

Erinn, diagnosed 1997



Amy, diagnosed 1988



MS Technology Collaborative



Chris, diagnosed 2005

“Staying Connected: An Investigative Survey of How Technology Affects People Living with MS”

Executive Summary

Commissioned by MSTechnology Collaborative



Introduction

In today's fast-paced, digital environment, more people are embracing the technology that has revolutionized the way we conduct business, interact with our family and friends, and manage our households. For some people with multiple sclerosis (MS), technological advances may offer benefits, but they can also pose challenges. Due to some MS symptoms, everyday tasks such as seeing a blinking cursor on a computer screen or manipulating a mouse may prove difficult. Industry leaders think they may be able to change this.

In a landmark alliance known as the MS Technology Collaborative, Bayer HealthCare Pharmaceuticals, Microsoft, and the National Multiple Sclerosis Society have come together to better understand how people with MS use technology and to connect them to information and resources to help move their lives forward and manage their disease. A project steering committee of people with MS from across the country oversees the efforts of the MS Technology Collaborative to help ensure that the outcomes from the project address unmet needs of the MS community.

MS is an unpredictable neurological disease that most often is diagnosed in people between the ages of 20 and 50. MS can cause problems with walking or maintaining balance, visual impairment (optic neuritis), lapses in memory, inability to solve problems or pay attention for long periods of time, pain, sexual dysfunction, spasticity, depression or mood swings, and disturbances in bladder or bowel function. These problems might be permanent, or they might come and go without warning. MS affects an estimated 400,000 people in the United States. While there is no cure, early and effective treatment is an important component of helping to control its progression.

One goal of the MS Technology Collaborative is to explore the ways in which effective treatment and the use of accessible technology can together enhance the lives of people with MS. Towards this end, the MS Technology Collaborative commissioned a comprehensive survey of people with MS to understand how they use technology throughout their disease and in their professional and personal lives.

Background & Objectives

“Staying Connected: An Investigative Survey of How Technology Affects People Living with MS” is a key initiative of the MS Technology Collaborative and a comprehensive examination of the role of technology among people with MS. This first-of-its kind initiative – exploring the challenges and opportunities technology poses to people living with MS – sought to identify unmet needs that will guide the MS Technology Collaborative in connecting the MS community to the Collaborative's unique combination of resources:

- Elevating awareness and understanding of *accessible technology*
- Offering greater opportunities for *connection* to the MS community and other sources of support
- Expanding access to information about *treatment* options



Methodology

StrategyOne, an applied-research consulting firm conducted the survey “*Staying Connected: an Investigative Survey of How Technology Affects People Living with MS*” among 2,390¹ American adults with MS. The survey was implemented via online and telephone, depending on the preference of the respondent, from May 8, 2007 through June 6, 2007 using the field services of Harris Interactive Service Bureau.

Overview of Research Findings

“*Staying Connected: An Investigative Survey of How Technology Affects People Living with MS*” revealed that technology plays a vital role in the lives of many people living with multiple sclerosis (MS) who experience visual, dexterity, and cognitive challenges. However, relatively few are using the assistive technologies available that could help them overcome many of these challenges.

This survey establishes the vital role that technology can play in the lives of people with MS and highlights the need for better information and more education to help people understand how they could benefit from making technological adaptations.

¹ The margin of error for the total sample (N=2390) is plus or minus 1.98 percentage points at the 95 percent confidence level.



Key Themes

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- Technology Adaptations: An Untapped Resource p. 8
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Key Research Findings

Independence and Connections Essential Priorities

The goals of remaining *active* and *engaged* are extremely important to survey respondents living with MS. Ninety-six percent of respondents agree that “independence is important to me and I do as much for myself as I can”; while 93 percent agree that “I do whatever I can to remain as active as possible.”

Respondents also emphasize the importance of *connecting* with others to cope with their MS. The majority agree that “talking to others with MS helps me face challenges” (52%) and “I feel comfortable asking for assistance in making accommodations to my MS” (56%). At the same time, 50 percent disagree that “my MS is a personal and private matter for me, only to be shared with close friends and family.” One quarter of the population participates in some type of support group (either in-person – 19% or online – 8%) for people living with MS.

