WELCOME !

April 25, 2022

Mobility and Equipment Needs of People With ALS: Results from the ALS Focus Mobility Survey

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ALS FOCUS

Mobility and Equipment Needs of People With ALS: Results from the ALS Focus Mobility Survey

Presenter

Sarah Parvanta
Senior Director of Mission Informatics
Director of the ALS Focus Survey Program
The ALS Association

April 25, 2022

ALS ASSOCIATION

- About ALS Focus
- ALS Mobility Survey

What is the ALS Focus Survey Program?

- **Patient- and caregiver-led**
  The Patient and Caregiver Advisory Committee (PCAC) informs Focus survey topics, survey questions, and other research components
- **Experience and preference data**
  Focus surveys measure the experiences, needs, and preferences of people with ALS and their caregivers in the United States
- **Informing research, policy, & care**
  Focus surveys are designed to inform patient-focused drug development, payment and reimbursement models, care services, and caregiver programs

Why is ALS Focus Unique?

Online surveys

Participate in research outside of clinical trials and from the comfort of one's home.

NeuroSTAmP™

Each participant receives unique identifier to ensure participant privacy and enable combined ALS data across studies.

Data are free to use

De-identified Focus data are free for the public and ALS researchers to use after an embargo period.

Regional ALS data

Analyses of Focus data by U.S. region, demographics, and disease progression are possible.

How to Participate in ALS Focus?

Eligibility

People with ALS, current caregivers, and former caregivers may participate. Must reside in the United States and be 18 years old or older.

ALS Focus Web page
www.als.org/als-focus

New ALS Focus Platform Coming Soon!

If you sign up on the current platform, your data will automatically transfer to the new platform.

ALS Focus Participation & Surveys

1,700+
People with ALS, Current Caregivers, & Past Caregivers consented to participate

- Demographics Survey
- ALSFRS-R and Vital Capacity
- Health Status
- Insurance Needs and Financial Burdens
- What Matters Most
- Caregiver Needs
- Telehealth
- ALS Mobility - 460 participants

ALS Mobility Survey

- Input from Patient and Caregiver Advisory Committee, ALS Association Care Services experts, occupational therapy expert, industry partners
- Survey designed for people with ALS, current caregivers, and past caregivers
- Questions asked about the person with ALS and his/her experiences with mobility equipment
  - ☐ Power wheelchair
  - ☐ Portable Ramp
  - ☐ Rollator
  - ☐ Use of equipment
  - ☐ Covering cost of equipment
  - ☐ Does the equipment meet their needs
- Online survey: October – December, 2021

