Cerebral Palsy ALLIANCE

ASSISTIVE TECHNOLOGY INNOVATION SURVEY REPORT

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Executive Summary

Purpose

Despite the benefits of assistive technology, significant barriers to adoption remain. These include the time, patience, and skill required from both individuals and their caregiver networks. This report presents findings from an international survey that sought to identify which technology innovations stakeholders would like to see developed or improved, to generate new knowledge and better understand the perspectives of people with cerebral palsy, their families, clinicians, and researchers.

Key findings

Ease of use
Current assistive technology is complex and not easy to use

Empowerment
Assistive technology needs to empower autonomy, attitudes, and participation

Equity
New assistive technology innovations must be made available to all

Education
Raising awareness on the benefits of new assistive technology is crucial for its implementation

Implications

- Current assistive technology is often complex and difficult to use for people with cerebral palsy.
- Researchers need to develop assistive technologies that empower autonomy, positive attitudes, and participation.
- Designers must ensure new innovations are accessible across all countries and regions.
- Researchers should raise awareness of the benefits of new assistive technologies to support successful implementation within the cerebral palsy community.

Conclusion

Stakeholders emphasised that assistive technology for people with cerebral palsy must be easy to use, empowering, and equitably accessible, supported by strong awareness and education. They highlighted co-design with families, clinicians, and other stakeholders as essential for successful uptake. This survey adds new insights by capturing perspectives from diverse contexts and outlining four clear themes to guide future innovation that strengthens communication, play, leisure, social, work, and participation outcomes.

BACKGROUND

Cerebral palsy is an umbrella term that “describes a group of permanent disorders of the development of movement and posture causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain” (Dan et al., 2026). The motor disorders are often accompanied by comorbidities such as communication difficulties, chronic pain, epilepsy, intellectual disability, and hearing impairment (Novak et al., 2017). It is the most common physical disability in childhood, with a current overall prevalence of 1.6 per 1000 live births in high-income countries (HICs), with higher rates of cerebral palsy being reported in low to middle income countries (LMIC) (McIntyre et al., 2022; McIntyre et al., 2010).

Due to motor and communication difficulties, people with cerebral palsy may need an alternative method to access many education, employment, and social opportunities. Assistive technology is equipment often used to assist and enhance learning, working, and daily living for persons with disability (Karlsson et al., 2017). Assistive technology is an umbrella term for “any product (including devices, equipment, instruments, and software), either specially designed and produced or generally available, whose primary purpose is to maintain or improve an individual’s functioning and independence and thereby promote their wellbeing” (Smith et al., 2018). Benefits to using assistive technology can include enhancing independence and autonomy and increasing social inclusion and participation (Howard et al., 2022).

Despite the benefits of assistive technology, there are significant barriers to their adoption, as these technologies often require significant time, patience, and skill from both the individual and their caregiver network (Taherian & Davies, 2018). The technologies are often discarded after limited use, due to their design and technological properties which are unable to adapt and change to the needs of the user (Halvorsrud et al., 2023). Additionally, costs of assistive technology remain high, with large out of pockets costs on assistive technology for families in Australia (Henry et al., 2023). Other factors that contribute to the high abandonment rates include the lack of end-user involvement in the design of assistive technology and decisions about their care (Howard et al., 2022).

Previous studies have suggested involving the end-user in the design process as a method of overcoming these barriers (Howard et al., 2022). Furthermore, it is also important to involve those who work with assistive technology , such as (but not limited to) occupational therapists, speech therapists, physiotherapists, and rehabilitation engineers (Layton et al., 2022). Considering the perspectives of those who use and interact with assistive technology daily, including people with cerebral palsy, their families/caregivers, clinicians, and researchers, is crucial to ensuring that new devices and technologies are successfully adopted by end-users.