The above findings suggest that people with MS may be well-served by increased utilization of technology.



A Technology-Reliant Population

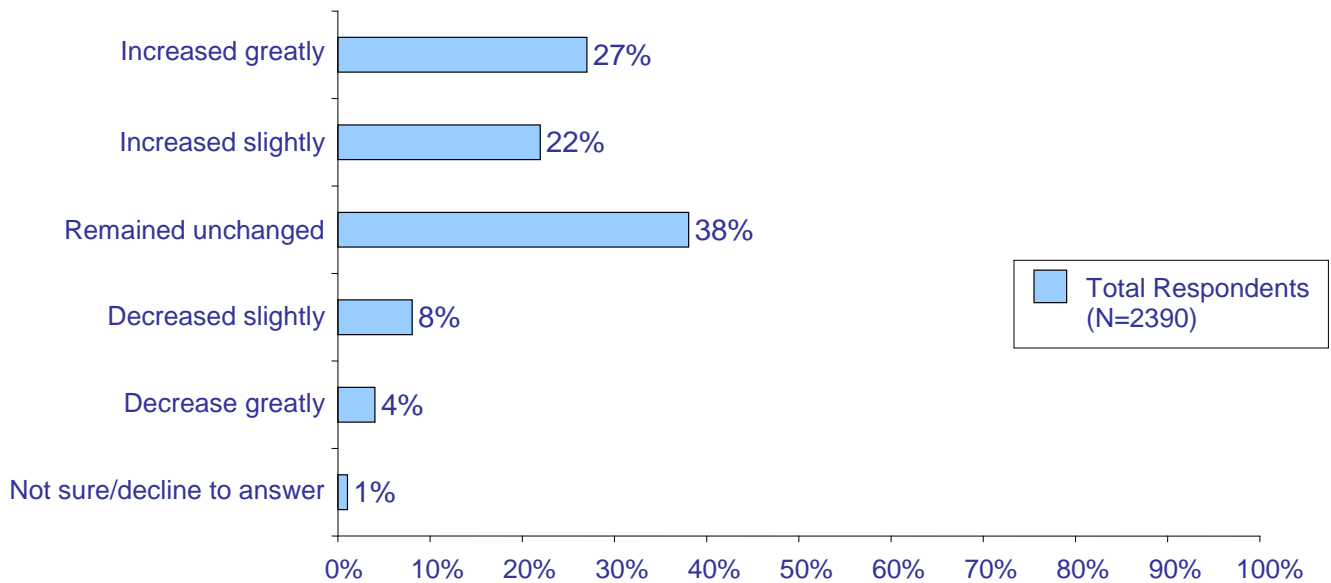
Indeed, the MS population appears to be highly oriented towards technology. Seventy percent of respondents agree that they are “very interested in keeping up with, and using, the latest technology” (only 9% disagree).

Nearly all survey respondents use computers (93%), the Internet (93%), cellular phones (91%). These usage rates are significantly higher than those observed in the general US adult population (80% computers, 75% Internet, 69% cellular phone)¹. Most survey respondents report strong levels of comfort with these tools as well (computers 6.3 on a 7-point scale, the Internet 6.4 on a 7-point scale and cellular phones 6.2 on a 7 point scale).

People living with MS perform many tasks and functions online, with the top reported activities among Internet users being e-mail (97%), research (79%), shopping (73%), getting the latest news (68%), and managing their finances (60%).

Moreover, 49 percent report that their use of technology has increased since being diagnosed with MS, while only 12 percent indicate that it has decreased.

Since your diagnosis with MS, would you say that your use of technology has...?

