

SCIA Assistive Technology Survey Final Report

Policy and Advocacy Team

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1. Background

As defined by WHO, Assistive Technology (AT) refers to any tool, device, or home modification designed to help individuals overcome challenges associated with disabilities (WHO, 2016). Examples include wheelchairs, ramps, electronic communication devices, prosthetic limbs, and screen-reading software. These solutions significantly enhance the lives of people with disability, their families, and carers by increasing independence and participation in daily activities, reducing reliance on carers, improving personal relationships, minimizing carer stress and physical and emotional burnout, preventing secondary health conditions, reducing the risk of accidents and falls, and enabling people to live in their own homes for as long as possible (Cleland, J., et al. 2024).

People with spinal cord injury (SCI) rely heavily on assistive devices and technology to increase independence and enhance participation (Wagner, A., et al., 2023). To better understand the experiences of accessing and using AT, SCIA conducted this survey in response to member feedback. The goal was to identify challenges and gather insights to address the specific AT needs of members with spinal cord injuries and neurological conditions, as well as their family members and carers, enabling more effective advocacy.

The AT Online Survey was launched in August 2024 and closed in October 2024, receiving responses from 60 participants.

2. Survey Objectives

The survey sought to engage SCIA members, people with spinal cord injuries and neurological conditions, as well as their carers and family members, to gather insights into their experiences with AT and the challenges they face in accessing and using it. It covered demographics and key themes related to AT access and use. This report provides a comprehensive analysis of responses to all 18 survey questions.

Additionally, one of the survey's main objectives was to gauge participants' interest in forming a group to support the development of the final SCIA AT Policy Briefing and to remain active in advocating for the rights of people with SCI and neurological conditions in relation to AT access and usage. 23 participants among 60 who answered showed interest in joining and actively engaging in SCIA's Advocacy Campaign Network activities.

3. Methodology

The survey included open-ended and closed questions, focusing on demographics, types and quantities of AT used by people with SCI and neurological conditions, and their methods of accessing AT. It also collected additional information to better understand AT usage within the SCI community and the barriers faced. SCIA promoted the survey through its website, social media platforms, and email outreach to members over a three-month period.

4. Survey results

4.1 Demographics

The survey recorded demographics based on gender identification, age, and geographical area type, including which Australian State or Territory the respondents lived in.

The gender split across respondents included 45% identifying as female and 55% identifying as male. The age breakdown skewed toward older age brackets, with 20% of respondents aged over 66, 40% aged between 54-65, 1.6% aged between 51- 55, 30% aged between 36-50, and 8.3% aged between 19-35.

The table below summarizes the location of the 60 respondents, with a distinction between regional and metropolitan areas:

States	Metropolitan area	Regional area	Total number of respondents
AUSTRALIAN CAPITAL TERRITORY	2	4	6
NSW	24	19	43
QUEENSLAND	1	2	3
SOUTH AUSTRALIA	1	2	3
VICTORIA	1	2	3
NEW ZELAND	-	1	1
WESTERN AUSTRALIA	-	1	1
			60

When asked how they would identify themselves, 53 respondents described themselves as people with disability (88.3%), four as carers (6.6%), and three (5%) as guardians or family members of a person with disability.

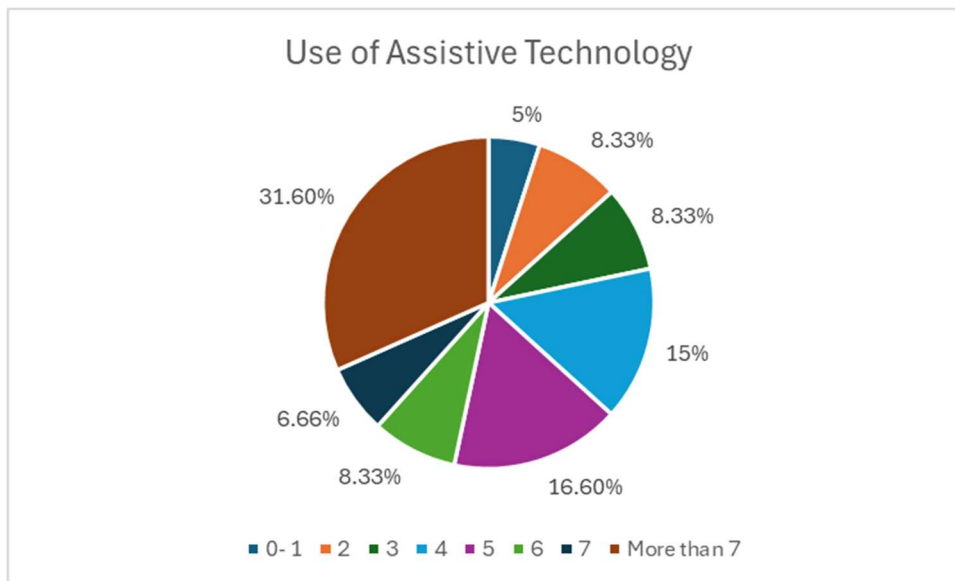
Another question explored the types of disabilities experienced by the respondents, allowing for multiple selections to account for those with more than one diagnosis, disability, or chronic health condition. Among the 60 respondents:

