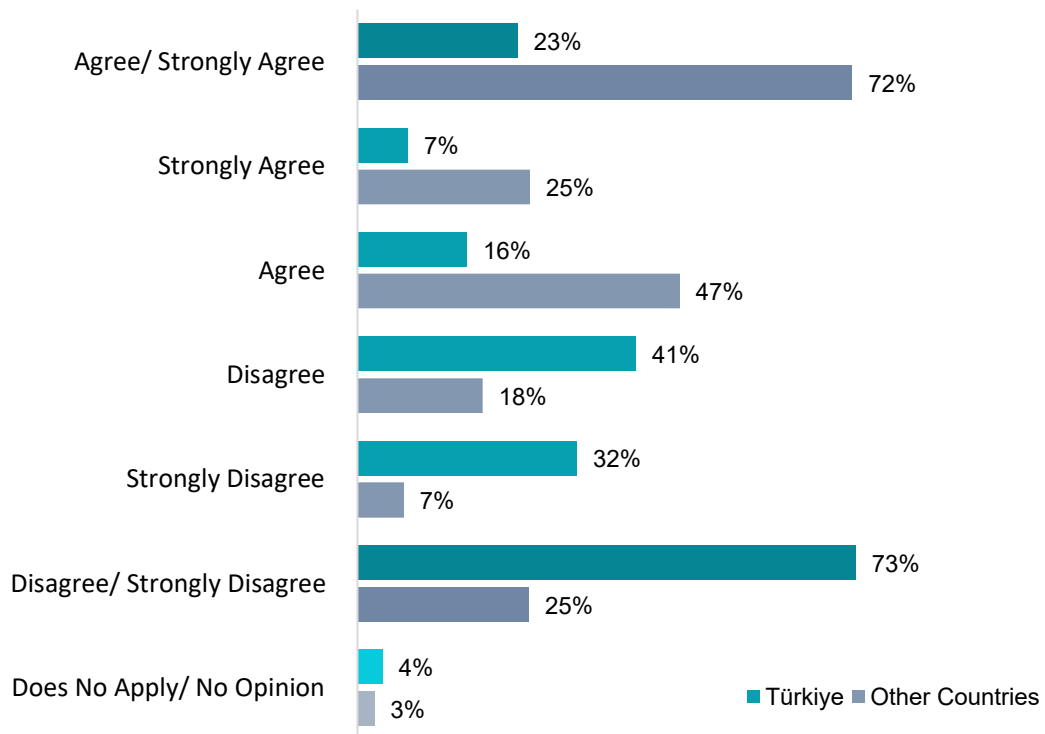


Person Living with ALS/MND [Türkiye, N = 81 Other Countries, N = 846]

Core Rights

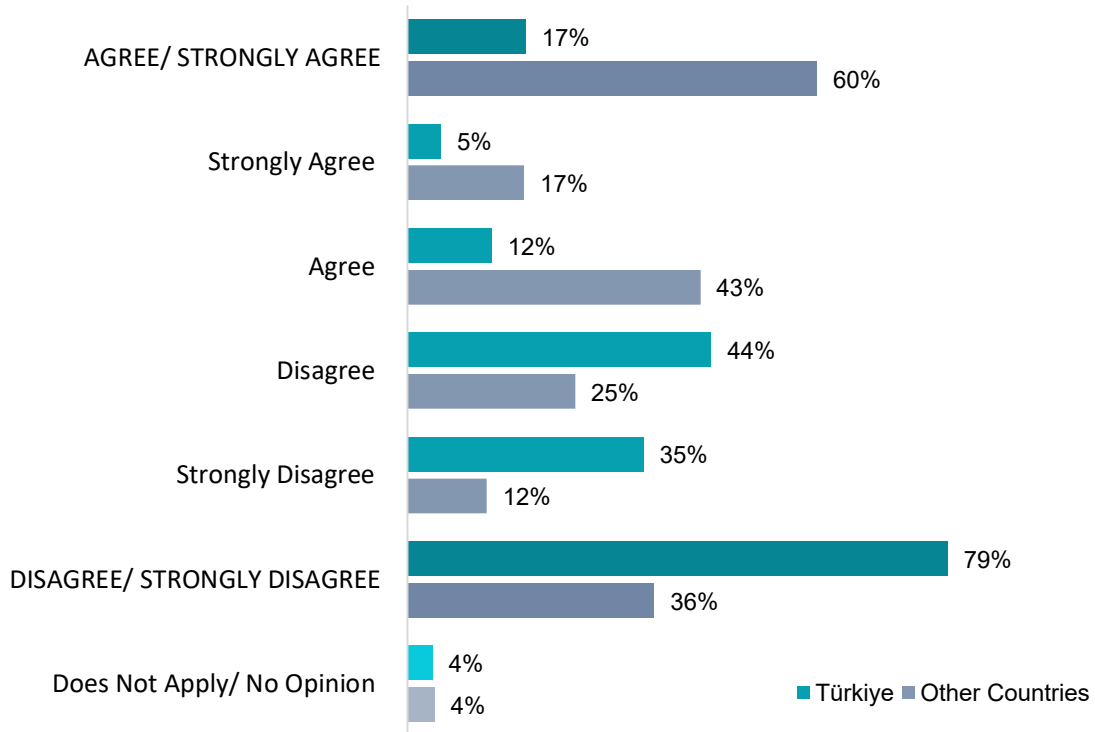
Has Highest Quality Care

I have the highest quality care available.



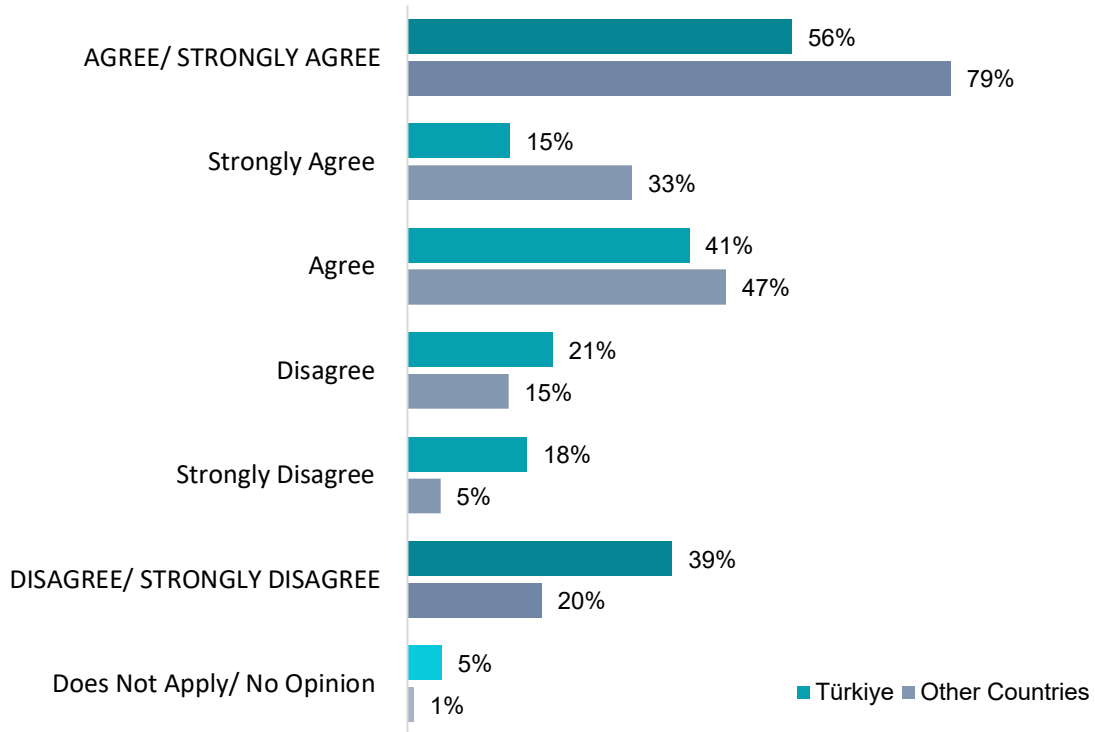
Has Highest Quality Treatments

I have the highest quality treatments available.



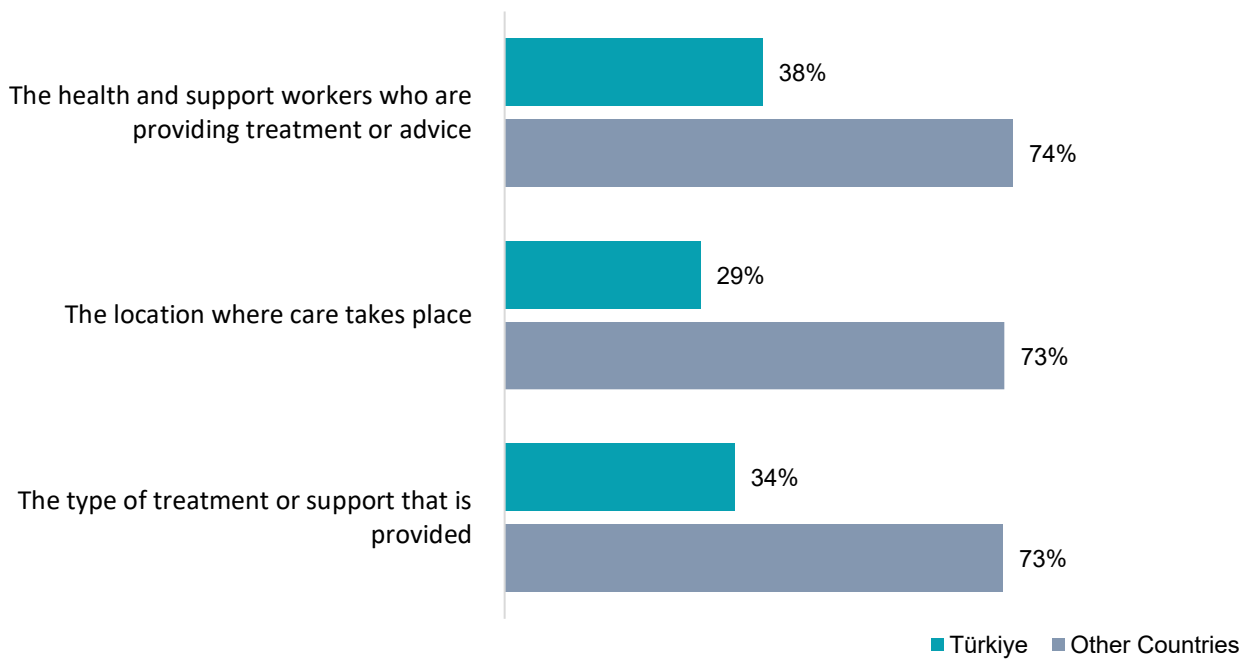
Has Adequate Information and Education

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



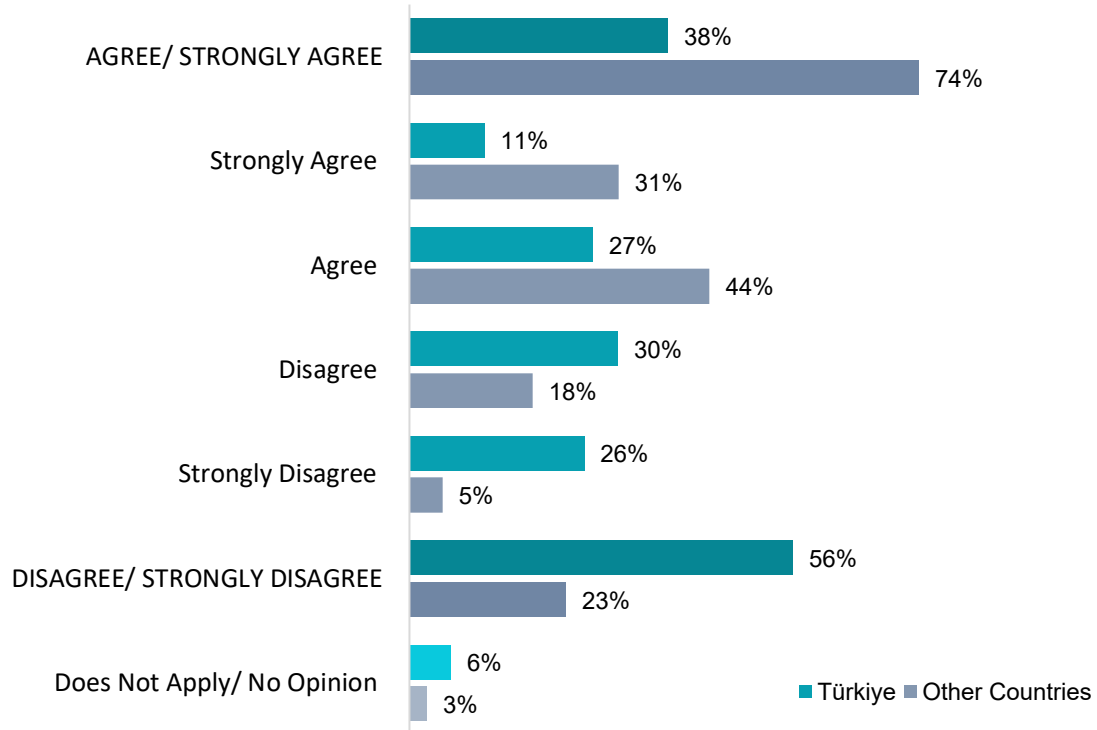
Has the Right to Choose:

Summary of those who Agree or Agree Strongly



Has the Right to Choose:

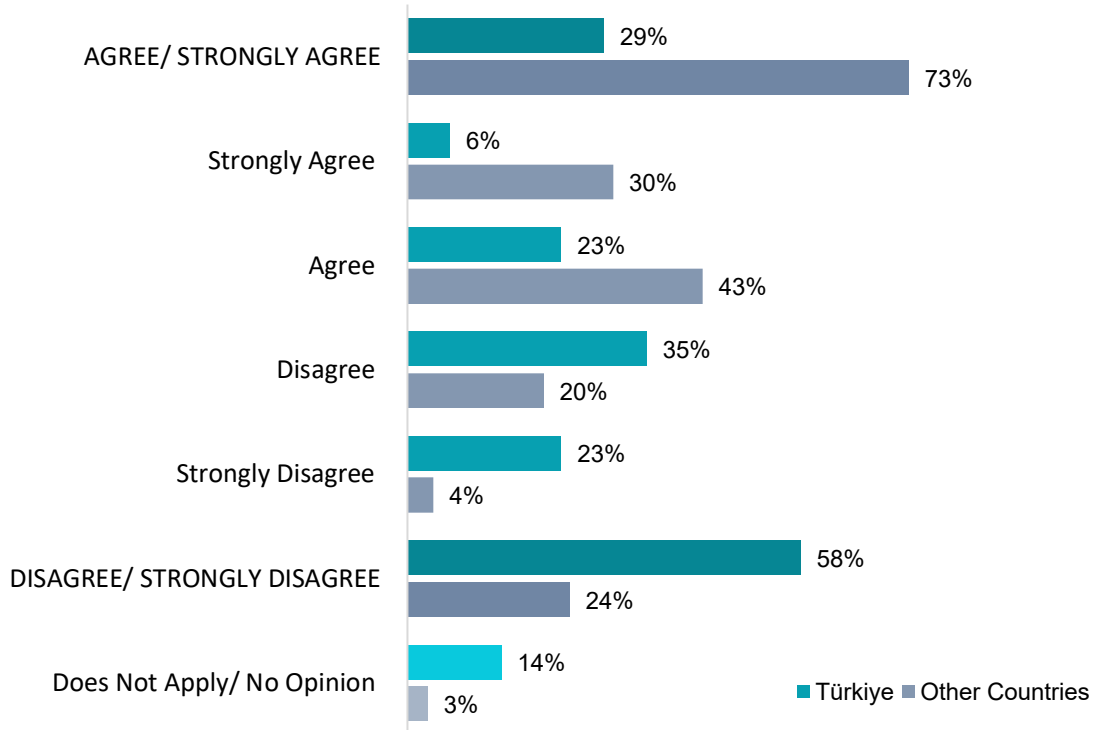
The health and support workers who are providing treatment or advice





Has the Right to Choose:

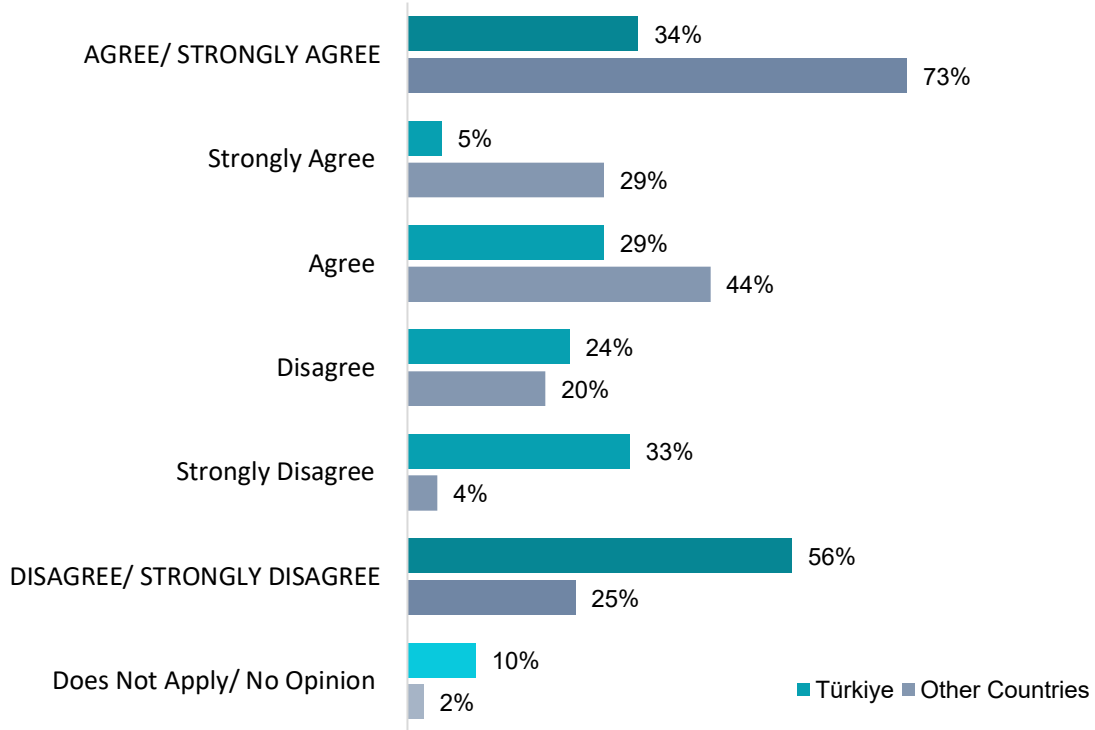
The location where care takes place





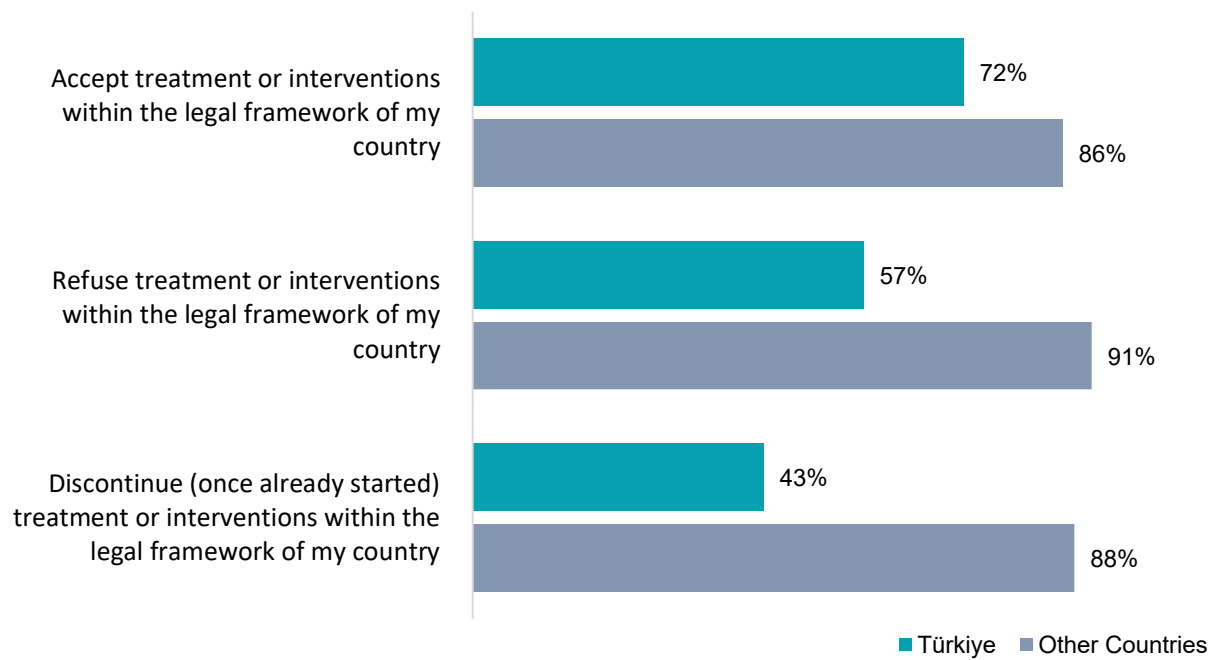
Has the Right to Choose:

The type of treatment or support that is provided



Has the Right to Choose to:

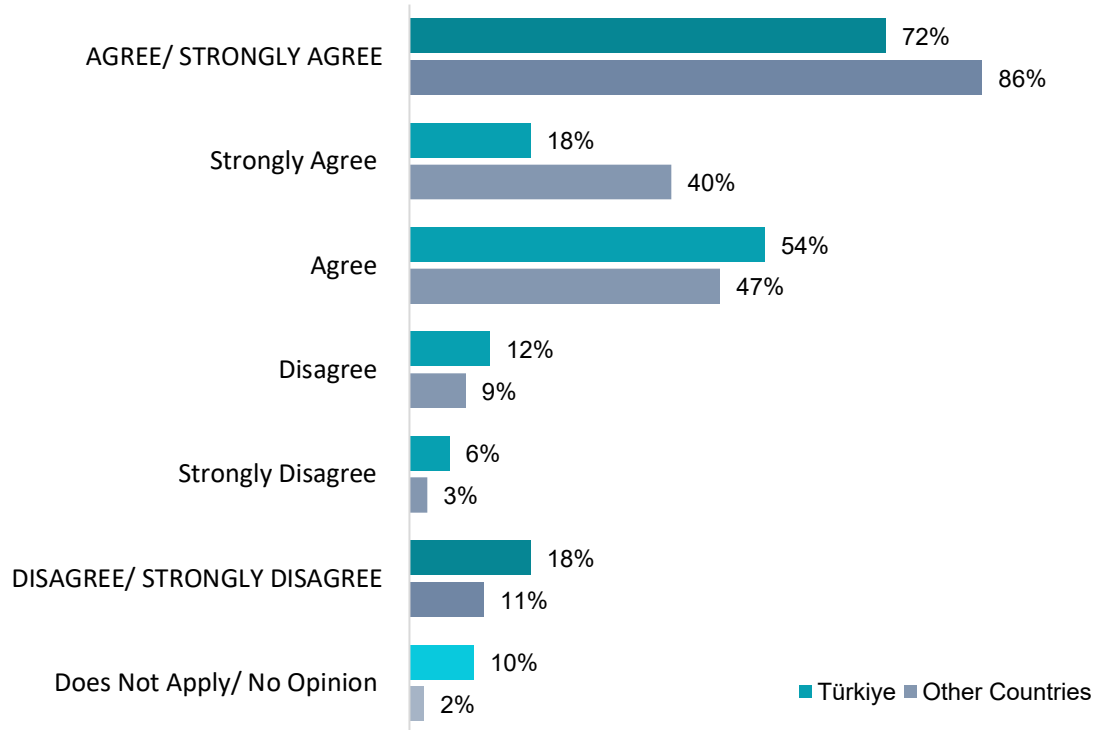
Summary of those who Agree or Agree Strongly





Has the Right to Choose to:

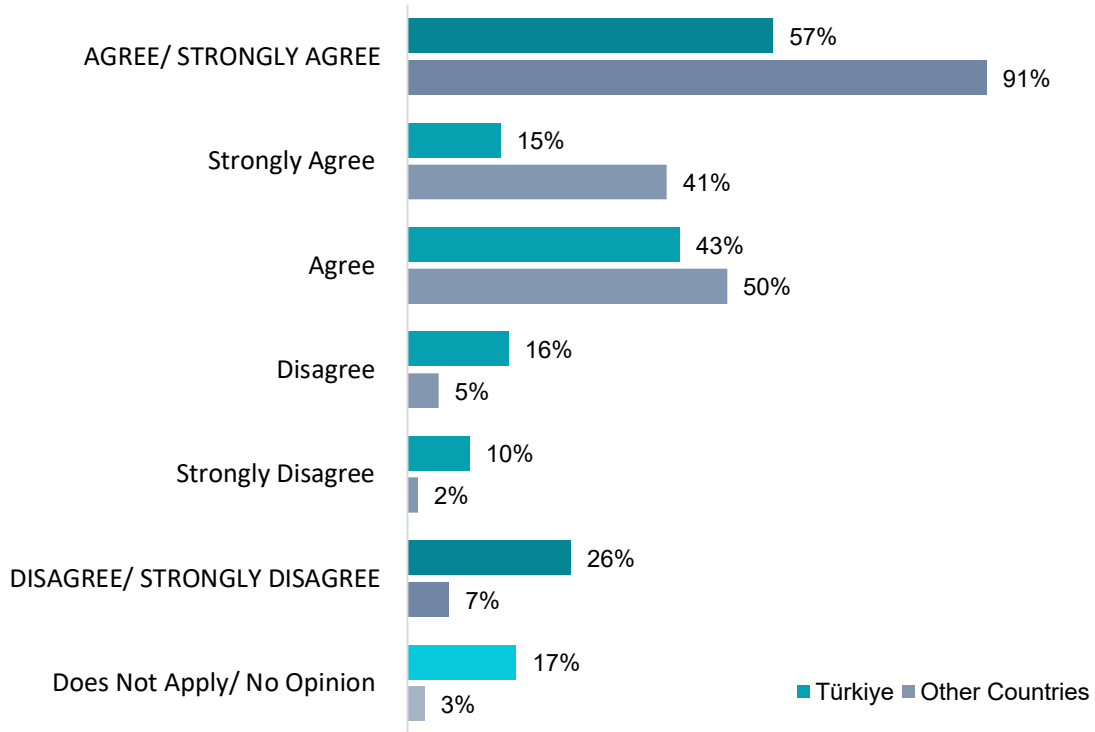
Accept treatment or interventions within the legal framework of my country





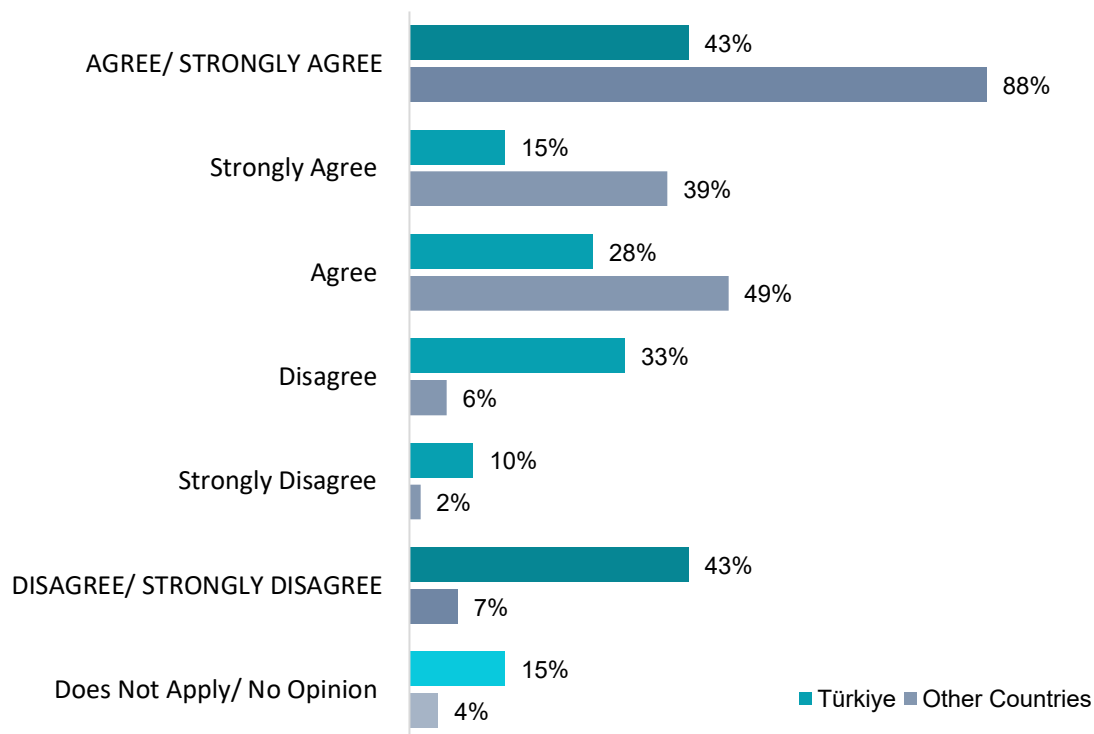
Has the Right to Choose to:

Refuse treatment or interventions within the legal framework of my country



Has the Right to Choose to:

Discontinue (once already started) treatment or interventions within the legal framework of my country

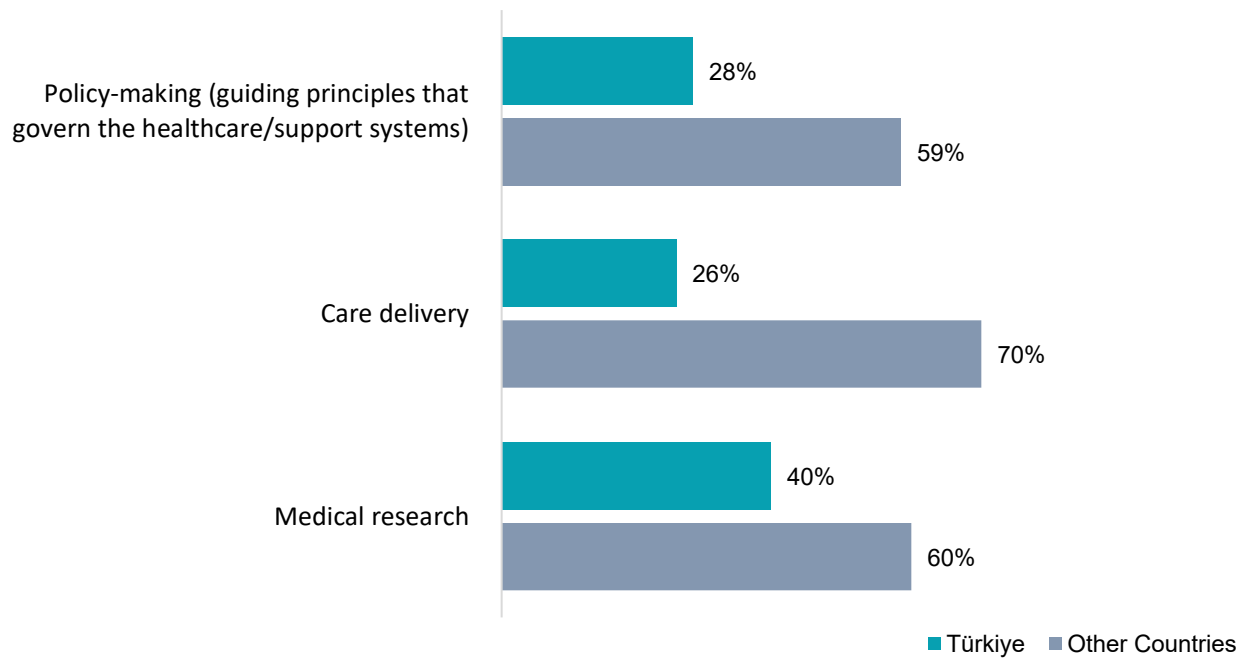




Able to Provide Input on the Healthcare and Support System

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

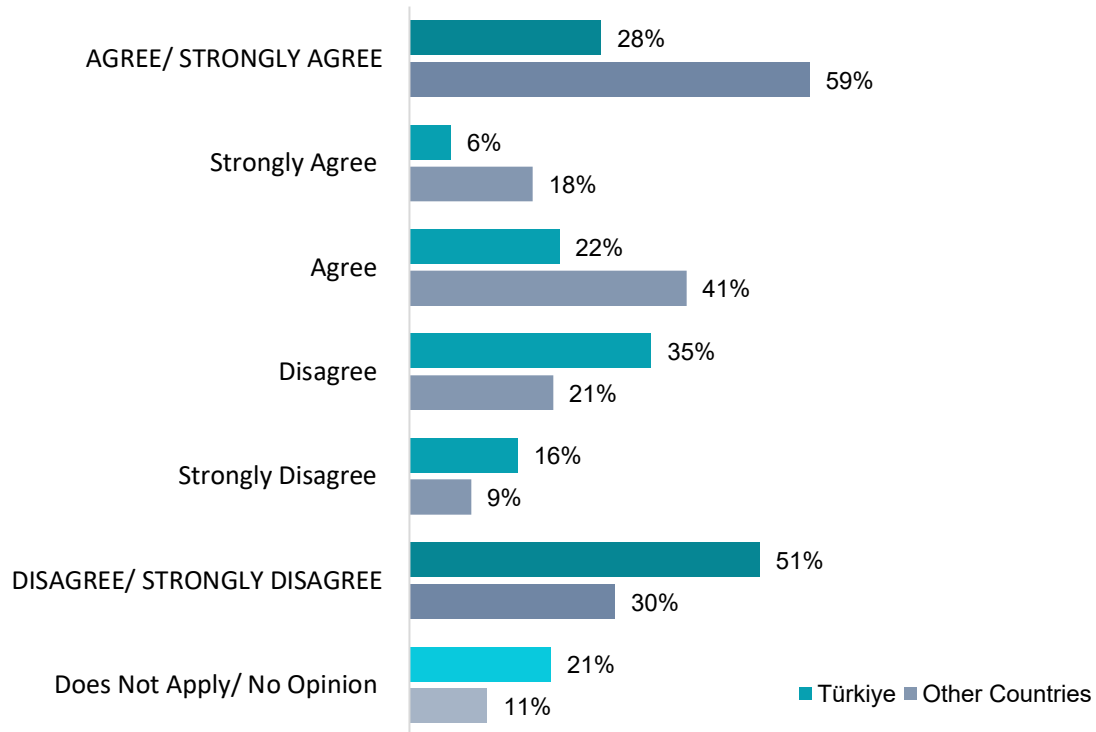
Summary of those who Agree or Agree Strongly





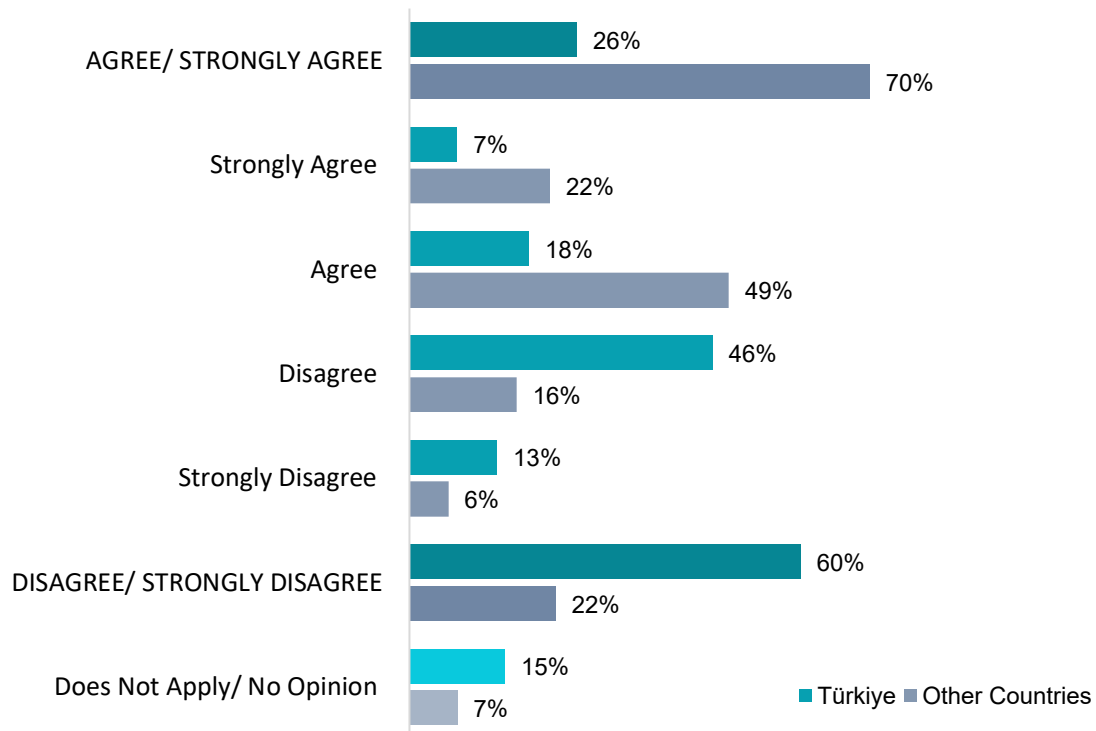
Able to Provide Input on the Healthcare and Support System:

Policy-making (guiding principles that govern the healthcare/support systems)



Able to Provide Input on the Healthcare and Support System:

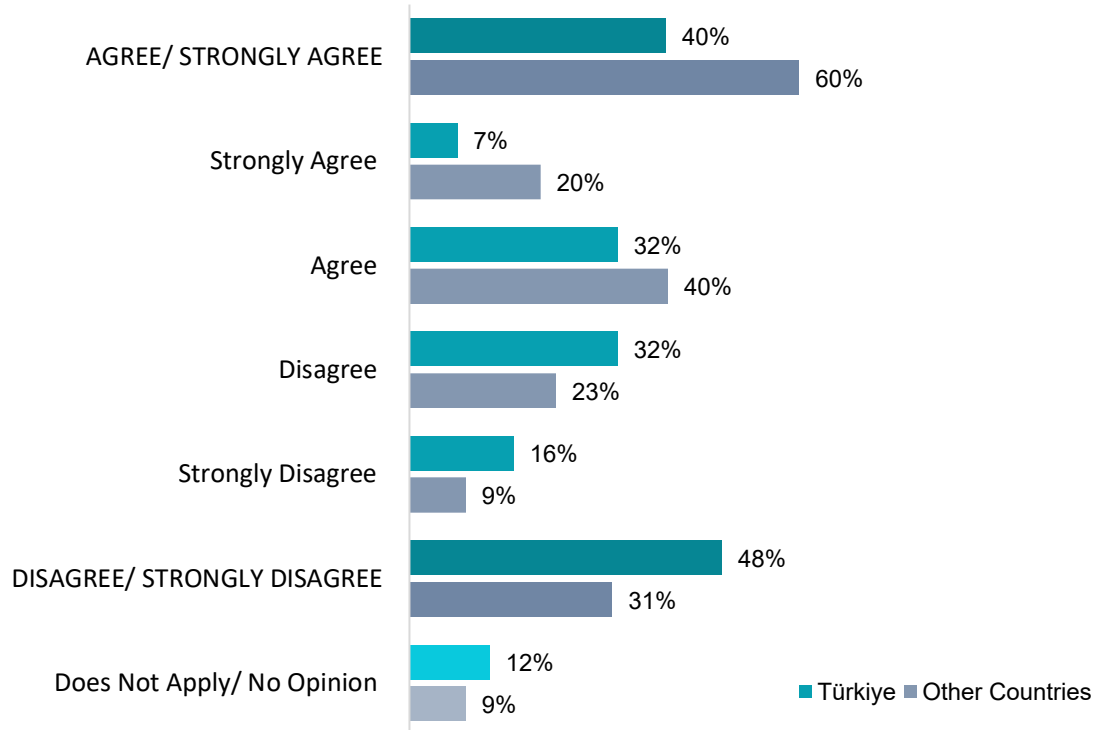
Care delivery





Able to Provide Input on the Healthcare and Support System:

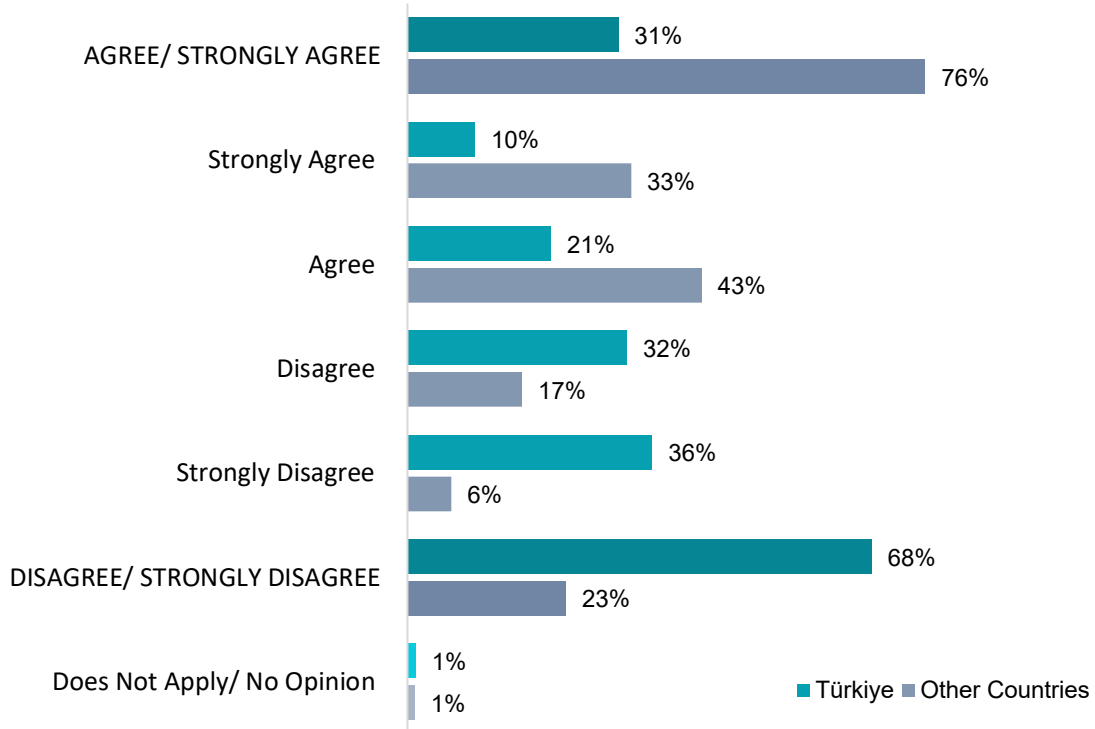
Medical research





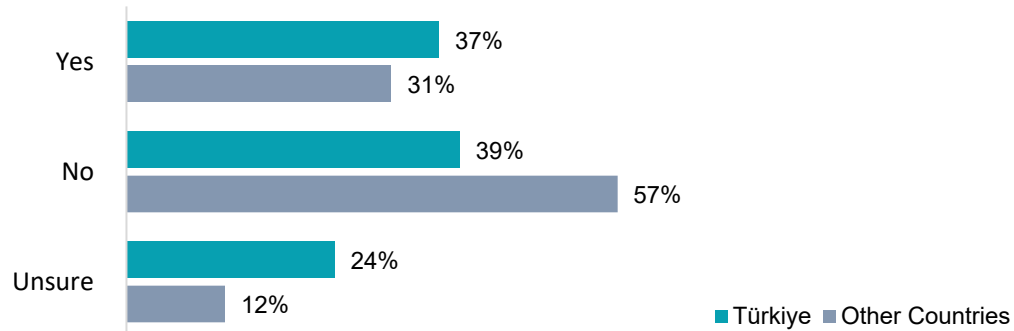
Has Best Quality of Life Possible

I have the liberty to live the best quality of life possible.



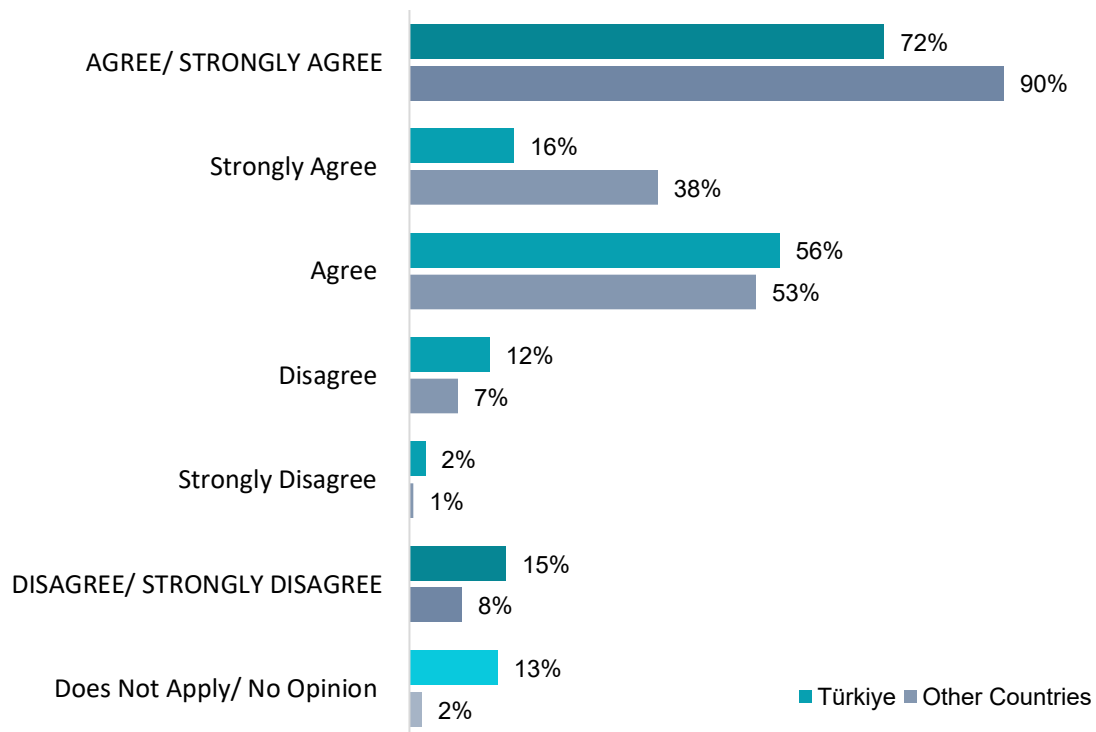
Has Experienced Discrimination

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 in the political, economic, social, cultural, civil, or any other field. It includes all forms of discrimination, including denial of access to adequate accommodation, public transport, or buildings, and interaction problems due to speech or mobility symptoms. Have you experienced discrimination since your ALS/MND diagnosis?



Assured of Confidentiality and Privacy

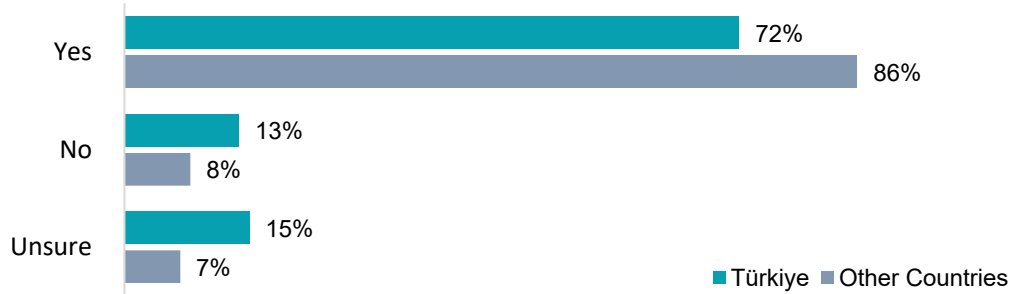
I am assured of confidentiality and privacy regarding my personal information.





Can Assign Communication Assent

I can assign consent to someone else to communicate on my behalf.



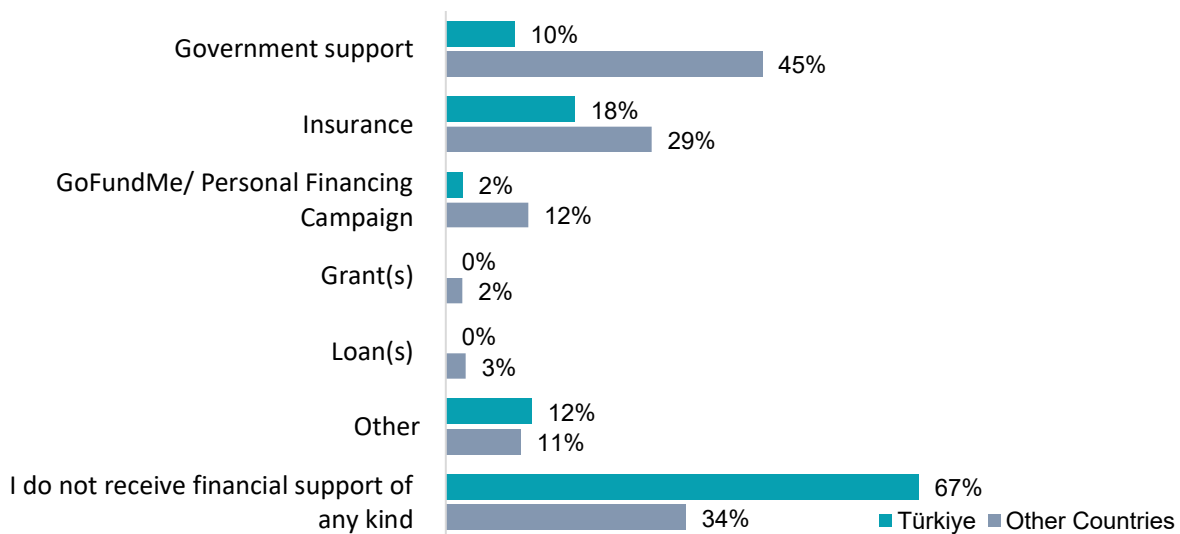
Economic Situation has been Affected

ALS/MND has affected my economic situation.



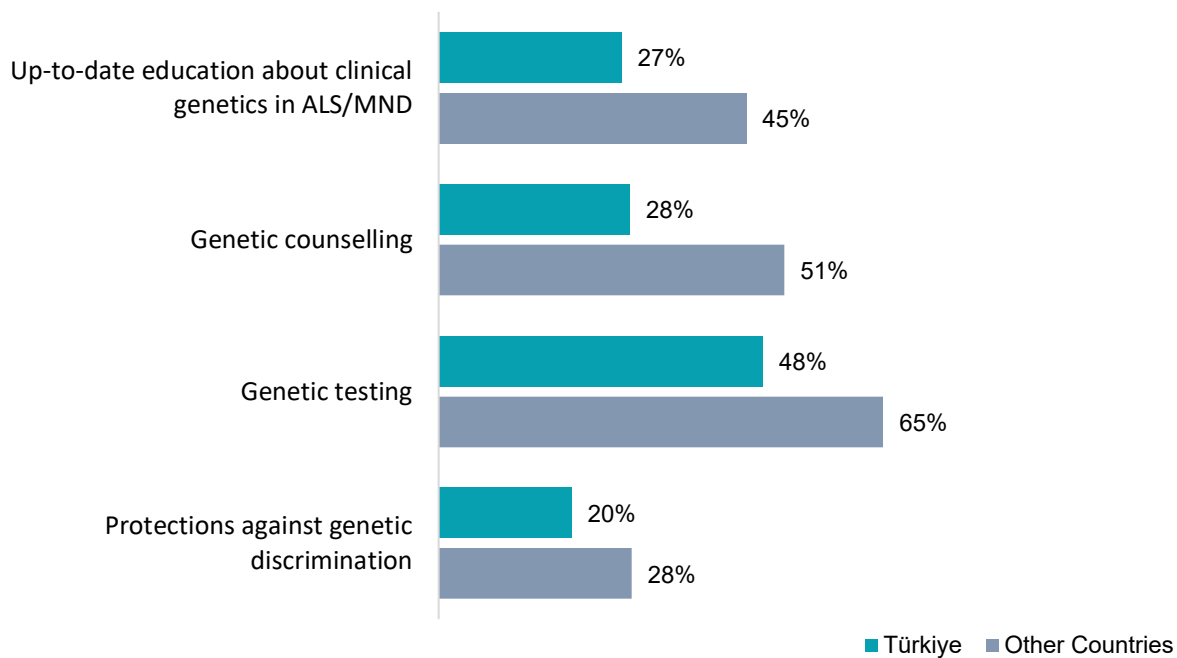
Form(s) of Financial Support

I receive financial support to assist with my care in the form of:



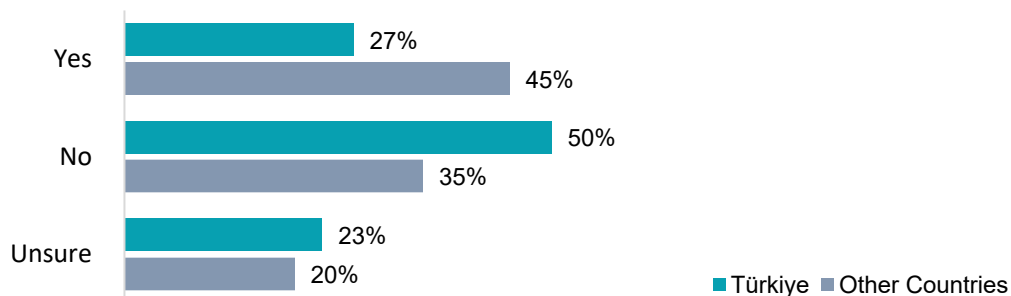
Has Access to Genetic Education, Counselling, Testing, and Protection against Discrimination

Summary of “Yes”

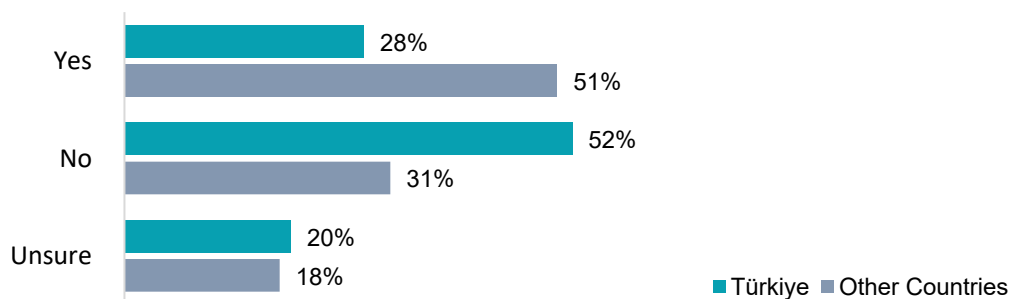


Has Access To:

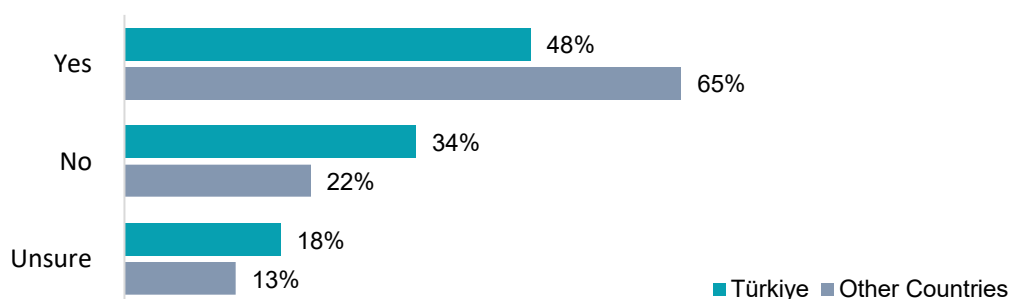
Up-to-date education about clinical genetics in ALS/MND



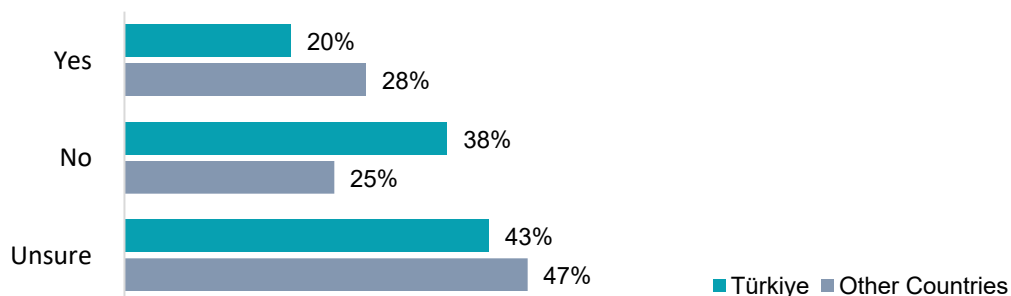
Genetic counselling



Genetic testing



Protections against genetic discrimination

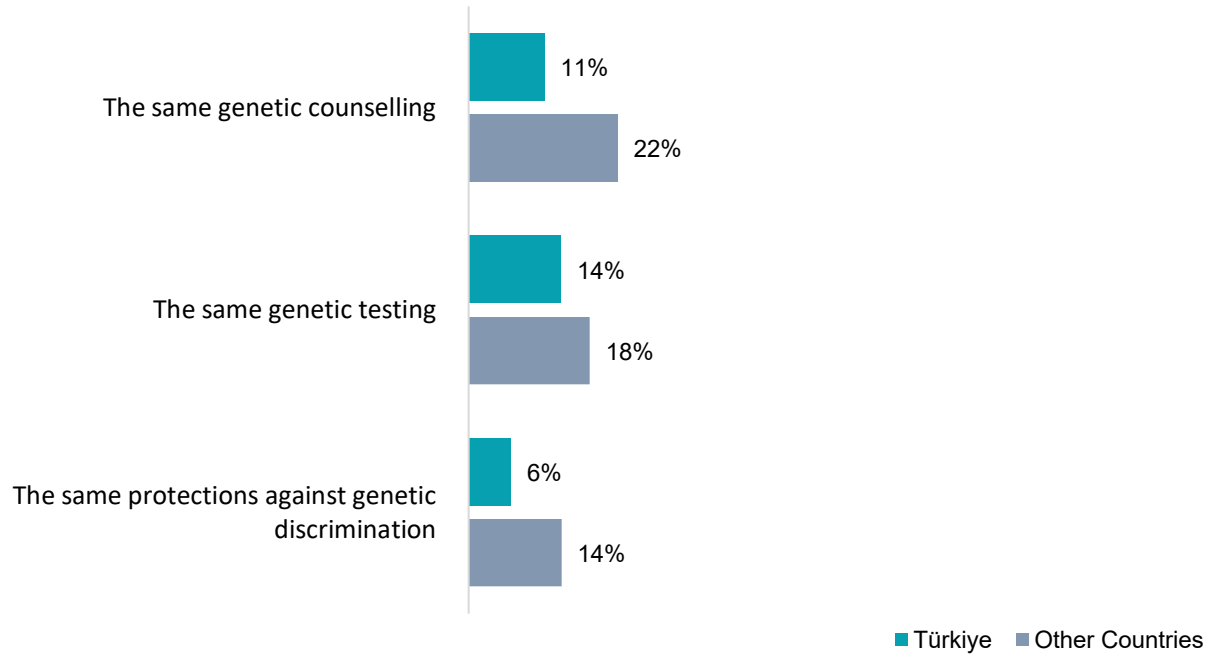




Blood Relatives have been Offered:

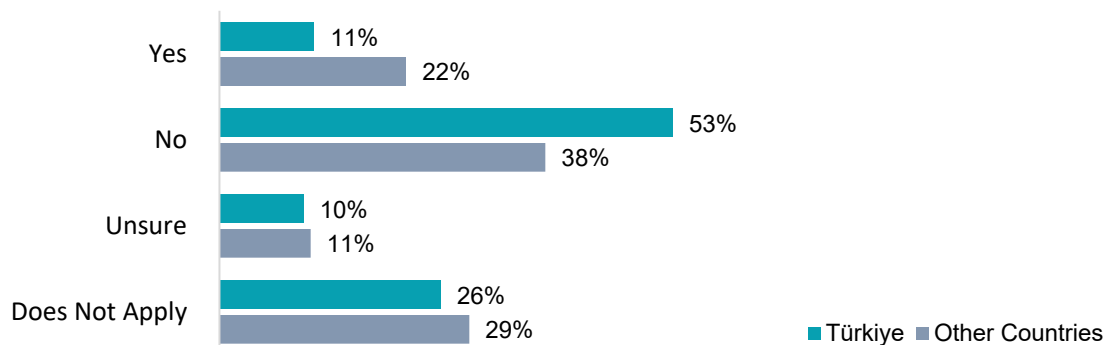
If relevant, my blood relatives have been offered:

Summary of “Yes”

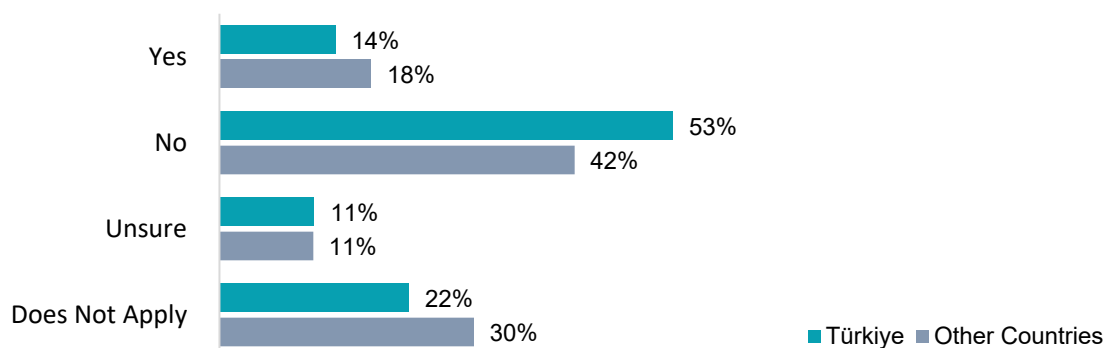


Blood Relatives have been Offered:

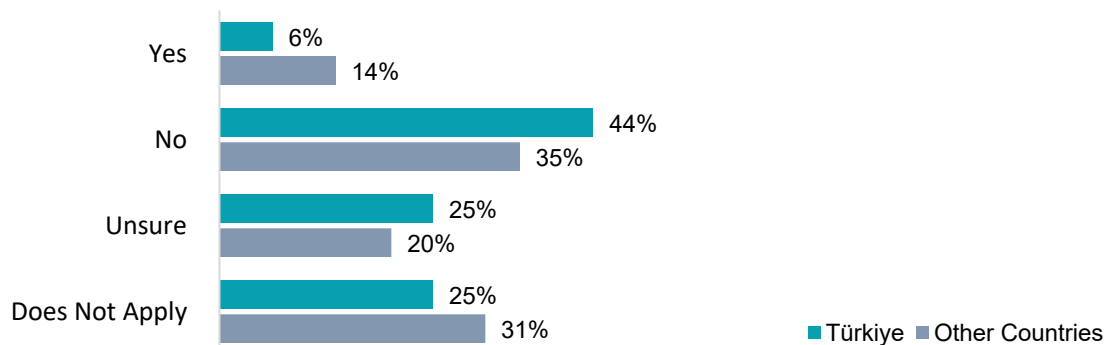
The same genetic counselling



The same genetic testing



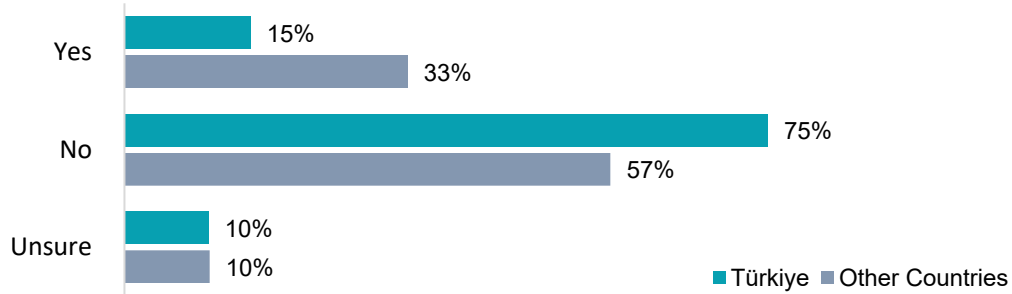
The same protections against genetic discrimination





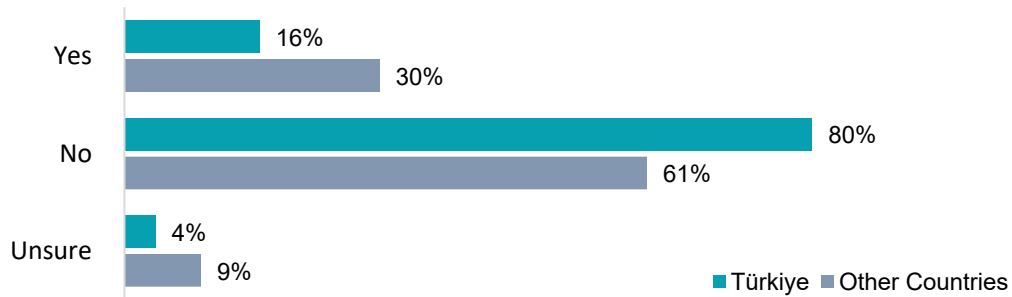
Offered Genetic Counselling

I have been offered genetic counselling.



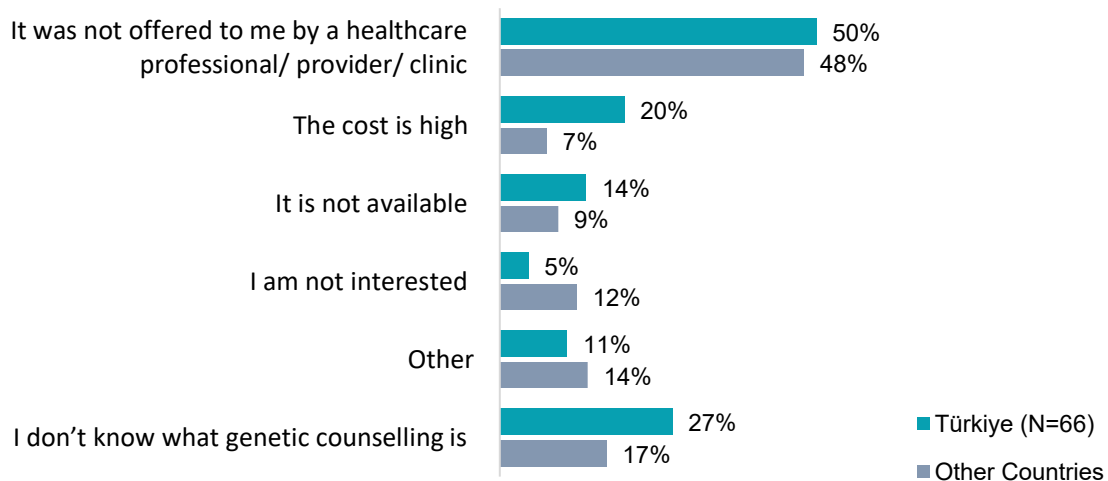
Received Genetic Counselling

I have received genetic counselling.



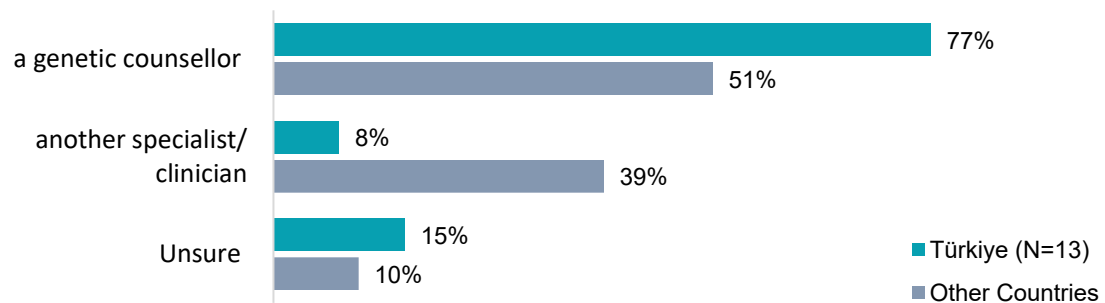
Reasons for Not Receiving Genetic Counselling

I have not received genetic counselling because:



Professional who Provided Genetic Counselling

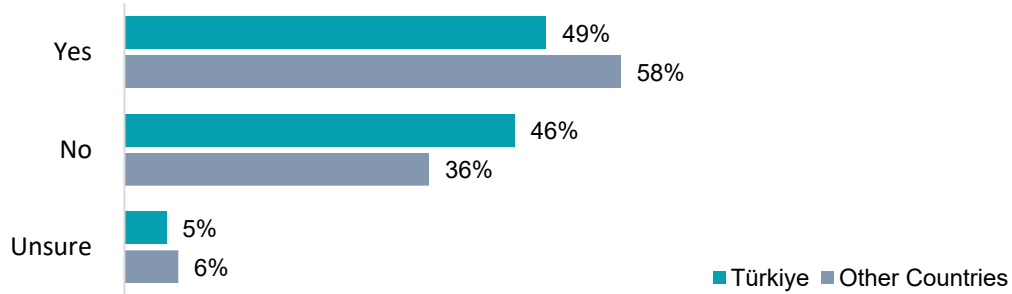
I received genetic counselling from:





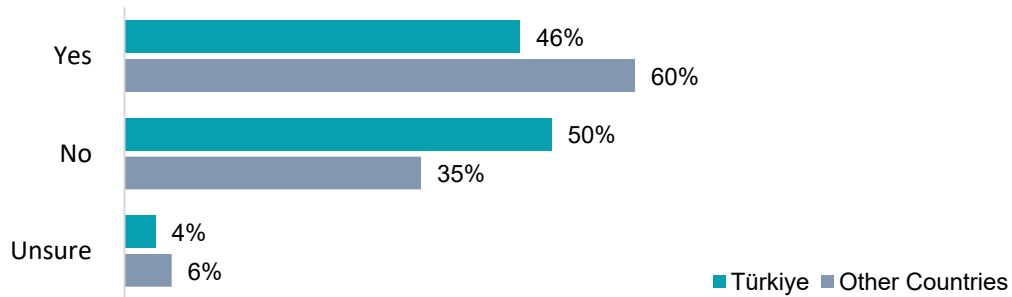
Offered Genetic Testing

I have been offered genetic testing.



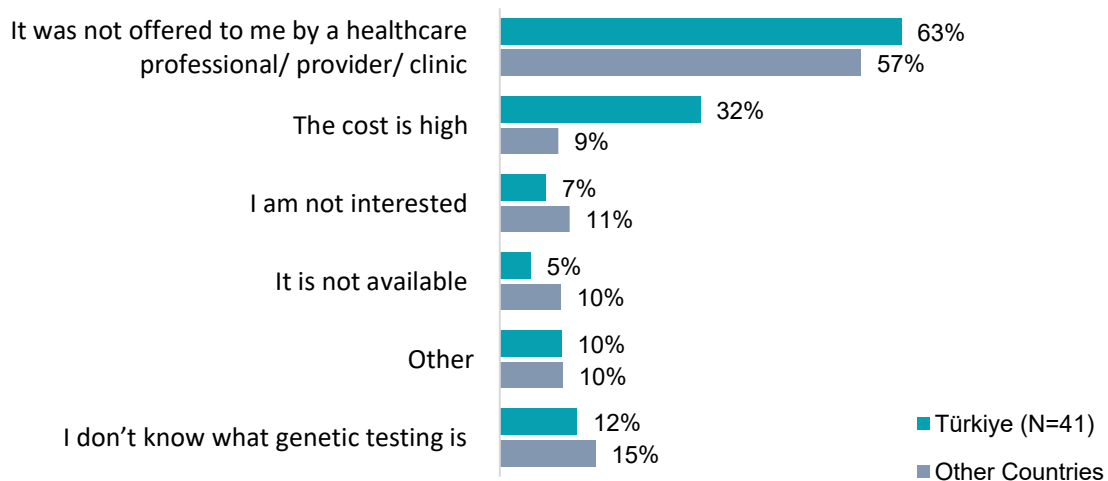
Received Genetic Testing

I have received genetic testing.



Reasons for Not Receiving Genetic Testing

I have not received genetic testing because:





Interesting in Knowing Possible Genetic Cause

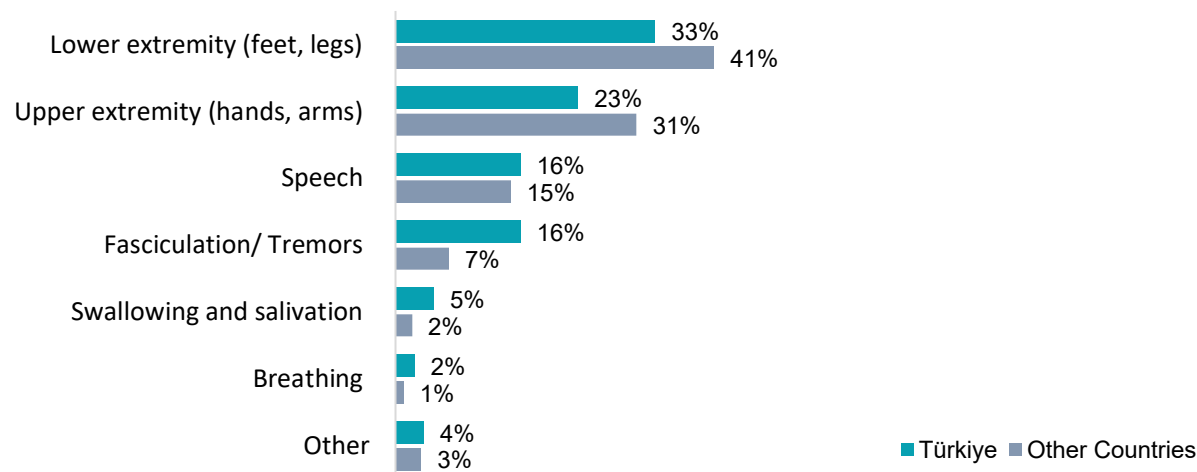
I am interested in knowing whether there is a genetic cause that contributed to my ALS/MND.