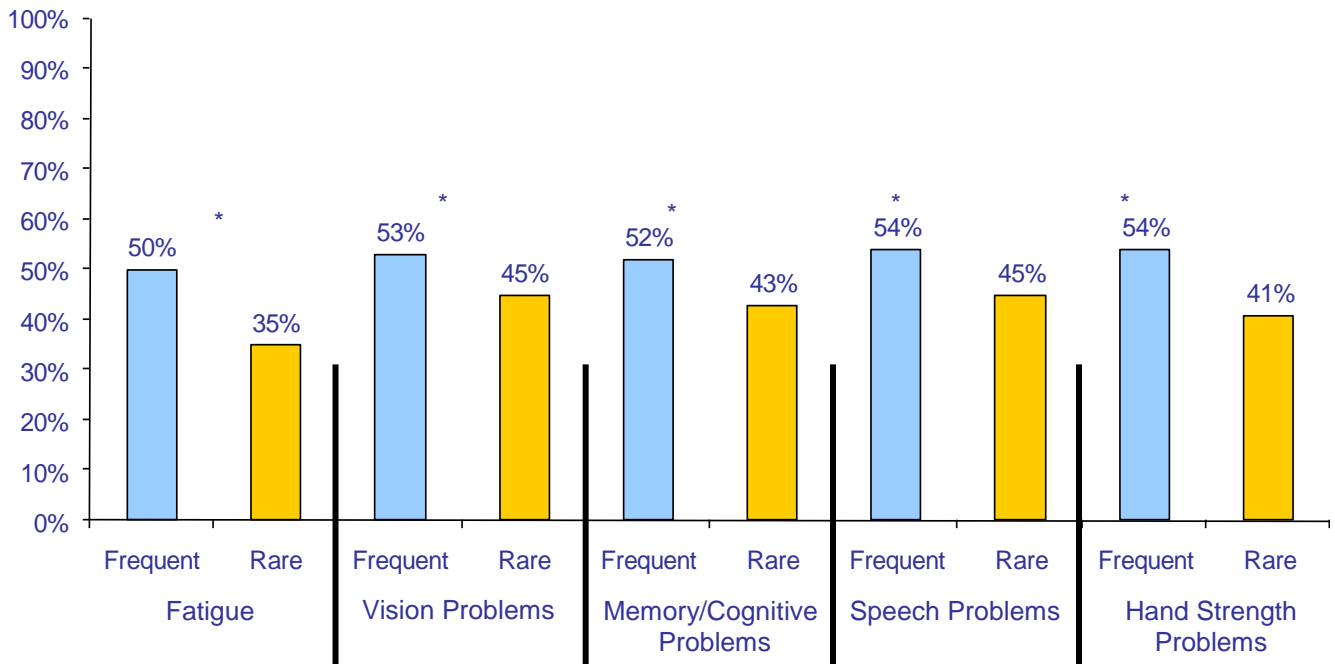


¹ Source: Simmons National Consumer Survey, Spring 2006 Adult full year survey (May 2005- June 2006)



Nearly half (48%) agree that “technology plays a vital role in helping me live with MS” (only 17% disagree). The more frequently a person experiences MS symptoms, the more likely they are to agree with this sentiment.

“Technology plays a vital role in helping me live with MS” % Agree (somewhat/strongly)