ALS Mobility Survey Sample

Total Survey Participants = 460

233
People
with ALS

132
Current
Caregivers

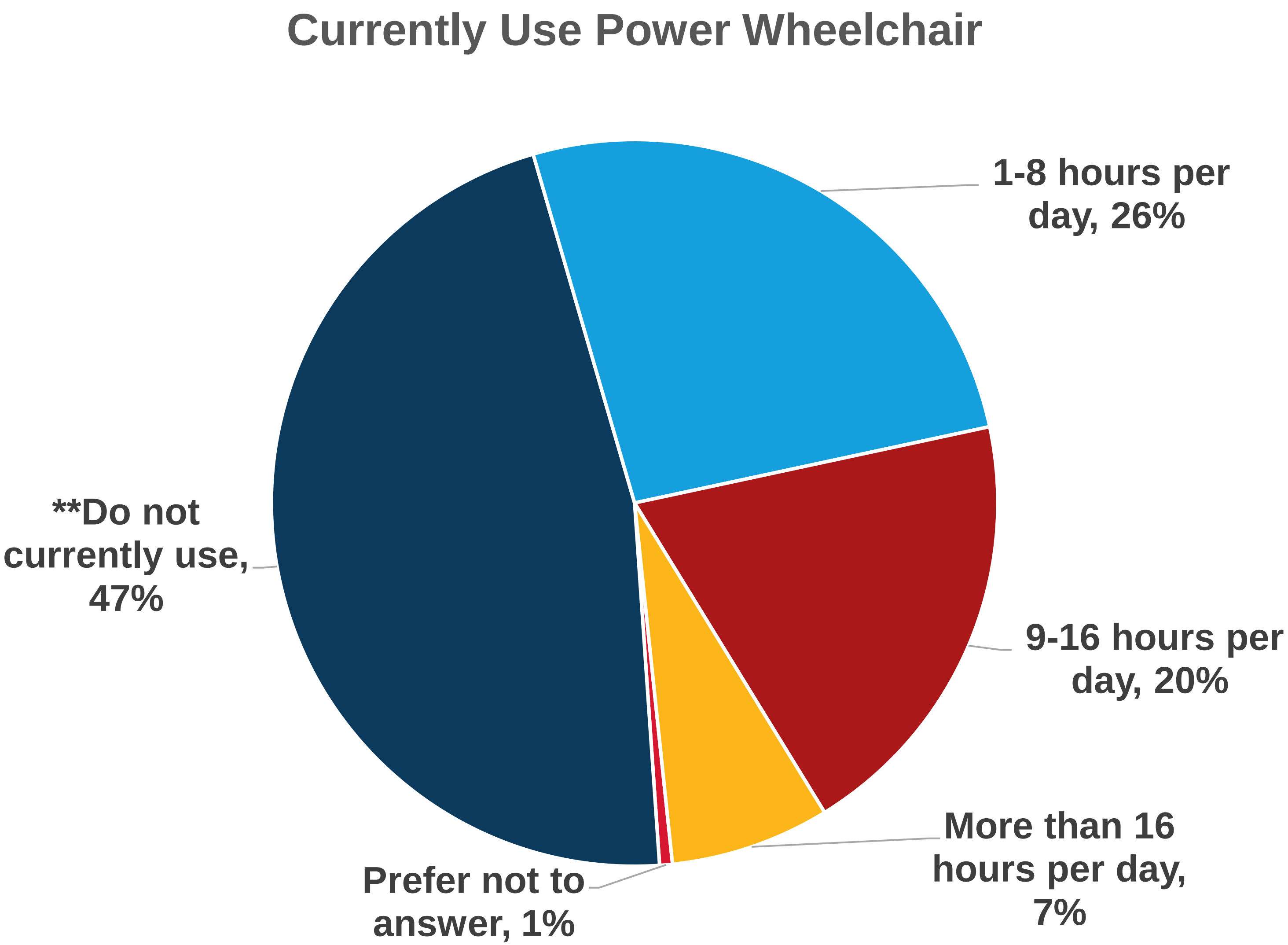
95
Past
Caregivers

Today's Analysis = 352

233
People
with ALS

119
Current
Caregivers*

Results – Power Wheelchair Use



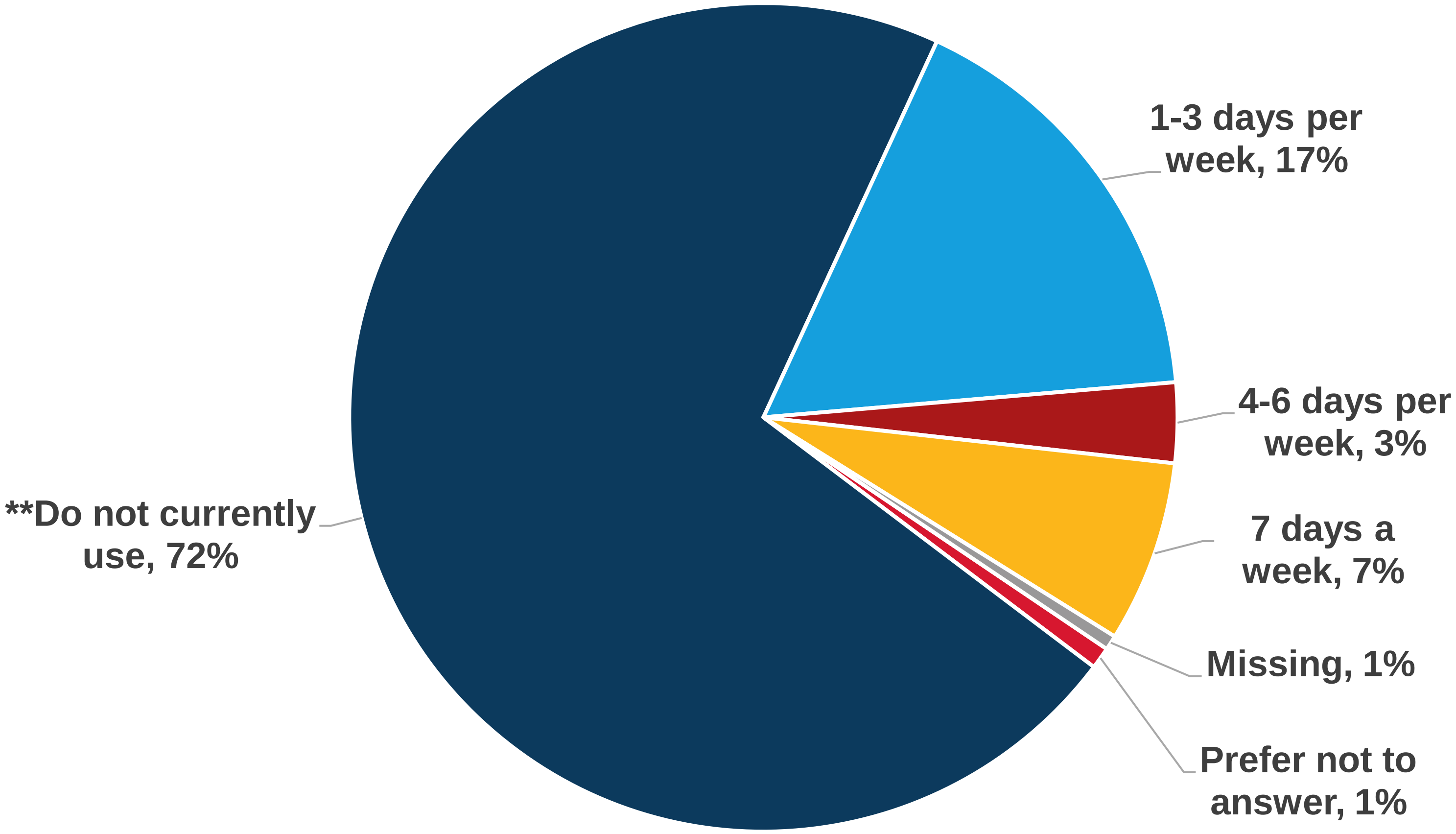
**An additional 8% of participants reported using a power wheelchair in the past.

Results – Portable Ramp Use

The survey described portable ramps:

“Portable ramps are used to move across areas of different height, such as one or two steps or a street curb. Portable ramps can be carried outside the home. Most portable ramps fold.”