This study’s overall aim is to generate new knowledge and to understand the perspectives of people with cerebral palsy, their families, clinicians, and researchers to identify what technology innovations various stakeholder groups would like to see for existing and new assistive technologies.
We hope these results will inform research priorities for innovative design and implementation solutions, which would ultimately increase communication, play, leisure, social, work, and participation outcomes for people with cerebral palsy.

METHODS

Survey Development

A cross-sectional survey, was designed and informed by discussions from the 8th international research summit on Assistive Technology Innovations for Communication and Mobility, organised and facilitated by Cerebral Palsy Alliance's International Summit Committee to collect data. Seventy-four delegates from 12 countries attended the research summit. This global interdisciplinary research summit featured collaborations with a distinguished group of world-class experts in the fields of brain computer interface, robotics, exoskeletons, virtual reality, cerebral palsy, neuroscience, brain stimulation, rehabilitative medicine, language development, speech recognition, assessment and access solutions. Ethics approval was obtained from the Human Research Ethics Committee, The University of Sydney, Australia.

The survey included 14 open ended questions to gauge stakeholder priorities, such as the positives and negatives of current assistive technologies, future technology innovations, and stakeholder engagement and implementation.

Demographic data was also collected and included: age, gender, country of residence and region of living (metropolitan, city, regional, remote), education level, stakeholder group (e.g., person with cerebral palsy, family/caregiver, clinician, researcher) and occupation (if they were a clinician or researcher).

Participants

Participants were recruited among the attendees at a mini symposium at the European Academy of Childhood Disability (EACD). Participants were invited to fill out the survey at the mini symposium via an online questionnaire distributed via Research Electronic Data Capture (REDCap). The survey was written in English, but the online survey tool used allowed translation into other languages.

People with lived experience of cerebral palsy, their caregivers, clinicians, researchers and others (e.g. teachers) with expertise in working with people with cerebral palsy and assistive technology were invited to participate in the survey.

Survey Analysis

Qualitative content analysis was used to analyse the responses to the open-ended questions. Content analysis is "a systematic coding and categorized approach used for exploring large amounts of textual information to determine trends" (Vaismoradi et al., 2013). Responses were analysed inductively to identify common threads and themes, with a conventional approach used to generate categories from the data whilst avoiding using preconceived categories (Hsieh & Shannon, 2005). NVivo software was used to conduct the coding process of the qualitative analysis. One researcher (DC) initially read through the open-ended text responses and coded common ideas into themes and subthemes. To increase the trustworthiness of the qualitative analysis, analyses of the responses and themes were then discussed and reviewed by two researchers (DC and PK), and any coding disagreements were resolved to identify themes that best represented the data.

FINDINGS

Participant Characteristics

Of the 51 people who attended the symposium, 42 responded to the survey. The majority of respondents identified as clinicians/technologists (n=26, 62%), whilst nine were researchers (21%), and five (12%) were family members or caregivers of a person with cerebral palsy. There were no people with cerebral palsy who responded to the survey (n=0). Of the clinicians/technologists and researchers, their occupational background included speech pathology (n=12, 29%), occupational therapy (n=8, 19%), medicine (n=8, 19%), engineering (n=3, 7%) and physiotherapy (n=3, 7%). Most of the respondents had a tertiary education (n=36, 86%). Partial responses were accepted as participants did not have to fill out the entire survey. Most of the respondents were female (n=36, 86%), and the age range of respondents were from 24-61 years old (mean age 41). 31 respondents resided in city areas (74%), whilst 6 were from regional areas (14%) and 5 from metropolitan regions (12%).

Responses to the survey came from countries throughout the world. Most of the responses were from participant living in Great Britain (n=11, 26%), France (n=6, 14%), Netherlands (n=6, 14%), and Australia (n=4, 10%) including LMIC countries (n=3, 6%) such as Bangladesh, Lebanon, and Lithuania (Figure 1).