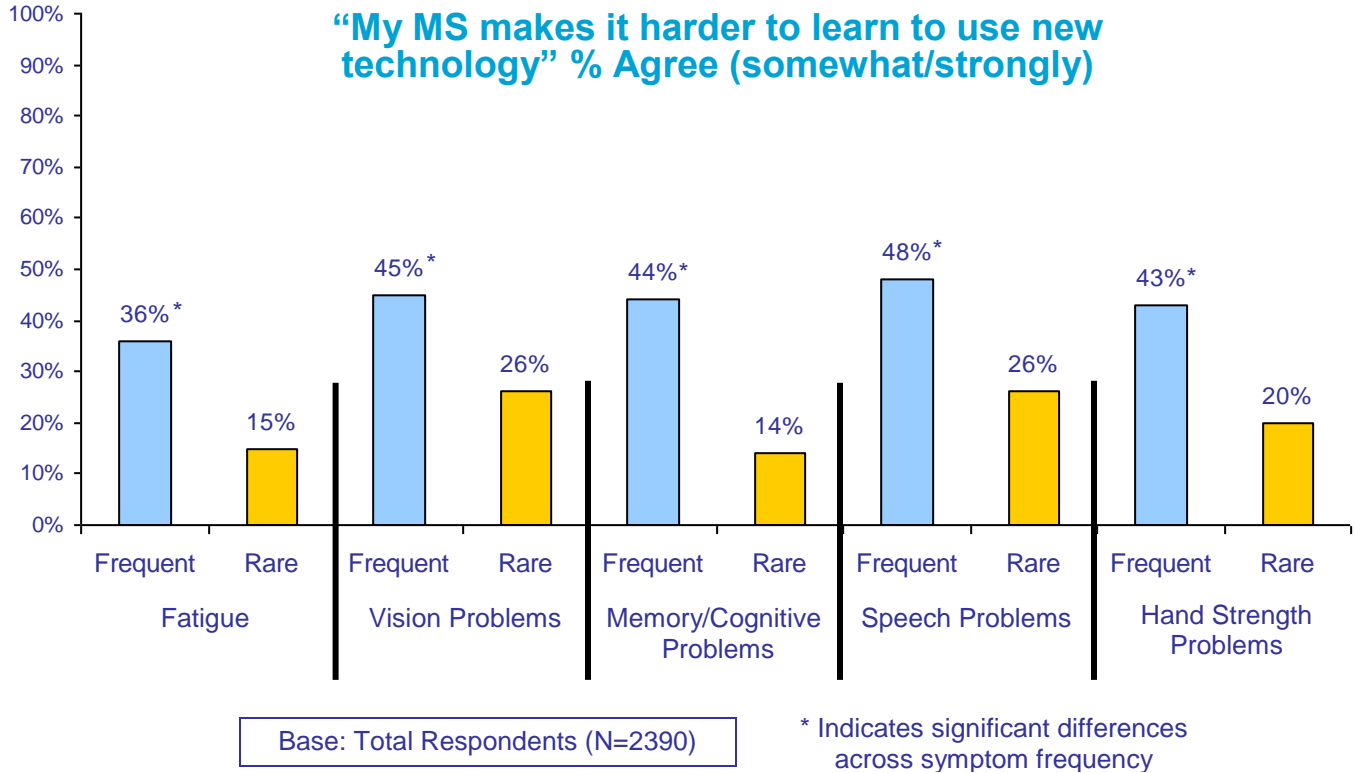
Base: Total Respondents (N=2390)