Path To Diagnosis

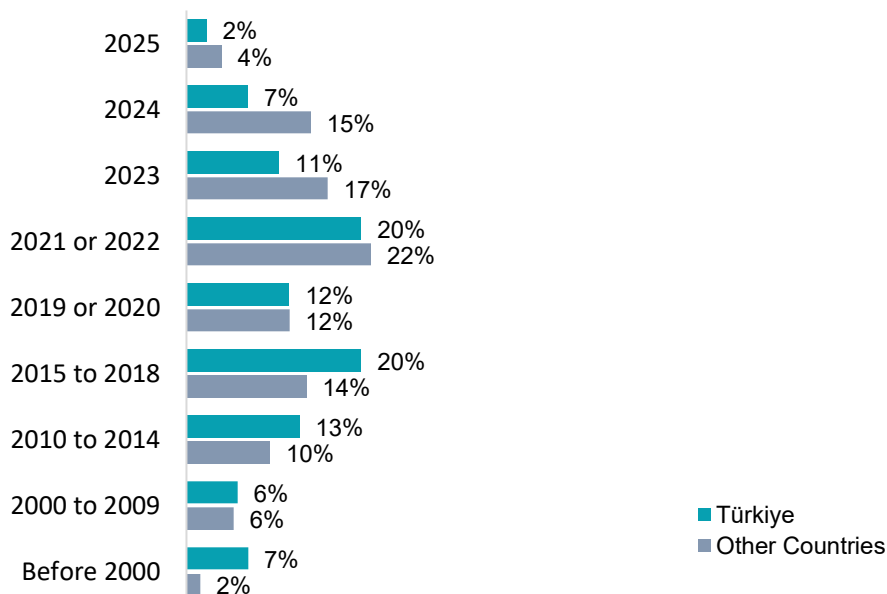
First Symptom Noticed

The first symptom I noticed was:



Year When Symptoms First Started

My symptoms first started in - Year

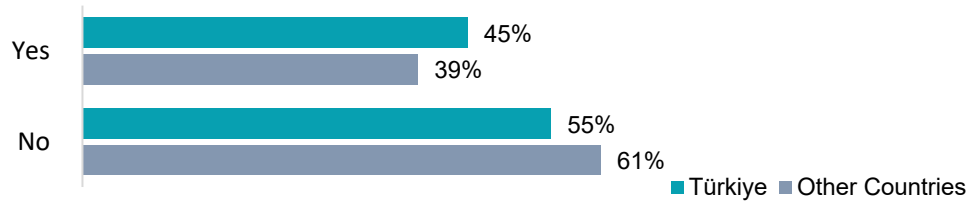


	Türkiye	Other
Average Year	2016	2019
Median Year	2019	2021



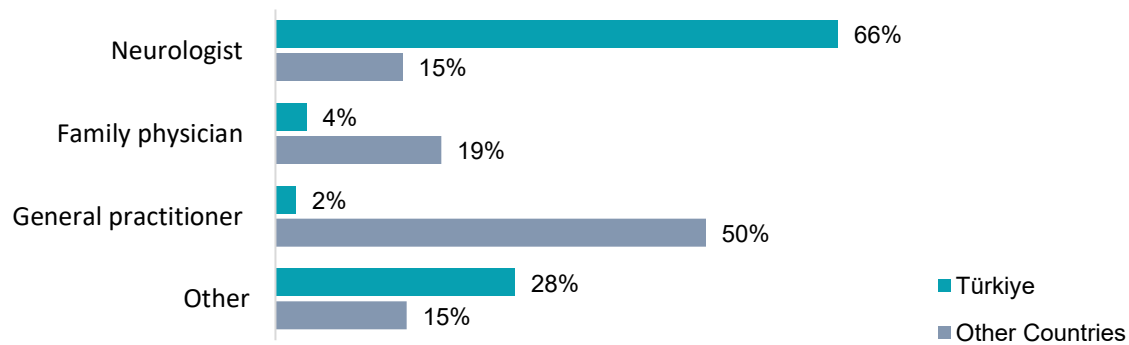
Was Given a Different Diagnosis Before ALS/MND

I was given another diagnosis before my ALS/MND diagnosis was confirmed.



Healthcare Provider Initially Consulted

When I first noticed symptoms, I saw my ... about them.



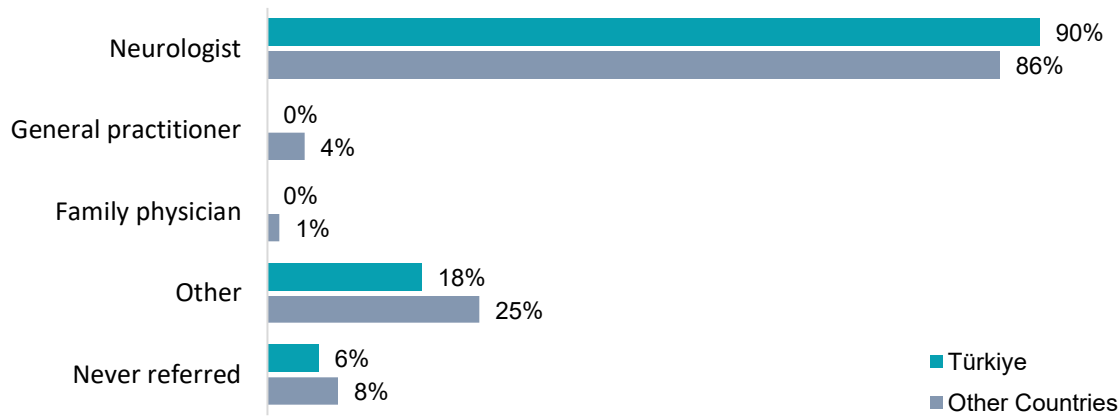
Respondents who responded with “Yes” to the question “I was given another diagnosis before my ALS/MND diagnosis was confirmed” were given the prompt:

“We would like to better understand your path to diagnosis. Please answer as many times as needed until you get to the healthcare professional who gave you your diagnosis.”

Questions in this section were repeated up to 10 times.

Healthcare Providers who Respondent was Referred To

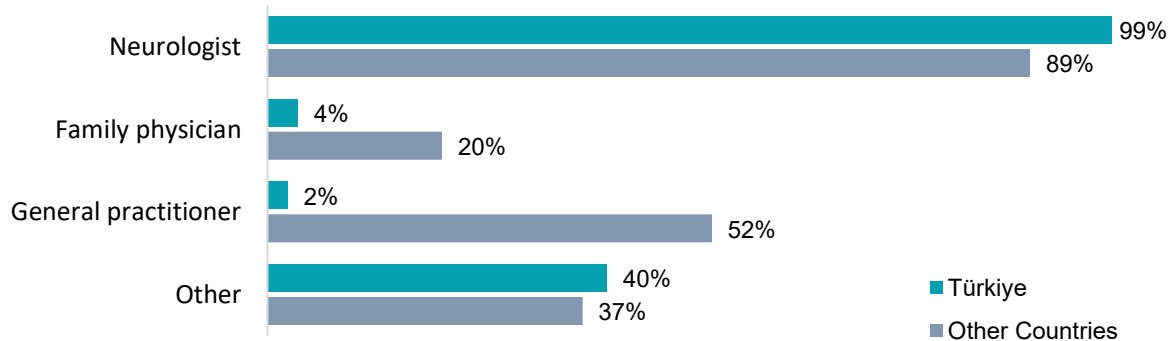
I was *then* referred to a... [up to 10 referrals]



Total Healthcare Providers Consulted

Combination of questions:

When I first noticed symptoms, I saw my ... about them
I was *then* referred to a... [up to 10 referrals]

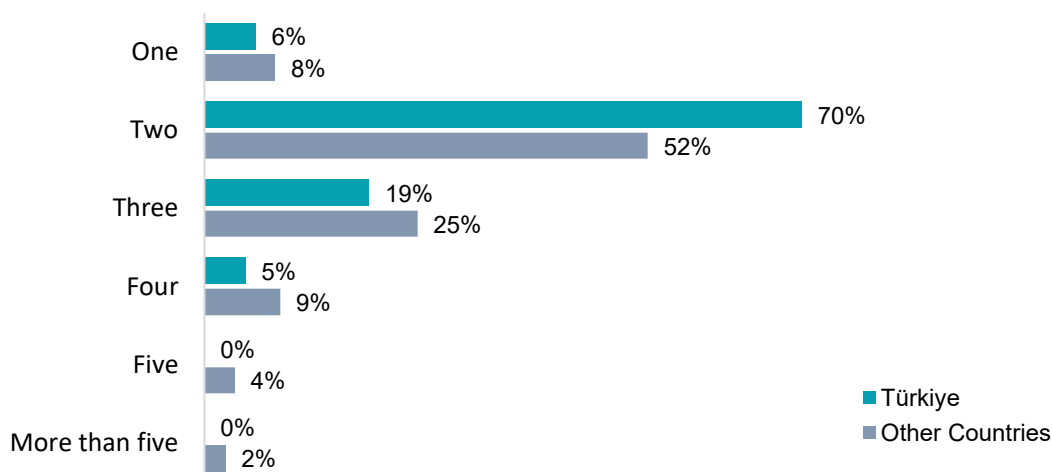


Number of Referrals/Diagnoses (with the ALS/MND diagnosis being the final one)

Combination of information from questions:

I was *then* referred to a... [up to 10 referrals]

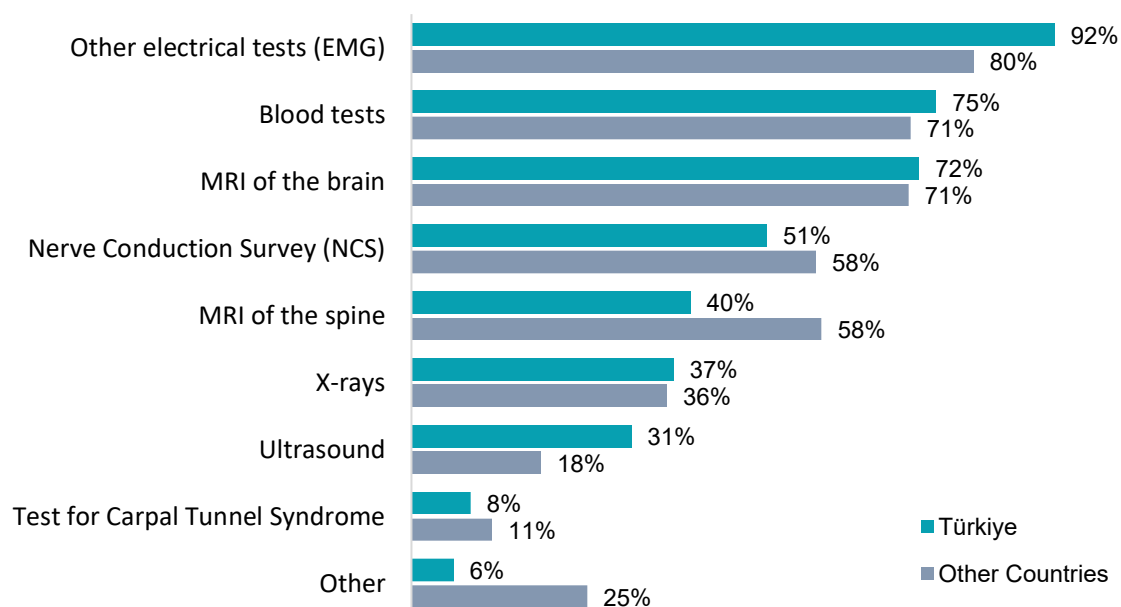
That healthcare professional/physician I was referred to diagnosed me with ALS/MND.



	Türkiye	Other
Average # of diagnoses	2.2	2.6
Median #	2	2

Underwent Investigations/Tests

Investigations/tests I underwent with that healthcare professional/physician included:

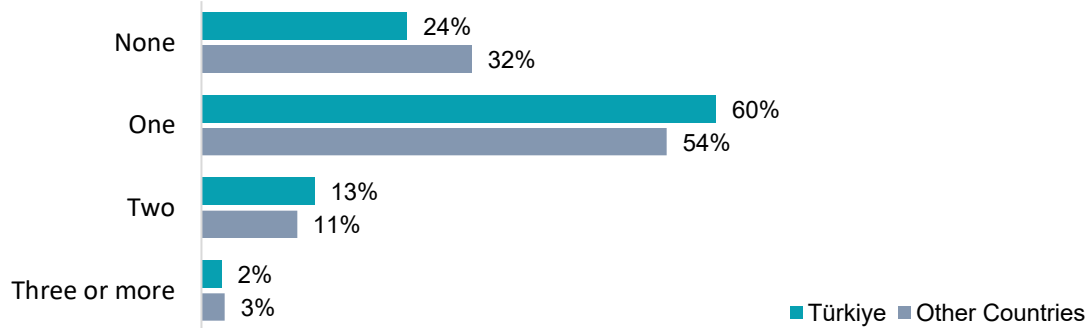




Number of Times that Treatments were Received

I received treatment(s) for my symptoms from that healthcare professional/physician.

[across up to 10 referrals]



Number of Surgical Procedures

I had a surgical procedure with that healthcare professional/physician.

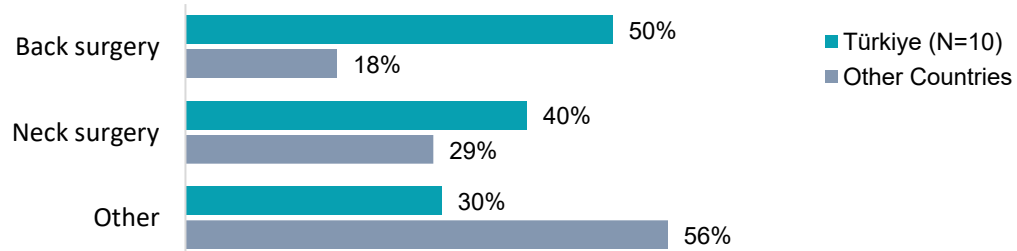
[across up to 10 referrals]



Type of Surgical Procedure(s)

The surgical procedure I underwent with that healthcare professional/physician was...

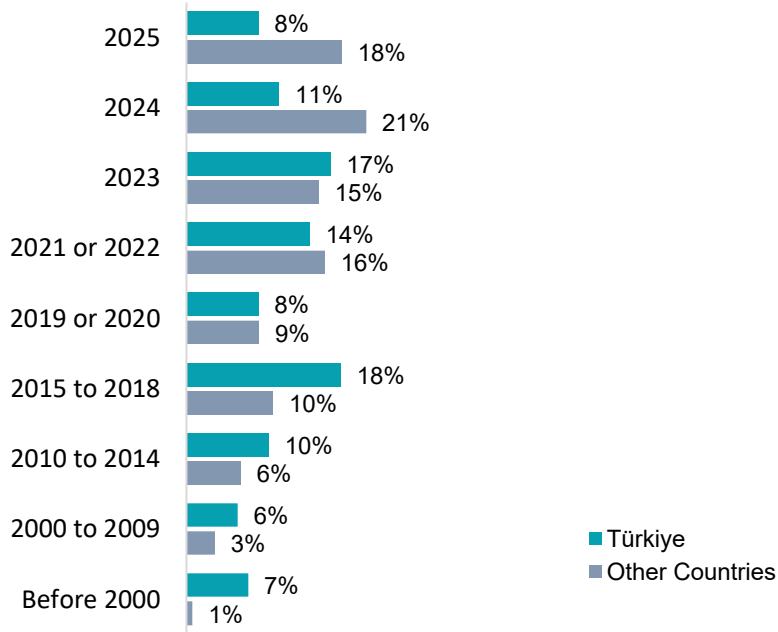
[across up to 10 referrals]





Year of Diagnosis

I received my ALS/MND diagnosis in:

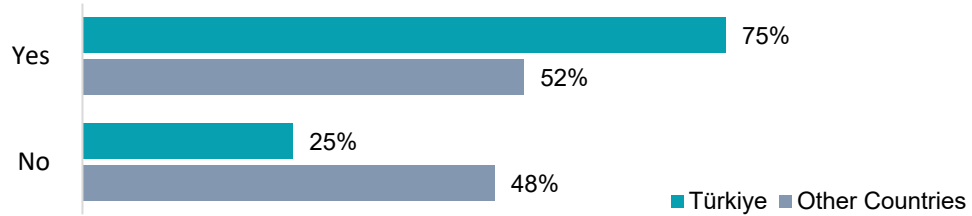


	Türkiye	Other
Average Year	2017	2021
Median Year	2021	2023



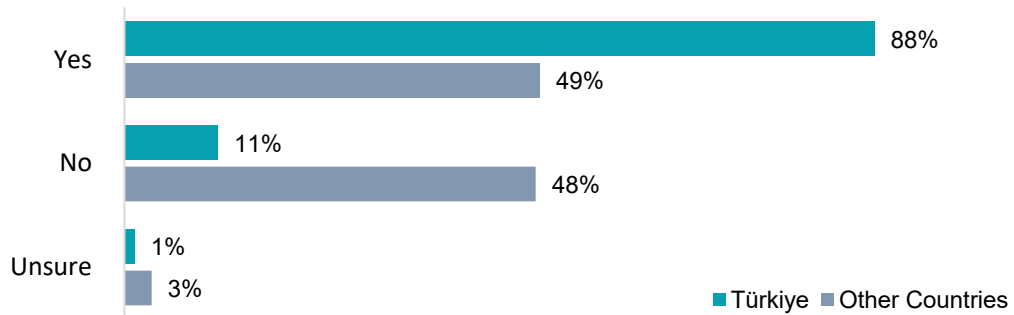
Got a Second Opinion on Diagnosis

I got a second opinion on my ALS/MND diagnosis.



Had to Pay Some or All of Expenses Related to Diagnosis

During the diagnostic process for ALS/MND, I had to pay some or all of the related expenses myself.



Multidisciplinary Care and Support

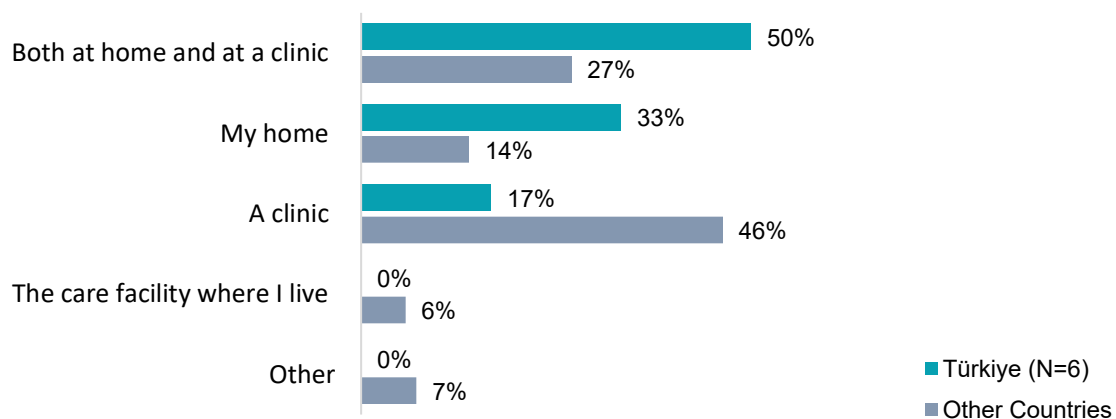
Receives Multidisciplinary Care

Multidisciplinary care consists of specialized professionals from various fields who collaborate to provide more efficient and comprehensive patient care. I receive multidisciplinary care.



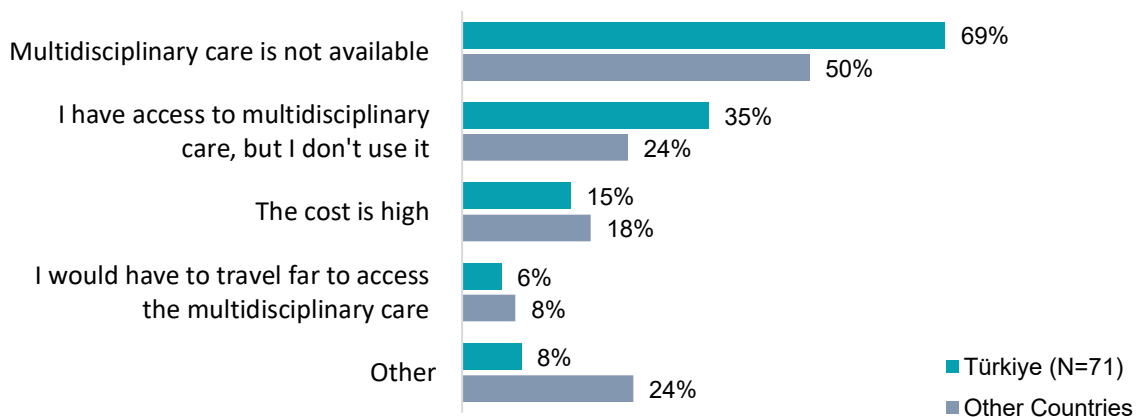
Receives Multidisciplinary Care In...

I receive multidisciplinary care in:



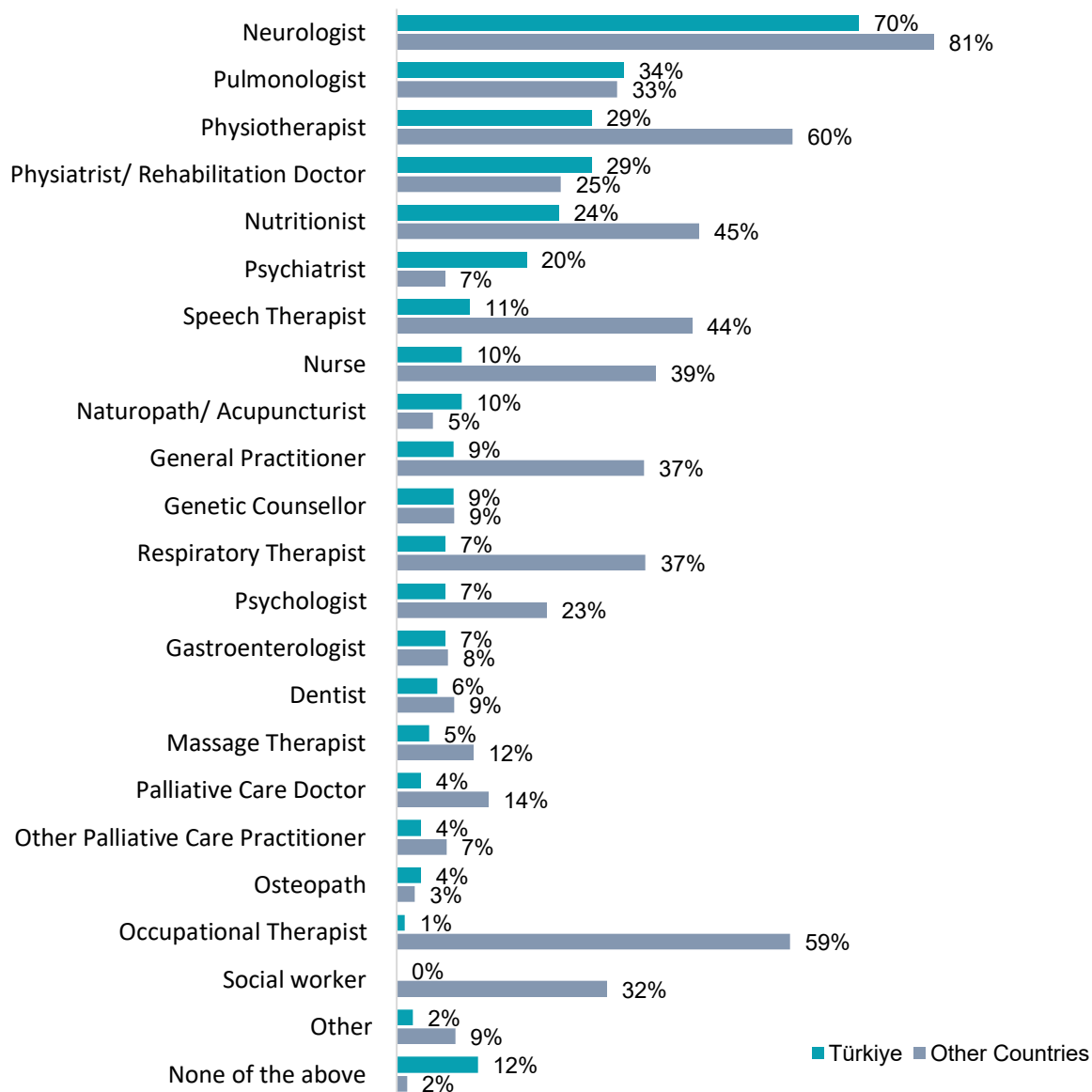
Reasons for Not Receiving Multidisciplinary Care

I do not receive multidisciplinary care because:



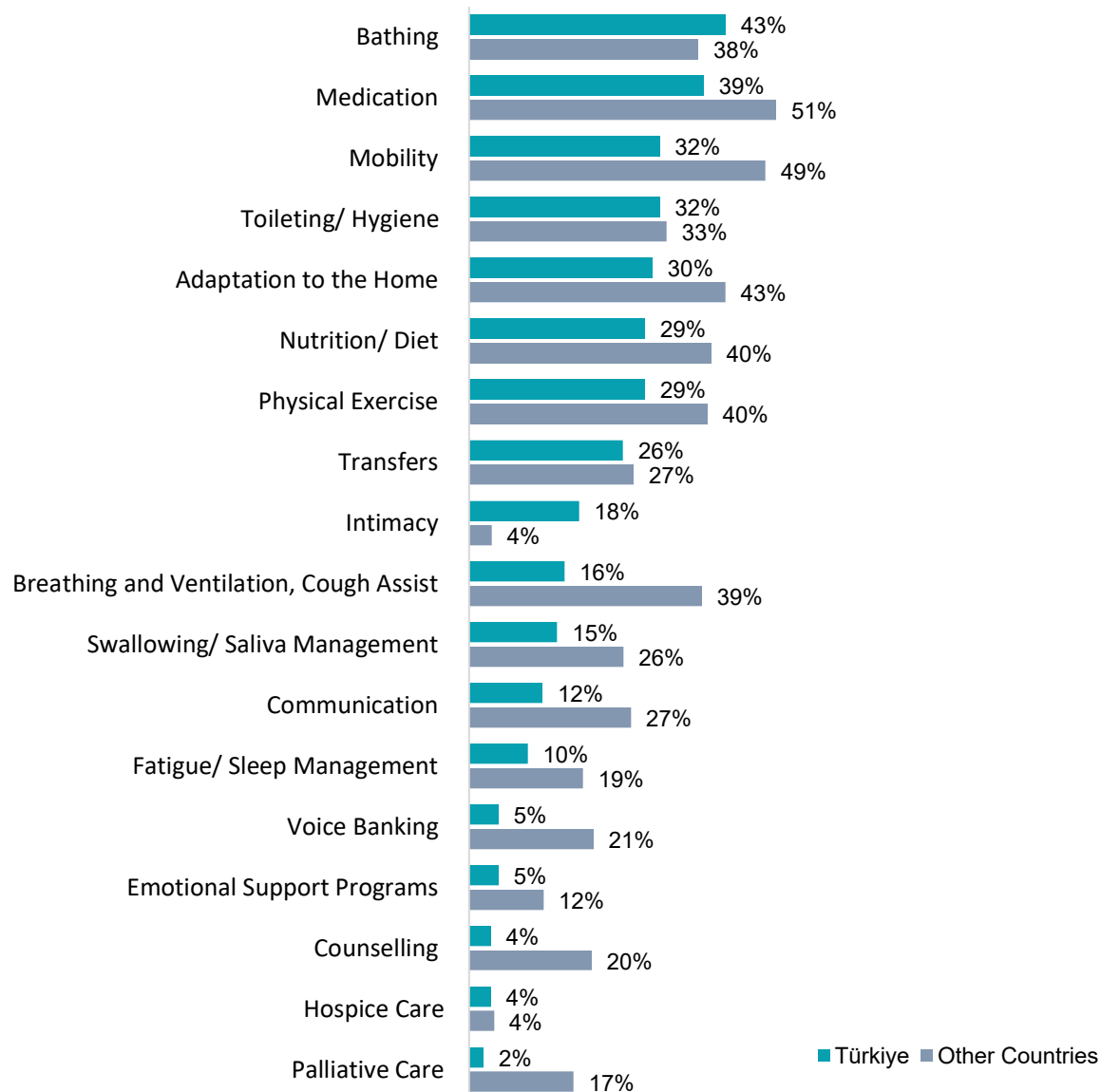
Healthcare Professionals who Provide Care

I receive ALS/MND care from the following physicians/healthcare professionals:



Areas of Support

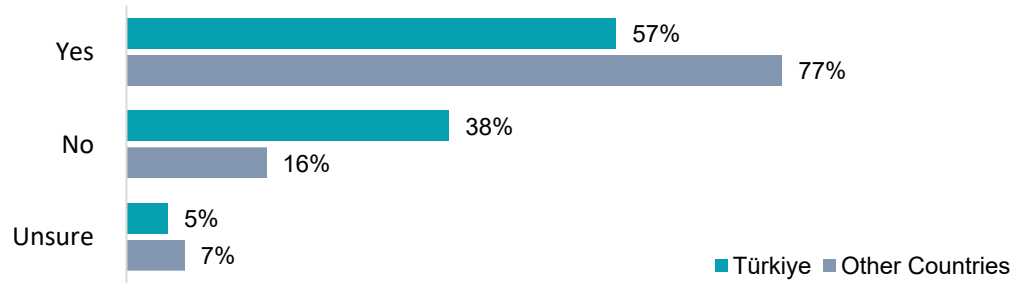
I receive support in the following areas:





Has Access to Care Supports Through ALS/MND Organization

I have access to an ALS/MND Association/Organization which provides care supports.



Treatments and Clinical Trials

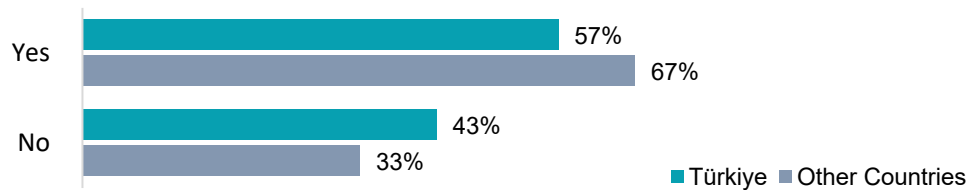
Riluzole (Tiglutik/Rilutek) is Available

Riluzole (Tiglutik/Rilutek) is available in my country.



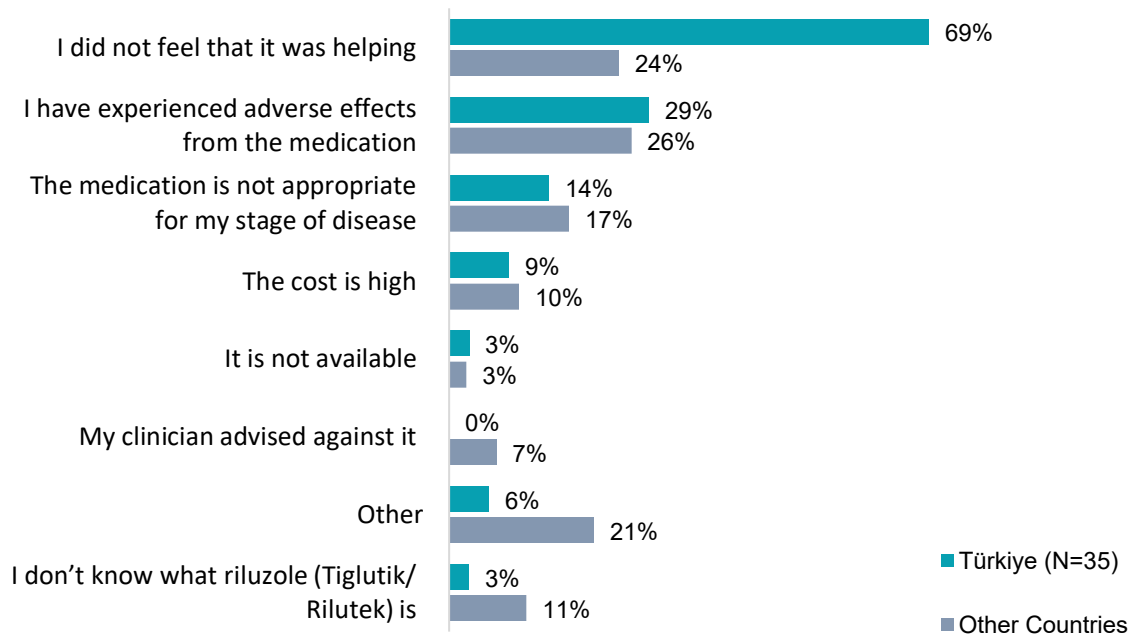
Taking Riluzole (Tiglutik/Rilutek)

I am taking Riluzole (Tiglutik/Rilutek)



Reasons for Not Taking Riluzole (Tiglutik/Rilutek)

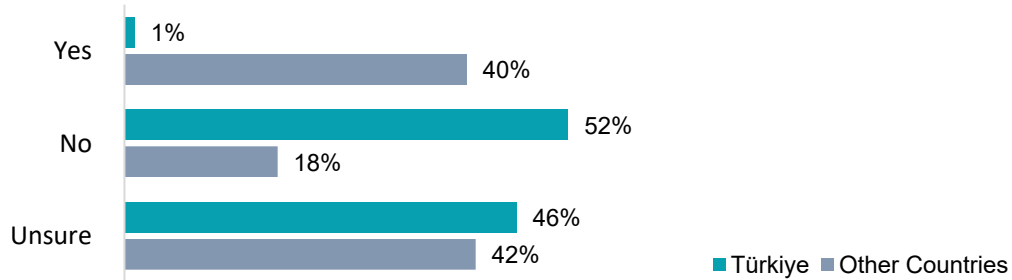
I am not taking Riluzole (Tiglutik/Rilutek) because:





Edaravone (Radicava) is Available

Edaravone (Radicava) is available in my country.



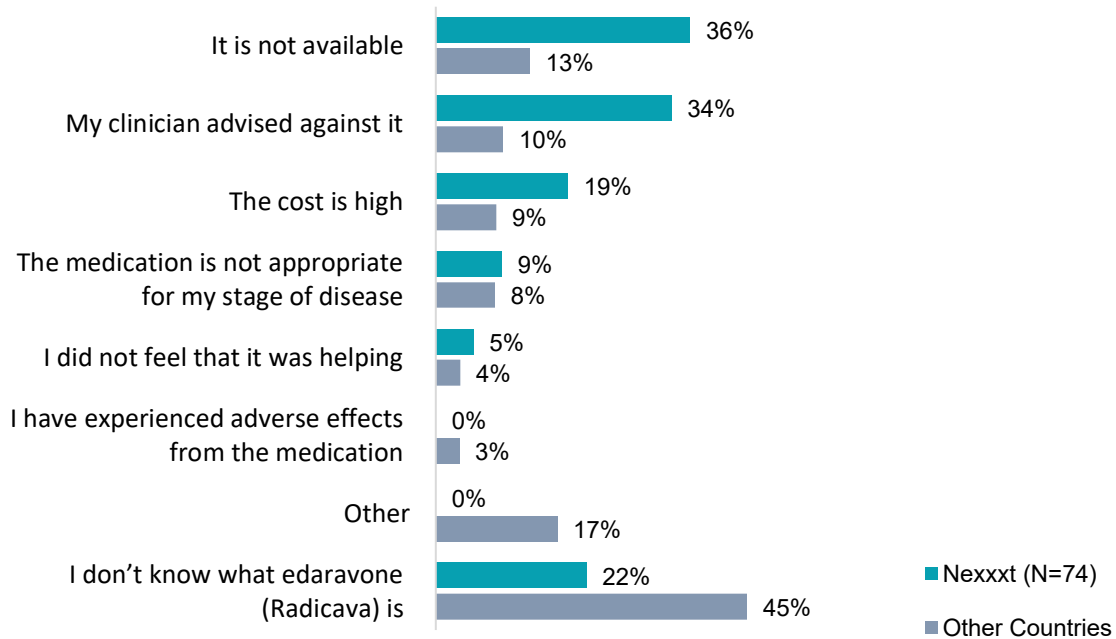
Taking Edaravone (Radicava)

I am taking Edaravone (Radicava)



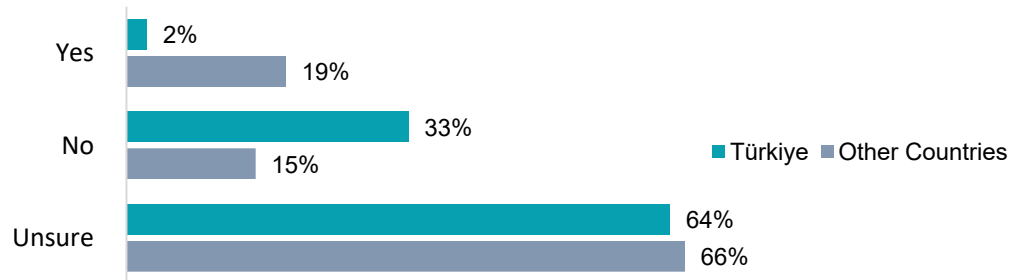
Reasons for Not Taking Edaravone (Radicava)

I am not taking Edaravone (Radicava) because:



Dextromethorphan/quinidine (Nuedexta) is Available

Dextromethorphan/quinidine (Nuedexta) is available in my country.