Currently Use Portable Ramp



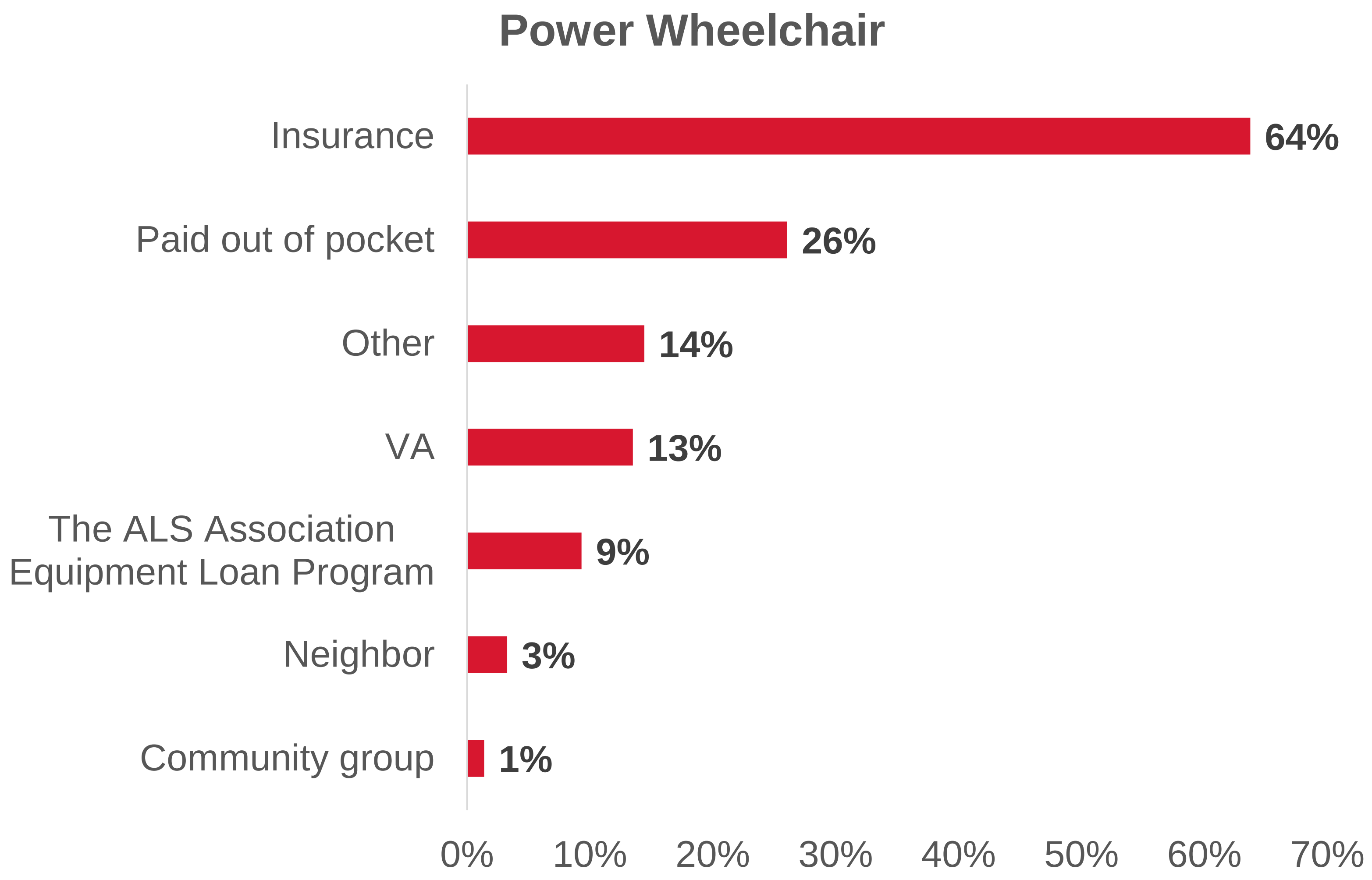
**An additional 15% of participants reported using a portable ramp in the past.