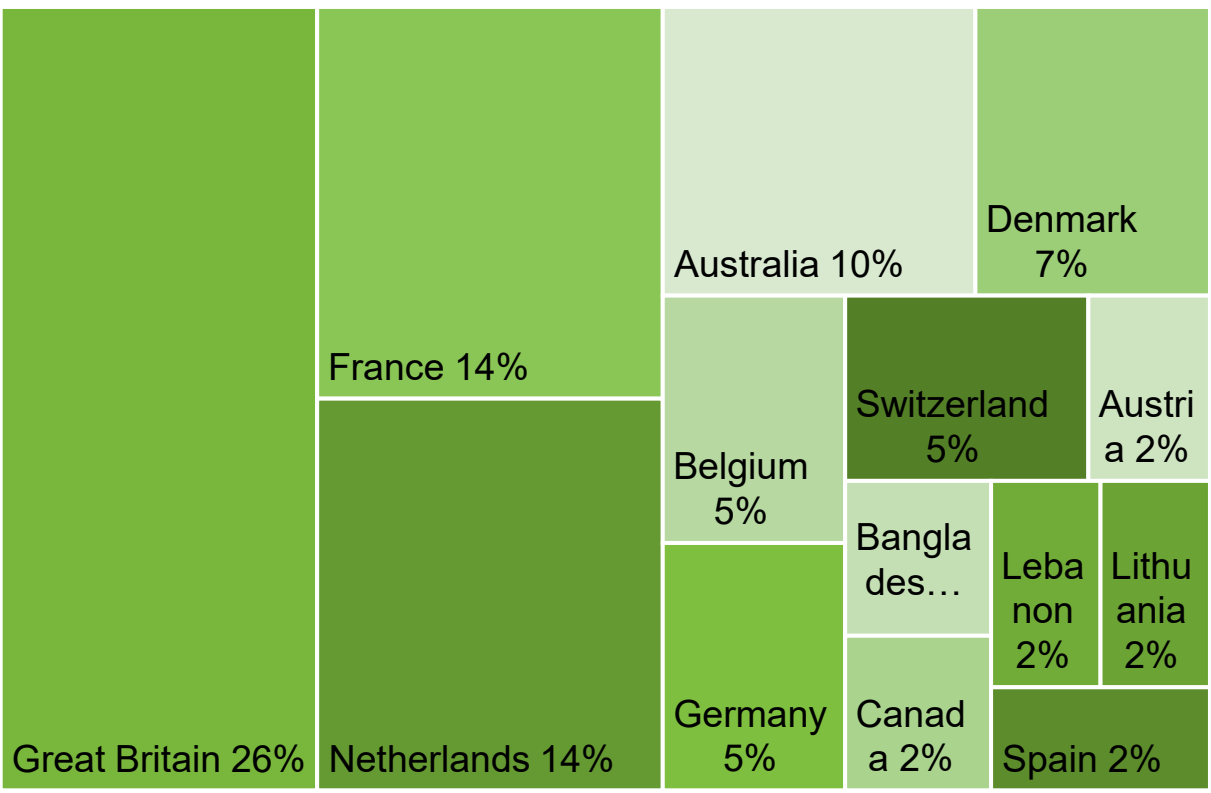


Figure 1. Countries represented in the survey demographics

Overarching themes

Respondents were already aware of current technologies, with mentions of thought to speech (n=9), eye-gaze technology software (n=12), implants (n=11), and exoskeletons (n=6). Some respondents (n=7) reported that they had some experience in implementing eye-gaze technology. However, respondents reported difficulties in getting the technologies to work.

Four overarching themes were generated from the survey responses describing the respondents' views associated with communication and mobility assistive technology innovations. The four themes were drawn not just from the respondents' current experiences with assistive technology, but their opinions on future assistive technology innovations.