- **24 respondents had quadriplegia.** Of these:
 - 1 was also blind/visually impaired.
 - 1 identified as deaf/hard of hearing.
 - 3 had quadriplegia along with blindness/visual impairment and another spinal cord injury/condition.
 - 2 had an additional spinal cord injury/condition.
 - 1 had a neurological condition/disorder (e.g. acquired brain injury, MS, CP, stroke, Parkinson's disease).
- **15 respondents had tetraplegia,** with 1 also reporting a neurological condition/disorder (e.g. acquired brain injury, MS, CP, stroke, Parkinson's disease).
- **6 respondents had a spinal cord injury/condition.**
- **7 respondents had other spinal cord injury/condition,** including:
 - 1 who was also blind/visually impaired.

- 1 with an additional neurological condition/disorder (e.g. acquired brain injury, MS, CP, stroke, Parkinson's disease).
- **5 respondents had a neurological condition/disorder** such as acquired brain injury, MS, CP, Parkinson's disease, or stroke.
- **2 respondents did not specify their type of disability.**
- **1 respondent identified as deaf/hard of hearing.**

4.2 Use of Assistive Technology

When asked how many assistive technology items the participants use daily, the data shows the variety of AT usage among respondents, aligning with studies highlighting SCI's diverse needs (Florio J. et al. 2016). The breakdown is as follows:



- 3 respondents use 0 to 1 AT (5 %)
- 5 respondents use 5 AT (8.33 %)
- 5 respondents use 3 AT (8.33 %)
- 9 respondents use 4 AT (15 %)
- 10 respondents use 5 AT (16.6 %)
- 5 respondents use 6 AT (8.33 %)
- 4 respondents use 7 AT (6.66 %) and
- 19 use more than 7 AT (31.6 %)

This distribution supports the findings that people with SCI require a range of AT types to perform daily functions or assist caregivers, reflecting the complexity of their needs.

4.3 Type of Assistive Technology Used

Respondents were asked about the types of AT they use, with multiple-choice responses permitted. Fifteen categories of AT, grouped by functionality and user benefits, were defined.

The data highlights a wide variety of assistive technologies used to support daily living, mobility, and independence. Key findings include:

- **Handing Equipment:** 31 respondents use equipment such as hoists, lifters, slings, slide sheets, and transfer boards to assist with movement and transfers.
- **Mobility and Postural Support Devices:** 29 respondents use mobility aids, including wheelchairs, scooters, lumbar support pillows, bed wedges, etc., to enhance posture and mobility. One participant uses a mobility scooter and walking stick, and another uses a quad bike.
- **Adjustable Electric Beds, Chairs, and Desks:** 34 respondents benefit from adjustable electric furniture that helps improve comfort and functionality.
- **Vehicle Modification and Transportation:** 29 respondents utilize motor vehicle adaptations, enabling independent transportation.
- **Computers, Smartphones, and Peripherals:** 23 respondents use advanced technologies such as voice and eye recognition software, highlighting the importance of technology for communication and access.
- **Pressure Care and Prevention Equipment:** 34 respondents rely on equipment such as wheelchair cushions, pressure air mattresses, and silicone fiber heel protectors to prevent pressure sores and ensure comfort.
- **Daily Living Aids:** 32 respondents use products like reachers, bookstands, and wheelchair cup holders to assist with daily tasks.
- **Personal Communication Devices:** 16 respondents use devices specifically designed for communication, aiding social interaction and work-related tasks.
- **Employment-Specific Aids:** 6 respondents use specialized aids to support employment needs, demonstrating the role of AT in enhancing vocational opportunities.
- **Home/Environmental Adaptations:** 38 respondents benefit from environmental modifications, including lifts, automated doors, and lighting control systems, to facilitate independent living at home.
- **Breathing Support Devices:** 12 respondents use equipment such as PAP machines for respiratory support. 1 respondent uses Nebuliser to aid in clearing aspiration due to dysphagia.
- **Vision Impairment Aids:** 6 respondents use products to assist with vision impairments.
- **Prosthetics and Orthotics:** 11 respondents utilize prosthetic and orthotic devices to improve mobility and function.
- **Educational Aids:** 4 respondents use aids such as modified computer hardware and braille textbooks for educational purposes.