Results – Rollator Use

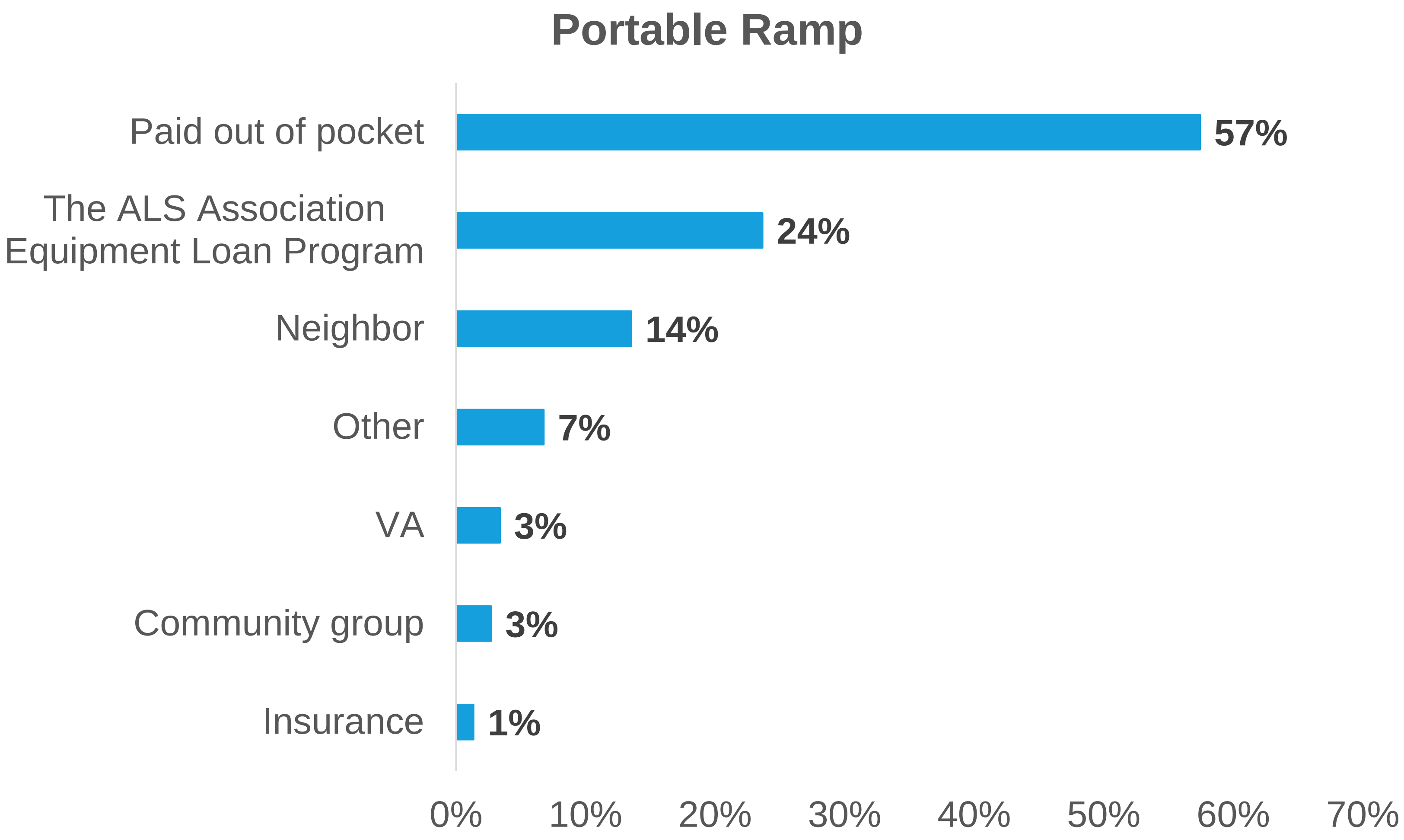
28% currently use a rollator

**An additional 103 participants reported using a rollator in the past.

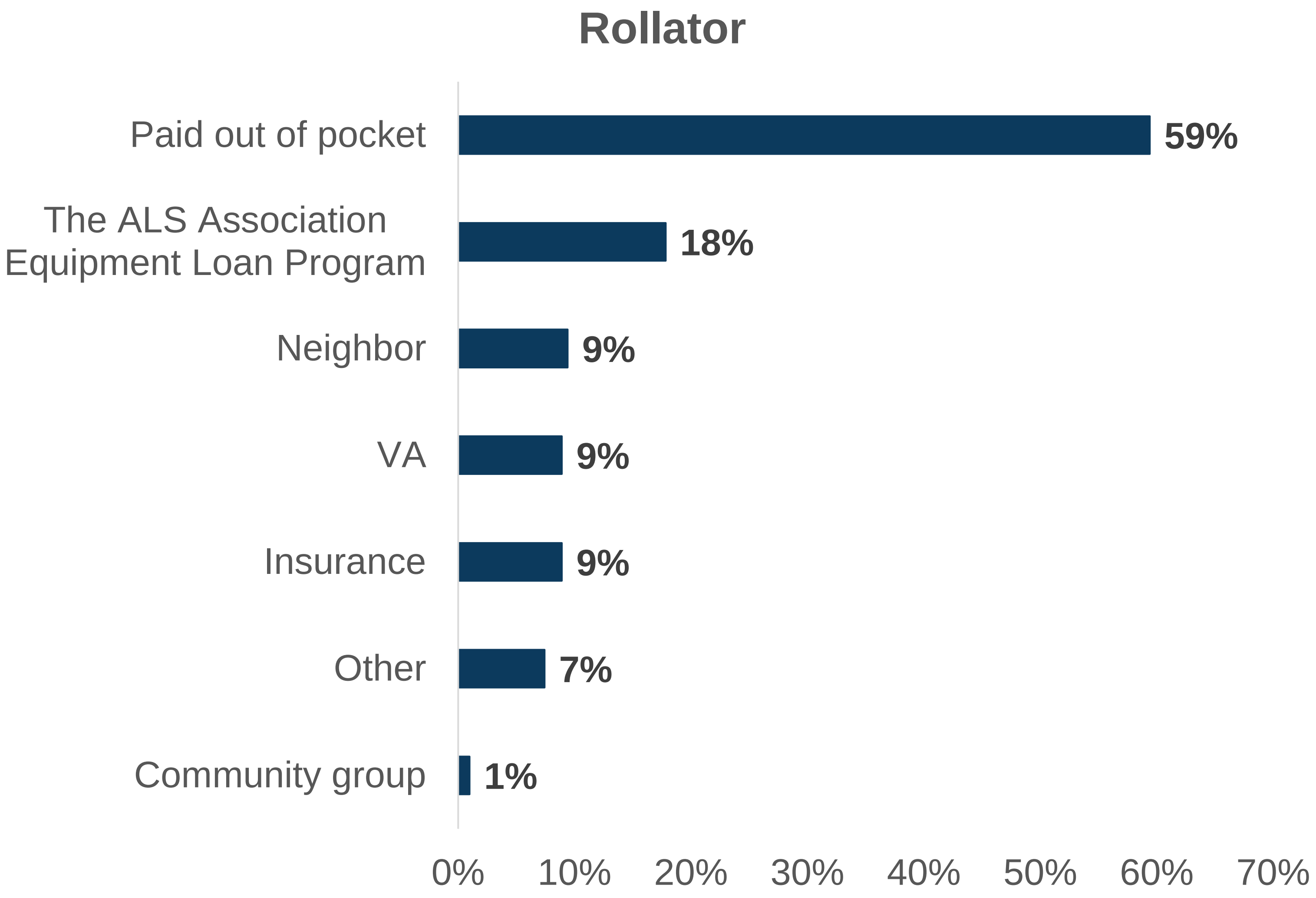
Results – Covering Cost of Power Wheelchair