* Indicates significant differences across symptom frequency



Technology Poses Its Own Challenges

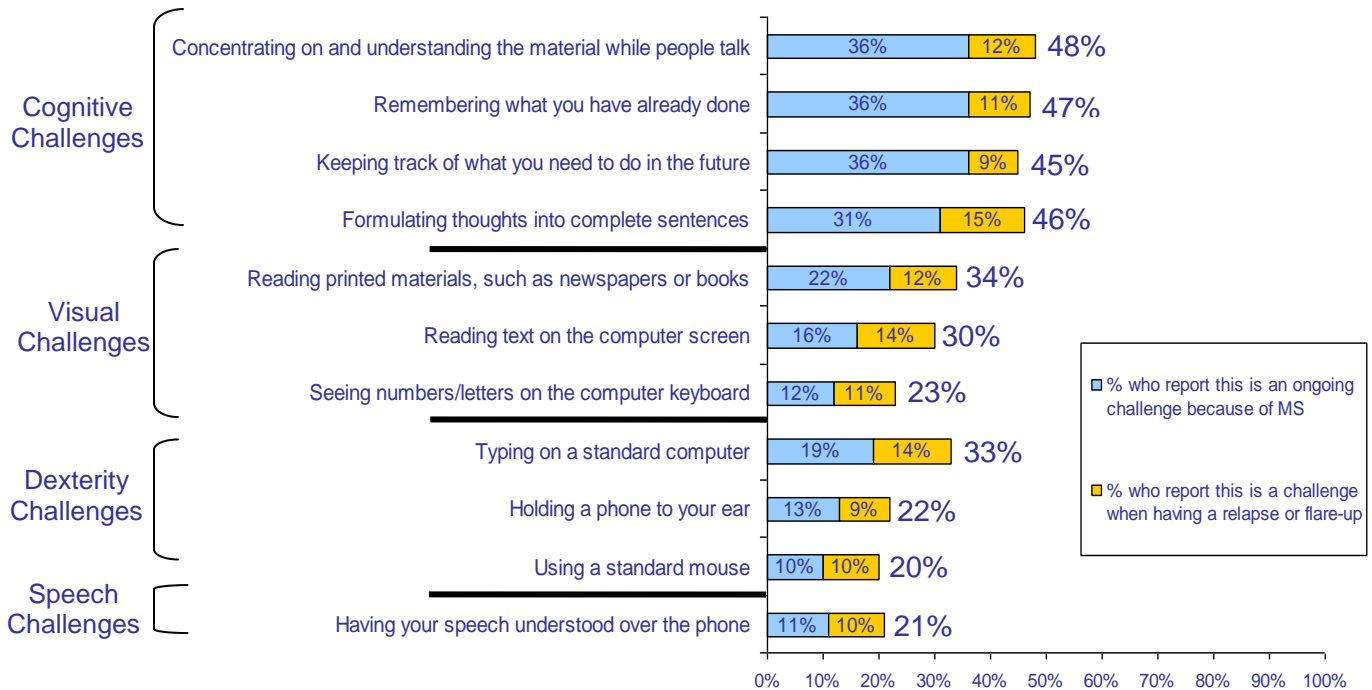
While respondents are highly reliant on technology, some face challenges specific to MS in using various tools and applications. One-third (33%) agree that “my MS makes it harder to learn to use new technology.” People who experience MS symptoms more frequently are significantly more inclined to agree with this sentiment.





Respondents report that MS poses challenges to many specific tasks – either on an ongoing basis or during flare-ups – with cognitive issues featuring most prominently.

For each one, please indicate if the task or goal is challenging to you personally, because of your MS.