These findings underscore the variety of assistive technologies required by people with SCI and neurological conditions and their carers to enable greater independence in daily activities. The diversity of AT solutions reflects this population's wide range of needs, from mobility aids and pressure care devices to advanced communication technologies and home and work adaptations.

4.4 Funding Sources for Assistive Technology

Participants reported diverse funding sources for their AT. Among the 39 respondents who answered that they fund themselves, The National Disability Insurance Scheme (NDIS) was the most common, with 27 participants utilizing it, including 12 who combined it with other sources. 5 respondents

reported receiving funding through the Aged Care system, while 8 used Lifetime Care or equivalent state schemes. 2 respondents accessed the Job Access/Employee Assistance Fund, and 1 respondent relied on private insurance and grants.

4.5 Challenges in Accessing and Using Assistive Technology

Respondents identified several significant barriers to accessing and using AT. High costs emerged as the most pressing issue, reported by 42 respondents. Many found accessing funding overly complex, with 28 participants highlighting this as a challenge. Another 25 respondents noted the lack of appropriate knowledge and technical skills among professionals such as occupational therapists (OTs), health professionals, and AT service providers. Additionally, 33 respondents reported a lack of information about available AT products, while 18 noted limited training for support workers and a further 18 long wait times for equipment maintenance and repair services.

Respondent insights underscored the financial strain of AT costs, with one respondent stating, *“Cost is ridiculous. My Batec (power assist) is \$16,500 + my manual wheelchair is \$10,500. I can buy the fanciest e-bike on the market which has the same electronics for less than half the price of my power assist that only has one wheel! Disability AT is an absolute joke with the prices they charge. They are taking advantage of the sector and all of us because they know they can.”*

Another respondent said: *“Battery-operated things tend to run out fast, adding extra expense. Cost of maintaining AT with NDIS funding is hard due to the lack of funds available in plans”.*

“Difficult and costly to get equipment serviced properly in Townsville (regional area)”.

Time-related challenges were also prevalent, with many describing lengthy waits for funding approvals and repair services. One participant noted, *“I’ve been waiting 12 months for a new Knee Ankle Foot Orthosis (KAFO). I’ve lost a significant amount of weight, and my I’ll fitting older one is causing pressure sores. I have finally been cast for a new one after NDIS took 9 months to process the application; it has taken 3 months to make, and I am still not ready, which is significantly impacting my mobility. I’m an incomplete paraplegic and walk short distances with my KAFO.”*

Another respondent stated: *“Repairs of wheelchairs, showering chair custom seating, adapted seating, car hand control adaptations and smart drive have all been long processes that are slowed initially by red tape then with poor responses to requests and long wait times for components, skilled staff to action repairs or adaptations required. Pre-approved solutions that can be tailored to be used when needed would be far more beneficial for all parties involved by drastically reducing costs but, more importantly- speeding up the process.”*

“The wait time for products to be approved and sent out can be hard if it’s something you need quickly”.

Warranty and maintenance issues were particularly problematic for users who moved interstate or required specialized repairs. *“I have a sit-to-stand lounge chair. Receiving any kind of warranty work, especially if you have moved interstate, is basically impossible”* said one respondent.