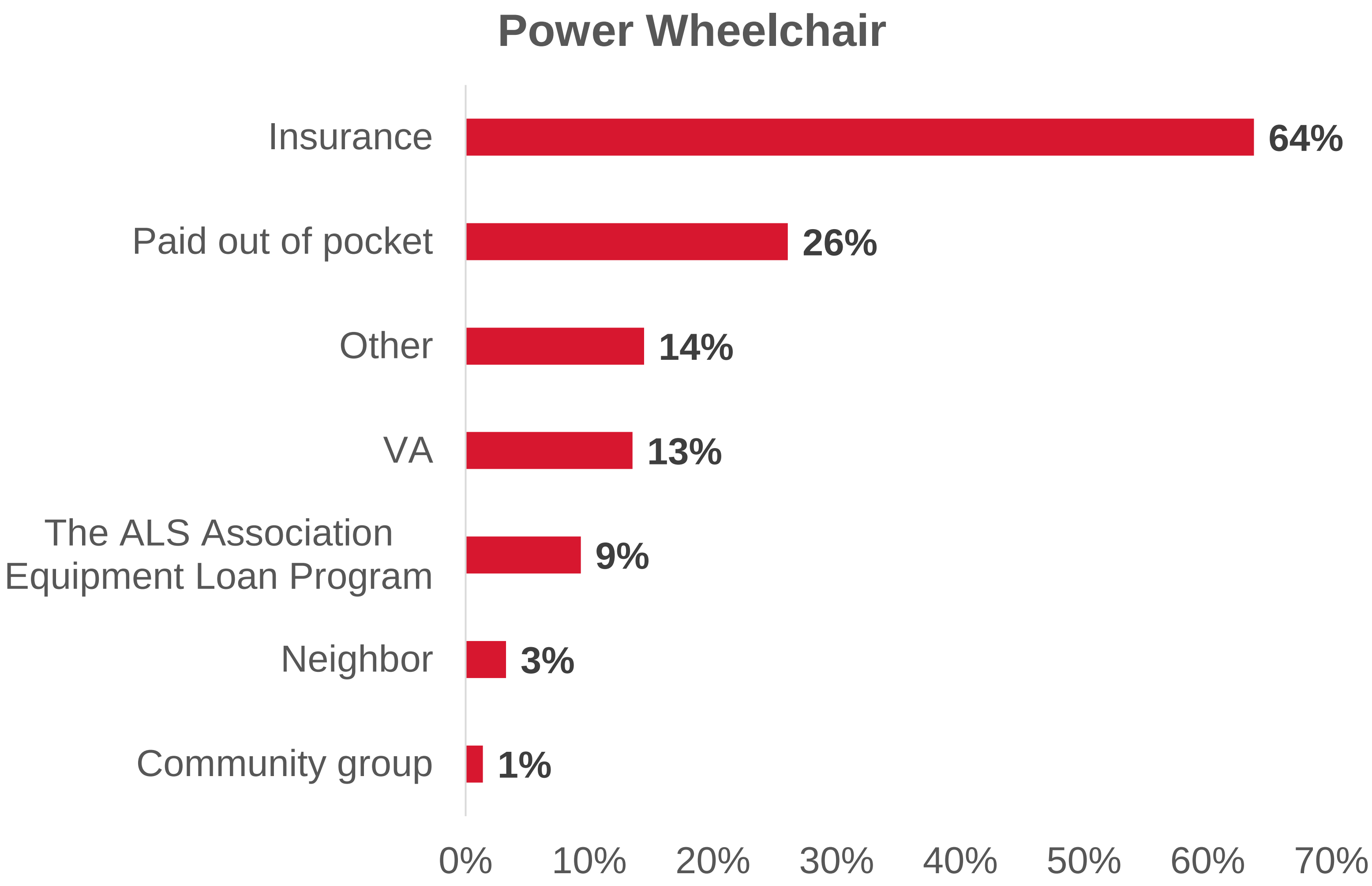
Results – Covering Cost of Portable Ramp