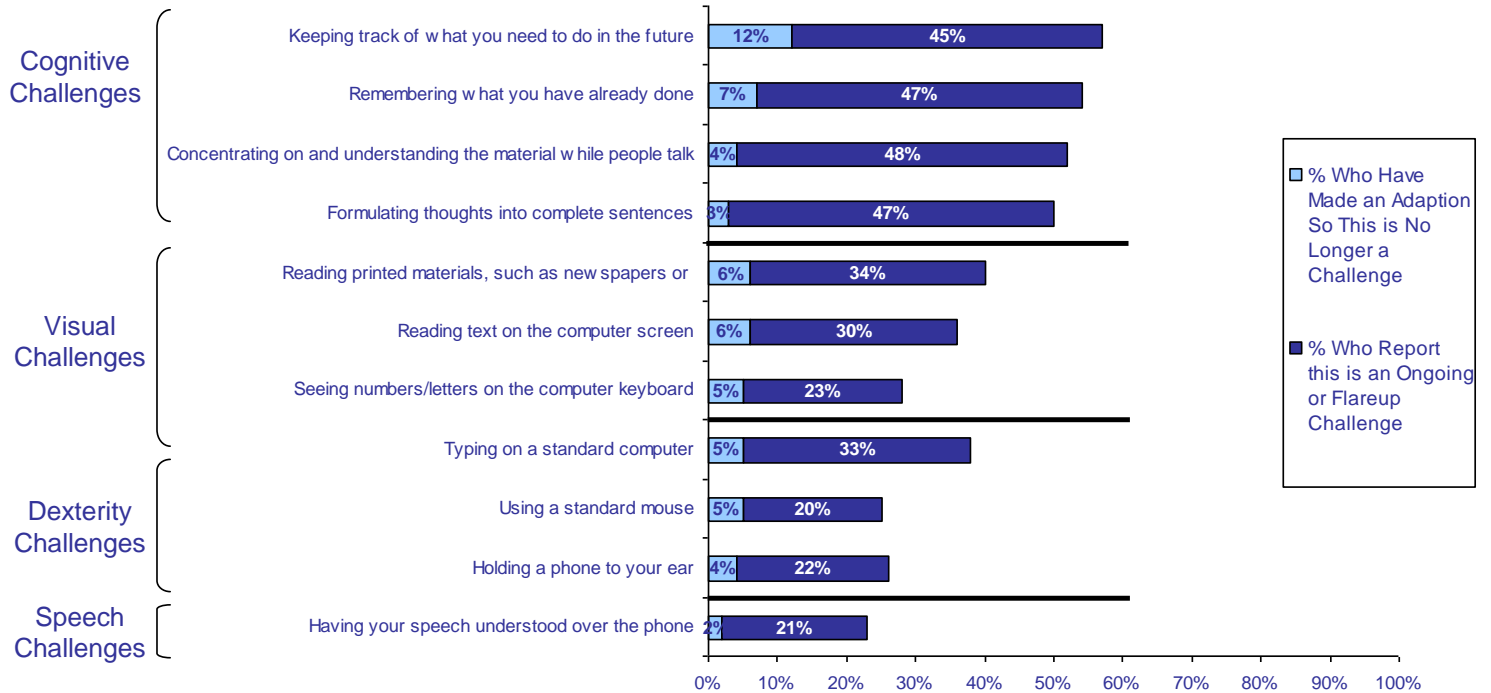




Technology Adaptations: An Untapped Resource

For the most part, the MS population is not taking advantage of accessible technology and adaptations available to them. For the same list of challenges, far fewer people with MS report having “made an adaptation so this is