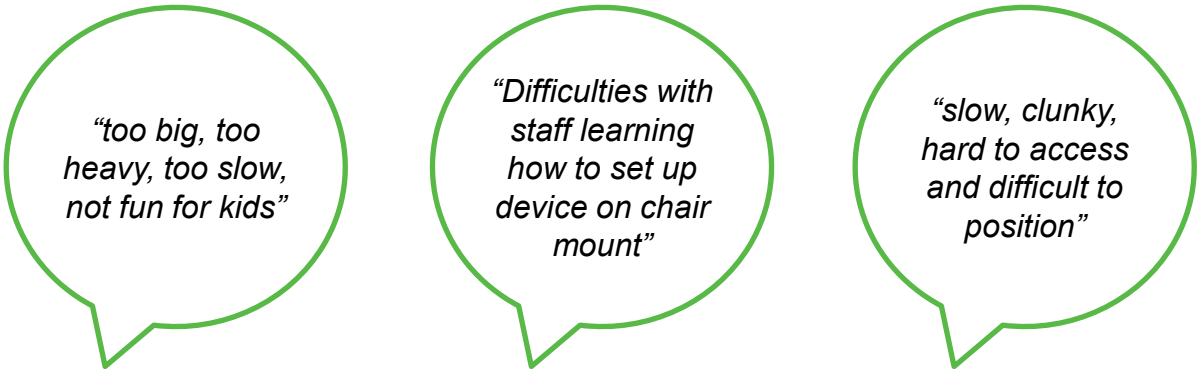
The first theme, '**Ease of use** – current assistive technology is complex and not easy to use', describes respondents' ongoing problems with using technology. The second, '**Empowerment** – Assistive technology needs to empower autonomy, attitudes, and participation' explores what respondents want assistive technology to achieve. The third, '**Equity** – new assistive technology innovations must be made available to all' highlights the need for assistive technology to be easily accessible. The fourth, '**Education** – raising awareness of assistive technology is crucial for its implementation' presents the perspectives of stakeholders on how assistive technology should be designed and implemented.

Theme 1: Ease of use – current assistive technology is complex and not easy to use.

Many respondents had negative experiences with current assistive technology, as it was complex and difficult in its design and operation. For the design of current assistive technologies, respondents found current technologies were *"slow, clunky, hard to access and difficult to position"* (R03, medical practitioner). Another respondent had a similar sentiment, stating that it was *"too big, too heavy, too slow, not fun for kids"* (R05, medical practitioner). One respondent mentioned that the design of the assistive technology led to the device not being suitable for the user: *"bulky or very fragile…not always user friendly"* (R09, caregiver). Others also mentioned that *"technology is still bulky and portability is an ongoing difficulty"* (R02, occupational therapist), highlighting that the current devices are not well designed to meet the needs of different stakeholders.

Respondents also stated that current assistive technology was not easy to operate. Many found that they were not flexible and specific enough for their needs. One respondent stated that *"some devices struggle to cope with users whose abilities vary throughout the day"* (U20, engineer). Another respondent echoed a similar sentiment: *"Oftentimes they are not working for the individual needs of certain people with disabilities."* (R17, caregiver). Another found that the inflexibility of the device led to poorer outcomes: *"They are not suitable for every person with a certain problem, depending on the intensity of the disability, cognitive level, which sometimes gives people 'false' hope if information is not given by clinicians or researchers who have more insight into whether a device could be suitable for someone or not."* (U16, speech pathologist).

Respondents also found that current assistive technologies were slow to use and required complex training. They had issues with both communication and mobility devices, with one mentioning that communication devices were *"slow still compared to non-tech…requires learning, not always intuitive"* (R06, speech pathologist). Another had issues learning how to use mobility devices: "*Difficulties with staff learning how to set up device on chair mount*" (R06, speech pathologist). One stated that it took time to learn how to use the technology: *"It took a long time to work quickly…it took a learning process"* (R35, occupational therapist).



Theme 2: Empowerment - Assistive technology needs to empower autonomy, attitudes, and participation.