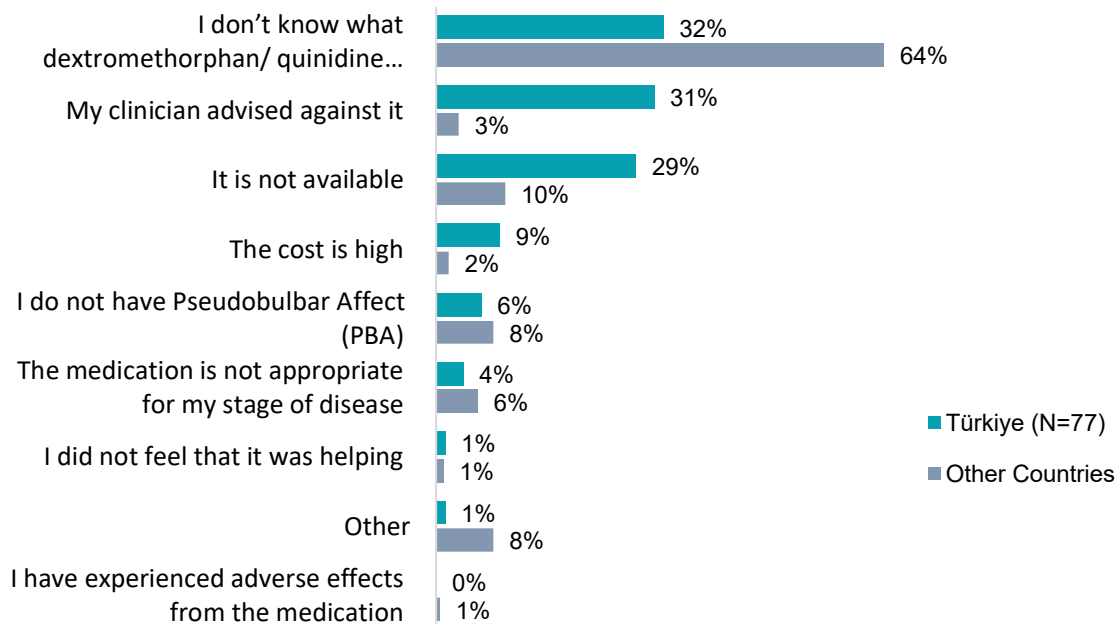
Taking Dextromethorphan/quinidine (Nuedexta)

I am taking Dextromethorphan/quinidine (Nuedexta)



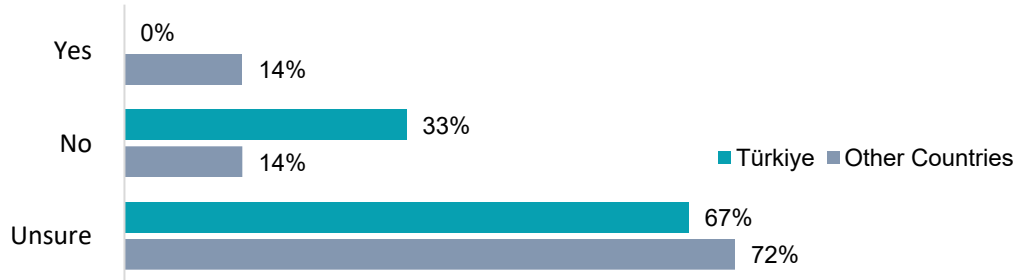
Reasons for Not Taking Dextromethorphan/quinidine (Nuedexta)

I am not taking Dextromethorphan/quinidine (Nuedexta) because:



Mecobalamin (Rozebalamin) is Available

Mecobalamin (Rozebalamin) is available in my country.



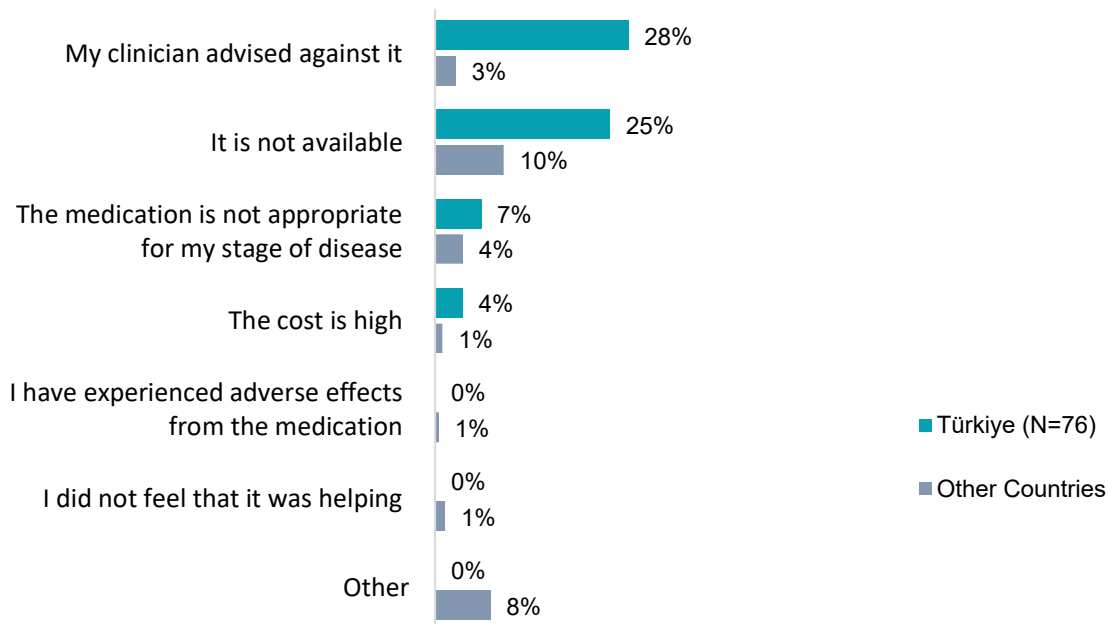
Taking Mecobalamin (Rozebalamin)

I am taking Mecobalamin (Rozebalamin)



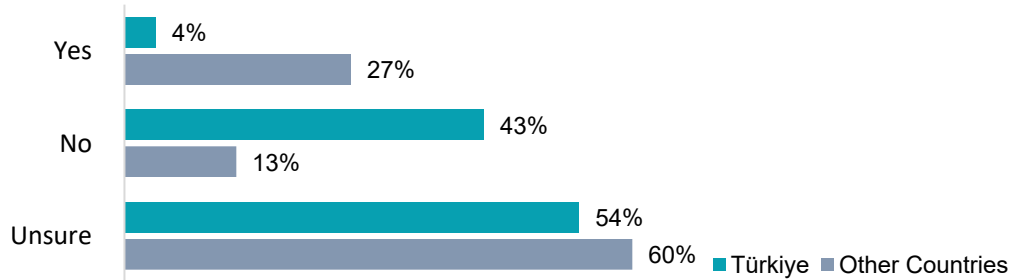
Reasons for Not Taking Mecobalamin (Rozebalamin)

I am not taking Mecobalamin (Rozebalamin) because:



Tofersen (Qalsody) is Available

Tofersen (Qalsody) is available in my country.



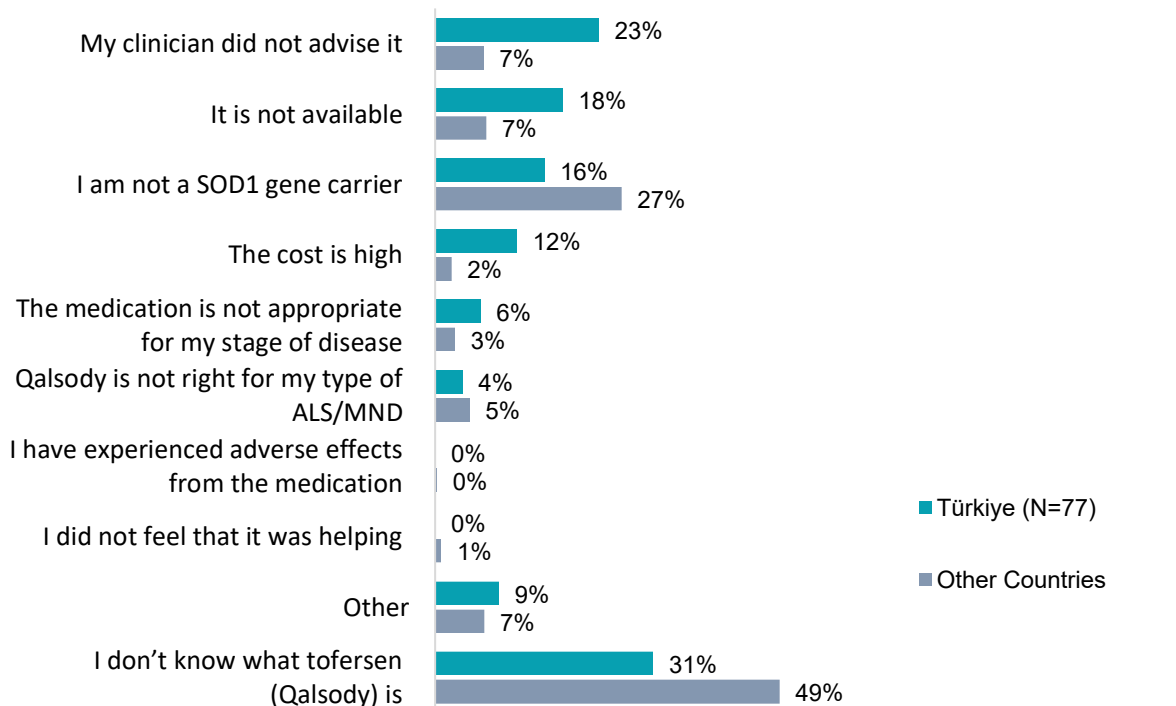
Taking Tofersen (Qalsody)

I am taking Tofersen (Qalsody)



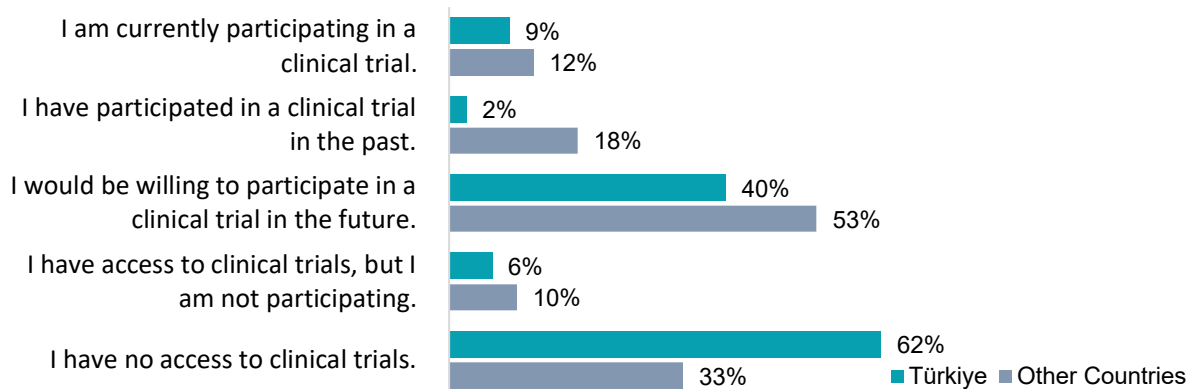
Reasons for Not Taking Tofersen (Qalsody)

I am not taking Tofersen (Qalsody) because:



Clinical Trial Situation

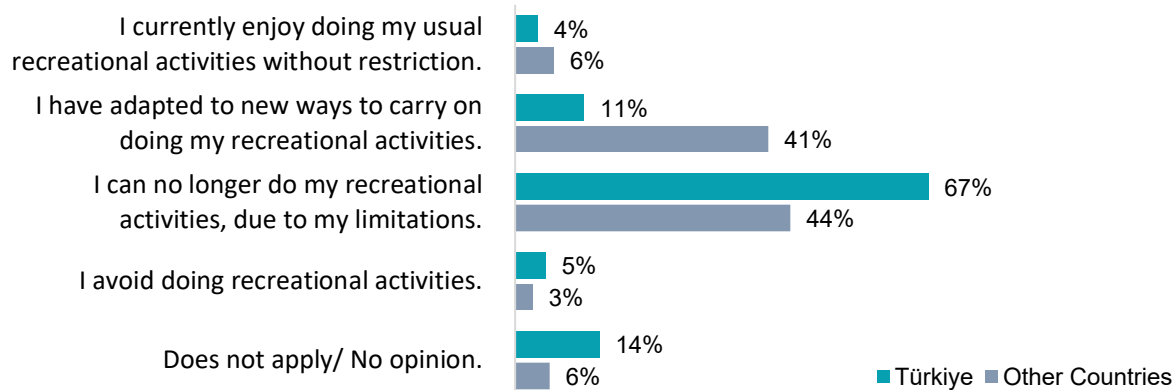
Which of the following statements best describes your situation as it relates to clinical trials?



Activity, Resources, Advance Directives, and Assistive Devices

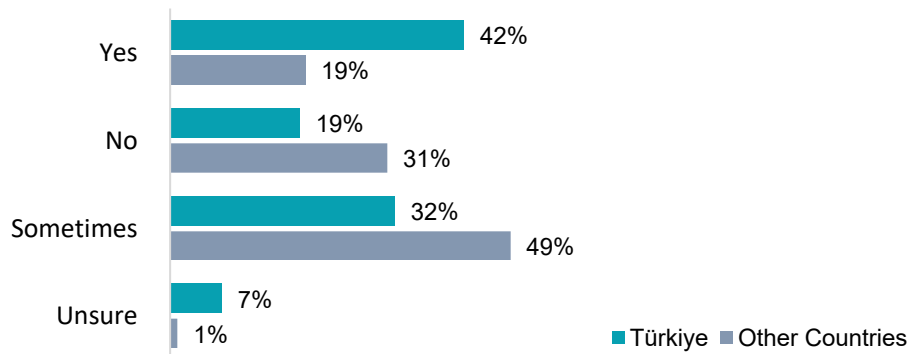
Recreational Involvement

Which of the following statements best describe your active involvement in recreational activities, such as the arts, culture, and sports (making art, playing sport, or enjoying art, music, games, or social events):



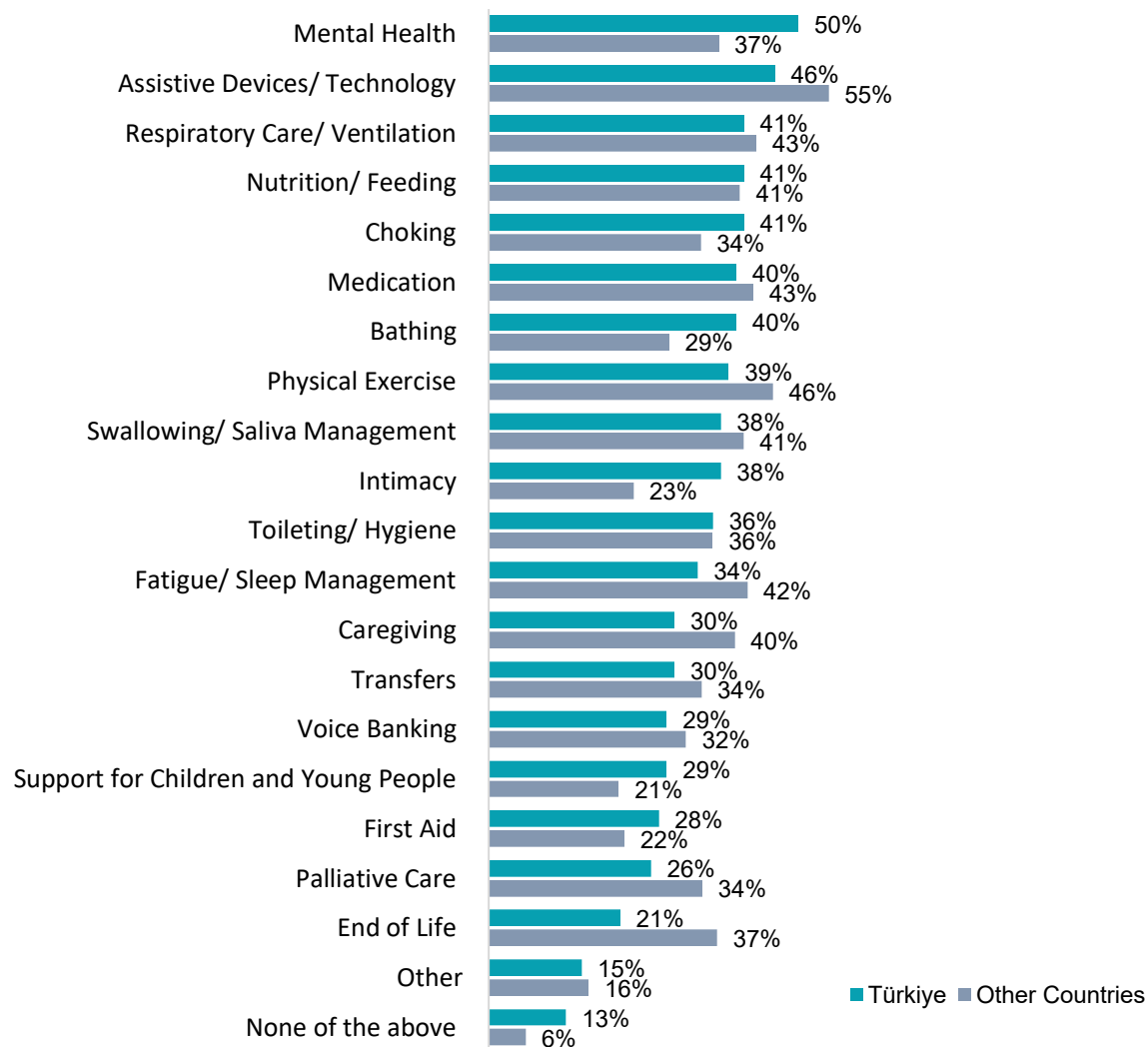
Feels Isolated

As a person living with ALS/MND, I feel isolated.



Interested in Resources Concerning These Topics

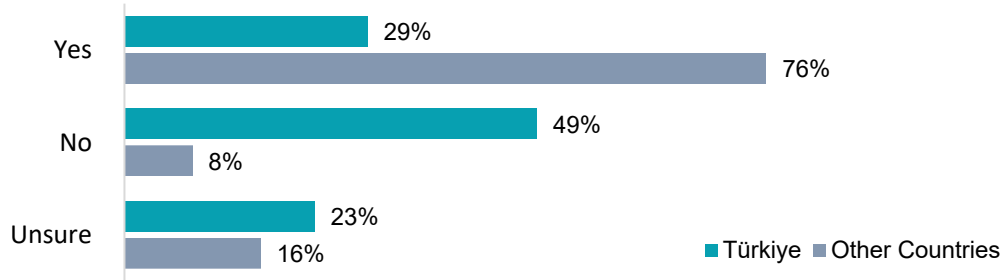
The resources, information, and training I am most interested in are about:





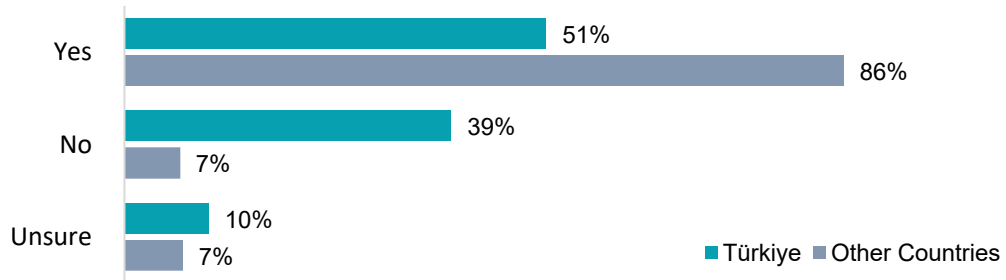
Resources Available in Language of Choice

I can get the resources I need in the language of my choice.



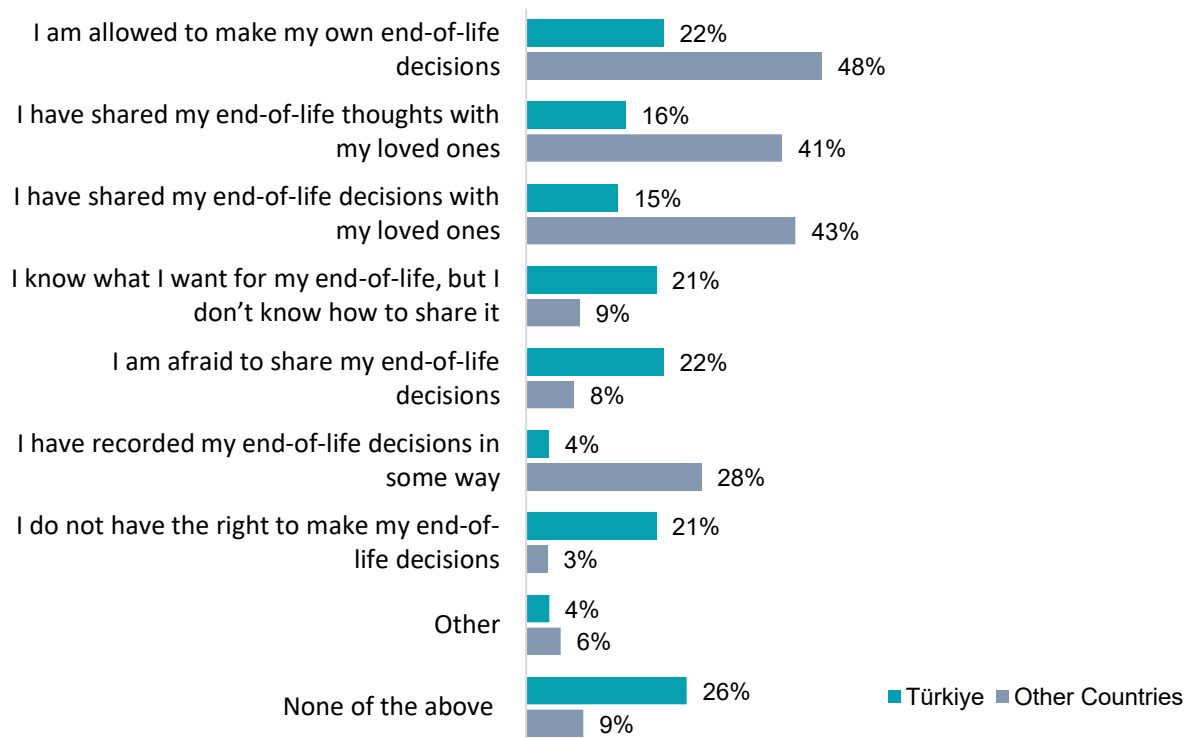
Can Interact with Providers in Language of Choice

I can interact with healthcare providers in the language of my choice.



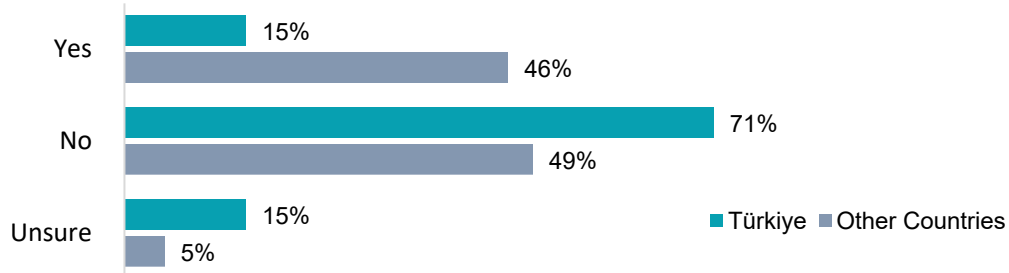
Statements Regarding End-of-Life Decisions

Please select all that apply regarding end-of-life decisions.



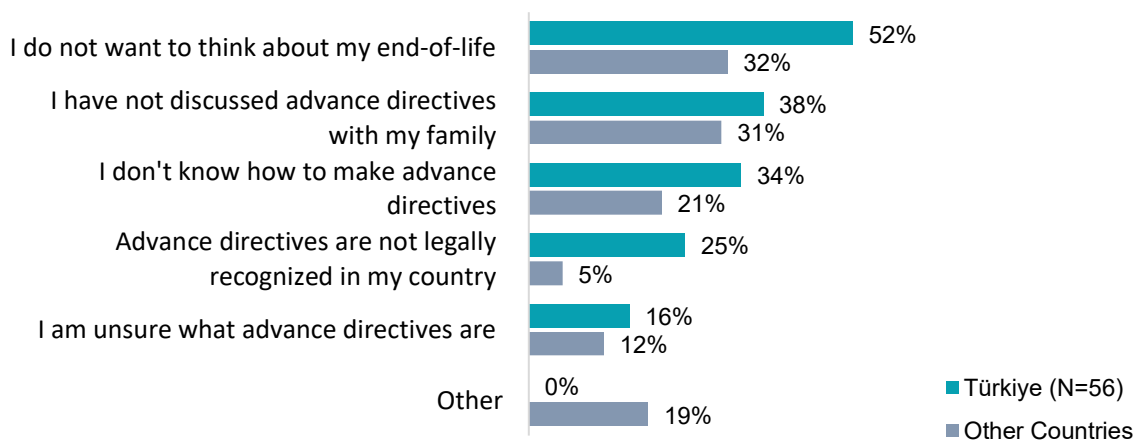
Have Prepared Advance Directives

Advance directives are legal documents that provide instructions for medical care and only go into effect if a person is unable to communicate their wishes. I have prepared advance directives.



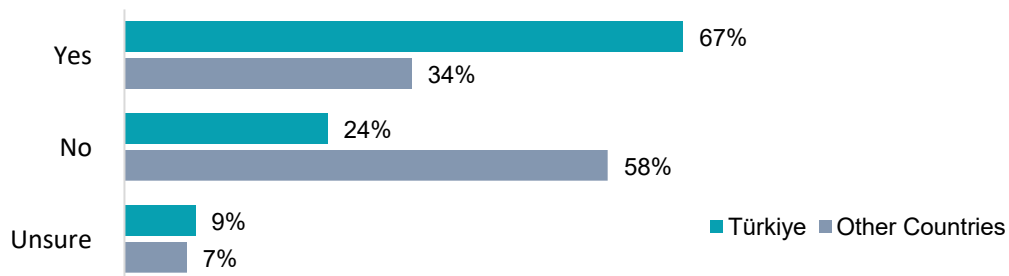
Reasons for Not Preparing Advanced Directives

I have not prepared advance directives because:



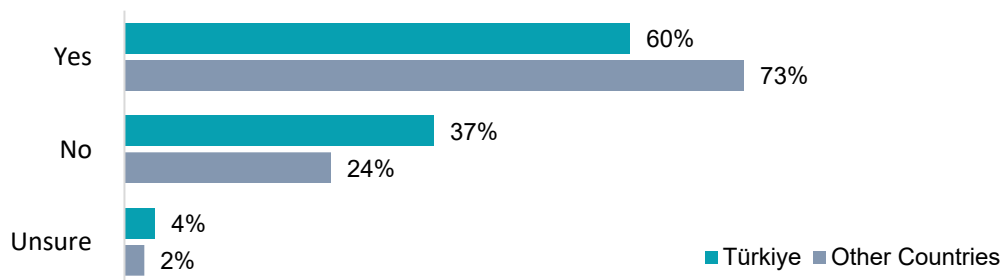
Have Experienced Cognitive Changes

I have experienced cognitive changes (personality changes, impaired judgment, and language difficulties) since my ALS/MND diagnosis.



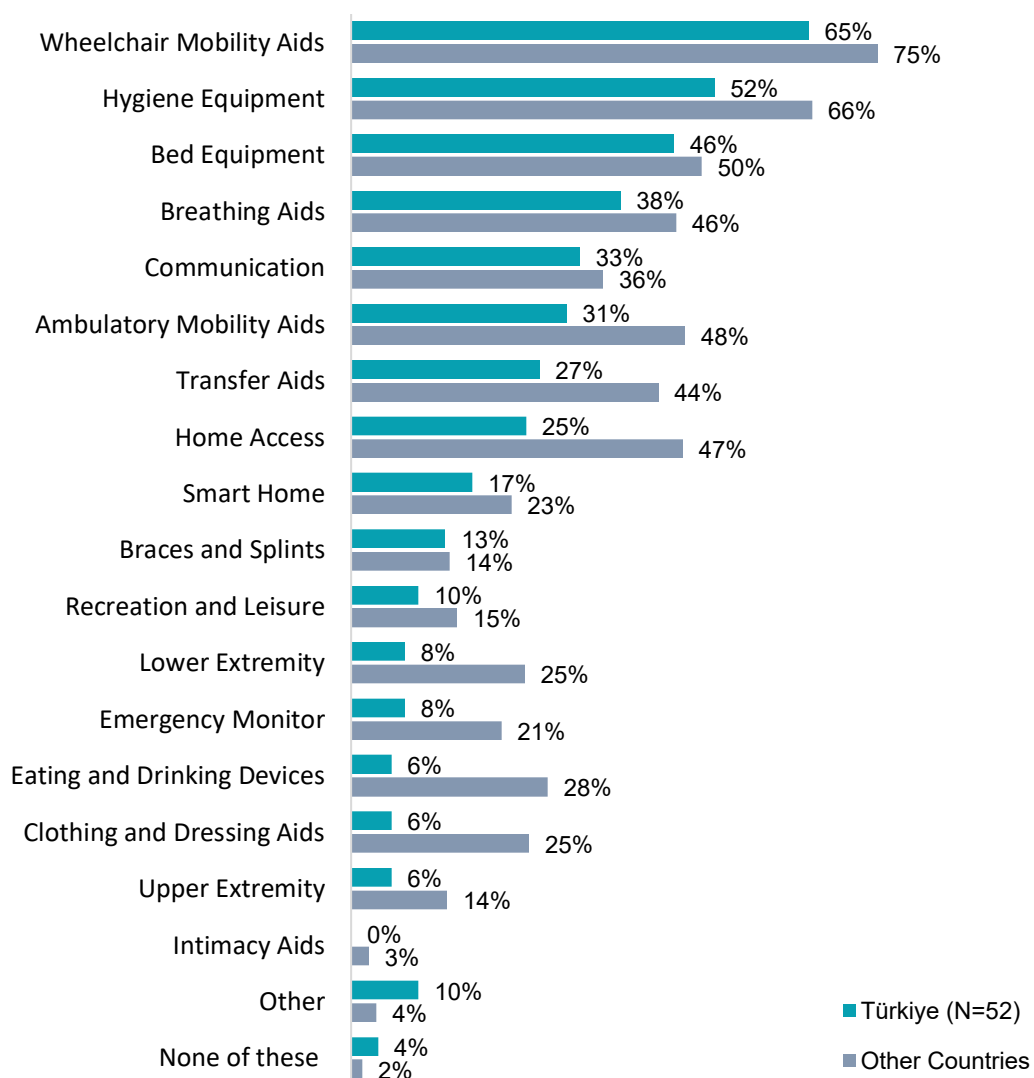
Uses Assistive Device(s)

I use assistive devices that make my life easier.



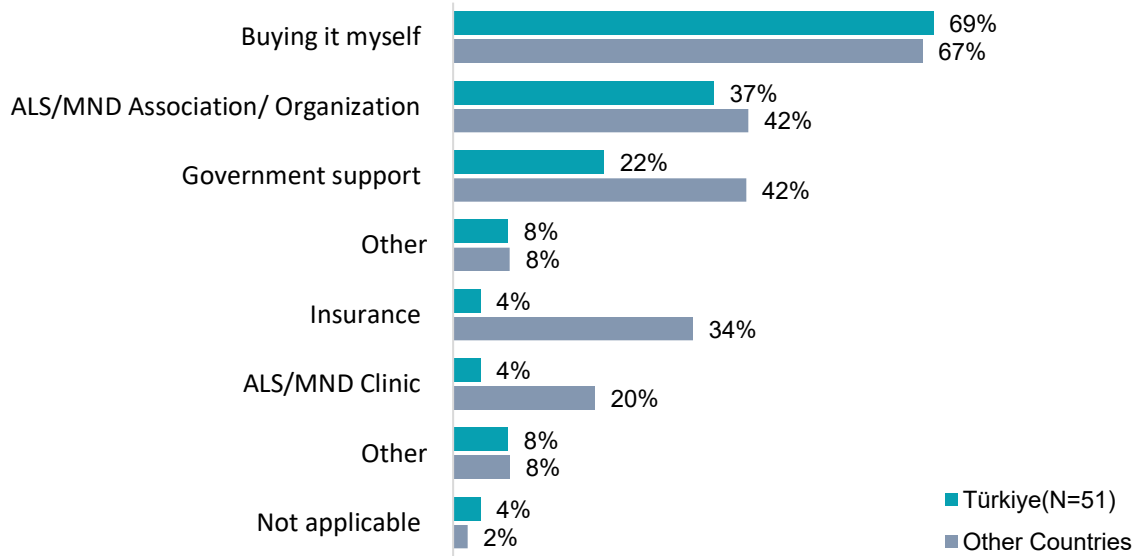
Assistive Devices Used

I use the following assistive devices to make my life easier:



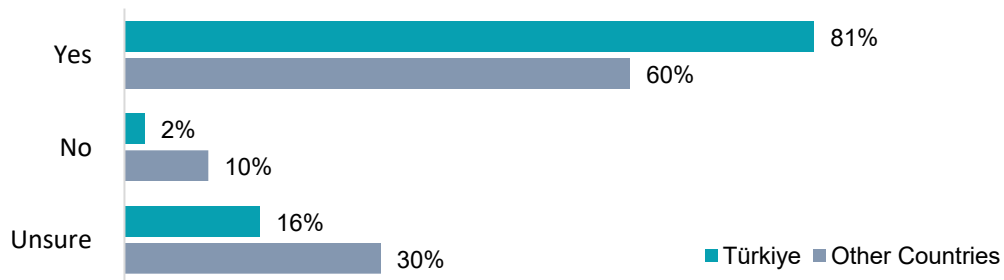
Assistive Devices Procured via...

My assistive devices are procured via:



Would Attend Global Virtual Groups

If the International Alliance of ALS/MND Associations had global virtual support groups for people living with ALS/MND, I would attend.



Young People in Household

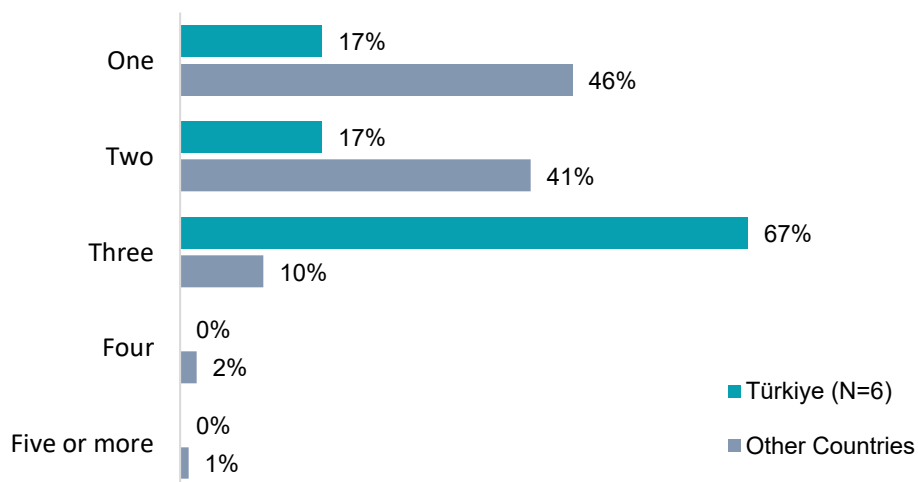
Young Caregivers Live in the Home

There are young caregivers (under 18 years of age) in the home where I live.



Number of Young People in the Home

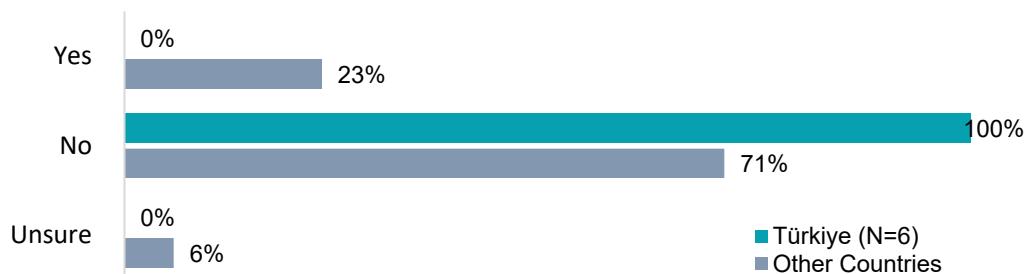
How many young people live in the home?