no longer a challenge” than report facing an MS-related challenge. Even among those facing more severe MS symptoms, very few have made adaptations to address their challenges.

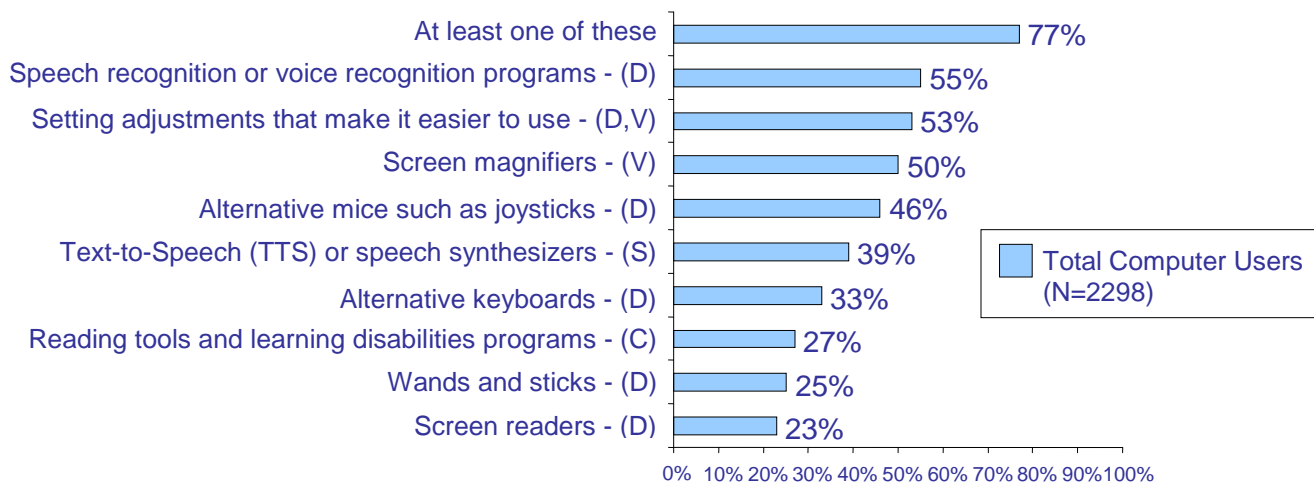
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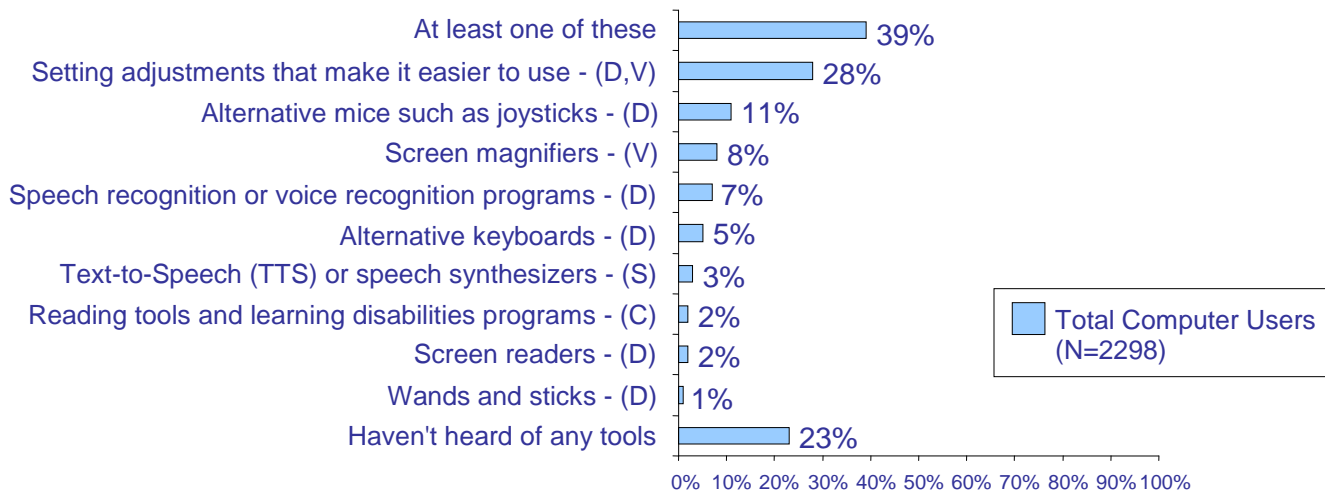