Despite respondents finding current assistive technology complex and hard to use, they were hopeful of what future assistive technologies can achieve for people with cerebral palsy. Respondents shared what they thought assistive technologies should provide, emphasising the need for future innovations to empower their autonomy, attitudes, and participation. When asked on the positives of future innovations, many respondents (n=14) shared similar ideas that assistive technologies for communication and mobility should empower a user's autonomy and independence in daily living. Assistive technology can *"increase individuals' opportunity for independent communication and mobility"* (R13, medical practitioner) and can *"enable users to be more independent and communicate their needs"* (R20, engineer). Others also mentioned that *"It could help people to get more independence in daily activities."* (R35, occupational therapist) and that "*The patient with CP can be understood by unfamiliar people thanks to these technological tools, which therefore allow him to be more autonomous"* (R43, speech pathologist).

Respondents also highlighted that they envision assistive technology to not only assist with one's communication and mobility, but to empower their attitudes and feelings. They emphasised that assistive technologies should allow users to express themselves and offer new possibilities to them. Speech pathologists felt that communication technology could enable people to *"communicate with each other and express themselves"* (R21, speech pathologist), that it could *"provide potential for self-expression and language learning that offer potential for self-determination, expression of identity, self-esteem etc...."* (R44, speech pathologist), and that it could *"help a child to express itself (augmentative communication) if they can't talk" (*R31, speech pathologist).

Furthermore, respondents stated that they wanted assistive technology to empower participation in society and in daily living. Many thought that assistive technologies will offer *"possibilities to participate with peers"* (R19, psychiatrist), and *"for communication access and participation in society"* (R18, speech pathologist). Some occupational therapists expressed that the focus of future assistive technologies should be able to allow people to participate in daily activities, not just during therapy sessions. *"I think exoskeletons are not functional in daily activities. There is a need for devices that support daily activities instead of devices for therapy."* (R35, occupational therapist). *"Remember to keep reevaluating the need of the assistance. You have to learn how to use an assistive device and integrate it into everyday living"* (R48, occupational therapist).

Theme 3: Equity – New assistive technology innovations must be made available to all.

When asked on the negatives of current assistive technology, as well as troubles they had on using/implementing the technology, many respondents answered that they were not readily accessible to them and to people with cerebral palsy. Cost was a large factor in inaccessibility, with many respondents citing expenses as a reason for not being able to access current devices. *"Assistive technology is not accessible to all people. Individuals with cognitive challenges and limited volitional movement have few options. Current assistive technology is expensive and does not meet all the needs of all people with disabilities."* (R08, speech pathologist). They felt that new assistive technologies must be made available to everyone, including people in lower socioeconomic areas and in LMIC. One respondent wrote that current technologies have a *"high price…no opportunity to buy, learn how to use in small country"* (R21, speech pathologist, Lithuania). Another mentioned that there were *" inequities in access to such devices owing to socioeconomic factors. Not widely piloted or used in the developing world."* (R14, medical practitioner, Bangladesh).

For new innovations, there was a heavy emphasis on having these technologies being accessible for everyone, especially in regional areas, LMICs, and non-English countries. Some predicted that new innovations would be expensive upon release: *"I envisage them being very selective and expensive initially meaning my poor, distract general patients have no access to technology available to a chosen few or those that have the money."* (R10, medical practitioner, regional area). Others hoped that technologies would be readily available. *"I hope we will get to a point where the access, implementation and usage of the technology is as easy as getting a sandwich at the supermarket… That it will be fitting like a glove and people will have the same possibilities as any healthy person."* (R07, caregiver). Another stated the need for more languages in communication technology, envisioning *"Mainstream support for multilingual immigration. Flexible system that adapts to the users' changing needs. Systems that dynamically support language learning in line with developing language skill."* (R44, speech pathologist)

"Assistive technology is not accessible to all people"

"I hope technology access is as easy as getting a sandwich"

"Current AT is expensive and does not meet all the needs"

Theme 4: Education – Raising awareness on the benefits of new assistive technology is crucial for its implementation.