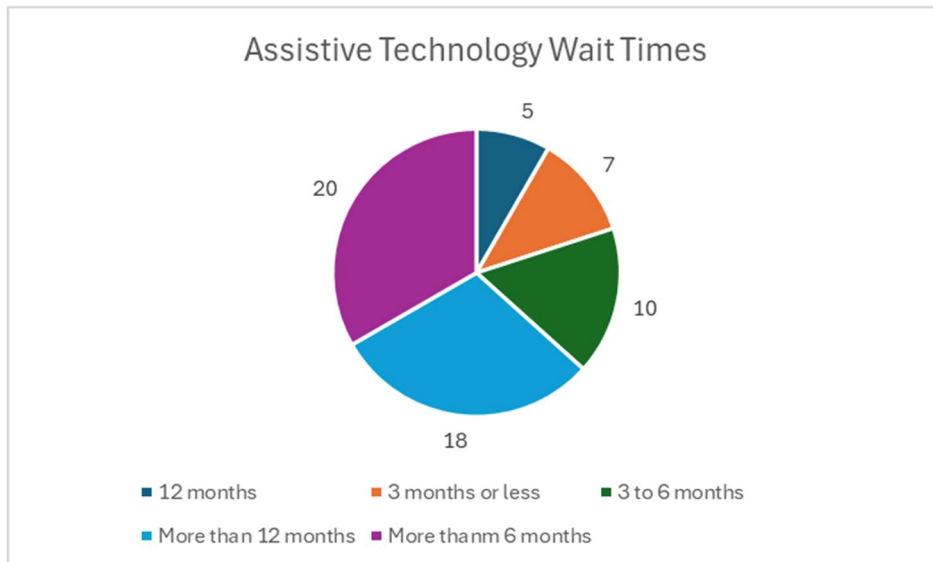
Regarding the lack of expertise and appropriate training from the Occupational Therapists (OTs) and health professionals, one respondent said: *“Rurally, many OTs do not have SCI experience for AT, such as wheelchairs and seating, which can differ from other “seated” disabilities”.* Another one: *“My previous OT had scripted the incorrect wheelchair. It is totally useless for use, despite many trials with*

the OT. Although I have a new OT, and the wheelchair has been modified, it still does not meet my needs. I see the NDIS as a money-grabbing opportunity for some providers”.

Other respondents stated that their most important challenges were related to identifying and knowing new AT products available that could help them in their daily activities. One person with spinal cord injury said: *“The biggest challenges are generally around identifying any new and more appropriate equipment/technology that makes your day-to-day life easier. Also, tricky finding information on how best to use equipment, e.g., iPhone”* another one confirmed: *“My biggest problem is keeping up with the assistive technology advances.”*

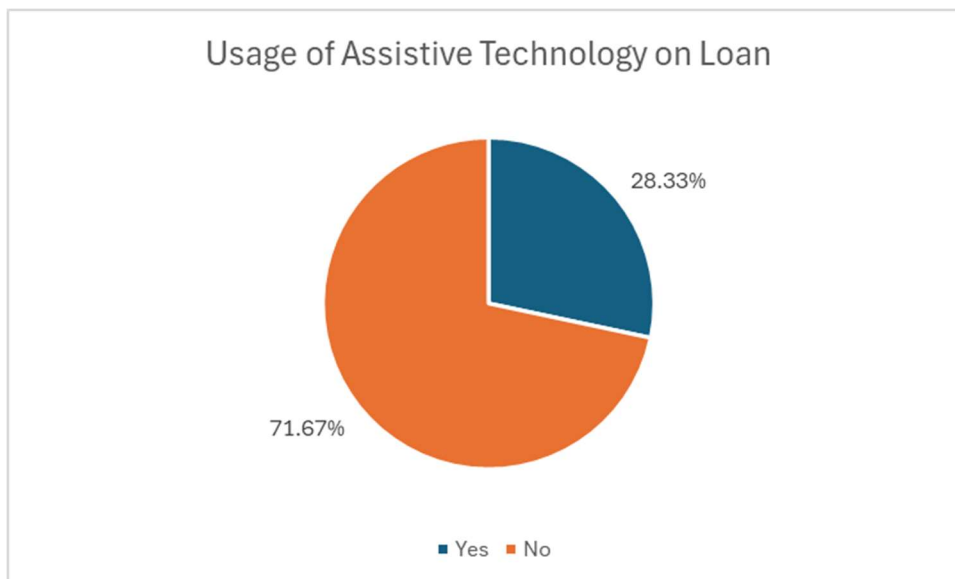
4.6 Longest Wait for Assistive Technology and Smart Home Modification

The survey results regarding the longest time respondents waited for an AT solution: 7 respondents indicated they waited for 3 months or less, 10 respondents waited between 3 to 6 months, 20 respondents waited more than 6 months, 5 selected 12 months, and 18 waited more than 12 months.