Fewer than a quarter (23%) say that they have ever made changes to a computer to manage a challenge they were experiencing due to MS (e.g., adjusted settings, added new software, or acquired a more accessible version of the technology). While awareness of specific accessible technology tools is moderate (77% have heard of at least one tool tested), very few indicate using specific forms of accessible technology. Respondents facing dexterity challenges are significantly more likely than others to have used settings, adjustments, alternative mice, speech recognition, and alternative keyboards. People with visual challenges are significantly more likely than others to have used settings, adjustments and screen magnifiers.

Have you ever heard of any of the following types of accessible technology?



Have you ever used any of the following types of accessible technology?



(C) = cognitive AT tool (D) = dexterity AT tool (S) = speech AT tool (V) = visual AT tool



Benefits & Barriers to Making Adaptations

Benefits: Respondents who have used accessible technology are more likely than others to give high ratings to many items related to employment, connections and treatment.

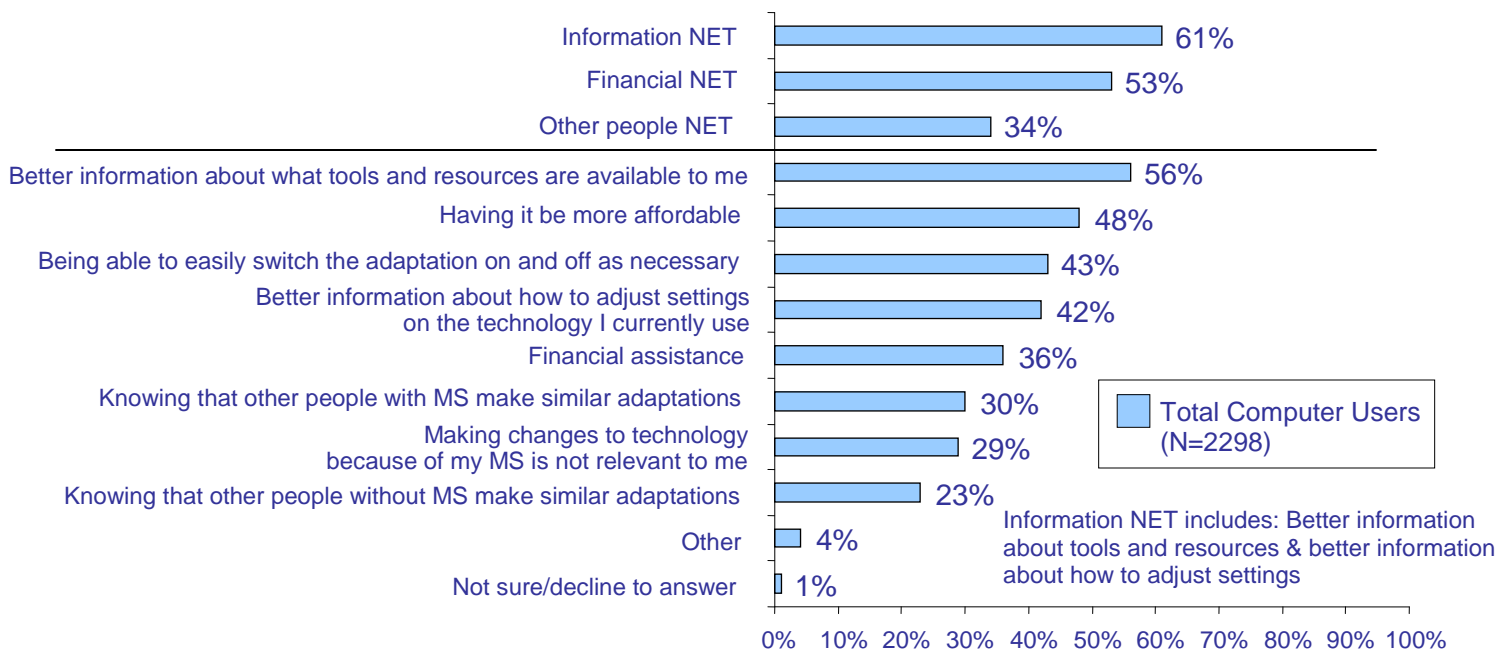
	Used AT** (N=888)	Did not use AT (N=883)
<i>% Agree (Somewhat/Strongly)</i>		
Technology plays a vital role in helping me live with MS	62%*	40%
The Internet helps me be my own advocate with MS	63%*	48%
Technology makes it possible for me to keep working with MS <i>[among employed respondents]</i>	55%*	32%
<i>High satisfaction (5-7 on 7 point scale) with the role of technology in...</i>		
Keeping you connected to important people in your life	76%*	66%
Keeping up with new developments in MS medications	70%*	65%
Keeping you engaged in the activities that matter to you	57%*	48%
Connecting you to resources to assist people living with MS	54%*	48%
Helping you select the medication that's right for you	46%*	40%
Making online connections to other people living with MS	34%*	25%
Providing you a place to socialize without judgment	32%*	26%

** Used at least one of the Accessible Technology tools mentioned in survey



Barriers: Better information tops the list of changes that would make it easier for people to take advantage of adaptations and accessible technology. Perceptions of expense and concerns about standing out are not as big a barrier: only about a third (37%) of respondents with MS believes that “it is too expensive to adapt technology to deal with MS-related challenges,” and only 19 percent say that they are “reluctant to use special technology that will stand out as obviously different.”

Which of the following would make it easier for you to make changes to technology that would benefit you because of your MS?





Conclusion

In today's fast-paced, digital environment, more people are embracing the technology that has transformed the way we conduct business, interact with our family and friends, and manage our households. For some people with multiple sclerosis (MS), technological advances may offer benefits, but they can also pose challenges.

“Staying Connected: An Investigative Survey of How Technology Affects People Living with MS” reveals that technology plays a vital role in the lives of many people living with multiple sclerosis (MS) who experience visual, dexterity, and cognitive challenges. However, relatively few are using the assistive technologies that could help them overcome many of these challenges. The survey establishes the vital role that technology can play in the lives of people with MS and highlights the need for better information and more education to help people understand how they could benefit from making technological adaptations.