Results – Covering Cost of Rollator



Results – Covering Cost of Power Wheelchair



Results – Insurance Coverage of Power Wheelchair Options

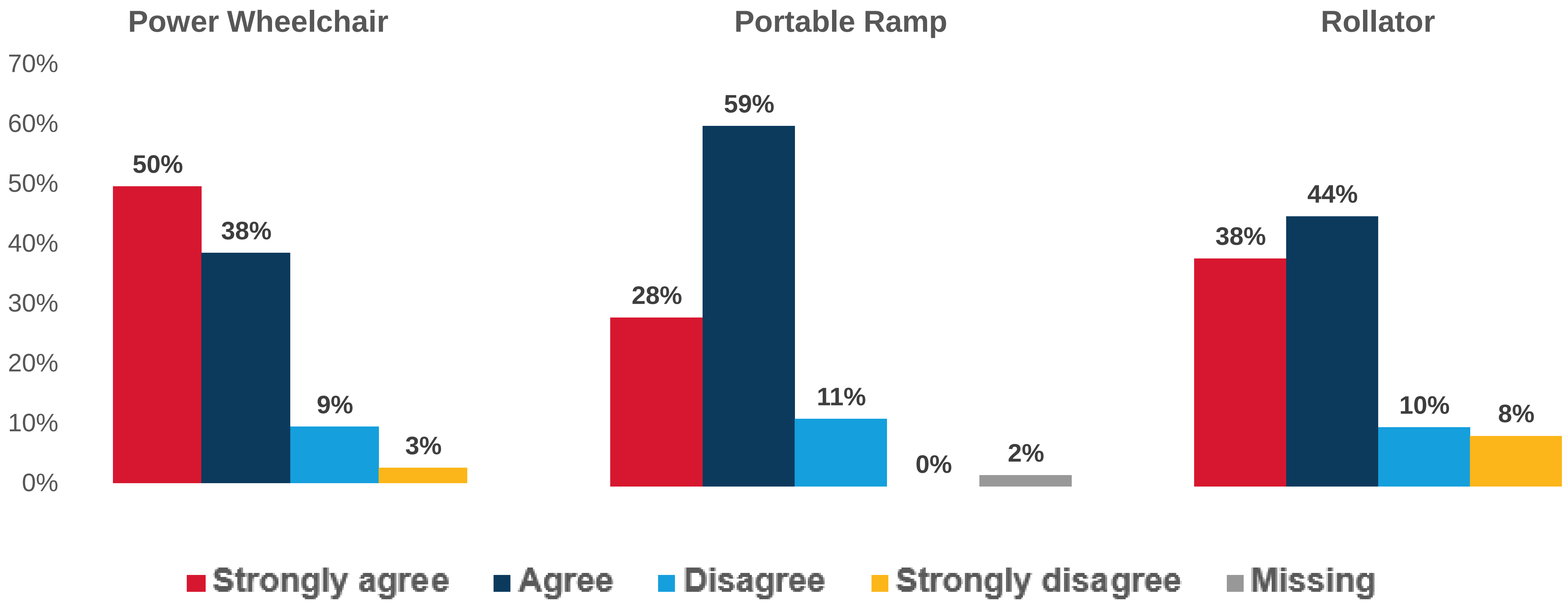
Advanced Power Wheelchair Options

- Tilt-in-Space
- Power elevating leg rests or foot platform
- Alternate drive controls
- Electronic seat elevation

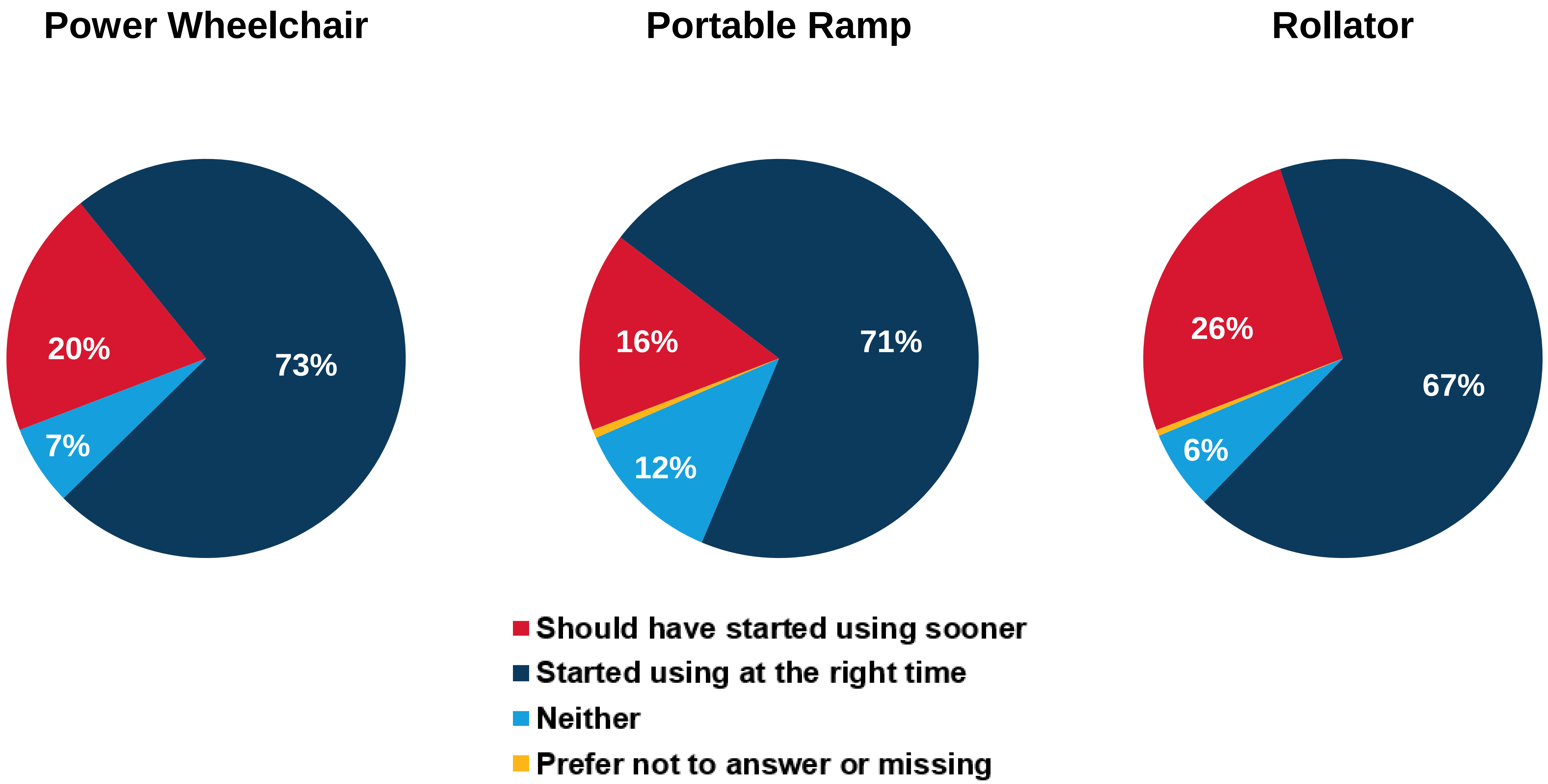
46% said insurance refused to cover **electronic seat elevation**

Results – Does equipment meet current mobility needs?

- Only participants with ALS were asked this question.