	Türkiye	Other Countries
Average # of Young People	2.5	1.7
Average # of Young People	3	2

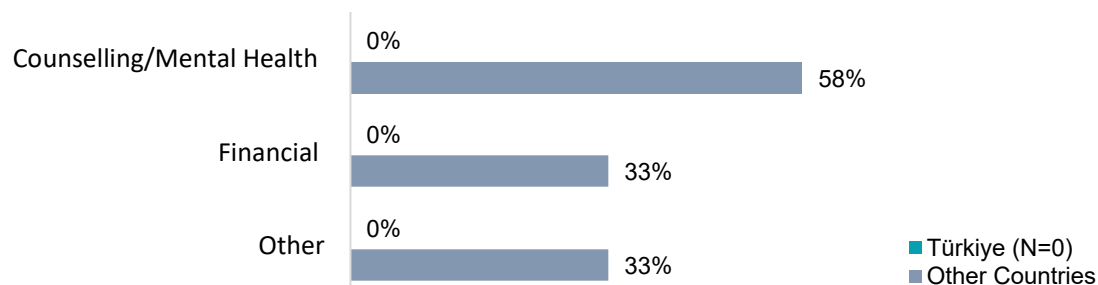
Support Received for Children/Young People

I receive support for children and young people.



Type of Support Received for Children/Young People

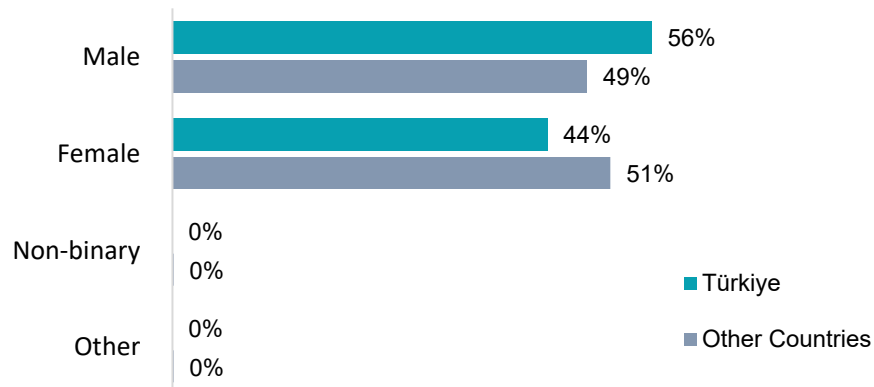
What type of support do you receive for them?



Demographics

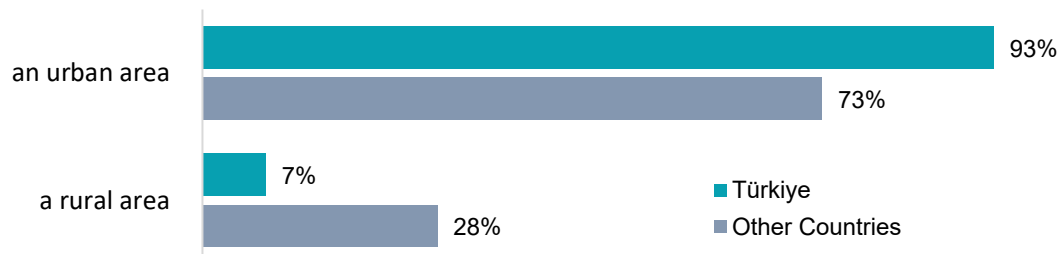
Gender

Gender:



Urban/Rural

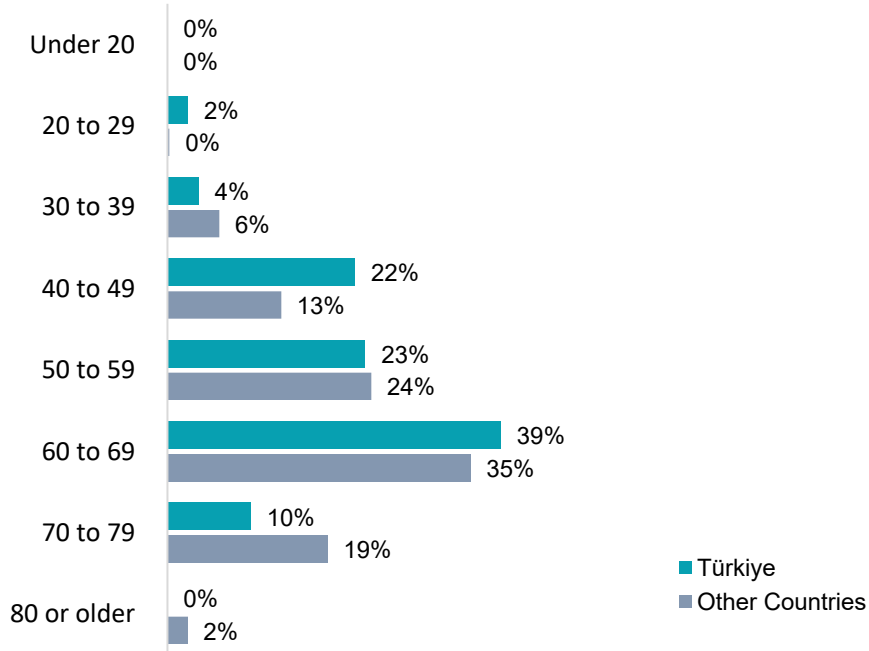
I consider my home to be in:





Age

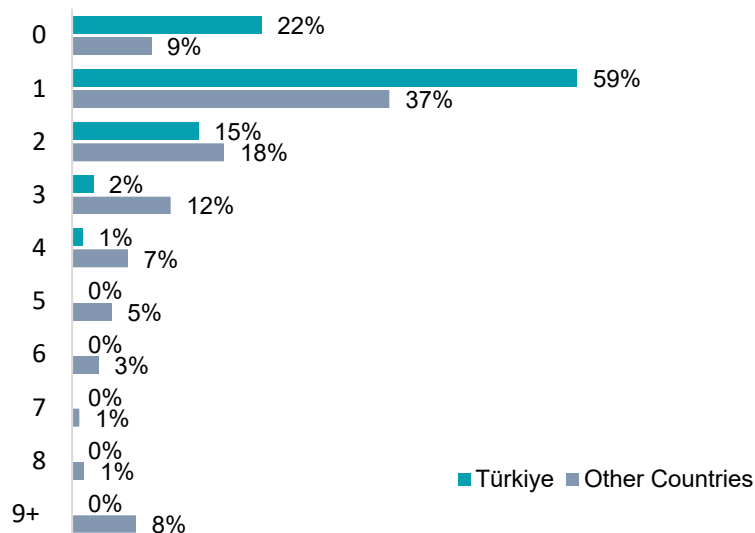
What is your age?



	Türkiye	Other Countries
Estimated Average Age	57.2	60.4

Number of Informal/Non-Professional Caregivers

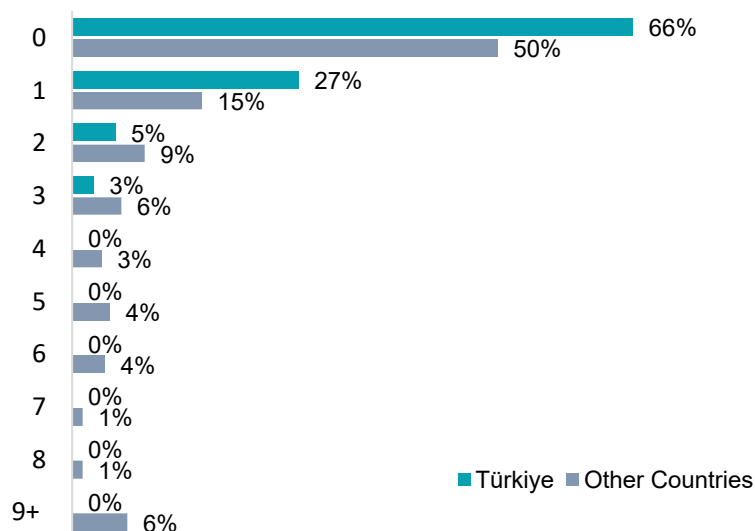
I have ... informal/non-professional caregivers (family, friends).



	Türkiye	Other Countries
Est. Avg. # of Informal Caregivers	1.0	2.8

Number of External/Professional Caregivers

I have ... external/professional caregivers.



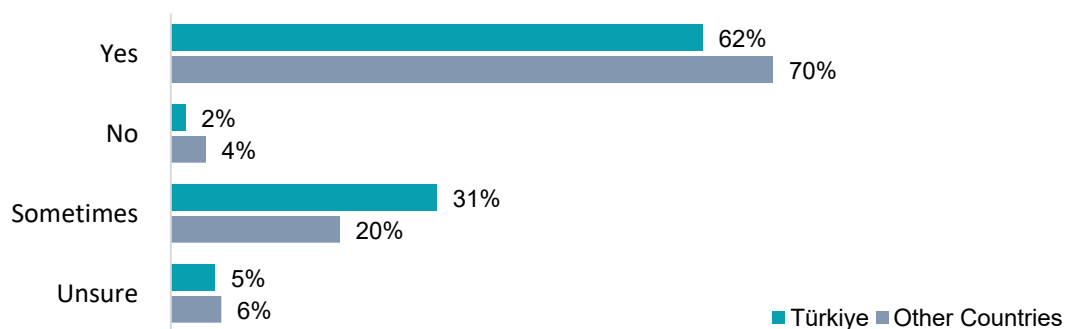
	Türkiye	Other Countries
Est. Avg. # of Informal Caregivers	0.4	2.0

Current or Former Caregiver of a Person Living with ALS/MND [Türkiye, N = 58 Other Countries, N = 778]

Core Rights

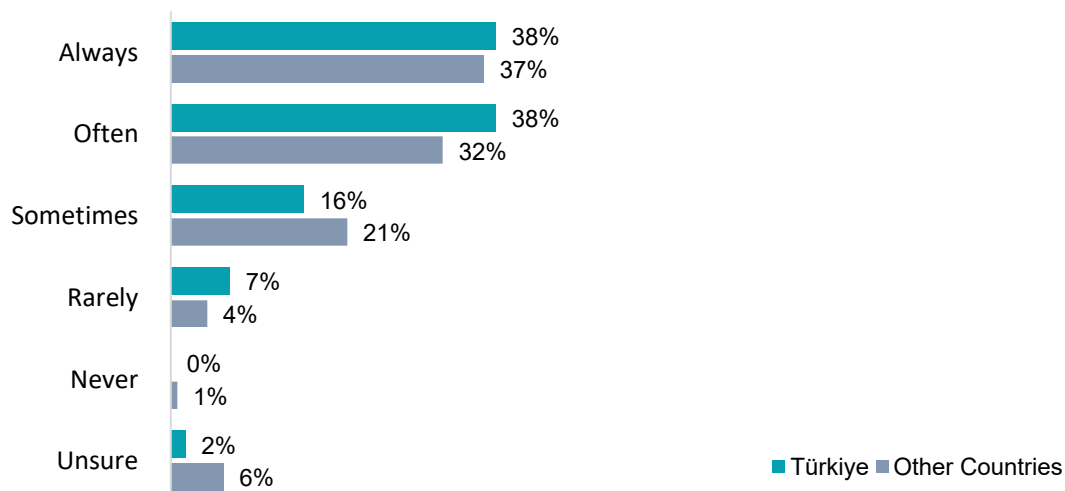
Treated with Respect

I am treated with respect as a caregiver.



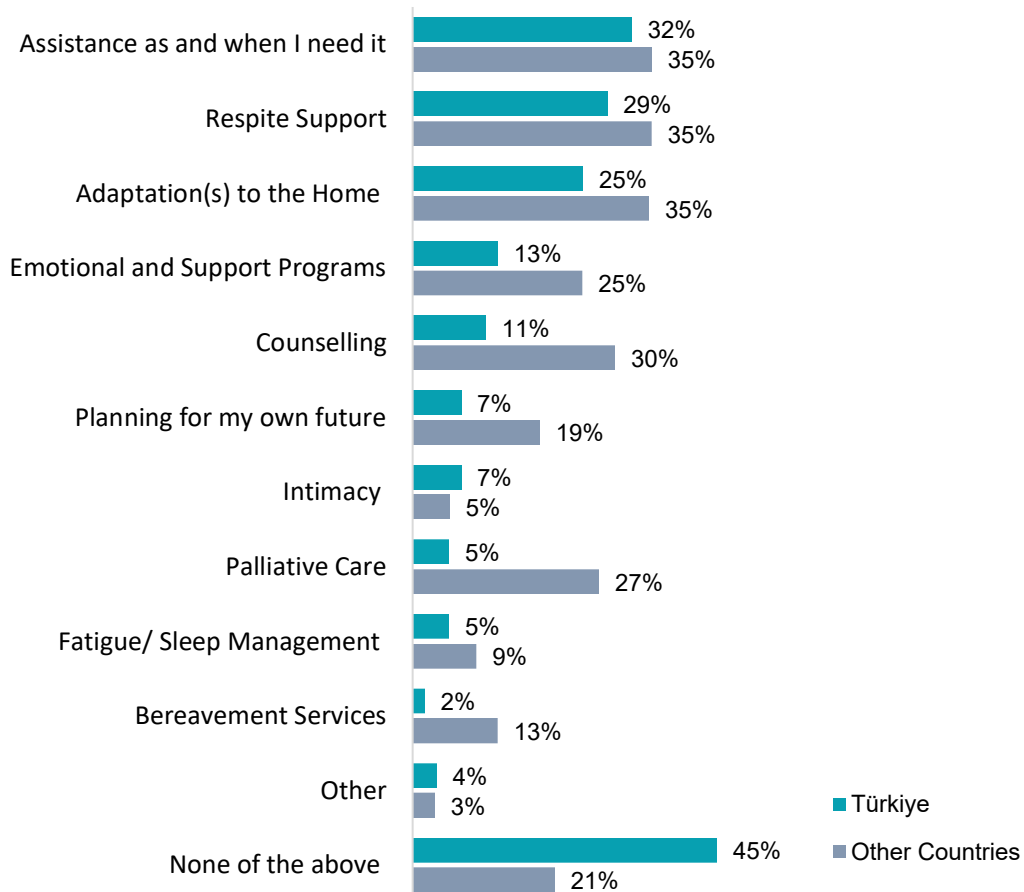
Frequency of Being Accepted as Knowledgeable

I am accepted by all as knowledgeable in managing the care of my person living with ALS/MND.



Receive Support in Areas:

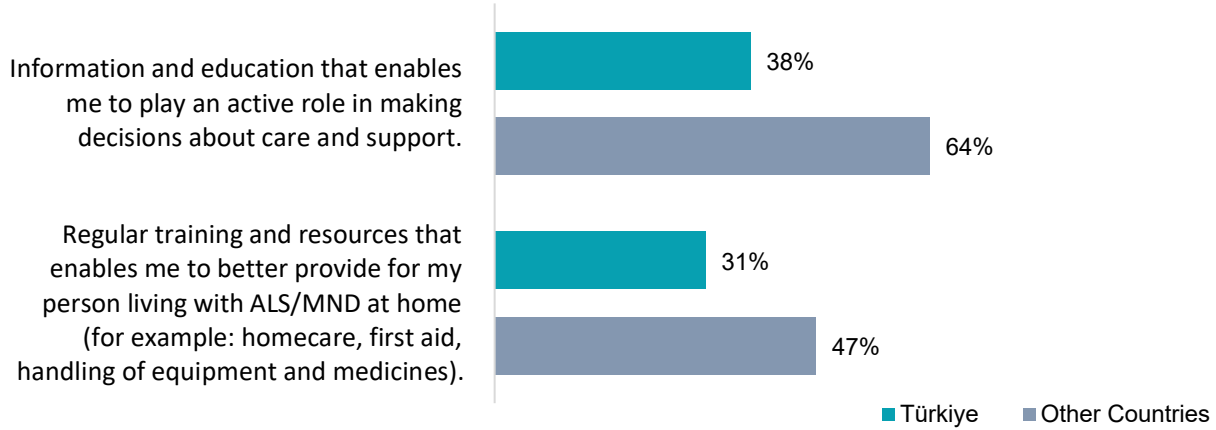
I am receiving support in the following areas:





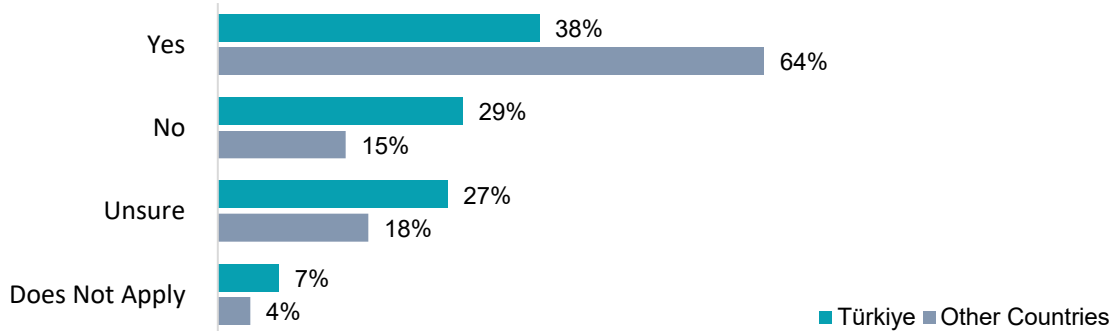
Have Access to...

Summary of those saying “Yes”



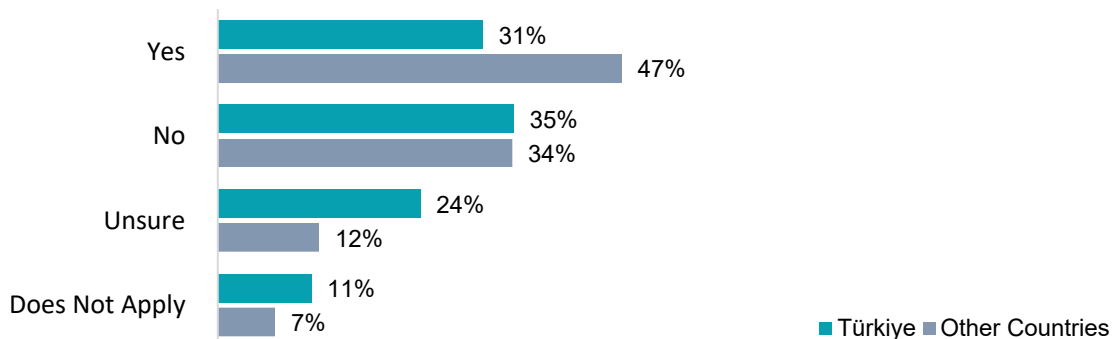
Have Access to Information/ Education

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



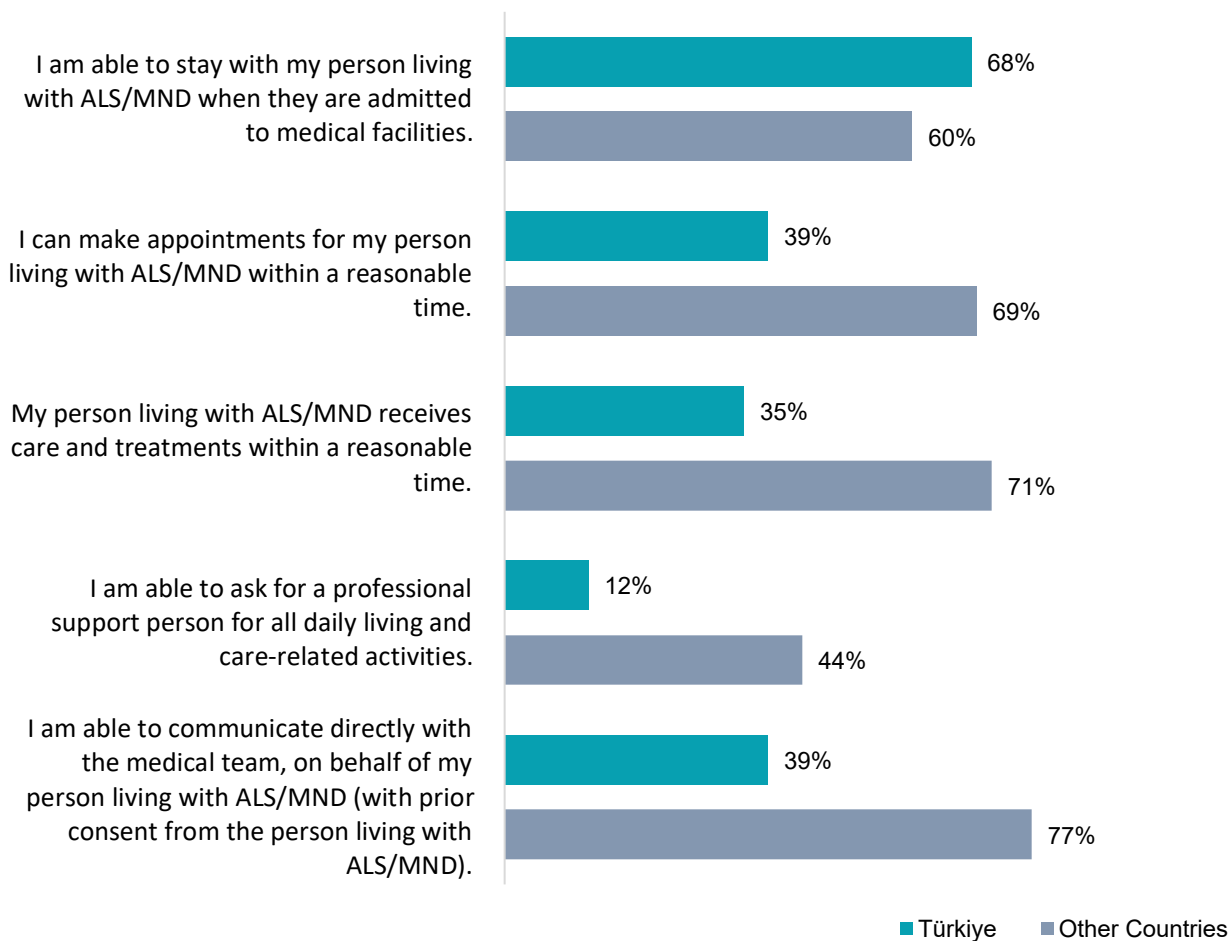
Have Access to Training and Resources

I have access to regular training and resources that enables me to better provide for my person living with ALS/MND at home (for example: homecare, first aid, handling of equipment and medicines).



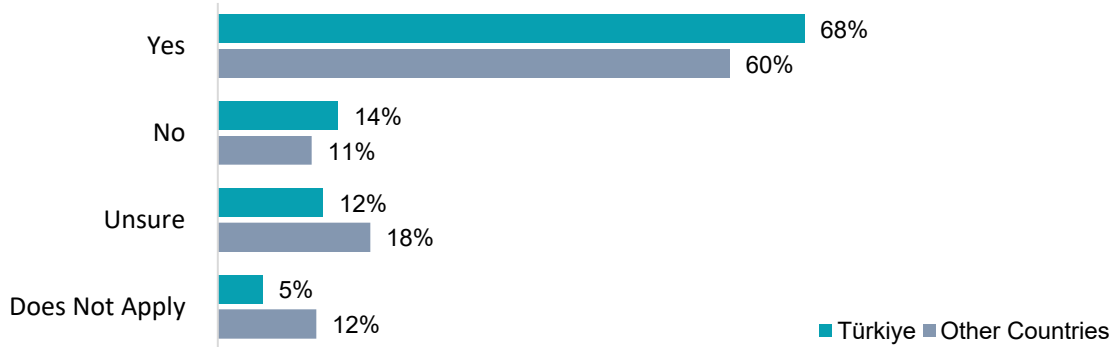
Agreement with Statements about Your Person with ALS/MND

Summary of those saying “Yes”



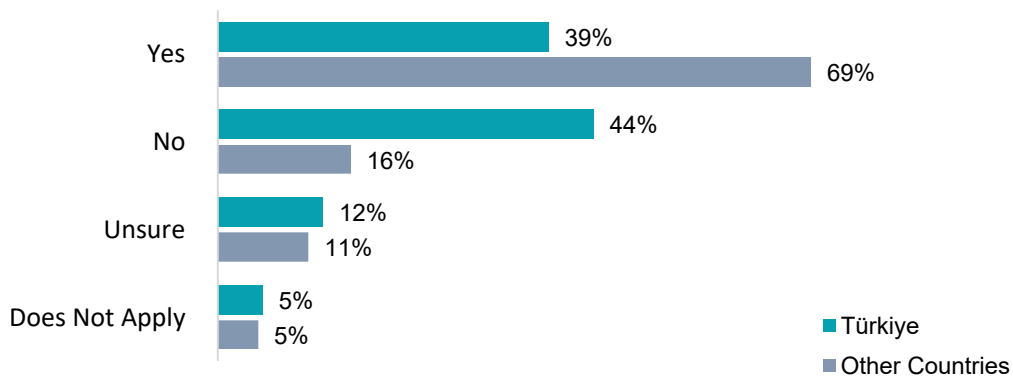
Able to Stay with My Person when they are Admitted

I am able to stay with my person living with ALS/MND when they are admitted to medical facilities.



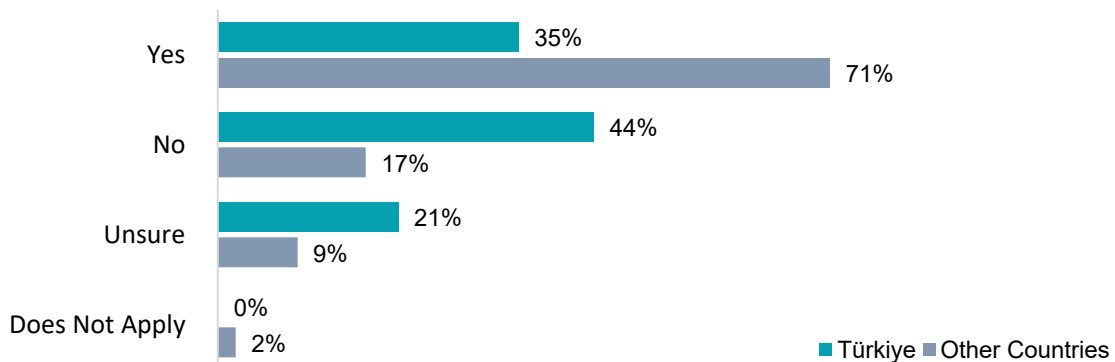
Can Make Appointments within a Reasonable Time

I can make appointments for my person living with ALS/MND within a reasonable time.



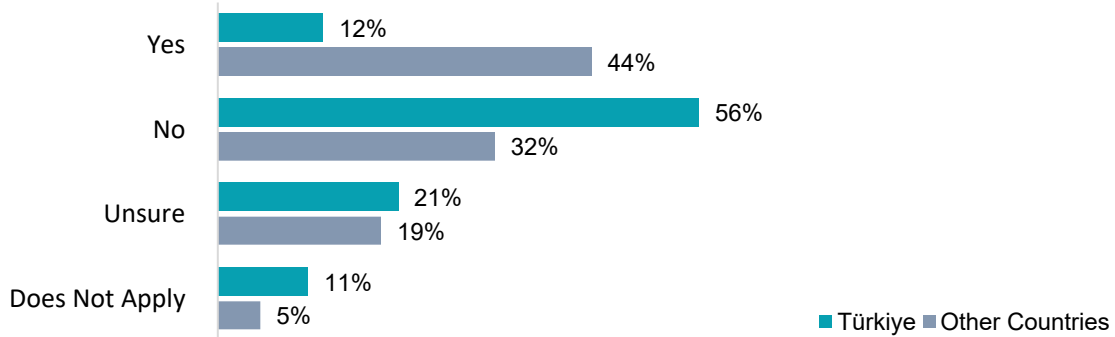
Receives Care and Treatment within a Reasonable Time

My person living with ALS/MND receives care and treatments within a reasonable time.



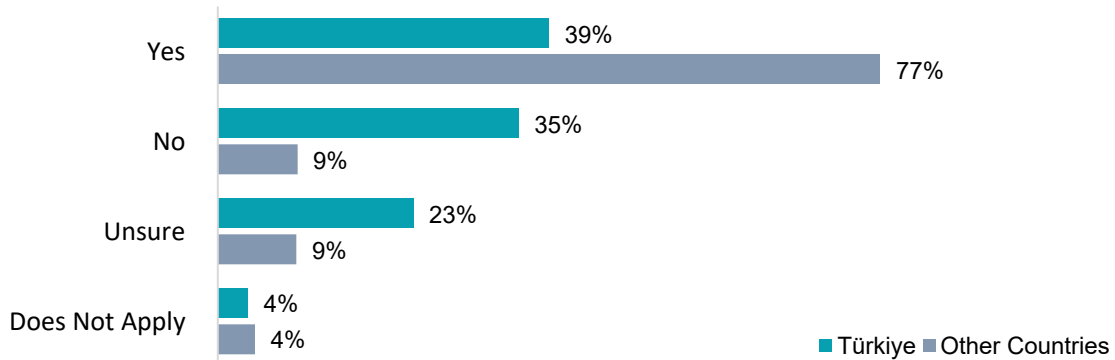
Able to Ask for a Professional Support Person

I am able to ask for a professional support person for all daily living and care-related activities.



Able to Communicate Directly with Medical Team

I am able to communicate directly with the medical team, on behalf of my person living with ALS/MND (with prior consent from the person living with ALS/MND).





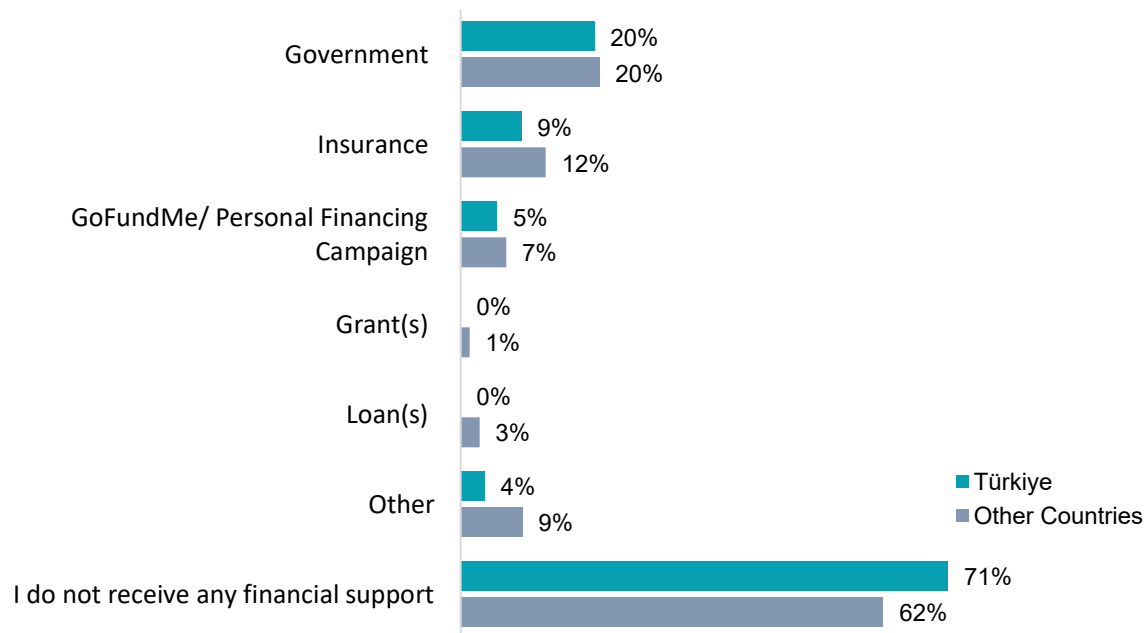
Economic Situation has been Affected

ALS/MND has affected my economic situation.