4.7 Usage of Assistive Technology on Loan

The survey revealed that 43 (71.67%) of 60 respondents had never used AT on loan. Among the 17 (28.33%) participants who had, the primary reasons included immediate post-hospital discharge, waiting for prescribed AT, environmental changes, and health-related adjustments. 4 respondents cited other unspecified reasons.



4.8 Sources of Information About Assistive Technology

Respondents used various methods to learn about new AT products. Personal research, including internet searches, social media, and subscriptions to AT magazines, was the most common, with 53 responses. Word of mouth was also significant, cited 33 times. Events and expos were mentioned 19 times, while service providers and AT suppliers were noted 16 and 15 times, respectively.

4.9 Priorities for Advocacy

Respondents highlighted several key areas for improvement in the AT sector, emphasizing the urgent need to address barriers like cost, access, and time. Cost reduction emerged as a top priority, with many citing the high expense of AT as a significant obstacle. As one respondent explained, *"High costs were the next barrier once an appropriate AT was identified,"* underscoring the financial strain individuals face when accessing essential equipment.

Access was another critical issue, encompassing faster approval processes, reduced wait times, and better availability of AT products and trials. One participant shared, *"If it were for me, my three priority areas would be cost, time, and access. Access was a big one for me as I had no idea what I needed or where to start."* This sentiment reflects the broader challenge of navigating AT options without sufficient guidance or information.

Education and awareness were also deemed essential. Respondents highlighted the need for better training for health professionals, particularly occupational therapists (OTs), and greater public knowledge about available AT. For instance, one individual emphasized the importance of *"a lot more information and examples around what is available and how best to use certain equipment to assist my independence."*

Streamlined processes within funding mechanisms like the National Disability Insurance Scheme (NDIS) were frequently mentioned, with respondents calling for improvements to bureaucratic

hurdles and approval timelines. Others expressed frustrations with delays, stating, *"The time it takes for equipment to be approved through funding providers"* creates unnecessary hardships.

Maintenance and repair services were another area of concern, particularly in rural and regional areas. One participant shared their preference for having *"spare parts supplied at the time of purchase,"* while another called for *"improved response time for repairs and better-trained OTs."*

Specific suggestions from respondents included creating a centralized register of qualified AT specialists, exploring second-life AT markets, and offering adaptive clothing options. Enhanced accessibility to AT expos and events, especially in regional areas, was also recommended to bridge the information gap. For example, a participant noted the importance of *"managing the cost, being able to find new products, and training on new technology."*

Above all, respondents emphasized the need for solutions that promote independence. As one individual succinctly put it, *"Anything that will promote independent living so that I do not have to rely on others."* These perspectives collectively highlight the multifaceted challenges and opportunities for improvement within the AT sector.

5. Conclusion

In conclusion, the results of the SCIA AT Online Survey provide a comprehensive understanding of the challenges and opportunities in accessing and using AT for people with spinal cord injuries (SCI) and neurological conditions. The survey reveals several important findings that shed light on the diverse needs of this population, the barriers they face, and their priorities for future advocacy.

One of the most striking findings from the survey is the sheer variety of assistive technology used by respondents, with many relying on multiple devices to assist with mobility, communication, daily activities, and environmental adaptations. The data shows that 31.6% of respondents use more than seven AT items daily, underscoring the complexity and scope of their needs. These technologies range from mobility aids like wheelchairs and scooters to more specialized devices such as pressure care equipment, prosthetics, and advanced communication tools. The diversity of AT usage highlights that a one-size-fits-all solution is not viable, and people with SCI and neurological conditions require personalized, multi-faceted approaches to meet their unique needs. Additionally, 38 respondents rely on home and environmental modifications, emphasizing the importance of tailored adaptations to support independent living and participation in daily life.