Results – Is Equipment Available When it is Needed?



Results - Reasons for Not Using Mobility Equipment

- Most participants (50% - 65%) said they did not need a power wheelchair, portable ramp, or rollator
- Remaining participants had other reasons for not using equipment

Power Wheelchair

Waiting for power wheelchair to arrive

Difficult to operate power wheelchair

Currently in power wheelchair trial run

Emotionally unprepared to start using power wheelchair

Portable Ramp

Did not know about a portable ramp, how to get one, or where to use one

Rollator

Physically unable to use a rollator

Discussion & Implications

- The ALS Mobility survey intended to quantify and illuminate the experiences of people with ALS as they navigate how to access mobility equipment.
- **Key take-aways:**
  - Power wheelchair logistics and functionality
  - Awareness on the utility of portable ramps
  - The ALS Association equipment loan program
- **Directions for action:**
  - Improving insurance coverage of seat elevation
  - Earlier access to equipment, before it's needed
- Systematic results like these inform the Association's advocacy efforts and care services programs.

Further Analysis

- More analyses are possible, such as…
  - Compare mobility equipment experiences by insurance status, type of ALS, and date of diagnosis
  - Other questions on other equipment (walkers, manual wheelchair, etc.), and equipment cost ($)

Data are free to use

ALS Mobility Survey data will be available **Summer 2022**

Harvard Dataverse
https://dataverse.harvard.edu/dataverse/NeuroVERSE

ALS Mobility results will be posted soon!

ALS Focus Results page

https://www.als.org/research/als-focus/survey-results

ALS Focus Web page
www.als.org/als-focus

Additional Focus Information

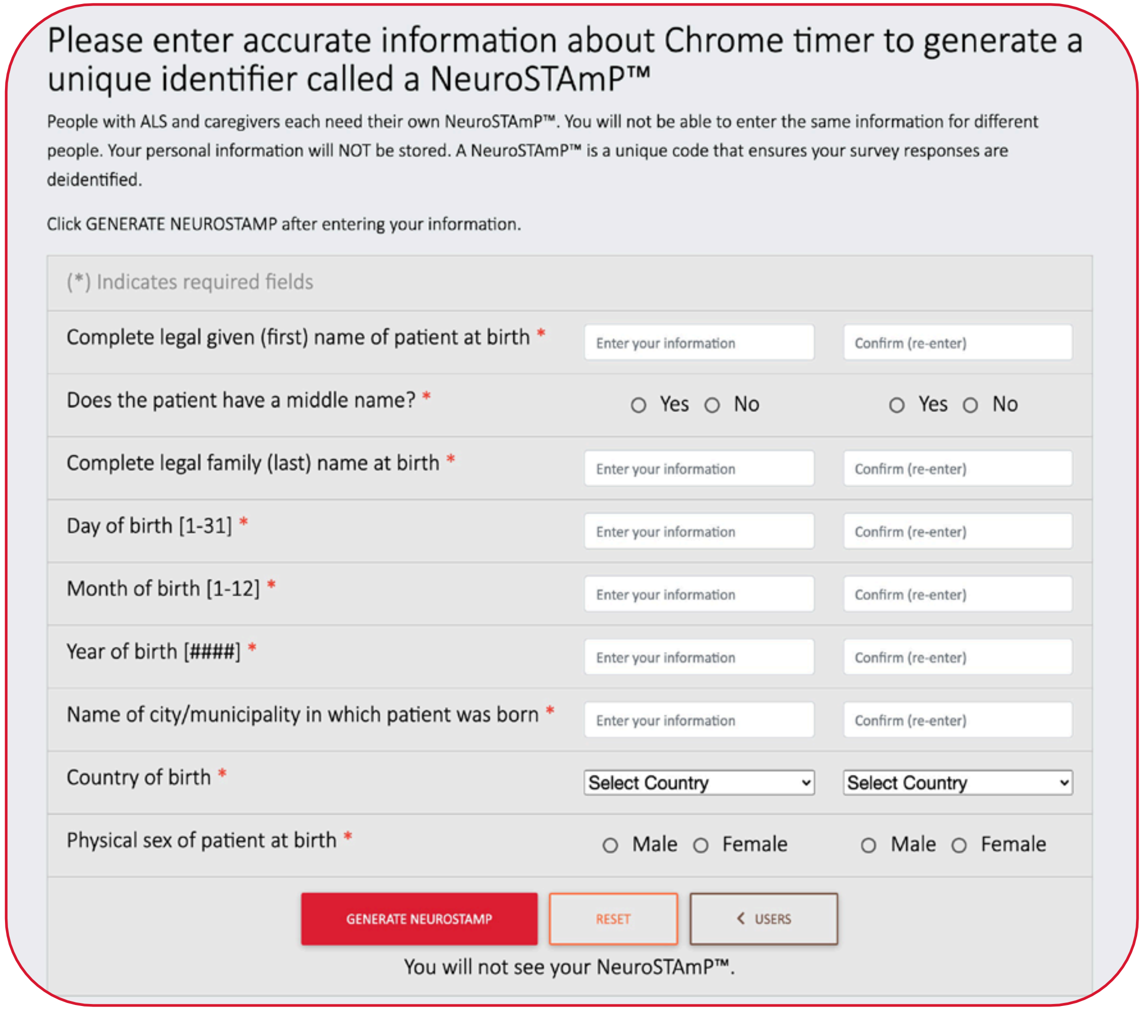
Why Participate in ALS Focus?

We need YOU to participate to ensure that we are collecting data that reflects the entire ALS community. Only you can share your experience!