Source(s) of Financial Support

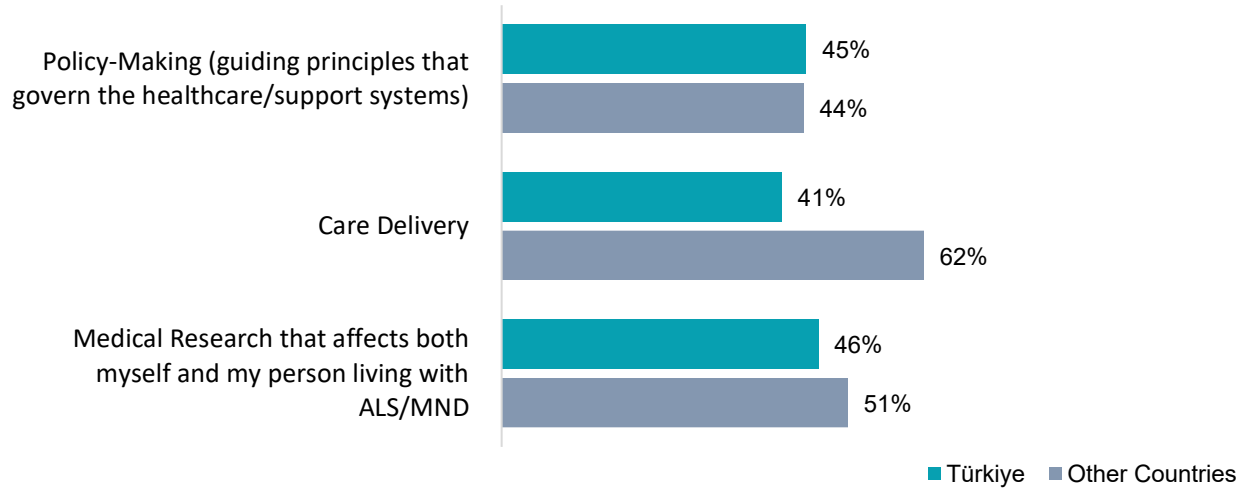
As a caregiver, I receive financial support from:





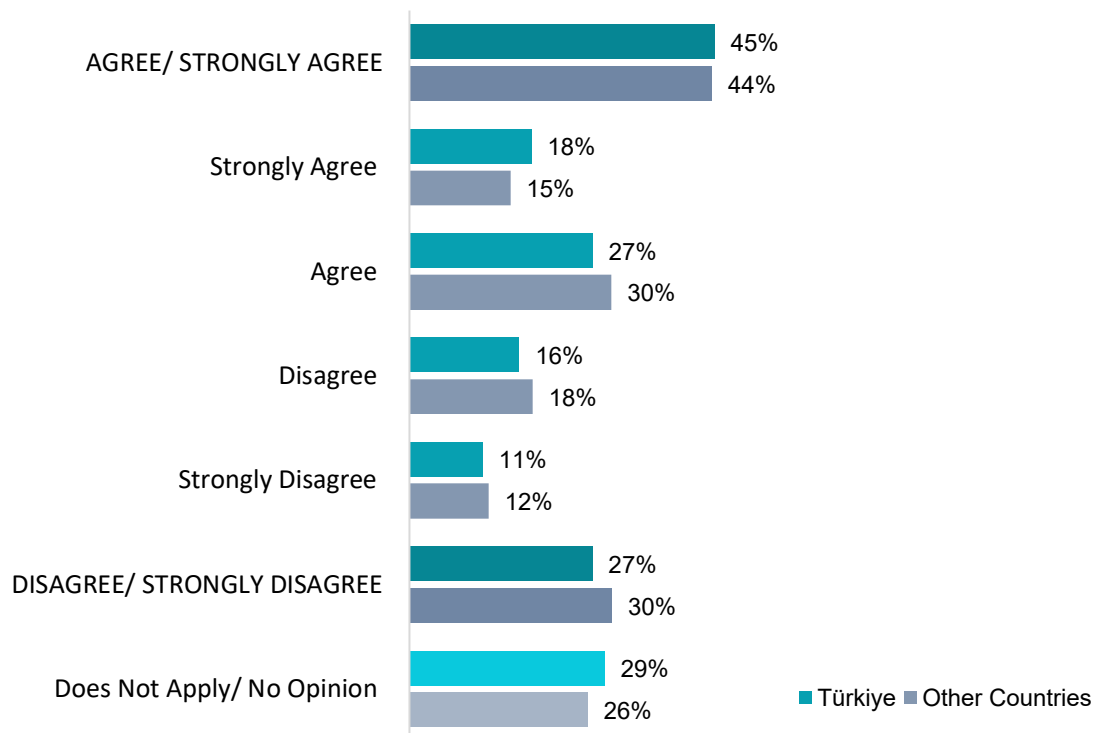
Able to Provide Input (Advocacy) on:

Summary of those who Agree or Agree Strongly



Able to Provide Input (Advocacy) on:

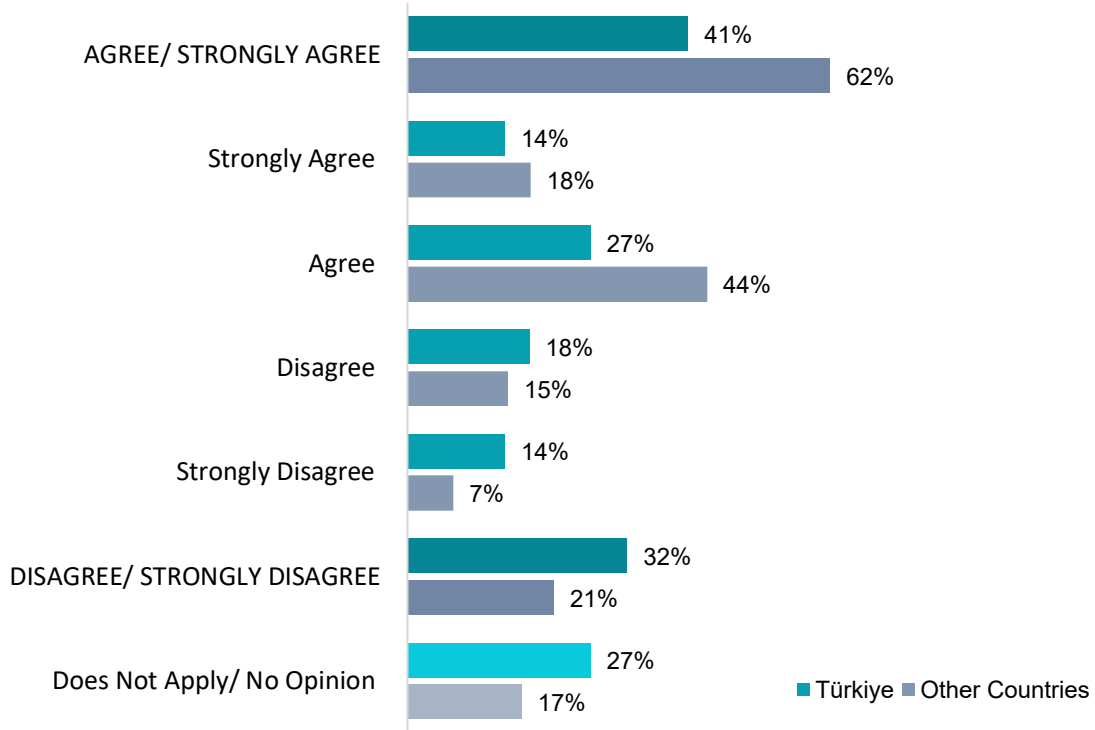
Policy-Making (guiding principles that govern the healthcare/support systems)





Able to Provide Input (Advocacy) on:

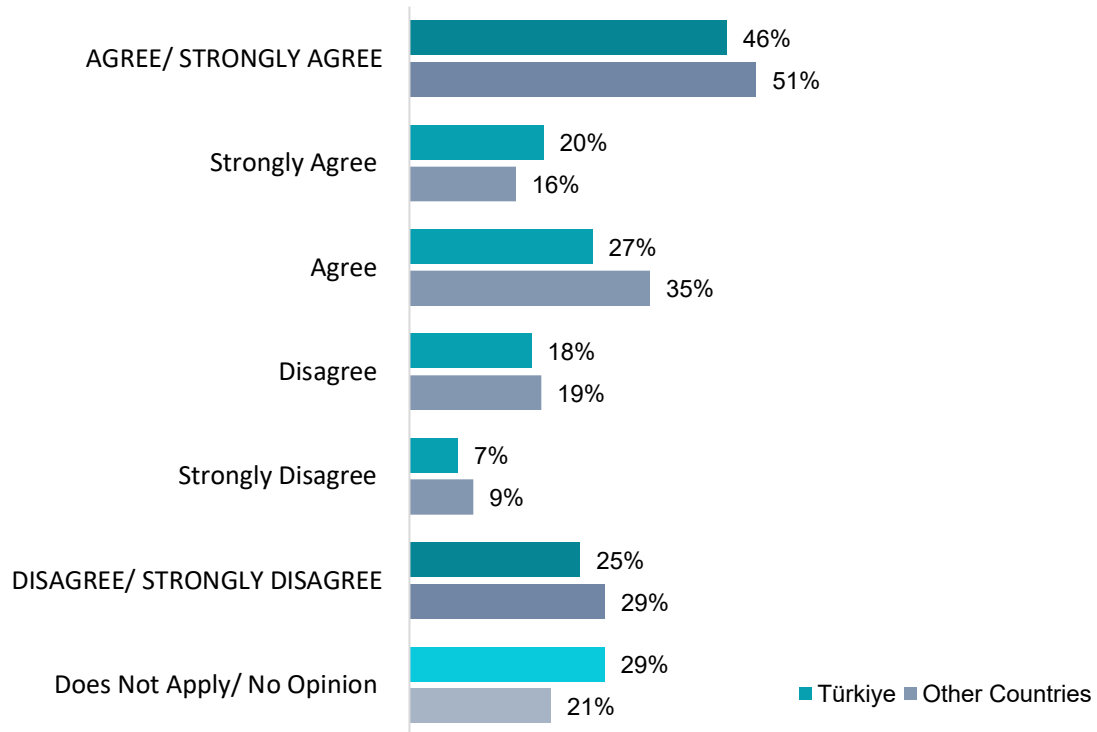
Care Delivery





Able to Provide Input (Advocacy) on:

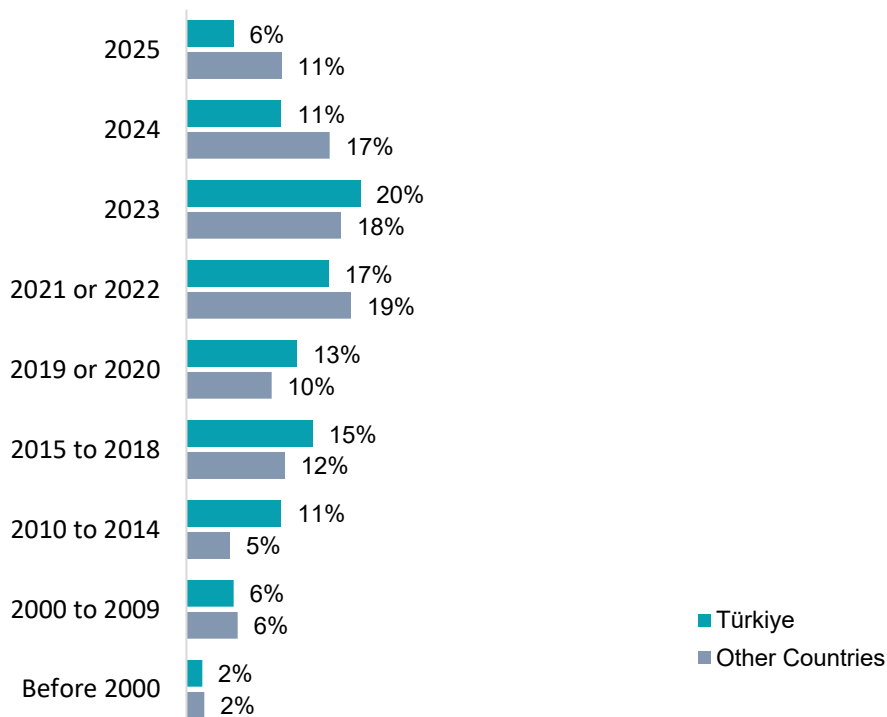
Medical Research that affects both myself and my person living with ALS/MND



Diagnosis of Person with ALS/MND

Year of Diagnosis

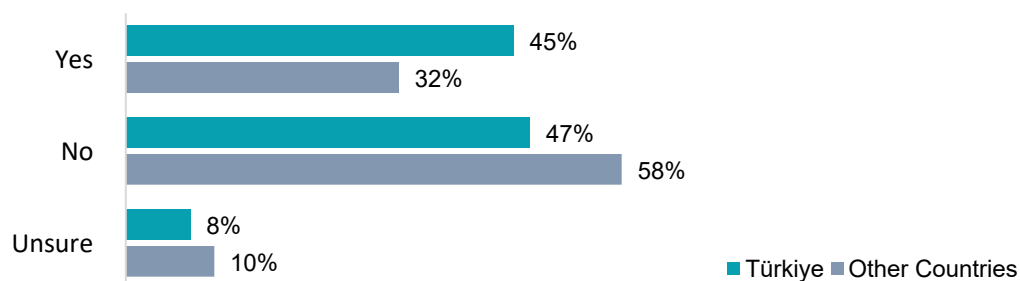
My person living with ALS/MND was diagnosed with ALS/MND in... Year:



	Türkiye	Other
Average Year	2019	2020
Median Year	2022	2022

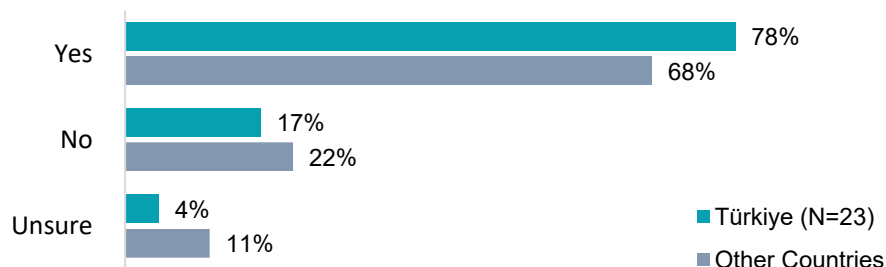
Caregiver Noticed Symptoms Before Their Person

I noticed the first signs and symptoms before my person living with ALS/MND did.



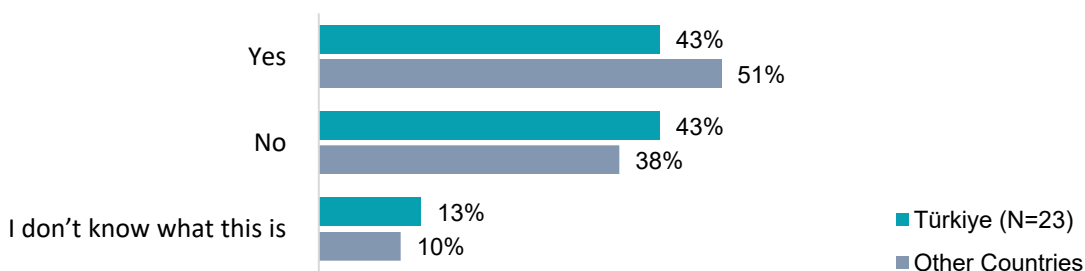
Interested in Knowing Possible Genetic Cause

I am interested in knowing whether there is a genetic cause that contributed to my person's ALS/MND.



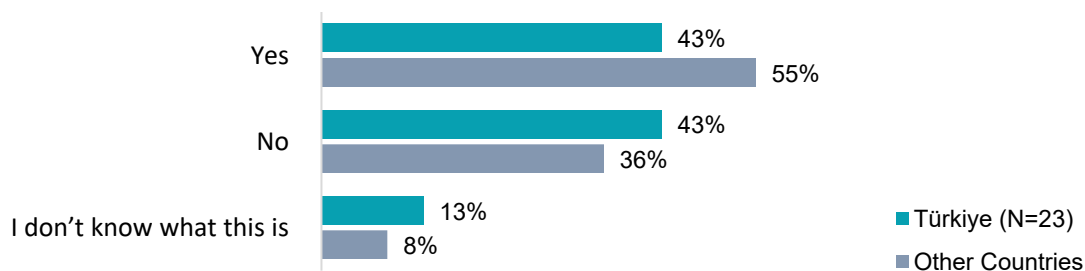
Encourages Blood Relatives to Consider Genetic Counselling

I encourage the blood relatives of my person living with ALS/MND to consider genetic counselling.



Encourages Blood Relatives to Consider Genetic Testing

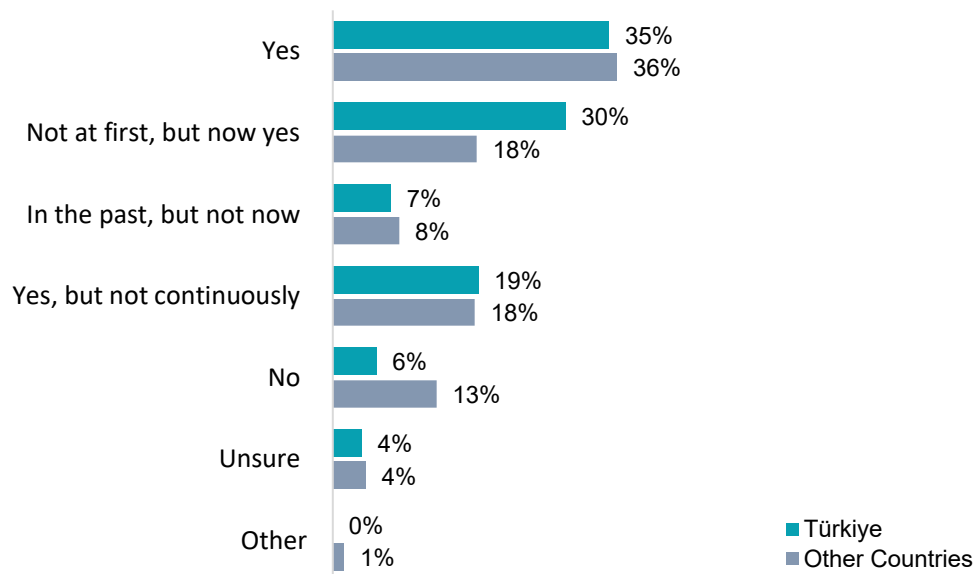
I encourage the blood relatives of my person living with ALS/MND to consider whether genetic testing is right for them.



Impact, Support, Caregiving Tasks, and Resources

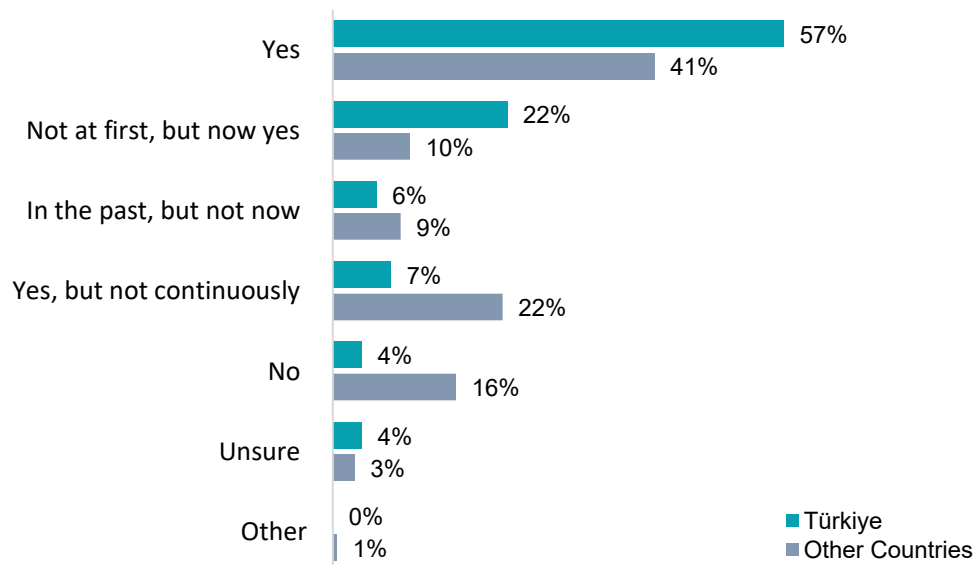
Negative Impact on Caregiver's Physical Health

Being a caregiver has had a negative impact on my physical health.



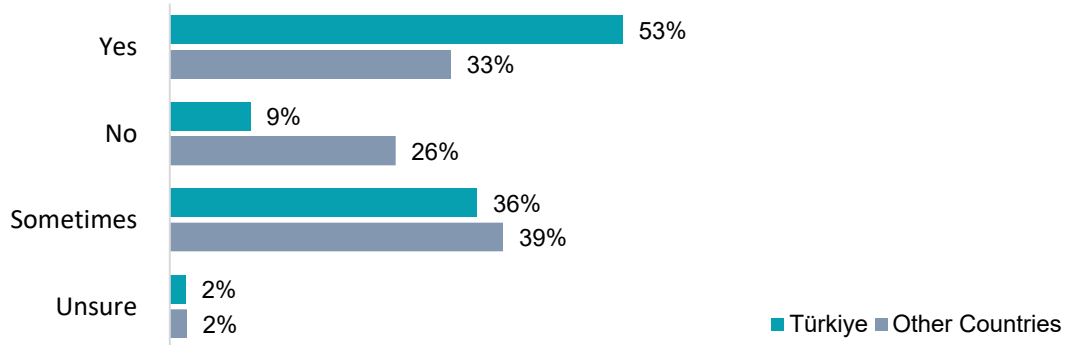
Negative Impact on Caregiver's Mental Health

Being a caregiver has had a negative impact on my mental health.



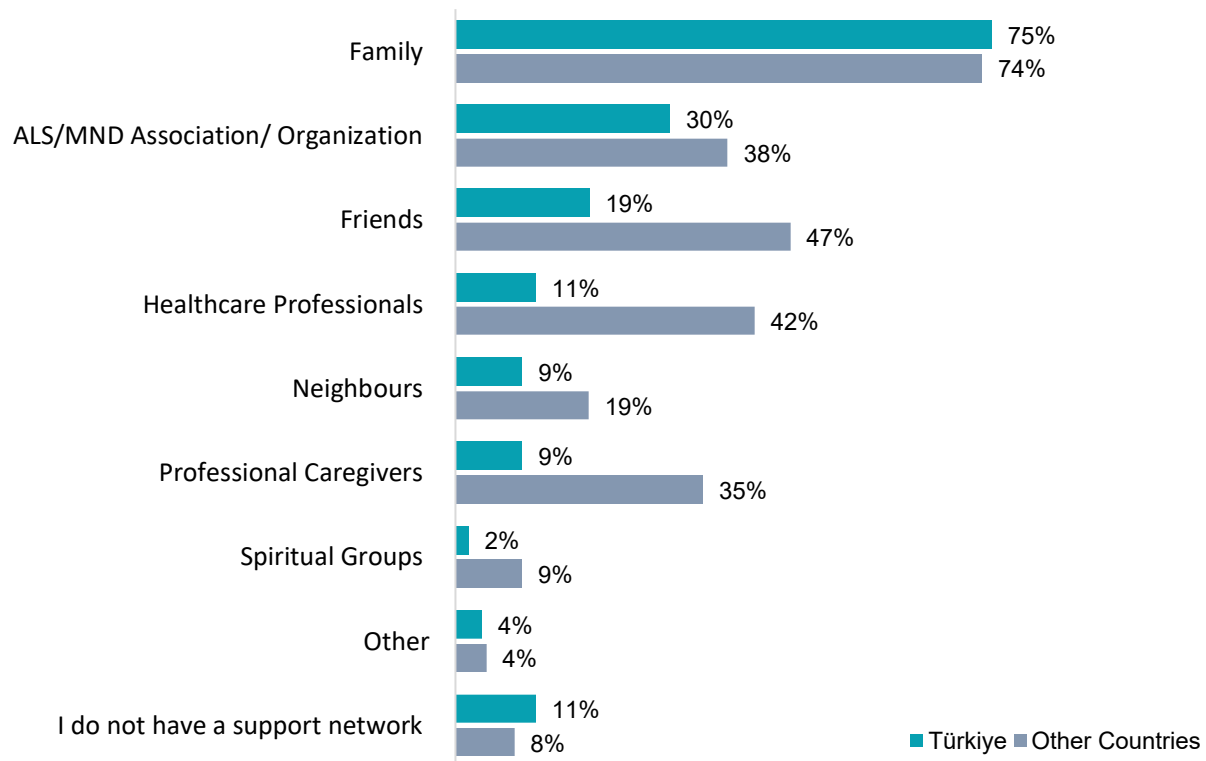
Caregiver Feels Isolated

As a caregiver, I feel isolated.



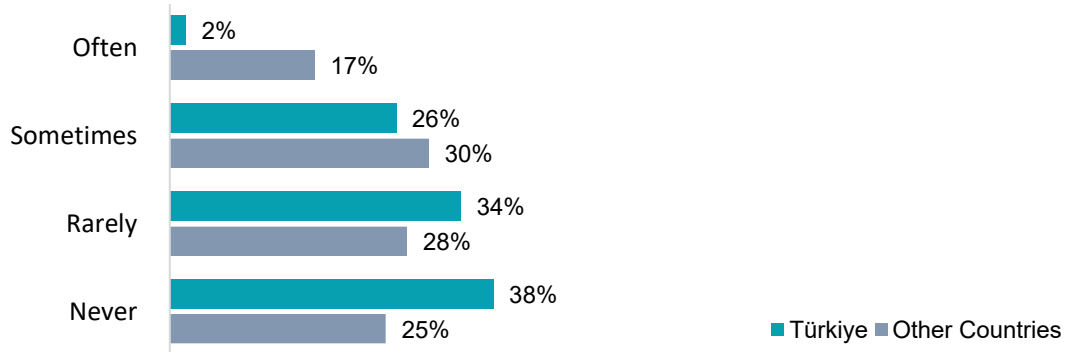
People in Caregiver's Support Network

My daily support network includes:



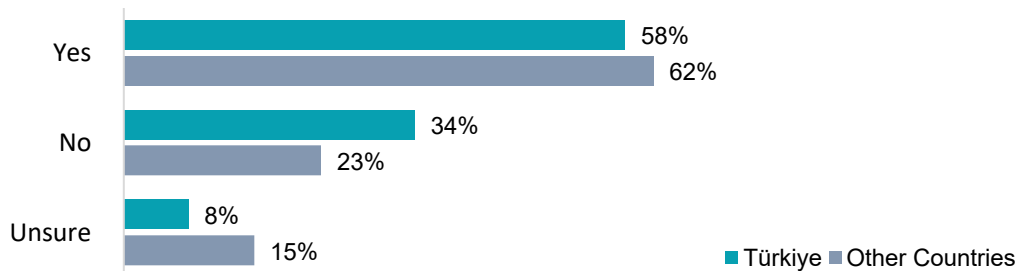
Frequency of Participating in Activity or Hobby

I participate in an activity or hobby just for myself, outside of caregiving.



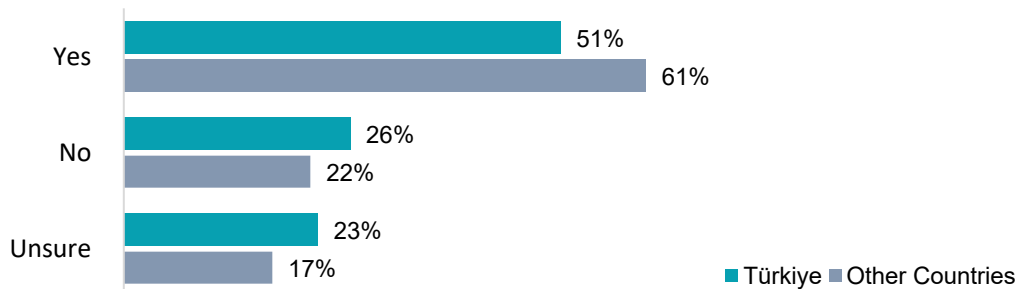
Has Access to an Association which Provides Supports

I have access to an ALS/MND Association/Organization which provides care-related supports.



Caregiver has Performed Healthcare Professional's Task(s)

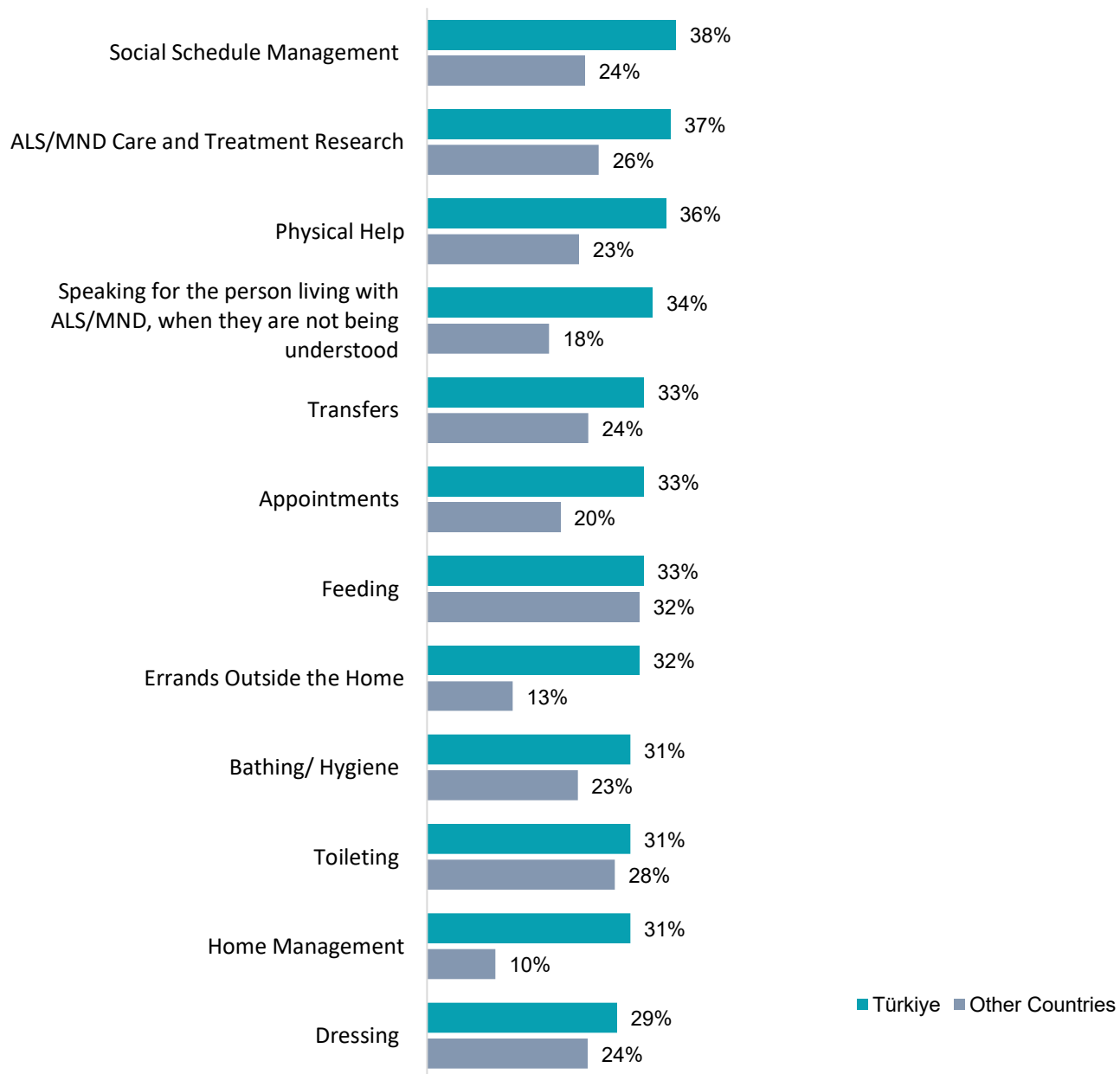
As a caregiver, I have had to perform a task that is normally done by a healthcare professional.



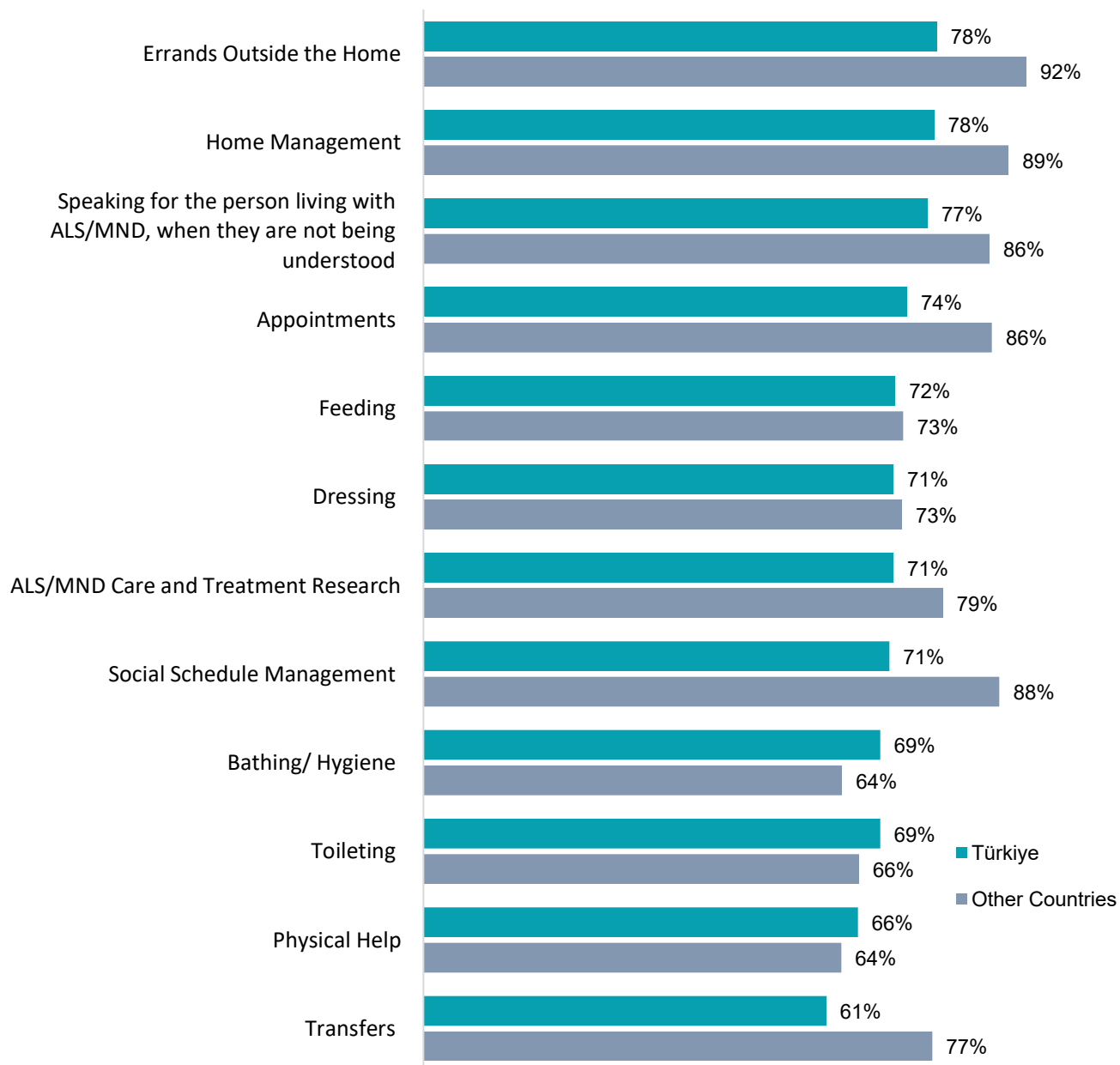
Person Who Performs Ongoing Tasks

At the present time, who performs these tasks on a regular, ongoing basis?

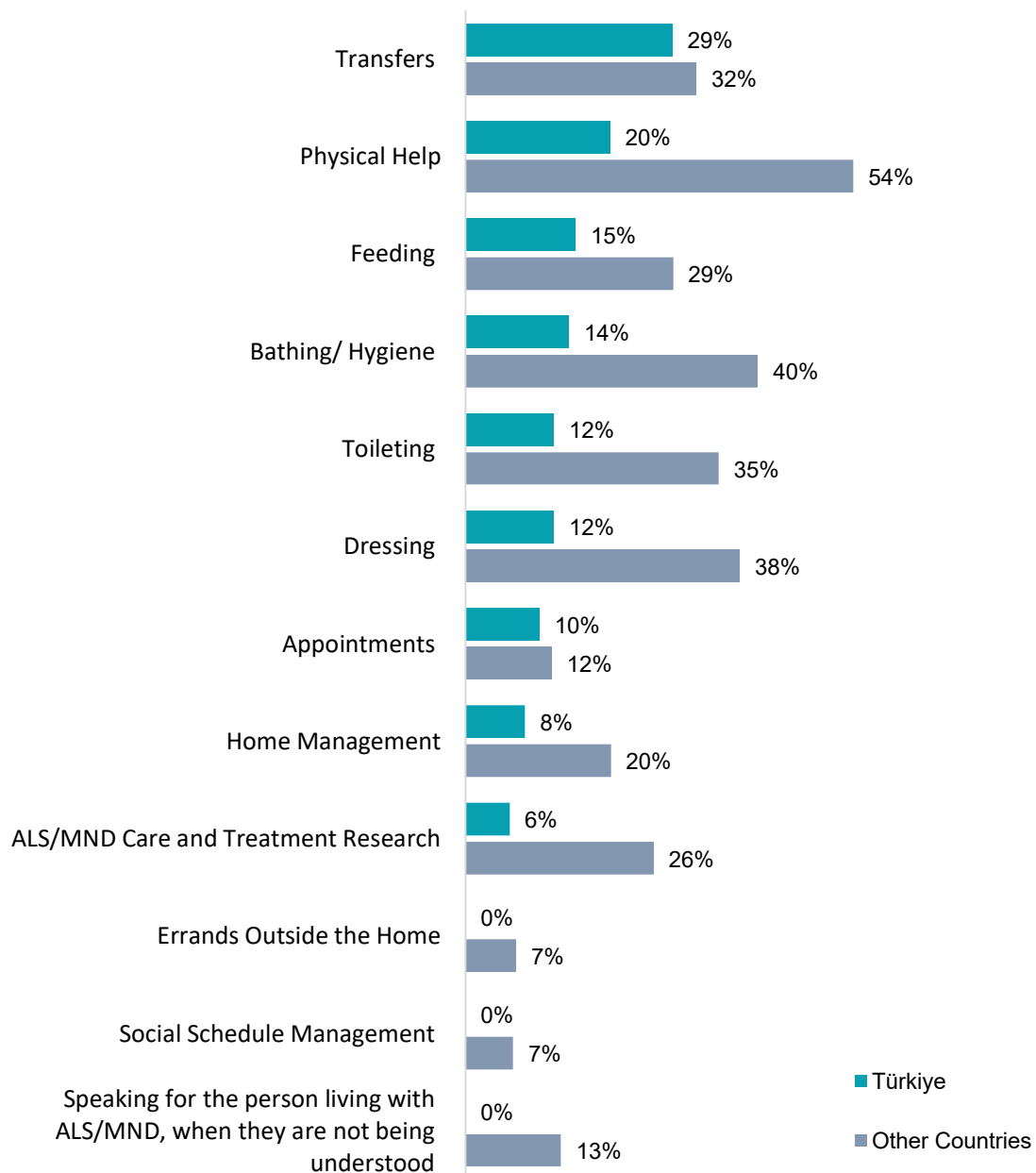
Summary of Tasks Presently Done by Informal/Non-professional Caregiver (Family/Friend)



Summary of Tasks Presently Done by Person Living with ALS/MND

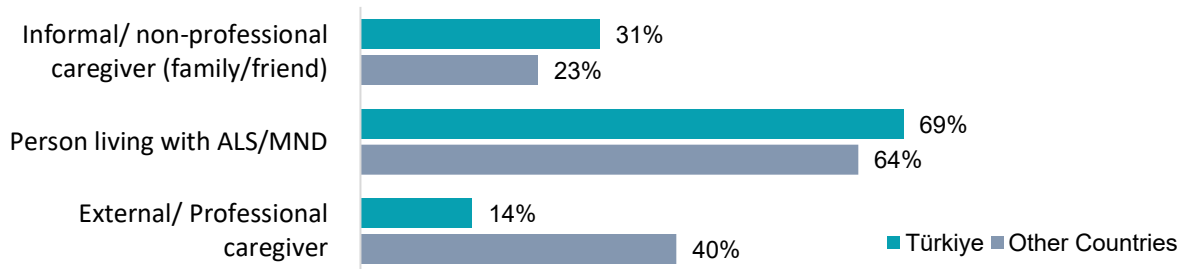


Summary of Tasks Presently Done by External/ Professional Caregiver

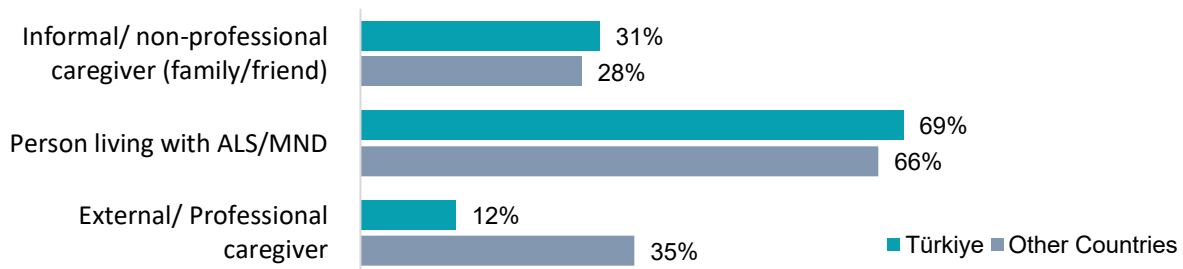




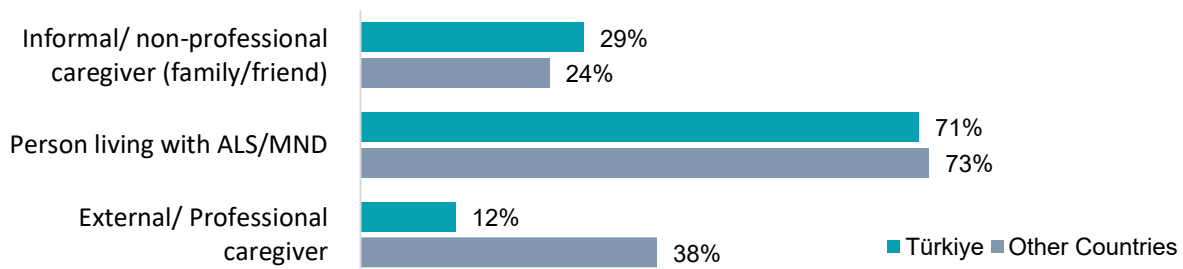
At the present time, who performs: Bathing/Hygiene