A key theme that was identified from the survey was that implementing new innovations required raising awareness and education of these technologies for people with cerebral palsy and their caregivers. Respondents emphasised involving people with them, as they would be the end users of the technologies and make the decisions about using the devices. *"It is the parents/family who often take care of finding new ways for their children to adapt and have more freedom. They are most desperate to get whatever they need that can better their kids (and eventually their) lives. And they will be the most motivated to get it to move forward and to get others involved. They are not only needed to find a solution, but also to promote and spread it."* (R07, caregiver). *"I believe it there is sufficient evidence on the benefits and no risk of harm, and if the parents are informed of them, it is up to caregivers to decide whether they want exoskeletons and/or implants for their children."* (R14, medical practitioner).

Respondents suggested involving them from the design phase onwards, as their input was key to ensuring that technology was able to be adopted by end users. *"I think the academics/clinicians should take the lead here, being advised and inspired by their patients and their caregivers since the industry doesn't have enough medical background."* (R16, speech pathologist). *"Families will be the best people to implement the new technologies"* (R23, occupational therapist). Respondents also suggested strategies to raise awareness of new technologies for people with cerebral palsy and their caregivers, such as utilising *"social media, reps in special school settings, engaging patent/carer groups"* (R11, medical practitioner) and through *"role models, personal stories, more integration into common society."* (R22, speech pathologist).

Another key aspect was the need to communicate the impact of these new technologies when educating stakeholders. When asked what evidence would be required for the adoption of new technologies, respondents highlighted that these innovations must be effective and beneficial for the user. They emphasised the need for *"peer reviewed quality evidence of efficacy - with outcomes related to improved activity and participation"* (R39, physiotherapist), and *"Evidence on safety, benefits (case stories, pilot and assess outcome of use of the technology with repeated longitudinal data collection)"* (R14, medical practitioner). One caregiver highlighted the importance of visual evidence for the acceptability of new technologies. *"Visual proof something works. Very often if people can see the result they are more inclined to use it, want it or accept it. Be honest and open how it works and show the result. If it really helps you can start to affect a small group which will grow to a large scale eventually, which will make it more sustainable and will reach the clinicians as well."* (R07, caregiver).

DISCUSSION

The findings of this survey highlight the perspectives of various stakeholders regarding the design and implementation of assistive technology innovations.

Four major themes were generated from the survey responses – ease of use, empowerment, equity and education. These overarching themes are key aspects of assistive technology that can assist researchers and technology companies to successfully design and implement assistive technology innovations when all themes are addressed. These four aspects of designing and implementing assistive technology should all be equally examined throughout the entire design process for new innovations, from the concept phase to the implementation stage.

The first recommendation to consider for researchers and designers when creating assistive technology solutions is the ease of use of the technology. The results from this survey are consistent with previous studies – many end users found some assistive technologies often take significant time to learn (Taherian & Davies, 2018). Additionally, users also mentioned that they found assistive technology to be complex and difficult to use due to the design of the technologies. Therefore, we recommend adopting a system thinking for assistive technology approach in which designers and researchers strongly consult and involve people with lived experience and various stakeholders from the beginning of the design process to ensure that their innovations meet the requirements of end users (MacLachlan & Scherer, 2018). Incorporating a co-design approach into the design process would enable various stakeholders to share their lived experience to help design solutions. These stakeholders should have a hands-on role in this stage, providing feedback on the ease of use of new technological innovations as each iteration progresses. Involving the end-user in the design process as a method of overcoming these barriers is consistent with previous studies (Desmond et al., 2018).

Furthermore, researchers must also consider how new assistive technology innovations can empower end users in their everyday lives. If devices are not able to be adapted to meet the ever-changing needs of the user, they are often discarded with limited use (Halvorsrud et al., 2023; Manzini et al., 2016; Smidt & Pebdani, 2023; Sugawara et al., 2018). Respondents strongly stated that they wanted future innovations to empower an end users' autonomy, attitudes, and participation in daily living, an opinion confirmed by existing research (Smith et al., 2018). Even if new technologies can meet the physical needs of users, these technologies must also enable the holistic needs of people with cerebral palsy, such as providing improved autonomy, leisure, play, social, work, and participation outcomes. We therefore recommend that a key priority when designing assistive technology innovations is to evaluate how their devices are not just used in therapy services, but also how they can be integrated into everyday living. Respondents highlighted that having technologies that are individualised for the end user and are flexible/adaptable would empower individuals in their daily activities. Additionally, providing support after innovations have been released for individuals to use is also crucial in ensuring that technologies are successfully empowering end users' independence and participation and keeping up with their ever-changing needs.