Another critical finding from the survey is the significant financial burden that AT places on people with SCI and neurological conditions. High costs were the most frequently cited challenge, with 42 respondents identifying it as a major barrier. This is compounded by the complexity of accessing funding through systems such as the National Disability Insurance Scheme (NDIS) and other government support programs.

While the NDIS is the most common funding source, with 27 respondents reporting its use, many participants also indicated that obtaining AT through these schemes is slow, bureaucratic, and difficult to navigate. This is particularly concerning for individuals who require timely access to equipment to maintain or improve their quality of life. The survey responses strongly suggest that reforming funding processes to streamline approvals and reduce wait times would significantly alleviate the strain on individuals and their families.

The lack of knowledge and technical expertise among professionals (OTs, health professionals, etc.), also emerged as a significant challenge. Many respondents reported that their OTs lacked experience with SCI-specific AT needs, leading to incorrect recommendations. This issue is especially prevalent in rural and regional areas, where specialized knowledge and access to qualified professionals are limited. Participants expressed frustration with the inability to access AT solutions suitable for their specific conditions, highlighting the importance of ongoing training for OTs and other health professionals to ensure they are equipped with the latest information on SCI-specific technologies. Furthermore, the lack of awareness about available AT products and their proper usage was another recurring theme, with many participants indicating that they struggled to keep up with new developments in assistive technology.

Wait times for repairs, replacements, and new equipment were another concern. Many respondents described lengthy delays in receiving new AT or necessary repairs, with some waiting up to 12 months for critical equipment. This lack of timely access to AT not only impacts the physical health and mobility of people with SCI but also contributes to psychological and emotional distress. One respondent shared the frustration of waiting for months for new equipment, which exacerbated their mobility challenges and led to additional health issues such as pressure sores.

Streamlining repair and maintenance services and ensuring quicker access to equipment would help mitigate these problems and reduce the stress, anxiety, and further physical deterioration associated with prolonged wait times.

AT not only supports the independence and quality of life of people with spinal cord injury and neurological conditions but also significantly eases the burden on their carers. By improving mobility, communication, and daily living activities, AT reduces the physical and emotional strain on carers, enabling them to focus on providing better overall care.

The survey also highlights the diverse ways in which individuals learn about AT. Personal research, including internet searches, social media, and subscriptions to AT magazines, was the most common method, followed by word of mouth and exposure at events or expos. This suggests that many individuals rely on self-directed approaches to discover new technologies, which could be improved with more accessible and centralized information sources. Creating better avenues for knowledge-sharing, such as specialized AT expos in regional areas and more comprehensive guides on available products, could empower people with SCI to make more informed decisions about the technologies that best meet their needs.

In terms of advocacy priorities, cost reduction emerged as the most urgent issue, with many participants expressing that the financial burden of AT was unsustainable. However, there were also strong calls for faster approval processes, better access to product trials, and more reliable and accessible repair services. Participants suggested that centralizing information about AT specialists, creating more affordable hire options, and improving accessibility to product trials would all improve the overall experience of using AT. These findings reflect the need for a more holistic and user-centered approach to AT access, where individuals are provided with the necessary equipment, support, and resources required to use it effectively.

In summary, the SCIA AT Online Survey provides valuable insights into the needs, challenges, and advocacy priorities of people with spinal cord injuries and neurological conditions. The findings highlight the diverse range of ATs required to support their independence and participation in daily life, the financial and logistical barriers to accessing AT, and the need for improved training and knowledge-sharing among professionals, service providers, and support workers. Addressing these issues through streamlined funding processes, better access to information, and targeted advocacy

efforts will be crucial in ensuring that people with SCI and neurological conditions can fully benefit from the advancements in assistive technology, ultimately enhancing their and their carer's quality of life and independence.

The Policy and Advocacy team appreciates the input from members and the SCI and Neuro community in this survey and plans to leverage the insights to tackle the identified barriers and challenges. SCIA will use the information provided in this report to develop an advocacy policy briefing on AT. This report will be distributed to respondents, made available on the SCIA website, and shared with relevant agencies. The survey findings will be crucial in informing future policy initiatives and advocacy actions focused on enhancing AT access and utilization for people with SCI and neurological conditions.

6. References

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