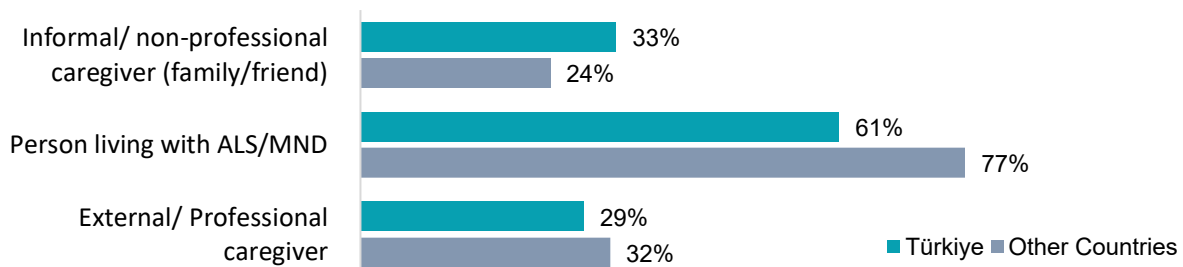
At the present time, who performs: Toileting



At the present time, who performs: Dressing

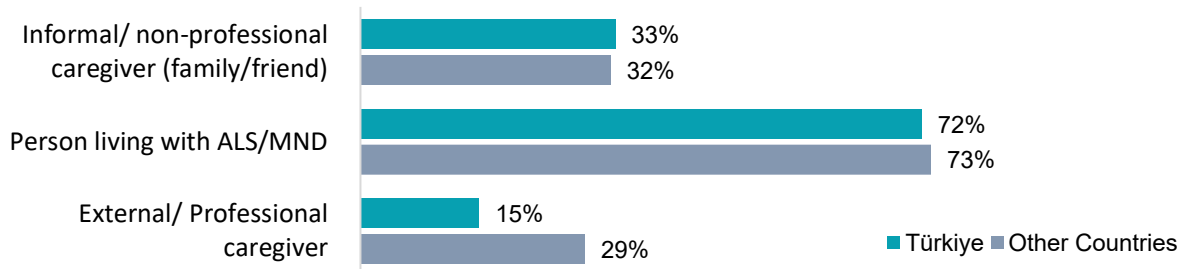


At the present time, who performs: Transfers

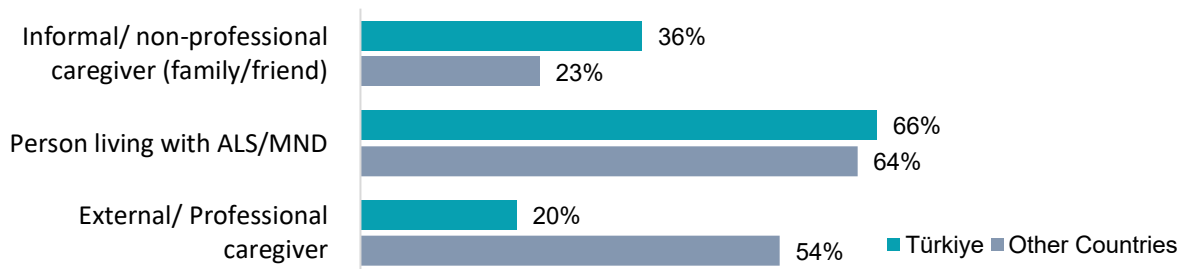




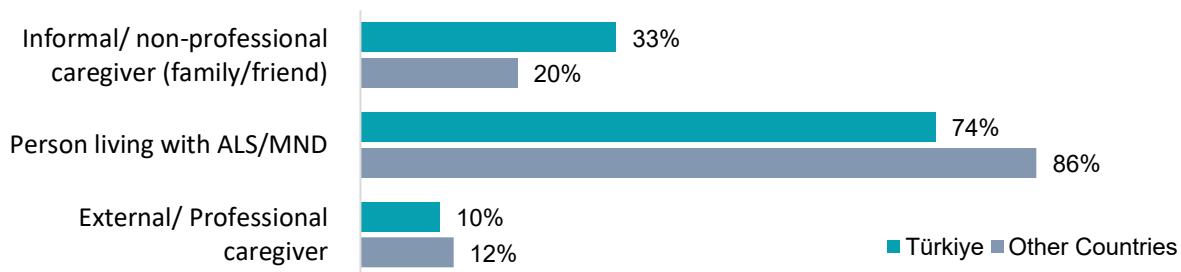
At the present time, who performs: Feeding



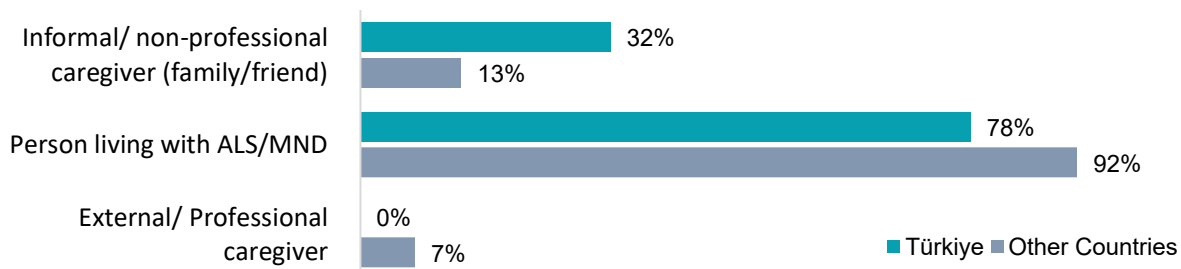
At the present time, who performs: Physical Help (stability, exercise, stretching, movement)



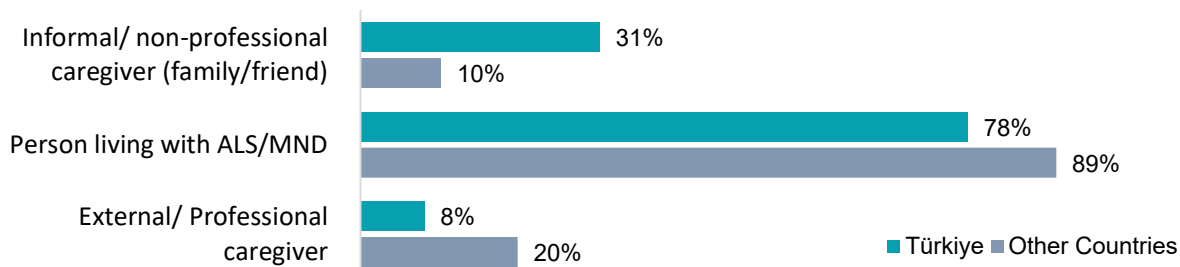
At the present time, who performs: Appointments



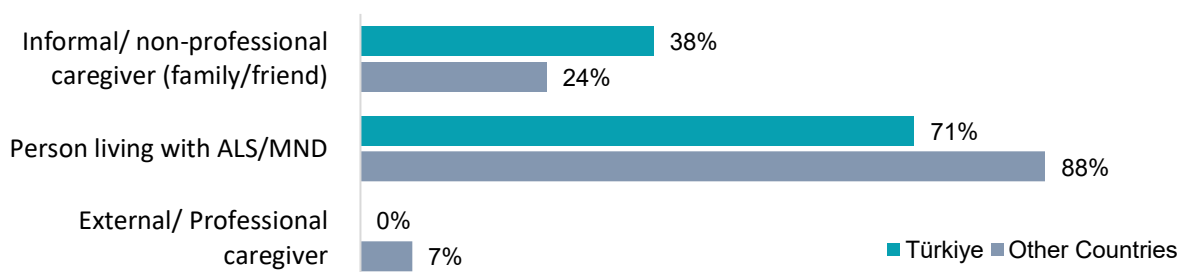
At the present time, who performs: Errands Outside the Home (groceries, pharmacy, post office, bank, etc.)



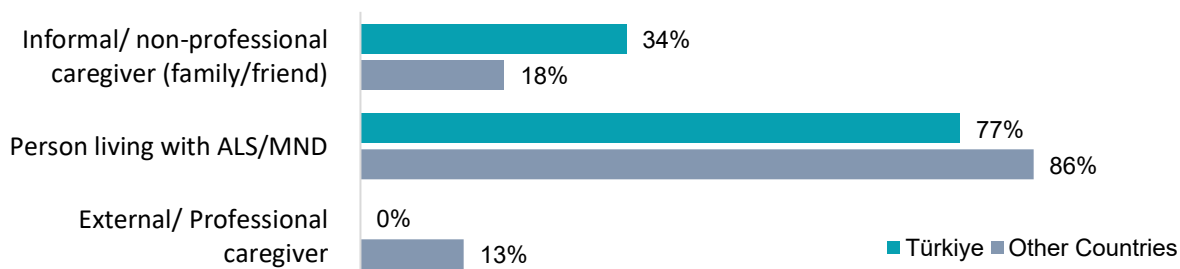
At the present time, who performs: Home Management (cleaning, meal preparation, laundry)



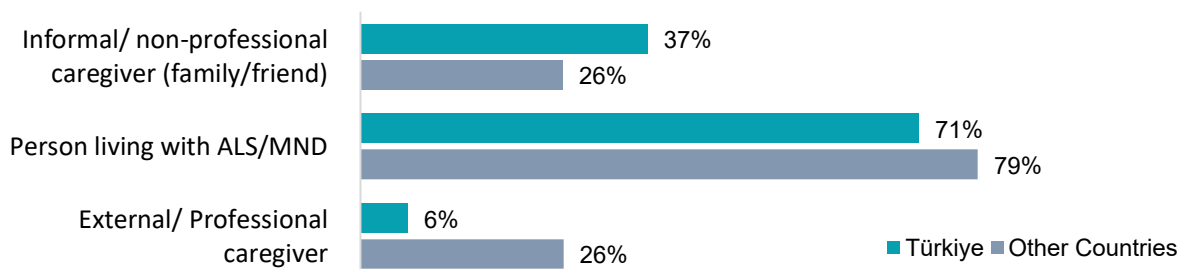
At the present time, who performs: Social Schedule Management



At the present time, who performs: Speaking for the person living with ALS/MND, when they are not being understood

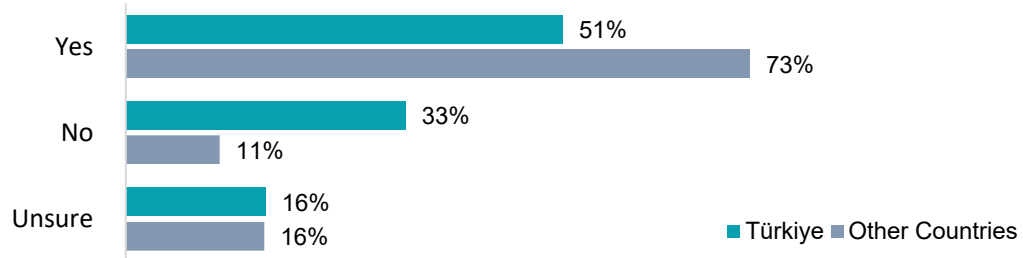


At the present time, who performs: ALS/MND Care and Treatment Research (adaptive clothing, assistive devices, clinical trials, treatment)



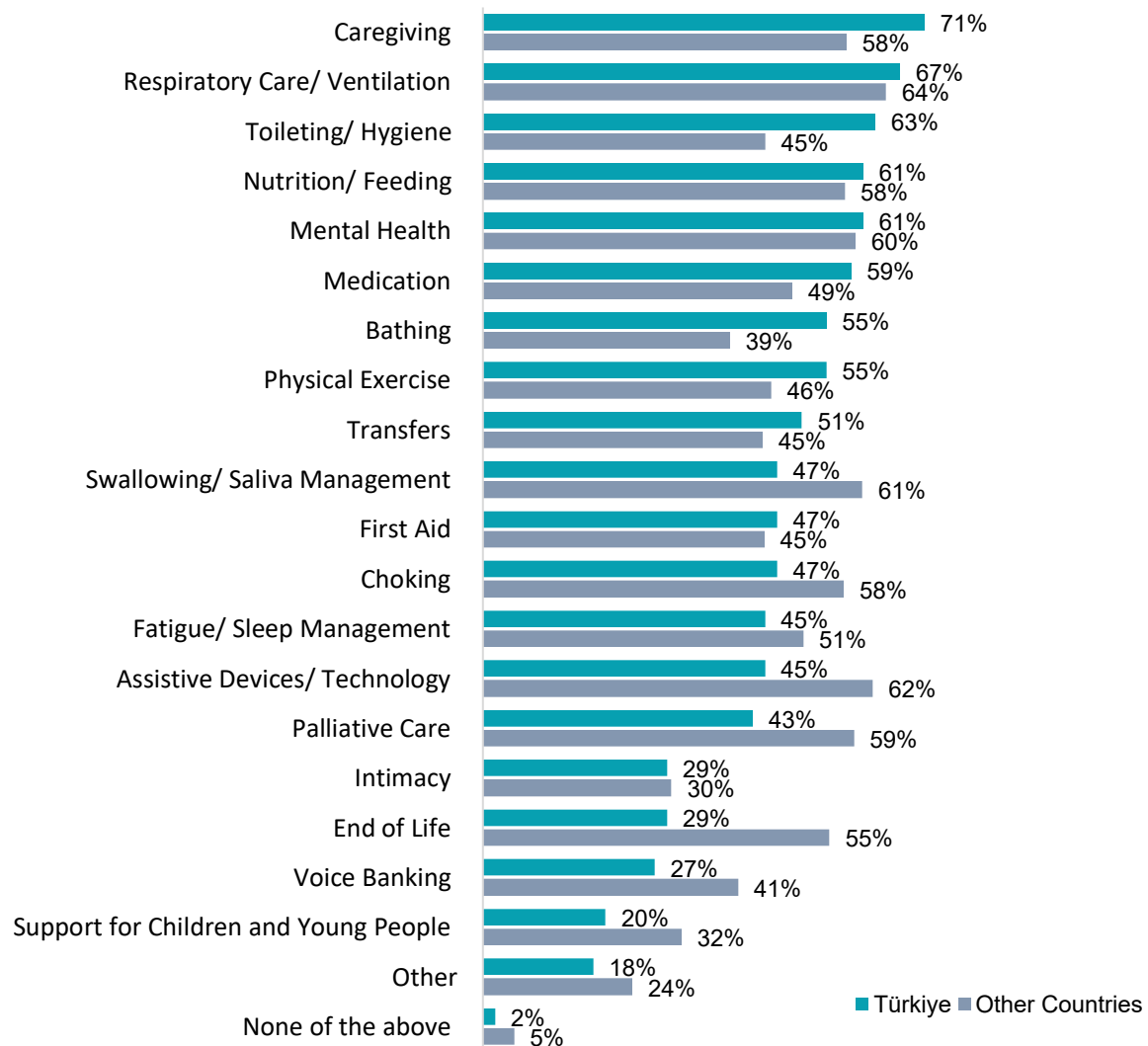
Gets Resources in Language of Choice

I can get the resources I need in my language of choice.



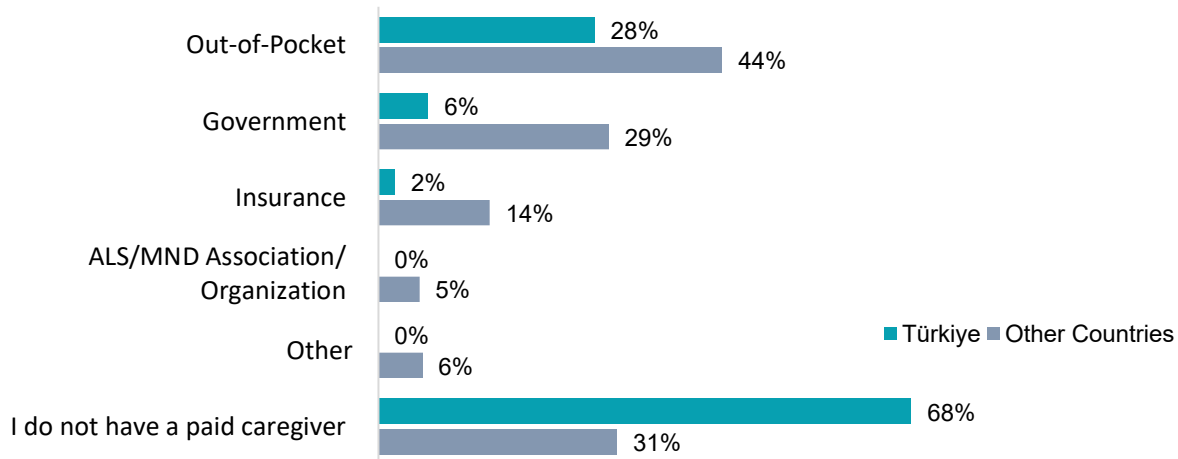
Resources Most Interested In

The resources, information, and training I am most interested in are about:



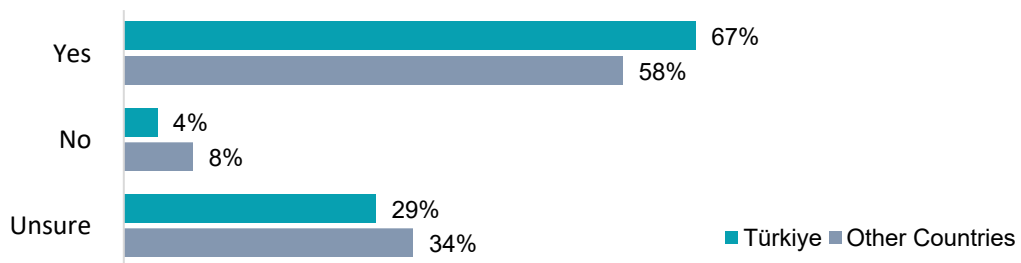
Who Pays for External Caregiver(s)

If you have external/professional caregiver(s), who pays for them?



Would Attend Virtual Support Group

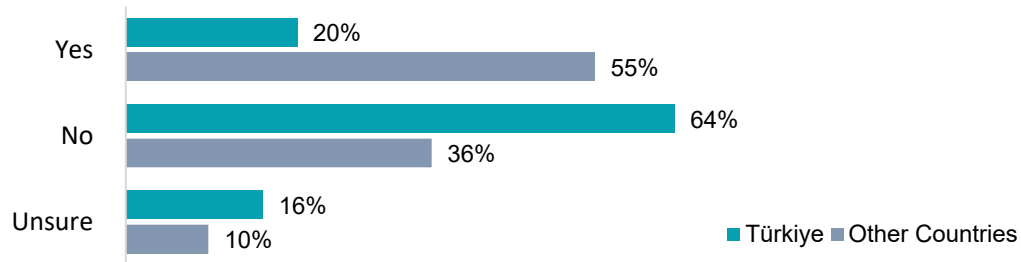
If the International Alliance of ALS/MND Associations had global virtual support groups for caregivers of people living with ALS/MND, I would attend.



Advance Directives and Cognitive Changes

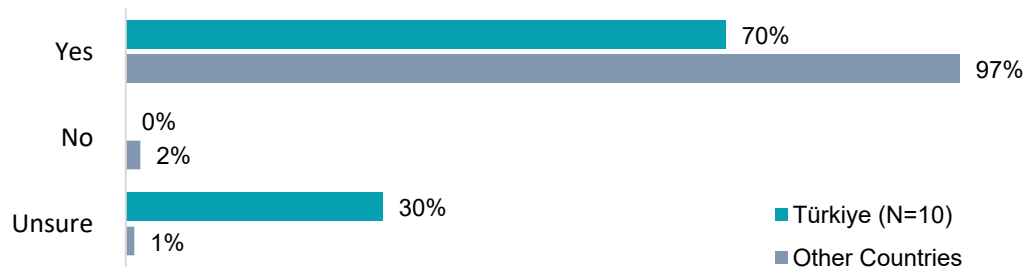
Advanced Directives Have Been Made

Advance directives are legal documents that provide instructions for medical care and only go into effect if a person is unable to communicate their wishes. My person living with ALS/MND has made advance directives.



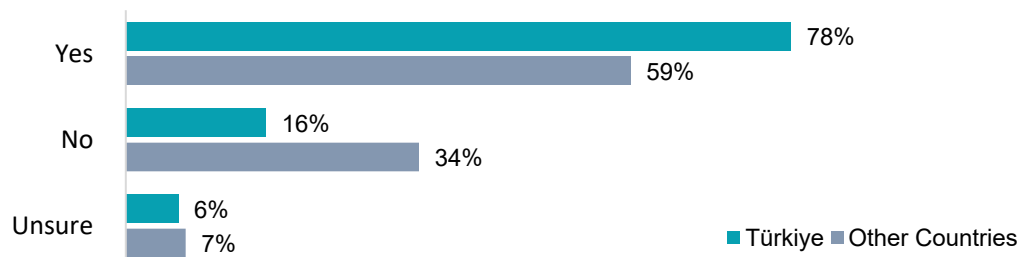
Aware of Advanced Directives

I am aware of the advance directives made by my person living with ALS/MND.



Person with ALS/MND has Experienced Cognitive Changes

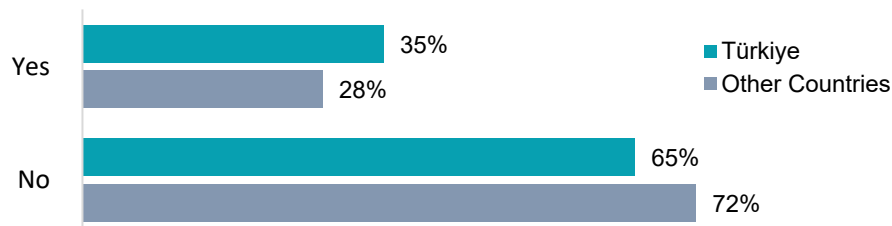
My person living with ALS/MND has experienced cognitive changes (personality changes, impaired judgment, and language difficulties) since their ALS/MND diagnosis.



Young People in Household

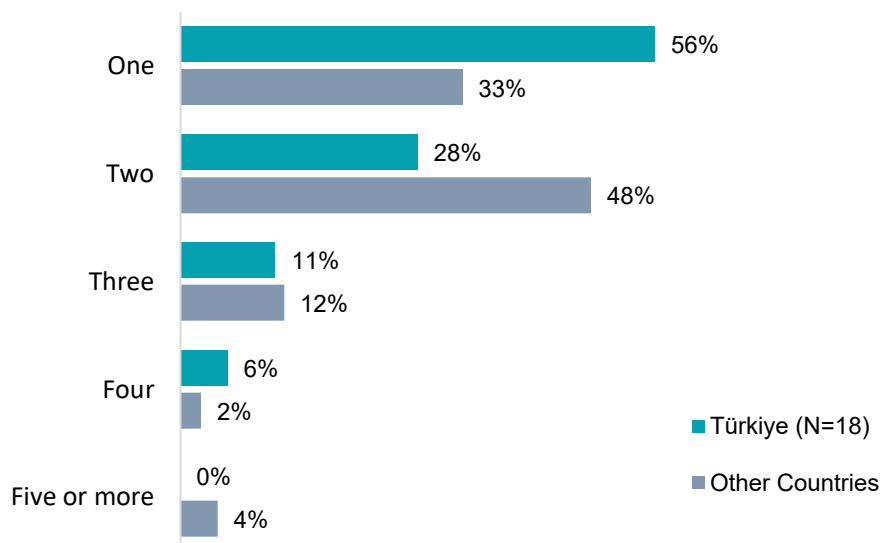
Any Young People in the Home

Are there young people (under 18 years of age) in the home where the person living with ALS/MND resides?



Number of Young People in the Home

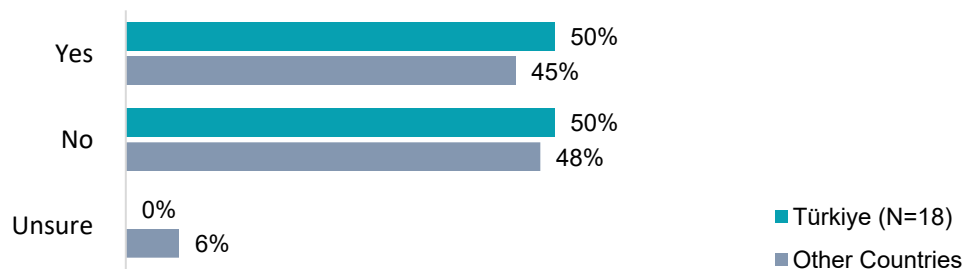
How many young people live in the home?



	Türkiye	Other Countries
Average Number of Young People	1.7	2.0
Median Number of Young People	1	2

Young People Provide Care

Do any of the young people provide care to the person living with ALS/MND?



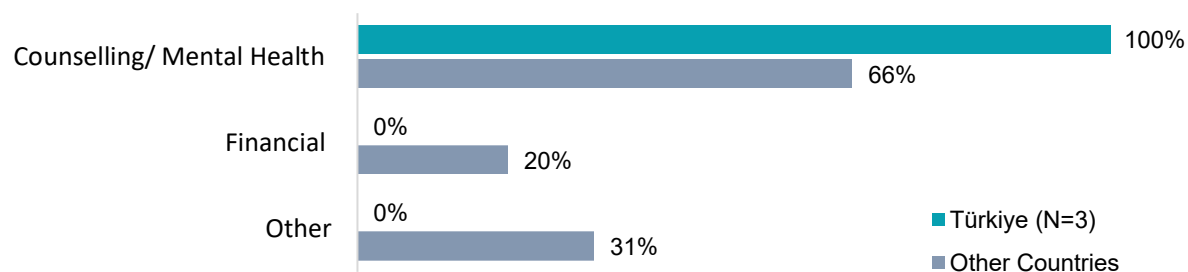
Receives Support for Young People

I receive support for the young people living in the home.



Type of Support Received for Young People

What type of support do you receive for them?

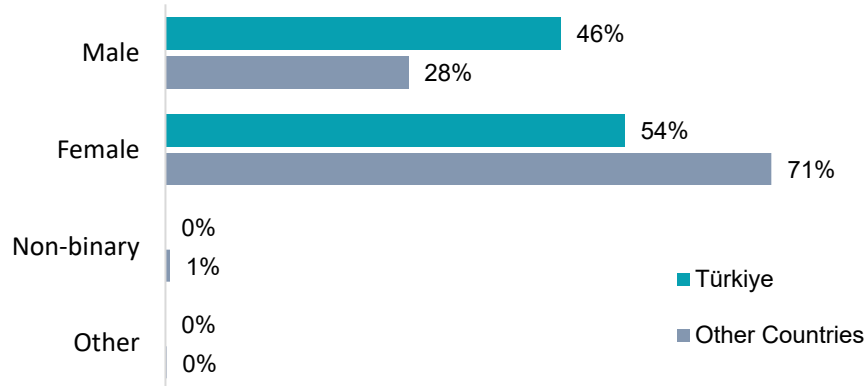




Demographics

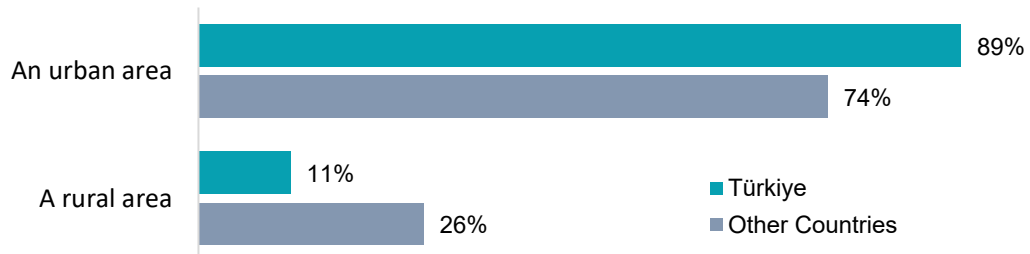
Gender

Gender:



Urban/Rural

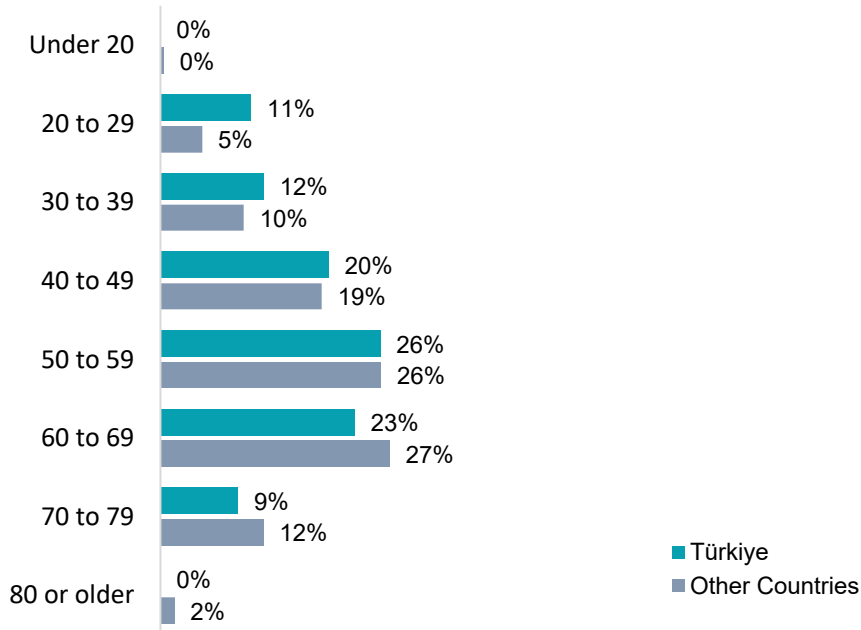
I consider my home to be in:





Age

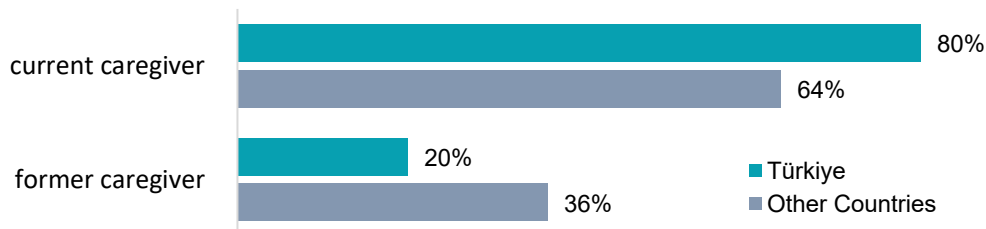
What is your age?



	Türkiye	Other Countries
Estimated Average Age	51.5	55.3

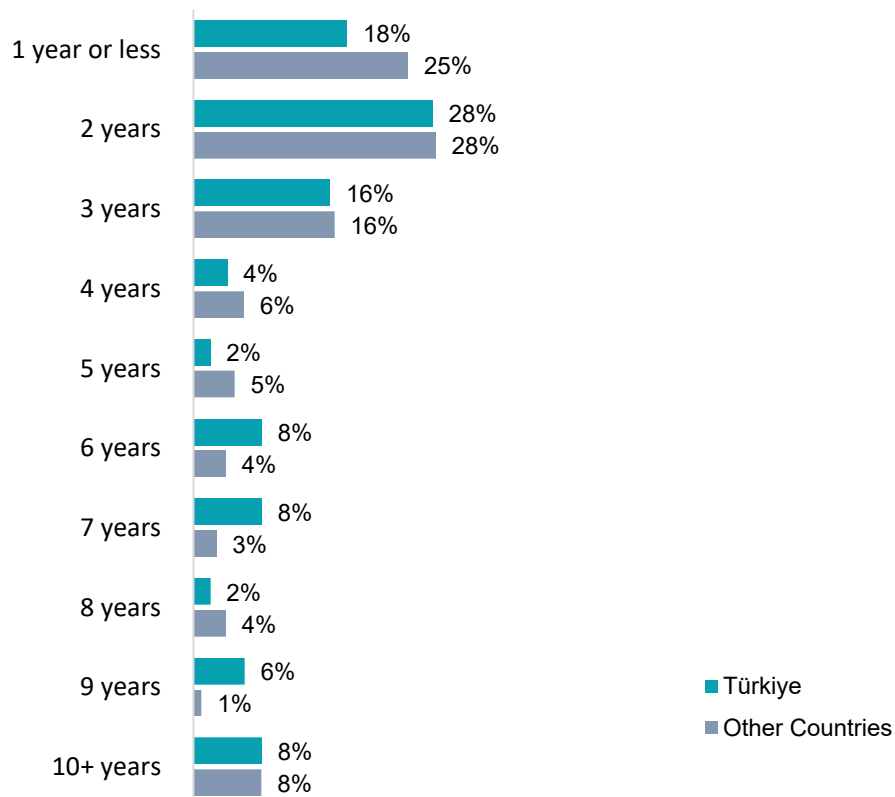
Current vs. Former Caregiver

I am a:



Number of Years as Caregiver

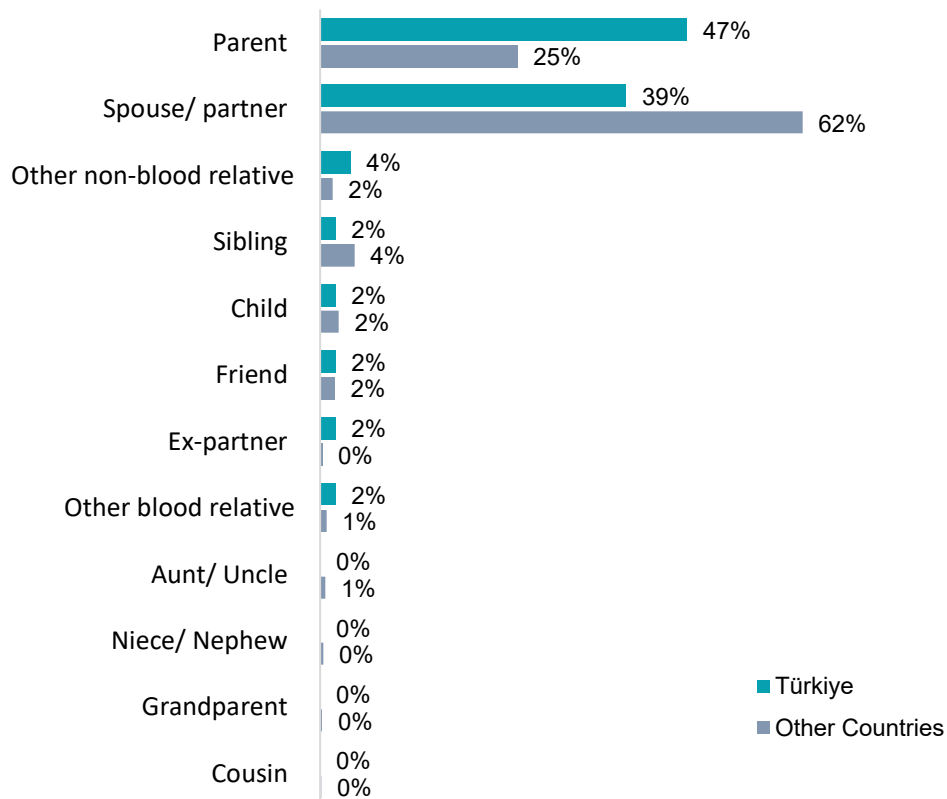
I have been a caregiver to my person living with ALS/MND for:



	Türkiye	Other Countries
Estimated Average Number of Years	3.7	3.0

Relationship with Person with ALS/MND

My person living with ALS/MND is my:



Blood Relative of Person Living with ALS/MND [Türkiye, N = 88 Other Countries, N = 853]