- Participating in ALS Focus brings the needs and perspectives of people impacted by ALS to the center of the conversation
- Data that is systematically collected from ALS Focus surveys:
  - Impacts decisions of ALS key opinion leaders
  - Shapes ALS public policy
  - Informs clinical trial design
  - Strengthens care and service programs for our community
- Results from ALS Focus participants provide valuable direction to the Association’s advocacy efforts and care services programs

Data Privacy

- Neurological Global Unique Identifier (NeuroGUID)
  - NeuroSTAmP
  - Random code of letters and numbers
  - Used to de-identify participants’ responses



Please enter accurate information about Chrome timer to generate a unique identifier called a NeuroSTAmP™

People with ALS and caregivers each need their own NeuroSTAmP™. You will not be able to enter the same information for different people. Your personal information will NOT be stored. A NeuroSTAmP™ is a unique code that ensures your survey responses are deidentified.

Click GENERATE NEUROSTAMP after entering your information.

(*) Indicates required fields

Complete legal given (first) name of patient at birth *	Enter your information	Confirm (re-enter)
Does the patient have a middle name? *	○ Yes ○ No	○ Yes ○ No
Complete legal family (last) name at birth *	Enter your information	Confirm (re-enter)
Day of birth [1-31] *	Enter your information	Confirm (re-enter)
Month of birth [1-12] *	Enter your information	Confirm (re-enter)
Year of birth [####] *	Enter your information	Confirm (re-enter)
Name of city/municipality in which patient was born *	Enter your information	Confirm (re-enter)
Country of birth *	Select Country	Select Country
Physical sex of patient at birth *	○ Male ○ Female	○ Male ○ Female

You will not see your NeuroSTAmP™.

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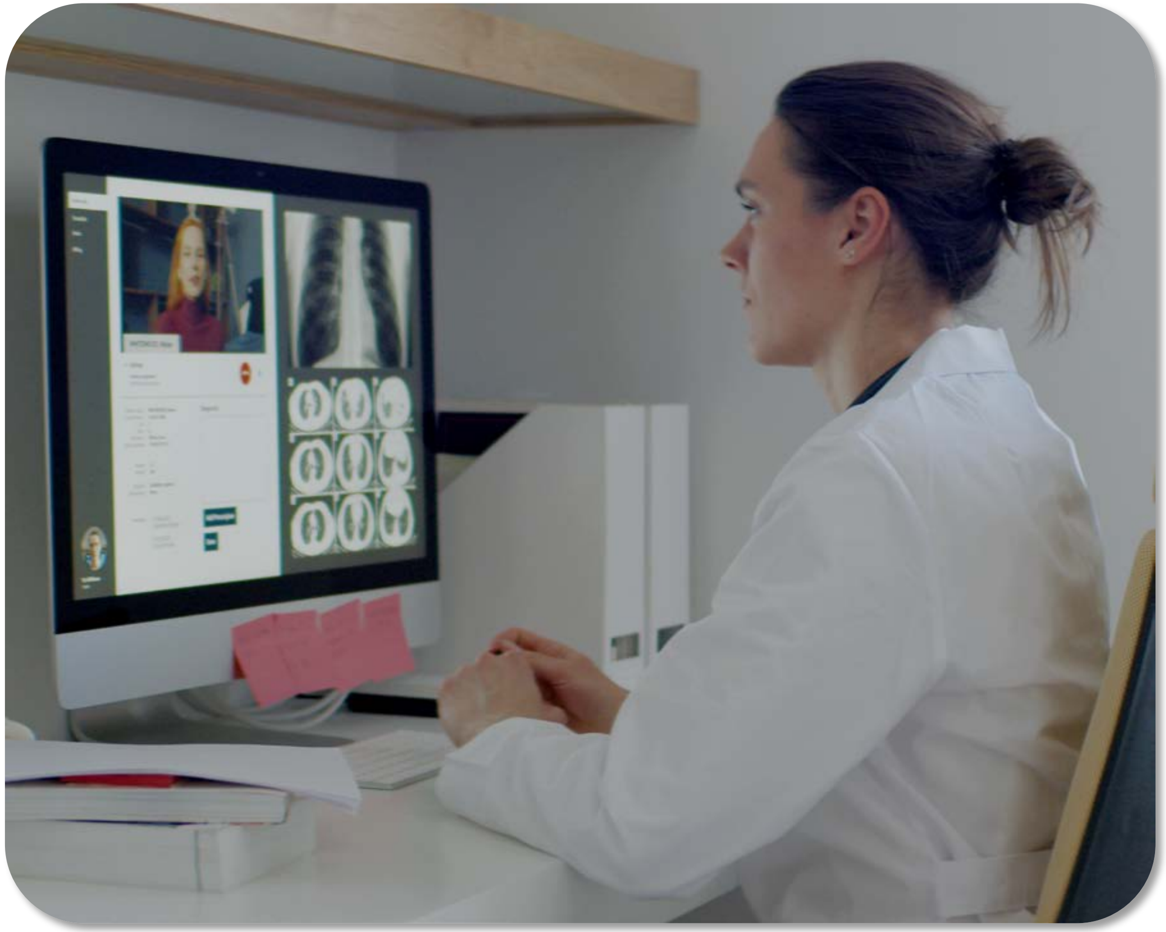
Registration Instructions

- We offer a step-by-step guide on how to register for ALS Focus and complete the surveys. You will need to register for a new account and add yourself as a user on your account.
- The full guide can be found here: https://www.als.org/research/als-focus/als-focus-registration-instructions



Thank You!

Acknowledgements

- ALS Focus Participants
- Patient and Caregiver Advisory Committee
- Steering Committee
- Working Groups
- Massachusetts General Hospital Neurological Clinical Research Institute

Current Industry Sponsors

- Apellis Pharmaceuticals
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- Cytokinetics
- Ionis Pharmaceuticals
- Revalesio

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