Another recommendation from this study is for researchers and designers to make equitable technology innovations that are available to all. Respondents highlighted that high costs and accessibility were major issues with current assistive technologies. This is also consistent with previous studies that have found assistive technologies are expensive for families with cerebral palsy (Bourke-Taylor et al., 2014; Taherian & Davies, 2018).

Findings show that a lack of funding for assistive technology could lead to high out of pocket costs for families, especially for people with severe cerebral palsy (Henry et al., 2023).

Researchers must consider how their technologies are designed, produced and distributed so that families with cerebral palsy are able to access these innovations. Furthermore, there is an urgent need for policy makers and those responsible for funding decisions to ensure assistive technologies are equitably available for all families (de Witte et al., 2018).

Consistent with previous findings (MacLachlan et al., 2018), the final recommendation from this study for researchers and designers is to raise awareness and education of their technology innovations for people with cerebral palsy, their caregivers, and clinicians. Results from this study highlighted the importance of end users being informed on the impact and efficacy of the innovation for continual use of these technologies. We recommend that researchers and designers continue to partner with end users and stakeholders past the design phase into the implementation stage. Working with people with lived experience will greatly assist with disseminating crucial information about new innovations to users who will benefit from it most. Respondents suggested using social media, school representatives and having role models and champions as ways to engage the community. Having personal anecdotes from families is crucial for the uptake and use of new assistive technology innovations.

Limitations and Strengths

This study has several strengths and limitations. A limitation of this study was that there were no survey responses from people with cerebral palsy. This may have been due to the survey recruitment occurring at a symposium at an international research conference, in which people with cerebral palsy may not have attended the symposium, and so would not have had the opportunity to complete the survey. A future direction of this project would be to survey people with cerebral palsy on their perspectives on assistive technology innovations to further contribute to the existing body of knowledge and refine the recommendations from this study. Additionally, the survey was only available in English and distributed amongst the attendees at the symposium, and so the findings may not be generalizable to other countries or regions. Despite this, the survey was able to capture responses from a variety of countries, including LMICs. The survey was also developed from the discussions at an international summit involving delegates from 12 countries.

CONCLUSION

Various stakeholders within the cerebral palsy community expressed the need for new assistive technology innovations to be easy to use and empowering for end users. They also highlighted that successful implementation of these solutions require them to be equitably available to all, and for there to be awareness and education of these devices within the community. The co-design of these innovations with families of cerebral palsy, clinicians, and various stakeholders through the design and implementation stages is crucial for the successful uptake of these technologies. This survey was able to gather a range of perspectives in the cerebral palsy community, with responses from a wide variety of different stakeholders and from a broad number of HIC and LMIC countries. The results from this survey contribute to the existing body of knowledge by providing four simple, easy to understand theme recommendations to inform research priorities for innovative solutions, ultimately increasing communication, play, leisure, social, work, and participation outcomes for people with cerebral palsy. Given the increasing rise of technological innovation, there is a large demand for new innovative solutions, and so this research will aim to assist researchers in designing and implementing new technologies.

Acknowledgements

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IMPLICATIONS

- Current assistive technology is often complex and not easy to use for people within the cerebral palsy community
- Researchers need to make assistive technology that empower the autonomy, attitudes, and participation of people with cerebral palsy
- Designers must make new assistive technology innovations available to all countries and regions
- Researchers must raise awareness on the benefits of new assistive technology for its successful implementation into the cerebral palsy community

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