Profile of Relative with ALS/MND

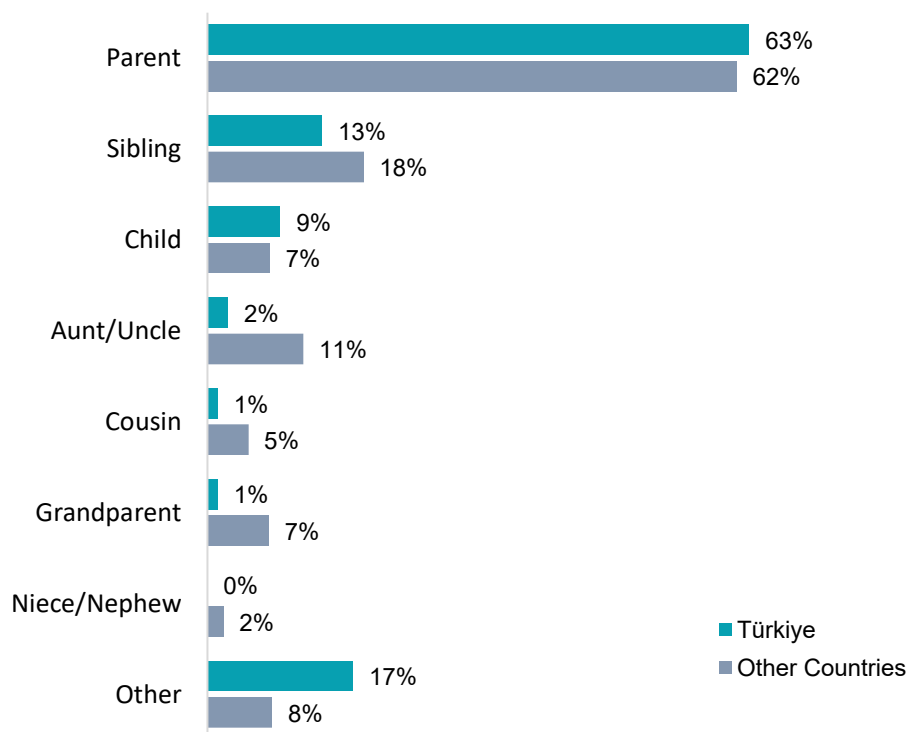
Blood Relatives with ALS/MND

This is a combination of three different questions:

CAL32. My person living with ALS/MND is my:

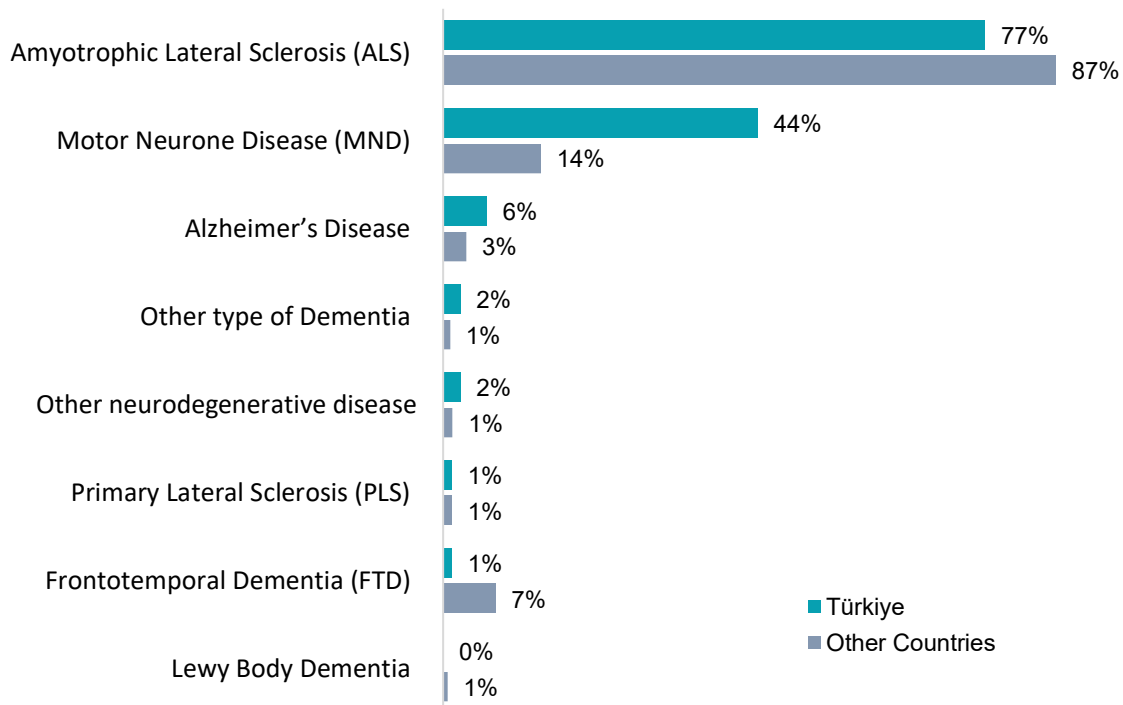
BR 1.ab) The other blood relative(s) with ALS/MND is (are) my:, and

BR1.b). My blood relative(s) with ALS/MND is (are) my:



Blood Relative(s) Diagnosed Neurological Disease(s)

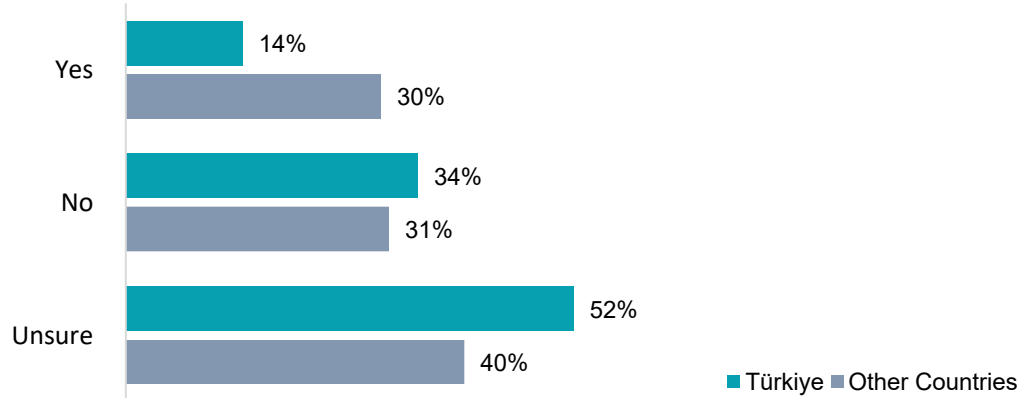
My blood relative(s) has:





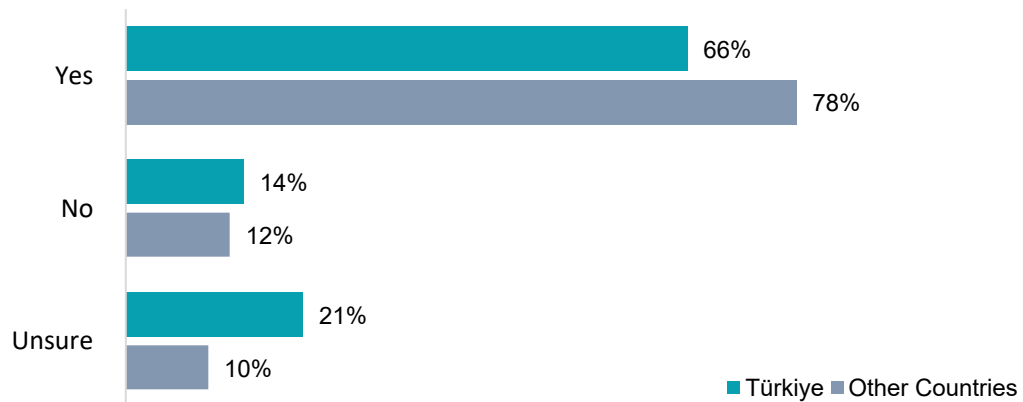
Known Genetic variant of ALS/MND

My blood relative(s) has a known genetic variant of ALS/MND.



Interested in Knowing Possible Genetic Cause

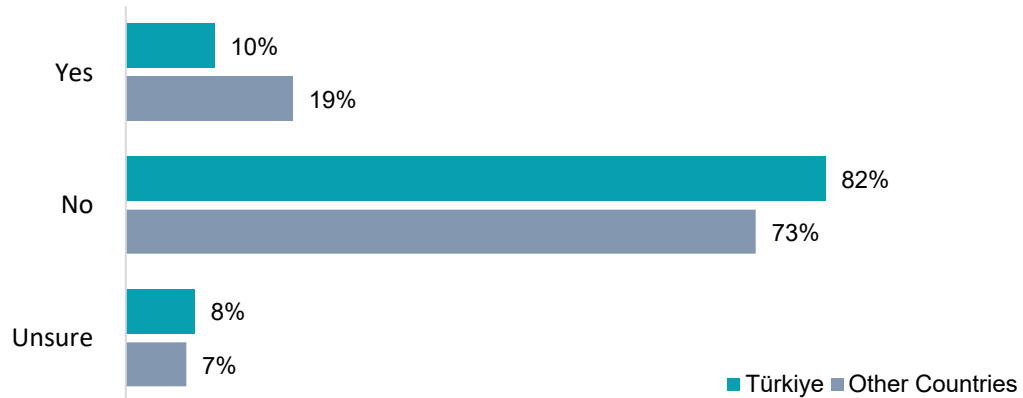
I am interested in knowing whether there is a genetic cause that contributed to my blood relative's ALS/MND.



Family History

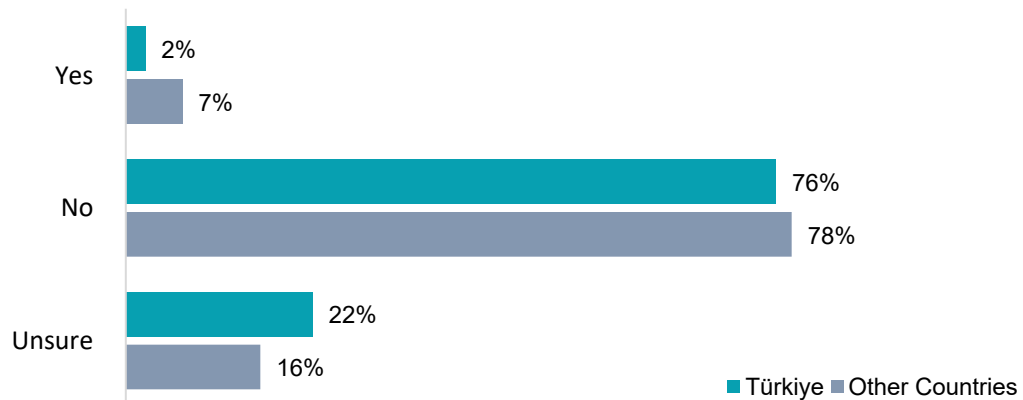
More than One Blood Relative Diagnosed with ALS/MND

I have/had **more than one** blood relative diagnosed with ALS/MND.



More than One Blood Relative Diagnosed with Frontotemporal dementia (FTD)

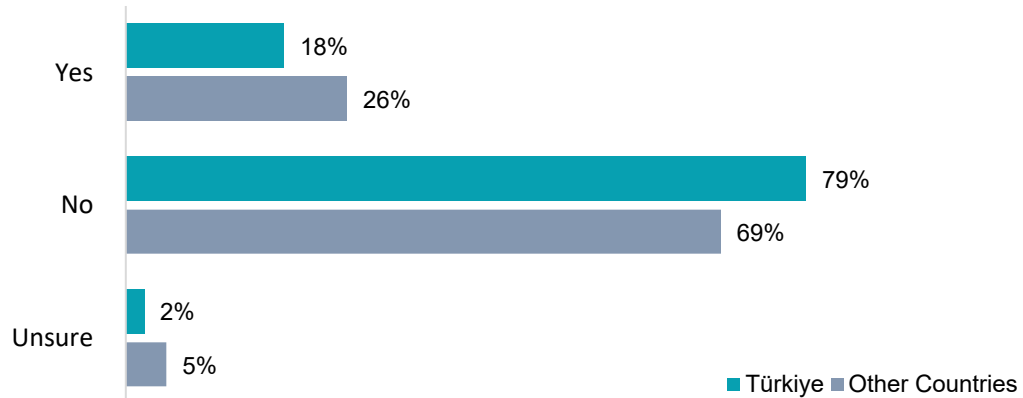
I have/had **more than one** blood relative diagnosed with Frontotemporal dementia (FTD).



Genetic Counselling, Testing, and Discrimination

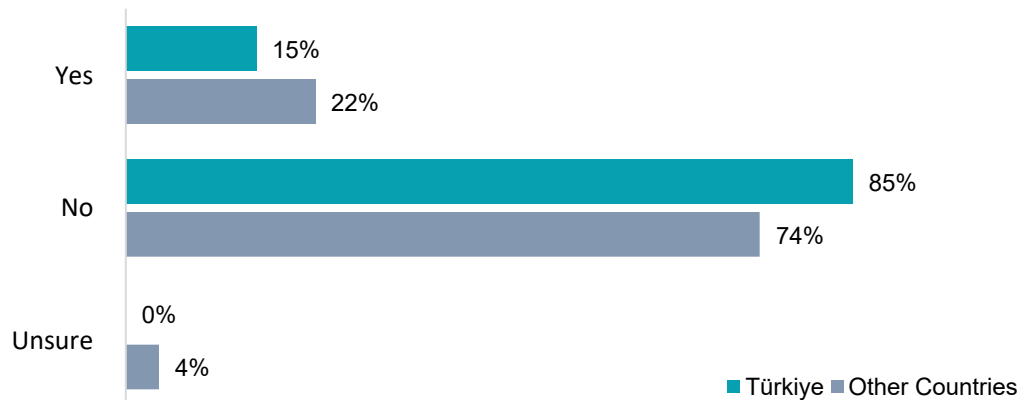
Offered Genetic Counselling

I have been offered genetic **counselling**.



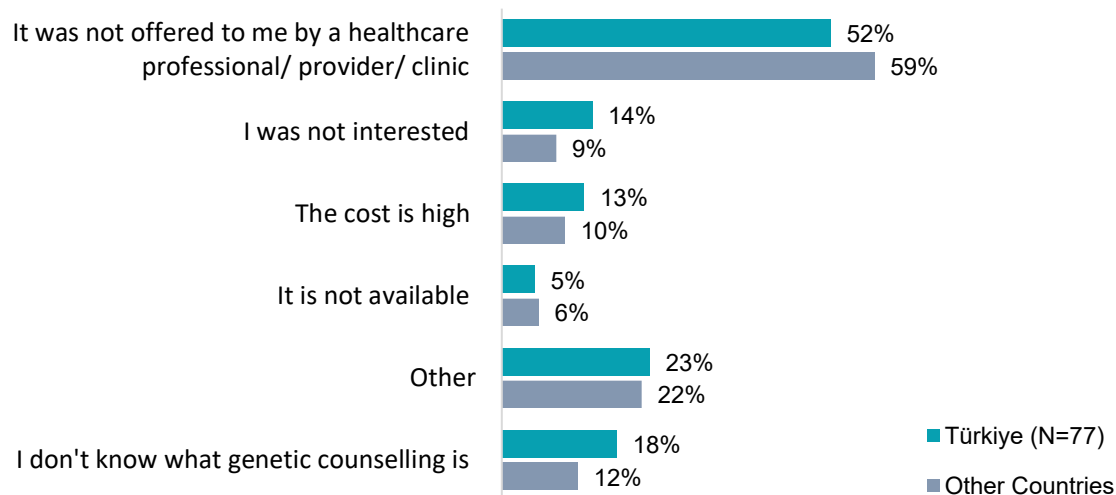
Received Genetic Counselling

I have received genetic **counselling**.



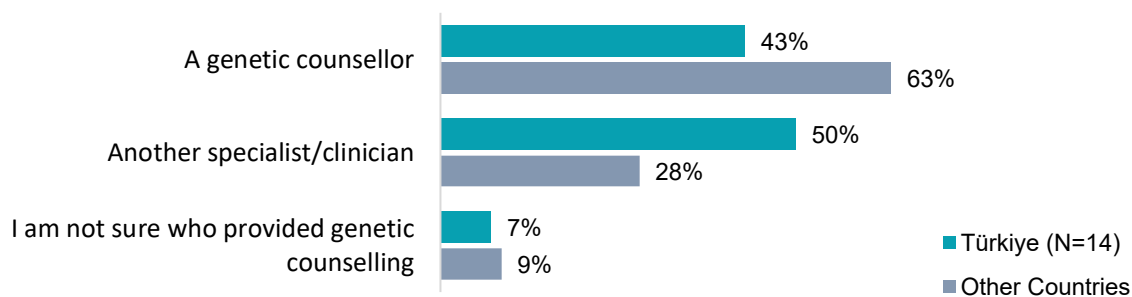
Reasons for Not Receiving Genetic Counselling

I have not received genetic **counselling** because:



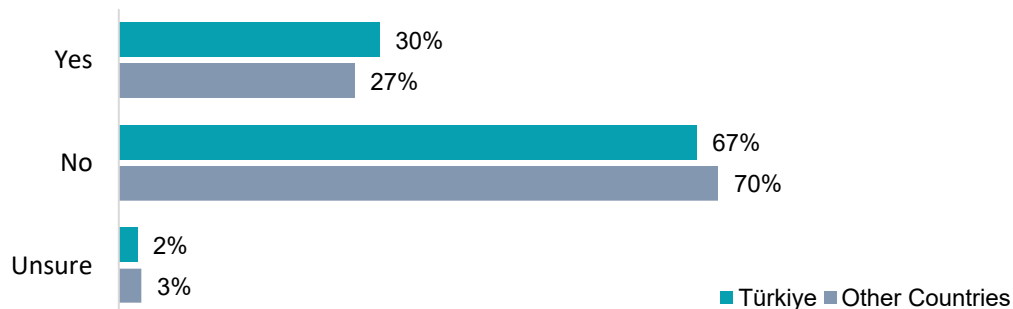
Received Genetic Counselling From...

I received genetic counselling from:



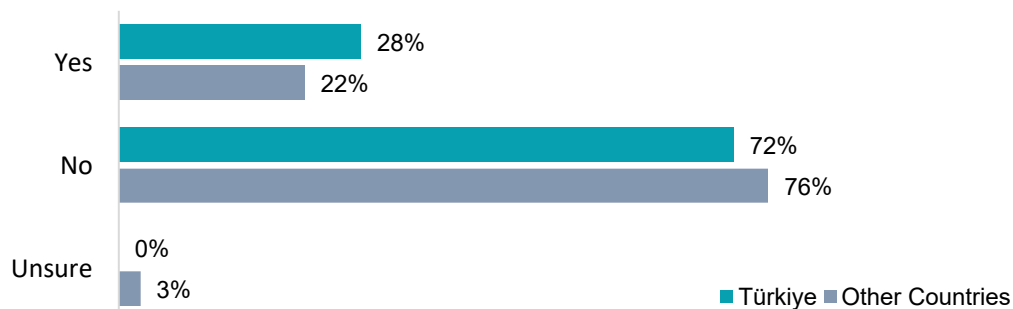
Offered Genetic Testing

I have been offered genetic **testing**.



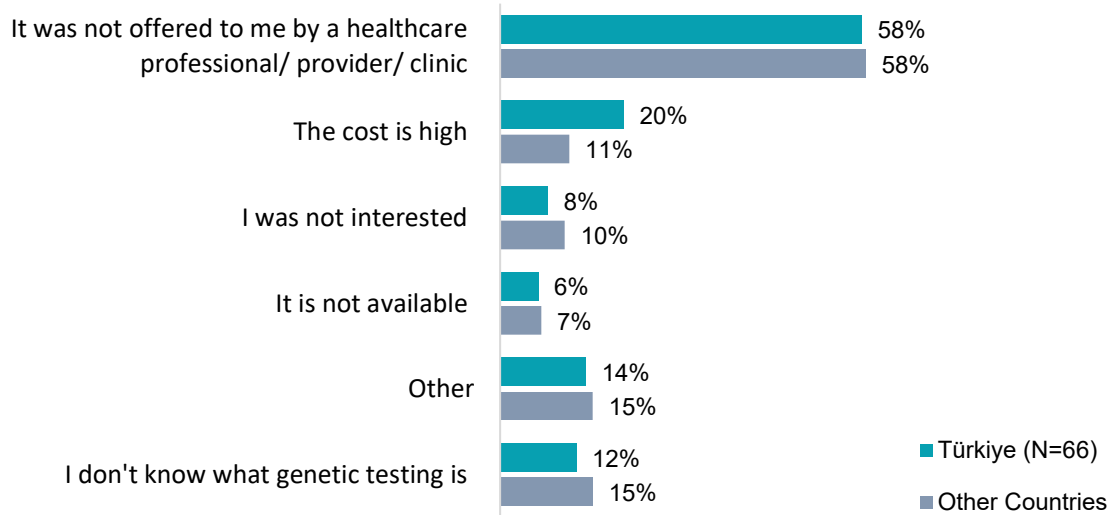
Received Genetic Testing

I have received genetic **testing**.



Reasons for Not Receiving Genetic Testing

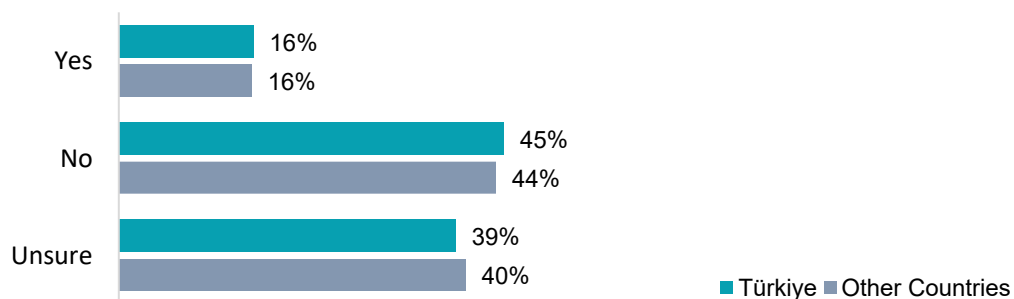
I have not received genetic **testing** because:



Have Protections Against Genetic Discrimination

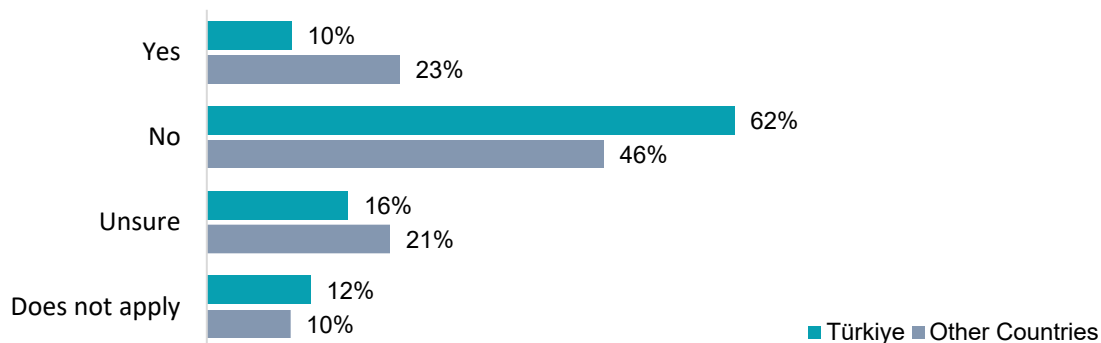
Genetic discrimination is when someone is treated differently because of their genetic makeup. This may include individuals at-risk for a genetic condition, who do not know whether they have a genetic variant. This can include treating someone differently when seeking employment, health care, insurance, or education.

I have protections against genetic discrimination.

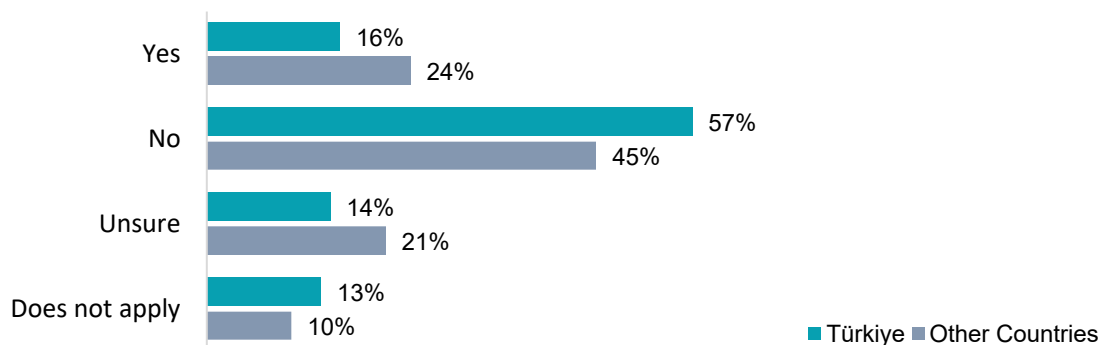


Services and Protections Offered to Blood Relatives

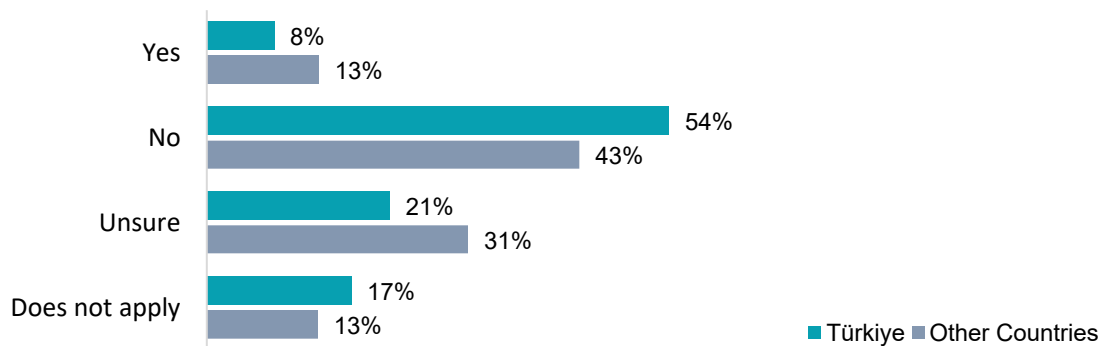
If relevant, my blood relatives have been offered: the same genetic counselling.



If relevant, my blood relatives have been offered: the same genetic testing.



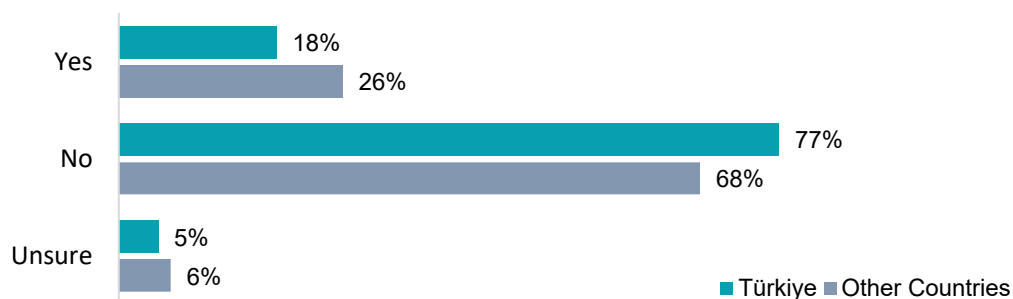
If relevant, my blood relatives have been offered: the same protections against genetic discrimination.



Information, Resources, and Education

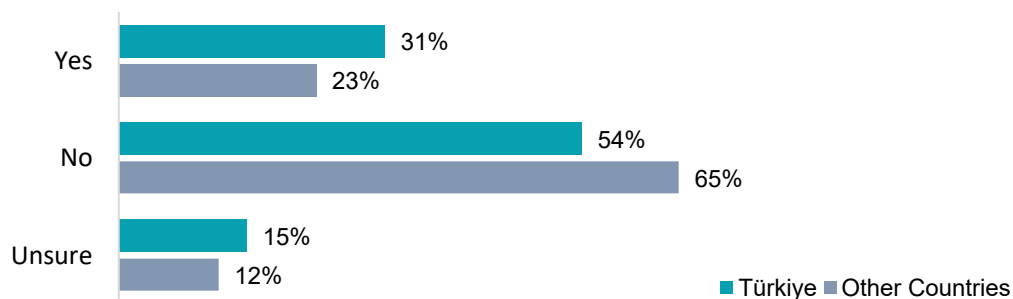
Have Encouraged Others re: Counselling and Testing

I have encouraged other blood relatives to get information about genetic counselling and testing.



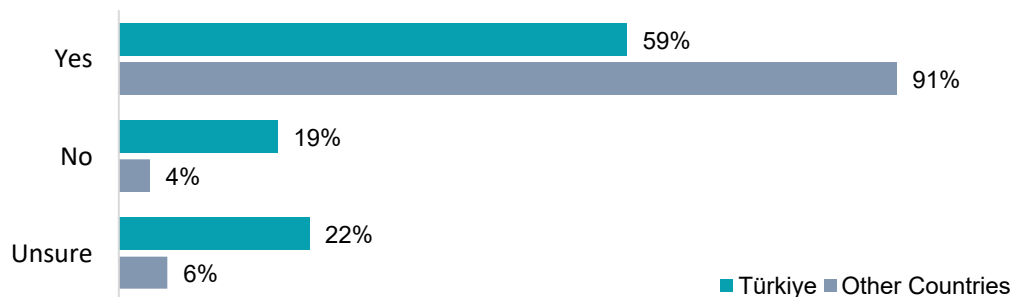
Have Information about Clinical Genetics

I have up-to-date information about clinical genetics in ALS/MND.



Clinical Genetics Information is in Language of Choice

The information about clinical genetics is available in my language of choice.



Have Resources about Clinical Genetics

I have up-to-date resources about clinical genetics in ALS/MND.



Clinical Genetic Resources are in Language of Choice

The resources about clinical genetics are available in my language of choice.



Have Education about Clinical Genetics

I have up-to-date education about clinical genetics in ALS/MND.



Clinical Genetic Education is in Language of Choice

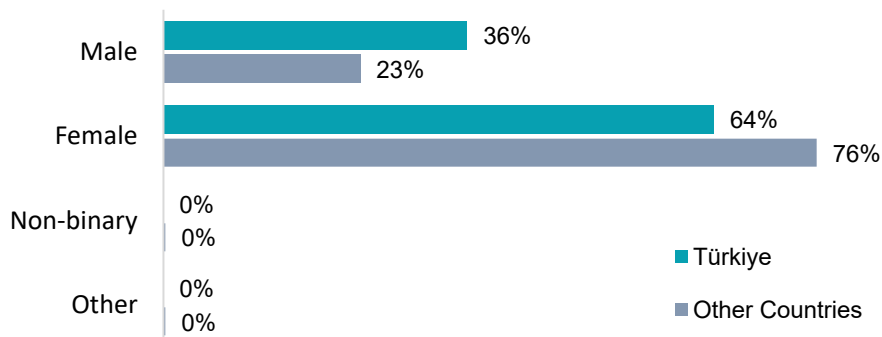
Up-to-date education about clinical genetics is available in my language of choice.



Demographics

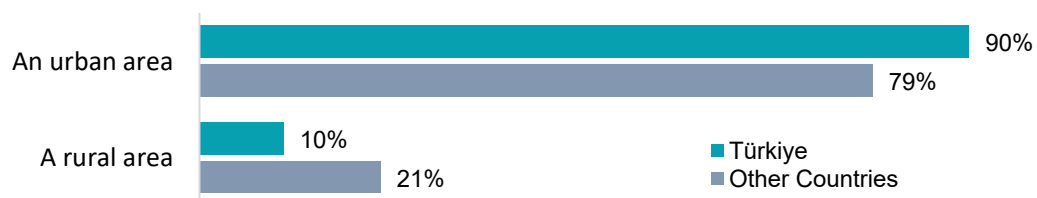
Gender

Gender:



Urban/Rural

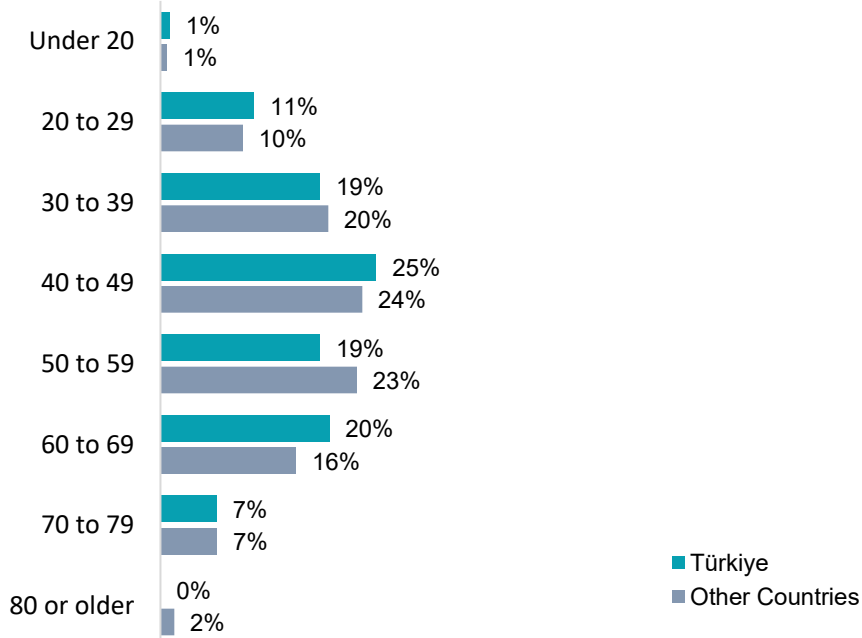
I consider my home to be in:





Age

What is your age?

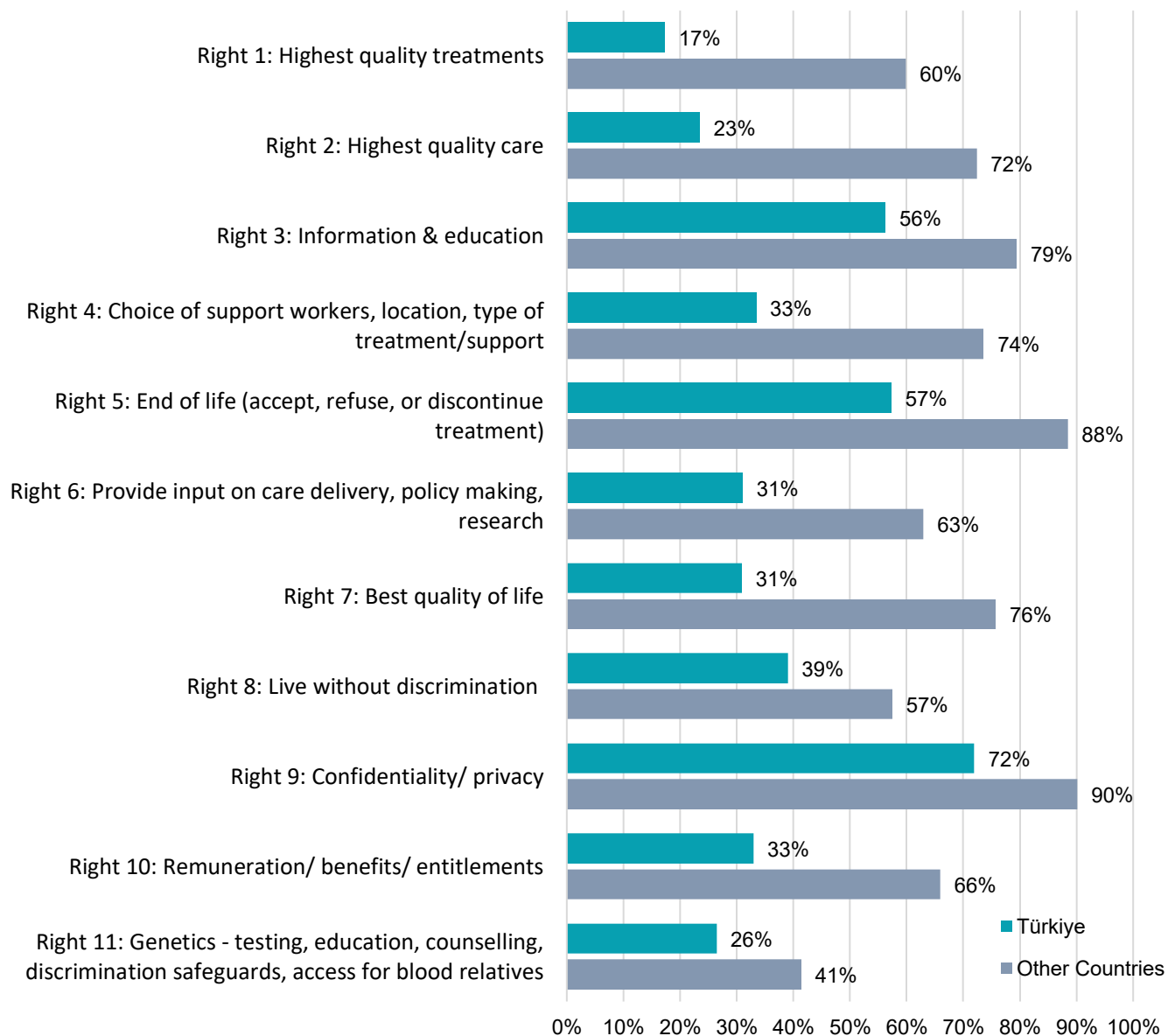


	Türkiye	Other Countries
Estimated Average Age	48.7	49.2

Appendix

Combined Rights

Person Living with ALS/MND



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

